



Starting at the Beginning

Laying the Foundation for Lifelong Mental Health

Edited by **Matthew Hodes, Susan Shur-Fen Gau, and Petrus J. de Vries**



IACAPAP

International Association for Child and
Adolescent Psychiatry and Allied Professions



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for Lifelong Mental
Health

Edited by

MATTHEW HODES

Division of Psychiatry, Imperial College London, London, United Kingdom

SUSAN SHUR-FEN GAU

Department of Psychiatry, National Taiwan University College of Medicine, Taipei, Taiwan

PETRUS J. DE VRIES

*Division of Child & Adolescent Psychiatry, University of Cape Town, Cape Town,
South Africa*



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Contributors

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- Nola J. Chambers** Centre for Autism Research in Africa, Division of Child and Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa
- Yi-Lung Chen** Department of Psychiatry, National Taiwan University Hospital and College of Medicine, Taipei, Taiwan
- Bruce Clark** OCD, BDD and Related Disorders Clinic, South London and Maudsley NHS Trust; Department of Child and Adolescent Psychiatry, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, United Kingdom
- David Coghill** Department of Paediatrics; Department of Psychiatry, University of Melbourne; Murdoch Children's Research Institute; RCH Mental Health, Royal Children's Hospital, Melbourne, VIC, Australia
- Dominic Cottrell** OCD, BDD and Related Disorders Clinic, South London and Maudsley NHS Trust, London, United Kingdom
- Mark Dadds** Child Behaviour Research Clinic, Principal NHMRC Research Fellow, University of Sydney, Sydney, NSW, Australia
- John-Joe Dawson-Squibb** Centre for Autism Research in Africa, Division of Child and Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa
- Paul H. Delfabbro** School of Psychology, The University of Adelaide, Adelaide, SA, Australia
- Petrus J. de Vries** Centre for Autism Research in Africa, Division of Child and Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa
- Valsamma Eapen** School of Psychiatry, Faculty of Medicine, University of New South Wales, Kensington; Academic Unit of Child Psychiatry, South West Sydney (AUCS); Early Life Determinants of Health, Sydney Partnership for Health, Education, Research and Enterprise (SPHERE), Darlington; Program 1, Co-operative Research Centre for Autism (CRC), Kelvin Grove, QLD; BestSTART-SWS (Systems Transformation and Research Translation—South West Sydney) Academic Unit, Sydney, NSW, Australia
- Lauren Franz** Centre for Autism Research in Africa, Division of Child and Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa; Duke Center for Autism and Brain Development, Department of Psychiatry and Behavioral Sciences; Duke Global Health Institute, Duke University, Durham, NC, United States

- Daniel Shuen Sheng Fung** Department of Developmental Psychiatry, Institute of Mental Health, Singapore, Singapore
- Susan Shur-Fen Gau** Department of Psychiatry, National Taiwan University Hospital and College of Medicine; Graduate Institute of Brain and Mind Sciences, National Taiwan University, Taipei, Taiwan
- Anthony P.S. Guerrero** Department of Psychiatry, University of Hawai'i John A. Burns School of Medicine, Honolulu, HI, United States
- Michal Harty** Centre for Autism Research in Africa, Division of Child and Adolescent Psychiatry; Division of Communication Sciences and Disorders, Department of Health and Rehabilitation Sciences, University of Cape Town, Cape Town, South Africa
- Tomoya Hirota** Department of Psychiatry, University of California San Francisco, San Francisco, CA, United States
- Yun-Chul Hong** Department of Preventive Medicine, Seoul National University College of Medicine, Seoul, South Korea
- Yoonyoung Jang** Department of Preventive Medicine, Seoul National University College of Medicine, Seoul, South Korea
- Takahiro A. Kato** Department of Neuropsychiatry, Graduate School of Medical Sciences, Kyushu University, Fukuoka, Japan
- Daniel L. King** College of Education, Psychology, and Social Work, Flinders University, Adelaide, SA, Australia
- Georgina Krebs** OCD, BDD and Related Disorders Clinic, South London and Maudsley NHS Trust; Social, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, United Kingdom
- Nami Lee** Department of Psychiatry, Seoul National University Hospital, Seoul, South Korea
- Angela Lewis** OCD, BDD and Related Disorders Clinic, South London and Maudsley NHS Trust, London, United Kingdom
- Antonio Mendoza Diaz** School of Psychiatry, Faculty of Medicine, University of New South Wales, Kensington, NSW, Australia
- Daniel Poremski** Department of Developmental Psychiatry, Institute of Mental Health, Singapore, Singapore
- Susan Prescott** The ORIGINS Project, Telethon Kids Institute, University of Western Australia, Perth Children's Hospital, Nedlands, WA, Australia; inVIVO Planetary Health of the Worldwide Universities Network (WUN), West New York, NJ, United States
- Liezl Schlebusch** Centre for Autism Research in Africa, Division of Child and Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa
- Sarah Seth** RCH Mental Health, Royal Children's Hospital, Melbourne, VIC, Australia

Norbert Skokauskas Centre for Child and Youth Mental Health and Child Protection, Faculty of Medicine, Norwegian University of Science and Technology, Trondheim, Norway

Susan Woolfenden School of Women & Children's Health, Faculty of Medicine, University of New South Wales, Kensington, NSW, Australia

Yi Zheng Beijing Anding Hospital, Capital Medical University, Beijing, PR China

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Preface

First, have a definite, clear, practical idea; a goal, an objective. Second, have the necessary means to achieve your ends; wisdom, money, materials and methods. Third, adjust all your means to that end. *Aristotle*

The field of child and adolescent psychiatry is an evolving one, developing not in a predictable linear manner but in a dialectic process of multidirectional vectors that converge and diverge depending on the historical, cultural, socioeconomic, and scientific pressures operating at any particular point in time. Our current situation is one that has evolved from this type of process, is currently embedded in its type of process, and will continue to develop within this type of process. Predictions about where we will end up are likely to be incorrect, as the variables that need to be considered are legion and the interactions amongst those variables impossible to fully understand. Thus simplistic suggestions for advancement of our field are likely to be wrong, and our current considerations of what we should be addressing and in what manner should be couched in humility and in the need to constantly evaluate what is being done with the intent to do better and to change direction when needed.

That being said, it is essential to consider our current state and develop plans for future directions in a manner that may increase the likelihood of the outcomes that we want to achieve. In this process a number of key considerations need to be kept in mind. These include but may not be limited to what should be done with the goal of increasing the public good, what should be done to effectively alleviate suffering, and what do we need to know to be able to achieve the two aforementioned goals.

1 Increasing the public good

This is a value proposition that arises from numerous historical considerations including the construct of eudaemonia (arising from the work of Aristotle and the Stoics) and the philosophical framework of utilitarianism, perhaps earliest defined by Bentham. In its current iteration, it is often considered within various human rights contexts, including the Universal Declaration of Human Rights ([United Nations General Assembly, 1948](#)), the Convention on the Rights of the Child ([United Nations General Assembly, 1989](#)), and the United Nations Declaration on the Rights of Indigenous

Peoples (United Nations General Assembly, 2007). Within these frameworks, mental health is seen as a human right, and the advancement and protection of this right are deemed to require active participation of the state across a full spectrum of legislative, regulatory, funding, and policy initiatives that address mental health promotion, prevention of mental illness and related morbidity, and the provision of appropriate mental health care. Indeed, perhaps unknown to many psychiatrists and other health care providers, there exists a United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (United Nations General Assembly, 1991). The current United Nations Sustainable Development Goals (<https://www.un.org/sustainabledevelopment/sustainable-development-goals/>. Accessed 16 October 2019) provide a global blueprint for actions that nations can engage in to help achieve these goals. Parenthetically, not all states have endorsed these values, and not all states that have endorsed them have moved rapidly to effectively implement them.

For those professionals working in child and adolescent psychiatry, this value proposition challenges us to consider and effectively address the social determinants of health—working with other health and human service providers, policy makers, and the public to enhance those factors that lead to positive health and mental health outcomes and working to decrease those factors that negatively impact positive health and mental health outcomes (for a practical approach to these issues see: [World Health Organization, 2016](#)).

These factors are not equally distributed within and across different jurisdictions globally. Some countries have made substantial progress in addressing them—universal publicly funded health care insurance, for example, while others have not. However, even within countries that have made positive strides in this direction, not all segments of society have shared equally in this advancement—for example, the economically disadvantaged, refugees, indigenous, or racialized populations. Child and adolescent psychiatrists and allied professionals must play an active role in both scenarios. They must be part of the sociopolitical force that increases the public good for those jurisdictions in which substantial progress is necessary for the general population and in those jurisdictions where segments of the population have not shared equally in these developments.

To help achieve this, training programs must be modified to enrich current clinical and research competencies with skills that address social determinants of mental health in a developmental framework consistent with the work of child and adolescent psychiatrists and allied health professionals. Additionally, child and adolescent psychiatry professionals and organizations such as IACAPAP can provide guidance, support, and consultation to policy makers and other decision makers; participate in civil society organizations (such as NGO's) collaborating with like-minded

health and human service professionals and related stakeholders that are working to address these issues; and engage with the political process to advance public support for these initiatives.

2 Effectively alleviate suffering

In our current sociocultural context, there is an increasing drive to focus our efforts and resources towards the amelioration of distress arising from experiencing normal and usual existential challenges of life while concurrently avoiding the more challenging address of the needs of those who live with a mental illness or those exposed to dire and traumatic situations. Simply put, much effort is now being expended in the domain of met unneed, with inadequate attention to unmet need.

The original conceptualization of this construct focussed on the gap between treatment need for mental disorders and access to that treatment (Andrews, 2000; Kohn, Saxena, Levav, & Saraceno, 2004). This has now evolved to include the hedonic components of ‘wellness’ which have shifted public attention from the needs of those living with a mental illness or those living in dire and traumatic circumstances to meeting wants driven by the subjective desire for enhancing pleasure and avoidance of emotional discomfort. The wellness industry, now a 4.2 trillion dollar global neoliberal economic juggernaut, has helped drive that direction (Global Wellness Institute, 2019). Suffering has been redefined as distress and combined with the widening diagnostic creep of criteria for mental disorders (see: Frances, A. *Saving Normal*. 2013); mental health resources are increasingly being allocated to little or low need states with insufficient resources being allocated to those with proportionally greater needs (see various criticisms of the New York City ‘Thrive’ initiative, such as Eisenberg, 2019; Jaffe, n.d.).

Child and adolescent psychiatrists and allied health professionals cannot turn their backs to those who have the greatest needs for treatment. We must advocate for those who have those needs and also ensure that what we provide is based on best available evidence, applied within the framework of evidence-based care.

Our discipline is still evolving from a hypothesis driven and practitioner experience led to an evidence-based medicine approach. An evidence-based medicine approach entails the application of best available evidence together with practitioner experience and patient values and needs (Masic, Miokovic, & Muhamedgic, 2008). It requires an appreciation that not all evidence is created equal and demands that critical analysis of literature and application of well-considered professional guidelines be used to direct clinical care and to inform public conversations and stakeholder consultations.

To put it bluntly the common adherence to ‘best practice’ or ‘evidence-informed’ frameworks for treatments do not meet the standard of evidence-based care.

While we accept that the optimal levels of evidence may not always be available to support what we do, we must ensure that, when that evidence is available, we apply it and that, when it is not available, we approach the use of interventions cautiously and with transparency to our patients. In particular, we must ensure that the highest standards of treatment research are applied to interventions that we choose to provide. For example, the rush to promote mindfulness for almost any form of mental ailment must be reconsidered based on the quality of the research upon which the hype was based and concerns about conflict of interest of many of authors who reported positive results in applying these interventions (see [Coyne, 2017, 2018](#); [van Dam, van Vugt, Vago, et al., 2018](#)).

3 What do we need to know

It is essential that policy makers have their considerations informed by best available evidence that comes from the highest quality research. This research must come from basic science, clinical science, epidemiology, and real-world experiences. The traditional approach of research silos and the historical exclusion of the end user of any and all interventions are now slowly being replaced by increasing cross-disciplinary collaborations and by research directions and activities informed by those who live with a mental illness. Such directions are to be applauded and supported. As these develop, it is essential that we use tools and methods of investigation that can provide us with the information that we need to make the difficult decisions about which programs to fund, where we need to invest given fierce competition for scarce financial resources and the impact of popular vagaries, fads, and fancies that can capture the minds of decision makers.

For example, two recent ‘research’ reports provide us with a cautionary lesson of how research of different quality can produce different results, which then must be responded to by policy makers.

First, a study in the United Kingdom in 2017 ([Patalay & Fitsimons, 2017](#)) reported that 25% of all 14-year-old girls suffered from depression. This conclusion was based on self-reported symptoms that were not only corroborated by parental report but also actually contradicted by parental report (where the incidence of Depression was reported to be about 7%). This finding of a 25% prevalence rate was widely publicized in both the print and electronic media with the general conclusion that girls in the United Kingdom were suffering from a mental health crisis. Numerous ‘reasons’ were put forward to account for this unprecedented rise in

depression. Reputable child and adolescent mental health professionals participated in promoting this crisis dialogue; very few provided a critical analysis of this report in the public forum or urged caution in the enthusiasm to embrace this information.

Soon thereafter the NHS Digital, Governmental Statistical Service's report was published (NHS Digital, 2018). This more methodologically rigorous case ascertainment based on semi-structured interview application reported that the prevalence of *all* mental disorders in 5–19 years old was about 13%, with depression at about 5%. This study received little or no media attention and little or no public promotion by mental health professionals.

A policy maker faced with these two research reports and the public response to them has a difficult challenge. Developing policy informed by these reports could result in interventions and funding allocations that move in divergent directions. Thus it is imperative that researchers and highly regarded child and adolescent mental health experts and organizations speaking for our professional community ensure that the work they are involved with is of the highest quality and that their public pronouncements related to research reports are informed by critical analysis of the science that these reports have been based on. Hype can lead to false hope and other unhelpful outcomes.

This monograph provides a cornucopia of thoughtful and challenging pieces. It illustrates the diversity and complexity of activities currently underway in our discipline, across different locations globally. It crosses traditional boundaries of academic and applied focus and brings different important aspects together in one place, moving from perspectives ranging from basic science to conceptual policy frameworks. For the reader of today, it illustrates how important it is to continuously and critically re-evaluate what we think we know and how to use the knowledge that we currently have to help inform our work as we focus on our common goal of building better lives for young people and their families.

Stanley Kutcher

Professor Emeritus, Dalhousie University, Halifax, NS, Canada

References

- Andrews, G. (2000). Meeting the unmet need with disease management. In G. Andrews & S. Henderson (Eds.), *Unmet need in psychiatry: Problems, resources, responses* (pp. 11–36). Cambridge: Cambridge University Press.
- Coyne, J. C. (2017). PLOS One corrects undeclared conflicts of interest for 5 articles from Bensen-Henry Institute for Mind Body Medicine. From <https://www.coyneoftherealm.com/2017/03/05/plos-one-corrects-undeclared-conflicts-of-interest-for-5-articles-from-bensen-henry-institute-for-mind-body-medicine/>.

- Coyne, J. C. (2018). *Headspace mindfulness training app no better than a fake mindfulness procedure for improving critical thinking, open-mindedness, and well-being*. From <https://www.coyneoftherealm.com/2018/04/11/headspace-mindfulness-training-app-no-better-than-a-fake-mindfulness-procedure-for-improving-critical-thinking-open-mindedness-and-well-being/>.
- Eisenberg, A. (2019). *With opaque budget and elusive metrics, \$850M ThriveNYC program attempts a reset*, *Politico*. Retrieved from <https://www.politico.com/states/new-york/albany/story/2019/02/26/with-obscure-budget-and-elusive-metrics-850m-thrivenyc-program-attempts-a-reset-873945>.
- Frances, A. (2013) *Saving normal*. New York: William Morrow.
- Global Wellness Institute. (2019). *Wellness industry statistics and facts*. From <https://global-wellnessinstitute.org/press-room/statistics-and-facts/>.
- Jaffe, D. J. n.d. Why \$800 Million Thrive/NYC is failing. *MentalIllnessPolicy.org*, <https://mentalillnesspolicy.org/wp-content/uploads/thrivenyc-fails.pdf>.
- Kohn, K., Saxena, S., Levav, I., & Saraceno, B. (2004). The treatment gap in mental health care. *Bulletin of the World Health Organization*, 82, 858–866.
- Masic, L., Miokovic, M., & Muhamedagic, B. (2008). Evidence-based medicine—New approaches. *Acta Informatica Medica*, 16(4), 219–225.
- NHS Digital. (2018). *Mental health of children and young people in England, 2017: Summary of key findings*. NHS Digital. <https://files.digital.nhs.uk/F6/A5706C/MHCYP%202017%20Summary.pdf>.
- Patalay, P., & Fitsimons, E. (2017). *Mental ill-health among children of the new century: Trends across childhood with a focus on age 14*. London: Centre for Longitudinal Studies.
- United Nations General Assembly. (1948). *Universal declaration of human rights*. United Nations Publishing.
- United Nations General Assembly. (1989). *Convention on the rights of the child*. UK: UNICEF.
- United Nations General Assembly. (1991). *United Nations principles for the protection of persons with mental illness and the improvement of mental health care*. United Nations.
- United Nations General Assembly. (2007). *United Nations declaration on the rights of indigenous peoples*. United Nations.
- van Dam, N., van Vugt, M., Vago, D., et al. (2018). Mind the hype: A critical evaluation and prescriptive agenda for research on mindfulness and medication. *Perspectives on Psychological Science*, 13(1), 36–61.
- World Health Organization. (2016). *The Innov8 approach for reviewing national health programs to leave no one behind: Technical handbook*. Geneva: WHO.

Introduction

Matthew Hodes^{a,b}, Susan Shur-Fen Gau^{c,d},
and Petrus J de Vries^e

^aDivision of Psychiatry, Hammersmith Hospital Campus, Imperial College London, London, United Kingdom, ^bCentral and North West London NHS Foundation Trust, London, United Kingdom, ^cDepartment of Psychiatry, National Taiwan University Hospital and College of Medicine, Taipei, Taiwan, ^dGraduate Institute of Brain and Mind Sciences, National Taiwan University, Taipei, Taiwan, ^eDivision of Child & Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa

1 Introduction

The International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) has a longstanding tradition of organizing a biennial congress, regular study groups, and ongoing support for the career development of child and adolescent mental health professionals. In conjunction with the biennial congresses, the Association has published IACAPAP Monographs since 1970. Over the last 2 years, we have been preparing this IACAPAP Monograph, scheduled for publication in July 2020 for release at the 24th IACAPAP World Congress in Singapore.

The global SARS-CoV-2 (COVID-19) pandemic unexpectedly put the brakes on the IACAPAP World Congress. Within a few months the pandemic had affected the lives of millions of people around the globe, led to the deaths of hundreds of thousands of people, and caused a major impact on all clinical and academic institutions and their activities (see, for instance, [Amaral & de Vries, 2020](#)). Lockdown, social distancing, self-isolation, and quarantine have affected whole populations. Directly or (more frequently) indirectly, children and adolescents have suffered as a result of, for instance, the death of family members, school closure, lack of peer contact, domestic violence, and abuse ([Van Lancker & Parolin, 2020](#)). The pandemic has caused financial hardship and food poverty to many families, particularly those in low- and middle-income countries. The physical and mental health consequences of the COVID-19 pandemic are as yet unknown ([Holmes et al., 2020](#)). At the time of writing this introduction, preliminary reports indicated heightened levels of stress and anxiety amongst many young people. Many of those with preexisting psychiatric disorders had become more distressed or impaired, either as a result of increased psychosocial stressors or due to an inability to access clinical care.

No doubt, future IACAPAP publications and events will address many of the mental health consequences of the pandemic as our knowledge base and experience grows.

In view of the impossibility of a face-to-face congress, the Local Organizing Committee supported by the IACAPAP Executive Committee, agreed to replace the traditional congress with a series of web-based events, with the first scheduled for Monday, 20 July 2020, the day the face-to-face congress would have started. As part of this new format, the Monograph will be available as an e-book. Fortunately, since 2016, the Monographs have been available in both paper and electronic forms and since 2017 have been freely available online via the IACAPAP website (see <https://iacapap.org/monographs/>) 1 year after the respective congress. The 2020 Monograph was therefore able to transition to an e-book format without major disruption. We are grateful that Elsevier, our publishing partner, has been supportive of our effort and, in particular, of the free access agreement, thus contributing to the IACAPAP mission to promote global dissemination of high-quality information about child and adolescent psychiatry and mental health.

In spite of all the unexpected events and the strange world we all found ourselves in, we are delighted to introduce this Monograph with a title from the theme of the Singapore congress: "Starting at the Beginning: Laying the foundation for lifelong mental health." The book chapters are grouped around four broad themes: (1) epidemiology and cultural perspectives; (2) environmental and other risk factors for neurodevelopmental disorders and perspectives from parents and systems to aid primary and secondary prevention; (3) new perspectives on a number of contemporary mental health problems; and (4) a section on child and adolescent mental health policy and services with an emphasis on the Asian context, given the expected location of the 24th IACAPAP Congress.

2 Epidemiological and cultural perspectives in child and adolescent mental health

Since 1997 many national surveys of child and adolescent mental health in high-income countries have been published. This has been made possible by the advances in research methodology, with surveys typically using both questionnaires and interview assessments with large numbers of children and adolescents. Gau and Chen provide a brilliant synthesis of these surveys. The authors use these historical studies as a background to compare the key findings of the Taiwanese survey of children aged 8–14 years, the first such survey in an Asian country. The authors select some major variables (e.g. gender, age, urban-rural differences, and socioeconomic status) and examine their associations with the risks for

disorders. They go on to report the discrepancy between community prevalence, clinic rates, and the burden of childhood psychiatric disorders in Taiwan and consider some of the reasons (including the perceived stigma of mental health disorders) for these discrepancies.

Sociocultural influences in child and adolescent mental health are the focus of the chapter by Guerro. The chapter is a timely reminder of the way culture and migration experiences may influence the prevalence of disorders such as psychosis and also may play a pathoplastic effect on symptoms. Many young people live in multicultural societies and become bicultural or multicultural themselves as successful strategies for adaptation. This observation highlights the need for mental health practitioners to be aware of these processes and achieve cultural competence for effective clinical practice.

3 Developmental neuropsychiatry: Risk and intervention opportunities

Industrialization and consequential environmental damage and neglect have occurred across the globe, including in many Asian countries in recent decades. It has been known for many years that chemical pollutants, including heavy metals, are detrimental to children's health. Jang and colleagues provide a timely review and discussion of the neurodevelopmental consequences of consumption of mercury, lead, and other contaminants, based on recent studies carried out in South Korea. They found impaired neurocognitive function with lower IQ scores and elevated neuropsychiatric symptoms (including inattention and autism spectrum behaviors) in many studies. These alarming findings will be relevant to many other countries and regions.

The range of causes of neurodevelopmental disorders, including the genetic, environmental, and possible role of the microbiome, is the starting point for the sophisticated integration of this topic by Eapen and colleagues. They go on to discuss diagnostic and cultural influences on service delivery. Finally the authors consider workforce issues, care pathways, and other elements required for system-based approaches to prevention and intervention delivery. One specific aspect of this is taken further by Schlebusch and colleagues, who provide a nuanced and comprehensive account of the considerations for implementing early interventions for autism spectrum disorders (ASD) in resource-limited settings. Although their account is related to substantial work carried out in South Africa, it will be highly relevant to the situation in other low- and middle-income countries and low-resource settings in high-income countries. They provide details about a range of parenting education and training (PET) and parent-mediated (PMT) programs for ASD and stress the importance of

deep knowledge of the local culture and parenting practices. This is a topic of active research that will be keenly watched by practitioners and policymakers who will be awaiting studies on cost-effectiveness to guide resource allocation.

4 New perspectives on problems and disorders

Psychiatric classificatory systems have national and local variations, as reflected by the inclusion in ICD-10 of culture-specific disorders (World Health Organisation, 1993). This is also recognized in ICD-11 (Gureje, Lewis-Fernandez, Hall, & Reed, 2019). In Asia a number of culture-specific disorders have been described. Here, we include a fascinating account of 'hikikomori', a form of severe withdrawal in which individuals, usually male, are house bound for long periods of time. Although the condition has been described in a number of countries, there are estimated to be more than 1 million sufferers in Japan. Kato provides a developmental model of hikikomori that encompasses interconnected cultural, family, and societal influences in the formulation. The author proposes operational definitions of hikikomori and gives detailed accounts of approaches to therapy.

The link between culture and international classifications is further illustrated by the inclusion of gaming disorder in the recently released ICD-11. The occurrence of gaming disorder is related to the widespread availability of computers, smartphones, and other mobile devices, on the one hand, and the increasing sophistication in the creation of enticing games and activities. King and Delfabbro give a comprehensive summary of gaming disorder, introducing the phenomenon and definitions, epidemiology, etiology, treatment, and prevention possibilities. Many practitioners will find this chapter immensely helpful, not least to guide recognition of comorbidities in some of their patients who may have ADHD and ASD, in particular, and who might benefit from an expanded formulation and treatment plan.

In this section, there are two further insightful and helpful chapters in areas that have seen a growing evidence base. Krebs and colleagues write about challenges and pitfalls in the treatment of OCD in young people. They address issues for CBT, such as enhancing motivation, tackling mental rituals, and reducing family accommodation. They also discuss obstacles to psychopharmacological management, attitudes to medication use, drugs of choice, and when to discontinue the medication. The final chapter in this section by Coghill and Seth is about ADHD. The authors address developmental perspectives, including discussion of the changing the age-of-onset criterion and comorbidities. The treatment section of the chapter discusses the general principle as well as a detailed consideration of medication management intending to achieve good outcomes.

5 Child and adolescent mental health policy and services— Asian perspectives

The final section of the IACAPAP Monograph addresses policy and service delivery issues with an emphasis on the Asian context. Fung and Poremski provide an overview of service issues addressing the structure of services, legal issues, information systems, and workforce issues. They address many aspects of system developments that can underpin policy. The chapter concludes with an illuminating account of school-based child and adolescent mental health services in Singapore. This very useful chapter sets the scene for the account by Zheng, who addresses these issues in China, the country that is home to the second-largest number of children in the world. China has many unique socioeconomic characteristics, including rapid development, one-child family policy, and large numbers of parents migrating to urban areas for work who then leave their children behind to be cared for by relatives. All these have significant implications for mental health. Zheng goes on to describe the structure of services and the plans for early intervention and detection. The final chapter by Hirota and colleagues address child and adolescent mental health needs, services, and gaps in East and Southeast Asia and the Pacific Islands. It picks up many of the themes discussed by Gau and Chen on the prevalence of child and adolescent psychiatric disorder and the treatment gap and by Fung and Poremski and also Zheng by addressing human resources issues. The focus here is on the relative shortage of and training of child and adolescent psychiatrists in the region. Hirota and colleagues usefully discuss findings from surveys into the availability of child and adolescent psychiatric training schemes in the region. The 5-year gap between the two surveys reveals how much progress has been made, as well as what there is still to achieve. This and other issues of the IACAPAP Monograph underline the enormous needs in child and adolescent psychiatry and mental health around the globe and highlight the importance of international Associations such as IACAPAP to support global actions to reduce the identification and treatment gap for all.

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References

- Amaral, D. G., & de Vries, P. J. (2020). COVID-19 and autism research: Perspectives from around the globe. *Autism Research*, 13, 844–869. <https://doi.org/10.1002/aur.2329>.
- Gureje, O., Lewis-Fernandez, R., Hall, B. J., & Reed, G. M. (2019). Systematic inclusion of culture-related information in ICD-11. *World Psychiatry*, 18(3), 357–358. <https://doi.org/10.1002/wps.20676>.
- Holmes, E. A., O'Connor, R. C., Perry, V. H., Tracey, I., Wessely, S., Arseneault, L., ... Bullmore, E. (2020). Multidisciplinary research priorities for the COVID-19 pandemic: A call for action for mental health science. *Lancet Psychiatry*. [https://doi.org/10.1016/s2215-0366\(20\)30168-1](https://doi.org/10.1016/s2215-0366(20)30168-1).

- Van Lancker, W., & Parolin, Z. (2020). COVID-19, school closures, and child poverty: a social crisis in the making. *Lancet Public Health*, 5(5), e243–e244. [https://doi.org/10.1016/S2468-2667\(20\)30084-0](https://doi.org/10.1016/S2468-2667(20)30084-0).
- World Health Organisation. (1993). *The ICD-10 classification of mental and behavioural disorders. Diagnostic criteria for research*. Geneva: World Health Organisation.



P A R T I

Epidemiological and
cultural perspectives in
child and adolescent
mental health

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Prevalence, risk factors, and disease burden of child and adolescent mental disorders: Taiwanese and global aspects

Susan Shur-Fen Gau^{a,b} and Yi-Lung Chen^a

^aDepartment of Psychiatry, National Taiwan University Hospital and College of Medicine, Taipei, Taiwan, ^bGraduate Institute of Brain and Mind Sciences, National Taiwan University, Taipei, Taiwan

1 Introduction

Although mental health issues across the lifespan have attracted tremendous attention during recent decades, mental illnesses in the child and adolescent population remain a global public-health challenge (Patel, Flisher, Hetrick, & McGorry, 2007). Mental disorders have been reported to contribute a substantial proportion of Global Burden of Disease (GBD) in terms of disability-adjusted life years (DALYs), years of life lost to premature mortality (YLLs), and years lived with disability (YLDs), especially for YLDs (Eaton et al., 2008; Kessler et al., 2009; Whiteford et al., 2013). It was estimated that 7.4% of the global burden of the disease had been attributed to mental disorders in the GBD Study 2010 (Whiteford et al., 2013). Some common child and adolescent mental disorders, such as autism spectrum disorder (ASD) (Baxter et al., 2015), attention-deficit/hyperactivity disorder (ADHD), and conduct disorder (CD) (Erskine et al., 2014), accounted for a notable proportion in the GBD caused by mental disorders. Furthermore, it is observed that there is an increasing trend of the disease burden of mental disorders since 1990 (Whiteford et al., 2013). These results have drawn attention to the importance of prevention of mental disorders, especially for children and adolescents because the relevant data are relatively less in these populations (Ustün, 1999). Since the

core symptoms of childhood-onset mental disorders may last to adolescence and adulthood, they are very likely to cause functional impairment and psychopathology in adulthood (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003). Hence, regular surveillance of mental conditions in the child and adolescent population is one fundamental element to prevent mental illness and improve mental well-being across the lifespan.

Since 1977 the World Health Organization has suggested that every country should have plans and research for child mental health (World Health Organization, 1977). However, only a few western countries have carried out epidemiological programs. Furthermore, previous national surveys have documented substantial prevalence rates changes between the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III)-based (American Psychiatric Association, 1980), and Fourth Edition (DSM-IV)-based (American Psychiatric Association, 1994). However, there is a lack of empirical data on the prevalence and distribution of a wide range of mental disorders based on the newly released DSM-5 from a representative sample of children since May 2013 (American Psychiatric Association, 2013). Due to added new disorders and changing diagnostic criteria for some disorders from the DSM-IV to the DSM-5 (van de Glind et al., 2014), there is an urgent need to have epidemiological studies based on DSM-5 to identify up-to-date prevalence rates, risk factors, and disease burden estimates. This chapter consists of four sections: prevalence rates, risk factors, disease burden, and clinical implications.

2 Prevalence rates of child mental disorders

2.1 National epidemiological surveys

Apart from the regular nationwide surveys of the mental health of children and young people in England, carried out in 1999, 2004, and 2017 (Table 1, <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>, accessed on November 16, 2019) (Ford, Goodman, & Meltzer, 2003), only a few Western countries have conducted national surveys, including Australia (Sawyer et al., 2001), Germany (Ravens-Sieberer et al., 2008), the Netherlands (Verhulst, van der Ende, Ferdinand, & Kasius, 1997), Israel (Farbstein et al., 2010), Italy (Frigerio et al., 2009), and the United States (Kessler et al., 2012; Merikangas, Avenevoli, Costello, Koretz, & Kessler, 2009; Nock et al., 2013) (Table 1). In Taiwan, we conducted the first National Epidemiological Study of Child Mental Disorders (Taiwan's survey) in 2015–17 in a nationally representative sample of children aged 8–14 years old using the Chinese version of the Kiddie Schedule for Affective Disorders and Schizophrenia Epidemiological

TABLE 1 Summary of National Surveys of Mental Disorders in children from different countries.

Countries	Netherlands ^a	Australia	United Kingdom	United States		Germany	Israel	Italy	Taiwan
First author	Verhulst	Sawyer	MHCYP	Merikangas	Kessler	Ravens-Sieberer	Farbstein	Frigerio	Chen
Time frame of prevalence	6 months ^b	12-months	Current (5–15 y/o) (1999, 2004, and 2017) ^c	Lifetime	12-months	Current ^c	Current ^c	Current ^c	Lifetime/current
Study period	1993	1997–98	1999, 2004, 2017	2001–03		2003–06	2004–05	Unspecified	2015–17
Publication year	1997	2001	2003–19	2010	2012	2008	2010	2009	2019
Assessment	CBCL(YSR and TRF) and DISC for parent and child versions (DSM-III)	CBCL(YSR and TRF) and SCID (DSM-IV)	DAWBA and SDQ (ICD)	A modification of the CIDI		Several questionnaires screen for anxiety, depression, ADHD, conduct disorder ^d	DAWBA	CBCL(YSR and TRF) and DWBA	K-SADS-E for DSM-5, CBCL (YSR and TRF also) and SDQ
Sampling method	Multistage cluster sampling	Multistage sampling	Stratified multistage sampling	Stratified multistage sampling		Stratified two-stage sampling	Two-stage cluster sampling	Two-stage cluster sampling	Stratified clustering sampling

Continued

TABLE 1 Summary of National Surveys of Mental Disorders in children from different countries—cont'd

Countries	Netherlands^a	Australia	United Kingdom	United States	Germany	Israel	Italy	Taiwan
Sample size	2916	4509	8664 (1999) 6405 (2004) 6219 (2017, 5–15)	9244	17,641	957	3418	9560 (questionnaires), 4816 (K-SADS)
Participant's age range	4–18	4–17	5–15 (1999, 2004) 2–19 (2017)	13–18	7–17	14–17	10–14	8–14
Examined risk factors	Demographics, comorbidities, and social class	Demographics, quality of life, risk behaviors, and services of mental health	Demographics, mental health services, family function, school performance, stress emulation, social adjustment, and physical health	Demographics, comorbidities, social class, sexual behaviors, environmental-, stress- and family-related factors, peer relationships, saliva	Demographics, rural–urban factor, family and parenting style, and social class	Demographics, social class, learning disability, physical health, chronic diseases, accident, exercise, and social support	Demographics, comorbidities, social class, social, family, and school factors, emotional difficulties, and genetic factors	Demographics, comorbidities, family/parent/environment factors, school functions, perinatal factors, bully, suicidal behaviors

ADHD	2.6	11.2	1.5, 1.5, 1.9	8.7	6.5	3.9 (aged 7–10) 2.2 (aged 11–17)	3.0	–	10.1/8.7
Autism spectrum disorder	–	–	N/A, 1.0, 1.3	–	–	–	–	–	1.0
ODD	–	–	3.0, 3.4, 3.5	12.6	8.3	–	1.8	–	2.0/1.5
Conduct disorder	6.0	3.0	1.5, 2.1, 1.3	6.8	5.4	8.7 (aged 7–10) 9.7 (aged 11–17)	0.9	–	0.5/0.1
Depressive disorders ^e	3.6	3.0	0.9, 0.8, 1.2	11.7	8.2	5.6 (aged 7–10) 4.9 (aged 11–17)	3.3	3.8	2.8/1.1
Bipolar disorder	–	–	–	2.9	2.1	–	–	–	–
Anxiety disorders	23.5	–	3.7, 3.5, 5.3	31.9	24.9	6.3 (aged 7–10) 4.0 (aged 11–17)	–	–	15.2/12.0
Generalized anxiety disorder	1.3	–	0.6, 0.8, 1.0	2.2	1.1	–	6.1	6.5	0.9/0.7
Specific phobia disorder	12.7	–	0.9, 0.9, 0.9	19.3	15.8	–	2.8	0.8	8.7/7.7
Social anxiety disorder	9.2	–	0.3, 0.2, 0.4	9.1	8.2	–	0.9	0.4	3.6/2.7

Continued

TABLE 1 Summary of National Surveys of Mental Disorders in children from different countries—cont'd

Countries	Netherlands ^a	Australia	United Kingdom	United States		Germany	Israel	Italy	Taiwan
Panic disorder	0.4	–	0.1, 0.1, 0.5	2.3	1.9	–	0.4	0.2	0.4/0.1
Agoraphobia	2.6	–	0.1, 0.1, 0.2	2.4	1.8	–	–	0.3	0.4/0.4
Separation anxiety disorder	–	–	0.8, 0.5, 0.9	7.6	1.6	–	–	–	4.4/2.2
OCD	1.0	–	0.3, 0.2, 0.3	–	–	–	1.2	–	1.4/0.8
Eating disorders	–	–	0.1, 0.1, 0.2	2.7	2.8	–	–	–	0.7/0.5
Bulimia nervosa	0.3	–	–	–	–	–	–	–	–
Anorexia nervosa	0.3	–	–	–	–	–	–	–	0.2/0.2
Tourette syndrome	0.1	–	0.1, 0.9, 0.9	–	–	–	–	–	2.6/2.1
Substance use disorder	3.5	–	–	11.4	8.3	1.6% for alcohol use disorder; 1.2% for drug use disorder (aged 11–17)	–	–	–

PTSD	–	–	0.2, 0.1, 0.3	5.0	3.9	–	0.8	–	0.1/0.0
Any mental disorder	35.5	–	9.7, 10.1, 11.2	49.5	40.3	–	11.7	8.2 for SCID; 9.8 for CBCL	31.6/25.0
Suicide-related problems									
Ideation	–	–	–	12.1 ^e	–	3.8 (aged 11–17)	–	–	8.2/3.1
Plan	–	–	–	4.0 ^e	–	–	–	–	3.6/1.7
Attempt	–	–	–	4.1 ^e	–	2.9 (aged 11–17)	–	–	0.7/0.3

ADHD, attention-deficit hyperactivity disorder; CBCL, Child Behavior Checklist; CIDI, Composite International Diagnostic Interview; TRF, Teacher Report Form of CBCL; YSR, Youth Self-Report Form; DISC, Diagnostic Interview Schedule for Children; MHCYP, Mental Health of Children and Young People in England (<https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>); DAWBA, development and well-being assessment; SDQ, Strengths and Difficulties Questionnaire; OCD, obsessive-compulsive disorder; ODD, oppositional defiant disorders; SCI, The Structured Clinical Interview for The Diagnostic and Statistical Manual of Mental Disorders; PTSD, posttraumatic stress disorder.

^aThe prevalence of mental disorders of the national survey in the Netherlands was based on the parent or child versions of the DISC. The results of the prevalence rates of suicide-related problems in the United States were extracted from Nock et al. (2013).

^bThe prevalence is the past 6-month prevalence.

^cTime frame of disorders changed according to their diagnostic criteria.

^dThe Child Anxiety-Related Emotional Disorders for anxiety disorder; Center for Epidemiological Studies Depression Scale for Children for depression; Child Behavior Checklist for conduct disorder; German ADHD Rating Scale and Conner's Scale for ADHD.

^eThe results of the prevalence rates of suicide-related problems in the United States were extracted from Nock et al. (2013).

version for DSM-5 criteria (K-SADS-E for DSM-5) (Chen et al., 2017; Chen, Chen, Lin, Shen, & Gau, 2020). Amongst these Western studies the national survey in the Netherlands was the first one conducted in 1993, whereas the latest one is conducted in the United Kingdom in 2017. After that, no other Western countries have conducted such national studies in child and adolescent population. The development and well-being assessment (DAWBA) (Goodman, Ford, Richards, Gatward, & Meltzer, 2000) and child behavior checklist (CBCL) (Achenbach & Edelbrock, 1983) are the most commonly used interview assessment and questionnaires tool in these surveys, respectively. The largest and smallest sample size was found in Germany ($n=17,641$) and Israel ($n=957$), respectively, probably depending on the country's population. Despite a wide range of varied prevalence rates across these studies (prevalence of any mental disorders: 8.2%–49.5%), it has been suggested that 25%–30% of children and adolescents are affected by any mental disorders (Costello, Egger, & Angold, 2005). Taiwan's weighted lifetime and 6-month prevalence rates for any DSM-5 child mental disorders were 32.3% and 25.8%, respectively (Chen et al., 2020).

2.2 Assessment tools for child and adolescent mental disorders

Two different methods, questionnaires and diagnostic interviews, are used to examine the mental disorders in children and adolescents in these national surveys. For the questionnaire the most common tool may be the CBCL, which was developed by Achenbach and colleagues to assess the common behavioral problems in children aged 4–18 years old with three different informant versions: Youth Self-Report, Parent's Report, and Teacher's Report Forms (Achenbach & Edelbrock, 1983). The Strengths and Difficulties Questionnaire (SDQ) is also commonly used in epidemiological studies (Goodman, 1997; Goodman, Meltzer, & Bailey, 1998), particularly used with the DAWBA. Like CBCL, SDQ has parent, teacher, and self-report forms and has been translated to more than 60 languages, and both are widely used worldwide to assess the child and adolescent psychopathology and function/competency. There are many advantages of self-administered questionnaires when compared with diagnostic interviews, such as more efficiency, no need for interviewer training. However, there are also some disadvantages derived from using the self-administered questionnaires, including self-informant bias, lack of adequate knowledge, and understanding of questions.

Several diagnostic interview instruments used in these national surveys include the Diagnostic Interview Schedule (DIS) (Robins, Helzer, Croughan, & Ratcliff, 1981), K-SADS (Ambrosini, 2000), Composite International Diagnostic Interview (CIDI) (Kessler & Üstün, 2004), and

DAWBA (Goodman et al., 2000). Currently the most often used instrument for making psychiatric diagnoses in the child and adolescent populations in Taiwan is the K-SADS for DSM-IV (Tsai, Wu, & Gau, 2005) and for DSM-5 (Chen et al., 2017). Nevertheless, it is common that large epidemiological surveys include both questionnaires and diagnostic interviews; for example, both Chinese version of the CBCL (Yang, Soong, Chiang, & Chen, 2000), SDQ (Liu et al., 2013), and K-SADS-E were used in Taiwan's survey.

2.3 Taiwan's survey: Lifetime and 6-month prevalence of child mental disorders

Taiwan's survey is a national epidemiological study on the common mental disorders amongst children at Grade 3, Grade 5, and Grade 7. It was conducted from May 2015 to January 2017 using a stratified cluster sampling to select 69 schools all over Taiwan. The school sampling frame was constructed using the schools stratified into seven major geographic regions (highly urbanized cities, moderately urbanized cities, boomtowns, general cities, aging cities, agriculture cities, and remote areas) based on five variables: (1) the population density, (2) the population ratio of people with educational levels of college or above, (3) the population ratio of people over the age of 65, (4) the population ratio of agricultural workers, and (5) the number of physicians per 100,000 people (Liu et al., 2006). The final nationally representative sample consisted of 4816 children in grades 3 ($n=1352$), 5 ($n=1297$), and 7 ($n=2167$). All the participants underwent face-to-face psychiatric interviews using the K-SADS-E for the DSM-5 (Chen et al., 2017), and they and their parents and teachers reported on the questionnaires such as CBCL, YSR, TRF, and SDQ (Chen, Chen, & Gau, 2019; Tsai, Chen, & Gau, 2019). Eight interviewers with bachelor's or master's degrees in psychology and > 6-month clinical and interview training participated in this survey. During the study period, all the interviews and data collection were reviewed and discussed weekly.

Taiwan's survey used the inverse probability of censoring weighting (IPCW) method to adjust for the weighted prevalence rates. After adjustment for the possible nonresponse bias, the IPCW-adjusted prevalence rates of mental disorders decreased by 0.1%–0.5% without any significant differences in any of the comparisons between the unadjusted weighted prevalence and IPCW prevalence rates (Chen et al., 2020). The lifetime and 6-month IPCW-adjusted weighted prevalence rates (> 1%) included anxiety disorders (15.2% and 12.0%), sleep disorders (11.7% and 6.2%), attention-deficit hyperactivity disorder (ADHD, 10.1% and 8.7%), tic disorder (2.6% and 2.1%), oppositional defiant disorder (ODD, 2.0% and 1.5%), depressive disorders (2.8% and 1.1%), obsessive–compulsive disorder (OCD, 1.4% and 0.8%), and autism spectrum disorder (ASD, 1.0%; only

lifetime prevalence). Overall the IPCW adjusted weighted lifetime, and 6-month prevalence rates for overall mental disorders were 32.3% and 25.8%, respectively, and at least two kinds of mental disorders were 12.9% and 8.3%, respectively. 40.8% and 24.6% of all affected children with lifetime and 6-month mental disorders also suffered from additional mental disorders, respectively. For suicide-related problems the lifetime and 6-month weighted prevalence rates were 8.2% versus 3.1% for suicidal ideation, 3.6% versus 1.7% for suicidal plan, and 0.7% versus 0.3% for suicidal attempts.

The discrepant prevalences of mental disorders across countries may be explained by several methodological issues, such as the respondents' age range, measurements, diagnostic criteria, the time frame of the prevalence estimate, and sampling methods. The lifetime prevalence rate of total mental disorders in children estimated in this study (32.3%) was within the range of figures reported from national studies in the United States (lifetime: 49.5% (Merikangas et al., 2010) and 12-months: 40.3% (Kessler et al., 2012) for adolescents, aged 13–18 years old) and the Netherlands (6-months: 35.5% (Verhulst et al., 1997) for subjects 4–18 years old) using diagnostic interviews but was considerably higher than national surveys in other countries (current: 9.5%–19.2% (Farbstein et al., 2010; Ford et al., 2003; Frigerio et al., 2009; Ravens-Sieberer et al., 2008; Sawyer et al., 2001) for subjects 4–17 years old) that mainly employed the development and well-being assessment to assess youth's psychopathology. Furthermore, regarding comorbidity in Taiwan's survey, our finding that 40.8% and 24.6% affected children would report other additional lifetime and 6-month mental disorders is highly close to the United States (lifetime: 40%) (Merikangas et al., 2010). Overall the prevalence rates of total mental disorders in children were similar across the east and west, despite different DSM versions used. One possible explanation might be that the prevalence rates of several common child mental disorders are more likely to be affected by the assessment tools rather than the diagnostic system from DSM-IV to DSM-5.

2.4 Comparisons of several major child and adolescent mental disorders (DSM-IV to DSM-5)

2.4.1 Attention-deficit/hyperactivity disorder and mood dysregulation disorder

Changes in the diagnostic criteria from the DSM-IV to the DSM-5 may proportionally account for the differences in the prevalence rates of certain mental disorders between Taiwan's survey and other national surveys. For example, prevalence rates of ADHD in Taiwan's survey were largely similar to those from the Australian national survey (12-month prevalence: 11.2%) (Sawyer et al., 2001) but were higher than figures from

other national surveys (2.2%–8.7%) (Farbstein et al., 2010; Ford et al., 2003; Frigerio et al., 2009; Kessler et al., 2012; Merikangas et al., 2009; Ravens-Sieberer et al., 2008; Verhulst et al., 1997). The increase in ADHD prevalence might be attributable to the fact that the DSM-5 has widened the threshold for ADHD diagnosis (van de Glind et al., 2014). For example, the onset age of ADHD changed from ‘before the age of 7 years’ in the DSM-IV to ‘before the age of 12 years’ in the DSM-5, the change of descriptions for the criteria of ADHD as ‘clinically significant impairment’ to ‘interfere with or reduce the quality’, and the addition of ‘taps hands’ in the first symptom of hyperactivity–impulsivity in the DSM-5.

Similarly, for MDD, the minimum duration of MDD required was shortened from ‘4 weeks’ in the DSM-IV to ‘2 weeks’ in the DSM-5. This change may at least in part, account for the increased 6-month prevalence rate of MDD in present Taiwan’s survey (Chen et al., 2020) compared with previous Taiwanese research (Tsai et al., 2005). The increase in the prevalence of these two disorders from the DSM-IV to the DSM-5 has also been reported in other studies (Uher, Payne, Pavlova, & Perlis, 2014; van de Glind et al., 2014).

2.4.2 Oppositional defiant disorder/conduct disorder

Although the prevalence rates of ODD in Taiwan’s survey were significantly lower than the figures in the US national survey (lifetime, 12.6% and 12-months, 8.3%) (Kessler et al., 2012; Merikangas et al., 2009), they were similar to those in national surveys from the United Kingdom (2.3%) (Ford et al., 2003) and Israel (1.8%) (Farbstein et al., 2010). On the other hand, our prevalence rates of CD (lifetime, 0.5% and 6 months, 0.1%) were significantly lower than the rates from all other national surveys (range from 0.9% to 9.7%) (Farbstein et al., 2010; Ford et al., 2003; Frigerio et al., 2009; Kessler et al., 2012; Merikangas et al., 2009; Ravens-Sieberer et al., 2008; Sawyer et al., 2001; Verhulst et al., 1997). One possible explanation is that ODD was usually identified in late childhood or early adolescence, whereas CD usually occurs during adolescence (Rowe, Costello, Angold, Copeland, & Maughan, 2010). Our participants were children aged 8–14 (Grades 3, 5, and 7), much younger than their counterparts in other national surveys (13–18 years old). Moreover, Asian youths were less likely to have CD compared with their Western counterparts at similar ages (Sakai, Risk, Tanaka, & Price, 2008). Other risk factors such as poor parenting, family dysfunction, socioeconomic inequality, and adverse neighborhood (Fairchild et al., 2019; Gau et al., 2007) may vary across countries.

2.4.3 Anxiety disorders

Table 1 presents the figures of anxiety disorders in Taiwan’s survey (Chen et al., 2020) similar to those from the majority of national surveys

(Farbstein et al., 2010; Kessler et al., 2012; Merikangas et al., 2010; Verhulst et al., 1997), suggesting similar patterns of anxiety disorders between the DSM-IV and the DSM-5 criteria. Although the extent of disability and relevant impairment resulting from anxiety disorders was lower than major mental disorders (Baxter, Vos, Scott, Ferrari, & Whiteford, 2014), the development of anxiety disorders in young children and adolescents was reported to be associated with increased risks of developing sequential depression and functional impairment in adulthood (Bongers, Koot, van der Ende, & Verhulst, 2003). As anxiety disorders in children have received relatively less attention from clinicians, family, educators, and society as shown in Taiwan's national health insurance data, our findings strongly suggest the need for primary prevention, early detection, and intervention for anxiety disorders in the child and adolescent population.

2.4.4 Autism spectrum disorder

The prevalence of ASD was 1.0% in this study, higher than the results from several earlier reports and the rate from a global metaanalysis (0.62%) (Elsabbagh et al., 2012). However, this figure was similar to those reported by the Mental Health of Children and Young People Survey in England in 2004 (1.0%) and 2017 (1.3%) and close to the recent estimate of ASD prevalence up to 2.2% in the National Health Interview Survey by the Centers for Disease Control and Prevention in the United States (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015) and 2.6% in South Korea (Kim et al., 2011). Although the elevated rates in recent surveys might have been derived from the differences in research methodology, they might also be attributed to an increased awareness of ASD in the past few decades. The increasing trend of prevalence of ASD highlights the importance of long-term care needs for individuals with ASD and their families in Taiwan and around the globe.

2.4.5 Suicide-related problems

Taiwan's survey identified similar prevalence of suicide ideation but a lower prevalence of suicidal attempts than Germany (current: 3.8% vs 2.9%) (Ravens-Sieberer et al., 2008) and the United States (lifetime: 12.1% vs 4.1%) (Nock et al., 2013) possibly due to younger age in Taiwan's survey than Germany and the United States (Tang et al., 2009). Combining our results and the report of suicide as the second-leading cause of death in the Taiwanese adolescent and early adult populations (Ministry of Welfare and Health, 2017), the efforts of suicide prevention should be prioritized in our mental welling plans for the young population. Several relevant issues warrant further investigation: (1) understanding the transition and risk factors from suicidal ideation to suicidal attempts, then to actual suicide in children; (2) comorbidities between suicide-related problems and mental dis-

orders in children, especially for impulsivity, hyperactivity, and depressive disorders; and (3) the family as an essential resource for the early detection of a suicide risk and the prevention of related injuries and death in children.

3 Risk factors for child and adolescent mental disorders

Several risk factors are specific to certain mental disorders in childhood. Sex, age, urban–rural, and socioeconomic status are specifically reviewed and discussed herein.

3.1 Sex differences

The sex difference in mental disorders is considered the most stable confounding factors in mental research (Riecher-Rössler, 2017); mood or anxiety disorders are more prevalent in females (Seedat et al., 2009), whereas neurodevelopment disorders, such as ADHD and ASD, are more common in men (Merikangas et al., 2010). Several underlying mechanisms are proposed to account for these sex differences: biological difference, sociocultural assigned gender roles, gender/sex equality, and discrimination (Park, Bang, & Kim, 2014). Taiwan's survey showed the same sex differences in the following mental disorders across the three school grade levels. Boys were more likely than girls to have neurodevelopmental disorders (ASD, ADHD, and tic disorder), ODD, CD, intermittent explosive disorder (IED), disruptive mood dysregulation disorder (DMDD), depressive disorders, and overall any psychiatric disorders (odds ratios, ORs, 1.52–17.38, all P s < .05). However, anxiety disorders, depressive disorders, gender dysphoria, and anorexia nervosa are more prevalent in girls than in boys (ORs, 0.02–0.66, all P < .05).

These sex differences found in Taiwan's survey are consistent with literature documenting higher rates of ASD (Zablotsky et al., 2015) and ADHD (Merikangas et al., 2010; Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007), ODD (Maughan, Rowe, Messer, Goodman, & Meltzer, 2004), CD (Loeber, Burke, Lahey, Winters, & Zera, 2000; Maughan et al., 2004), IED (Kessler et al., 2006), and DMDD in boys, contributing to a higher total psychiatric morbidity than girls, and higher rates of anxiety disorders (Kessler et al., 2012; Merikangas et al., 2010), depressive disorders (Lin et al., 2008), and anorexia nervosa (Bulik et al., 2006) in girls. The novel findings of significant sex differences in DMDD (more common in boys) and gender dysphoria (more common in girls) warrant further replication because they have been rarely examined, especially amongst child and adolescent populations (Coccaro, 2012; Copeland, Angold, Costello, & Egger, 2013; Zucker & Lawrence, 2009).

3.2 Age effects

The onset, prevalence rates, and symptomatology of some mental disorders are the functions of age across the developmental stage from childhood to adolescence. For example, the essential features of neurodevelopment disorders such as ADHD, tic disorder, and ASD are usually observed starting from early childhood; impulse-control disorders, including ODD and CD, and anxiety disorders emerge at adolescence or earlier at childhood; and mood disorders and OCD had their onset across adolescence. Schizophrenia is rarely found in adolescents. Hence the understanding of the age of onset and age effect in mental disorders allows us to provide precisely the early detection or diagnosis of mental disorders for timely intervention to offset adverse outcomes (Kessler et al., 2007).

Taiwan's survey showed that MDD/PDD, suicide-related problems, and OCD were more prevalent in Grade 7 children (ages of 12–14), whereas reactive attachment disorder (RAD) and IED were more prevalent in Grade 3 (ages of 8–9) and Grade 5 (ages of 10–11) children. In addition to the biological aspect of development, the increased trends of these disorders may be partially explained by increasing academic stress in junior high school (Lee, Wong, Chow, & McBride-Chang, 2006; Tan & Yates, 2011), adverse life event (Lensi et al., 1996), and developmental transition (Burke, Loeber, Lahey, & Rathouz, 2005; Leckman & Bloch, 2008). The new finding of age differences in RAD and IED (more common in 3rd and 5th graders than 7th graders) needs further investigations (Coccaro, 2012; Copeland et al., 2013; Zucker & Lawrence, 2009).

3.3 Urban–rural differences

The finding of Dohrenwend and Dohrenwend (1974) regarding a higher prevalence of mental disorders in urban areas has been consistently replicated and is still supported by a recent review (Peen, Schoevers, Beekman, & Dekker, 2010). Such differences are most robust in some mental disorders related to social problems and environmental stressors such as depression, anxiety disorders, and sleep disorders. On the other hand, although the prevalence of substance use disorders has been reported higher in rural areas, some studies showed opposite results (Peen et al., 2010). Such inconsistent results might come from the difficulty in defining the 'urban' and 'rural'. Taiwan's survey found that the overall rates of mental disorders were consistently higher in urban areas than rural areas. Children who live in the urban area were more likely to have IED (odds ratio, OR=9.19, 95% confidence interval (CI) of OR, 1.85–45.66), DMDD (OR=22.54, 95% CI, 4.29–118.42), RAD (OR=1.95, 95% CI, 1.23–116.25), and suicide-related problems (plan and attempt) (OR=1.99, 95% CI, 1.07–3.73) when compared with those who live in rural areas.

Such findings revealed by Taiwan's survey are consistent with some recent studies (Sharma et al., 2016; Vassos, Agerbo, Mors, & Pedersen, 2016; Weaver, Himle, Taylor, Matusko, & Abelson, 2015) but contrary to earlier Taiwan's study by Tsai et al. (2005). The change might reflect that social and environmental transformation, and that social inequality might have affected the mental health of children (Fu, Lee, Gunnell, Lee, & Cheng, 2013). The increased stigma of mental disorders in modern urban cities may be another reason (Ta et al., 2016).

3.4 Socioeconomic status

The association between poverty/low income and poor mental health is another particular concern in current psychiatric research (McLeod & Shanahan, 1993). Such associations can be explained by poor parenting, psychological distress, and adverse developmental experiences such as trauma, bullying, and substance use (McLeod & Shanahan, 1993) and are closely linked and interacted in a complex negative cycle (Funk, Drew, & Knapp, 2012). In addition the impact of differential social capital in rural and urban on mental health may be another reason. It has been hypothesized that the low social capital of a population would lead to increasing the prevalence of mental disorders (Henderson & Whiteford, 2003). The current literature has two hypotheses with opposite directions to interpret the causal relationships of low socioeconomic status and mental disorders: social selection and causation (Mossakowski, 2014). Amongst the measures of socioeconomic status, community income (mean incomes of households in a community) is amongst common measures in large-scale epidemiological studies. Taiwan's survey found that children who lived in areas with lower community income were more likely to have neurodevelopmental disorders (particularly in ASD and ADHD), suicide attempts, ARFID, RAD, and any mental disorders. However, we found higher suicidal ideation in children who lived in higher community income than those in lower community income across the three graders (ages 8–14), particularly significantly in Grade 5 children (ages of 8–9).

Taiwan's finding of urban–rural differences and low community income on mental disorders seems to be paradoxical at the first glance, that is, the community income is usually higher in an urban area than in a rural area. However, this finding may indicate that these two social environmental factors may share common underlying mental health hazards such as childhood adversity, socioeconomic stress (Bradley & Corwyn, 2002), and parental neglect due to work or psychopathology (Ethier, Lacharite, & Couture, 1995). Several disorders including depressive disorders, suicide-related problems, and RAD are all associated with living in urban areas and low socioeconomic communities. These disorders were subject to family and environmental factors as well as life stress (Brent, 1995),

supporting the social causation hypothesis—economic stress and related adversity increase the risk of subsequent mental illness, which may further cause lower socioeconomic status for the next generation (social selection hypothesis). Community income was positively correlated with suicide ideation yet inversely correlated with a suicide attempt, which is consistent with the previous study (Toprak, Cetin, Guven, Can, & Demircan, 2011). These results suggest that different levels of family economic pressure on children and adolescents may lead to distinct stressors for suicide ideation and attempt.

Since ASD can be highly explained by biological and genetic factors (Geschwind, 2009), children with ASD compared with healthy individuals had a higher likelihood of living in communities with lower income that may be explained by high maternal unemployment rate and the large economic and care burden in the ASD family (Chang et al., 2018). The expenditure is not affordable in general family. It has been reported that American family with one ASD child would have an additional \$3020 and \$14,061 in healthcare and nonhealthcare costs, respectively (Lavelle et al., 2014).

4 Disease burden of child mental disorders between clinic and community settings

The GBD framework synthesizes epidemiological measures, such as prevalence, incidence, and mortality, to estimate the disease burden based in epidemiological data (Lopez, 2006). In the current GBD framework regarding the estimation of disease burden in mental disorders, data from community studies is most commonly used (Eaton et al., 2008; Ustün, 1999; Üstün, Ayuso-Mateos, Chatterji, Mathers, & Murray, 2004). Although a few countries such as the United Kingdom and United States (Kessler et al., 2012) have their national surveys in large representative samples, these countries did not have a universal healthcare system with comparable nationally representative clinic-based data, and the treated prevalence from the clinic-based data is seldom reported (Bijl et al., 2003). The obstacle to the comparison may be the lack of reliable clinic-based data from a nationally representative sample; hence, GBD studies did not include the comparison between community-based and clinic-based data (Eaton et al., 2008; Wittchen et al., 2011). Lack of such crucial information may prevent the government from identifying an unmet need in healthcare and subsequently impede allocating the resources to the people in need efficiently.

For instance, although there are two large healthcare systems, that is, Medicaid and Medicare in the United States, the enrollees in these systems are not representative because Medicaid and Medicare are developed for

adults aged 65 and older, and people with a severe disability or low income. It has been reported that the prevalence of common mental disorders such as MDD and substance use disorders is higher in the Medicaid and Medicare enrollees than amongst the general population (Adelmann, 2003; Thomas et al., 2005). The possible explanation of this phenomenon is that those who join Medicaid and Medicare are socially vulnerable and generally less healthy (Adelmann, 2003; Thomas et al., 2005). In specific healthcare systems with low population coverage, these enrollees would share specific characteristics, thus leading to selection bias. Selection bias is the key reason why the administrative data has rarely been used in the GBD framework. Only the administrative data from a national or quasi-national healthcare system is recommended (Lopez, 2006).

Taiwan may serve as the best example to address the issue mentioned earlier since reliable data from both sources is available. In addition to Taiwan's recent survey, Taiwan started the National Health Insurance in 1995, which has medical coverage for all the people living in Taiwan (> 99%) (National Health Research Institutes, 2013). The Taiwan National Health Insurance Database (TNHID) has been established for research purposes. The estimate of treated prevalence in the TNHID should be unbiased due to its near 100% coverage.

The TNHID is a medical claims database, including patients' demographics, diagnoses, treatments, medical expenditures, and prescriptions. We utilized the outpatient and ambulatory claims derived from TNHID to compute the prevalence rates. As of 2016, amongst the total population ($N=23,539,816$) population in Taiwan, TNHID had coverage of 99.9% ($N=23,443,972$) enrollees (National Health Research Institutes, 2013). After age matching to Taiwan's survey (aged 8–14), 1,389,372 child enrollees (girl = 663,752 and boy = 726,120) in TNHID 2016 were included in the analysis.

The diagnoses for enrollees in TNHID were identified based on a recorded International Classification of Disease, Ninth Revision (ICD-9) code 290 to 319. Specific ICD-9 code for each mental disorder was made according to the GBD Study 2016 (Institute for Health Metrics and Evaluation, 2017a).

We used the YLDs to measure the disease burden of mental disorders because mortality is relatively uncommon in mental disorders. The YLDs was computed by using the product of the prevalence rates based on epidemiological data and estimates of disease disability. We used the disability weights for mental disorders defined in the GBD 2016 to define the disease disability (Institute for Health Metrics and Evaluation, 2017b). We compared the explained proportion of YLDs for each mental disorder (sum of the explained proportions of YLDs for all the mental disorders assessed herein is equal to 100%) from Taiwan's survey and TNHID with GBD 2016 using the latter's results of 5- to 14-year age group obtained

from the GBD Compare Data Visualization (<https://vizhub.healthdata.org/gbd-compare/>) (Institute for Health Metrics and Evaluation, 2017a).

A rates ratio (RR) of YLDs was reported to describe the size of the difference in YLDs rates between Taiwan's survey and TNHID using the TNHID as the reference. If the RR of YLDs for a particular mental disorder is > 1 , it indicates that the YLD rate of this mental disorder was higher in Taiwan's epidemiological survey (community-based) than TNHID (clinic-based). Ninety-five percent uncertainty interval (UI) is calculated using Katz's logarithm method. If the 95% UI of RR of YLDs includes the null value of 1, there is no statistically significant difference.

Our analysis of YLDs showed different patterns of prevalence rates in mental disorders between community-based and clinic-based data. In Taiwan's survey (community-based), the most prevalent mental disorders were anxiety disorders (12.0%) and ADHD (8.7%), followed by CD/ODD, ASD, and the other disorders $< 1\%$. By contrast the prevalence rates of mental disorders were much lower in TNHID with the most prevalent disorder for ADHD (2.7%), followed by ASD (0.4%), CD/ODD (0.2%), and the other disorders $< 0.1\%$. These figures were also reflected in the YLDs between the two datasets. For the disorders with notable YLD rates (Taiwan's survey vs TNHID), the highest is ADHD (0.401% vs 0.120%), followed by CD/ODD (0.384% vs 0.038%), anxiety disorders (0.351% vs 0.001%), and ASD (0.253% vs 0.113%). Depressive disorders and schizophrenia contributed to relatively less YLDs rates in these two datasets. The overall YLD rate for mental disorders in children was 1.576% for Taiwan's survey and 0.292% for TNHID. According to the analysis of RR of YLDs, the estimates of YLDs for mental disorders in Taiwan's survey were consistently greater than those in TNHID. The overall YLD rate from all mental disorders in Taiwan's survey was 5.24 times (95% UI: 4.15–6.70) more than those in TNHID, with the lowest and highest YLDs RR for anxiety disorders (RR: 351.00 and 95% UI: 175.05–703.80) and ASD (RR: 2.24 and 95% UI: 1.28–3.93), respectively.

We also compared the explained proportion of YLDs for mental disorders amongst Taiwan's survey, TNHID, and GBD 2016. Compared with GBD 2016, Taiwan's survey and TNHID had a higher proportion of YLDs explained by ADHD (25.42% and 40.96% vs 2.46%), but a lower proportion in the MDD/PDD (4.68% and 5.12% vs 15.63%). The total proportion explained by CD/ODD and anxiety disorders were similar between GBD 2016 (34.49% and 29.70%) and Taiwan's survey (24.37% and 22.27%), but lower in TNHID (13.01% and 0.34%), respectively. Especially, anxiety disorders had much lower explained proportion of YLDs in TNHID (0.34%) than Taiwan's survey and GBD 2016.

Regarding the comparison between Taiwan's survey and TNHID, ADHD (25.42% vs 40.96%) and ASD (16.07% vs 38.57%) accounted for the substantial proportion of YLDs with higher proportion in clinic-based

(TNHID) than community-based data. On the other hand, depressive disorders and other mental disorders had a comparatively small proportion of total YLDs in Taiwan's survey and TNHID.

In this section, we describe the first study comparing the disease burden, regarding YLDs, of mental disorders in children between community-based and clinic-based data: a national survey and national health insurance dataset, respectively. We found that the overall estimated YLDs of mental disorders in children and young adolescents from the community-based data was 5.24 times more than those in the clinic-based data, ranging from 2.24- to 351.00-folds across different mental disorders. The significant gap of YLDs may mostly come from the prevalence difference between Taiwan's survey and TNHID as well as disability weight between mental disorders. Three possible explanations might account for the low treated prevalence of mental disorders in children found in TNHID: (1) insufficient access to medical and psychiatric service, (2) stigma of the mental disorders, and (3) parent's low awareness of children's mental disorders. Taking the first possible explanation, after the launch of Taiwan's National Health Insurance in 1995, the cost of the clinical visit is not expensive (about 5–10 US dollars), and it is easy to see psychiatrists in Taiwan. The average number of clinical visits to doctors amongst the National Health Insurance enrollees is 15.36 visits per year ([Ministry of Health and Welfare, 2016](#)). Furthermore the human resources of mental healthcare professionals in Taiwan are in the same range as those in high-income countries. For example, the number of psychiatrists and child psychiatrists in Taiwan was 7.4 per 100,000 population and 5.8 per 100,000 youth with an age range from 0 to 17 ([National Statistics, 2016](#)). These figures are close and even higher than those in high-income countries (over 7 per 100,000 population) reported by [World Health Organization \(2014\)](#) and in the United States (8.7 per 100,000 youth) ([Thomas & Holzer, 2006](#)).

On the other hand, some evidence supports the other two explanations. The stigma of mental disorders is prevalent and even more severe in Asian countries compared with Western ones ([Ng, 1997](#)). Moreover, in the long working hours in Taiwan, the average annual hours worked in Taiwan is 2034 h ranking sixth in the world ([Organisation for Economic Co-operation and Development, 2017](#)), which might prevent parents from providing adequate care to, and notice behavioral and emotional problems of their children. Even if they notice their children's problems, they may be too busy to take their children to visit psychiatrists and other child mental health professionals such as psychologists, counselors, and pediatricians.

Surprisingly, ADHD only accounts for a small proportion of YLDs, whereas the depressive disorders explain notable proportions of YLDs for the age group of 5–14-years in the GBD 2016. The debate about the relative ranking in mental disorders in children has been reported ([Erskine et al., 2015](#)). It is reported that the previous GBD framework might overestimate

the contribution of MDD amongst all mental disorders. For example, in the GBD 2010 for ages of 5–14 years, MDD accounted for almost 50% of all mental disorders YLDs (Erskine et al., 2015). Although recent GBD studies showed different results, MDD and CD accounted for about 15% and one-third in all mental disorders YLDs in the GBD 2016, respectively. Such a figure might still overestimate the contribution of MDD and underestimate the contribution of ADHD in this young age group. As a result, ADHD has never been shown on the list of top 20 diseases causing the most DALYs in any countries, but CD and anxiety disorders usually are the first and second amongst mental disorders, whereas MDD and ASD alternated between ranking third or fourth in the GBD 2015 in children (Baranne & Falissard, 2018). Whether the comparatively low disability weight of ADHD, that is, merely 0.045, explains the underestimate of YLDs is uncertain (Baranne & Falissard, 2018). However, we found that ADHD attributed to a notable proportion of YLDs in all mental disorders in both Taiwan's survey and TNHID. Underestimation of the prevalence of ADHD in the GBD framework might be one of the explanations. This claim is supported in the GBD 2016, which reported a similar number of ADHD and ASD cases in thousand (62,624 vs 62,174) in the whole populations estimated (Vos et al., 2017). Such finding is contradictory to the current literature, that is, ADHD is much more prevalent than ASD.

ADHD and ASD shared high and similar proportions of YLDs in both data, whereas the explained proportions of total YLDs in anxiety disorders and CD/ODD were lower in TNHID than Taiwan's survey and GBD 2016. It is possible that ADHD and ASD are more common and pervasive with significant behavioral problems and functional impairment since early childhood, which can be easily observed by parents, teachers, and significant others (Jang et al., 2013). On the other hand, anxiety disorders in children may be underestimated by their parents if they did not speak out their worry and anxiety; CD/ODD in children may not be considered as mental disorders that need medical care from the parents. This explanation was supported by previous studies that reported the low detection, referral, and treated rates in these disorders amongst children (Hughes, Crothers, & Jimerson, 2007). However, anxiety disorders and CD/ODD in childhood may have an adverse impact on their psychosocial dysfunctions in adolescence and adulthood. For example, childhood anxiety disorders are associated with depression in later life (Egger & Angold, 2006); CD/ODD in childhood predicts the risks of antisocial personality disorders and substance use disorders in adulthood (Egger & Angold, 2006). These results call for more efforts on mental health promotion and prevention of childhood anxiety disorders and CD/ODD.

Despite potentially underestimating the YLD differences between community-based and clinic-based data, our findings have provided strong evidence to indicate that the estimated YLDs of overall child mental

disorders in the clinic-based data was significantly lower than the data obtained from a national epidemiological study. Our results highlight the lack of provision of medical and nonmedical resources and efforts for children with an unmet need for mental healthcare.

5 Conclusion and implications

Combining several lines of evidence and Taiwan's studies on the prevalence rates, major risk factors, and disease burdens of child mental disorders, we gave the following conclusions. First, mental disorders are common not only in adults but also in children and adolescents. Second, we found relatively consistent results in the effects of sex, age, urban-rural, and socioeconomic status across countries. Third the disease burdens of some child mental disorders may be underestimated. Taiwan's survey is the first national epidemiological study to estimate the DSM-5 child mental disorders, which provided substantial evidence to indicate that mental disorders in Taiwanese children are common and their rates corresponded to the DSM-IV prevalence rates reported in Western countries (Chen et al., 2020). The trends for increase of ADHD, MDD, and ASD may be explained by the change of diagnostic criteria in the DSM-5, increasing awareness of child mental disorders, or actual increase in prevalence rates over time. These explanations need further investigation. Emerging evidence supports the existence of some new DSM-5 diagnoses such as ARFID and DMDD. The overall YLDs from all mental disorders in Taiwan's survey (community-based) were much higher than those in TNHID (clinic-based). Unlike ADHD and ASD the total proportions explained by anxiety disorders and CD/ODD were significantly lower in TNHID than those in Taiwan's survey and GBD 2016. As regards to the different prevalence rates across countries (Table 1), in addition to methodological reasons, it is warranted to investigate whether there could be some actual differences in prevalences and identify the factors for such differences.

The implications of the findings from national surveys in several countries and Taiwan include the urgent need for early detection of neurodevelopmental disorders (such as ASD, ADHD, tic disorders, and other developmental delays) and childhood attachment and anxiety disorders and secondary and tertiary prevention of these mental disorders in both community and clinic settings. There is a need to promote public awareness of child mental disorders and highlight the priorities for future mental health policies of prevention, early detection, and intervention for the youth population. Regarding the implications of disease burden, the findings of significant differences in YLD estimation between community-based and clinic-based data suggest that more outreach programs are needed to

reduce possible barriers to mental healthcare, and the budget analysis and cost-effective analysis may be the next step to provide the estimate of future possible financial reimbursement of mental healthcare in the child and adolescent populations based on the differences of YLDs. Moreover the disability weight of mental disorders in the GBD framework is outdated, incomplete, and unable to capture the current practice in psychiatry. For example, the definitions of some mental disorders are too broad. OCD and PTSD have been removed from anxiety disorders in the DSM-5. However, in the GBD 2016, they still included OCD and PTSD in the category of anxiety disorders based on the ICD. On the other hand the disability weight for ADHD is too low to reflect its true disease burden.

Several suggestions for research are proposed herein. First the comparison of the prevalence rates of mental disorders based on DSM-IV and DSM-5 has not been throughout examined. Second, in addition to demographic and psychosocial risk factors, some important risk factors, especially environmental exposures and biological factors, need to be included in the epidemiological studies to provide a comprehensive set of risk factors for child and adolescent mental disorders. Third, further exploration of the community-clinic difference of disease burden regarding physical and mental disorders across the lifespan is suggested. Lastly the estimation of the age- and sex-specific disease burden of physical and mental disorders in addition to YLLs and DALYs between community-based and clinic-based data is warranted.

References

- Achenbach, T. M., & Edelbrock, C. S. (1983). *Manual for the child behavior checklist*. University of Vermont, Department of Psychiatry.
- Adelmann, P. K. (2003). Mental and substance use disorders among Medicaid recipients: Prevalence estimates from two national surveys. *Administration and Policy in Mental Health and Mental Health Services Research, 31*, 111–129.
- Ambrosini, P. J. (2000). Historical development and present status of the schedule for affective disorders and schizophrenia for school-age children (K-SADS). *Journal of the American Academy of Child & Adolescent Psychiatry, 39*, 49–58.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders, third edition (DSM-III)*. Washington, DC: American Psychiatric Publishing.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders, fourth edition (DSM-IV)*. Washington, DC: American Psychiatric Publishing.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5)*. Washington, DC: American Psychiatric Publishing.
- Baranne, M. L., & Falissard, B. (2018). Global burden of mental disorders among children aged 5–14 years. *Child and Adolescent Mental Health, 12*, 19.
- Baxter, A., Brugha, T., Erskine, H., Scheurer, R., Vos, T., & Scott, J. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine, 45*, 601–613.
- Baxter, A., Vos, T., Scott, K. M., Ferrari, A. J., & Whiteford, H. A. (2014). The global burden of anxiety disorders in 2010. *Psychological Medicine, 44*, 2363–2374.
- Bijl, R. V., de Graaf, R., Hiripi, E., Kessler, R. C., Kohn, R., Offord, D. R., et al. (2003). The prevalence of treated and untreated mental disorders in five countries. *Health Affairs, 22*, 122–133.

- Bongers, I. L., Koot, H. M., van der Ende, J., & Verhulst, F. C. (2003). The normative development of child and adolescent problem behavior. *Journal of Abnormal Psychology, 112*, 179–192.
- Bradley, R. H., & Corwyn, R. F. (2002). Socioeconomic status and child development. *Annual Review of Psychology, 53*, 371–399.
- Brent, D. A. (1995). Risk factors for adolescent suicide and suicidal behavior: Mental and substance abuse disorders, family environmental factors, and life stress. *Suicide & Life-Threatening Behavior, 25*, 52–63.
- Bulik, C. M., Sullivan, P. F., Tozzi, F., Furberg, H., Lichtenstein, P., & Pedersen, N. L. (2006). Prevalence, heritability, and prospective risk factors for anorexia nervosa. *JAMA Psychiatry, 63*, 305–312.
- Burke, J. D., Loeber, R., Lahey, B. B., & Rathouz, P. J. (2005). Developmental transitions among affective and behavioral disorders in adolescent boys. *Journal of Child Psychology and Psychiatry, 46*, 1200–1210.
- Chang, J. P., Lai, M. C., Chou, M. C., Shang, C. Y., Chiu, Y. N., Tsai, W. C., et al. (2018). Maternal and family processes in different subgroups of youth with autism spectrum disorder. *Journal of Abnormal Child Psychology, 8*, 018–0404.
- Chen, C. H., Chen, H. I., Chien, W. H., Li, L. H., Wu, Y. Y., Chiu, Y. N., et al. (2017). High resolution analysis of rare copy number variants in patients with autism spectrum disorder from Taiwan. *Scientific Reports, 7*, 11919. <https://doi.org/10.1038/s41598-017-12081-4>.
- Chen, Y. Y., Chen, Y. L., & Gau, S. S. (2019). Attention-deficit hyperactivity disorder and suicidality: The mediating effects of psychiatric comorbidities and family function. *Journal of Affective Disorders, 242*, 96–104. <https://doi.org/10.1016/j.jad.2018.08.023>. Epub 2018 Aug 24.
- Chen, Y. L., Chen, W. J., Lin, K. C., Shen, L. J., & Gau, S. S. (2020). Prevalence of DSM-5 mental disorders in a nationally representative sample of children in Taiwan: Methodology and main findings. *Epidemiology and Psychiatric Sciences, 29*, e15.
- Coccaro, E. F. (2012). Intermittent explosive disorder as a disorder of impulsive aggression for DSM-5. *American Journal of Psychiatry, 169*, 577–588.
- Copeland, W. E., Angold, A., Costello, E. J., & Egger, H. (2013). Prevalence, comorbidity, and correlates of DSM-5 proposed disruptive mood dysregulation disorder. *American Journal of Psychiatry, 170*, 173–179.
- Costello, E. J., Egger, H., & Angold, A. (2005). 10-year research update review: The epidemiology of child and adolescent psychiatric disorders: I. Methods and public health burden. *Journal of the American Academy of Child & Adolescent Psychiatry, 44*, 972–986.
- Costello, E. J., Mustillo, S., Erkanli, A., Keeler, G., & Angold, A. (2003). Prevalence and development of psychiatric disorders in childhood and adolescence. *JAMA Psychiatry, 60*, 837–844.
- Dohrenwend, B. P., & Dohrenwend, B. S. (1974). *American handbook of psychiatry*. American Psychological Association.
- Eaton, W. W., Martins, S. S., Nestadt, G., Bienvenu, O. J., Clarke, D., & Alexandre, P. (2008). The burden of mental disorders. *Epidemiologic Reviews, 30*, 1–14.
- Egger, H. L., & Angold, A. (2006). Common emotional and behavioral disorders in preschool children: Presentation, nosology, and epidemiology. *Journal of Child Psychology and Psychiatry, 47*, 313–337.
- Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., et al. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research, 5*, 160–179.
- Erskine, H. E., Ferrari, A. J., Polanczyk, G. V., Moffitt, T. E., Murray, C. J., Vos, T., et al. (2014). The global burden of conduct disorder and attention-deficit/hyperactivity disorder in 2010. *Journal of Child Psychology and Psychiatry, 55*, 328–336.
- Erskine, H. E., Moffitt, T. E., Copeland, W. E., Costello, E. J., Ferrari, A. J., Patton, G., et al. (2015). A heavy burden on young minds: The global burden of mental and substance use disorders in children and youth. *Psychological Medicine, 45*, 1551–1563.

- Ethier, L. S., Lacharite, C., & Couture, G. (1995). Childhood adversity, parental stress, and depression of negligent mothers. *Child Abuse & Neglect*, *19*, 619–632.
- Fairchild, G., Hawes, D. J., Frick, P. J., Copeland, W. E., Odgers, C. L., Franke, B., et al. (2019). Conduct disorder. *Nature Reviews Disease Primers*, *5*, 43. <https://doi.org/10.1038/s41572-019-0095-y>.
- Farbstein, I., Mansbach-Kleinfeld, I., Levinson, D., Goodman, R., Levav, I., Vograft, I., et al. (2010). Prevalence and correlates of mental disorders in Israeli adolescents: Results from a national mental health survey. *Journal of Child Psychology and Psychiatry*, *51*, 630–639.
- Ford, T., Goodman, R., & Meltzer, H. (2003). The British child and adolescent mental health survey 1999: The prevalence of DSM-IV disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, *42*, 1203–1211.
- Frigerio, A., Rucci, P., Goodman, R., Ammaniti, M., Carlet, O., Cavolina, P., et al. (2009). Prevalence and correlates of mental disorders among adolescents in Italy: The PRISMA study. *European Child & Adolescent Psychiatry*, *18*, 217–226.
- Fu, T.S.-T., Lee, C.-S., Gunnell, D., Lee, W.-C., & Cheng, A.T.-A. (2013). Changing trends in the prevalence of common mental disorders in Taiwan: A 20-year repeated cross-sectional survey. *Lancet*, *381*, 235–241.
- Funke, M., Drew, N., & Knapp, M. (2012). Mental health, poverty and development. *Journal of Public Mental Health*, *11*, 166–185.
- Gau, S. S., Chong, M. Y., Yang, P., Yen, C. F., Liang, K. Y., & Cheng, A. T. (2007). Psychiatric and psychosocial predictors of substance use disorders among adolescents: Longitudinal study. *The British Journal of Psychiatry*, *190*, 42–48.
- Geschwind, D. H. (2009). Advances in autism. *Annual Review of Medicine*, *60*, 367–380.
- Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *38*, 581–586.
- Goodman, R., Ford, T., Richards, H., Gatward, R., & Meltzer, H. (2000). The development and well-being assessment: Description and initial validation of an integrated assessment of child and adolescent psychopathology. *Journal of Child Psychology and Psychiatry*, *41*, 645–655.
- Goodman, R., Meltzer, H., & Bailey, V. (1998). The strengths and difficulties questionnaire: A pilot study on the validity of the self-report version. *European Child & Adolescent Psychiatry*, *7*, 125–130.
- Henderson, S., & Whiteford, H. (2003). Social capital and mental health. *Lancet*, *362*, 505–506.
- Hughes, T. L., Crothers, L. M., & Jimerson, S. R. (2007). *Identifying, assessing, and treating conduct disorder at school*. Springer Science & Business Media.
- Institute for Health Metrics and Evaluation. (2017a). *GBD compare data visualization*. Seattle, WA: IHME, University of Washington. 2017. Available.
- Institute for Health Metrics and Evaluation. (2017b). *Global Burden of Disease Study 2016 (GBD 2016) causes of death and nonfatal causes mapped to ICD codes*. IHME.
- Jang, J., Matson, J. L., Williams, L. W., Tureck, K., Goldin, R. L., & Cervantes, P. E. (2013). Rates of comorbid symptoms in children with ASD, ADHD, and comorbid ASD and ADHD. *Research in Developmental Disabilities*, *34*, 2369–2378.
- Kessler, R. C., Aguilar-Gaxiola, S., Alonso, J., Chatterji, S., Lee, S., Ormel, J., et al. (2009). The global burden of mental disorders: An update from the WHO World Mental Health (WMH) surveys. *Epidemiology and Psychiatric Sciences*, *18*, 23–33.
- Kessler, R. C., Amminger, G. P., Aguilar-Gaxiola, S., Alonso, J., Lee, S., & Ustun, T. B. (2007). Age of onset of mental disorders: A review of recent literature. *Current Opinion in Psychiatry*, *20*, 359.
- Kessler, R. C., Avenevoli, S., Costello, E. J., Georgiades, K., Green, J. G., Gruber, M. J., et al. (2012). Prevalence, persistence, and sociodemographic correlates of DSM-IV disorders in the National Comorbidity Survey Replication Adolescent Supplement. *JAMA Psychiatry*, *69*, 372–380.

- Kessler, R. C., Coccaro, E. F., Fava, M., Jaeger, S., Jin, R., & Walters, E. (2006). The prevalence and correlates of DSM-IV intermittent explosive disorder in the National Comorbidity Survey Replication. *JAMA Psychiatry*, *63*, 669–678.
- Kessler, R. C., & Üstün, T. B. (2004). The world mental health (WMH) survey initiative version of the world health organization (WHO) composite international diagnostic interview (CIDI). *International Journal of Methods in Psychiatric Research*, *13*, 93–121.
- Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., et al. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, *168*, 904–912.
- Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders. *Pediatrics*, *133*, e520–e529.
- Leckman, J. F., & Bloch, M. H. (2008). A developmental and evolutionary perspective on obsessive-compulsive disorder: Whence and whither compulsive hoarding? *American Journal of Psychiatry*, *165*, 1229–1233.
- Lee, M. T., Wong, B. P., Chow, B. W. Y., & McBride-Chang, C. (2006). Predictors of suicide ideation and depression in Hong Kong adolescents: Perceptions of academic and family climates. *Suicide and Life-threatening Behavior*, *36*, 82–96.
- Lensi, P., Cassano, G. B., Correddu, G., Ravagli, S., Kunovac, J., & Akiskal, H. S. (1996). Obsessive-compulsive disorder: Familial-developmental history, symptomatology, comorbidity and course with special reference to gender-related differences. *British Journal of Psychiatry*, *169*, 101–107.
- Lin, H. C., Tang, T. C., Yen, J. Y., Ko, C. H., Huang, C. F., Liu, S. C., et al. (2008). Depression and its association with self-esteem, family, peer and school factors in a population of 9586 adolescents in southern Taiwan. *Psychiatry and Clinical Neurosciences*, *62*, 412–420.
- Liu, S. K., Chien, Y. L., Shang, C. Y., Lin, C. H., Liu, Y. C., & Gau, S. S. (2013). Psychometric properties of the Chinese version of strength and difficulties questionnaire. *Comprehensive Psychiatry*, *20*, 00029-1.
- Liu, C., Hung, Y., Chuang, Y., Chen, Y., Weng, W., Liu, J., et al. (2006). Incorporating development stratification of Taiwan townships into sampling design of large scale health interview survey. *Journal of Health Management*, *4*, 1–22.
- Loeber, R., Burke, J. D., Lahey, B. B., Winters, A., & Zera, M. (2000). Oppositional defiant and conduct disorder: A review of the past 10 years, part I. *Journal of the American Academy of Child & Adolescent Psychiatry*, *39*, 1468–1484.
- Lopez, A. D. (2006). *Global burden of disease and risk factors*. Washington, DC: World Bank Publications.
- Maughan, B., Rowe, R., Messer, J., Goodman, R., & Meltzer, H. (2004). Conduct disorder and oppositional defiant disorder in a national sample: Developmental epidemiology. *Journal of Child Psychology and Psychiatry*, *45*, 609–621.
- McLeod, J. D., & Shanahan, M. J. (1993). Poverty, parenting, and children's mental health. *American Sociological Review*, *58*, 351–366.
- Merikangas, K. R., Avenevoli, S., Costello, E. J., Koretz, D., & Kessler, R. C. (2009). National comorbidity survey replication adolescent supplement (NCS-A): I. Background and measures. *Journal of the American Academy of Child & Adolescent Psychiatry*, *48*, 367–379.
- Merikangas, K. R., He, J.-P., Burstein, M., Swanson, S. A., Avenevoli, S., Cui, L., et al. (2010). Lifetime prevalence of mental disorders in US adolescents: Results from the national comorbidity survey replication-adolescent supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry*, *49*, 980–989.
- Ministry of Health and Welfare. (2016). *Information of Medical statistics for National Health Insurance*. (ed. D. o. Statistics): Taipei.
- Ministry of Welfare and Health. (2017). *2016 causes of death statistics Taipei*.
- Mossakowski, K. N. (2014). Social causation and social selection. In *Wiley Blackwell encyclopedia of health, illness, behavior, and society*. John Wiley & Sons, Ltd.

- National Health Research Institutes. (2013). *Introduction to the National Health Insurance Research Database (NHIRD)*, Taiwan Taipei.
- National Statistics. (2016). *Statistics of medical services and health professionals*. Taipei.
- Ng, C. H. (1997). The stigma of mental illness in Asian cultures. *Australian and New Zealand Journal of Psychiatry*, 31, 382–390.
- Nock, M. K., Green, J. G., Hwang, I., McLaughlin, K. A., Sampson, N. A., Zaslavsky, A. M., et al. (2013). Prevalence, correlates, and treatment of lifetime suicidal behavior among adolescents: Results from the national comorbidity survey replication–adolescent supplement. *JAMA Psychiatry*, 70, 300–310.
- Organisation for Economic Co-operation and Development. (2017). *Hours worked*.
- Park, J. H., Bang, Y. R., & Kim, C. K. (2014). Sex and age differences in psychiatric disorders among children and adolescents: High-risk students study. *Psychiatry Investigation*, 11, 251–257.
- Patel, V., Flisher, A. J., Hetrick, S., & McGorry, P. (2007). Mental health of young people: A global public-health challenge. *Lancet*, 369, 1302–1313.
- Peen, J., Schoevers, R. A., Beekman, A. T., & Dekker, J. (2010). The current status of urban-rural differences in psychiatric disorders. *Acta Psychiatrica Scandinavica*, 121, 84–93.
- Polanczyk, G., de Lima, M. S., Horta, B. L., Biederman, J., & Rohde, L. A. (2007). The worldwide prevalence of ADHD: A systematic review and metaregression analysis. *American Journal of Psychiatry*, 164, 942–948.
- Ravens-Sieberer, U., Wille, N., Erhart, M., Bettge, S., Wittchen, H.-U., Rothenberger, A., et al. (2008). Prevalence of mental health problems among children and adolescents in Germany: Results of the BELLA study within the National Health Interview and Examination Survey. *European Child & Adolescent Psychiatry*, 17, 22–33.
- Riecher-Rössler, A. (2017). Sex and gender differences in mental disorders. *Lancet Psychiatry*, 4, 8–9.
- Robins, L. N., Helzer, J., Croughan, J., & Ratcliff, K. S. (1981). Diagnostic interview schedule. *JAMA Psychiatry*, 38, 381–389.
- Rowe, R., Costello, E. J., Angold, A., Copeland, W. E., & Maughan, B. (2010). Developmental pathways in oppositional defiant disorder and conduct disorder. *Journal of Abnormal Psychology*, 119, 726.
- Sakai, J. T., Risk, N. K., Tanaka, C. A., & Price, R. K. (2008). Conduct disorder among Asians and Native Hawaiian/Pacific Islanders in the USA. *Psychological Medicine*, 38, 1013–1025.
- Sawyer, M. G., Arney, F. M., Baghurst, P. A., Clark, J. J., Graetz, B. W., Kosky, R. J., et al. (2001). The mental health of young people in Australia: Key findings from the child and adolescent component of the National Survey of Mental Health and Well-being. *Australian and New Zealand Journal of Psychiatry*, 35, 806–814.
- Seedat, S., Scott, K. M., Angermeyer, M. C., Berglund, P., Bromet, E. J., Brugha, T. S., et al. (2009). Cross-national associations between gender and mental disorders in the World Health Organization World Mental Health Surveys. *JAMA Psychiatry*, 66, 785–795.
- Sharma, S., Raina, S. K., Bhardwaj, A. K., Chaudhary, S., Kashyap, V., & Chander, V. (2016). Prevalence of mental retardation in urban and rural populations of the goiter zone in Northwest India. *Indian Journal of Public Health*, 60, 131.
- Ta, T. M. T., Zieger, A., Schomerus, G., Cao, T. D., Dettling, M., Do, X. T., et al. (2016). Influence of urbanity on perception of mental illness stigma: A population based study in urban and rural Hanoi, Vietnam. *International Journal of Social Psychiatry*, 62, 685–695.
- Tan, J. B., & Yates, S. (2011). Academic expectations as sources of stress in Asian students. *Social Psychology of Education*, 14, 389–407.
- Tang, T. C., Ko, C. H., Yen, J. Y., Lin, H. C., Liu, S. C., Huang, C. F., et al. (2009). Suicide and its association with individual, family, peer, and school factors in an adolescent population in southern Taiwan. *Suicide & Life-Threatening Behavior*, 39, 91–102.
- Thomas, C. R., & Holzer, C. E. (2006). The continuing shortage of child and adolescent psychiatrists. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45, 1023–1031.

- Thomas, M. R., Waxmonsky, J. A., Gabow, P. A., Flanders-McGinnis, G., Socherman, R., & Rost, K. (2005). Prevalence of psychiatric disorders and costs of care among adult enrollees in a Medicaid HMO. *Psychiatric Services, 56*, 1394–1401.
- Toprak, S., Cetin, I., Guven, T., Can, G., & Demircan, C. (2011). Self-harm, suicidal ideation and suicide attempts among college students. *Psychiatry Research, 187*, 140–144.
- Tsai, T. H., Chen, Y. L., & Gau, S. S. (2019). Relationships between autistic traits, insufficient sleep, and real-world executive function deficits in children: A mediation analysis of a national epidemiological survey. *Psychological Medicine, 1–8*.
- Tsai, F. J., Wu, C. S., & Gau, S. F. (2005). Lithium intoxication and nephrogenic diabetes insipidus in a bipolar patient. *Tzu Chi Medical Journal, 17*, 181–185.
- Uher, R., Payne, J. L., Pavlova, B., & Perlis, R. H. (2014). Major depressive disorder in DSM-5: Implications for clinical practice and research of changes from DSM-IV. *Depression and Anxiety, 31*, 459–471.
- Ustün, T. (1999). The global burden of mental disorders. *American Journal of Public Health, 89*, 1315–1318.
- Üstün, T. B., Ayuso-Mateos, J. L., Chatterji, S., Mathers, C., & Murray, C. J. (2004). Global burden of depressive disorders in the year 2000. *British Journal of Psychiatry, 184*, 386–392.
- van de Glind, G., Konstenius, M., Koeter, M. W. J., van Emmerik-van Oortmerssen, K., Carpentier, P.-J., Kaye, S., et al. (2014). Variability in the prevalence of adult ADHD in treatment seeking substance use disorder patients: Results from an international multi-center study exploring DSM-IV and DSM-5 criteria. *Drug and Alcohol Dependence, 134*, 158–166.
- Vassos, E., Agerbo, E., Mors, O., & Pedersen, C. B. (2016). Urban–rural differences in incidence rates of psychiatric disorders in Denmark. *British Journal of Psychiatry, 208*, 435–440.
- Verhulst, F. C., van der Ende, J., Ferdinand, R. F., & Kasius, M. C. (1997). The prevalence of DSM-III-R diagnoses in a national sample of Dutch adolescents. *JAMA Psychiatry, 54*, 329–336.
- Vos, T., Abajobir, A. A., Abate, K. H., Abbafati, C., Abbas, K. M., Abd-Allah, F., et al. (2017). Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. *Lancet, 390*, 1211–1259.
- Weaver, A., Himle, J. A., Taylor, R. J., Matusko, N. N., & Abelson, J. M. (2015). Urban vs rural residence and the prevalence of depression and mood disorder among African American women and non-Hispanic white women. *JAMA Psychiatry, 72*, 576–583.
- Whiteford, H. A., Degenhardt, L., Rehm, J., Baxter, A. J., Ferrari, A. J., Erskine, H. E., et al. (2013). Global burden of disease attributable to mental and substance use disorders: Findings from the Global Burden of Disease Study 2010. *Lancet, 382*, 1575–1586.
- Wittchen, H.-U., Jacobi, F., Rehm, J., Gustavsson, A., Svensson, M., Jönsson, B., et al. (2011). The size and burden of mental disorders and other disorders of the brain in Europe 2010. *European Neuropsychopharmacology, 21*, 655–679.
- World Health Organization. (1977). *Paper no. 623*.
- World Health Organization. (2014). *Mental health atlas 2014*. Geneva: World Health Organization.
- Yang, H. J., Soong, W. T., Chiang, C. N., & Chen, W. J. (2000). Competence and behavioral/emotional problems among Taiwanese adolescents as reported by parents and teachers. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*, 232–239.
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., & Blumberg, S. J. (2015). *Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey*. Centers for Disease Control and Prevention.
- Zucker, K. J., & Lawrence, A. A. (2009). Epidemiology of gender identity disorder: Recommendations for the standards of care of The World Professional Association for Transgender Health. *International Journal of Transgenderism, 11*, 8–18.

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Cultural psychiatry as the basic science of addressing health and mental health disparities

Anthony P.S. Guerrero and Joy K.L. Andrade

Department of Psychiatry, University of Hawai'i John A. Burns School of Medicine, Honolulu, HI, United States

1 History of psychiatry and diversity

Psychiatry, 'the branch of medicine focussed on the diagnosis, treatment, and prevention of mental, emotional, and behavioural disorders' ([American Psychiatric Association, 2019](#)), is the specialty caring for specific mental or brain functions that make us uniquely human, that are significantly influenced by interactions with other humans and the overall environment, and that are as diverse as the numbers of neurons and neuronal connections in any one brain are plentiful. Psychiatry naturally embraces the diversity of human experience and behaviours.

However, psychiatry, in its history, has not been immune to attitudes and policies that have harmed people representing different varieties of diversity. Some psychiatrists have promoted colonial ideologies that have justified inequality, colonialism, and imperialism ([Pols, 2007](#)), and they have been instrumental in programmes that have sterilized and killed children and adults with disabilities ([Hassenfeld, 2002](#)). Even psychiatrists with otherwise positive regard in the specialty have published racist scientific theories, for example, in proposing that the 'black colour of the Negroes' is a disease ('derived from the leprosy') that could be transmitted via marriage or cohabitation ([Rush, 1799](#)). Indeed, as recently as the 20th century, medical terms (e.g. for trisomy 21) continued to reflect deeply racist theories about evolution and human variation ([Stevenson, 2009](#)).

Certain authors (McKenzie & Bhui, 2007; Sashidharan, 2001) have noted that darker-skinned ethnic minority groups are more likely to be treated with medications and via involuntary admission and that these trends may reflect a continued systemic racism in the way psychiatric care is delivered. Singh and Burns (2006) have presented, somewhat in contrast, that findings of higher rates of psychosis and other mental illnesses in minority groups may reflect stress from discrimination, social exclusion, and urbanicity more so than putative racism and bias affecting diagnosis; that findings of higher rates of detention among minority groups may reflect unemployment, living alone, low levels of social support, and noncompliance with medication more so than racial stereotyping; and that accusations of institutional racism may be counterproductive in feeding into alienation and mistrust of psychiatric services. Based on a review of the evidence, Morgan, Knowles, and Hutchinson (2019) have posited that greater lifetime exposure to systemic social risks—particularly those involving threat, hostility, and violence—likely explain high rates of psychoses in certain migrant and minority ethnic groups.

So even though psychiatry itself may have evolved beyond the degree of institutional racism that existed earlier in its history, there remain other social disadvantages and injustices that impact the people served by the specialty, which is inherently well positioned to understand and effectively address the mechanisms behind such disparities.

2 Evolution of ‘cultural psychiatry’: Training and practice

Cultural psychiatry, described as ‘The comparative study of mental health and mental illness among diverse societies, nations, and cultures and the multiple interrelationships of mental disorders with cultural environments’, is a relatively new field within psychiatry that rose to prominence following post World War II globalization and with the formation of national and international committees focussed on cultural and/or transcultural psychiatry in the 1960s and 1970s (American Psychiatric Association, 2013a, 2013b).

In 1959, Wittkower and Fried described a cross-cultural approach to mental illness that considered differences in incidence or prevalence of mental disorders, differences in manifestations of mental disease, and presence of geography or culture-specific psychiatric syndromes (Wittkower & Fried, 1959). A 1968 survey of US psychiatric residencies indicated that 100 of the 141 programme directors submitting a reply had no programme in transcultural psychiatry (Jeffress, 1969). The examples that programmes provided of transcultural psychiatry training included acceptance of clerks from abroad, visiting lecturers from abroad, inclusion of transcultural subjects in lectures and seminars, presence in programme of ‘natives of

other countries' (with one example being an arrangement to take a resident from Hawai'i) or residents with previous experience abroad, presence of staff from abroad or who trained abroad, clinical work with patients from other cultures, a training programme for psychiatrists from abroad, social psychiatry or anthropology training, cross-cultural affiliations, and trans-cultural psychiatry research. Foulks (1980) argued on the importance of culture in psychiatric residency education, as the cultural model provides 'unique insights and approaches in patient care', and listed various curriculum approaches, including cultural sensitivity groups, didactic courses, field experiences, study groups, and clinical experiences.

As described by Shim (2018), cultural psychiatry has evolved from an initial focus on 'culture-bound syndromes', often reflecting colonial, Western majority perspectives; to an understanding of the way cultures shape psychopathology and training in competence to work with diverse populations; to a modern emphasis on eliminating mental health inequities. The authors of this paper fully embrace the role of cultural psychiatry as a means (rather than an end) to effectively address health and mental health disparities and the importance of integrating cultural psychiatry into contemporary training and practice.

Faced with the need to ensure that the workforce can effectively serve a diverse population, educators of health professionals have made the case for training in cultural competence in medicine and other professions, including clinical psychology (Yutrzenka, 1995). Accrediting organizations in psychiatry, throughout the world, include culturally competent care as part of educational milestones (Corral, Johnson, Shelton, & Glass, 2017) and/or required training modules in caring for indigenous populations (Royal Australian and New Zealand College of Psychiatrists, 2019). In the United States, current psychiatry training requirements include exposure to and competence in working with patients from a variety of ethnic, racial, sociocultural, and economic backgrounds; knowledge of sociocultural, economic, and ethnic factors that significantly develop or impact upon psychiatric conditions; and awareness of cultural elements of the relationship between the resident and the patient of the dynamics of differences in cultural identity, values and preferences, and power (ACGME, 2019a). These requirements are similarly reflected in child and adolescent psychiatry training, which specifies evaluation and treatment of patients from diverse cultural backgrounds and varied socioeconomic levels; knowledge of basic neurobiological, psychological, and clinical sciences relevant to psychiatry and the application of developmental, psychological, and sociocultural theories relevant to the understanding of psychopathology; knowledge of diversity and cultural issues pertinent to children, adolescents, and their families; and instruction in the integration of neurobiological, phenomenological, psychological, and sociocultural issues into a comprehensive formulation of clinical problems (ACGME, 2019b).

Cross-culturally trained physicians, through understanding different perspectives on illness and treatment and through practicing effective communication styles, have an important role in improving rapport, adherence, and outcomes for patients who otherwise may be marginalized or underserved (Juckett, 2005). Cultural formulation interviews (American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th edition [DSM-5]*, 2013b) are examples of tools to 'hard-wire' a culturally effective/culturally humble approach to patient care. The DSM-5 Cultural Formulation Interview includes the consideration of cultural definition of the problem; cultural perceptions of cause, context, and support; and cultural factors affecting coping and help seeking. Owiti et al. (2014) explain that cultural competence is less a static set of skills and more a long-standing personal and professional developmental process that should be facilitated through availability of a cultural consultation resource in clinical settings.

Authors such as Dogra, Vostanis, and Frake (2007) have pointed out the need to evaluate clinical outcomes of cultural diversity training. A review in 2007 by Bhui et al. demonstrated a lack of studies demonstrating service user experiences and outcomes from cultural competence training among mental health providers (Bhui, Warfa, Edonya, McKenzie, & Bhugra, 2007).

Recognizing the mental health impacts of systemic violence and discrimination based on race, ethnicity, religion, sex, and sexual orientation, Hansen, Braslow, and Rohrbaugh (2018) have called upon psychiatric educators to move beyond traditional cultural competency training and to rigorously train residents to better understand social determinants of mental health and work more effectively at system levels to eliminate the structural causes of illness. Modern psychiatric textbooks have described approaches to addressing disparities through practical applications of the Cultural Formulation Interview and an open-minded, continuous formulation-focussed approach (Eckert & Goebert, 2018). The literature is also growing in the area of education to increase awareness of implicit biases that lead to errors in clinical decision-making, particularly in the context of diversity (Sukhera & Watling, 2018). Examples of such implicit biases include unconscious associations that may lead clinicians to be less likely to recommend beneficial care to minority/underprivileged patients versus nonminority/upper socioeconomic status patients. Rousseau, Johnson-Lafleur, Papazian-Zohrabian, and Measham (2018) have discussed the value of interdisciplinary case discussions in teaching cultural formulation in child mental health. Educators have also described the value of global mental health experiences that focus upon disadvantaged populations and that develop leadership in addressing health inequities (Griffith et al., 2016; Lam, Gajaria, Matthews, & Zaheer, 2016).

3 Culture and child and adolescent psychiatry

Prominent organizations in our specialty, including the American Academy of Child and Adolescent Psychiatry (AACAP), have published on the importance of culture in the specialty.

The AACAP practice parameters for cultural competence in child and adolescent psychiatric practice (Pumariega et al., 2013) have highlighted the importance of addressing barriers to obtaining mental health services, conducting interviews in the family's preferred language, understanding the importance of dual-language competence, addressing cultural biases in healthcare delivery, applying knowledge of culture to clinical diagnosis and formulation, screening for and addressing loss or trauma, assessing for acculturation stress and intergenerational acculturation family conflict, including in care the family members and key members of traditional extended families, incorporating cultural strengths in treatment interventions, providing treatment in familiar cultural settings, promoting culturally consonant parent management skills, and considering ethnicity and race in implementing evidence-based psychological and pharmacologic treatments.

Similarly, child and adolescent psychiatrists in Europe have written on the importance of bridging, in mental healthcare, psychopathology, and culture (Bhugra & Bhui, 2018), which shapes the definitions of pathology and influences clinical presentations and response to treatment (Ang, 2017). The paper by Ang (2017) emphasized the importance of cultural formulation that considers cultural identity, cultural conceptualization of illness, psychosocial stressors and culturally related vulnerabilities and strengths, cultural fit in the clinician/patient relationship, and overall cultural assessment including implications on diagnosis and plan of care.

Because of a lack of biological markers and other gold-standard measures, there remain controversies on the degree to which psychiatric conditions are universal or variable—in relation to cultural influences—in core definitions and constellation of symptoms (Canino & Alegría, 2008). Kleinman (1987) described the inherent challenge in assuming that there must be universals in mental disorders across diverse cultures, the tendency for current pathogenetic/pathoplastic models used in psychiatric research to overemphasize the biological dimensions of disease and deemphasize the cultural dimensions of disease, the invalidity of purely lexical translations of assessment tools that fail to consider local idioms of distress, and the overall fallacy of applying nosological categories developed for a particular culture to other cultures for whom the categories lack coherence and validity. Seeking evidence favouring either a universalist or relativistic view of child psychiatric disorders, Canino and Alegría (2008) reviewed the literature and found that, while the prevalence of specific conditions and risk and protective factors may vary across cultures,

comorbid patterns and treatment responses seem to vary little across cultures. They concluded that there is variation in the degree to which child psychiatric disorders appear to have cross-cultural validity, and further studies must be done to investigate the extent to which gene–environment interactions are related to specific disorders across cultures.

As reviewed by [Koydemir and Essau \(2018\)](#), child-rearing in cultures that emphasize collectivism, interdependence, self-control, and concern with others' evaluations may increase the risk for social anxiety and other conditions such as *Taijin kyofusho*, involving an intense fear that one's body parts or functions displease, embarrass, or are offensive to others. Conversely, child-rearing in cultures that emphasize individualism and independence may increase the risk for externalizing and other conditions. [Koydemir and Essau \(2018\)](#) have also described how cultural values in the collectivist context may influence help-seeking behaviour, and interventions that reflect a bias towards individualism may lead to an underuse of mental health services.

Overall the growing literature from the past few years has continued to affirm core principles articulated in existing position statements, including the principles that culture is relevant in ensuring accurate formulation and appropriate treatment and in ensuring access to mental healthcare.

[Sritharan and Koola \(2019\)](#) found that, for immigrant families of children with autism spectrum disorder (ASD), barriers to receiving timely care include cultural beliefs about child development and ASD and negative perceptions of services. [Straiton, Ledesma, and Donnelly \(2018\)](#) found that, among immigrant Filipino women living in Norway, socioeconomic status (SES), educational background, familiarity with health services, and experience of mental health can influence help seeking for mental health problems.

While culture clearly influences how psychiatric conditions present, [E Azevêdo et al. \(2019\)](#) found that certain common child and adolescent psychiatric conditions such as attention deficit hyperactivity disorder exist and are recognizable and impairing even in traditional cultures (e.g. among indigenous youth in the Brazilian Amazon) that preserve ancestral characteristics. Furthermore, [Rescorla, Althoff, Ivanova, and Achenbach \(2019\)](#) found that society plus culture may only account for a relatively small percentage of the difference in how parents rate children's mental health problems. It appears that to the degree that children and families identify distress, assessment procedures familiar to mental health practitioners may still be helpful in confirming a diagnoses to guide timely and accessible treatments, and the clinician's focus should appropriately include not only the role that culture plays in the development and manifestations of specific psychiatric condition but also the roles of cultural barriers and social inequities that affect ability to access beneficial care.

Acculturative, socioeconomic, and related stressors can increase risk for psychiatric disorders and symptoms in youth. [El Bouhaddani, van Domburgh, Schaefer, Doreleijers, and Veling \(2019\)](#) found that, although prevalence of psychotic experiences may not differ between ethnic minority and majority adolescents in the Netherlands, perceived discrimination, weak ethnic identity, and cultural marginalization and/or assimilation may increase risk for psychotic experiences. [Martinez and Polo \(2018\)](#) found that, among Latino youth in higher SES neighbourhoods, increased fit between youth cultural values and neighbourhood Latino and immigrant concentration were associated with fewer externalizing problems. [Wei et al. \(2017\)](#) found that, among Puerto Rican youth, risk for youth antisocial behaviour was decreased by higher effective parenting and increased by youth cultural stress; for youth who perceived higher cultural stress, the positive effect of effective parenting on risk for antisocial behaviour was weakened. And while it is known that higher SES protects against psychiatric risks in youth, [Assari and Caldwell \(2019\)](#) found that this protective effect appears to be less for Black than for White families, and therefore the solution to health and mental health disparities is not only simply to reduce the racial gap in SES but also to address the impact of resources on outcomes.

4 Cultural psychiatry, preventive psychiatry, and population-based child and adolescent mental health

In a recent review, [Guerrero, Chock, Lee, Sugimoto-Matsuda, and O'Kelly \(2019\)](#) summarized that youth mental health disparities result from differential exposures, throughout development, to poverty, trauma, discrimination, and barriers to accessing mental healthcare, and significantly impact indigenous and other disadvantaged populations. They provided examples from Hawai'i, a physically beautiful and positively regarded place within the United States, a high income-classified nation where health and mental health disparities nonetheless exist, often based on geographic or financial barriers to accessing care, stigma of mental illness, alternate beliefs about illness etiology, and disconnection from indigenous cultural heritage and cultural trauma. They further proposed that addressing these disparities involves insuring access to mental healthcare that is population focussed, culturally grounded, multidisciplinary, and accessible in settings beyond traditional healthcare settings.

It appears clear that thoroughly understanding and appreciating culture on multiple levels (patient, family, provider, community, and society as a whole) is key to effectively addressing and preventing mental health disparities affecting youth and families. Most of the tools used to hard-wire the process of cultural psychiatry assessments, such as the Cultural

Formulation Interview, properly focus on individual/family culture rather than larger-scale societal culture, as the former is likely more observable and more a potential focus of intervention than the latter.

But consider the following fictitious, but realistic, case vignette:

A part-Native Hawaiian, mixed Asian older adolescent female with no previous psychiatric history, good academic standing, and no significant medical history was referred to a clinic (located in urban Honolulu, Hawai'i) for anxiety and depression. She recently started at her new school, whose curriculum emphasizes Hawaiian language and culture. The academic studies were, as expected, challenging; however, the patient's chief concern was feeling unable to "fit in" by virtue of not being "Hawaiian" enough. She reported difficulty in making friends, in feeling a sense of belonging, and in sharing interests with peers, who participated in Hawaiian cultural activities and who followed Hawaiian politics. Most days, she found herself studying independently in the library when not in class. She began to doubt herself, and she began to feel that she was letting her family down. Her grades declined slightly, and her family noted her to be more irritable and isolative.

There were no safety issues, drug use, or history of trauma. Family (nuclear and extended) was described as very supportive. Diagnosis was likely Major Depressive Disorder, Single Episode, Mild to Moderate.

The patient responded very well to adolescent interpersonal and supportive psychotherapy, focused on discussing her cultural identity, her genuine connections to Hawaiian culture (including through her given name), and her experience of being raised in a mixed ethnicity home. Psychotherapy also focused on building confidence, irrespective of whether she chose to be involved in her peers' cultural activities.

This case raises the significant possibility that, even if the cultural formulation was accurate and comprehensive, the cultural fit between the patient and provider was completely positive, and the individual and family psychotherapeutic interventions (based on the accurate cultural formulation) were flawlessly implemented; the patient's outcome and prognosis might have been much worse were it not for the reality that, in this case, the larger societal culture in Hawai'i had a relatively high degree of intermarriage, a historical acceptance of cultural diversity (without a history of institutionalized racism—*notwithstanding* historical injustices and current disparities that remain to be fully addressed), and the absence of a majority ethnic/racial group. Indeed, assessment of larger societal culture and its interface with individual/family culture is important in understanding risk for acculturative stress, which is, in turn, a potential risk factor for adjustment and other psychiatric difficulties among youth in Hawai'i (Guerrero et al., 2010; Yuen, Nahulu, Hishinuma, & Miyamoto, 2000).

Berry (2011) has described acculturation strategies on the individual ethnocultural group and societal levels. On the ethnocultural group level, integration implies high maintenance of heritage culture/identity and seeking of relationships outside of ethnocultural group, assimilation implies low maintenance of heritage culture/identity and high seeking

of relationships outside of ethnocultural group, separation implies high maintenance of heritage culture/identity and low seeking of relationships outside ethnocultural group, and marginalization implies low maintenance of both heritage culture/identity and seeking of relationship outside ethnocultural group. On the larger societal level, the analogous strategies are multiculturalism, melting pot, segregation, and exclusion. [Berry \(2011\)](#) agrees that bicultural competence, defined by knowledge of both cultures' beliefs and values, positive attitudes towards majority and minority groups, confidence in living effectively in both cultures, effective communication in both languages, knowledge of appropriate roles/behaviours in both cultures, and a sense of being grounded with a well-developed social support system, may be a key element of psychological well-being. [Berry \(2011\)](#) further explains that the integration and multiculturalism options, distinct from the other acculturation strategies, may be foundational towards achieving social solidarity.

Similarly, [McDermott and Andrade \(2011\)](#) have described that, unlike the more commonly considered 'melting pot' model based on assimilation and renunciation of one's nationality and culture, the 'Hawaiian Stewpot' model that appears to exist in Hawai'i, which is the setting of the fictitious vignette, is based on accommodation and interaction and is grounded in the indigenous Hawaiian cultural concepts of inclusiveness, including the values of *aloha* (selfless giving and empathy), *lōkahi* (harmony and balance, especially in relationships), and *'ohana* (family or team bonded by a continuous thread of history, culture, and/or aims). Indeed, some writers ([Velasquez-Manoff, 2019](#)) have posited that places like Hawai'i, with a long history of multiculturalism and high proportions of mixed ethnicity individuals, are less likely to cultivate racism and race-based ideologies than societies that are more segregated.

5 Conclusion

So, if we accept the notion that there are social environments that promote development of healthy cultural identity and social environments that do just the opposite (e.g. through institutionalized racism, even ethnic cleansing as an extreme example), we propose that future applications of cultural psychiatry should focus on finding and promoting strengths in settings of diversity. Furthermore, this focus should encompass eliminating or reducing—just as we would other types of trauma and other known risk factors for psychopathology—stressors that adversely affect healthy cultural identification and cultural adjustment in children all over the world. We propose that healthy cultural identification and healthy intercultural interactions are important components in laying the foundation for lifelong mental health. In this regard the authors are grateful for the

opportunity to provide these perspectives from multicultural Hawai'i and to wholeheartedly support the International Association for Child and Adolescent Psychiatry and Allied Professions in its historic 2020 Congress in the multicultural city of Singapore.

References

- ACGME. (2019a). https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/400_Psychiatry_2019.pdf?ver=2019-06-19-091051-927. (Accessed 2 August 2019).
- ACGME. (2019b). https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/405_ChildAdolescentPsychiatry_2019_TCC.pdf?ver=2019-03-28-161025-277. (Accessed 9 September 2019).
- American Psychiatric Association. (2013a). *Resource document on cultural psychiatry as a specific field of study relevant to the assessment and care of all patients approved by the board of trustees, July 2013 approved by the assembly, May 2013*. https://www.psychiatry.org/File%20Library/Psychiatrists/Directories/Library-and-Archive/resource_documents/rd2013_CulturalPsychiatry.pdf. (Accessed 26 July 2019).
- American Psychiatric Association. (2013b). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- American Psychiatric Association. (2019). (Webpage) *What is psychiatry?*. <https://www.psychiatry.org/patients-families/what-is-psychiatry>. (Accessed 26 July 2019).
- Ang, W. (2017). Bridging culture and psychopathology in mental health care. *European Child & Adolescent Psychiatry*, 26(2), 263–266.
- Assari, S., & Caldwell, C. H. (2019). Family income at birth and risk of attention deficit hyperactivity disorder at age 15: Racial differences. *Children*, 6(1), 10.
- Berry, J. W. (2011). Integration and multiculturalism: Ways towards social solidarity. *Papers on Social Representations*, 20(1), 2.1–2.21.
- Bhugra, D., & Bhui, K. (Eds.), (2018). *Textbook of cultural psychiatry*: Cambridge University Press.
- Bhui, K., Warfa, N., Edonya, P., McKenzie, K., & Bhugra, D. (2007). Cultural competence in mental health care: A review of model evaluations. *BMC Health Services Research*, 7(1), 15.
- Canino, G., & Alegria, M. (2008). Psychiatric diagnosis—is it universal or relative to culture? *Journal of Child Psychology and Psychiatry*, 49(3), 237–250.
- Corral, I., Johnson, T. L., Shelton, P. G., & Glass, O. (2017). Psychiatry resident training in cultural competence: An educator's toolkit. *Psychiatric Quarterly*, 88(2), 295–306.
- Dogra, N., Vostanis, P., & Frake, C. (2007). Soapbox: Child mental health services: Cultural diversity training and its impact on practice. *Clinical Child Psychology and Psychiatry*, 12(1), 137–142.
- E Azevêdo, P. V. B., Caixeta, L. F., Taveira, D. L. R., Giglio, M. R. P., do Rosário, M. C., & Rohde, L. A. (2019). Suggestive diagnosis of attention-deficit/hyperactivity disorder in indigenous children and adolescents from the Brazilian Amazon. *European Child & Adolescent Psychiatry*, 1–12. <https://doi.org/10.1007/s00787-019-01356-y>.
- Eckert, D., & Goebert, D. (2018). Addressing healthcare disparities. In A. P. S. Guerrero, P. C. Lee, & N. Skokauskas (Eds.), *Pediatric consultation-liaison psychiatry* (pp. 365–376). Cham: Springer.
- El Bouhaddani, S., van Domburgh, L., Schaefer, B., Doreleijers, T. A., & Veling, W. (2019). Psychotic experiences among ethnic majority and minority adolescents and the role of discrimination and ethnic identity. *Social Psychiatry and Psychiatric Epidemiology*, 54(3), 343–353.
- Foulks, E. F. (1980). The concept of culture in psychiatric residency education. *The American Journal of Psychiatry*, 137(7), 811–816.

- Griffith, J. L., Kohrt, B., Dyer, A., Polatin, P., Morse, M., Jabr, S., et al. (2016). Training psychiatrists for global mental health: Cultural psychiatry, collaborative inquiry, and ethics of alterity. *Academic Psychiatry, 40*(4), 701–706.
- Guerrero, A. P., Chock, S., Lee, A. K., Sugimoto-Matsuda, J., & O’Kelly, A. S. (2019). Mental health disparities, mechanisms, and intervention strategies: Perspective from Hawai’i. *Current Opinion in Psychiatry, 32*(6), 549–556.
- Guerrero, A. P., Nishimura, S. T., Chang, J. Y., Ona, C., Cunanan, V. L., & Hishinuma, E. S. (2010). Low cultural identification, low parental involvement and adverse peer influences as risk factors for delinquent behaviour among Filipino youth in Hawai’i. *International Journal of Social Psychiatry, 56*(4), 371–387.
- Hansen, H., Braslow, J., & Rohrbaugh, R. M. (2018). From cultural to structural competency—Training psychiatry residents to act on social determinants of health and institutional racism. *JAMA Psychiatry, 75*(2), 117–118.
- Hassenfeld, I. N. (2002). Doctor–patient relations in Nazi Germany and the fate of psychiatric patients. *Psychiatric Quarterly, 73*(3), 183–194.
- Jeffress, J. E. (1969). Training in transcultural psychiatry in the United States a 1968 survey. *International Journal of Social Psychiatry, 15*(1), 69–72.
- Juckett, G. (2005). Cross-cultural medicine. *American Family Physician, 72*(11), 2267–2274.
- Kleinman, A. (1987). Anthropology and psychiatry: The role of culture in cross-cultural research on illness. *The British Journal of Psychiatry, 151*(4), 447–454.
- Koydemir, S., & Essau, C. A. (2018). Anxiety and anxiety disorders in young people: A cross-cultural perspective. In M. Hodes, S.S.-F. Gau, & P. J. de Vries (Eds.), *Understanding uniqueness and diversity in child and adolescent mental health* (pp. 115–134). Academic Press. See <https://iacapap.org/monographs/>.
- Lam, J. S., Gajaria, A., Matthews, D. M., & Zaheer, J. (2016). Bridging cultural psychiatry and global mental health: A resident-led initiative. *Academic Psychiatry, 40*(4), 729–730.
- Martinez, W., & Polo, A. J. (2018). Neighborhood context, family cultural values, and Latinx youth externalizing problems. *Journal of Youth and Adolescence, 47*(11), 2440–2452.
- McDermott, J. F., & Andrade, N. N. (2011). Introduction. In N. N. Andrade & J. F. McDermott Jr., (Eds.), *People and cultures of Hawai’i: The evolution of culture and ethnicity* (pp. 11–23): University of Hawai’i Press.
- McKenzie, K., & Bhui, K. (2007). Institutional racism in mental health care. *BMJ, 334*(7595), 649–650.
- Morgan, C., Knowles, G., & Hutchinson, G. (2019). Migration, ethnicity and psychoses: Evidence, models and future directions. *World Psychiatry, 18*(3), 247–258.
- Owiti, J. A., Ajaz, A., Ascoli, M., De Jongh, B., Palinski, A., & Bhui, K. S. (2014). Cultural consultation as a model for training multidisciplinary mental healthcare professionals in cultural competence skills: Preliminary results. *Journal of Psychiatric and Mental Health Nursing, 21*(9), 814–826.
- Pols, H. (2007). Psychological knowledge in a colonial context: Theories on the nature of the “native mind” in the former Dutch East Indies. *History of Psychology, 10*(2), 111–131.
- Pumariega, A. J., Rothe, E., Mian, A., Carlisle, L., Toppelberg, C., Harris, T., et al. (2013). Practice parameter for cultural competence in child and adolescent psychiatric practice. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(10), 1101–1115.
- Rescorla, L. A., Althoff, R. R., Ivanova, M. Y., & Achenbach, T. M. (2019). Effects of society and culture on parents’ ratings of children’s mental health problems in 45 societies. *European Child & Adolescent Psychiatry, 28*(8), 1107–1115.
- Rousseau, C., Johnson-Lafleur, J., Papazian-Zohrabian, G., & Measham, T. (2018). Interdisciplinary case discussions as a training modality to teach cultural formulation in child mental health. *Transcultural Psychiatry, https://doi.org/10.1177/1363461518794033*. [Epub ahead of print].
- Royal Australian and New Zealand College of Psychiatrists. (2019). <https://www.ranzcp.org/pre-fellowship/about-the-training-program/stage-1>. (Accessed 26 July 2019).

- Rush, B. (1799). Observations intended to favour a supposition that the black color (as it is called) of the negroes is derived from the LEPROSY. *Transactions of the American Philosophical Society*, 4, 289–297.
- Sashidharan, S. P. (2001). Institutional racism in British psychiatry. *Psychiatric Bulletin*, 25(7), 244–247.
- Shim, R. S. (2018). The evolution of cultural psychiatry. *Psychiatric Annals*, 48(3), 134–136.
- Singh, S. P., & Burns, T. (2006). Race and mental health: There is more to race than racism. *BMJ*, 333(7569), 648–651.
- Sritharan, B., & Koola, M. M. (2019). Barriers faced by immigrant families of children with autism: A program to address the challenges. *Asian Journal of Psychiatry*, 39, 53–57.
- Stevenson, T. N. (2009). The power of language in medicine. Case study: Mongolism. *The Pharos of Alpha Omega Alpha Honor Medical Society*, 72, Autumn. 4–9.
- Straiton, M. L., Ledesma, H. M. L., & Donnelly, T. T. (2018). “It has not occurred to me to see a doctor for that kind of feeling”: A qualitative study of Filipina immigrants’ perceptions of help seeking for mental health problems. *BMC Women’s Health*, 18(1), 73.
- Sukhera, J., & Watling, C. (2018). A framework for integrating implicit bias recognition into health professions education. *Academic Medicine*, 93(1), 35–40.
- Velasquez-Manoff, M. (2019). *Want to be less racist? Move to Hawaii: The “aloha spirit” may hold a deep lesson for all of us.* The New York Times. June 28.
- Wei, C., Eisenberg, R. E., Ramos-Olazagasti, M. A., Wall, M., Chen, C., Bird, H. R., et al. (2017). Developmental psychopathology in a racial/ethnic minority group: Are cultural risks relevant? *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(12), 1081–1088.
- Wittkower, E. D., & Fried, J. (1959). A cross-cultural approach to mental health problems. *American Journal of Psychiatry*, 116(5), 423–428.
- Yuen, N. Y., Nahulu, L. B., Hishinuma, E. S., & Miyamoto, R. H. (2000). Cultural identification and attempted suicide in native Hawaiian adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 39(3), 360–367.
- Yutrzenka, B. A. (1995). Making a case for training in ethnic and cultural diversity in increasing treatment efficacy. *Journal of Consulting and Clinical Psychology*, 63(2), 197–206.



P A R T II

Developmental
neuropsychiatry: Risk,
prevention, and intervention
opportunities

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Developmental neurocognitive and neuropsychiatric consequences of chemical exposure amongst children in South Korea

Yoonyoung Jang^a, Yun-Chul Hong^a, and Nami Lee^b

^aDepartment of Preventive Medicine, Seoul National University College of Medicine, Seoul, South Korea, ^bDepartment of Psychiatry, Seoul National University Hospital, Seoul, South Korea

1 Introduction

South Korea has prioritized technological advancement over environmental safety. Until very recently, overcoming poverty by rapid industrialization outweighed environmental concerns. The result of this is a high level of pollution in the environment, food, and contamination from utensils used for eating, drinking, and conveniences of life.

Children's neurological systems are very susceptible to the harmful effects of environmental chemicals, and early exposure may cause long-lasting developmental impairment. We reviewed the neurocognitive and neuropsychiatric impairments associated with the widespread use of major heavy metals and chemicals, mercury (Hg), lead (Pb), bisphenol A (BPA), and phthalates. Although there are other chemicals that are hazardous in terms of children's health, these four toxic chemicals are ubiquitous and have been more extensively studied with respect to their relationship with neurological impairment in Korea, as compared with other toxins. Children in Korea, if neglected and live in poor conditions, are susceptible

to these four chemicals. Living in time-worn houses with Pb pipes, drinking water from BPA- and phthalate-coated containers, using antiseptics and cosmetic creams containing Hg, and eating canned or frozen seafood containing bioaccumulated Hg is unsafe. If we educate the general population about the neurotoxic effects of chemicals present in daily life, we may be able to protect vulnerable children from neuropsychological impairment and therefore reduce associated costs.

Hg, a neuro-, nephro-, and immunotoxin, is found in gold mines, medicinal devices, interior paints, antiseptics, cosmetic creams, inactivated vaccines, thermometers, and aquatic food chains (Bose-O'Reilly, McCarty, Steckling, & Lettmeier, 2010). Hg disrupts cell cycle progression and/or induces apoptosis in several tissues. Hg-induced neurotoxicity may be mediated by reactive oxygen species (ROS) by altering Na^+/K^+ ATPase activity and mitochondrial function. Hg also leads to the depletion of glutathione (GSH) content and forms GS-HgCH₃, which inhibits GSH reductase and GSH peroxidase activities (Ahmad et al., 2011). With the natural emission of Hg, its industrial emissions/levels have exponentially increased over several decades in Korea. Since the blood-brain barrier of infants and children is significantly weaker than that of adults, the impact of Hg may be considerably more severe in children. Human exposure to methylmercury due to consumption of fish has been associated with long-term accumulation, with possible adverse health effects. Although there are extensive studies associated with neurotoxicity from methylmercury due to fish consumption, the molecular events associated with the effect of Hg and other neurotoxicants on neurodevelopment remain unclear.

Pb, a bluish-grey heavy metal that naturally exists in Earth's crust, exists in the air, water, soil, and dust. Humans are exposed to lead in the form of vapours or fine dust from leaded paints, vehicle emission, and workplaces using lead as raw material. Recently the Korean Agency for Technology and Standards (kats.go.kr) has found that lead in some children's leather clothing, toys, and school supplies exceed the acceptable safety standard. Pb may impair neuronal migration and differentiation; synapse formation; differentiation of glial cells; and GABAergic, dopaminergic, and cholinergic neurotransmitter release. Mitochondrial self-destruction, modified energy metabolism, and calcium release from mitochondria are related to neurotoxicity. Exposure to Pb during embryonic development impedes the elaboration of dendritic arborization of dentate granule cells and damages hippocampal astrocytes (Petit, Alfano, & LeBoutillier, 1983). Postmortem findings of Pb encephalopathy include oedema, capillary disruption, proliferation of glia, and diffuse anoxic injury (Mason, Harp, & Han, 2014).

Dibutyl phthalate (di-*n*-butyl phthalate, DBP), one of the most common phthalate esters used in plastics for packaging, medical equipment, toys, and cosmetics, can cross the placental and blood-brain barriers. A study

showed that DBP is associated with decreased cell viability and induces apoptosis, which may be related to neurotoxicity (Wojtowicz, Szychowski, Wnuk, & Kajta, 2017). High prenatal phthalate exposure may influence neonatal neurological status and executive function of infants, and cause behavioural and social problems, and attention-deficit/hyperactivity disorder (ADHD) symptoms (Li, Jiang, Chen, Chen, & Li, 2013).

BPA exists in various products: bottles, containers, toys, medical equipment, lenses, packaging materials, window panels, coating for water pipes in homes, paints, dental sealants, resins, and paper products like receipts (Mason et al., 2014). Although the biochemical mechanism of BPA toxicity has not completely been elucidated, many countries like Canada, Denmark, and France have developed plans to reduce the use of BPA. In 2017 the European Chemical Agency concluded that BPA is an endocrine-disrupting chemical (EDC). This chemical is related to premature delivery, childhood obesity, male genitalia abnormalities, asthma, thyroid dysfunction, and neurodevelopmental abnormalities (Mason et al., 2014). Exposure to BPA during the early stages of life can disrupt normal patterns of brain development and function, resulting in disease susceptibility later in life. A recent review article summarized the neurotoxicity of BPA: (a) during the gestational period, BPA impairs brain development and behaviour, (b) perinatal or neonatal exposure influences brain sexual development and increases anxiety-like behaviour in male mice, and (c) lactation with BPA exposure is associated with hyperactivity and degeneration of dopaminergic neurons (Inadera, 2015).

2 Chapter aim

This chapter aimed to review systematically available epidemiological studies into the impact of environmental chemical exposure on neuropsychological performance and neuropsychiatric symptoms, specifically during the prenatal and early childhood periods, in South Korea. Our review focused on articles reporting the neuropsychological effects in children from exposure to mercury, lead, phthalates, and bisphenol A in South Korea. Fortunately, there are many studies on the health effects of environmental chemical exposure in children in South Korea, which provided the opportunity for this review.

3 Article search strategy

We searched for reference papers published during the 6 years between January 2014 and September 2019, using PubMed and EMBASE. Fourteen papers were selected for inclusion in this study. Keywords used for the

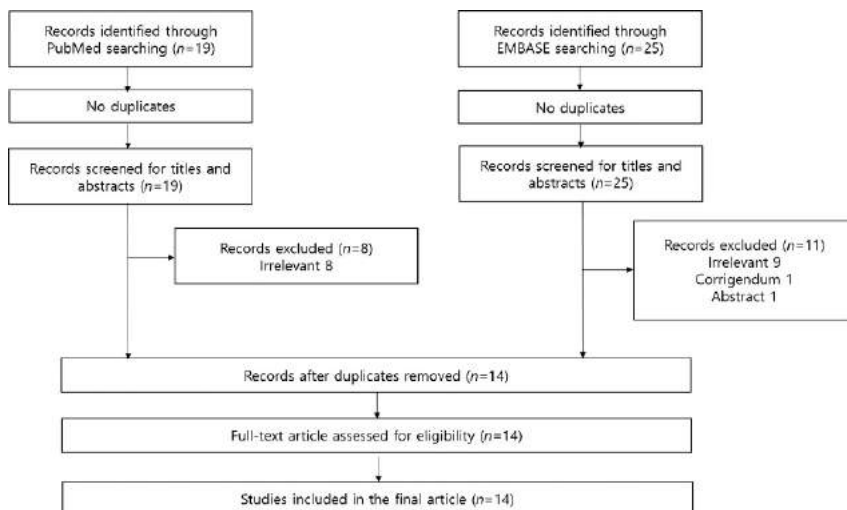


FIG. 1 Prisma flow diagram.

search were ‘(Hg or mercury) or (Pb or lead) or (“bisphenol A” or BPA) or phthalate* and (autism or ADHD or neurobehavioral or IQ) and children and Korea’. The search was carried out on 4 October 2019 in PubMed and 11 October 2019 in EMBASE. From the PubMed search, amongst 19 results, we excluded 8 articles which were irrelevant to our aims. From the EMBASE search, amongst the first 25 results, we eliminated 9 articles which were not related to our aims. Two were excluded because one was a corrigendum, and the other was just an abstract. Finally, without duplicates, 14 articles were accepted for further analysis. Article search strategy is also shown in Fig. 1; amongst these 14 studies, 2 studies focused on Hg, 5 on Pb, 1 on BPA, 4 on phthalates, and 2 on multiple exposures.

4 Results and discussion

4.1 Mercury

The first study to be described here investigated the levels of mercury in human breast milk. During 2011–12, 157 breast-feeding mothers were recruited from the Children’s Health and Environmental Chemicals of Korea (CHECK) cohort, and their breastmilk samples were collected at 15–30 days after childbirth ($n = 207$). Hg was detected in 100% of breast milk, with a median concentration of $0.59 \mu\text{g/L}$. Hg levels in infants were higher than those reported in France and Italy but lower than those in Taiwan (Park et al., 2018).

A multicentre prospective birth cohort study of 1751 pregnant women (the Mothers and Children's Environmental Health, MOCEH) was conducted in Korea from May 2006 to December 2010. Using the MOCEH study, [Jeong et al. \(2017\)](#) investigated the relationship between the IQ of children and maternal blood Hg concentration during late pregnancy. The results indicated that a twofold increase in Hg level in maternal blood during pregnancy was associated with a decrease in verbal and total IQ levels by 2.482 (95% confidence interval (CI)=0.749–4.214) and 2.402 (95% CI=0.526–4.279), respectively, at the age of 5 years.

Only a small number of longitudinal studies have investigated the association between prenatal and early childhood Hg exposure and autistic behaviours in later childhood in Korea. [Ryu et al. \(2017\)](#) conducted a longitudinal cohort study and measured blood Hg levels at the following intervals: early and late pregnancy in cord blood, and at 2–3 years of age. Autistic behaviours were assessed using the Social Responsiveness Scale (SRS) at 5 years of age. Blood Hg levels in late pregnancy and early childhood were reportedly associated with a higher degree of autistic behaviours in children aged 5 years.

It has been proposed that an estimated 300,000–600,000 American children might have possible reductions in IQ related to Hg ([Ryu et al., 2017](#)). However, in a literature review on the association of the pharmaceutical preservative thimerosal and other Hg exposures with the risk for autism, the causal association between autism and Hg was not clear, and the risk for autism from other Hg exposures, such as from dental amalgam restorations or Hg released into the atmosphere, was also ambiguous ([Schultz, 2010](#)). The review addressed autism spectrum disorder (a category), so this does not invalidate the findings of slightly higher scores on a continuous scale of autistic behaviours in association with Hg.

4.2 Lead

Hong and colleagues ([Hong et al., 2015](#)) investigated the association of environmental Pb exposure with poor intelligence and ADHD symptoms and correlations between Pb and specific ADHD-related domains in Korean school-age children. They measured blood Pb concentrations in a general population of 1001 children (8–11 years of age) from five South Korean administrative regions. After adjustment for demographic characteristics (along with other environmental exposures), a 10-fold increase in blood Pb concentration was associated with lower full-scale IQ, higher parent- and teacher-rated hyperactivity/impulsivity scores, and errors of commission. Blood Pb levels were inversely associated with intelligence in school-age children, independent of ADHD. Environmental Pb exposure was selectively associated with impulsivity amongst the clinical features of ADHD. In the aforementioned MOCEH study, multivariate

linear regression analysis found that Pb and ferritin concentrations were inversely and significantly associated with IQ after adjustment for covariates. Statistical analysis demonstrated that blood Pb concentration was a significant partial mediator of the relationship between iron deficiency and verbal IQ. Cognitive deficit in children may be associated with both iron deficiency and blood Pb concentration (Jeong et al., 2015).

Joo and colleagues (Joo et al., 2018) investigated the effects of Pb exposure on the neurobehavioural development of 5-year-old children to identify the vulnerable time window and potential sex differences. Pb levels in late pregnancy were significantly associated with an increased risk of behavioural problems in boys, whilst Pb levels in 2- and 5-year-old children's blood significantly increased behavioural risks in girls. It is therefore possible to infer that boys are more susceptible to prenatal exposure, whilst girls were more susceptible to postnatal exposure. Several other studies have also reported sex differences in the effects of Pb toxicity on children's neurobehavioural development. Despite differences in design and the participants' demographic features, many studies have revealed a negative impact of Pb exposure on childhood neurological development. For example, a similar prospective cohort study of 3-year-old children and reported that prenatal Pb exposure was inversely associated with cognitive function in boys but not girls (Jedrychowski et al., 2009a). Taylor and colleagues (Taylor, Kordas, Golding, & Emond, 2017) showed that verbal performance and total IQ score demonstrated a significantly inverse association with Pb exposure in 8-year-old boys. The protective role of oestrogens on neural growth and oxidative stress responses may explain the greater vulnerability of male sex to heavy metals, such as Pb (Malagutti et al., 2009; Miller, De Silva, Jackman, & Sobey, 2007).

Regarding the relationship between Pb exposure and autism spectrum symptoms, Kim and colleagues (Kim, Kwon, & Hong, 2016) hypothesized an association between high blood Pb concentration and autistic behaviours, including impaired social interactions and communication, stereotypical behaviours, and restricted interests amongst school-age children. Two thousand four hundred seventy-three Korean children aged 7–8 years, without any form of developmental disorder, participated in two follow-up biennial surveys until the children reached 11–12 years of age. Blood Pb concentrations at 7–8 years of age were associated with autistic behaviours at 11–12 years of age, according to the Autism Spectrum Screening Questionnaire (ASSQ) ($\beta = 0.151$, 95% CI = 0.061–0.242) and Social Responsiveness Scale (SRS) ($\beta = 2.489$, 95% CI = 1.378–3.600). SRS subscale analysis also revealed associations between blood Pb concentration and social awareness, cognition, communication, motivation, and mannerisms.

Kim and colleagues (Kim et al., 2018) examined the interaction effects of the dopamine receptor D2 (*DRD2*) genotype and Pb exposure on the

cortical thickness of the frontal lobe in patients with ADHD. Both the *DRD2* gene and Pb exposure may contribute to the pathophysiology of ADHD. The D2 receptors located in the prefrontal cortex were affected by Pb exposure, which indicates a possible association between the neural correlates of ADHD, *DRD2*, and Pb exposure. There was a significant negative correlation between the cortical thickness of the right superior frontal gyrus and inattention scores. The study findings demonstrated significant interaction effects of the *DRD2* genotype and Pb exposure on the cortical thickness of the frontal lobe in ADHD.

In a systematic review a significant associations were found between blood Pb levels and inattentive/hyperactive-impulsive symptoms (Daneshparvar et al., 2016). In other systematic studies identified from PubMed and Scopus, concentrations of Pb in the hair and blood Pb levels of ASD patients were significantly higher than in controls (Saghazadeh & Rezaei, 2017). It is too early to assess the nature of the link between lead exposure and ADHD or ASD (or symptoms of these disorders), but at least it appears plausible that the metal could play a causal role, in view of the studies and known effects on neuronal function.

4.3 Phthalates

Kim and colleagues (Kim et al., 2017) investigated the effects of phthalate exposure on the intelligence and attentional performance in 6-year-old children. They also investigated the differential effects of phthalate exposure on intelligence and attention according to exposure period, such as the foetal or childhood period. Urine concentrations of mono-(2-ethyl-5-hydroxyhexyl) phthalate (MEHHP), mono-(2-ethyl-5-oxohexyl) phthalate (MEOHP), and mono-n-butyl phthalate (MBP) were analyzed. There were robust associations between childhood MEHHP and MEOHP levels with full-scale IQ (FSIQ), even after adjusting for demographic variables and continuous performance test (CPT) scores. An increase of childhood MEHHP and MEOHP levels exaggerated errors of omission and negatively influenced the response time variability of the CPT after adjusting for demographic variables and IQ. Foetal phthalate exposure had no effects on IQ or CPT. These results suggested that childhood phthalate exposure, rather than to foetal exposure, has an adverse effect on IQ and attentional performance.

To investigate the correlation between di-(2-ethylhexyl) phthalate (DEHP) and neurodevelopmental disturbances in children, Lee and colleagues (Lee, Kim, Lim, Lee, & Hong, 2018) conducted a systematic review and meta-analysis focusing on the association between exposure to DEHP and neurodevelopmental outcomes. In cross-sectional data, they observed a statistically significant association between the concentration of DEHP metabolites and neurodevelopment outcomes in children. They

also found a significant association between DEHP exposure, measured in the prenatal period, and psychomotor development outcomes measured later in childhood.

Park and colleagues (Park et al., 2014) reported that phthalate metabolites in urine were associated with poor neuropsychological performance in children with ADHD. Correlations between urine phthalate metabolite concentration and CPT scores were investigated, and the interaction of phthalate metabolite levels with selected polymorphisms related to major candidate genes for ADHD, particularly the dopamine receptor D4 gene (*DRD4*), was evaluated. Amongst the individuals with the *DRD4* 4/4 genotype, there were significant associations between urine phthalate metabolite concentration and 'the number of errors of omission and commission and the response time variability scores for the CPT'. However, for individuals without the *DRD4* 4/4 genotype, there were no significant associations. The results of this study suggest a possible association between phthalate metabolite concentration and the poor attentional performances of ADHD, as well as a genetic influence on this association.

Using clinical diagnostic testing for ADHD, Park and colleagues (Park et al., 2015) aimed to determine whether phthalate metabolites in urine were higher in children with ADHD than in those without ADHD, and if there was a correlation with symptom severity and cortical thickness in ADHD children. Concentrations of phthalate metabolites, particularly the DEHP metabolite, were significantly higher in boys with ADHD than in boys without ADHD. Concentrations of DBP metabolites were significantly higher in the combined or hyperactive-impulsive subtypes than the inattentive subtype and positively correlated with the severity of externalizing symptoms. Concentrations of the DEHP metabolites were negatively correlated with cortical thickness in the right middle and superior temporal gyri. These results suggest an association between phthalate concentration and both the diagnosis and symptom severity of ADHD.

To summarize, although there are methodological issues including uncertain dose-response relationships, diverse measures, and differences in the pattern of the results, studies have converged in finding an association between phthalates and lower intellectual ability and attentional problems in Korean children.

4.4 Bisphenol A

Lim and colleagues (Lim et al., 2017) investigated the association between prenatal and postnatal exposure to BPA and social impairment in a sample of 4-year-old children. They examined social impairment associated with prenatal exposure during midterm pregnancy and postnatal exposure to BPA at 4 years of age.

The relationship between prenatal BPA exposure and social communication impairment was statistically significant at or above the cut-off point for BPA levels of 3.0 µg/g creatinine in girls (58.4%, 95% CI = 6.5%–135.8%). A twofold increase in postnatal BPA exposure was significantly associated with an 11.8% (95% CI = 0.6%–24.3%) increase in impairment in social communication in 4-year-old girls, in a linear regression model. Prenatal and postnatal BPA exposures were associated with social impairment at the age of 4 years, and the association was greater in girls than in boys. However, because epidemiological studies of sex-specific BPA effects on behaviour have produced inconsistent results, further research may be required to address the differential effects of exposure to BPA on neurobehavioural development between boys and girls.

5 Significance of the findings

This review aimed to examine the evidence from epidemiological studies during the period from January 2014 to September 2019 in South Korea, to evaluate the effect of the common environmental chemicals Hg, Pb, phthalates, and BPA in relation to neurocognitive development and neuropsychiatric symptoms from the prenatal period to primary school age. We further briefly reviewed currently available literature from other countries, which reported on the neurocognitive development and neuropsychiatric symptoms of the four chemicals. Many studies demonstrated significant findings, whilst others reported negative associations between the chemical exposures and neurocognitive or neuropsychological dysfunction over the early childhood period. Several studies reported sex-specific effects, which require further epidemiological and experimental investigation.

The present review has some limitations. Only studies in English were included in the review, which possibly did not fully reflect the situation in South Korea. Several of the reviewed studies were longitudinal epidemiological studies, whilst the others were cross-sectional in nature. The quality of the studies might vary, but this was not assessed and presented here.

Some recent studies place the levels of the four contaminants found in Korean children in international perspective. [Table 1](#) shows the level of exposure in several countries. The geometric mean of BPA concentration in Korean children was higher than that in children from other countries, except China and Taiwan. The blood Hg concentration in Korean children was also higher than that in US children, and the blood Pb level was higher than that in children from Japan and Taiwan.

Despite the impending global environmental crisis, regulations and laws against overusing chemicals, plastics, and other hazardous

TABLE 1 Levels of exposure in Asian, American, and European.

Chemicals/ heavy metals	Matrix	Country/ region	Study population	Concentrations (µg/L; median)					Reference
				MMP ^a	MEP ^b	MBP ^c	MiBP ^d	MDEHP ^e	
Phthalate	Urine	China	430 children (208 girls and 222 boys)	15.7	4.14	21.9		14.3	Wang, Zhu, and Kannan (2019)
	Urine	Japan	111 pregnant women	5.7	7.75	46.6		18.5	
	Urine	Korea	171 children		2.71	12.4	5.25	12.3	
	Urine	Taiwan	59 (children, age: 5)			75.2	25.2	148.9	
	Urine	Europe	1335 children		34.4	38.4	45.4	47.6	
	Urine	US	35 children		177.7	52.4	16.6	1025.9	
BPA	Urine	China	671 boys (9–18 years old)	Median 2.06 (ng/mL)					Huang et al. (2018)
	Urine	Japan	36 general population (average 32)	GM 0.84 (ng/mL)					
	Urine	Korea	215 children (13–8 years old)	GM 1.73 (ng/mL)					
	Urine	Taiwan	200 children (6 years old)	GM 8.84 (ng/mL)					
	Urine	Greece	500 children (average 4.24)	GM 1.1 (ng/mL)					
	Urine	US	462 children (12–19 years old)	GM 1.28 (ng/mL)					

Mercury	Hair	China	1,982 children (0–6 years old)	GM 191.9 ($\mu\text{g}/\text{Kg}$)	Yan, Gao, Wang, and Yan (2017)
	Blood	Japan	229 children (9–10 years old)	GM 4.55 ($\mu\text{g}/\text{L}$)	Ilmiawati et al. (2015)
	Hair	Japan	229 children (9–10 years old)	GM 1.31 ($\mu\text{g}/\text{g}$)	
	Blood	Korea	859 children (10–19 years old)	GM 2.20 ($\mu\text{g}/\text{dL}$)	Eom et al. (2018)
	Blood	US	4858 children (6–11 years old)	GM 0.33 (ng/mL)	Jain (2017)
Lead	Blood	China	31280 children (0–8 years old) ^f	GM 40.85 ($\mu\text{g}/\text{L}$)	Han, Guo, Zhang, Liao, and Nie (2018)
	Blood	Japan	229 children (9–10 years old)	GM 0.96 ($\mu\text{g}/\text{L}$)	Ilmiawati et al. (2015)
	Blood	Korea	845 children (10–19 years old)	GM 1.36 ($\mu\text{g}/\text{dL}$)	Eom et al. (2018)
	Urine	Taiwan	38 children (11–17 years old)	GM 0.95 ($\mu\text{g}/\text{L}$)	Liao et al. (2019)
	Blood	US	3223 children (16 years old)	GM 1.73 ($\mu\text{g}/\text{dL}$)	Benson et al. (2017)

^a MMP, Monomethyl phthalate.

^b MEP, Monoethyl phthalate.

^c MBP, Mono-*n*-butyl phthalate.

^d MiBP, Monoisobutyl phthalate.

^e MDEHP: Sum of five DEHP metabolites (MEHP, MEHHP, MEOHP, MECPP, and MCMHP).

^f This is summation of six dataset sampled in 2015 at Chongqing, Guangdong, Guangxi, Jilin, Jiangxi, and Zhejiang, China.

materials have not completely come into force, even in some developed countries. The Korean government passed the 'Environmental Health Law' in 2008 to protect people from environmental hazards. This law particularly aims to protect the health of susceptible individuals in the population including the elderly, pregnant women, and children. Although the law provides grounds for research and practices to prevent the effects of environmental toxicants, development of a safe environment for children's health still seems far away. Insensitivity and unrealistic optimism regarding the exploitation of the earth are both dangerous. Families may become aware of the toxins and environmental damage and act responsibly as consumers. They should be encouraged to spend less on plastic items, stop using unnecessary disinfectants, and reduce waste for the benefit of their own health and the health of others.

6 Conclusions

Despite the limitations, this review has found that neurocognitive development or neuropsychiatric symptoms in children are influenced by exposure to Hg, Pb, BPA, and phthalates in the prenatal and early childhood periods. In conclusion, we found evidence suggesting a causal link between these four chemicals and neurocognitive or neuropsychiatric consequences. Further research on the relationship between neurological impairments in children and environmental risks with robust longitudinal designs is necessary to inform policy and draw the attention of professionals and the public to the dangers of these chemicals. Medical professionals need to be more aware of their responsibilities for a sustainable future. It is time to stop poisoning the earth and our children.

References

- Ahmad, I., Mohmood, I., Mieiro, C. L., Coelho, J. P., Pacheco, M., Santos, M. A., ... Pereira, E. (2011). Lipid peroxidation vs. antioxidant modulation in the bivalve *Scrobicularia plana* in response to environmental mercury—Organ specificities and age effect. *Aquatic Toxicology*, *103*(3–4), 150–158. <https://doi.org/10.1016/j.aquatox.2011.02.017>.
- Benson, S. M., Talbott, E. O., Brink, L. L., Wu, C., Sharma, R. K., & Marsh, G. M. (2017). Environmental lead and childhood blood lead levels in US children: NHANES, 1999–2006. *Archives of Environmental & Occupational Health*, *72*(2), 70–78. <https://doi.org/10.1080/19338244.2016.1157454>.
- Bose-O'Reilly, S., McCarty, K. M., Steckling, N., & Lettmeier, B. (2010). Mercury Exposure and Children's Health. *Current Problems in Pediatric and Adolescent Health Care*, *40*(8), 186–215. <https://doi.org/10.1016/j.cppeds.2010.07.002>.
- Daneshparvar, M., Mostafavi, S. A., Zare Jeddi, M., Yunesian, M., Mesdaghinia, A., Mahvi, A. H., & Akhondzadeh, S. (2016). The role of lead exposure on attention-deficit/hyperactivity disorder in children: A systematic review. *Iranian Journal of Psychiatry*, *11*(1), 1–14.

- Eom, S. Y., Lee, Y. S., Lee, S. G., Seo, M. N., Choi, B. S., Kim, Y. D., ... Park, J. D. (2018). Lead, mercury, and cadmium exposure in the Korean general population. *Journal of Korean Medical Science*, 33(2), e9. <https://doi.org/10.3346/jkms.2018.33.e9>.
- Han, Z., Guo, X., Zhang, B., Liao, J., & Nie, L. (2018). Blood lead levels of children in urban and suburban areas in China (1997-2015): Temporal and spatial variations and influencing factors. *Science of the Total Environment*, 625, 1659–1666. <https://doi.org/10.1016/j.scitotenv.2017.12.315>.
- Hong, S. B., Im, M. H., Kim, J. W., Park, E. J., Shin, M. S., Kim, B. N., ... Cho, S. C. (2015). Environmental lead exposure and attention deficit/hyperactivity disorder symptom domains in a community sample of South Korean school-age children. *Environmental Health Perspectives*, 123(3), 271–276. <https://doi.org/10.1289/ehp.1307420>.
- Huang, R.-P., Liu, Z.-H., Yin, H., Dang, Z., Wu, P.-X., Zhu, N.-W., & Lin, Z. (2018). Bisphenol A concentrations in human urine, human intakes across six continents, and annual trends of average intakes in adult and child populations worldwide: A thorough literature review. *Science of the Total Environment*, 626, 971–981. <https://doi.org/10.1016/j.scitotenv.2018.01.144>.
- IImiawati, C., Yoshida, T., Itoh, T., Nakagi, Y., Saijo, Y., Sugioka, Y., ... Kayama, F. (2015). Biomonitoring of mercury, cadmium, and lead exposure in Japanese children: A cross-sectional study. *Environmental Health and Preventive Medicine*, 20(1), 18–27. <https://doi.org/10.1007/s12199-014-0416-4>.
- Inadera, H. (2015). Neurological effects of bisphenol A and its analogues. *International Journal of Medical Sciences*, 12(12), 926–936. <https://doi.org/10.7150/ijms.13267>.
- Jain, R. B. (2017). Trends in and factors affecting the observed levels of urinary inorganic and total blood mercury among US children, adolescents, adults, and senior citizens over 2005-2012. *Environmental Toxicology and Pharmacology*, 56, 268–281. <https://doi.org/10.1016/j.etap.2017.09.003>.
- Jedrychowski, W., Perera, F., Jankowski, J., Mrozek-Budzyn, D., Mroz, E., Flak, E., ... Lisowska-Miszczuk, I. (2009a). Gender specific differences in neurodevelopmental effects of prenatal exposure to very low-lead levels: The prospective cohort study in three-year olds. *Early Human Development*, 85(8), 503–510. <https://doi.org/10.1016/j.earlhumdev.2009.04.006>.
- Jeong, K. S., Park, H., Ha, E., Hong, Y. C., Ha, M., Park, H., ... Kim, Y. (2015). Evidence that cognitive deficit in children is associated not only with iron deficiency, but also with blood lead concentration: A preliminary study. *Journal of Trace Elements in Medicine and Biology*, 29, 336–341. <https://doi.org/10.1016/j.jtemb.2014.08.014>.
- Jeong, K. S., Park, H., Ha, E., Shin, J., Hong, Y. C., Ha, M., ... Kim, Y. (2017). High maternal blood mercury level is associated with low verbal IQ in children. *Journal of Korean Medical Science*, 32(7), 1097–1104. <https://doi.org/10.3346/jkms.2017.32.7.1097>.
- Joo, H., Choi, J. H., Burm, E., Park, H., Hong, Y. C., Kim, Y., ... Ha, M. (2018). Gender difference in the effects of lead exposure at different time windows on neurobehavioral development in 5-year-old children. *Science of the Total Environment*, 615, 1086–1092. <https://doi.org/10.1016/j.scitotenv.2017.10.007>.
- Kim, J. I., Hong, Y. C., Shin, C. H., Lee, Y. A., Lim, Y. H., & Kim, B. N. (2017). The effects of maternal and children phthalate exposure on the neurocognitive function of 6-year-old children. *Environmental Research*, 156, 519–525. <https://doi.org/10.1016/j.envres.2017.04.003>.
- Kim, J. I., Kim, J. W., Lee, J. M., Yun, H. J., Sohn, C. H., Shin, M. S., ... Kim, B. N. (2018). Interaction between DRD2 and lead exposure on the cortical thickness of the frontal lobe in youth with attention-deficit/hyperactivity disorder. *Progress in Neuro-Psychopharmacology & Biological Psychiatry*, 82, 169–176. <https://doi.org/10.1016/j.pnpbp.2017.11.018>.
- Kim, K. N., Kwon, H. J., & Hong, Y. C. (2016). Low-level lead exposure and autistic behaviors in school-age children. *Neurotoxicology*, 53, 193–200. <https://doi.org/10.1016/j.neuro.2016.02.004>.

- Lee, D. W., Kim, M. S., Lim, Y. H., Lee, N., & Hong, Y. C. (2018). Prenatal and postnatal exposure to di-(2-ethylhexyl) phthalate and neurodevelopmental outcomes: A systematic review and meta-analysis. *Environmental Research*, *167*, 558–566. <https://doi.org/10.1016/j.envres.2018.08.023>.
- Li, X. J., Jiang, L., Chen, L., Chen, H. S., & Li, X. (2013). Neurotoxicity of dibutyl phthalate in brain development following perinatal exposure: A study in rats. *Environmental Toxicology and Pharmacology*, *36*(2), 392–402. <https://doi.org/10.1016/j.etap.2013.05.001>.
- Liao, K. W., Pan, W. H., Liou, S. H., Sun, C. W., Huang, P. C., & Wang, S. L. (2019). Levels and temporal variations of urinary lead, cadmium, cobalt, and copper exposure in the general population of Taiwan. *Environmental Science and Pollution Research International*, *26*(6), 6048–6064. <https://doi.org/10.1007/s11356-018-3911-0>.
- Lim, Y. H., Bae, S., Kim, B. N., Shin, C. H., Lee, Y. A., Kim, J. I., & Hong, Y. C. (2017). Prenatal and postnatal bisphenol A exposure and social impairment in 4-year-old children. *Environmental Health*, *16*(1), 79. <https://doi.org/10.1186/s12940-017-0289-2>.
- Malagutti, K. S., da Silva, A. P., Braga, H. C., Mitozo, P. A., Soares Dos Santos, A. R., Dafre, A. L., ... Farina, M. (2009). 17beta-estradiol decreases methylmercury-induced neurotoxicity in male mice. *Environmental Toxicology and Pharmacology*, *27*(2), 293–297. <https://doi.org/10.1016/j.etap.2008.11.005>.
- Mason, L. H., Harp, J. P., & Han, D. Y. (2014). Pb neurotoxicity: Neuropsychological effects of lead toxicity. *BioMed Research International*, *2014*, 840547. <https://doi.org/10.1155/2014/840547>.
- Miller, A. A., De Silva, T. M., Jackman, K. A., & Sobey, C. G. (2007). Effect of gender and sex hormones on vascular oxidative stress. *Clinical and Experimental Pharmacology & Physiology*, *34*(10), 1037–1043. <https://doi.org/10.1111/j.1440-1681.2007.04732.x>.
- Park, S., Kim, B. N., Cho, S. C., Kim, Y., Kim, J. W., Lee, J. Y., ... Han, D. H. (2014). Association between urine phthalate levels and poor attentional performance in children with attention-deficit hyperactivity disorder with evidence of dopamine gene-phthalate interaction. *International Journal of Environmental Research and Public Health*, *11*(7), 6743–6756. <https://doi.org/10.3390/ijerph110706743>.
- Park, S., Lee, J. M., Kim, J. W., Cheong, J. H., Yun, H. J., Hong, Y. C., ... Kim, B. N. (2015). Association between phthalates and externalizing behaviors and cortical thickness in children with attention deficit hyperactivity disorder. *Psychological Medicine*, *45*(8), 1601–1612. <https://doi.org/10.1017/s0033291714002694>.
- Park, Y., Lee, A., Choi, K., Kim, H. J., Lee, J. J., Choi, G., ... Park, J. (2018). Exposure to lead and mercury through breastfeeding during the first month of life: A CHECK cohort study. *Science of the Total Environment*, *612*, 876–883. <https://doi.org/10.1016/j.scitotenv.2017.08.079>.
- Petit, T. L., Alfano, D. P., & LeBoutillier, J. C. (1983). Early lead exposure and the hippocampus: A review and recent advances. *Neurotoxicology*, *4*(1), 79–94.
- Ryu, J., Ha, E. H., Kim, B. N., Ha, M., Kim, Y., Park, H., ... Kim, K. N. (2017). Associations of prenatal and early childhood mercury exposure with autistic behaviors at 5 years of age: The Mothers and Children's Environmental Health (MOCEH) study. *Science of the Total Environment*, *605–606*, 251–257. <https://doi.org/10.1016/j.scitotenv.2017.06.227>.
- Saghazadeh, A., & Rezaei, N. (2017). Systematic review and meta-analysis links autism and toxic metals and highlights the impact of country development status: Higher blood and erythrocyte levels for mercury and lead, and higher hair antimony, cadmium, lead, and mercury. *Progress in Neuro-Psychopharmacology & Biological Psychiatry*, *79*(Pt B), 340–368. <https://doi.org/10.1016/j.pnpbp.2017.07.011>.
- Schultz, S. T. (2010). Does thimerosal or other mercury exposure increase the risk for autism? A review of current literature. *Acta Neurobiologiae Experimentalis (Wars)*, *70*(2), 187–195.
- Taylor, C. M., Kordas, K., Golding, J., & Emond, A. M. (2017). Effects of low-level prenatal lead exposure on child IQ at 4 and 8 years in a UK birth cohort study. *Neurotoxicology*, *62*, 162–169. <https://doi.org/10.1016/j.neuro.2017.07.003>.

- Wang, Y., Zhu, H., & Kannan, K. (2019). A review of biomonitoring of phthalate exposures. *Toxics*, 7(2), <https://doi.org/10.3390/toxics7020021>.
- Wojtowicz, A. K., Szychowski, K. A., Wnuk, A., & Kajta, M. (2017). Dibutyl phthalate (DBP)-induced apoptosis and neurotoxicity are mediated via the aryl hydrocarbon receptor (AhR) but not by estrogen receptor alpha (ERalpha), estrogen receptor beta (ERbeta), or peroxisome proliferator-activated receptor gamma (PPARgamma) in mouse cortical neurons. *Neurotoxicity Research*, 31(1), 77–89. <https://doi.org/10.1007/s12640-016-9665-x>.
- Yan, J., Gao, Z. Y., Wang, J., & Yan, C. H. (2017). Hair mercury levels and their relationship with seafood consumption among preschool children in Shanghai. *Biomedical and Environmental Sciences*, 30(3), 220–223. <https://doi.org/10.3967/bes2017.030>.

Further reading

- Jedrychowski, W., Perera, F. P., Jankowski, J., Mrozek-Budzyn, D., Mroz, E., Flak, E., ... Lisowska-Miszczuk, I. (2009b). Very low prenatal exposure to lead and mental development of children in infancy and early childhood: Krakow prospective cohort study. *Neuroepidemiology*, 32(4), 270–278. <https://doi.org/10.1159/000203075>.
- Kougias, D. G., Sellinger, E. P., Willing, J., & Juraska, J. M. (2018). Perinatal exposure to an environmentally relevant mixture of phthalates results in a lower number of neurons and synapses in the medial prefrontal cortex and decreased cognitive flexibility in adult male and female rats. *The Journal of Neuroscience*, 38(31), 6864–6872. <https://doi.org/10.1523/jneurosci.0607-18.2018>.
- Razzoli, M., Valsecchi, P., & Palanza, P. (2005). Chronic exposure to low doses bisphenol A interferes with pair-bonding and exploration in female Mongolian gerbils. *Brain Research Bulletin*, 65(3), 249–254. <https://doi.org/10.1016/j.brainresbull.2004.11.013>.

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Early life determinants of health: Invest early to break the cycle of long-term disadvantage in neurodevelopmental disorders

*Valsamma Eapen^{a,b,c,d,e}, Susan Woolfenden^f,
Susan Prescott^{g,h}, Antonio Mendoza Diaz^a,
and Mark Daddsⁱ*

^aSchool of Psychiatry, Faculty of Medicine, University of New South Wales, Kensington, NSW, Australia, ^bAcademic Unit of Child Psychiatry, South West Sydney (AUCS), Sydney, NSW, Australia, ^cEarly Life Determinants of Health, Sydney Partnership for Health, Education, Research and Enterprise (SPHERE), Darlington, NSW, Australia, ^dProgram 1, Co-operative Research Centre for Autism (CRC), Kelvin Grove, QLD, Australia, ^eBestSTART-SWS (Systems Transformation and Research Translation—South West Sydney) Academic Unit, Sydney, NSW, Australia, ^fSchool of Women & Children’s Health, Faculty of Medicine, University of New South Wales, Kensington, NSW, Australia, ^gThe ORIGINS Project, Telethon Kids Institute, University of Western Australia, Perth Children’s Hospital, Nedlands, WA, Australia, ^hinVIVO Planetary Health of the Worldwide Universities Network (WUN), West New York, NJ, United States, ⁱChild Behaviour Research Clinic, Principal NHMRC Research Fellow, University of Sydney, Sydney, NSW, Australia

1 Introduction

Many children globally are not achieving optimal health, development, and wellbeing. Adverse environmental risk factors interact with a child's innate biological risk and genetic make-up in a cumulative manner, resulting in adverse health and wellbeing outcomes (Grantham-McGregor et al., 2007). A suboptimal start to life prevents children from reaching their health, social, educational, and vocational potential as they progress along their life-course trajectory into adulthood. The case is particularly pressing for children who present early with neurodevelopmental disorders (NDDs). Further, there is evidence to suggest that, while childhood mortality has reduced in the last 25 years, neurodevelopmental disorders have remained constant (Olusanya et al., 2018; Scott, Mihalopoulos, Erskine, Roberts, & Rahman, 2016). Such evidence reflects inadequate attention to the developmental potential of children despite significant improvements in healthcare (Walker et al., 2011). However, recent initiatives such as the 'Sustainable Development Goals of the United Nations' and the 'Nurturing Care Framework' endorsed by the WHO aimed at a holistic view of health that ensures that children not only survive but also thrive to reach their full potential (UN High Commissioner for Refugees, 2017).

NDDs including intellectual disability, autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), and specific learning disorders and motor disorders affect approximately 52.9 million children under 5 years of age globally, incurring considerable cost to government health budgets and adversely impacting the social and mental capital of the future generations. Moreover, comorbidities between developmental disorders and mental health (MH) concerns are a significant global challenge accounting for 13.3% of the 29.3 million *years lived with disability* for all health conditions in the 0–5 age group. In this regard, it is noteworthy that NDDs do not exist in isolation and there is a fivefold increased risk for comorbid MH problems for those with NDD, with consequent poor quality of life and reduced life expectancy (Coghill, Danckaerts, Sonuga-Barke, Sergeant, & ADHD European Guidelines Group, 2009), as well as a higher risk of MH problems for their family (Gilson et al., 2018).

While the highest prevalence of total and individual disability was found in low- and middle-income countries, for specific NDD conditions such as *ADHD and ASD*, Sweden and Australia were rated joint highest among 195 countries in terms of years lived with disability (Olusanya et al., 2018)—however, this is in part due to better access to data, as some of the biggest increases in NDDs have been seen in sub-Saharan Africa and South East Asia. This suggests that the burden of NDDs is universal, yet country-specific challenges must be carefully considered when designing targeted solutions. In this regard, Australian Early Development Census suggests that one in five children is starting school with a NDD, with higher rates in vulnerable

populations (Brinkman, Gregory, Goldfeld, Lynch, & Hardy, 2014). One of the major barriers to addressing this issue is that the most disadvantaged families are the least likely to access care. This is particularly true in disadvantaged communities across the globe, who show an ‘inverse care law’ whereby the most disadvantaged families with children at highest risk of developmental and behavioural disability are least likely to engage with or have access to preventative and health promotion programmes that would facilitate early identification and early intervention, thereby exacerbating health inequalities (Eapen et al., 2017; Overs et al., 2017).

1.1 The challenge

Inequities in accessing evidence-based assessments and treatments precipitate further problems, engendering barriers that prevent timely and effective delivery of care. The challenge is therefore threefold. First, understanding early life stress, genetic and microbial interactions with stress, and the emergence of clinical phenotypes is critical to our understanding of how best to intervene. Second, neurodevelopmental phenotypes are at times inadequately captured by diagnostic criteria, meaning that even if children are diagnosed early, diagnoses are not always helpful in determining treatment choice. Third, the systemic nature of the challenges—such as the inequity described—makes intervention difficult; unless a transdiagnostic, system-based approach is taken with the goal of establishing equity-focussed pathways of care.

This chapter starts by discussing the association between early life stress—particularly interactions between biological systems and stress—and the emergence of clinical phenotypes. This discussion allows us to make a direct connection between the systemic inequity discussed earlier and the individual presentations we see in the clinic. While there is some compelling new evidence in this field, much remains to be investigated. Importantly the study of biological models of NDDs raises many questions that are fundamental to our understanding of NDDs. Chief among these is what is the best course of action to take when the profiles emerging from biological models only partially maps onto diagnostic categories. The second section discusses this issue with a view that the development of transdiagnostic models seems like the most promising avenue towards the accurate identification of treatment targets and the development of effective interventions at the population level. The third section then broadens the scope of discussion, refocussing on inequities from the point of view that, *if* biological and transdiagnostic models are to be taken into account and *if* solutions to the challenge of NDDs are to be rolled out in the messy reality of an unequal and capacity-limited healthcare system, then what approach(s) might we conjure to ensure the right intervention at the right time and in the right place is delivered to the right child.

2 The importance of understanding early life stress, genetic and microbial interactions with stress, and the emergence of clinical phenotypes

Established research in the Developmental Origins of Health and Disease (DOHaD) demonstrates the inextricable link between maternal, perinatal, and early childhood factors and the risk of physical health conditions including heart disease, diabetes, obesity, cancer, and many other noncommunicable diseases (NCDs) including developmental and mental health conditions in later life (Reading, 2006). Thus children who have been affected by early life stress are more likely to have NDDs with the dysfunction in early systems leading to adverse morbidity trajectories throughout the lifespan (Felitti et al., 2019), including early mortality. In this sense, early life stress is a common precursor to a range of health conditions, with different forms of stress or adversity showing specific relationships with clinical presentations.

Available evidence suggests that different types of adversity may have different effects on brain and behaviours (Sheridan, Fox, Zeanah, McLaughlin, & Nelson, 2012). In this regard, neglect or deprivation may have a fundamentally different impact on the neuronal development and circuitry formation as compared with those having been exposed to domestic violence, aggression, or harsh punishment (Hart & Rubia, 2012). Further, it may alter the brain morphology with long-term consequences such as the reduced prefrontal cortical thickness associated with neglect. Since higher executive functions including organization, problem-solving, and attentional processes are linked to the activity of the dorsolateral prefrontal cortex, it is plausible that the involvement of this brain area through neglect may increase the risk for NDDs such as ADHD. However, even this can be a complex process as each individual has an innate biological risk and resilience profile upon which such environmental factors are operating as a 'second hit' (Nabeshima & Kim, 2013). In this regard, it has been shown that the neuronal circuitry most plastic during early life stress exposure in animal models have been shown to have maximum gene expression changes (Lewis & Olive, 2014).

Emerging evidence from animal models suggests that disruptions in the maternal–infant interactions may have different neuronal, metabolic, and phenotypic outcomes based on the sex of the offspring (Kawakami, Quadros, Machado, & Suchecki, 2013; Kawakami, Quadros, Takahashi, & Suchecki, 2007). There is also emerging evidence to suggest that early life stress in the form of prenatal stress may exert unique sex-dependent developmental outcomes mediated by placental effects that are sex-dependent (Bronson & Bale, 2014; Bronson, Chan, & Bale, 2017). Even regardless of the placental effects, sex-dependent effects following early life stress may manifest in the early postnatal period (Coutellier & Würbel, 2009). Thus it

appears that early life stress may predispose each child in a unique way to shape the individual neuronal circuitry to specific psychopathology, whether it is externalizing, internalizing, or dysregulatory behaviours which in turn may be influenced by not only the type of biological vulnerability and the type of early life stress but also the sex of the child (Keyes et al., 2012). This is in keeping with the evidence from epidemiological studies that internalizing disorders are more common in females (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995) while the risk for externalizing disorders and NDDs are higher in males (Cover, Maeng, Lebrón-Milad, & Milad, 2014). This is also consistent with the findings from the Virginia adolescent twin study which showed that emotional disorders were more common in females while behavioural disorders were more common in males suggesting a sex–environment interaction in the genesis of psychopathology. Of further interest was the observation that females who had experienced early life stress were more likely to develop emotional disorders (Bale & Epperson, 2015). Similar sex-dependent differences in the phenotypic expression of the underlying putative neurodevelopmental gene(s) have also been shown in NDDs. Examples are those of Tourette syndrome (TS), ADHD, and obsessive–compulsive disorder (OCD), where there is evidence to suggest that male members of the family are more at risk of exhibiting tics and ADHD while obsessive–compulsive symptoms may be another phenotypic expression in female first-degree relatives (Eapen, Pauls, & Robertson, 2006).

In the presence of biological vulnerability, the type and timing of environmental events may play a critical role in determining the risk to different NDDs as different parts of the brain are developing at different time points during the intrauterine and postnatal life and subsequently consolidated in the early or middle childhood and adolescent years. For example, it has been proposed that there may be differential impact of *deprivation* or neglect and *threat*-related experiences. The latter in the form of exposure to violence or physical threat has been found to be associated with changes in the hippocampus and the amygdala–prefrontal cortex minicircuitry resulting in changes in fear responses and fear learning and consequent impact on emotion regulation (McLaughlin, Sheridan, & Lambert, 2014). Thus the nature and extent of circuitry involvement in a developing brain consequent to different environmental events may be dependent on the underlying biological vulnerability as well as the type and timing of the events (Edwards, Holden, Felitti, & Anda, 2003). This in turn in a cumulative manner is likely to increase the risk of specific cognitive, social, and emotional developmental outcomes, as well as clinical and functional outcomes that set in motion a particular trajectory through childhood, adolescence, and adulthood which may be amenable to specific interventions (Nelson, 2014; Nelson, Fox, & Zeanah, 2016).

2.1 Genetic interactions with early life stress

There is emerging evidence to suggest that specific neurodevelopmental genes may have a critical role in maintaining the excitatory/inhibitory balance of the developing brain and, when that balance is altered resulting in the net excitatory or inhibitory state, this will in turn impact the nature and type of clinical symptoms (Selten, van Bokhoven, & Nadif Kasri, 2018). Further the synaptic homeostasis is known to be determined by the balance between the strength of excitation, inhibition, and the intrinsic excitability of the neuronal circuitry (Turrigiano, 2012). In this regard, early life stress has been shown to either delay or accelerate critical periods of development, which in turn has been linked to changes in maturation of the inhibitory GABA circuitry and critical neurodevelopmental genes involved in maturation such as the brain-derived neurotrophic factor (BDNF) and the circadian rhythm genes (Narducci et al., 2018). It is also known that even a small change that affects the neuronal firing can alter the balance between neuronal excitation and inhibition (Atallah & Scanziani, 2009) and that the resulting imbalance in the excitatory/inhibitory ratio can impact the development and stability of different neuronal regions and circuitry. This may further be affected by additional genetic and/or environmental events (Eapen, Ward, & Clarke, 2014).

It also appears that the phenotypic variability between different NDDs such as ASD, Tourette syndrome, ADHD, and learning disorder could be due to the fact that the genes converge towards a core set of dysregulated biological processes that affect distinct neurodevelopmental pathways involved in synapse development/maintenance and circuitry formation through effects on neurogenesis, axon guidance in dendritic projections, and/or neuronal migration (Eapen, 2012). Thus defects in synaptic development can result in abnormal development across disorders and broad domains but yet carry distinct neurocognitive and behavioural profiles. The penetrance of the different comorbidities may in turn be related to the dosage effects of gene abnormality or the timing of events when different neuronal regions and circuitry are being formed, as may be the influence of gender, intrauterine and perinatal events, epigenetics, and other environmental modulators (Eapen, 2011). There is also accumulating evidence that supports the notion that immune cells play important roles in normal brain function, outside of neuroinflammation. In this regard, we have suggested the involvement of synaptic dysfunction and abnormal immune responses and especially the role of microglia in synaptic pruning during postnatal brain development and the consequent impact on brain function (Voineagu & Eapen, 2013). Furthermore, genetically mediated deficits and consequent functional impairments involve activity-dependent synapse development (Vivanti, Barbaro, Hudry, Dissanayake, & Prior, 2013) that depends on postnatal learning and experience as well

as additional environmental events. Such a model would predict that early intervention would prevent or reduce the risk of genetically mediated deficits cascading into a trajectory towards full expression of the disorder by exploiting the neuronal maturation and brain plasticity (Eapen, Crncec, & Walter, 2013, 2016).

2.2 Microbes, stress, and the brain

Potentially critical yet previously unrecognized pathways through which the early environment influences all aspects of development—including the brain—are through the host microbiome. As with all bodily systems, immature infant microbiotas are more vulnerable to environmental stressors, with potential lifelong implications (Blaser, 2016). Emerging evidence has suggested that early life risk factors (stress, nutrition, antibiotics, toxins, and environmental biodiversity) may influence the developing microbiome in ways that may predispose individuals to the development of subsequent NCDs, including mental illness (Logan, Jacka, & Prescott, 2016; Prescott, Wegienka, Logan, & Katz, 2018; Renz et al., 2017).

There have been longstanding clues that microbes play an important role in brain physiology (Hegstrand & Hine, 1986) and development (Sudo et al., 2004). A landmark study found that BDNF gene expression was lower in the hippocampus and the cortex of germ-free animals compared with conventionally raised specific pathogen-free animals (Sudo et al., 2004). Given the role of BDNF in nerve plasticity, this suggested that commensal microbes could influence brain structure and function. Other studies have since replicated the finding that early life microbial colonization initiates signalling mechanisms that may impact the neuronal circuits involved in motor control and anxiety behaviour (Diaz Heijtz et al., 2011). Likewise, enhanced hypothalamic–pituitary–adrenal axis activity seen in germ-free animals following acute stress showed that microbiota was involved in aspects of the programming and modulation of stress responses (Sudo et al., 2004). Since then, there has been growing evidence of a gut–brain axis in humans. Observational studies have linked measures of microbial dysbiosis in humans with perceptions of psychological stress, depressive symptoms, and anxiety (Karl et al., 2017; Knowles, Nelson, & Palombo, 2008; Sundin et al., 2015; Zijlmans, Korpela, Riksen-Walraven, de Vos, & de Weerth, 2015). Notably, early life antibiotic exposures (Slykerman et al., 2017) and repeated antibiotic use in adolescents and adults (Lurie, Yang, Haynes, Mamtani, & Boursi, 2015) have been linked to subsequent depression, although the nature of this relationship requires further study. Furthermore the intestinal microbiome profiles of patients with major depressive disorder and other mental disorders have been noted to differ from healthy individuals (Evans et al., 2017; Hemmings et al., 2017; Jiang

et al., 2015; Lin et al., 2017; Naseribafrouei et al., 2014; Schwarz et al., 2018). Even aspects of personality such as conscientiousness have been linked to microbiome signatures (Kim et al., 2018).

Although the links between human stress and alterations to the microbiome are correlational (Chen et al., 2018), emerging experimental evidence argues for some degree of causality. For example, when faecal material from human donors with depression or anxiety is transplanted into healthy recipient rodents, these animals display behaviours that are indicative of depression and anxiety. These behavioural changes did not occur in animals that received faecal material from healthy human donors (De Palma et al., 2017; Kelly et al., 2016; Zheng et al., 2016).

The pathways by which the microbiome might influence cognition, mental health, and brain development have not been understood, but may include neural routes (the vagus nerve in particular), humoral signalling molecules (e.g. cytokines), neuropeptides, hormonal pathways, and immune-mediated effects through the microglia. Gut microbes influence the integrity of the intestinal barrier, which can initiate a cascade of low-grade inflammation and metabolic dysregulation if compromised (Stevens et al., 2017). In addition, the gut microbiome can act upon dietary components ranging from amino acids (e.g. tryptophan, the serotonin precursor) to polyphenols (producing bioactive metabolites) that are directly and indirectly capable of influencing mood (Martinez-Guryn et al., 2018; Marx, Moseley, Berk, & Jacka, 2017).

If the causal evidence base in the field is confirmed in human studies, the implications would be that any early life factors that alter the developing microbiome may have the potential to influence the developing brain through these pathways. Indeed, studies investigating various forms of stress—maternal separation, crowding, physical exhaustion, restraint, food deprivation, heat, cold, and acoustic stressors—can disrupt the normal gastrointestinal microbiota in animals. Ongoing work in this area still has several questions in need of answers. For example, even short-term social stress has been shown to disturb the mammalian microbiome (Galley et al., 2014; Partrick et al., 2018), making it uncertain whether microbiome responses correspond to the magnitude, type, and duration of stress. Social disadvantage may also drive predisposition for microbial dysbiosis through diet and other environmental pressures (Harrison & Taren, 2018; Miller et al., 2016). This may therefore potentially add another dimension of the physical and mental health disparities between lower-income and higher-income groups in the same society.

The mechanisms by which stress can cause dysbiosis are not well understood. It has been proposed that stress hormones may directly influence the growth of select microorganisms and/or indirectly influence microbial adhesion to mucosal surfaces (Gur & Bailey, 2016). Stress can promote the production of inflammatory signalling chemicals that

subsequently influence dysbiosis, and it can change gastrointestinal motility, gastric secretions, and other aspects of gastrointestinal physiology (Konturek, Brzozowski, & Konturek, 2011; Lewis et al., 2015). Other pathways include the impact of stress on dietary choices (such as the preference for energy-dense, additive-rich, nutrient-poor foods) (Errisuriz, Pasch, & Perry, 2016; Leigh, Lee, & Morris, 2018; Steinsbekk, Barker, Llewellyn, Fildes, & Wichstrom, 2017; Tryon, Carter, Decant, & Laugero, 2013) implicated in gut microbiome dysbiosis (Logan & Prescott, 2017; Prescott & Logan, 2017).

Collectively, these observations underscore the importance of taking an ecological approach to health, in particular, a recognition that the ecology of the *early* environment (including nutrition, nature contact, social interactions, environmental health, and potentially microbial diversity) impacts health across the lifespan. Moreover, it emphasizes the need to recognize the diverse biological impact of these stressors across a plurality of biological systems, which together contribute towards the maintenance of the gradient towards socioeconomic disadvantage (Logan, 2015). This is a matter of social justice.

2.3 Critical periods in development and brain plasticity

The penetrance of the different NDDs is associated with sex, gene dosage effects, and the timing of events when different brain regions are being formed, thus resulting in different clinical phenotypes (Eapen et al., 2013). In addition, changes in the excitatory/inhibitory balance may be extremely powerful such that the excitatory/inhibitory imbalance may easily lead to NDDs. In this regard, ASD and schizophrenia have been associated with derailment of development and the consequent mistiming of plastic windows (LeBlanc & Fagiolini, 2011; Marin, 2012). Thus the critical period may either be triggered or halted by early life stress with a shift in developmental timing resulting from factors that may hasten or slow GABA circuit maturation and also be influenced by neurodevelopmental genes such as BDNF known to accelerate the maturation of GABAergic synapses selectively (Porcher, Medina, & Gaiarsa, 2018). Thus the genomic and proteomic profiling of the circuitry implicated in the genesis of the clinical symptoms may help uncover the mechanisms that underpin the way early life stress exerts its effect on brain development. In this regard, findings such as the disruption of a developmental proteome involved in adenosine triphosphate (ATP) production and mitochondrial homeostasis could have important clinical implications (Gokoolparsadh et al., 2017). The role of mitochondria-associated protein changes is receiving considerable attention with further evidence revealing the developmental origins of sex-dependent mitochondrial dysfunction (Cameron, Eagleson, Fox, Hensch, & Levitt, 2017). Concerning NDDs, further research is indicated

in terms of establishing how early adaptive responses to allostatic load result in long-term dysfunction with consequent adverse impact on development and future health.

An exemplar for understanding the impact of critical periods in early life stress on long-term outcomes is the Bucharest Early Intervention Project. This unique study provided an opportunity to see using a randomized controlled trial the impact of a foster care intervention on Romanian children exposed to early psychosocial adversity and living in an institutional setting. These children at baseline assessment were significantly delayed in intellectual ability and had abnormal attachment-like behaviours towards caregivers along with stereotypies and aggressive behaviours and underlying reduced EEG alpha power (Zeanah et al., 2009). Half of the group at mean age of 22 months were randomized to be placed in a foster home, and the other half remained in institutional care. They were reassessed at 30, 42, and 54 months, as well as at 8 and 12 years of age across a number of different domains, including cognitive functioning, socioemotional responses, brain activity (visual attention and alertness measured with EEG), brain structure and connectivity (measured with MRI), and psychiatric status. There was evidence of a critical period for the impact of the intervention in that those placed in foster care before 24 months of age seemed to be closer to developmentally matched controls in terms of their psychological functioning. Attachment was found to mediate the mental health outcomes, with children who formed good attachment relationships with their foster parents having better outcomes. This is consistent with extant literature that suggests the key role that attachment plays in regulating stress responses. Further, when these children were challenged at 12 years for stress response using the Trier Social Stress Test, those who remained at the institutional setting had a blunted stress response as measured by hypothalamic–pituitary–adrenal axis reactivity and autonomic responses, while those who were placed in foster care before 24 months of age showed the same responses as community control children of similar age (McLaughlin et al., 2015). This clearly illustrates the power of early intervention in recovery and adaptation leading to better biological, cognitive, and social outcomes. Thus there is a critical need to integrate the different early life determinants (Fig. 1) given the significant interaction between the genetic and other biological and environmental risk factors that exert a cumulative impact on the neurodevelopmental trajectory and adult mental and physical health, as well as educational, employment, and social and criminal justice outcomes. For example, persistent toxic stress changes brain architecture, and in this regard, persistent violence, abuse, and neglect whether within home environments or because of civil unrest produce high levels of cortisol. Sustained and elevated cortisol levels can damage the neurons and reduce the brain connections, thereby disrupting brain development while also influencing genetic expression through

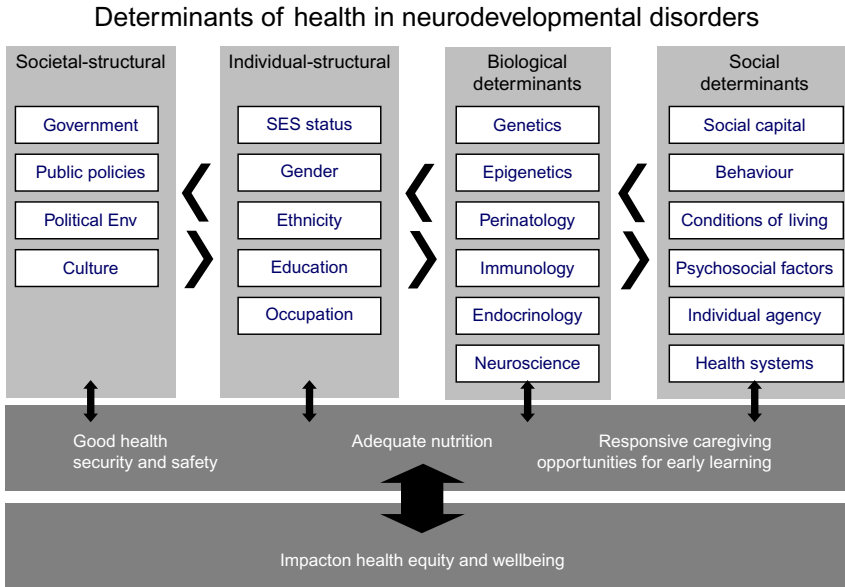


FIG. 1 Integration of early life determinants.

epigenetics and increasing vulnerability of the developing brain. Thus the interaction between biological vulnerability and the toxic stress response needs further exploration, and so does the relative impact of unique risk factors such as the stress-type and timing on the sex and other biological characteristics of the individual child. In this regard, childhood development depends on a complex interplay between the *nature*, genetics providing a blueprint for the developing brain, and the *nurture*, environmental factors determining whether a child will reach his/her developmental potential. Hence, it is not a question of *nature* VERSUS *nurture* but rather an issue of *nature* VIA *nurture*.

So far, this chapter discussed the evidence behind the interactions between different types of stress and different biological systems, and yet arguably the full clinical potential of this knowledge remains unfulfilled. The evidence for genetic and hormonal associations with stress has been known for decades, and there is solid evidence that excessive stress disrupts the developing brain; likewise, there is emerging evidence that the microbiome plays a role in these complex relationships. Despite these advances, it has been difficult to pinpoint exactly which relationships are critical for the development of specific NDDs. That is, it has been difficult to move beyond the overgeneral relationship that more stress is bad and that stress can have negative impacts in a variety of systems. One reason for this may be that stress is not properly understood and that, if it was

parcelled and dissected correctly, it would reveal a hitherto undiscovered relationship. Yet, as suggested by the evidence earlier, the combination of factors we term 'stress' is not subtle in their trundling over the biological landscape, but rather, stress's footprints are felt across biological systems. It may, therefore, be the case that it is not stress which is misunderstood or understudied. Could it be instead that it is *the outcome* which has been mischaracterised? That instead, the boxes used to cluster symptoms into discrete categories are not well suited to the mechanistic study of NDDs. That is, that the labels we use to group symptoms into categories such as ASD, ADHD, etc. lead us to miss a lot of the commonality in processes and systems that is at play across these conditions. To investigate this the next section discusses neurodevelopmental phenotypes as transdiagnostic complements to diagnostic criteria.

3 Neurodevelopmental phenotypes and diagnostic criteria

Labels, in general, and psychiatric labels, in particular, are often the source of controversy. The purpose of this section is not to use psychiatric labels as a metaphorical punching bag, as all authors agree that diagnostic categories have been extremely useful in communicating about illnesses, targeting the right treatment to the right intervention, and in clustering symptoms into phenomenologically sound clusters with face validity. Rather the position we subscribe to is that certain dimensions or domains are common across a number of diagnostic categories and that these dimensions or domains can be just as useful—and in some cases even more so—in communicating, intervening, and grouping conditions. In most cases, transdiagnostic models—those domains or dimensions of functioning—complement our work on diagnostic criteria. An important example of this kind of complementarity comes from outside of NDDs in the form of the 'limited prosocial emotions' (LPE) specifier spanning the DSM diagnoses of conduct disorder (CD) and (increasingly) oppositional defiant disorder (ODD). Children with ODD/CD who have LPE are at a higher risk of pervasive misbehaviour continuing beyond childhood. By labelling these dimensions and looking out for it in the clinical presentation, we can develop therapies directed at this group that are able to tackle the challenges associated with both ODD/CD as well as those specific to LPE. This is to say that there is no need to throw out the baby with the bathwater. The old diagnostic categories can and will coexist with transdiagnostic dimensions that will enrich case conceptualization. In some cases, old categories will disappear, and in others, they will endure; neither of these scenarios negates the fact that we have developed a language to communicate about psychiatric illnesses that is meaningful and useful in knowing how best to

help others. This section therefore discusses topics aimed at expanding a more nuanced discussion about neurodevelopmental models or phenotypes (presentations) and diagnostic criteria.

3.1 The impact of diagnostic change

The changing definitions and diagnostic criteria for NDDs can have a negative impact on the wellbeing of families seeking help, who are forced to seek reassessments and reevaluation and who are often left wondering whether the label and treatment they had been pursuing were at all adequate to their child (Beighley, Matson, Rieske, Konst, & Tureck, 2014; King & Bearman, 2009; Wills, 2014). This type of discussion came to a head with diagnostic changes to ASD and the publication of the DSM-5 (Beighley et al., 2014; Wills, 2014). Diagnostic criteria are meant to characterize symptoms at a distinct point in time, but at times, these fail to incorporate temporal change in real time as development—and therefore neurodevelopment—is a dynamic process that evolves as children age. Although change in diagnostic categories is necessary and indeed desirable as knowledge expands, it is undeniable that these changes impact families ‘on the ground’ who struggle to live and conform to their labels. Through the inclusion of transdiagnostic dimensions, we may be able to typify neurodevelopmental phenotypes in such a way that, even though clusters of symptoms are rearranged, some dimensions of functioning can be said to be maintained (or vice versa), providing some continuity even as aspects of the neurodevelopmental phenotype change labels.

Further, genetically mediated neurodevelopmental changes involve activity-dependent synapse development that depends on postnatal learning, environment, and experiences, and hence a number of peri- and postnatal factors are likely to have an impact. Thus the clinical presentations may change over time, and so may the diagnosis. This would mean that one child may lose a diagnostic label while another may pick up clinical symptoms and comorbidities along the developmental journey. This malleability also offers a unique opportunity for preventative strategies and early intervention programmes that exploit the neuronal maturation and brain plasticity. Hence, as the genetically programmed but environmentally modulated developmental process progresses, the diagnosis will need to be seen as a dynamic process. It is important to assess the dimensions known to be associated with the best and worst outcomes. The way forward is starting from a transdiagnostic approach and taking into account the convergence and the divergence between and within the different NDDs to examine shared developmental and functional characteristics. Such an integrated biopsychosocial perspective will transform our understanding of and our response to NDDs.

3.2 Transdiagnostic intervention

There is good evidence that intervening early in the life course to reduce risk prevents later problems and gets better results (Griffiths & Meinicke, 2014), and yet significant challenges remain in *detecting* children at risk of having NDDs sufficiently early, stratifying them according to neurocognitive profiles and matching them with comprehensive, multimodal, evidence-based interventions at scale that are both equitable and accessible to all children. While many groups attempt to use diagnostic criteria as outcome variables, this approach is ineffective if the aim is to identify and intervene as and when neurodevelopmental differences emerge and before symptoms worsen and diagnostic criteria are met. In this sense, tracking transdiagnostic dimensions along continuous scales may allow a more efficient system of risk recognition.

One such system could be the development of risk stratification algorithms that can identify when conditions are met, indicating a client is at a 'tipping point' or a point in which they are most amenable to change. It is possible that further risk stratification alongside the pathogenetic pathways on the domains of genetics; biomarker; and neurocognitive, social, and environmental stress determinants can operate within a transdiagnostic model, to help delineate the neurodevelopmental pathways that are shared by different NDDs. This type of stratification can be facilitated by data platforms that are shared between healthcare stakeholders, so different inputs are integrated carefully into the development of clinical and phenotypic profiles of biopsychosocial risk across the different NDDs. Hence, integrating knowledge on the precursors of risk and resilience is critical, and bottom-up, data-driven stratification is an important part of better understanding the unique and cumulative contributions of the different risk and resilience factors. However, despite all the advances in data linkage and analytics, the usefulness of data-driven approaches rests on the accuracy of the original data and the models that the data are being fitted to. That is to say that there is a considerable amount of work that needs to be undertaken in which data scientists work hand in hand with clinical researchers to develop risk stratification models that can recognize and use the underlying transdiagnostic dimensions common to NDDs.

Emerging evidence also suggests considerable overlap of NDDs aetiologically (Kelleher & Corvin, 2015), but publications are still constrained by concern about diagnosis rather than health outcomes based on children's abilities and their functional impacts. There are two important future directions worthy of consideration: The first is that we need to exploit the genetic, biological, social, and environmental dimensions that underlie different NDDs to create interventions that cut across disorders. The second direction that needs exploring to take a step forward in the discovery of preventative interventions in care is a refocussing towards integrated

solutions. The second of these directions is discussed in more detail in the third part of the chapter, whereas the first is briefly discussed here.

To develop effective transdiagnostic interventions, a programme of research will need to develop that takes into account common pathways to understand the pathogenesis of clinical symptoms through approaches such as genetics and functional genomics, social and environmental risk, and resilience factors across a number of conditions that have a cumulative impact rather than correlating individual risk to individual conditions. This will require transdiagnostic data platforms and innovative technology. One such example is to integrate neurocognitive biomarkers such as facial emotion recognition using phone-based technology, eye tracking, and other techniques to develop a *new-to-world culture-fair and language-free* battery of assessments in the early identification and stratification of NDDs between and within the specific conditions. Such assessments will therefore be sensitive to the needs of children across diverse language and cultural contexts from different countries and continents across the globe.

4 How best to intervene: A transdiagnostic, system-based approach towards the establishment of equity-focussed pathways of care

To address systemic inequity successfully, a ‘whole-of-system’ approach is needed. This starts with a confluence of early identification and intervention during the ‘first 2000 days’ (from pregnancy to start of school) at the point of care, where it is possible to redefine the relationship between the family and the health system. Next a transdiagnostic approach is required to look beyond diagnostic thresholds and focus on dimensions of functioning. Lastly, families’ priorities should inform care, such that families remain engaged from pregnancy to the start of school without feeling strained to meet arbitrary deadlines. Such a system would generate the right intervention at the right time and in the right place. Achieving this necessitates innovations in early identification, smart risk stratification, and profile characterization, with opportunities for targeted individualized care and personalized medicine where relevant, thereby maximizing opportunities for lifelong good health, education, and social participation.

Every child has biological, family, community, and social factors that influence their life (Fig. 2). It is imperative to focus on adverse health outcomes as a whole to identify the early risk factors and the neurodevelopmental differences that interact to produce these, rather than narrowing focus to one diagnostic group. As mentioned in the sections earlier, this integration is critical to identify, track, and stratify both emerging

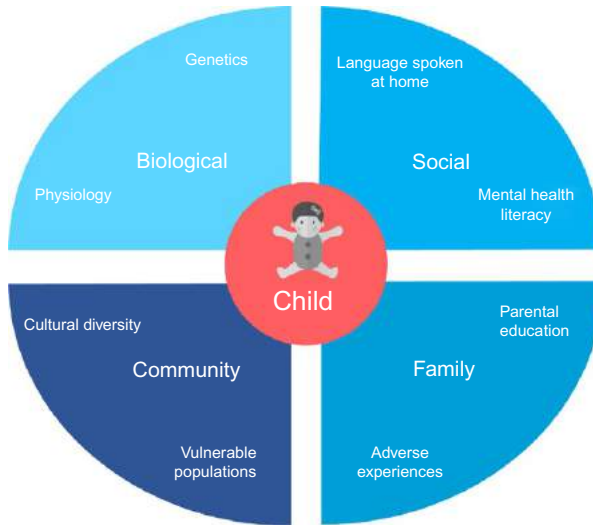


FIG. 2 Child development in the context of their family, culture, and environment.

NDD-specific symptoms and functional dimensions common across NDDs. While better outcomes can be achieved, improvements are often limited due to research and clinical services operating in separate silos. Sustained, long-term, and large-scale improvements in child health and wellbeing will only occur through transdisciplinary, integrated, and collaborative approaches to translational research over the life course. While information is available about early life determinants of NDDs, including moderators and mediators leading to resilience or ill health, to date, there has been little focus on integrating, disseminating, and implementing this knowledge at scale across systems, settings, and geographical boundaries. This in turn has a direct impact on increased inequality in social opportunity, lower labour force participation, and further entrenched intergenerational disadvantage (McLachlan, Gilfillan, & Gordon, 2013).

To develop a successful, system-wide intervention, several key ingredients are necessary. These are briefly discussed in the coming sections and include culture, workforce capacity, health literacy, social prescribing, and the timing of interventions. These ingredients are then brought together into a model that describes several of the changes that need to take place for the realization of this vision.

4.1 Culture

Sociocultural factors need special attention in the assessment process as the measures that are used to identify NDDs need to be culturally and linguistically appropriate. There are some cultures where there are no

words to describe ‘autism spectrum disorder’ and certain items used in the Autism Diagnostic Observation Schedule (ADOS) are not appropriate for sociocultural norms of the society. It is thereby difficult to correlate failure in that test item to the existence a specific clinical symptom without due consideration of the cultural appropriateness of the tool (Smith, Malcolm-Smith, & de Vries, 2016). Thus there is a critical need to develop and implement at scale a *universal system of early identification and stratification* of children at developmental risk or showing early signs of developmental differences. Such a system will need to incorporate elements of assessment that are culture fair and language free, thereby making care more accessible.

In this regard, our understanding of the physical, developmental, and mental health needs of children from LMIC settings is limited by a lack of data. Our research has shown that even in a high-income country such as Australia, culturally and linguistically diverse (CALD) groups are underrepresented in engagement with health services for prevention and health promotion and also they are underrepresented in research, particularly as a common exclusion criterion for research is being a non-English speaker (Eapen et al., 2014; Woolfenden et al., 2016). This is another expression of the ‘inverse care law’ mentioned in the introduction, whereby the ones most likely to need help are the least likely to access services. This means that we are missing essential information on outcomes and potentially modifiable risk and protective factors to inform the design of not only a more responsive identification system but of the healthcare system more broadly.

4.2 Workforce capacity

Yet, another factor behind the ‘inverse care law’ is ‘capacity’, which is particularly limited in low- and middle-income countries and even in high-income countries within regional, rural, and remote areas. A lack of capacity leads to an absence of care integration (patient-centric and coordinated care) and thereby limits the effective rollout of evidence-based treatments for NDDs.

Workforce and resource factors, such as shortages of child health professionals with the required training or prioritization systems that overly focus on the most severe presentations and draw resources away from effective prevention, cement existing inequities into the healthcare system. One of the processes by which this happens is through a distortion of priorities and a favouring of ‘hard’ diagnoses, while in reality elements considered ‘secondary’, such as concomitant behaviour or emotional problems, may cause the most distress to most families and are often missed or ignored, having further negative impacts on child and family functioning.

It is also paramount that we identify workforce and resource issues with a particular focus on the special needs of low- and middle-income countries (LMIC) as well as regional, rural, and remote communities in high-income countries. Designing targeted interventions need to consider integrating the best approaches for diagnostic conditions while also taking into consideration complex presentations with comorbidities that often cause families most distress, such as concomitant behaviour or emotional problems. Similarly the social determinants and psychosocial context of the child are well-known essential considerations, as the service systems are often complex and operate in silos and rely on parental capacity to navigate a system that is often unresponsive and inconsistent.

4.3 Mental health literacy

There is now considerable evidence that early interventions for many common childhood mental health problems are effective, a point made elsewhere by [Weisz and Kazdin \(2010\)](#), yet evidence-based treatments are rarely accessed, and the prevalence rates of childhood mental health disorders are therefore not decreasing. One reason for the low uptake of evidence-based interventions may be low levels of child mental health literacy (CMHL). Over the last decade, there has been significant research on mental health literacy, both in adolescents and adults, and population-level interventions have demonstrated that targeted campaigns can improve mental health literacy in the general populations ([Jorm et al., 1997](#)). However, there is a dearth of research conducted on CMHL, internationally. The reasons for the lack of research on CMHL to date are unclear. However, we believe that they may include four main concerns: (1) concern about stigmatizing children and/or parents; (2) the challenge of differentiating mental health disorders from developmentally normal and transient challenging behaviours, especially in young children; (3) concerns about creating anxiety in parents resulting in unwarranted help seeking; and (4) concerns about the availability of sufficient treatment services in the community to deal with increased demand that may occur if CMHL is improved. It is important to note that some of these concerns are legitimate and should be addressed explicitly in future research. Regardless of the reasons, however, we believe that the lack of focus on CMHL has resulted in widespread community ignorance regarding child mental health disorders, which has resulted in the absence of a common language to describe child neurodevelopmental disorders and mental health concerns, unnecessary stigma towards children and parents, and low levels of appropriate help seeking by parents.

Research to date is sparse but suggests that childhood mental disorders are poorly recognized and understood in the general population. For example, the US National Stigma Study-Children (NSS-C) found that the

US public lacked knowledge about ADHD and depression and their respective treatments (Pescosolido, Martin, Lang, & Olafsdottir, 2008). Only 42% of a community sample recognized ADHD (58% for depression), and 46% labelled it as a mental illness (69% for depression) (Pescosolido et al., 2008). A recent survey conducted by The Royal Children's Hospital with over 2000 Australian parents found that only 35% were confident that they could recognize the signs of a mental health problem in their child (Goldfeld, Kvalsvig, Inledon, & O'Connor, 2017; Tully, Hawes, Doyle, Sawyer, & Dadds, 2019). This survey found low levels of knowledge about some aspects of child mental health. For example, 41% of parents did not know that persistent difficulties with anger and aggression were not normal in primary school-age children. Similarly the second Australian Child and Adolescent Survey of Mental Health and Wellbeing found that not knowing whether children needed help and/or whether problems would get better by themselves posed barriers to help seeking by parents of children with mental health problems (Lawrence et al., 2016), barriers which are clearly related to low mental health literacy. Research is urgently needed to develop and validate measures of CMHL and stigma; obtain benchmark levels of CMHL and stigmatizing attitudes in the community; and develop, implement, and evaluate community campaigns to increase CMHL and reduce stigma. Such an Australian initiative focussed on enhancing CMHL may subsequently increase the likelihood that children would be able to access evidence-based early interventions for neurodevelopmental disorders and mental health concerns, thereby helping to reduce the prevalence and burden of these problems in the community.

4.4 Social prescribing

Another barrier to the successful implementation of therapies and interventions for NDDs has often been that health professionals operate within silos and feel disempowered to act on aspects that are beyond what has been normally considered their sphere of work. One possible solution is the use of what is being termed 'social prescribing', where health professionals are empowered to consider socioenvironmental aspects of health as important contributors to the aetiology of neurodevelopmental phenotypes.

There is emerging evidence from the United States that identification and treatment of the social determinants of health—'social prescribing' by clinicians—can be effective in reducing the burden of the social determinants of health (Chung et al., 2016; de la Vega et al., 2019; Garg & Dworkin, 2011, 2016; Garg, Sandel, Dworkin, Kahn, & Zuckerman, 2012; Gottlieb et al., 2016). In Boston, United States, randomized controlled trials have demonstrated that, when paediatric residents screened for the social determinants of health and provided information on social support

services, that disadvantaged families were much more likely to have their social needs met (Garg et al., 2007). In San Francisco, when a 'social needs coordinator' supported this process, gains were observed in child health and in the likelihood of family social needs being met (Gottlieb et al., 2016). This is a perspective that is gaining traction elsewhere in the English-speaking world; for example, the NHS in the United Kingdom has added social prescribing as part of its long-term plan, and primary care networks are being funded to employ social prescribers (Drinkwater, Wildman, & Moffatt, 2019). Although these approaches are mostly in their infancy and have not been trialled specifically with children with NDD, metaanalysis data show support of the general effectiveness of social prescribing although the methodological challenges in the implementation of these programmes are acknowledged (Bickerdike, Booth, Wilson, Farley, & Wright, 2017).

To truly provide family-centred care for children with NDD, we need to address the family's social priorities. This is essential for families to be able to engage successfully in early intervention (Dunst & Leet, 1987). Social prescribing is a nascent area that is of interest in that it acknowledges that health is but one aspect of an interconnected system.

4.5 Timing

Over the past three decades, data have emerged showing that programmes beginning in infancy and toddler years impact key outcomes for children with developmental delay and, the earlier the intervention, the better the outcome. There is also increasing evidence that intervening early in the life course to reduce risk prevents later problems and gets better results in NDDs. Further, early detection and intervention are efficacious and cost-effective, and it may be a way of decreasing health inequality and breaking the cycles of intergenerational disadvantage in society (Finlay-Jones et al., 2019). However, achieving an effective early detection and intervention programme requires an approach that is not vulnerable to derailment by problems like multiple referrals leading to families waiting for long periods for healthcare input, prohibitive costs, or limited parental capacity. Specific examples of exclusion points that need targeting during the period from pregnancy through preschool years include the following: (1) women not accessing antenatal care sufficiently early; (2) children not accessing well baby checks and developmental surveillance; (3) children not accessing child care/preschool due to cost, access, or other barriers and thereby losing the opportunity for engaging with the systems in place; (4) missing the opportunity for early identification of neurodevelopmental disorders and mental health concerns as parents may not be aware of the issues or of the relevant services or unable to access the services; (5) inadequate resources in terms of cultural

competency and sensitive interpreting that are key to assessing children for developmental problems and in particular language delay and ASD; (6) limited or lack of appropriate support programmes in the community through place-based initiatives or insufficient engagement; and (7) paucity of sensitive and responsive health services.

There is also increasing evidence from both animal and human studies pointing to the specificity of clinical and behavioural characteristics that result from the long-term effects of early life stress or adverse childhood experiences early in life. For example, what affects the attentional circuitry may be different from those that govern behavioural regulation or aggression and yet others for attachment and social relationships and so on (Noonan, Mars, Sallet, Dunbar, & Fellows, 2018). While earlier studies have focussed more on the general behavioural outcomes and the differences in severity, stratifying both the type of early life stress, the underlying processes, and the behavioural response patterns to homogeneous groups has significant advantage in defining specific neuronal circuitry that responds to each type of early life stress and the differences in developmental pathways that result in varying long-term changes in functioning (Dadds & Frick, 2019). Thus the type of adversity, the timing, and the specific ways in which neuronal development and circuitry formation has been impacted may help in matching the right client with the right interventions. For example, in animal studies (Callaghan & Richardson, 2011), early life stress has been shown to accelerate transition to mature fear memories that are more enduring (Gogolla, Takesian, Feng, Fagiolini, & Hensch, 2014). Further, it has been shown that intrauterine events may have an impact leading to hippocampal and prefrontal PV⁺ circuit anomalies with a suggestion that the mechanism underlying the impact of early life stress is through an earlier biochemical maturation of PV⁺ circuits. Animal findings have enticing implications that are yet to be confirmed in humans. For example, in addition to the impact of early life stress on limiting the critical caregiver interactions, events such as ‘maternal separation’, ‘social isolation’, and ‘maternal immune factors’ may also exert additional effects through prematurely closing critical windows of opportunity and thereby depriving the children the opportunity to correct the developmental derailment. This also has clinical implications for the timing of interventions.

4.6 Bringing it all together

4.6.1 *Proportionate universalism and integrated care*

A lack of integration at the point of care is commonly discussed as a translational or implementation problem. That is, although treatments continue to be developed for conditions like ASD and other forms of NDDs, problems of access and translation help preserve the socioeconomic

gradient. As problems in early childhood remain undetected, these escalate and prevent children at need from accessing early intervention in the first years of life, preventing them in turn from maximizing their potential. As an example, while most high-income countries have well-established and organized self-help and parent groups that advocate for better services, the connection between research and the community's needs is haphazard, and the lack of strong lines of communication is a significant barrier to achieving equitable changes in the healthcare system. Social determinants and the psychosocial context of the child are also an important contributor in that the current system relies on parental literacy and capacity to report behavioural changes sufficiently early and in families' means to access help and advocate for the child. At the same time, parental insight is often disregarded instead of integrated into clinical decision-making models.

There is a critical need for stratifying children as per functional needs and availability of supports and ensuring a stepped-care model within a 'proportionate universalism' framework consisting of universal programmes plus targeted care commensurate with needs. This requires an approach that sees interventions targeted to the right child, early enough to make use of the significant opportunities presented by brain plasticity in a developing brain, rather than leaving identification and triage until it is too late when the scope of successful interventions is narrower. Engaging parents during opportunistic contacts and then providing ongoing monitoring and care will provide a universal system of developmental surveillance accessible to all children and families. Such a programme will also need to combine and harness available international data resources. Large data consortia, if gathered together and used in integration, could vastly increase the effectiveness of services. An approach is needed that draws together the fragments of discipline-based (e.g. allied health, psychiatry, and paediatrics) and diagnosis-specific services that operate in silos, between geographical regions (e.g. urban and rural), and at a policy level between different government departments (e.g. health, education, disability, justice, and housing) and jurisdictions (e.g. local or provincial, state, or federal). For example, starting from antenatal care, if we begin to combine these data to identify children at risk of NDDs in real time and to deploy the most effective evidence-based interventions to modify the trajectories of vulnerable children early enough, the parents and the wider system will begin to be empowered to make a real difference leading to system change and better long-term outcomes. This could be combined with technological solutions using data visualization, data linkage, and an analytics platform to facilitate each child's varying risks, needs, and psychosocial determinants to be identified and stratified so that a matching personalized and integrated model of care can be provided. This will also lead to better integration in education, better productivity for parents, improved economic participation in adulthood, and higher rates of independent living.

4.6.2 *Developmental vulnerability index and stepped care*

Using data integration and service coordination along a dimensional and transdiagnostic approach will allow cohesiveness, continuity, and coordination in the care provided to the child taking into account the nature of the developmental risk as assessed using a 'developmental vulnerability index' (see [Figs 3 and 4](#)) while taking into account the multiple domain involvement and the comorbidities. This can be done using a *stepped-care approach* starting with health literacy programmes on healthy development and universal developmental surveillance programmes by engaging the parents during routine visits in primary care settings or early childhood centres and addressing specific determinants and developmental risk as and when identified. The second step will be to set up stepped-care pathways that will harness the information at different scales to coordinate interventions at both the group (e.g. communities and clinical networks) and individual levels. At the individual level, this would occur early, by identifying and stratifying children according to their vulnerabilities and strengths. Here, children would be referred on to appropriate pathways, whereby for some it will be the implementation of targeted interventions, while, for others displaying strength and resilience, the provision of minimal support may be all that is needed. For example, in a case where there are a number of risk factors evident on a developmental vulnerability index ([Eapen, 2014](#)) ([Fig. 3](#) in the succeeding text) such as history of perinatal depression, birth asphyxia, temperament difficulties, and speech delay, there is considerably higher risk of secondary impacts such as behavioural problems and school-related issues. Here, social determinants play a critical role in development beginning even in the preconception period. This includes intermediary factors such as living conditions and material circumstances; psychosocial factors such as relationships between parents, children, and peers; and structural determinants such as the sociodemographic profile of the family, living conditions, learning environments of day care and schools alongside the physical environment such as access to green spaces, neighbourhood safety, and the wider sociopolitical context (see [Fig. 1](#)). Available evidence also suggests that cumulative adversities are more detrimental to a child's development than a single adversity. In such a case a transdisciplinary approach involving paediatric, psychiatric, and allied health professionals in the assessment followed by primary, secondary, or tertiary interventions would be indicated. Such a complex interaction of different vulnerability factors involving the child, the constitutional and innate biological architecture, and the social and environmental determinants can be best conceptualized using bioecological model. Such a model takes into account the amount of risk and protection factors that are in operation and the 'dose' of cooccurring factors that are in the immediate environment that directly impact the child (proximal factors) and those that exert an influence indirectly (distal factors) ([Walker et al.,](#)

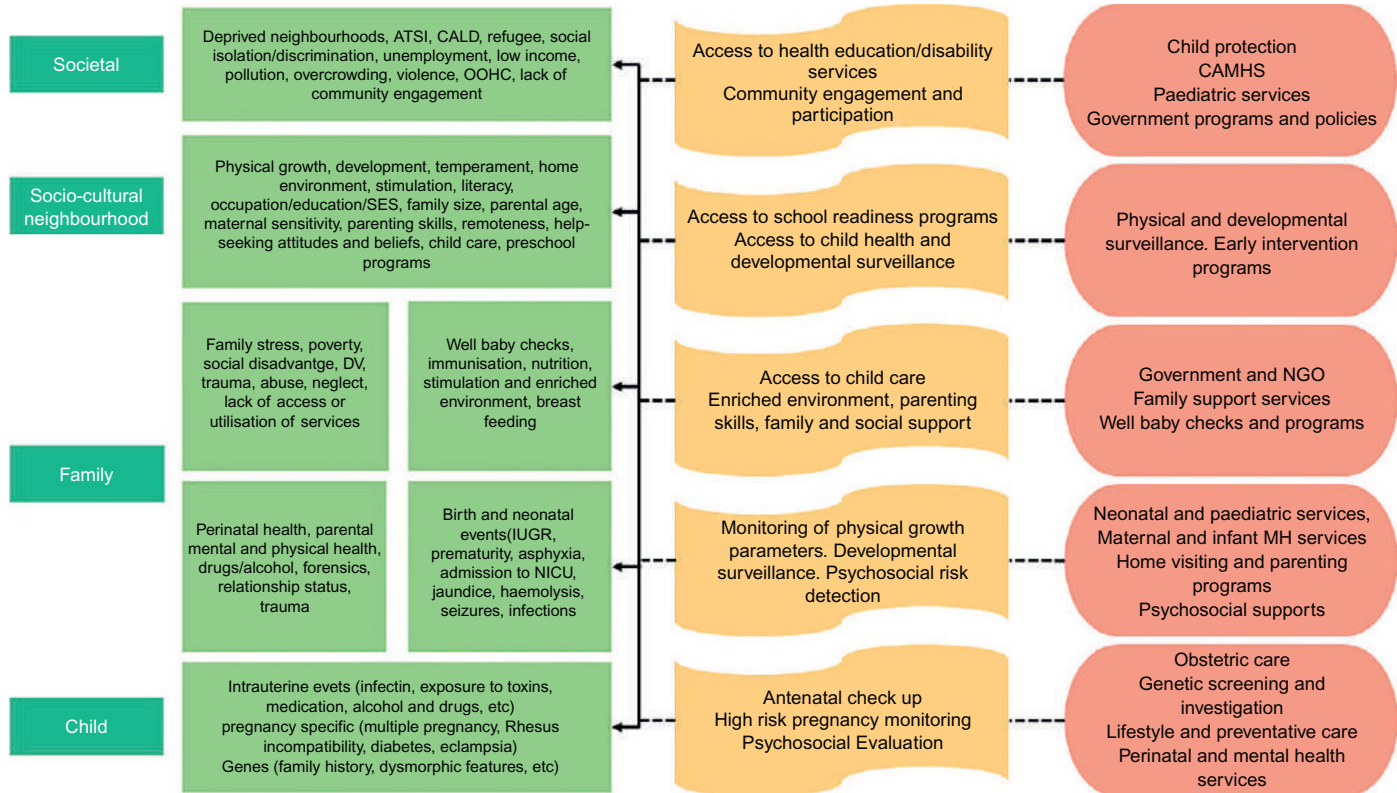


FIG. 3 Factors informing developmental vulnerability.

Developmental risk index:

1.	Biological factors - Biological vulnerability such as genetic (positive family history, dysmorphic features), difficult temperament etc.	1 point per risk item up to a max of 2
2.	Individual child factors – Intrauterine environment (e.g. exposure to smoking, Alcohol/drugs, toxins) perinatal (e.g. prematurity, IUGR, low Apgar), postnatal growth (developmental, social-emotional or behavioural problems), seizures, infections, chronic physical illness, lack of stimulation (play, reading to child) and nurturing care (physical, nutrition, emotional)	0.5 points per risk item up to a max of 2
3.	Parental factors – Younger or older age of parents, parental physical and mental health, drug/alcohol, criminality, maternal sensitivity/ parenting skills, child exposed to DV, trauma, violence, abuse or neglect, single parent, family relationships, parental sensitivity and attitudes, poor literacy, low IQ etc.	0.5 points per positive risk item up to a max of 3
4.	Family and psychosocial factors – Family stress, poverty, food insecurity, social disadvantage, low socioeconomic status (income, education, occupation), housing/family stability, large family size, overcrowding, mobility, refugee/minority groups, trauma, abuse, out of home care, parents in prison	0.5 points per positive risk item up to a max of 2
5.	Socio-cultural and service-related factors – Poor access to or utilization of services (antenatal, early childhood, preschool), poor community participation, help seeking attitudes/beliefs, deprived or violent neighbourhood, pollution (e.g. lead), remoteness, social isolation/discrimination, lack of social supports	0.25 points per risk item up to a max of 1

FIG. 4 Developmental vulnerability index. Based on Eapen, V. (2014). Developmental and mental health disorders: Two sides of the same coin. *Asian Journal of Psychiatry*, 8, 7–11.

2011). For example, perinatal depression does not have a direct impact on the child’s development, but it operates indirectly through poverty, poor stimulation, and parenting behaviour that has a direct effect on the child’s development (Linver, Brooks-Gunn, & Kohen, 1999). As detailed by Eapen (2014), the cumulative risk index of potential risk factors (that is the sum of individual risk factors) is a robust way of conceptualizing how risk factors interact together in a bioecological model (Eapen, 2014). Here the risk variables across levels are dichotomized (present/absent) and then grouped into a single score and their effect analysed (Sameroff & Seifer, 1983). While it is difficult to capture the true interdependent and compounding nature of such risk factors, all these factors need due consideration using the micro-, meso-, *exo-*, and macrosystem model by Bronfenbrenner (1986). Fig. 4 details an example of how such a scoring system may be put in place.

Risk stratification would also need to occur at the community level. Those at low risk will be provided light broad-brush interventions such as community awareness and child health literacy programmes on neurodevelopment, while those at moderate risk will receive stimulation and access to Early Childhood Education Centres (ECECs), and those at high-risk will receive more intensive interventions. In the succeeding text, Fig. 5 illustrates how the principles of risk stratification and the belief in universal health coverage underpin the transformation of the health system. Opportunities will also need to be pursued for developing an integrated platform internationally for NDDs through a combination of three core elements, namely, (1) implementation of existing knowledge of NDD

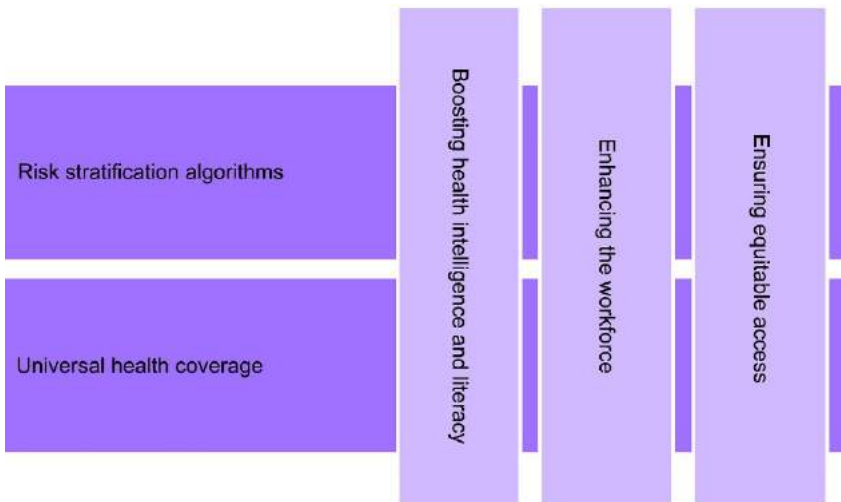


FIG. 5 Transformation of the health system consistent with government priorities.

through leveraging partnerships with large-scale international consortia; (2) discovery of novel underlying mechanisms for NDDs; and (3) paving the way for the development of novel therapies or drug repurposing that will enable personalized care.

Thus, to achieve sustained, long-term, and large-scale improvements in child health and wellbeing across geographical and socioeconomic boundaries, a concerted effort is needed. As indicated in the introduction, the Sustainable Development Goals by the United Nations provide a blueprint to achieve a viable shared future for all by 2030 by addressing the global challenges of poverty, inequality, climate, environment, peace, and justice (UN High Commissioner for Refugees, 2017). These goals together with the Nurturing Care Framework created in response to strong evidence and growing recognition that the early years are critical for human development provide the basis for a sustainable action plan for early child development. This enabling framework involves good health, adequate nutrition, responsive caregiving, security and safety, and opportunities for early learning (as seen in Fig. 1). The following provides an emerging framework.

1. To identify modifiable early life determinants of wellbeing, including biological, environmental, and psychosocial risk factors and their causal pathways through rigorous basic, clinical, and population science.
2. To use intervention mapping and apply evidence-based clinical and population health interventions to improve child/family outcomes by modifying existing biological and environmental risk profiles in individuals and populations using the following principles and practices:
 - partnering with children and families through participatory research;
 - bringing together biological, psychosocial, clinical, epidemiological, and service information;
 - focussing on adverse health outcomes to identify early risk factors;
 - reducing inequity in access to evidence-based assessments;
 - identifying workforce and resource issues;
 - designing interventions that add value for complex presentations;
 - addressing social determinants and psychosocial contexts;
 - facilitating interventions at scale;
 - embracing innovative technologies;
 - designing sustainable models of care leading to cost savings across the lifespan.

An example of intervention mapping commensurate with need is the implementation of reading programmes in disadvantaged communities. There is emerging evidence on socioeconomic differences in language processing skills and vocabulary even

before the child is 2 years of age. This is primarily due to the difference in language environment with children growing up in poor neighbourhoods and from lower-income families hearing up to 30 million fewer words by the age of 3 years, compared with those children from rich and affluent backgrounds resulting in a significant vocabulary gap (Fernald, Marchman, & Weisleder, 2013). A specific intervention to address this would be to implement reading programmes targeting those children at risk of poor language exposure and stimulation. Applying the principles detailed earlier, this can be done in partnership with families and the respective communities using participatory research to design an appropriate reading programme that is sustainable and cost-effective. This is then followed by identification of relevant workforce and resources, with implementation aided by innovative technologies that facilitate scaling up, and thereby reaching those children at highest risk in poor neighbourhoods or remote communities and from culturally and linguistically diverse, indigenous, or other priority populations.

3. To codesign with children and families an integrated intervention programme to create a global benchmarking system to measure and feedback success across each country and community on how to develop, implement, and evaluate interventions at scale. It is critical that each country and population group *codesign integrated care pathways for NDDs* (that may also be applicable for other physical and mental health conditions) that is underpinned by the *voice* of the child and with the input from the parents/carers, health service providers, council and community-based organizations, and the early childhood education sector to ascertain the essential elements of a comprehensive and responsive health service system as relevant to the local needs. Using the bioecological framework of the Andersen's behavioural model of health service use (BM), the model will need to define and measure equitable access to healthcare for children with NDDs that address inequality and risk by taking a multilevel approach to psychosocial and family-level factors. The model will need to focus on family-centred measures and tools and provide purposeful data sharing across health services and other agencies to ensure a sustainable, systematic change to approaching and addressing biological and social determinants of NDDs as relevant to individual countries and population groups.
4. To develop a global child mental health literacy initiative that will form the cornerstone of an integrated programme with real-life cost-effective professional educational development, practice, and policy for better maternal/child/youth and family health and consequent adult wellbeing using knowledge mobilization.

5 Conclusions

All NDDs and half of all lifetime mental health disorders emerge in childhood (Kessler et al., 2005). Further the most important early childhood predictor of adult life satisfaction is emotional health during childhood followed by child conduct (Layard, Clark, Cornaglia, Powdthavee, & Verneit, 2014). This highlights the role of early emotional and behavioural wellbeing for long-term adult outcomes. In this regard the period between birth and start of school also referred to as ‘The First 2000 Days’ is a critical time of rapid development, which provides a compelling argument for programmes directed at NDDs to start as early as possible. Further, if appropriate pointers to developmental risk can be identified early, as it relates to individual children or population groups, it will be possible to develop targeted intervention to address the individual child’s needs or to support disadvantaged groups in certain geographical locations through access to high-quality early interventions, parenting programmes and attendance at reading programmes, early childhood education and care centres, etc. Such an approach will be an important investment that will yield measurable long-term benefits (Oberklaid, Baird, Blair, Melhuish, & Hall, 2013) and will prevent the cascade of a negative developmental trajectory with the neurodevelopmental difficulties becoming entrenched with secondary consequences such as academic failure, school absence, social dysfunction, and forensic involvement. However, despite the likely long-term benefits and cost-saving potential of early identification and intervention services for NDDs, short-term cost and knowledge barriers currently limit progress globally. A transformation is needed to optimize service utilization and harmonize intervention approaches to ensure equity of care for children with NDDs and their families while maximizing resources and capacity for professionals—which together would result in cost-effective programmes and practices that would provide the right care that would allow best start in life for all children with NDDs at the right time and setting.

References

- Atallah, B. V., & Scanziani, M. (2009). Instantaneous modulation of gamma oscillation frequency by balancing excitation with inhibition. *Neuron*, 62(4), 566–577.
- Bale, T. L., & Epperson, C. N. (2015). Sex differences and stress across the lifespan. *Nature Neuroscience*, 18(10), 1413.
- Beighley, J. S., Matson, J. L., Rieske, R. D., Konst, M. J., & Tureck, K. (2014). Differences in communication skills in toddlers diagnosed with autism spectrum disorder according to the DSM-IV-TR and the DSM-5. *Research in Autism Spectrum Disorders*, 8(2), 74–81. <https://doi.org/10.1016/j.rasd.2013.10.014>.
- Bickerdike, L., Booth, A., Wilson, P. M., Farley, K., & Wright, K. (2017). Social prescribing: Less rhetoric and more reality. A systematic review of the evidence. *BMJ Open*, 7(4), e013384. <https://doi.org/10.1136/bmjopen-2016-013384>.

- Blaser, M. J. (2016). Antibiotic use and its consequences for the normal microbiome. *Science*, 352(6285), 544–545. <https://doi.org/10.1126/science.aad9358>.
- Brinkman, S. A., Gregory, T. A., Goldfeld, S., Lynch, J. W., & Hardy, M. (2014). Data resource profile: The Australian early development index (AEDI). *International Journal of Epidemiology*, 43(4), 1089–1096. <https://doi.org/10.1093/ije/dyu085>.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), 723.
- Bronson, S. L., & Bale, T. L. (2014). Prenatal stress-induced increases in placental inflammation and offspring hyperactivity are male-specific and ameliorated by maternal anti-inflammatory treatment. *Endocrinology*, 155(7), 2635–2646.
- Bronson, S. L., Chan, J. C., & Bale, T. L. (2017). Sex-specific neurodevelopmental programming by placental insulin receptors on stress reactivity and sensorimotor gating. *Biological Psychiatry*, 82(2), 127–138.
- Callaghan, B. L., & Richardson, R. (2011). Maternal separation results in early emergence of adult-like fear and extinction learning in infant rats. *Behavioral Neuroscience*, 125(1), 20.
- Cameron, J. L., Eagleson, K. L., Fox, N. A., Hensch, T. K., & Levitt, P. (2017). Social origins of developmental risk for mental and physical illness. *The Journal of Neuroscience*, 37(45), 10783. <https://doi.org/10.1523/JNEUROSCI.1822-17.2017>.
- Chen, Z., Li, J., Gui, S., Zhou, C., Chen, J., Yang, C., ... Xie, P. (2018). Comparative metaproteomics analysis shows altered fecal microbiota signatures in patients with major depressive disorder. *NeuroReport*, 29(5), 417–425. <https://doi.org/10.1097/WNR.0000000000000985>.
- Chung, E. K., Siegel, B. S., Garg, A., Conroy, K., Gross, R. S., Long, D. A., ... Fierman, A. H. (2016). Screening for social determinants of health among children and families living in poverty: A guide for clinicians. *Current Problems in Pediatric and Adolescent Health Care*, 46(5), 135–153. <https://doi.org/10.1016/j.cppeds.2016.02.004>.
- Coghill, D., Danckaerts, M., Sonuga-Barke, E., Sergeant, J., ADHD European Guidelines Group. (2009). Practitioner review: Quality of life in child mental health—conceptual challenges and practical choices. *Journal of Child Psychology and Psychiatry*, 50(5), 544–561.
- Coutellier, L., & Würbel, H. (2009). Early environmental cues affect object recognition memory in adult female but not male C57BL/6 mice. *Behavioural Brain Research*, 203(2), 312–315.
- Cover, K., Maeng, L., Lebrón-Milad, K., & Milad, M. (2014). Mechanisms of estradiol in fear circuitry: Implications for sex differences in psychopathology. *Translational Psychiatry*, 4(8), e422.
- Dadds, M. R., & Frick, P. J. (2019). Toward a transdiagnostic model of common and unique processes leading to the major disorders of childhood: The REAL model of attention, responsiveness and learning. *Behaviour Research and Therapy*, 119, 103410. <https://doi.org/10.1016/j.brat.2019.103410>.
- de la Vega, P. B., Losi, S., Martinez, L. S., Bovell-Ammon, A., Garg, A., James, T., ... Sandel, M. (2019). Implementing an EHR-based screening and referral system to address social determinants of health in primary care. *Medical Care*, 57, S133–S139.
- De Palma, G., Lynch, M. D., Lu, J., Dang, V. T., Deng, Y., Jury, J., ... Bercik, P. (2017). Transplantation of fecal microbiota from patients with irritable bowel syndrome alters gut function and behavior in recipient mice. *Science Translational Medicine*, 9(379), <https://doi.org/10.1126/scitranslmed.aaf6397>.
- Diaz Heijtz, R., Wang, S., Anuar, F., Qian, Y., Bjorkholm, B., Samuelsson, A., ... Pettersson, S. (2011). Normal gut microbiota modulates brain development and behavior. *Proceedings of the National Academy of Sciences*, 108(7), 3047–3052. <https://doi.org/10.1073/pnas.1010529108>.
- Drinkwater, C., Wildman, J., & Moffatt, S. (2019). Social prescribing. *BMJ*, 364, 11285. <https://doi.org/10.1136/bmj.11285>.
- Dunst, C. J., & Leet, H. E. (1987). Measuring the adequacy of resources in households with young children. *Child: Care, Health and Development*, 13(2), 111–125.

- Eapen, V. (2011). Genetic basis of autism: Is there a way forward? *Current Opinion in Psychiatry*, 24(3), 226–236. <https://doi.org/10.1097/YCO.0b013e328345927e>.
- Eapen, V. (2012). Neurodevelopmental genes have not read the DSM criteria: Or, have they? *Frontiers in Psychiatry*, 3, 75. <https://doi.org/10.3389/fpsy.2012.00075>.
- Eapen, V. (2014). Developmental and mental health disorders: Two sides of the same coin. *Asian Journal of Psychiatry*, 8, 7–11.
- Eapen, V., Crncec, R., & Walter, A. (2013). Exploring links between genotypes, phenotypes, and clinical predictors of response to early intensive behavioral intervention in autism spectrum disorder. *Frontiers in Human Neuroscience*, 7, 567.
- Eapen, V., Crncec, R., & Walter, A. (2016). There are gains, but can we tell for whom and why? Predictors of treatment response following group early start denver model intervention in preschool-aged children with autism spectrum disorder. *Autism—Open Access*, 6(2), <https://doi.org/10.4172/2165-7890.1000168>.
- Eapen, V., Pauls, D. L., & Robertson, M. M. (2006). The role of clinical phenotypes in understanding the genetics of obsessive–compulsive disorder. *Journal of Psychosomatic Research*, 61(3), 359–364.
- Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., ... The 'Watch Me Grow' Study Group. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*, 53(10), 963–969. <https://doi.org/10.1111/jpc.13607>.
- Eapen, V., Ward, P., & Clarke, R. (2014). Clonidine in tourette syndrome and sensorimotor gating. *Psychiatry Research*, 215(2), 494–496.
- Eapen, V., Woolfenden, S., Williams, K., Jalaludin, B., Dissanayake, C., Axelsson, E. L., ... Beasley, D. (2014). "Are you available for the next 18 months?" methods and aims of a longitudinal birth cohort study investigating a universal developmental surveillance program: The 'watch me grow' study. *BMC Pediatrics*, 14(1), 234.
- Edwards, V. J., Holden, G. W., Felitti, V. J., & Anda, R. F. (2003). Relationship between multiple forms of childhood maltreatment and adult mental health in community respondents: Results from the adverse childhood experiences study. *American Journal of Psychiatry*, 160(8), 1453–1460.
- Errisuriz, V. L., Pasch, K. E., & Perry, C. L. (2016). Perceived stress and dietary choices: The moderating role of stress management. *Eating Behaviors*, 22, 211–216. <https://doi.org/10.1016/j.eatbeh.2016.06.008>.
- Evans, S. J., Bassis, C. M., Hein, R., Assari, S., Flowers, S. A., Kelly, M. B., ... McInnis, M. G. (2017). The gut microbiome composition associates with bipolar disorder and illness severity. *Journal of Psychiatric Research*, 87, 23–29. <https://doi.org/10.1016/j.jpsy.2016.12.007>.
- Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., ... Marks, J. S. (2019). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The adverse childhood experiences (ACE) study. *American Journal of Preventive Medicine*, 56(6), 774–786.
- Fernald, A., Marchman, V. A., & Weisleder, A. (2013). SES differences in language processing skill and vocabulary are evident at 18 months. *Developmental Science*, 16(2), 234–248. <https://doi.org/10.1111/desc.12019>.
- Finlay-Jones, A., Varcin, K., Leonard, H., Bosco, A., Alvares, G., & Downs, J. (2019). Very early identification and intervention for infants at risk of neurodevelopmental disorders: A transdiagnostic approach. *Child Development Perspectives*, 13(2), 97–103.
- Galley, J. D., Nelson, M. C., Yu, Z., Dowd, S. E., Walter, J., Kumar, P. S., ... Bailey, M. T. (2014). Exposure to a social stressor disrupts the community structure of the colonic mucosa-associated microbiota. *BMC Microbiology*, 14, 189. <https://doi.org/10.1186/1471-2180-14-189>.
- Garg, A., Butz, A. M., Dworkin, P. H., Lewis, R. A., Thompson, R. E., & Serwint, J. R. (2007). Improving the management of family psychosocial problems at low-income children's well-child care visits: The WE CARE project. *Pediatrics*, 120(3), 547–558.

- Garg, A., & Dworkin, P. H. (2011). Applying surveillance and screening to family psychosocial issues: Implications for the medical home. *Journal of Developmental and Behavioral Pediatrics*, 32(5), 418–426. <https://doi.org/10.1097/DBP.0b013e3182196726>.
- Garg, A., & Dworkin, P. H. (2016). Surveillance and screening for social determinants of health: The medical home and beyond. *JAMA Pediatrics*, 170(3), 189–190.
- Garg, A., Sandel, M., Dworkin, P. H., Kahn, R. S., & Zuckerman, B. (2012). From medical home to health neighborhood: Transforming the medical home into a community-based health neighborhood. *Journal of Pediatrics*, 160(4), 535–536.e531. <https://doi.org/10.1016/j.jpeds.2012.01.001>.
- Gilson, K.-M., Davis, E., Corr, L., Stevenson, S., Williams, K., Reddihough, D., ... Waters, E. (2018). Enhancing support for the mental wellbeing of parents of children with a disability: Developing a resource based on the perspectives of parents and professionals. *Journal of Intellectual & Developmental Disability*, 43(4), 463–472. <https://doi.org/10.3109/13668250.2017.1281386>.
- Gogolla, N., Takesian, A. E., Feng, G., Fagiolini, M., & Hensch, T. K. (2014). Sensory integration in mouse insular cortex reflects GABA circuit maturation. *Neuron*, 83(4), 894–905.
- Gokoolparsadh, A., Fang, Z., Braidy, N., Lin, P., Pardy, C. J., Eapen, V., ... Voineagu, I. (2017). Transcriptional response to mitochondrial protease IMP2L knockdown in human primary astrocytes. *Biochemical and Biophysical Research Communications*, 482(4), 1252–1258.
- Goldfeld, S., Kvalsvig, A., Inclendon, E., & O'Connor, M. (2017). Epidemiology of positive mental health in a national census of children at school entry. *Journal of Epidemiology and Community Health*, 71(3), 225–231. <https://doi.org/10.1136/jech-2015-207061>.
- Gottlieb, L. M., Hessler, D., Long, D., Laves, E., Burns, A. R., Amaya, A., ... Adler, N. E. (2016). Effects of social needs screening and in-person service navigation on child health: A randomized clinical trial. *JAMA Pediatrics*, 170(11), e162521.
- Grantham-McGregor, S., Cheung, Y. B., Cueto, S., Glewwe, P., Richter, L., & Strupp, B. (2007). Developmental potential in the first 5 years for children in developing countries. *The Lancet*, 369(9555), 60–70. [https://doi.org/10.1016/S0140-6736\(07\)60032-4](https://doi.org/10.1016/S0140-6736(07)60032-4).
- Griffiths, A., & Meinicke, C. (2014). *Introduction to social impact bonds and early intervention* (p.28). Early Intervention Foundation.
- Gur, T. L., & Bailey, M. T. (2016). Effects of stress on commensal microbes and immune system activity. *Advances in Experimental Medicine and Biology*, 874, 289–300. https://doi.org/10.1007/978-3-319-20215-0_14.
- Harrison, C. A., & Taren, D. (2018). How poverty affects diet to shape the microbiota and chronic disease. *Nature Reviews Immunology*, 18(4), 279–287. <https://doi.org/10.1038/nri.2017.121>.
- Hart, H., & Rubia, K. (2012). Neuroimaging of child abuse: A critical review. *Frontiers in Human Neuroscience*, 6, 52.
- Hegstrand, L. R., & Hine, R. J. (1986). Variations of brain histamine levels in germ-free and nephrectomized rats. *Neurochemical Research*, 11(2), 185–191. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/2422565>.
- Hemmings, S. M. J., Malan-Muller, S., van den Heuvel, L. L., Demmitt, B. A., Stanislawski, M. A., Smith, D. G., ... Lowry, C. A. (2017). The microbiome in posttraumatic stress disorder and trauma-exposed controls: An exploratory study. *Psychosomatic Medicine*, 79(8), 936–946. <https://doi.org/10.1097/PSY.0000000000000512>.
- Jiang, H., Ling, Z., Zhang, Y., Mao, H., Ma, Z., Yin, Y., ... Ruan, B. (2015). Altered fecal microbiota composition in patients with major depressive disorder. *Brain, Behavior, and Immunity*, 48, 186–194. <https://doi.org/10.1016/j.bbi.2015.03.016>.
- Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). “Mental health literacy”: A survey of the public’s ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Medical Journal of Australia*, 166(4), 182–186. <https://doi.org/10.5694/j.1326-5377.1997.tb140071.x>.

- Karl, J. P., Margolis, L. M., Madslie, E. H., Murphy, N. E., Castellani, J. W., Gundersen, Y., ... Pasiakos, S. M. (2017). Changes in intestinal microbiota composition and metabolism coincide with increased intestinal permeability in young adults under prolonged physiological stress. *American Journal of Physiology Gastrointestinal and Liver Physiology*, 312, https://doi.org/10.1152/ajpgi.00066.2017.
- Kawakami, S. E., Quadros, I. M., Machado, R. B., & Suchecki, D. (2013). Sex-dependent effects of maternal separation on plasma corticosterone and brain monoamines in response to chronic ethanol administration. *Neuroscience*, 253, 55–66.
- Kawakami, S. E., Quadros, I. M. H., Takahashi, S., & Suchecki, D. (2007). Long maternal separation accelerates behavioural sensitization to ethanol in female, but not in male mice. *Behavioural Brain Research*, 184(2), 109–116.
- Kelleher, E., & Corvin, A. (2015). Overlapping etiology of neurodevelopmental disorders. In K. J. Mitchell (Ed.), *The genetics of neurodevelopmental disorders* (pp. 29–48). https://doi.org/10.1002/9781118524947.ch2.
- Kelly, J. R., Borre, Y., O'Brien, C., Patterson, E., El Aidy, S., Deane, J., ... Dinan, T. G. (2016). Transferring the blues: Depression-associated gut microbiota induces neurobehavioural changes in the rat. *Journal of Psychiatric Research*, 82, 109–118. https://doi.org/10.1016/j.jpsychires.2016.07.019.
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. *Archives of General Psychiatry*, 62(6), 593–602.
- Kessler, R. C., Sonnega, A., Bromet, E., Hughes, M., & Nelson, C. B. (1995). Posttraumatic stress disorder in the national comorbidity survey. *Archives of General Psychiatry*, 52(12), 1048–1060.
- Keyes, K. M., Eaton, N. R., Krueger, R. F., McLaughlin, K. A., Wall, M. M., Grant, B. F., & Hasin, D. S. (2012). Childhood maltreatment and the structure of common psychiatric disorders. *The British Journal of Psychiatry*, 200(2), 107–115.
- Kim, H. N., Yun, Y., Ryu, S., Chang, Y., Kwon, M. J., Cho, J., ... Kim, H. L. (2018). Correlation between gut microbiota and personality in adults: A cross-sectional study. *Brain, Behavior, and Immunity*, 69, 374–385. https://doi.org/10.1016/j.bbi.2017.12.012.
- King, M., & Bearman, P. (2009). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology*, 38(5), 1224–1234. https://doi.org/10.1093/ije/dyp261.
- Knowles, S. R., Nelson, E. A., & Palombo, E. A. (2008). Investigating the role of perceived stress on bacterial flora activity and salivary cortisol secretion: A possible mechanism underlying susceptibility to illness. *Biological Psychology*, 77(2), 132–137. https://doi.org/10.1016/j.biopsycho.2007.09.010.
- Konturek, P. C., Brzozowski, T., & Konturek, S. J. (2011). Stress and the gut: Pathophysiology, clinical consequences, diagnostic approach and treatment options. *Journal of Physiology and Pharmacology*, 62(6), 591–599. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/22314561.
- Lawrence, D., Hafekost, J., Johnson, S. E., Saw, S., Buckingham, W. J., Sawyer, M. G., ... Zubrick, S. R. (2016). Key findings from the second Australian child and adolescent survey of mental health and wellbeing. *Australian and New Zealand Journal of Psychiatry*, 50(9), 876–886. https://doi.org/10.1177/0004867415617836.
- Layard, R., Clark, A. E., Cornaglia, F., Powdthavee, N., & Vernoit, J. (2014). What predicts a successful life? A life-course model of well-being. *The Economic Journal*, 124(580), F720–F738.
- LeBlanc, J. J., & Fagiolini, M. (2011). Autism: A “critical period” disorder? *Neural Plasticity*, 2011, 921680.
- Leigh, S. J., Lee, F., & Morris, M. J. (2018). Hyperpalatability and the generation of obesity: Roles of environment, stress exposure and individual difference. *Current Obesity Reports*, 7(1), 6–18. https://doi.org/10.1007/s13679-018-0292-0.

- Lewis, J. D., Chen, E. Z., Baldassano, R. N., Otley, A. R., Griffiths, A. M., Lee, D., ... Bushman, F. D. (2015). Inflammation, antibiotics, and diet as environmental stressors of the gut microbiome in pediatric crohn's disease. *Cell Host & Microbe*, *18*(4), 489–500. <https://doi.org/10.1016/j.chom.2015.09.008>.
- Lewis, C. R., & Olive, M. F. (2014). Early-life stress interactions with the epigenome: Potential mechanisms driving vulnerability toward psychiatric illness. *Behavioural Pharmacology*, *25*(5–6), 341–351. <https://doi.org/10.1097/fbp.0000000000000057>.
- Lin, P., Ding, B., Feng, C., Yin, S., Zhang, T., Qi, X., ... Li, Q. (2017). Prevotella and Klebsiella proportions in fecal microbial communities are potential characteristic parameters for patients with major depressive disorder. *Journal of Affective Disorders*, *207*, 300–304. <https://doi.org/10.1016/j.jad.2016.09.051>.
- Linver, M. R., Brooks-Gunn, J., & Kohen, D. (1999). Parenting behavior and emotional health as mediators of family poverty effects upon young low-birthweight children's cognitive ability. *Annals of the New York Academy of Sciences*, *896*(1), 376–378.
- Logan, A. C. (2015). Dysbiotic drift: Mental health, environmental grey space, and microbiota. *Journal of Physiological Anthropology*, *34*, 23. <https://doi.org/10.1186/s40101-015-0061-7>.
- Logan, A. C., Jacka, F. N., & Prescott, S. L. (2016). Immune-microbiota interactions: Dysbiosis as a global health issue. *Current Allergy and Asthma Reports*, *16*(2), 13. <https://doi.org/10.1007/s11882-015-0590-5>.
- Logan, A. C., & Prescott, S. L. (2017). Astrofood, priorities and pandemics: Reflections of an ultra-processed breakfast program and contemporary dysbiotic drift. *Challenges*, *8*(2), 24.
- Lurie, I., Yang, Y. X., Haynes, K., Mamtani, R., & Boursi, B. (2015). Antibiotic exposure and the risk for depression, anxiety, or psychosis: A nested case-control study. *Journal of Clinical Psychiatry*, *76*(11), 1522–1528. <https://doi.org/10.4088/JCP.15m09961>.
- Marín, O. (2012). Interneuron dysfunction in psychiatric disorders. *Nature Reviews Neuroscience*, *13*(2), 107.
- Martinez-Guryn, K., Hubert, N., Frazier, K., Urlass, S., Musch, M. W., Ojeda, P., ... Chang, E. B. (2018). Small intestine microbiota regulate host digestive and absorptive adaptive responses to dietary lipids. *Cell Host & Microbe*, *23*(4), 458–469. e455 <https://doi.org/10.1016/j.chom.2018.03.011>.
- Marx, W., Moseley, G., Berk, M., & Jacka, F. (2017). Nutritional psychiatry: The present state of the evidence. *The Proceedings of the Nutrition Society*, *76*(4), 427–436. <https://doi.org/10.1017/S0029665117002026>.
- McLachlan, R., Gilfillan, G., & Gordon, J. (2013). *Deep and persistent disadvantage in Australia*. Retrieved from Commonwealth of Australia.
- McLaughlin, K. A., Sheridan, M. A., & Lambert, H. K. (2014). Childhood adversity and neural development: Deprivation and threat as distinct dimensions of early experience. *Neuroscience & Biobehavioral Reviews*, *47*, 578–591. <https://doi.org/10.1016/j.neubiorev.2014.10.012>.
- McLaughlin, K. A., Sheridan, M. A., Tibu, F., Fox, N. A., Zeanah, C. H., & Nelson, C. A. (2015). Causal effects of the early caregiving environment on development of stress response systems in children. *Proceedings of the National Academy of Sciences*, *112*(18), 5637–5642.
- Miller, G. E., Engen, P. A., Gillevet, P. M., Shaikh, M., Sikaroodi, M., Forsyth, C. B., ... Keshavarzian, A. (2016). Lower neighborhood socioeconomic status associated with reduced diversity of the colonic microbiota in healthy adults. *PLoS One*, *11*(2), e0148952. <https://doi.org/10.1371/journal.pone.0148952>.
- Nabeshima, T., & Kim, H.-C. (2013). Involvement of genetic and environmental factors in the onset of depression. *Experimental Neurobiology*, *22*(4), 235–243. Retrieved from <http://synapse.koreamed.org/DOLx.php?id=10.5607%2Fen.2013.22.4.235>.
- Narducci, R., Baroncelli, L., Sansevero, G., Begenisic, T., Prontera, C., Sale, A., ... Maffei, L. (2018). Early impoverished environment delays the maturation of cerebral cortex. *Scientific Reports*, *8*(1), 1187. <https://doi.org/10.1038/s41598-018-19459-y>.

- Naseribafrouei, A., Hestad, K., Avershina, E., Sekelja, M., Linlokken, A., Wilson, R., & Rudi, K. (2014). Correlation between the human fecal microbiota and depression. *Neurogastroenterology and Motility*, 26(8), 1155–1162. <https://doi.org/10.1111/nmo.12378>.
- Nelson, C. A. (2014). *Romania's abandoned children*. Harvard University Press.
- Nelson, C. A., Fox, N. A., & Zeanah, C. H. (2016). *The effects of early psychosocial deprivation on brain and behavioral development: Findings from the Bucharest early intervention project*. In *Development and Psychopathology*. New York: John Wiley & Sons Inc. (pp. 1–37).
- Noonan, M. P., Mars, R. B., Sallet, J., Dunbar, R. I. M., & Fellows, L. K. (2018). The structural and functional brain networks that support human social networks. *Behavioural Brain Research*, 355, 12–23. <https://doi.org/10.1016/j.bbr.2018.02.019>.
- Oberklaid, F., Baird, G., Blair, M., Melhuish, E., & Hall, D. (2013). Children's health and development: Approaches to early identification and intervention. *Archives of Disease in Childhood*, 98(12), 1008–1011.
- Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N.-Y., Nair, M., Halpern, R., ... Gladstone, M. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the global burden of disease study 2016. *The Lancet Global Health*, 6(10), e1100–e1121.
- Overs, B., Woolfenden, S., Williams, K., Jalaludin, B., Axelsson, E., Dissanayake, C., ... Murphy, E. (2017). Predictors of developmental surveillance completion at six months of age in south western Sydney. *Child: Care, Health and Development*, 43(2), 307–315.
- Partrick, K. A., Chassaing, B., Beach, L. Q., McCann, K. E., Gewirtz, A. T., & Huhman, K. L. (2018). Acute and repeated exposure to social stress reduces gut microbiota diversity in Syrian hamsters. *Behavioural Brain Research*, 345, 39–48. <https://doi.org/10.1016/j.bbr.2018.02.005>.
- Pescosolido, B. A., Martin, J. K., Lang, A., & Olafsdottir, S. (2008). Rethinking theoretical approaches to stigma: A framework integrating normative influences on stigma (FINIS). *Social Science & Medicine*, 67(3), 431–440. <https://doi.org/10.1016/j.socscimed.2008.03.018>.
- Porcher, C., Medina, I., & Gaiarsa, J.-L. (2018). Mechanism of BDNF modulation in GABAergic synaptic transmission in healthy and disease brains. *Frontiers in Cellular Neuroscience*, 12, 273.
- Prescott, S. L., & Logan, A. C. (2017). Each meal matters in the exposome: Biological and community considerations in fast-food-socioeconomic associations. *Economics and Human Biology*, 27(Pt. B), 328–335. <https://doi.org/10.1016/j.ehb.2017.09.004>.
- Prescott, S. L., Wegienka, G., Logan, A. C., & Katz, D. L. (2018). Dysbiotic drift and biopsychosocial medicine: How the microbiome links personal, public and planetary health. *BioPsychosocial Medicine*, 12, 7. <https://doi.org/10.1186/s13030-018-0126-z>.
- Reading, R. (2006). The enduring effects of abuse and related adverse experiences in childhood. A convergence of evidence from neurobiology and epidemiology. *Child: Care, Health and Development*, 32(2), 253–256.
- Renz, H., Holt, P. G., Inouye, M., Logan, A. C., Prescott, S. L., & Sly, P. D. (2017). An exposome perspective: Early-life events and immune development in a changing world. *The Journal of Allergy and Clinical Immunology*, 140(1), 24–40. <https://doi.org/10.1016/j.jaci.2017.05.015>.
- Sameroff, A. J., & Seifer, R. (1983). Familial risk and child competence. *Child Development*, 54, 1254–1268.
- Schwarz, E., Maukonen, J., Hyytiainen, T., Kiesepa, T., Oresic, M., Sabunciyani, S., ... Suvisaari, J. (2018). Analysis of microbiota in first episode psychosis identifies preliminary associations with symptom severity and treatment response. *Schizophrenia Research*, 192, 398–403. <https://doi.org/10.1016/j.schres.2017.04.017>.
- Scott, J. G., Mihalopoulos, C., Erskine, H. E., Roberts, J., & Rahman, A. (2016). Childhood mental and developmental disorders. In V. Patel, D. Chisholm, T. Dua, R. Laxminarayan, & M. E. Medina-Mora (Eds.), Vol. 4. *Mental, neurological, and substance use disorders: Disease control priorities* (3rd ed.). Washington, DC: The International Bank for Reconstruction and Development/The World Bank.

- Selten, M., van Bokhoven, H., & Nadif Kasri, N. (2018). Inhibitory control of the excitatory/inhibitory balance in psychiatric disorders. *F1000 Research*, 7, 23. <https://doi.org/10.12688/f1000research.12155.1>.
- Sheridan, M. A., Fox, N. A., Zeanah, C. H., McLaughlin, K. A., & Nelson, C. A. (2012). Variation in neural development as a result of exposure to institutionalization early in childhood. *Proceedings of the National Academy of Sciences*, 109(32), 12927–12932.
- Slykerman, R. F., Thompson, J., Waldie, K. E., Murphy, R., Wall, C., & Mitchell, E. A. (2017). Antibiotics in the first year of life and subsequent neurocognitive outcomes. *Acta Paediatrica*, 106(1), 87–94. <https://doi.org/10.1111/apa.13613>.
- Smith, L., Malcolm-Smith, S., & de Vries, P. J. (2016). Translation and cultural appropriateness of the Autism diagnostic observation schedule-2 in Afrikaans. *Autism*, 21(5), 552–563. <https://doi.org/10.1177/1362361316648469>.
- Steinsbekk, S., Barker, E. D., Llewellyn, C., Fildes, A., & Wichstrom, L. (2017). Emotional feeding and emotional eating: Reciprocal processes and the influence of negative affectivity. *Child Development*, <https://doi.org/10.1111/cdev.12756>.
- Stevens, B. R., Goel, R., Seungbum, K., Richards, E. M., Holbert, R. C., Pepine, C. J., & Raizada, M. K. (2017). Increased human intestinal barrier permeability plasma biomarkers zonulin and FABP2 correlated with plasma LPS and altered gut microbiome in anxiety or depression. *Gut*, <https://doi.org/10.1136/gutjnl-2017-314759>.
- Sudo, N., Chida, Y., Aiba, Y., Sonoda, J., Oyama, N., Yu, X. N., ... Koga, Y. (2004). Postnatal microbial colonization programs the hypothalamic-pituitary-adrenal system for stress response in mice. *The Journal of Physiology*, 558(Pt. 1), 263–275. <https://doi.org/10.1113/jphysiol.2004.063388>.
- Sundin, J., Rangel, I., Fuentes, S., Heikamp-de Jong, I., Hultgren-Hornquist, E., de Vos, W. M., & Brummer, R. J. (2015). Altered faecal and mucosal microbial composition in post-infectious irritable bowel syndrome patients correlates with mucosal lymphocyte phenotypes and psychological distress. *Alimentary Pharmacology & Therapeutics*, 41(4), 342–351. <https://doi.org/10.1111/apt.13055>.
- Tryon, M. S., Carter, C. S., Decant, R., & Laugero, K. D. (2013). Chronic stress exposure may affect the brain's response to high calorie food cues and predispose to obesogenic eating habits. *Physiology and Behavior*, 120, 233–242. <https://doi.org/10.1016/j.physbeh.2013.08.010>.
- Tully, L. A., Hawes, D. J., Doyle, F. L., Sawyer, M. G., & Dadds, M. R. (2019). A national child mental health literacy initiative is needed to reduce childhood mental health disorders. *Australian and New Zealand Journal of Psychiatry*, 53(4), 286–290. <https://doi.org/10.1177/0004867418821440>.
- Turrigiano, G. (2012). Homeostatic synaptic plasticity: Local and global mechanisms for stabilizing neuronal function. *Cold Spring Harbor Perspectives in Biology*, 4(1), a005736. <https://doi.org/10.1101/cshperspect.a005736>.
- UN High Commissioner for Refugees. (2017). *The Sustainable Development Goals and Addressing Statelessness*.
- Vivanti, G., Barbaro, J., Hudry, K., Dissanayake, C., & Prior, M. (2013). Intellectual development in autism spectrum disorders: New insights from longitudinal studies. *Frontiers in Human Neuroscience*, 7, 354.
- Voineagu, I., & Eapen, V. (2013). Converging pathways in autism spectrum disorders: Interplay between synaptic dysfunction and immune responses. *Frontiers in Human Neuroscience*, 7, 738.
- Walker, S. P., Wachs, T. D., Grantham-McGregor, S., Black, M. M., Nelson, C. A., Huffman, S. L., ... Lozoff, B. (2011). Inequality in early childhood: Risk and protective factors for early child development. *The Lancet*, 378(9799), 1325–1338.
- Weisz, J. R., & Kazdin, A. E. (2010). *Evidence-based psychotherapies for children and adolescents*. Guilford Press.

- Wills, C. D. (2014). DSM-5 and neurodevelopmental and other disorders of childhood and adolescence. *The Journal of the American Academy of Psychiatry and the Law*, 42(2), 165–172. Retrieved from <http://jaapl.org/content/jaapl/42/2/165.full.pdf>.
- Woolfenden, S., Eapen, V., Axelsson, E., Hendry, A., Jalaludin, B., Dissanayake, C., ... Einfeld, S. (2016). Who is our cohort: Recruitment, representativeness, baseline risk and retention in the “watch me grow” study? *BMC Pediatrics*, 16(1), 46.
- Zeanah, C. H., Egger, H. L., Smyke, A. T., Nelson, C. A., Fox, N. A., Marshall, P. J., & Guthrie, D. (2009). Institutional rearing and psychiatric disorders in Romanian preschool children. *American Journal of Psychiatry*, 166(7), 777–785.
- Zheng, P., Zeng, B., Zhou, C., Liu, M., Fang, Z., Xu, X., ... Xie, P. (2016). Gut microbiome remodeling induces depressive-like behaviors through a pathway mediated by the host's metabolism. *Molecular Psychiatry*, 21(6), 786–796. <https://doi.org/10.1038/mp.2016.44>.
- Zijlmans, M. A., Korpela, K., Riksen-Walraven, J. M., de Vos, W. M., & de Weerth, C. (2015). Maternal prenatal stress is associated with the infant intestinal microbiota. *Psychoneuroendocrinology*, 53, 233–245. <https://doi.org/10.1016/j.psyneuen.2015.01.006>.

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Challenges and opportunities of implementing early interventions for autism spectrum disorders in resource-limited settings: A South African example

Liezl Schlebusch^a, Nola J. Chambers^a,
John-Joe Dawson-Squibb^a, Michal Harty^{a,b},
Lauren Franz^{a,c,d}, and Petrus J. de Vries^a

^aCentre for Autism Research in Africa, Division of Child and Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa, ^bDivision of Communication Sciences and Disorders, Department of Health and Rehabilitation Sciences, University of Cape Town, Cape Town, South Africa, ^cDuke Center for Autism and Brain Development, Department of Psychiatry and Behavioral Sciences, Duke University, Durham, NC, United States, ^dDuke Global Health Institute, Duke University, Durham, NC, United States

1 Introduction

In this chapter, we outline a range of challenges and opportunities for implementing and evaluating early autism spectrum disorder (ASD) services in resource-limited contexts. The term ‘resource limited’ was purposefully selected given that the majority of children with ASD and their families live in resource-limited settings around the globe. Most of these settings have inadequate access to high-quality early identification, inadequate referral to early childhood intervention services, and inadequate support services for caregivers and families. To transform service

solutions for this vulnerable group of people, we propose that researchers and clinicians should prioritize thinking about the sustainability and scalability of interventions from the very beginning. This requires thinking about a number of fundamental interconnected and interdependent components including (a) selecting effective interventions, (b) ensuring effective implementation, (c) understanding the context and setting that makes it possible to implement the intervention, (d) having a good understanding of caregivers (or other beneficiaries of the intervention), and (e) using a pragmatic approach to evaluate a range of important outcomes. We use examples from current projects in South Africa to illustrate how these fundamental principles could be implemented. With a focus on what works, for whom, under what contextual circumstances, and whether interventions are scalable, researchers and clinicians can enhance the likelihood of improving access to care for young children with ASD and their families living in resource-limited environments.

2 Early identification and intervention services for ASD in resource-limited settings

2.1 The challenges

It is estimated that there are close to 53 million children under the age of 5 with developmental disabilities in the world. Approximately 95% (or about 50 million) of them live in low- and middle-income countries (LMICs) (Olusanya et al., 2018). Global rates of developmental disabilities have remained stable, but in sub-Saharan Africa, for instance, the number of children with developmental disabilities has increased by > 70% between 1990 and 2016. This observation suggests that the needs in resource-limited settings are likely to increase even further in the coming decades.

Infants and young children with developmental disabilities may have a range of difficulties in the areas of cognitive, language, social-emotional, behavioural, and neuromotor development. Without intervention, these children are at greater risk of suboptimal outcomes in health, educational attainment, and wellbeing than children without such disabilities (Black et al., 2017). Developmental disabilities include autism spectrum disorders (ASD), now clearly acknowledged by the World Health Organization (WHO) as a major global public health challenge (World Health Organization, 2013).

Children with ASD have difficulties with social communication, paying less attention to the social world, thus missing out on multiple learning opportunities throughout the day, which may greatly impact their learning. They might also be overly dependent on routines and highly sensitive to changes in their environment, respond inappropriately in conversations,

or use unusual forms of communication, such as using an adult's hand as a tool. Children with ASD have difficulties developing, maintaining, and understanding relationships with others, including their caregivers and family members (Chawarska, Macari, & Volkmar, 2014).

Like all children, having a child with ASD brings both positive and negative experiences for families. Caregivers and families can experience and appreciate the positive effects of raising a child with ASD, such as a greater appreciation of differences between people, a greater awareness of the needs of others, and a greater clarity about what matters in life (Schlebusch & Dada, 2018). However, raising a child with ASD is also associated with a range of stressors for caregivers, including increased parenting stress, decreased parenting efficacy, and increased mental and physical health problems (Karst & Van Hecke, 2012; Phelps, McCammon, Wuensch, & Golden, 2009). Caring for a child with ASD has been shown across a range of cultures and countries to impact significantly on caregivers' quality of life (Eapen & Guan, 2016) and places a significant economic burden on families. Families may lack financial resources and may face environmental barriers, discrimination and social exclusion, and stigma from society (Karst & Van Hecke, 2012). Together, these challenges place a significant burden on families raising children with ASD.

The majority of children with ASD and their families living in resource-limited contexts do not have appropriate access to care. For example, at the time of a scoping review done by Franz and colleagues, there were no publications on the development or implementation of early ASD intervention in sub-Saharan Africa, and no population-based prevalence studies of ASD had been performed in any African country (Franz, Chambers, Von Isenburg, & de Vries, 2017). A number of reasons contribute to the few prevalence studies in LMIC including lack of funding, lack of suitable screening and diagnostic tools, and lack of expertise (Abubakar, Ssewanyana, de Vries, & Newton, 2016; de Vries, 2016; Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013; Marlow, Servili, & Tomlinson, 2019; Ruparelia et al., 2016). The relative paucity of ASD diagnoses in current health and educational records suggests that ASD is significantly underidentified and that the majority of individuals with ASD are therefore likely not to be receiving appropriate services (Pillay, Duncan, & de Vries, 2018). Specialist providers typically implement early ASD identification and intervention, but in sub-Saharan Africa, access to specialist care is extremely limited (Franz et al., 2018; Morris et al., 2011; Ruparelia et al., 2016). In countries such as South Africa, there is a growing recognition that specialist providers are highly unlikely ever to meet the needs of the population. This reality necessitates creative thinking around how ASD services can be integrated into existing systems and which individuals can provide such services.

2.2 The opportunities

We propose that, in resource-limited contexts, there should be a greater focus, from the outset, on the potential of early identification and intervention services to be scalable and sustainable. Building on prior work done by [de Vries \(2016\)](#), [Fig. 1](#) illustrates a different way of thinking about service delivery to address the twin burden of high needs and limited resources—the answer will not be a ‘one-size-fits-all solution’, but rather ‘a suite of interventions, all with a good evidence base, delivered by a range of facilitators in appropriate and acceptable ways to families and individuals in communities, while ensuring adequate expert supervision, oversight, and ongoing development’ ([de Vries, 2016, p. 133](#)).

In such a ‘pyramid of interventions’, for example, the smallest proportion of interventions should be ones with a high degree of complexity and/or complicated implementation requirements (e.g. extensive training, expensive infrastructure requirements, or high proprietary costs) delivered by specialists to caregivers and children with complex clinical needs. These specialists should also be involved in the development, training, and supervision of less experienced or early career specialists and nonspecialist facilitators. This can be done through the process of task sharing, whereby tasks are moved (where appropriate) to less specialized facilitators, thus making more efficient use of the available human resources ([Seidman & Atun, 2017](#)). The first opportunity in resource-limited environments is therefore to embrace ‘task sharing’ as philosophical principle. Task sharing will equip a bigger middle group of early career specialists and nonspecialists with skills to provide targeted support for children and families with diagnosed conditions, presenting a viable option to increase access to

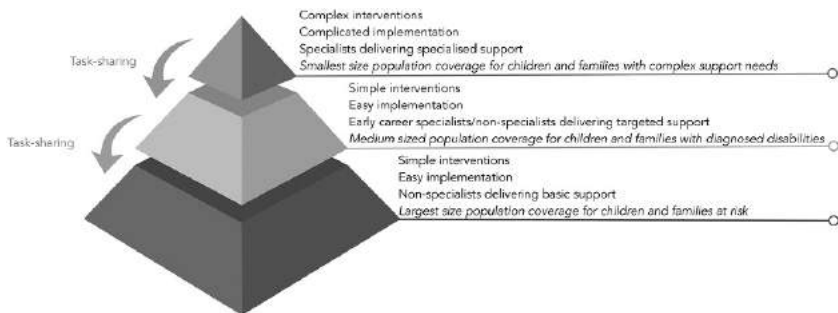


FIG. 1 The pyramid of interventions model. In this model a range of early ASD interventions are available from specialist support (for children with ASD and highly complex needs), cascading to targeted support (for all children diagnosed with ASD) and to universal or general interventions (for those at high risk of ASD or related disabilities). The model integrates the complexity of the intervention, the degree of difficulty to implement the intervention, the level of expertise of the interventionists, and the needs of the targeted caregivers.

support services for many children and families in resource-limited contexts. At the base of the ‘pyramid of interventions’, where the majority of efforts should be focussed, interventions should be simple, affordable, and delivered by nonspecialists (meaning that it is not too complicated, nor too difficult or too expensive to implement) to support caregivers and families of children with ASD or other developmental delays and disabilities.

A second opportunity in resource-limited settings is to use a strength-based approach to uncover the existing strengths of communities (Eloff & Ebersöhn, 2001). This is a very different perspective from a ‘needs-based’ approach. While a needs-based approach focusses on the deficiencies and service needs of a community, a strength-based approach focusses on the existing capabilities, skills, and social resources of people and their communities. It does not ignore the external context of and constraints on communities, nor does it imply that these communities do not need additional resources from outside. Rather, it suggests that outside resources can be more effectively utilized if the community has already identified and mobilized its own resources. By building relationships with communities through participatory approaches, researchers and clinicians can leverage the communities’ strengths to develop and sustain implementation capacity. Engagement of stakeholders such as future implementers and caregivers is therefore far more likely to produce interventions that are relevant, appropriate, feasible, and sustainable (Pfadenhauer et al., 2017).

A third opportunity in resource-limited settings is to borrow from positive examples or ‘lessons learnt’ through global initiatives in related fields. For example, the work described here is situated in the fields of (a) early ASD identification and interventions (e.g. Broder Fingert et al., 2019; Marlow et al., 2019; Vivanti et al., 2018), (b) implementation and dissemination science (e.g. Barker, Reid, & Schall, 2016; Pfadenhauer et al., 2017), (c) other global health initiatives such as the child and adolescent mental health field (Murray, Dorsey, & Lewandowski, 2014), and (d) innovative research methodologies such as sophisticated mixed-method research (Poth, 2018). Building on an existing evidence base means that it might be possible to have a shorter timeframe of translating research into community settings to reduce inequalities. While efforts to implement early ASD intervention in community settings are increasing worldwide (Rahman et al., 2016; Tekola et al., 2019; Zhou et al., 2018), the cross-cultural evidence base for determining whether these interventions improve outcomes is lacking. Thus leveraging international cross-institutional collaborations and working collaboratively within a country and continent can advance the reality of delivering and sustaining ASD services in resource-limited contexts.

In the next, section we will describe the Centre of Autism Research in Africa (CARA) that has been proactively set up as a hub of regional expertise to promote interdisciplinary cooperation with colleagues from national and international institutions.

2.3 The Centre for Autism Research in Africa (CARA)

CARA is based at the University of Cape Town in South Africa and was founded in 2012 by Professor Petrus J. de Vries, a child and adolescent psychiatrist. His vision was to grow an interdisciplinary team of academics and clinicians with a shared passion for conducting socially responsible research in support of sustainable development (www.cara.uct.ac.za). CARA offers a unique setting where cross-disciplinary collaborations and mentorship are encouraged. For example, the Africa Autism Treatment Network (AATN) is a mechanism within CARA to support cross-project research that focusses specifically on early ASD interventions (Chambers et al., 2019). This cross-disciplinary team is a committed group of independent researchers who meet regularly to discuss problems and opportunities, develop and test potential solutions, capture and share learning, and plan for continual improvement. Other benefits of this collaboration across research projects include the development of a common research language and a selection of common outcome measures for comparability across studies. It also minimizes the unnecessary duplication of research efforts. The insights from these researchers with experience of the local context are critical to accelerating the translation of knowledge and the generation of new knowledge for solving the complex ASD service needs. One of the outcomes of the AATN group was the development of a list of key considerations when implementing and evaluating early ASD interventions in resource-limited contexts such as South Africa, which we will discuss next.

3 Key considerations for implementing and evaluating scalable and sustainable early interventions for ASD in resource-limited settings

Research on implementation over the past decade demonstrated that achieving sustainable and scalable services requires more than just effective, evidence-based interventions. To achieve significant service outcomes, other interconnected and interdependent components must be considered, such as ensuring effective implementation, establishing a good understanding of the local context and setting, getting a deep understanding of the local caregivers (and/or other intervention beneficiaries), and conducting pragmatic evaluations (Fig. 2).

3.1 Select effective interventions

In this section, we present two broad categories of interventions for young children with ASD that are important components of the ‘pyramid

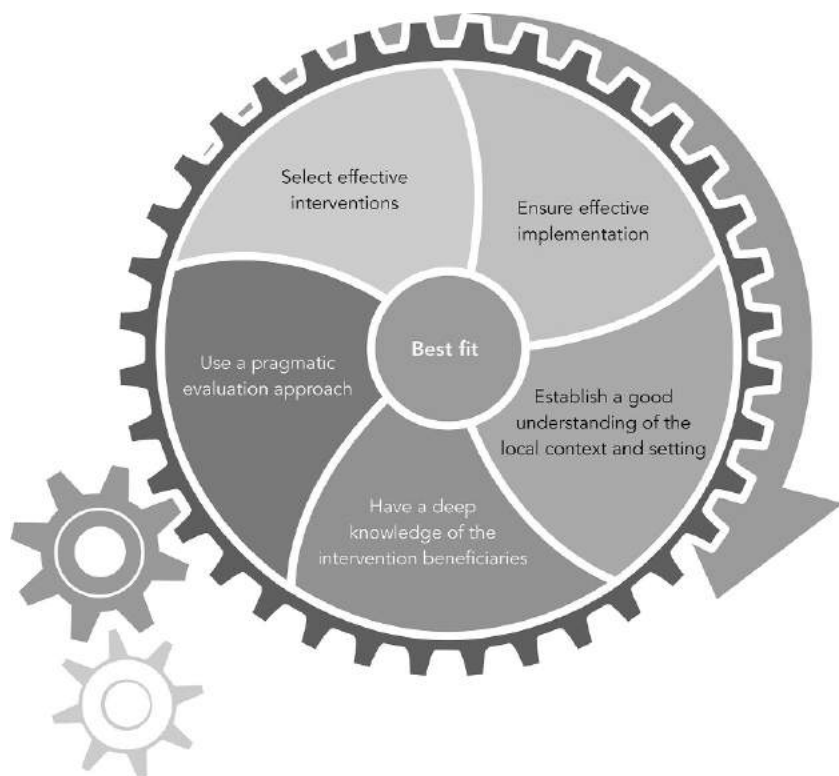


FIG. 2 Key areas to consider for establishing sustainable and scalable early ASD intervention services in resource-limited settings.

of interventions' as outlined in Fig. 1. These are parent education and training (PET) programmes and caregiver-implemented naturalistic developmental behavioural interventions (NDBIs). Acknowledging that the evidence base for these comes from high-income countries, we highlight key considerations that researchers, clinicians, and policy-makers should consider when selecting interventions for resource-limited environments. We will introduce and discuss six interventions under investigation at CARA.

3.1.1 The importance of caregivers

The early years of children with ASD represent a critical time to ensure optimal development by providing them with opportunities for child-focused learning, play, communication activities, and peer interaction. Caregivers and families play a fundamental role in the development of all young children (Black et al., 2017). When development is compromised, health and intervention services are difficult to access in resource-limited settings; hence, caregivers will be the primary support and care coordinator

for their child. Caregivers' ability to provide responsive caregiving to their child becomes even more important in this context. Therefore a top priority for early intervention services should be the provision of training and support for caregivers to enable them to support their child's development.

3.1.2 Parent/Caregiver Education and Training programmes (PET)

PET programmes are an essential first step in the suite of interventions that should be available to caregivers. The goal of PET programmes is to transfer knowledge to caregivers using a range of teaching materials and methods (Bears, Burrell, Stewart, & Scahill, 2015; Dawson-Squibb, Davids, & de Vries, 2019). PET programmes have a positive effect on caregiver mental health outcomes (such as decrease in stress and increase in sense of competence, self-efficacy, and social support) and improve their responsiveness when interacting with their child (Dawson-Squibb, Davids, Harrison-Johnson, Molony, & de Vries, 2019; Hohlfeld, Harty, & Engel, 2018). In most PET programmes, children are not present in the sessions, although facilitators may visit the home to provide parents with individualized feedback on how to implement the skills they have learnt with their child. Thus the caregivers are the primary participants in the training. PET indirectly benefits the child by improving a caregiver's knowledge of the child's condition and their confidence to manage challenging behaviours. The World Health Organization (WHO) has strongly encouraged the use of caregiver training to empower those who have children with ASD or other neurodevelopmental disabilities. Many PET programmes are delivered in a group format. Stuttard and colleagues state that cost per session of delivering a group-based PET ranges from £185 to £490 per session (Stuttard, Beresford, Clarke, Beecham, & Morris, 2016). With 10 parents attending the programme, the cost per session per parent is as little as £18. They state the main determiner of cost is the level of expertise of the trainer and the trainer's profession. Therefore, depending on who delivers the PET, a group-based parent education and training format can be a cost-effective way of providing early intervention in a resource-constrained setting. Group formats may also provide a natural way to facilitate social support for families, thus making group-based PET programmes a logical first step for families with a child who is at risk or who has recently received a diagnosis of ASD.

There are many proprietary PET programmes available; however, very few have been routinely implemented in resource-limited settings (de Vries, 2016; Dawson-Squibb, Davids, & de Vries, 2019; Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). Key considerations for implementing PET in these settings require the need to (a) identify who is the most suitable caregiver to receive the training and what are the characteristics, needs, and preferences of these caregivers; (b) ensure sensitivity to educational information; and (c) include sensitivity to training skills and training methods

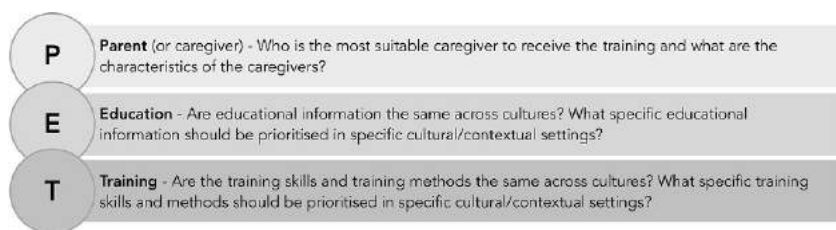


FIG. 3 Key considerations for implementing effective parent (or caregiver) education and training (PET) programmes in resource-limited contexts.

(Fig. 3). With regard to caregivers, it is important to bear in mind that the traditional model of parenthood (biological mother and father) is often not the norm in many resource-limited settings (McCarthy & Edwards, 2011). Many children are cared for by a fluid extended family structure that may include aunts, grandmothers, and even older siblings. This means that, when we think about providing training to ‘caregivers’ in resource-limited settings, we must take an expansive view on a child’s caregiver(s).

3.1.3 Naturalistic developmental behavioural interventions (NDBIs)

For young children with ASD, there is widespread consensus that NDBIs have considerable empirical support for their effectiveness (Schreibman et al., 2015; Tiede & Walton, 2019). NDBIs refer to a class of interventions for young children with ASD that merge applied behavioural and developmental approaches to intervention. Although there are numerous proprietary NDBIs, they share many common features, including implementation in natural settings, shared control between child and interventionist, use of natural contingencies, and use of a variety of behavioural strategies to teach developmentally appropriate and prerequisite skills (Schreibman et al., 2015).

Although trained professionals can implement NDBIs and be the primary intervention partner for the child, many of the professionals trained in NDBIs also coach parents to implement the NDBI strategies with their child, that is, the parent becomes the primary intervention partner. These programmes are also known as caregiver-mediated interventions or caregiver-coaching programmes. During the coaching process the skill or strategy being taught is often first demonstrated (modelled) by the trainer. The caregiver then implements the skill with their child and receives structured feedback from the trainer on their performance. Benefits of caregiver-coaching programmes include improvements in the child’s social communication, cognition, patterns of parent–child interaction, and a decrease in ASD symptom severity (Nevill, Lecavalier, & Stratis, 2018). A recent metaanalysis of published NDBI group design studies showed

positive effects of NDBIs on a range of child outcomes, with the largest effect sizes noted for children's social engagement ($g=0.0.65$) and cognitive development ($g=0.48$) (Tiede & Walton, 2019).

As stated earlier, there are many proprietary caregiver-mediated NDBI programmes available, yet most of these interventions were developed in high-income countries and were designed for their particular cultural group of caregivers and families. Key considerations for implementing NDBIs in low-resource contexts therefore include the need to understand (a) the context in which intervention occurs, (b) which developmental and (c) behavioural targets should be taught within certain cultural/contextual settings, and (d) how we measure the effectiveness of the intervention when we do not have assessment and outcome tools which are culturally and contextually valid (Fig. 4).

The majority of NDBI research has been conducted on nonrepresentative populations. A review by Nielsen, Haun, Kärtner, and Legare (2017) identified that < 3% of participants came from Africa, Central and South America, Asia, or the Middle East (Nielsen et al., 2017). However, these interventions can be implemented effectively by caregivers (Kasari et al., 2014; Wetherby et al., 2014; Zhou et al., 2018) and by nonspecialists (Reichow, Servili, Yasamy, Barbui, & Saxena, 2013), regardless of where in the world they are based. The option to train caregivers and nonspecialists is particularly promising within a resource-limited context.

3.1.4 The suite of evidence-based interventions being investigated at the Centre for Autism Research in Africa (CARA)

At the time of writing, the AATN team at CARA was examining six different ASD interventions in various South African contexts (Table 1). The vision is to be able to implement a range of effective early interventions that can support the capacity development of caregivers and of those who have the responsibility for caring and educating children with ASD in early childhood development settings. Three of the projects implemented

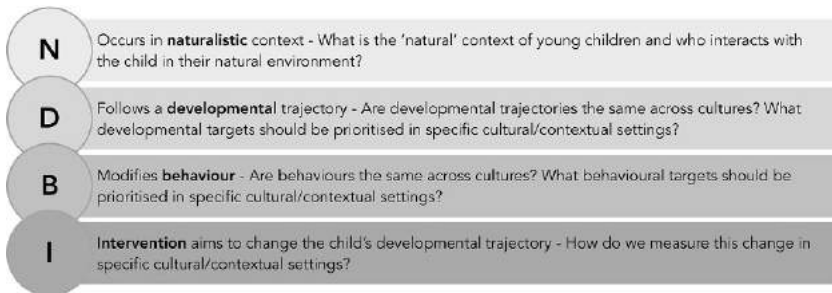


FIG. 4 Key considerations for implementing effective naturalistic developmental behaviour interventions (NDBIs) in resource-limited contexts.

TABLE 1 Description of the six early ASD intervention programmes at CARA discussed in this chapter.

	Parent education and training (PET) programmes			Naturalistic developmental behavioural interventions		
Intervention	World Health Organization Caregiver Skills Training Programme	EarlyBird	Communication Parenting Strategies (COMPAS)	Early Start Denver Model (ESDM) South Africa	Enhanced Milieu Teaching (EMT)	Autism Navigator
<i>Focus of the intervention</i>	Caregiver support and caregiver-mediated intervention programme	Caregiver/providers support programme	Caregiver support programme (specific focus on social communication)	Caregiver-mediated intervention programme	Therapist-mediated intervention programme	Caregiver-mediated intervention programme
<i>Dosage</i>						
Duration (how long)	12 weeks	10 weeks	3 weeks OR 1 day	12 weeks	12–18 weeks	12 weeks
Frequency (how often)	Meeting 1 × per week	Meeting 1 × per week	Meeting 1 × per week	Meeting 1 × per week	Meeting 2 × per week	Meeting 1 × per week
Intensity (how much)	2.5h session	2.5h session	3h session OR 1 day × 8h session	1h session	½h session	1h session
Refresher/ follow-up sessions		After 3 months Meeting 1 × 2.5h session				
<i>Format</i>	9 facilitator–caregiver group sessions	9 facilitator–caregiver group sessions	1 or 3 facilitator–caregiver group session(s)	12 individual caregiver–child coaching sessions	24–36 individual interventionist–child sessions	12 individual caregiver–child coaching sessions

Continued

TABLE 1 Description of the six early ASD intervention programmes at CARA discussed in this chapter—cont'd

	Parent education and training (PET) programmes			Naturalistic developmental behavioural interventions		
Intervention	World Health Organization Caregiver Skills Training Programme	EarlyBird	Communication Parenting Strategies (COMPAS)	Early Start Denver Model (ESDM) South Africa	Enhanced Milieu Teaching (EMT)	Autism Navigator
<i>Location(s)</i>	3 individual caregiver–child coaching sessions Community venue Family home	2 individual caregiver–child coaching sessions Academic hospital Family home	Academic hospital	School	School	Family home
<i>Child's age</i>	2–9 years	4–8 years	2–8 years	18–72 months	4–7 years	< 4 years
<i>Child's disability</i>	Developmental delays or disabilities, including ASD No diagnosis required	ASD diagnosis	ASD diagnosis	ASD diagnosis	ASD diagnosis	Confirmed early signs of ASD
<i>Intervention facilitators</i>	Pair of nonspecialist facilitators	Pair of facilitators who have done the EarlyBird facilitator training	Speech and language therapists together with parent facilitators	Nonspecialist early childhood development practitioners	Speech and language therapist	Specialist and nonspecialist intervention providers

<i>Training of facilitators</i>	7 days train-the-trainer training for specialists 7 days training and apprenticeship model for nonspecialists	Each facilitator must complete the 3-day training run by the National Autistic Society in the United Kingdom. There is no train-the-trainer model available	Training process not yet finalized	Early childhood development practitioners receive a 3- to 4-day training to introduce principles of ESDM and caregiver coaching; continued supervision by certified ESDM therapist	Training process conducted on the Vanderbilt University Campus	30-h web-based training course for professionals and 15-h training course for nonspecialists
<i>International implementation partners</i>	World Health Organization, with support from Autism Speaks, USA	National Autistic Society, UK	Locally developed intervention	Duke Centre for Autism and Brain Development, USA	KidTalk Lab, Vanderbilt University, USA	Autism Institute, Florida State University, USA
<i>National implementation partners</i>	National Department of Social Development; Autism South Africa; Community-academic partnership with key organizations and stakeholders	Autism Western Cape	Not yet specified	Western Cape Department of Education	Western Cape Department of Education	Collection of Autism-Specific, Nonprofit Organizations; public and private health settings

by AATN researchers are PET programmes: the WHO Caregiver Skills Training Programme (WHO CST, global initiative); EarlyBird (developed in the United Kingdom); and Communication Parenting Strategies (COMPAS), a locally developed programme. The other three are NDBIs: the Early Start Denver Model (ESDM), Autism Navigator, and Enhanced Milieu Teaching (EMT). All three NDBIs were developed in the United States and are being adapted and evaluated for implementation in the South African context.

The six interventions vary in terms of, among other things, the type of caregiver involvement, the specificity to children with ASD (exclusive to ASD vs inclusive of children with other developmental disabilities), and training strategies (in-person vs web based). There is also variation on who provides the training to caregivers (psychologists, speech and language therapists, occupational therapists, early childhood development workers, and nonspecialists workers). Despite the variation, there is a common thread that runs through all the interventions—the focus on effectiveness of intervention *and* of implementation. Each project is systematically taking an evidence-based/evidence-informed intervention and considering its compatibility (or ‘fit’) in local settings. Compatibility can be broadly described as how well an intervention aligns with the existing values, norms, goals, and environment of the proposed local setting (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). The closer the intervention aligns with the elements of the local setting, the more likely it is to be adopted by individuals who work in that setting (Greenhalgh et al., 2004). As a result, formative work in the six research projects documented both the effectiveness of the intervention and the elements of the intervention that may need to be adapted or modified to increase the fit with the settings in which the interventions will ultimately be implemented. These implementation elements will be explored in subsequent sections.

Key messages about selecting effective interventions

- Support caregivers to support their children’s development
- Start with evidence-based or evidence-informed early interventions
- Parent/caregiver education and training programmes and naturalistic developmental behavioural interventions are potentially feasible solutions to increase access to early intervention services in resource-limited contexts
- Think about a ‘pyramid of interventions’ to fit with local context and settings

3.2 Ensure effective implementation

While research has increasingly focussed on the importance of supporting children with ASD in their early years, little attention has been paid to the challenges of effectively implementing early assessment and intervention services in real-life communities (Stahmer, Dababnah, & Rieth, 2019). *Implementation science* is the study of methods to promote the adoption of interventions, practices, or policies into real-life settings, while *implementation* is the actively planned and deliberate process of integrating evidence-based interventions within a setting (Ghate & Ghate, 2016). Planning implementation from the beginning can strengthen implementation efforts, identify potential barriers and facilitators, and may be linked to more successful scale-up efforts.

A range of different implementation science theories, models, and frameworks can be drawn upon to navigate the decision-making processes involved in implementing and evaluating intervention programmes in real-life settings (e.g. Albers, Mildon, Lyon, & Shlonsky, 2017; Murray et al., 2014; Nilsen, 2015) and to identify the implementation and scale-up requirements (Koorts et al., 2018). These include questions about people (e.g. the type and number of people that the intervention will reach and the individuals that will deliver the intervention), places (e.g. the setting or organizations that will be involved), the processes (e.g. planning the implementation process that will occur in practice), provisions (e.g. the human, physical and fiscal resources that will be necessary to achieve implementation and scale-up), and principles (e.g. the underlying principles of the intervention and implementation).

Answering these questions helps to identify aspects that will hinder implementation and aspects that will facilitate implementation. When we think about potential implementation barriers in resource-limited settings, we pay special attention to (a) training and supervision, (b) monitoring and evaluation, and (c) programme adaptation. With respect to training, for example, many proprietary interventions have a high cost associated with the process of becoming a certified trainer or coach. Sourcing funding for individuals in LMICs to complete the certification process successfully can be problematic. Also, supervision is often provided by trainers in high-income countries, using a blended approach of online and in-person supervision. This approach may be feasible; however, no or slow-speed internet connections, high data costs, and difficulties uploading video footage or accessing teaching and training materials (which underpin the success of this type of supervision structure) can be problematic. Fidelity is often measured by the coding of video observations to set criteria. This requires infrastructure and coding capacity that might not be feasible in most settings. Similarly, training and intervention materials (e.g., videos and handouts) may need to be adapted to be culturally relevant. These are all examples of implementation barriers.

On the other hand, innovative alternatives such as train-the-trainer training models, task sharing, the apprenticeship model of training and supervision (Murray et al., 2014), and interventions specifically designed with dynamic and continuous adaptations in mind (Chambers, Glasgow, & Stange, 2013) are promising solutions to address the aforementioned challenges. It is important to be mindful of a balanced approach when considering implementation barriers and facilitators. For example, while international training costs might be high (implementation barrier), it also allows us access to international technical support and extensive multistakeholder input (implementation facilitator). Thus considering the potential barriers and facilitators helps us to develop implementation strategies that can address these issues. Implementation strategies consist of a set of activities that are chosen and tailored to fit our local context. We showcase some of the implementation strategies selected by three of the research teams in Box 1 while acknowledging that much more focussed research is required to determine the effectiveness of these implementation strategies (Ghate & Ghate, 2016).

BOX 1

Example: Selecting and evaluating implementation strategies in South Africa

Autism Navigator courses use a number of implementation strategies. This includes principles of adult learning, an extensive library of video clips to demonstrate the intervention and coaching strategies, web-based training, and a mobile supervision strategy. Preliminary evidence shows promise for the feasibility of these implementation strategies for training in the South African context (Chambers, de Vries, Delehanty, & Wetherby, 2018).

The Enhanced Milieu Teaching (EMT) team is exploring a cascading training model together with the evidence-informed teach-model-coach-review framework to determine if they can overcome the need for interested practitioners to have to travel to the United States to receive their initial training in the intervention. This training model uses a combination of local and international experts and web-based technologies to train three providers to implement EMT to fidelity.

The COMPAS team trained expert caregivers to be the facilitators of the group sessions. They showed video recordings of these caregivers implementing the intervention strategies with their children with ASD, and they also help to facilitate group discussions during the small group activities for each session.

Key messages about ensuring effective implementation

- Use implementation science to actively plan implementation from the very beginning
- Ask questions to identify the people, places, processes, provisions, and principles required for implementation and scale-up
- Identify potential implementation barriers and facilitators in the local context and setting
- Develop and evaluate a range of implementation strategies to address the implementation barriers and facilitators

3.3 Establish a good understanding of the local context and setting

Careful consideration of the implementation context is essential, because ‘fit’ between context and intervention will promote broader intervention reach and ensure greater benefit to children and families. The implementation context contains unique factors that will interact with the intervention and may facilitate or constrain uptake of evidence-based practice. Context is therefore not a backdrop, but a pivotal and active component that could determine implementation success or failure. Implementation science provides various frameworks to examine context systematically across multiple levels and to identify implementation barriers and facilitators (Damschroder et al., 2009; Stahmer et al., 2019).

In the past few years, the CARA research teams have carried out fundamental work in the Western Cape and beyond to improve our understanding of the implementation context relevant to early ASD intervention (Franz et al., 2018; Guler, de Vries, Seris, Shabalala, & Franz, 2018; Pillay, Duncan, & de Vries, 2019; Ramseur II et al., 2019). Even though South Africa is classified as an upper middle-income country, it is the world’s most unequal society, with the highest Gini coefficient (World Bank, 2018). Therefore the needs of the vast majority of the population requiring early ASD intervention are not met (Franz et al., 2017; Guler et al., 2018). The lack of access to early intervention for ASD in South Africa is due to a combination of factors, including the following: (a) There is limited ASD government education services (e.g. nine government ASD schools in South Africa for a population of over 52 million people); (b) the majority of South Africans live in poverty (more than half of the population live on R992 South African Rand ~ USD\$78, per person per month) (Statistics South Africa, 2017), and (c) while some private services are available in cities, these services are expensive and likely not evidence

based (van Schalkwyk, Beyer, & de Vries, 2016). Springer and colleagues documented racial variations in expressive language abilities at ASD diagnosis in South Africa (Springer, van Toorn, Laughton, & Kidd, 2013), which suggests that the legacy of apartheid and related socioeconomic challenges on people of colour still acts as a barrier to accessing services (Khalfani & Zuberi, 2001; Mayosi & Solomon, 2014). In South Africa, this disparity is an essential contextual consideration relevant to early ASD intervention.

Importantly the unmet need for early ASD intervention in South Africa is increasing. While no population-based prevalence data exist in South Africa or any other African country, recent counts of the number of children in the Western Cape Province waiting for ASD special education services have been conducted. Children on this waiting list would have received a clinical diagnosis of ASD from a developmental paediatrician or medical officer who work at a tertiary neurodevelopmental clinic. In 2016 940 children with clinically diagnosed ASD were in special education schools in the Western Cape Province, while 744 children were waiting for placement, 70% of whom were younger than 7 years of age (Pillay et al., 2018). There has been a 276% increase in the number of children with ASD on the waiting list between 2012 and 2016, a trend likely to continue. It is therefore a critical priority to support caregivers and families of young children with ASD who are not in school and staying at home.

With the need for early ASD intervention increasing, it is beneficial that early childhood development is an emerging priority, both globally and nationally. In South Africa the National Integrated Early Childhood Development Policy acknowledges the South African government's 'responsibility to ensure a sufficient number of appropriately qualified human resources, including early childhood development practitioners and their supervisors, to facilitate centre- and noncentre-based early childhood development programmes, including parent support programmes' (Republic of South Africa, 2015). This suggests that early childhood development practitioners could be an important nonspecialist workforce targeted for early ASD intervention implementation. In addition, this policy highlights the importance of supporting the practitioners who are the 'caregivers' of many young children with developmental difficulties. They need the skills and training to provide inclusive education to children with ASD (Franz et al., 2018; McLinden et al., 2018).

In terms of identifying the service delivery sector for early ASD intervention, formative work with senior management level stakeholders has indicated that early ASD intervention is more closely aligned with education department goals than with health or social development goals

(Guler et al., 2018). However, ‘fit’ with education department goals and priorities without the mutual alignment of the other government departments would not make this service delivery sector a sustainable approach for early ASD intervention. This is because the education department does not typically provide services for children younger than 7 years. As specified in the Nurturing Care Framework, a ‘whole-of-government’ approach is required when introducing services and support for young children and their families (World Health Organization, United Nations Children’s Fund, & World Bank Group, 2018). Such a response would enable policies across all service delivery sectors that could systematically improve care. Importantly, intersectoral government structures—with political and financial support—could facilitate care coordination, identify common goals, monitor joint actions, build effective collaboration, and positively impact upon the lives of young children with ASD. At CARA, we are actively trying to bring these important stakeholders together through stakeholder workshops and research-community partnerships (Box 2).

BOX 2

Example: A community–academic partnered project

The WHO Caregiver Skills Training (CST) team established a community–academic partnered project by involving key stakeholders (national government departments, nonprofit organizations, and community-based organizations) from the beginning of the project. This multisectoral partnership seeks to understand the uniqueness of the local South African system. The group helps to identify potential barriers and facilitators to implementation and propose solutions of how to best integrate ASD interventions within the existing service delivery systems.

In the absence of any generally accepted evaluation framework to select ASD-specific parent education and training (PET) programmes in different settings, Dawson-Squibb, and de Vries (2019) used a multistakeholder approach to generate such a tool. The development of the ‘evaluation framework checklist’ included the building of relationships to establish stakeholder buy-in and consensus-building workshops. This approach ensured that the newly developed tool is appropriate and relevant for the local context and setting.

Key messages about understanding the local context and setting

- Understand the implementation context because it is key to integrating evidence-based interventions
- Implementation science provides frameworks to systematically examine the context
- Early childhood development is an emerging global and national priority
- Early childhood development practitioners could be a nonspecialist workforce targeted for early ASD intervention implementation
- Strengthen intersectoral government collaboration and build community–academic partnerships

3.4 Have a deep knowledge of local caregivers and families

3.4.1 Consider the intervention beneficiaries

Interventions targeting caregivers need to consider caregivers as active partners in the intervention process. To do this, researchers and implementation agencies should go through the important decision-making process to determine who should be the focus of interventions. Mismatches between interventions and end-users (in this case caregivers) can result when the context and population differ from the initial intervention testing (Chambers & Norton, 2016). These mismatches could be the result of a host of factors, including age, race, culture, organization, accessibility, the duration of intervention, staffing, and resource limitations (Chambers & Norton, 2016). For example, while parenting practices have some universal components, these are heavily culturally based and often dependent on beliefs and orientations (e.g. the role of respect or gender practices) (Berg, Lachman, & Voges, 2018). As described by Murray and colleagues, if an intervention developed for a group of caregivers is delivered for a different group and engagement or outcomes are not promising, careful examination is required to determine whether the problem was with the implementation process or rather with the mismatch between the intervention components and the population and context into which it was implemented (Murray et al., 2014). For these reasons, researchers should actively get to know the characteristics, preferences, and needs of the chosen group. Implementation science can provide relevant and helpful guidelines to ensure scalable and sustainable solutions to these questions.

3.4.2 In-depth knowledge of caregivers

Mthombeni and Nwoye (2018) provide an example of researchers exploring an in-depth understanding of caregivers of children with ASD. This qualitative study reported on the dominant themes given by Black South African caregivers regarding their understanding of ASD. It drew attention to the caregivers' frustration and their experience that there were few benefits to either indigenous or Western approaches to ASD symptoms. The authors highlighted the need for mental health care providers to be adequately informed about the cultural aetiological and treatment imperatives of ASD and remain respectfully sensitive to them. In addition, the authors discussed the importance of creating constructive partnerships between government and caregivers to find solutions to the significant treatment gap given the excessive financial burdens faced by many Black South African caregivers of children with ASD (Mthombeni & Nwoye, 2018). In another study of Malawian caregivers of children aged 0–2, researchers used focus groups, participatory research groups, and in-depth interviews to gain an understanding of child-care practices (Gladstone et al., 2018). The results emphasized that the socioeconomic situation of most caregivers necessitated that income generation and food security were prioritized and mothers had limited time to dedicate to play, responsiveness, or communication with their children. The authors of the study discussed the value of ensuring intervention programmes that provide advice on developmental stimulation, play, early communication, and responsive feeding and ensure that topics are culturally appropriate to the setting. Successful implementation of caregiver programmes must incorporate an understanding of caregiver needs and local context (Box 3).

BOX 3

Example: Getting to know a group of South African caregivers

Work by the Early Start Denver Model (ESDM) team has revealed that caregivers of young children with ASD in South Africa considered eight contextual factors to be important in early ASD intervention, including culture, language, location of treatment, cost of treatment, type of service provider, support, parenting practices, and stigma. Caregivers reported a preference for affordable, in-home, individualized early intervention, where they have an active voice in shaping treatment goals (Guler et al., 2018). This work represents an important start when planning intervention research to meet the stated needs of South African caregivers of children with ASD.

3.4.3 In-depth knowledge of family life

Given that NDBIs are delivered in the context of common family routines, it is essential to understand how such routines present in local families. This provides key information about how to embed NDBI strategies within family life. Pilot data from a separate study by the ESDM team included descriptions of caregiver–child interactions, primarily during play, from 22 ethnically diverse caregivers of young children with ASD in South Africa. In this study, caregivers reported regularly interacting with their young child with ASD during toy play and sensory-social games, such as chase and tickle games. During toy play, caregivers described back and forth interactions, where they joined with their child in activities they knew their child enjoyed and tried to incorporate learning into those interactions. During sensory-social games, caregivers were aware of how their child was feeling, and they reported noticing when their child was trying to communicate with them. Sensory-social games occurred with a variety of adults and children (Ramseur II et al., 2019). Another South African study investigated the family-based activities of children in a resource-limited setting and found that, while they participated in a variety of activities, those were dependent on the local context and their caregivers' perceptions (Balton, Uys, & Alant, 2019). These two studies provide evidence for the importance of understanding local family life when considering implementation of intervention programmes for caregivers and have laid a foundation on which our intervention efforts are based.

3.4.4 Ethical considerations of caregiver interventions

Western-styled parenting practices are often based in attachment theory (Morelli et al., 2018). These can run counter to the different ways many people from diverse cultures and with other lifestyles may seek to raise their children. In contrast to attachment-based approaches, Morelli and colleagues highlighted communities in LMICs with rural and subsistence lifestyles, the most common of lifestyles worldwide. They emphasize the importance of understanding how encouraging changes to caregiver practices and views might affect children, families, and communities. Core principles of fairness, justice, and beneficence are highlighted, and researchers are reminded to keep these in mind during the implementation process. Attending to local codes of ethics (e.g. the African Charter on the welfare and rights of the child) is therefore an important recommendation to overcome potential ethical challenges (Morelli et al., 2018). As emphasized by Timyan, hegemonic Western notions of childrearing practices, good and bad, should not be accepted uncritically (Berg et al., 2018). Another important consideration, especially in resource-limited contexts, is the subgroup of caregivers that might not find caregiver

support or coaching programmes helpful due to the combination of numerous challenges that they face (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Estes, Swain, & Macduffie, 2019).

3.4.5 Adaptations

Adaptations are needed when the ‘culture’ of the original programme is different from the culture of the target audience. There is growing evidence to suggest that cultural adaptations improve the effectiveness of programmes by ensuring cultural and contextual fit (Chambers & Norton, 2016; Resnicow, Branowski, Ahluwalia, & Braithwaite, 1999). The adaptation process aims to maximize accessibility, feasibility, and acceptability while maintaining fidelity. The principle of adaptation is a core component of all six research projects at CARA outlined in Table 1. Box 4 illustrates the adaptation work done by the South African WHO CST team.

BOX 4

Example: Adapting a caregiver skills training programme for the South African context

The WHO Caregiver Skills Training (CST) team appointed a community representative to evaluate the cultural appropriateness of the intervention materials. The team also conducted adaptation workshops with local caregivers to discuss the appropriateness of the illustrations in resource-limited settings. The original illustrations were then adapted for resource-limited settings (Schlebusch, de Vries, & South Africa Diamond Families Project Partners, 2019).



Original illustration to demonstrate an activity that promotes caregiver wellbeing (Illustrator Miguel Mendes)



Adapted illustration to reflect an activity that promotes caregiver wellbeing, considering the local resource-limited setting that does not have brick houses (Illustrator Zanmari Norman)

Key messages about having a deep knowledge of local caregivers and families

- Consider caregivers and families as partners in the intervention process
- Determine who should be the focus of the intervention
- Understand the diversity of caregivers and families
- Consider the ethical considerations of interventions for caregivers
- Adapt interventions as required by local and cultural needs

3.5 Use a pragmatic evaluation approach

To achieve more rapid translation of evidence into practice, it is important to incorporate the recommendations of the implementation science literature in the choice of research designs and outcome measures (Barker et al., 2016; Reed, Howe, Doyle, & Bell, 2018; Vivanti et al., 2018). In line with recommendations by Vivanti et al. (2018), we have focussed on feasibility and acceptability aspects during the proof-of-concept and pilot testing phases of intervention studies (Chambers et al., 2018; Hampton, Harty, Fuller, & Kaiser, 2019) using effectiveness–implementation hybrid designs (Curran, Bauer, Mittman, Pyne, & Stetler, 2012). Hybrid designs allow for the collection of implementation process data, such as barriers and facilitators to an intervention collected early on in the research process, examples of which have been discussed earlier. We have used mixed methods for data collection with an iterative approach, allowing for formative data to inform subsequent iterations of implementation and continuous quality improvement (Palinkas et al., 2011; Proctor, Powell, & Feely, 2014). Fig. 5 illustrates the range of outcomes that we are considering, and each section is discussed next.

3.5.1 Implementation outcomes

All studies have collected data relevant to the implementation process and implementation outcomes, which include the constructs of acceptability (being agreeable to those benefiting from the intervention, those affected by the intervention, and those implementing an intervention and society at large), adaptability (the extent to which an intervention can be modified to fit the needs of end-users in their local setting), appropriateness (the extent to which an intervention fits with or is apt in a particular situation), and feasibility (the extent to which an activity is practical and can be successfully used within any given setting (Leeman, Birken, Powell, Rohweder, & Shea, 2017; Proctor et al., 2011). See example in Box 5. We are utilizing three new pragmatic measures of these constructs with multiple stakeholders, namely, the Feasibility of Intervention Measure (FIM), Acceptability of Intervention Measure (AIM), and Intervention Appropriateness Measure (IAM) (Weiner et al., 2017), that

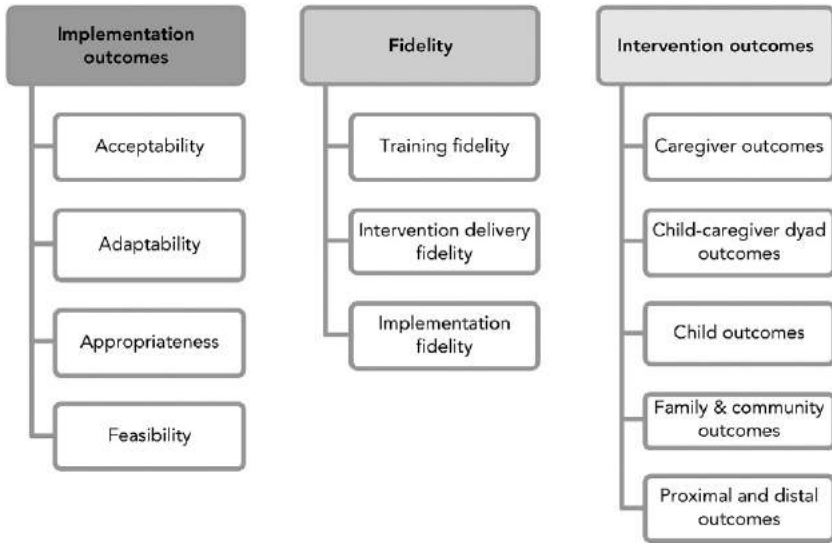


FIG. 5 Implementation, fidelity, and intervention outcomes being considered across the studies outlined in the chapter.

BOX 5

Example: Pragmatic evaluation of two pet programmes in South Africa

We conducted a study to evaluate EarlyBird in comparison with a locally developed parent education and training (PET) programme in South Africa. This study assessed a range of feasibility and outcome measures along with caregiver interviews to determine the strengths and weaknesses of the two programmes. Implementation outcomes of acceptability, adaptability, and appropriateness were examined in conjunction with child and caregiver outcomes. Results were evaluated by a multistakeholder panel using a locally developed parent education and training evaluation framework checklist (see Box 4) to consider what changes and recommendations could be made for future implementation of the programmes in the local setting.

have demonstrated promising test–retest reliability and structural validity. Given the relative novelty of these tools, we anticipate that use of these measures in our resource-constrained settings may contribute to evaluation not only of our interventions but also of these instruments.

Qualitative measures have formed a significant part of our formative and summative outcome measures. Focus groups and key individual interviews with relevant stakeholders such as the intervention providers, families, and other stakeholders at multiple time points before, during, and after the provision of intervention have been essential methods for understanding the context of implementation and the needs for, facilitators of, and barriers to implementation that have been discussed earlier (Franz et al., 2018; Guler et al., 2018; Ramseur II et al., 2019). These rich data help us to understand the information obtained in the quantitative measures and provide a narrative to inform our ongoing and future iterations of training or intervention implementation.

3.5.2 Fidelity

Fidelity is a construct that can be considered an integral part of both implementation feasibility and clinical outcomes (Carroll et al., 2007). Measures of fidelity can be used not only to help explain clinical outcomes but also as a means of informing possible adaptations to the training or implementation procedures. Fidelity and training are also inextricably linked (Murray et al., 2014). Training to fidelity has had to occur in all studies and followed a rigorous and tiered process, starting with training local master clinicians in the intervention itself, followed by training other local specialist and nonspecialist providers, and finally parent training or coaching to implement evidence-based strategies with their children. Ensuring fidelity at each tier of training has generally been assessed using fidelity checklists designed specifically to tap critical features of intervention implementation and coded by expert raters using video-recorded data. Such expert ratings of video records are considered effective, though not efficient measures of fidelity (Schoenwald, Garland, Chapman, Frazier, & Sheidow, 2011). While this resource-intensive process is necessary during the pilot stages, more pragmatic and feasible solutions will need to be considered for larger-scale real-world implementation.

3.5.3 Intervention outcomes

It has been important to select appropriate clinical outcome measures to detect proximal and distal changes in both caregivers, who are the primary recipients of the training or coaching interventions (e.g. caregivers' use of evidence-based strategies, caregiver stress, and caregiver sense of competence), the child (e.g. changes in social communication, development, and adaptive behaviours), and in the caregiver–child dyad (e.g. joint engagement). One major challenge in the selection of measures is the

lack of locally developed, validated, or normed tools for use with South African families and children.

3.5.4 Caregiver measures

All the projects outlined here aim to impact caregivers' use of evidence-based strategies to work with their children with the ultimate goal of improving their children's engagement and social learning. Measures of caregivers' use of the desired strategies include project-specific measures, for example, the measure of active engagement and transactional supports (Wetherby, Morgan, & Holland, 2015) used in the Autism Navigator study. Parental self-efficacy is another important parental construct and the parent self-efficacy measuring instrument has been developed specifically for South African caregivers (Harty, 2009). Using this alongside similar international tools, such as the Parent Sense of Competence Scale (Ohan, Leung, & Johnston, 2000), should provide the opportunity to establish more extensive reliability and validity data on this locally developed tool.

3.5.5 Caregiver-child dyad measures

Measures that capture changes in interactional variables are important for determining how parent strategies influence child engagement. Non-ASD specific tools such as the Parenting Interactions with Children: Checklist of Observations Linked to Outcomes (PICCOLO) rating scales have been used to this end in the COMPAS project. For future research, we are considering the use of intervention programme 'neutral' measures, such as the Joint Engagement Rating Inventory (Adamson, Bakeman, Suma, & Robins, 2019), for characterizing joint engagement across projects to aid comparability.

3.5.6 Child outcomes

Measuring change following intervention in proximal child skills such as social communication is important for demonstrating clinically meaningful change. The Autism Navigator study is making use of the Communication and Symbolic Behaviour Scales (Wetherby & Prizant, 2002) which has some pilot data demonstrating suitability for English and isiZulu-speaking South African toddlers with and without ASD under 3 years of age (Chambers et al., 2017; Chambers, Stronach, & Wetherby, 2016). For capturing change in child distal skills such as developmental level and adaptive behaviour, we have selected measures with some South African data, including the Griffiths Scales of Child Development (Gowar, 2003; Jacklin & Cockcroft, 2012), and the Mullen Scales of Early Learning (Bornman et al., 2018; Ronski et al., 2018). It will be important in our ongoing work to consider wider clinical outcomes on family functioning and other relevant community constructs. For example, the WHO CST project is proposing to evaluate the potential broader impact of the intervention

on the family by assessing family quality of life using the Family Quality of Life Scale already used in previous research (Schlebusch, Dada, & Samuels, 2017).

Key messages about using a pragmatic evaluation approach

- Use research designs that explore the implementation process from the start
- Use mixed methods to explore implementation and effectiveness
- Consider the balance needed between fidelity to the original intervention and adaptation to the local context
- Choose valid and contextually meaningful measures for proximal and distal intervention outcomes

4 Conclusion

The purpose of this chapter was to outline challenges and opportunities for implementing and evaluating early ASD intervention services in resource-limited contexts, using work underway in South Africa as examples of how this could be approached. In addition, we aimed to identify fundamental considerations to improve access to care for young children with ASD and their families that may apply across resource-limited settings.

We focussed on the early years of life, a time when the brain is primed to develop social and language skills and therefore a critically important period for intervention in ASD. The majority of young children with ASD live in resource-limited environments with inadequate access to high-quality early identification and intervention services and inadequate support for caregivers and families. The stark reality of life with ASD around the globe is therefore that the majority of young children with ASD currently receive little or no intervention. We know that, for many children, early intervention has the potential to optimize outcomes and improve long-term independence. Therefore it is critical that concerted efforts are made globally to extend early intervention to as many children as we can reach. Integral to these efforts is the simultaneous development of an evidence base on how best to implement these interventions in settings with cultural and linguistic diversity along with significant societal pressures and resource constraints. To integrate evidence-based ASD interventions into multicultural global settings, we have to specifically consider the implementation process, the local context, and the local caregivers and families. Researchers and clinicians can enhance the likelihood of improving access to care for young children with ASD and their families living in resource-limited environments by understanding what works, for whom,

under what contextual circumstances, and whether these interventions are scalable. The true global reach of such an approach could have a great impact.

References

- Abubakar, A., Ssewanyana, D., de Vries, P. J., & Newton, C. R. (2016). Autism spectrum disorders in sub-Saharan Africa. *The Lancet Psychiatry*, 3(9), 800–802. [https://doi.org/10.1016/S2215-0366\(16\)30138-9](https://doi.org/10.1016/S2215-0366(16)30138-9).
- Adamson, L. B., Bakeman, R., Suma, K., & Robins, D. L. (2019). An expanded view of joint attention: Skill, engagement, and language in typical development and autism. *Child Development*, 90(1), e1–e18. <https://doi.org/10.1111/cdev.12973>.
- Albers, B., Mildon, R., Lyon, A. R., & Shlonsky, A. (2017). Implementation frameworks in child, youth and family services—Results from a scoping review. *Children and Youth Services Review*, 81, 101–116. <https://doi.org/10.1016/j.childyouth.2017.07.003>.
- Balton, S., Uys, K., & Alant, E. (2019). Family-based activity settings of children in a low-income African context. *The Lancet Disability*, 8, 1–14. <https://doi.org/10.4102/ajod.v8i0.364>.
- Barker, P. M., Reid, A., & Schall, M. W. (2016). A framework for scaling up health interventions: Lessons from large-scale improvement initiatives in Africa. *Implementation Science*, 11(1), 1–11. <https://doi.org/10.1186/s13012-016-0374-x>.
- Beauss, K., Burrell, T. L., Stewart, L., & Scahill, L. (2015). Parent training in autism spectrum disorder: What's in a name? *Clinical Child and Family Psychology Review*, 18(2), 170–182. <https://doi.org/10.1007/s10567-015-0179-5>.
- Berg, A., Lachman, A., & Voges, J. (2018). Infant mental health in Africa: Embracing cultural diversity. In M. Hodes, S.S.-F. Gua, & P. J. de Vries (Eds.), *Understanding uniqueness and diversity in child and adolescent mental health*. Elsevier Inc. <https://doi.org/10.1016/C2017-0-00934-5>.
- Black, M. M., Walker, S. P., Fernald, L. C. H., Andersen, C. T., DiGirolamo, A. M., Lu, C., ... Grantham-McGregor, S. (2017). Early childhood development coming of age: Science through the life course. *The Lancet*, 389(10064), 77–90. [https://doi.org/10.1016/S0140-6736\(16\)31389-7](https://doi.org/10.1016/S0140-6736(16)31389-7).
- Bornman, J., Romski, M., Tonsing, K., Sevcik, R., White, R., Barton-Hulsey, A., & Morwane, R. (2018). Adapting and translating the Mullen scales of early learning for the South African context. *South African Journal of Communication Disorders*, 65(1), 1–9. <https://doi.org/10.4102/sajcd.v65i1.571>.
- Broder Fingert, S., Carter, A., Pierce, K., Stone, W. L., Wetherby, A., Scheldrick, C., ... Feinberg, E. (2019). Implementing systems-based innovations to improve access to early screening, diagnosis, and treatment services for children with autism spectrum disorder: An autism spectrum disorder pediatric, early detection, engagement, and services network study. *Autism*, 23(3), 653–664. <https://doi.org/10.1177/1362361318766238>.
- Carroll, C., Patterson, M., Wood, S., Booth, A., Rick, J., & Balain, S. (2007). A conceptual framework for implementation fidelity. *Implementation Science*, 2(1), 1–9. <https://doi.org/10.1186/1748-5908-2-40>.
- Chambers, D. A., Glasgow, R. E., & Stange, K. C. (2013). The dynamic sustainability framework: Addressing the paradox of sustainment amid ongoing change. *Implementation Science*, 8(117), 1–11.
- Chambers, N., Dawson-Squibb, J. J., Franz, L., Harty, M., Schlebusch, L., & de Vries, P. J. (2019). *African Autism Treatment Network (AATN): Lessons learned*. In: SA-ACAPAP congress: Sustaining development, investing in child and adolescent mental health, Johannesburg. <https://doi.org/10.13140/RG.2.2.23190.91209>.
- Chambers, N. J., de Vries, P. J., Delehanty, A. D., & Wetherby, A. (2018). Feasibility of utilizing Autism Navigator® for primary care in South Africa. *Autism Research*, 11(11), 1511–1521. <https://doi.org/10.1002/aur.2018>.

- Chambers, D. A., & Norton, W. E. (2016). The Adaptome: Advancing the science of intervention adaptation. *American Journal of Preventive Medicine*, 51(4), S124–S131. <https://doi.org/10.1016/j.amepre.2016.05.011>.
- Chambers, D. A., Stronach, S. T., & Wetherby, A. (2016). Performance of South African children on the Communication and Symbolic Behavior Scales-Developmental Profile (CSBS DP). *International Journal of Language and Communication Disorders*, 51(3), 265–275. <https://doi.org/10.1111/1460-6984.12203>.
- Chambers, D. A., Wetherby, A., Stronach, S. T., Njongwe, N., Kauchali, S., & Grinker, R. R. (2017). Early detection of autism spectrum disorder in young isiZulu-speaking children in South Africa. *Autism*, 21(5), 518–526. <https://doi.org/10.1177/1362361316651196>.
- Chawarska, K., Macari, S., & Volkmar, F. R. (2014). ASD in infants and toddlers. In F. R. Volkmar, S. J. Rogers, R. Paul, & K. A. Pelphrey (Eds.), *Handbook of autism and pervasive developmental disorders* (4th ed., pp. 121–138). John Wiley & Sons Inc.
- Curran, G. M., Bauer, M., Mittman, B., Pyne, J. M., & Stetler, C. (2012). Effectiveness-implementation hybrid design: Combining elements of clinical effectiveness and implementation research to enhance public health. *Medical Care*, 50(3), 217–226. <https://doi.org/10.1097/MLR.0b013e3182408812>.
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, 4(1), 1–15. <https://doi.org/10.1186/1748-5908-4-50>.
- Dawson-Squibb, J. J., & de Vries, P. J. (2019). Developing an evaluation framework for parent education and training in autism spectrum disorder: Results of a multi-stakeholder process. *Journal of Autism and Developmental Disorders*, 49, 4468–4481.
- Dawson-Squibb, J. J., Davids, E. L., & de Vries, P. J. (2019). Scoping the evidence for EarlyBird and EarlyBird Plus, two United Kingdom-developed parent education training programmes for autism spectrum disorder. *Autism*, 23(3), 542–555. <https://doi.org/10.1177/1362361318760295>.
- Dawson-Squibb, J. J., Davids, E. L., Harrison-Johnson, A., Molony, M. A., & de Vries, P. J. (2019). Parent education and training for autism spectrum disorders: Scoping the evidence. *Autism*, <https://doi.org/10.1177/1362361319841739>.
- de Vries, P. J. (2016). Thinking globally to meet local needs. *Current Opinion in Neurology*, 29(2), 130–136. <https://doi.org/10.1097/WCO.0000000000000297>.
- Eapen, V., & Guan, J. (2016). Parental quality of life in autism spectrum disorder: Current status and future directions. *Acta Psychopathologica*, 2(1), 1–14. <https://doi.org/10.4172/2469-6676.100031>.
- Eloff, I., & Ebersöhn, L. (2001). The implications of an asset-based approach to early intervention. *Perspectives in Education*, 19(3), 147–157.
- Estes, A., Swain, D. M., & Macduffie, K. E. (2019). The effects of early autism intervention on parents and family adaptive functioning. *Pediatric Medicine*, 2(21), 1–14. <https://doi.org/10.21037/pm.2019.05.05>.
- Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J. N., & de Vries, P. J. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: Stakeholder perspectives from the Western Cape province. *Journal of Child and Adolescent Mental Health*, 30(3), 149–165. <https://doi.org/10.2989/17280583.2018.1525386>.
- Franz, L., Chambers, N., Von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. *Autism Research*, 10(5), 723–749. <https://doi.org/10.1002/aur.1766>.
- Ghate, D., & Ghate, D. (2016). From programs to systems: Deploying implementation science and practice for sustained real world effectiveness in services for children and families. *Journal of Clinical Child & Adolescent Psychology*, 45(6), 812–826. <https://doi.org/10.1080/15374416.2015.1077449>.

- Gladstone, M., Phuka, J., Mirdamadi, S., Chidzalo, K., Chitimbe, F., Koenraads, M., & Maleta, K. (2018). The care, stimulation and nutrition of children from 0-2 in Malawi—Perspectives from caregivers; “Who’s holding the baby?”. *PLoS One*, *13*(6), 1–20. <https://doi.org/10.1371/journal.pone.0199757>.
- Gowar, R. V. (2003). *The performance of children with autism on the revised extended Griffiths scales of mental development*. University of Port Elizabeth.
- Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *Milbank Quarterly*, *82*(4), 581–629.
- Guler, J., de Vries, P. J., Seris, N., Shabalala, N., & Franz, L. (2018). The importance of context in early autism intervention: A qualitative South African study. *Autism*, *22*(8). <https://doi.org/10.1177/1362361317716604>.
- Hampton, L. H., Harty, M., Fuller, E. A., & Kaiser, A. P. (2019). Enhanced milieu teaching for children with autism spectrum disorder in South Africa. *International Journal of Speech-Language Pathology*, *21*(6), 635–645. <https://doi.org/10.1080/17549507.2018.1559357>.
- Harty, M. (2009). *The validation of a task-specific measure of parenting self-efficacy for use with mothers of young children*. South Africa: University of Pretoria. Retrieved from <https://repository.up.ac.za/bitstream/handle/2263/28789/Complete.pdf?sequence=4&isAllowed=y>.
- Hohlfeld, A. S. J., Harty, M., & Engel, M. E. (2018). Parents of children with disabilities: A systematic review of parenting interventions and self-efficacy. *African Journal of Disability*, *7*, 1–12. <https://doi.org/10.4102/ajod.v7i0.437>.
- Jacklin, L., & Cockcroft, K. (2012). The Griffiths Mental Development Scales: An overview and a consideration of their relevance for South Africa. In S. Laher & K. Cockcroft (Eds.), *Psychological assessment in South Africa: Research and applications* (pp. 169–185). Johannesburg, South Africa: Wits University Press.
- Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, *15*(3), 247–277. <https://doi.org/10.1007/s10567-012-0119-6>.
- Kasari, C., Lawton, K., Shih, W., Barker, T. V., Landa, R., Lord, C., ... Senturk, D. (2014). Caregiver-mediated intervention for low-resourced preschoolers with autism: An RCT. *Pediatrics*, *134*(1), e72–e79. <https://doi.org/10.1542/peds.2013-3229>.
- Khalfani, A. K., & Zuberi, T. (2001). Racial classification and the modern census in South Africa, 1911-1996. *Race and Society*, *4*(2), 161–176. [https://doi.org/10.1016/S1090-9524\(03\)00007-X](https://doi.org/10.1016/S1090-9524(03)00007-X).
- Koorts, H., Eakin, E., Estabrooks, P., Timperio, A., Salmon, J., & Bauman, A. (2018). Implementation and scale up of population physical activity interventions for clinical and community settings: The PRACTIS guide. *International Journal of Behavioral Nutrition and Physical Activity*, *15*(1), 1–11. <https://doi.org/10.1186/s12966-018-0678-0>.
- Leeman, J., Birken, S. A., Powell, B. J., Rohweder, C., & Shea, C. M. (2017). Beyond “implementation strategies”: Classifying the full range of strategies used in implementation science and practice. *Implementation Science*, *12*(125), 1–9. <https://doi.org/10.1186/s13012-017-0657-x>.
- Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G., & de Vries, P. J. (2013). Autism spectrum disorders-global challenges and local opportunities. *Journal of Child and Adolescent Mental Health*, *25*(1), 1–5.
- Marlow, M., Servili, C., & Tomlinson, M. (2019). A review of screening tools for the identification of autism spectrum disorders and developmental delay in infants and young children: Recommendations for use in low- and middle-income countries. *Autism Research*, *12*(2), 176–199. <https://doi.org/10.1002/aur.2033>.
- Mayosi, B. M., & Solomon, R. B. (2014). Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine*, *371*(14), 1344–1353.
- McCarthy, J. R., & Edwards, R. (2011). *Key concepts in family studies*. London: SAGE Publications Inc.

- McLinden, M., Lynch, P., Soni, A., Artiles, A., Kholowa, F., Kamchedzera, E., ... Mankhwazi, M. (2018). Supporting children with disabilities in low- and middle-income countries: Promoting inclusive practice within community-based childcare centres in Malawi through a bioecological systems perspective. *International Journal of Early Childhood*, *50*(2), 159–174. <https://doi.org/10.1007/s13158-018-0223-y>.
- Morelli, G., Quinn, N., Chaudhary, N., Vicedo, M., Rosabal-Coto, M., Keller, H., ... Takada, A. (2018). Ethical challenges of parenting interventions in low- to middle-income countries. *Journal of Cross-Cultural Psychology*, *49*(1), 5–24. <https://doi.org/10.1177/0022022117746241>.
- Morris, J., Belfer, M., Daniels, A., Flisher, A., Villé, L., Lora, A., & Saxena, S. (2011). Treated prevalence of and mental health services received by children and adolescents in 42 low-and-middle-income countries. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *52*(12), 1239–1246. <https://doi.org/10.1111/j.1469-7610.2011.02409.x>.
- Mthombeni, Z. C., & Nwoye, A. (2018). Black South African caregivers' understanding and responses to their children with autism spectrum disorder symptoms: A qualitative study. *South Africa Journal of Psychology*, *48*(1), 99–111. <https://doi.org/10.1177/0081246317696453>.
- Murray, L. K., Dorsey, S., & Lewandowski, E. (2014). Global dissemination and implementation of child evidence-based practices in low resources countries. In R. S. Beidas & P. C. Kendall (Eds.), *Dissemination and implementation of evidence-based practices in child and adolescent mental health* (pp. 179–203). Oxford: Oxford University Press.
- Nevill, R. E., Lecavalier, L., & Stratis, E. A. (2018). Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder. *Autism*, *22*(2), 84–98. <https://doi.org/10.1177/1362361316677838>.
- Nielsen, M., Haun, D., Kärtner, J., & Legare, C. H. (2017). The persistent sampling bias in developmental psychology: A call to action. *Journal of Experimental Child Psychology*, *162*, 31–38. <https://doi.org/10.1016/j.jecp.2017.04.017>.
- Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation Science*, *10*(53), 1–13. <https://doi.org/10.1186/s13012-015-0242-0>.
- Ohan, J. L., Leung, D. W., & Johnston, C. (2000). The parenting sense of competence scale: Evidence of a stable factor structure and validity. *Canadian Journal of Behavioural Science*, *32*(4), 251–261. <https://doi.org/10.1037/h0087122>.
- Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N.-Y., Nair, M. K. C., Halpern, R., ... Kassebaum, N. J. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the global burden of disease study 2016. *The Lancet Global Health*, *6*(10), e1100–e1121. [https://doi.org/10.1016/S2214-109X\(18\)30309-7](https://doi.org/10.1016/S2214-109X(18)30309-7).
- Palinkas, L. A., Arons, G. A., Horwitz, S., Chamberlain, P., Hurlburt, M., & Landsverk, J. (2011). Mixed method designs in implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, *38*(1), 44–53. <https://doi.org/10.1007/s10488-010-0314-z>.
- Pfadenhauer, L. M., Gerhardus, A., Mozygemba, K., Lysdahl, K. B., Booth, A., Hofmann, B., ... Rehfuess, E. (2017). Making sense of complexity in context and implementation: The Context and Implementation of Complex Interventions (CICI) framework. *Implementation Science*, *12*(1), 1–17. <https://doi.org/10.1186/s13012-017-0552-5>.
- Phelps, K. W., McCammon, S. L., Wuensch, K. L., & Golden, J. A. (2009). Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, *34*(2), 133–141. <https://doi.org/10.1080/13668250902845236>.
- Pillay, S., Duncan, M., & de Vries, P. J. (2019). Doing the best we can. Service provider and government stakeholder perspectives of autism spectrum disorder services in the Western Cape Province of South Africa. In: *International society for autism research conference, Montreal*. <https://doi.org/10.5840/intstudphil199022324>.

- Pillay, S., Duncan, M., & de Vries, P. J. (2018). Who's waiting for a school? A systemic database search for children with autism spectrum disorder waiting for educational services in the Western Cape province of South Africa. In: *International society for autism research conference, Rotterdam*.
- Poth, C. N. (2018). *Innovation in mixed methods research. A practical guide to integrative thinking with complexity*. Thousand Oaks, California: Sage Publications.
- Proctor, E. K., Silmere, H., Raghavan, R., Hovmand, P., Aarons, G., Bunger, A., ... Hensley, M. (2011). Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(2), 65–76. <https://doi.org/10.1007/s10488-010-0319-7>.
- Proctor, E., Powell, B. J., & Feely, M. A. (2014). Measurement in dissemination and implementation science. In R. S. Beidas & P. C. Kendall (Eds.), *Dissemination and implementation of evidence-based practices in child and adolescent mental health* (pp. 22–43). Oxford University Press.
- Rahman, A., Divan, G., Hamdani, S. U., Vajaratkar, V., Taylor, C., Leadbitter, K., ... Cardozo, P. (2016). Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in South Asia in India and Pakistan (PASS): A randomised controlled trial. *The Lancet Psychiatry*, 3(2), 128–136. [https://doi.org/10.1016/S2215-0366\(15\)00388-0](https://doi.org/10.1016/S2215-0366(15)00388-0).
- Ramseur, K., II, de Vries, P. J., Guler, J., Shabalala, N., Seris, N., & Franz, L. (2019). Caregiver descriptions of joint activity routines with young children with autism spectrum disorder in South Africa. *Pediatric Medicine*, 2(March), 6. <https://doi.org/10.21037/pm.2019.03.04>.
- Reed, J. E., Howe, C., Doyle, C., & Bell, D. (2018). Simple rules for evidence translation in complex systems: A qualitative study. *BMC Medicine*, 16, 92. <https://doi.org/10.1186/s12916-018-1076-9>.
- Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013). Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: A systematic review. *PLoS Medicine*, 10(12), 1–27. <https://doi.org/10.1371/journal.pmed.1001572>.
- Republic of South Africa. (2015). *National integrated early childhood development policy*. Pretoria: Government Printers. <https://doi.org/10.1007/s00112-008-1824-6>.
- Resnicow, K., Branowski, T., Ahluwalia, J. S., & Braithwaite, R. (1999). Cultural sensitivity in public health. *Ethnicity and Disease*, 9, 516–542.
- Romsik, M. A., Bornman, J., Sevcik, R. A., Tönsing, K., Barton-Hulsey, A., Morwane, R., ... White, R. (2018). Language assessment for children with a range of neurodevelopmental disorders across four languages in South Africa. *American Journal of Speech-Language Pathology*, 27(2), 602–615. https://doi.org/10.1044/2017_AJSLP-17-0035.
- Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., ... Newton, C. R. (2016). Autism spectrum disorders in Africa: Current challenges in identification, assessment, and treatment. *Journal of Child Neurology*, 31(8), 1018–1026. <https://doi.org/10.1177/0883073816635748>.
- Schlebusch, L., & Dada, S. (2018). Positive and negative cognitive appraisal of the impact of children with autism spectrum disorder on the family. *Research in Autism Spectrum Disorders*, 51, 86–93. <https://doi.org/10.1016/j.rasd.2018.04.005>.
- Schlebusch, L., Dada, S., & Samuels, A. E. (2017). Family quality of life of South African families raising children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(7), 1966–1977. <https://doi.org/10.1007/s10803-017-3102-8>.
- Schlebusch, L., de Vries, P. J., & South Africa Diamond Families Project Partners. (2019). *Adapting a caregiver skills training intervention for families of children with developmental disabilities in South Africa*. In: *International society for autism research conference, Montreal*. <https://doi.org/10.13140/RG.2.2.12403.37925>.
- Schoenwald, S. K., Garland, A. F., Chapman, J. E., Frazier, S. L., & Sheidow, A. J. (2011). Toward the effective and efficient measurement of implementation fidelity. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(1), 32–43. <https://doi.org/10.1007/s10488-010-0321-0>. Toward.

- Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., ... Halladay, A. (2015). Naturalistic developmental behavioral interventions: Empirically validated treatments for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(8), 2411–2428. <https://doi.org/10.1007/s10803-015-2407-8>.
- Seidman, G., & Atun, R. (2017). Does task shifting yield cost savings and improve efficiency for health systems? A systematic review of evidence from low-income and middle-income countries. *Human Resources for Health*, 15(1), 1–13. <https://doi.org/10.1186/s12960-017-0200-9>.
- Springer, P. E., van Toorn, R., Laughton, B., & Kidd, M. (2013). Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health*, 7(3), 95–99. <https://doi.org/10.7196/SAJCH.530>.
- Stahmer, A. C., Dababnah, S., & Rieth, S. R. (2019). Considerations in implementing evidence-based early autism spectrum disorder interventions in community settings. *Pediatric Medicine*, 2(18), 1–10. <https://doi.org/10.21037/pm.2019.05.01>.
- Statistics South Africa. (2017). *Statistical release: Gross domestic product*. Pretoria: Statistics South Africa.
- Stuttard, L., Beresford, B., Clarke, S., Beecham, J., & Morris, A. (2016). An evaluation of the Cygnet parenting support programme for parents of children with autism spectrum conditions. *Research in Autism Spectrum Disorders*, 23, 166–178. <https://doi.org/10.1016/j.rasd.2015.12.004>.
- Tekola, B., Girma, F., Kinfe, F., Abdurahman, R., Tesfaye, M., Yenus, Z., & Hoekstra, R. A. (2019). Adapting and pre-testing the World Health Organization's caregiver skills training programme for autism and other developmental disorders in a very low-resource setting: Findings from Ethiopia. *Autism*, 1–13. <https://doi.org/10.1177/1362361319848532>.
- Tiede, G., & Walton, K. M. (2019). Meta-analysis of naturalistic developmental behavioral interventions for young children with autism spectrum disorder. *Autism*, 23(8), 2080–2095. <https://doi.org/10.1177/1362361319836371>.
- van Schalkwyk, G. I., Beyer, C., & de Vries, P. J. (2016). South Africa and autism. In F. R. Volkmar (Ed.), *Encyclopedia of autism spectrum disorders*. New York: Springer Science and Business Media. https://doi.org/10.1007/978-1-4614-6435-8_102111-1.
- Vivanti, G., Kasari, C., Green, J., Mandell, D., Maye, M., & Hudry, K. (2018). Implementing and evaluating early intervention for children with autism: Where are the gaps and what should we do? *Autism Research*, 11, 16–23. <https://doi.org/10.1002/aur.1900>.
- Weiner, B. J., Lewis, C. C., Stanick, C., Powell, B. J., Dorsey, C. N., Clary, A. S., ... Halko, H. (2017). Psychometric assessment of three newly developed implementation outcome measures. *Implementation Science*, 12(1), 1–12. <https://doi.org/10.1186/s13012-017-0635-3>.
- Wetherby, A., & Prizant, B. (2002). *Communication and symbolic behavior scales: Developmental profile*. Baltimore: Brookes Publishing.
- Wetherby, A., Guthrie, W., Woods, J., Schatschneider, C., Holland, R. D., Morgan, L., & Lord, C. (2014). Parent-implemented social intervention for toddlers with autism: An RCT. *Pediatrics*, 134(6), 1084–1093. <https://doi.org/10.1542/peds.2014-0757>.
- Wetherby, A., Morgan, L., & Holland, R. (2015). *MAETS manual: Measure of active engagement and transactional support*. Florida State University.
- World Bank. (2018). *Overcoming poverty and inequality in South Africa: An assessment of drivers, constraints and opportunities*. Washington, DC: World Bank.
- World Health Organization. (2013). *Meeting report: autism spectrum disorders and other developmental disorders: from raising awareness to building capacity*.
- World Health Organisation, United Nations Children's Fund, & World Bank Group. (2018). *Nurturing care for early childhood development*. In *A framework for helping children survive and thrive to transform health and human potential*. Geneva: World Health Organisation.
- Zhou, B., Xu, Q., Li, H., Zhang, Y., Wang, Y., Rogers, S. J., & Xu, X. (2018). Effects of parent-implemented early Start Denver Model Intervention on Chinese toddlers with autism spectrum disorder: A non-randomized controlled trial. *Autism Research*, 11(4), 654–666. <https://doi.org/10.1002/aur.1917>.



P A R T III

New perspectives on
problems and disorders

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A developmental model of hikikomori: Possible ways to prevent and treat pathological social withdrawal

Takahiro A. Kato

Department of Neuropsychiatry, Graduate School of Medical Sciences,
Kyushu University, Fukuoka, Japan

1 Introduction

Pathological social withdrawal known as hikikomori has been observed amongst youth in Japan since around 1970s, and the word ‘hikikomori’ became widely used as a noun in the latter half of the 1990s when a Japanese psychiatrist, Tamaki Saito, published *Hikikomori: Adolescence without End* (Saito, 1998). Saito tentatively defined hikikomori as a person who has ceased to go to school or work for more than 6 months and has stayed at home for most of this time. In 2010 the Oxford Dictionary published a new entry for the word ‘hikikomori’ signifying its presence and acceptance outside of a purely Japanese context. The Oxford Dictionary’s definition is ‘(in Japan) the abnormal avoidance of social contact, typically by adolescent males’. Hitherto hikikomori had been discussed as a culture-bound syndrome unique to Japan (as it is defined in the Oxford Dictionary) (Kato & Kanba, 2016). However, more recently hikikomori-like cases have been reported in many other countries (Chauliac, Couillet, Faivre, Brochard, & Terra, 2017; De Michele, Caredda, Delle Chiaie, Salviati, & Biondi, 2013; Furuhashi et al., 2012; Garcia-Campayo, Alda, Sobradie, & Sanz Abos, 2007; Gondim, Aragao, Holanda Filha, & Messias, 2017; Kato et al., 2012; Kato, Shinfuku, Sartorius, & Kanba, 2011; Liu, Li, Teo, Kato, & Wong, 2018; Malagon-Amor et al., 2018; Malagon-Amor, Corcoles-Martinez,

Martin-Lopez, & Perez-Sola, 2015; Sakamoto, Martin, Kumano, Kuboki, & Al-Adawi, 2005; Wong et al., 2015; Wong, Liu, Li, Kato, & Teo, 2017; Wu, Ooi, Wong, Catmur, & Lau, 2019).

Hikikomori negatively impacts not only the affected individual's mental health but also wider education and workforce stability and as such is an urgent issue in the administration of Health, Welfare and Labor in Japan (Harding, 2018; Kato et al., 2011; Kato, Kanba, & Teo, 2016, 2018).

The aetiology of hikikomori has not been well understood. We propose that a variety of experiences during developmental periods may induce hikikomori-like conditions. Especially, we are proposing that family dynamic relationships (with a mother, a father, and brothers/sisters), school life with peers, and online 'indirect' communications using Internet are three major contributing factors for the occurrence of hikikomori.

In this review paper, we will introduce the developmental model of hikikomori and suggest possible ways to prevent and treat social withdrawal.

2 Epidemiology of hikikomori in Japan

Regarding hikikomori the earliest epidemiological survey in Japan between 2002 and 2006 targeting individuals aged between 15 and 49 found that 1.2% of the population has experienced social withdrawal (hikikomori) for a period greater than 6 months (Koyama et al., 2010). In 2016 a Cabinet Office survey in Japan reported that the number of 'persons socially withdrawn for more than 6 months between 15 years old and 39 years old' is 540,000 (Japan-Cabinet-Office, 2016). Just recently the Cabinet Office announced the estimated number of hikikomori between 40 and 65 years of age is 610,000 in Japan (Japan-Cabinet-Office, 2019). Thus more than 1 million people are suffering from this social withdrawal condition in Japan. Male prevalence of hikikomori is more than three times higher than females. The following vignettes are typical hikikomori cases amongst youth in Japan (cited and modified from Kato et al., 2012). The phenomenon of 'hikikomori' especially as related to schooling has been otherwise described as 'school refusal (called 'futoko' in Japanese)' since the 1970s and 1980s.

2.1 Clinical case A

Case: Mr. A is a 15-year-old junior high school student. His parents say he obstinately refuses to see them and never comes out of his own room for 2 years.

Social history: He is the first son, with a younger brother. He is brought up by his father who is a company employee and his mother who works part-time. His father, a salesman, has been transferred every 2–3 years and

moved with his whole family, but when he entered junior high school, his father started to live alone, so he now lives with his mother and a brother 3 years his junior. There was nothing particularly problematic during his early development, and his school grades were mediocre, but not bad. He found it hard to make friends, and he would prefer reading books rather than participating in sports. Half a year after entering junior high school at age 12, he suddenly stopped going to school. At home, he is absorbed in PC games and Internet, he hardly ever leaves his room, and his day and night are reversed. He did not have a past psychiatric history, and there was no history of psychiatric disorder in the family.

History of present illness: After 2 years of his school absenteeism, when his entrance exams for senior high school were near at hand, his father returned home and warned him, 'Why don't you go to school once in a while? Can't you be serious about your future?', to which he yelled, 'I don't need you tell me that!', and he suddenly used violence on his father. Whilst his father was dumbfounded, he headed back to his room. A few days later, his parents made up their mind to force him to come with them to the nearby psychiatric service where he was assessed.

Mental status exam on first interview: Mr. A is just standing between his parents kept silent, with his head hung down. His parents bowed and described his life history and problematic situation. From beginning to end, he just kept looking downwards. His attitude does not imply any depressive and psychotic experience, such as depressive mood, delusions, or hallucinations. He just seems to be withdrawn into his own shell. Even when a psychiatrist addressed him 'Mr. A', he did not reply at all.

2.2 Clinical case B

Case: Mr. B is a 24-year-old male living with his parents. His parents say he never comes out of his own room. Mr. B just keeps saying 'I don't know'.

Social history: He is an only child. He is brought up by his parents in a two-bedroom urban apartment. There was nothing particularly problematic during his development until elementary school. In junior high school at age 15, he often skipped school and avoided mingling with peers, which he linked to experiences such as being bullied by classmates in elementary school. His academic performance was historically good, and he directly entered a middle-level university of engineering faculty, but 3 years ago (third grade, 21 years old), Mr. B dropped out of university for lack of motivation. There was no family history of psychiatric disorder.

History of present illness: For the last 3 years, he has hardly ever left his room, spending 23h a day behind its closed door. He eats food prepared by his mother who leaves trays outside his bedroom. He sleeps all day then awakes in the evening to spend his time surfing the Internet, chatting

on online bulletin boards, reading manga (comic books), and playing video games. Despite parental encouragement, he has repeatedly resisted going to vocational school or taking a job.

Psychiatric history: Since last year, his parents have taken him to several local hospitals where he was variously diagnosed with ‘depression’ and ‘latent schizophrenia’. On mental status exam, he had a flat affect, denied depressed mood or anxiety, and answered most questions by saying ‘I don’t know’. Neuropsychological testing revealed no cognitive abnormalities. Brain imaging and standard screening laboratory studies were unremarkable. He failed trials of psychotropic medications including antidepressants and antipsychotics.

Mental status exam on first interview: Expecting a possible solution of his social withdrawal, his parents brought him to the psychiatric faculty where he is examined by a psychiatrist. Mr. B, just standing between his parents, kept silent politely. His attitude does not imply any psychotic experience, such as delusions or hallucination. He just seems to be a quiet person. Even when asked questions, he just replied ‘I don’t know’.

3 Definition of hikikomori and psychiatric comorbidities

In the 2010 guideline of hikikomori for evaluation and supports by the Ministry of Health, Labour and Welfare (MHLW), the definition of hikikomori was given as, ‘as a result of various factors, a withdrawal from social participation (schooling including compulsory education, employment including part-time jobs, and other interactions outside of the home), which in principle has continued under the condition of being housebound for a period of more than 6 months (this may include leaving the home whilst still avoiding interactions with others). In general, hikikomori is considered to be a nonpsychotic phenomenon that is distinguishable from the withdrawal state based on the positive or negative symptoms of schizophrenia, but it should be noted that it is not unlikely that in fact it may include schizophrenia before definitive diagnosis’ (Saito, 2010).

Based on these guidelines, hikikomori is a concept that does not generally include schizophrenia, but according to a survey by Kondo et al. conducted before the establishment of guidelines, the DSM-IV-based psychiatric diagnosis of sufferers under the condition of hikikomori attending mental health welfare centres showed association with psychiatric disorders including schizophrenia, mood disorders, anxiety disorders, personality disorders, and pervasive developmental disorder (Kondo et al., 2013). Thus we believe that a variety of psychiatric disorders are comorbid with hikikomori (Kato, Kanba, & Teo, 2019; Kondo et al., 2013). Some cases show hikikomori-like behaviours as a symptom of the aforementioned psychiatric disorders. For example, anhedonia, social anxiety, and

delusions can induce pathological social withdrawal. On the other hand, hikikomori behaviours may induce psychiatric disorders. In each hikikomori case, we should consider both possibilities (Kato, Kanba, et al., 2019).

Especially, amongst young hikikomori cases, we should consider the comorbidity of autism spectrum disorder (ASD) (Kato, Kanba, et al., 2019; Kondo et al., 2013; Tateno, Park, Kato, Umene-Nakano, & Saito, 2012). Due to ASD-like tendencies including difficulty in communication with others and the inability to perceive the feelings of others which often results in social maladjustment, the susceptibility to bullying and a loss of 'place to be' (such as educational facilities and youth social clubs), there are many cases which result in hikikomori. Amongst hikikomori sufferers in Japan, especially those with the experience of truancy or 'school refusal (futoko)' at the initial stage of their hikikomori, often also have the traumatic experience of bullying (ijime). The consequences of bullying itself may not result in post-traumatic stress disorder (PTSD). However, in addition to direct physical violence from peers, indirect violence such as being ignored or ostracized is (typical forms of ijime), in many teen cases, a trigger for hikikomori.

Based on the aforementioned knowledge, we have proposed the current conceptualization model of hikikomori as shown in Fig. 1. Even in the

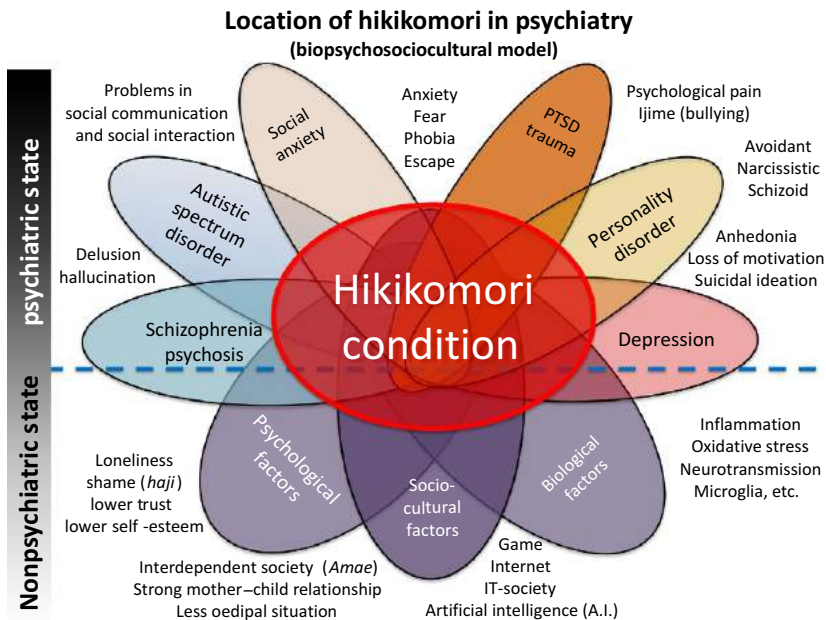


FIG. 1 Biopsychosociocultural understandings of hikikomori. Modified from Kato, T. A., Kanba, S., & Teo, A. R. (2019). Hikikomori: Multidimensional understanding, assessment, and future international perspectives. *Psychiatry and Clinical Neurosciences*, 73(8), 427–440. <https://doi.org/10.1111/pcn.12895>.

absence of a clear diagnosis of psychiatric disorders, many persons with hikikomori find themselves in a 'grey zone', and the fact that no formal diagnosis of psychiatric disorders has been made does not equate to the absence of mental suffering (distress), and therefore we strongly believe that the suffering should be taken seriously.

To combat the limitations of our previous criteria of hikikomori (Teo et al., 2015), we have just revised the diagnostic criteria of hikikomori (Kato, Kanba, et al., 2019; Kato, Kanba, & Teo, 2020). The main point of our revised criteria is as follows:

Hikikomori is a form of pathological social withdrawal or social isolation whose essential feature is physical isolation in one's home. The person must meet the following criteria: (1) marked social isolation in one's home, (2) duration of continuous social isolation for at least 6 months, and (3) significant functional impairment or distress associated with the social isolation. Individuals with a duration of continuous social withdrawal of at least 3 (but not 6) months should be noted as prehikikomori. We have decided to exclude several specifiers (lack of social participation, lack of in-person social interaction, experience of loneliness, and a cooccurring psychiatric condition) from the necessary criteria. However, we suggest that these specifiers are very useful for additional characterization of hikikomori especially in the process of assessing the severity, and considering the treatment strategy. It is important to note that even though an individual has a certain psychiatric disorder, this revised definition can diagnose his/her as hikikomori as a comorbid diagnosis.

4 Developmental model of hikikomori

To understand hikikomori, we should consider the sociocultural factors in the development of the problem. We propose that Japanese concepts deeply rooted in the culture such as 'amae' and 'haji' may strongly influence the phenomena of hikikomori in Japan. Fig. 2 presents our current hypothesis/understanding of the developmental model of hikikomori.

4.1 Amae (strong mother relationship)

In Japanese society, family dynamics especially during the child and adolescent phase of development have long pointed to a particularly strong maternal relationship, which has been discussed as 'amae' and 'kahogo'. It has often been pointed out that Japanese society is more accepting of dependence compared with Western societies. Amae is a form of culturally accepted overdependent behaviours in Japan. A Japanese psychoanalysis

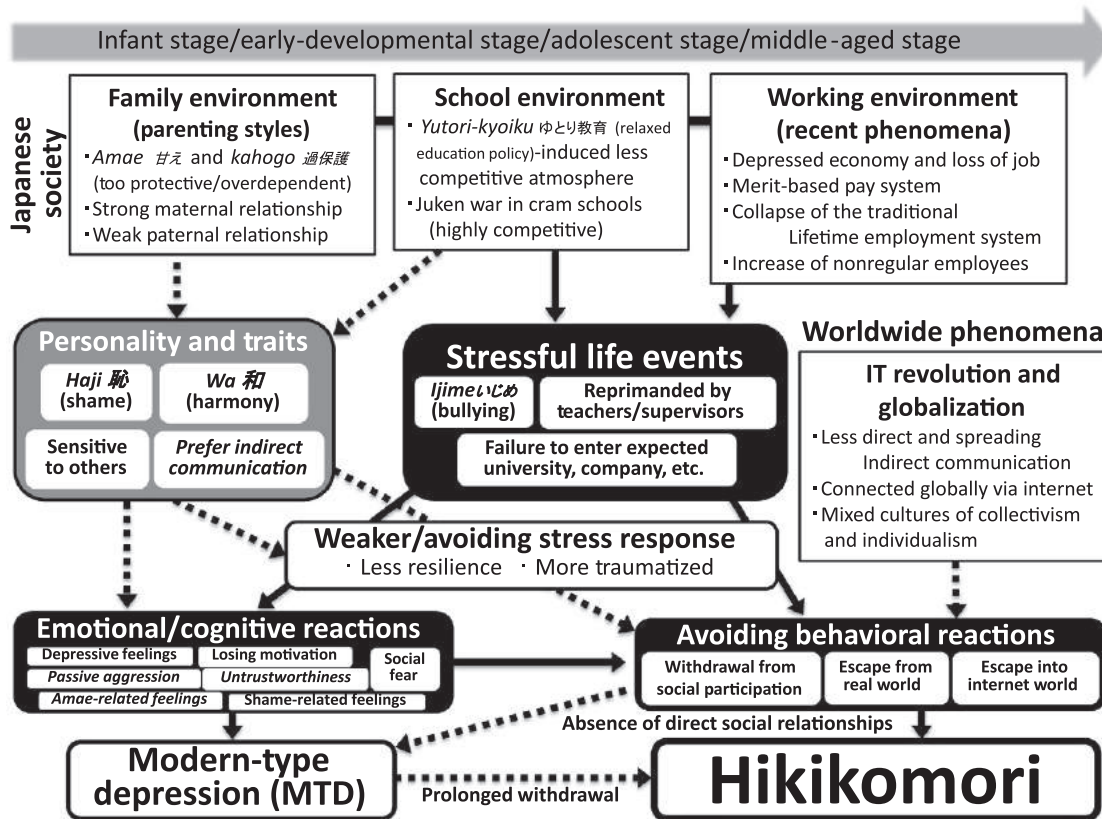


FIG. 2 Developmental model in hikikomori. Modified from Kato, T. A., Kanba, S., & Teo, A. R. (2019). Hikikomori: Multidimensional understanding, assessment, and future international perspectives. *Psychiatry and Clinical Neurosciences*, 73(8), 427–440. <https://doi.org/10.1111/pcn.12895>.

Takeo Doi pointed out that Japanese society has widely accepted overdependent behaviours as 'amae' (Doi, 1973). We propose that 'amae' may be a major influence on the occurrence of hikikomori in Japanese society (Kato et al., 2018; Kato, Kanba, et al, 2016). Dependent behaviours related to 'amae' tend to be conducted with the belief that the parent will forgive all. Doi believed that Western societies tend to consider such dependence in children to be something that should be overcome or corrected, whilst in Japan, 'amae' remains an acceptable mode of behaviour even in adult life (Doi, 1973). Doi describes 'sullenness' or a sullen withdrawal as one transformation of 'amae'. Thus the behaviours of hikikomori may be seen to be a close relation to the classic behaviour of 'amae'. Persons with hikikomori, especially those living with families, may be affected by 'amae' to the extent that parents accept their child staying at home for prolonged periods of time (Kato et al., 2012). 'Amae' is especially related to attachment between mother and child, and hikikomori behaviours could be interpreted as a strong never-ending mother-child relationship with nonexistent separation.

Rorschach Comprehensive System (RCS) has been shown to measure some deeper psychological characteristics and psychological defence mechanisms in humans (Exner, 2003). Interestingly, our recent case-control study amongst clinical patients with and without hikikomori condition using the RCS has shown some society-based unconscious aspects related to 'amae' (Katsuki et al., 2019). Higher form-colour (FC) reactions and more frequent texture-related reactions were observed amongst the hikikomori group, indicating that the hikikomori phenomenon may reflect coping behaviours to satisfy one's desire for dependence as a form of 'amae' at least amongst some persons with the hikikomori condition (Katsuki et al., 2019). In addition, this study has shown that avoidant, depressive, narcissistic, paranoid, passive-aggressive, schizoid, and schizotypal personality in the SCID-II personality questionnaire were significantly higher in psychiatric patients with the hikikomori condition (Katsuki et al., 2019).

4.2 Weaker paternal roles (absent father)

Even in the presence of the aforementioned family and psychological constellations, there might be completely different outcomes that do not lead to hikikomori in other societies, due to different social pressures and accepted norms. In psychodynamic developmental theory a strong mother-child relationship would be challenged by a father figure, which is regarded as an 'oedipal situation' in psychoanalytic theory.

In Japanese society the theme of the 'absent father' has been emphasized. In reality, in Japanese society, there is a strong view that fathers should prioritize work which has led to the 'absent father' (less oedipal situation). Such family situations/dynamics make it difficult for children

to detach from their mothers and provide children with an environment where it is easy to 'stay at home'. In most western societies, babies may be given their own bedroom, but in Japan even older children commonly sleep in the same room as their parents. Such norms may make it harder for children to become independent (Kitayama, 2010).

4.3 Haji (shame)

The Japanese have tended to form social groups and structures that have emphasized indirect (nonverbal) communication, and behind, this has been the influence of particular values emphasized within Japanese society such as 'haji (shame)' (Kitayama, 1998, 2010). Japanese people tend to be especially sensitive to shame, acutely conscious of others, and highly valuing of harmony with preference for indirect exchanges. Generally, for Japanese, in situations where one is shamed, the idea of 'making oneself disappear' has long been considered a kind of virtue. We suppose that this kind of mindset may be linked to not only the high prevalence of hikikomori but also suicide in Japan (Kato, Shinfuku, Sartorius, & Kanba, 2017).

4.4 Schooling and working environmental shift in Japan

Even in education, with the introduction of 'yutori kyoiku' (relaxed education policy) for a time in Japan since around 1980 (Ashby, 2001), competitiveness was no longer emphasized at least superficially. However, in reality, many students are forced to attend 'cram schools' and find themselves caught in what the media came to term 'exam hell' mainly because of their parents' strong pressures to enrol them in prestigious schools. Until recently the myth that attending a good university enabled employment at a top-notch company within a secure lifetime employment system and a prosperous life was widely believed. Many parents believed this, and many students went through an education based on this myth. Under this, there was room for few choices, only a few correct answers, and little room for diverse ways of being. However, since the late 1990s, these myths began to crumble. A prolonged recession has led to increased unemployment since around the late 1990s, a collapse of the long-established lifetime employment system, and a shift to a merit-based pay system and nonregular employment.

Such schooling and work environments in Japan tend to induce a variety of stressful life events. Young people tend to have difficulty in entering the university or company of their choice, or even if they are accepted to such institutions, come into conflict with their school mates or colleagues, which may induce bullying. When such situations arise the possibility of an avoidance response occurs. This may exacerbate the problem and result in a tendency for poor resilience and more traumatization.

Emotional and cognitive reactions such as depression, decreased motivation, social phobia, distrust, anger (indirect), 'amae' (overdependence), and shame are likely to occur. Such emotional cognitive reactions are thought to cause hikikomori-related behaviours such as avoidance of social participation, escapism from the realities of life, and withdrawal to the world of the Internet.

When such a situation continues for a period greater than 6 months, it may be termed as 'hikikomori'. In addition, we propose that hikikomori-like conditions are likely to result from prolonged modern-type depression (MTD, see in the succeeding text) which have many commonalities especially avoidant behaviours.

4.5 Modern-type depression (MTD)

The Japanese psychopathologist, [Tarumi \(2005\)](#) and [Tarumi and Kanba \(2005\)](#) proposed a novel form of depression in Japan around late 1990s, which was later termed (especially in the media) 'modern-type depression (MTD)' 5. People with MTD easily complain about their depressive feelings without hesitation and easily escape from social situations, and once escaped their symptoms are quickly relieved. Prolonged social difficulties based on such symptoms can induce social withdrawal condition; thus we have been proposing MTD as a 'gate-way disorder' to more serious adjustment problems and especially hikikomori ([Kato & Kanba, 2017, 2018](#)). The premorbid characteristics of MTD are self-centeredness, socially evasive and narcissistic tendencies, easy traumatization, and low resilience, which are very similar in some features to hikikomori ([Kato, Katsuki, et al., 2019](#); [Kato, Kanba, et al., 2016](#)). In addition, we have revealed that lower self-esteem is another important factor of MTD ([Kato, Katsuki, et al., 2019](#)). We hypothesize that Japan's educational system, which emphasizes shame in its pursuit of conformity and can undermine personal confidence, may seed reclusive tendencies ([Subramanian, 2019](#)). Compared with Japan's educational situation, a child in the United States is encouraged to do things freely with his/her own decision-making, and their self-esteems tend to become high. Such environmental differences may reflect the higher number of hikikomori in Japan.

4.6 Technological evolution

The manifestations of mental illness have shifted through time, from late 19th century hysteria, to 1950s eating disorders, to 1980s borderline personality disorder, now to hikikomori and MTD ([Kato, Kanba, et al., 2019](#)). These phenotypes have been greatly influenced by lifestyles and social environment characteristic of each era.

The spread of the Internet and the international diffusion of indirect communication through the information technology (IT) revolution may be the crucial factors that caused the emergence of hikikomori sufferers outside of Japan. With the development of IT technologies, the way children play has shifted from 'direct (face-to-face)' to 'indirect (non-face-to-face)' methods, and this may strongly affect the behavioural characteristics of modern youth. In 1983 Nintendo's 'Famicom' was released, and since then the way children play has shifted significantly to indoor play. Children who played baseball and soccer outdoors, other suddenly began to meet at the home of a child with a Famicom station and to play via a TV monitor. Today it is possible through the Internet to play fighting games online even when physically we are physically distant from each other. Thus, worldwide, the youth of today (although not necessarily limited to youth) seem to have less opportunities for direct face-to-face communication. With social media and texting replacing other activities, such youth spend less time with their friends in person—perhaps why they may be experiencing unprecedented levels of anxiety, depression, and loneliness (Twenge, 2017). On the other hand the problem of 'bullying' via indirect communication has become a major social issue not only in Japan but also in other countries (Fujikawa et al., 2018; Kanetsuna & Smith, 2002). The Japanese saying 'Rain strengthens the foundation' means that adversity or conflict can strengthen what came before and it was not rare that a direct fight between youths could lead to a stronger friendship.

Developing direct communication skills and building up trustful human relationships are very difficult only through 'indirect' communication/playing/gaming experiences. Our modern societies have unfortunately produced many young people who are not able to build appropriate communication skills and relationships, and these young people might be regarded as solitary.

5 Therapeutic approaches for hikikomori

Providing support to hikikomori sufferers who have withdrawn from society over a long period of time is challenging. Kondo et al. reported that the average period from the start of withdrawal to the initiation of first-time support in Japan is 4.4 years (Kondo et al., 2010). Various forms of support such as telephone consultations, the creation of 'meeting spaces' for people with hikikomori, and job placement support have been undertaken for hikikomori sufferers mainly through mental health welfare centres and more than 50 MHLW-funded community support centres for hikikomori located throughout all the prefectures of Japan (Kato et al., 2018). In addition a variety of private institutions provide support for sufferers with hikikomori and their parents. However, there is yet to be a unified evidence-based method for these public/private interventions.

Multidimensional therapeutic approaches based on the physical/social situation of hikikomori

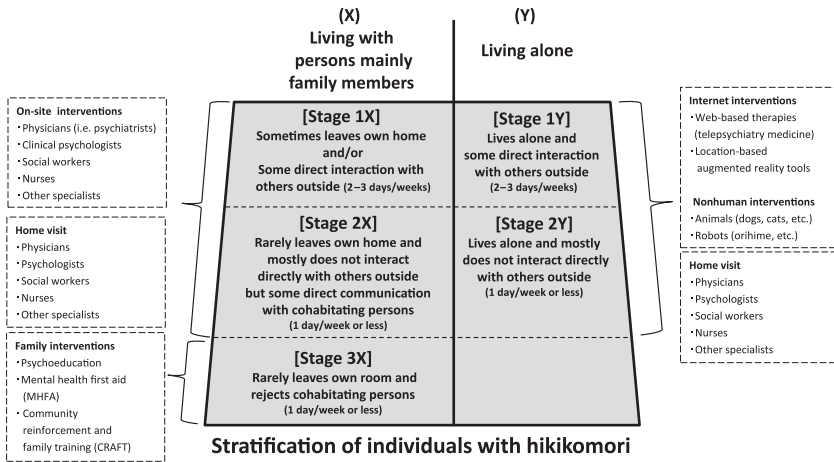


FIG. 3 Multidimensional therapeutic approaches based on the physical/social situations of hikikomori. Individuals with hikikomori can be classified into the following five stages based on living with others mainly family members (X category) or living alone (Y category): (3X) rarely leaves own room and rejects cohabitating family; (2X) rarely leaves own home but some communication with cohabitating family; (1X) sometimes leaves own home and/or some interaction with others; (2Y) lives alone and mostly does not interact with others; and (1Y) lives alone but some interaction with others. Modified from Kato, T. A., Kanba, S., & Teo, A. R. (2019). Hikikomori: Multidimensional understanding, assessment, and future international perspectives. *Psychiatry and Clinical Neurosciences*, 73(8), 427–440. <https://doi.org/10.1111/pcn.12895>.

A four-step intervention is recommended by the 2010 MHLW guideline for hikikomori: (Step 1; S1) family support, first contact with the individual and his/her evaluation, (S2) starting individual support, (S3) training with intermediate-transient group situation (such as group therapy), and (S4) social participation trial (Saito, 2010). We are now proposing to provide a variety of supports for hikikomori based on the situation of each individual (Fig. 3).

5.1 Family support programs

Initially, it is unlikely that the people with hikikomori themselves would seek treatment, and so family interventions are crucial for those living with family members. Due to a lack of knowledge (about mental illness in general and hikikomori in particular) and prejudices against such mental conditions, in many cases family members cannot respond directly to individuals with these ailments, are unable to intervene at all, and tend to turn a blind eye for many years without seeking help.

Not a few parents tend to refuse to receive any professional assistance because of social stigma. Due to a lack of knowledge regarding mental illness and treatment options, parents tend to worry whether their son/daughter would be locked in the strange and fearful psychiatric hospital for life. Moreover, some individuals with hikikomori have violent tendencies towards their parents (*kateinai bouryoku*), and in such situations, parents tend to fear their reprisals after consulting professional help. Thus it is important for family members to acquire the appropriate knowledge and techniques for dealing with individuals with hikikomori in early intervention.

We are now developing an educational program for parents of individuals with hikikomori partially based on Mental Health First Aid (MHFA). MHFA was originally developed as a 12-h educational course that teaches participants (mainly laypeople) how to identify, understand, and respond to signs of mental illnesses and crisis including suicidal and violent behaviours (Kitchener & Jorm, 2002, 2006). The five steps of the MHFA (third version) are as follows: Step (1) Approach the person, assess and assist with any crisis; Step (2) Listen nonjudgmentally; Step (3) Give support and information; Step (4) Encourage the person to get appropriate professional help; Step (5) Encourage other support (Kitchener, Jorm, & Kelly, 2013). We have been promoting usage of the MHFA in Japan (Hashimoto et al., 2016; Kato et al., 2010; Kubo et al., 2018; Nakagami et al., 2018; Suzuki et al., 2014) and are now in the process of developing an evidence-based educational support model that enables families (especially parents) of persons with hikikomori to obtain specific skills and knowledge in dealing with hikikomori based on the MHFA. In this program, we are especially focusing on how to assess sufferers and bring them to places of professional support smoothly and safely using the MHFA-based materials including hikikomori-case role-play scenarios (Kubo et al., 2020).

5.2 Home visiting

Home visits by physicians (family doctors), nurses, psychologists, and social workers also play an important role as an initial stage of hikikomori support (Lee, Lee, Choi, & Choi, 2013; Watanabe, 2005). In South Korea a social worker home-visit program has been developed for people withdrawn into their homes, and a pilot intervention study has demonstrated that this has allowed for appropriate psychological evaluations to be conducted and for such individuals to more efficiently access the next treatment step including direct psychotherapy (Lee et al., 2013). We believe that the development of an effective home-visiting approach may be important in the support of hikikomori sufferers.

5.3 Multidimensional assessment and therapeutic strategies

Multidimensional assessment is essential before providing therapeutic materials to sufferers of hikikomori themselves. In our hikikomori research clinic, we have been evaluating a variety of aspects based on the biopsychosocial model.

Age of onset, triggering life events, and severity of hikikomori conditions (withdrawal duration, frequency of going out from their own room/house, and contact with family members and friends, etc.) are evaluated. As shown earlier, we have just developed a novel hikikomori diagnostic criteria. To shorten the evaluation time, we have recently developed a self-rated questionnaire called Hikikomori Questionnaire (HQ)-25 (Teo et al., 2018). In addition, psychiatric diagnostic interviews based on DSM-5/ICD-11 should be conducted due to high comorbidity of psychiatric disorders, and those under the threshold levels should also be evaluated. Psychometrics to grasp personality, attachment, and Internet addiction tendencies are recommended (Mandai, Kaso, Takahashi, & Nakayama, 2018; Nitta et al., 2008; Shirahama et al., 2018; Tateno, Skokauskas, Kato, Teo, & Guerrero, 2016; Tateno, Teo, et al., 2016; Tateno et al., 2018). The Rorschach test is also recommended to understand deeper psychodynamic defence mechanisms of personality (Katsuki et al., 2019). Economic games are now highlighted to understand behavioural characteristics, which can quantitatively evaluate unconscious decision-making and consequently estimate interpersonal relationships (Watabe et al., 2015). We propose that the trust game, one of the economic games, can estimate the levels of trustworthiness to others, which tend to be low amongst individuals with hikikomori (Kato, Kanba, et al., 2019). Biological assessments including blood tests and brain functional analysis such as electroencephalography (EEG) may help to understand the biological bases of hikikomori (Hayakawa et al., 2018).

According to the findings of such assessments, various interventions are provided (Fig. 3). If hikikomori sufferers have psychiatric disorders, the guidelines for each disorder should be followed, using pharmacotherapy, psychotherapy, and/or psychosocial interventions. To our knowledge the majority of hikikomori people require not only pharmacotherapy but also psychosocial supports.

5.4 Psychodynamic approach based on the developmental model of hikikomori

Generally, psychotherapy is suggested to be effective for hikikomori (Saito, 2010). The concept of hikikomori was originally developed by psychoanalytically oriented psychiatrists in Japan. Even now, many hikikomori experts in Japan are psychoanalytically oriented psychiatrists, psychologists, and psychopathologists. Psychoanalytic (psychodynamic)

approaches are not fully empirically validated, but based on the aforementioned foundations, we introduce psychoanalytic understandings and approaches, which also may help to find the cues to prevent hikikomori.

We propose that psychodynamic individual/group approaches are especially effective for individuals with hikikomori in resolving their difficulties with interpersonal relationships between family members and future school/workplace colleagues in the outside world (Kato, Kanba, et al., 2019). We have described hikikomori as a pathological phenomenon and behaviour, but we strongly believe that not only negative (pathological) aspects but also positive (protective) aspects should be focused on hikikomori phenomenon. From psychoanalytic research into war neurosis (presently known as PTSD), the British Psychoanalyst W. Ronald D. Fairbairn proposed only two personality components in all human beings including healthy individuals—the exciting object and the rejecting object (Fairbairn, 1952). The hikikomori and hikikomori-like behaviours may be extreme expressions of the rejecting object. According to Fairbairn's theory the tendency to social withdrawal is intrinsic to what it is to be a human being. With the popularization of the Internet, mobile phones, and other mobile devices, we are connected to someone wherever we are. In such situations, hidden (private) worlds are suddenly in clear (public) view creating a modern society where it is near impossible to 'be (comfortably) alone'. Perhaps exactly because we exist in a society where we are constantly connected and without delineation between private and public that 'withdrawal' takes on an extreme form. The action of 'hikikomori' ('hikikomoru' as a verb in Japanese) may be a desperate acting out of the desire of a modern person who has lost the space to withdraw (Kato & Kanba, 2016).

We believe that the key to rescuing sufferers with the hikikomori condition is the 'reacquisition of the mental space where a person can be comfortably/safely alone' and this reacquisition may be achieved by advocating the usefulness of psychoanalysis. In psychoanalytic psychotherapy, especially psychoanalysis by non-face-to-face 'couch' method, extremes of ambivalent feelings of 'wanting to engage' and 'wanting to leave out' are shared by both patient and therapist often in silent moments during a therapy session. When two people create a space-time when they are together but in silence, this gives birth to what the British Psychoanalyst/Paediatrician Donald W. Winnicott advocated as the 'capacity to be alone' (Winnicott, 1958), and we believe that this approach relieves the person from defensive physical withdrawal. In addition to individual psychotherapy, psychoanalytic group psychotherapy allows sufferers with hikikomori condition to experience the aforementioned ambivalence inside a group whilst observing 'the other'. This appears effective based on a series of case reports from Japanese group psychotherapists (Aida, 2006; Kubo, Kato, & Kanba, 2017; Watanabe, 2011). On the other hand, cognitive

behavioural therapy may also be effective for hikikomori with comorbid psychiatric conditions such as social anxiety and depression, but strong evidence for this is also lacking.

5.5 Possible ways to prevent hikikomori

What can be done to prevent hikikomori? In light of the aforementioned hypothesis based on psychoanalytic theory, mother–child separation needs to be sufficiently achieved through the development of ‘the capacity to be alone’ (Winnicott, 1958). derived from the formation of secure attachment with a ‘good–enough’ mother and supported by the father. From a sociological perspective, it is crucial to building a society that accepts diverse ways of life. The Japanese educational system tends to create environments where the lesson is that there is only one answer and debate is very limited.

Such one-answer educational methods tend to narrow diversity amongst Japanese youth suggesting that there is only one pathway in life and has created limited ‘winner’ groups and many ‘loser’ groups. And some of the losers will withdraw as hikikomori. Such an education simply creates a hierarchy of students. We must move towards an educational system that respects the individual strengths and diversity of people.

On the other hand, with the widespread use of the Internet, indirect communications, exchanges, and relationships have increased, whilst the opportunity for direct exchanges has diminished. The experience of building relationships of trust through direct interaction is not only important but also closely associated with the experience of making lifelong friends. Such friendship may be an important protective factor against hikikomori-like behaviours.

5.6 Indirect approaches especially robots and internet-based interventions

As suggested earlier, we believe that human-direct approach with face-to-face contact is the most powerful approach for hikikomori. However, hikikomori sufferers tend to be avoidant of direct contact with other people. Interestingly an animal therapy program has been introduced as a stepping stone in alleviating this reluctance to meet others in Hong Kong (Wong, Liu, et al., 2017; Wong, Yu, et al., 2017). Coming into direct contact with animals such as dogs and cats can be a first step towards leaving the confines of one’s home (Wong, Liu, et al., 2017; Wong, Yu, et al., 2017). Furthermore, pet-like robots such as Sony’s Aibo, a dog-like robot, and Orylab’s OriHime, a shadow robot using Internet technology, have been developed based on advanced technologies, which might enable humans

to communicate with emotional satisfaction (Kerepesi, Kubinyi, Jonsson, Magnusson, & Miklosi, 2006; Kato, 2020). These robots have been utilized in a variety of situations to combat social difficulties with psychiatric disorders especially autism and dementia (Kumazaki, Warren, et al., 2018; Kumazaki, Yoshikawa, et al., 2018; Tamura et al., 2004). We believe that these robots can reduce loneliness especially for single-person households with hikikomori (Gent, 2019; Prosser, 2018). In our hikikomori research clinic, we have just started to utilize OriHime as a remote support method for hikikomori. In this era, we could not live without the Internet. Thus we should also consider how effectively the Internet may function as protective and therapeutic tool for hikikomori.

One example of Internet-based therapies is the online game 'Pokémon Go' which was released in the summer of 2016 and utilizes location information, and augmented reality (AR) became a global hit. Augmented reality (AR) is a technique of superimposing sound and graphics on images reflecting and expanding the real world, and this technique may be useful in the support of hikikomori sufferers. Some people with hikikomori who have not gone out for years are leaving their homes in search of Pokémons (Tateno, Skokauskas, et al., 2016). Surprisingly, in our clinical practice, a male patient who previously was barely able to go out and who lives alone has begun to venture out daily with the emergence of Pokémon Go (Kato, Shinfuku, et al., 2017; Kato, Teo, et al., 2017). In a few months he grew tired of the game, and thus its effect was transient, but we believe a hikikomori support approach based on such technology has the possibility of being particularly effective during the early stages of the condition and much can be expected from the development such tools through industry-academia collaboration.

In summary a combination of methods of direct and indirect ways using augmented reality technique, web camera, and similar technologies (as telepsychiatry style) should be developed to prevent and treat hikikomori in the future.

6 Conclusion

In this review, we have introduced up-to-date knowledge about hikikomori in Japan and presented our recent hypothesis of a 'developmental model of hikikomori'. To prevent increasing the number of hikikomori in the future, further longitudinal studies are needed to evaluate our hypothesis and to clarify the multifaced risk factors for hikikomori (Pozza, Coluccia, Kato, Gaetani, & Ferretti, 2019), which will contribute to developing evidence-based preventive methods and therapeutic approaches for hikikomori.

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Conflicts of interest statement

The author has declared that no conflicts of interest exist.

References

- Aida, N. (2006). *Practical psychoanalytic individual and group psychotherapy*. Tokyo: Kongoshuppan.
- Ashby, J. (2001). *Young Japanese struggle to find their way*. Japan Times. <https://www.japan-times.co.jp/culture/2001/2012/2016/books/book-reviews/young-japanese-struggle-to-find-their-way-2002/#.Xdi2002Ui2003APKk>.
- Chauliac, N., Couillet, A., Faivre, S., Brochard, N., & Terra, J. L. (2017). Characteristics of socially withdrawn youth in France: A retrospective study. *The International Journal of Social Psychiatry*, 63(4), 339–344. <https://doi.org/10.1177/0020764017704474>.
- De Michele, F., Caredda, M., Delle Chiaie, R., Salviati, M., & Biondi, M. (2013). Hikikomori (ひきこもり): A culture-bound syndrome in the web 2.0 era. *Rivista di Psichiatria*, 48(4), 354–358. <https://doi.org/10.1708/1319.14633>.
- Doi, T. (1973). *The anatomy of dependence*. Tokyo: Kodansha International.
- Exner, J. E., Jr. (2003). *The Rorschach, a comprehensive system volume 1 basic foundations and principles of interpretation* (4th ed.). New Jersey: John Willer & Sons, Inc.
- Fairbairn, W. D. (1952). *Psychoanalytic studies of the personality*. London: Tavistock Publications Limited.
- Fujikawa, S., Ando, S., Nishida, A., Usami, S., Koike, S., Yamasaki, S., ... Kasai, K. (2018). Disciplinary slapping is associated with bullying involvement regardless of warm parenting in early adolescence. *Journal of Adolescence*, 68, 207–216. <https://doi.org/10.1016/j.adolescence.2018.07.018>.
- Furuhashi, T., Figueiredo, C., Pionnie-Dax, N., Fansten, M., Vellut, N., & Castel, P. H. (2012). Pathology seen in French “Hikikomori”. *Seishin Shinkeigaku Zasshi*, 114(10), 1173–1179.
- Garcia-Campayo, J., Alda, M., Sobradie, N., & Sanz Abos, B. (2007). A case report of hikikomori in Spain. *Medicina Clínica (Barcelona)*, 129(8), 318–319.
- Gent, E. (2019). *The plight of Japan's modern hermits*. BBC. January 29, 2019. Retrieved from <http://www.bbc.com/future/story/20190129-the-plight-of-japans-modern-hermits>.
- Gondim, F. A. A., Aragao, A. P., Holanda Filha, J. G., & Messias, E. L. M. (2017). Hikikomori in Brazil: 29 years of voluntary social withdrawal. *Asian Journal of Psychiatry*, 30, 163–164. <https://doi.org/10.1016/j.ajp.2017.10.009>.
- Harding, C. (2018). Hikikomori. *Lancet Psychiatry*, 5(1), 28–29. [https://doi.org/10.1016/S2215-0366\(17\)30491-1](https://doi.org/10.1016/S2215-0366(17)30491-1).

- Hashimoto, N., Suzuki, Y., Kato, T. A., Fujisawa, D., Sato, R., Aoyama-Uehara, K., ... Otsuka, K. (2016). Effectiveness of suicide prevention gatekeeper-training for university administrative staff in Japan. *Psychiatry and Clinical Neurosciences*, *70*(1), 62–70. <https://doi.org/10.1111/pcn.12358>.
- Hayakawa, K., Kato, T. A., Watabe, M., Teo, A. R., Horikawa, H., Shimokawa, N., Sato-Kasai, M., Kubo, H., Ohgidani, M., Sagata, N., Toda, H., Tateno, M., Shinfuku, N., Kishimoto, J., & Kanba, S. (2018). Blood biomarkers of Hikikomori, a severe social withdrawal syndrome. *Scientific Reports*, *8*, 2884. <https://doi.org/10.1038/s41598-018-21260-w>.
- Japan-Cabinet-Office. (2016). *Wakamono no Seikatsu ni Kansuru Chousa-Houkokusho [investigation on life of youth]* Retrieved from <https://www8.cao.go.jp/youth/kenkyu/hikikomori/h27/pdf/teigi.pdf>.
- Japan-Cabinet-Office. (2019). *Seikatsu Joukyou ni Kansuru Chousa [investigation on living conditions]*. <https://www8.cao.go.jp/youth/kenkyu/life/h30/pdf-index.html>.
- Kato, T. A. (2020). Multidimensional understanding of hikikomori and therapeutic approach: Can robots rescue hikikomori sufferers? *Japanese Journal of General Hospital Psychiatry*. (in press)
- Kanetsuna, T., & Smith, P. K. (2002). Pupil insights into bullying, and coping with bullying: A bi-National Study in Japan and England. *Journal of School Violence*, *1*(3), 5–29. https://doi.org/10.1300/J202v01n03_02.
- Kato, T. A., & Kanba, S. (2016). Boundless syndromes in modern society: An interconnected world producing novel psychopathology in the 21st century. *Psychiatry and Clinical Neurosciences*, *70*(1), 1–2. <https://doi.org/10.1111/pcn.12368>.
- Kato, T. A., & Kanba, S. (2017). Modern-type depression as an “adjustment” disorder in Japan: The intersection of collectivistic society encountering an individualistic performance-based system. *The American Journal of Psychiatry*, *174*(11), 1051–1053. <https://doi.org/10.1176/appi.ajp.2017.17010059>.
- Kato, T. A., & Kanba, S. (2018). Is a socio-cultural analysis of depressive disorders a matter of concern? Response to Kaiya. *The American Journal of Psychiatry*, *175*(5), 483–484. <https://doi.org/10.1176/appi.ajp.2018.17121404r>.
- Kato, T. A., Kanba, S., & Teo, A. R. (2016). A 39-year-old “Adulolescent”: Understanding social withdrawal in Japan. *The American Journal of Psychiatry*, *173*(2), 112–114. <https://doi.org/10.1176/appi.ajp.2015.15081034>.
- Kato, T. A., Kanba, S., & Teo, A. R. (2018). Hikikomori: Experience in Japan and international relevance. *World Psychiatry*, *17*(1), 105–106. <https://doi.org/10.1002/wps.20497>.
- Kato, T. A., Kanba, S., & Teo, A. R. (2019). Hikikomori: Multidimensional understanding, assessment, and future international perspectives. *Psychiatry and Clinical Neurosciences*, *73*(8), 427–440. <https://doi.org/10.1111/pcn.12895>.
- Kato, T. A., Kanba, S., & Teo, A. R. (2020). Defining pathological social withdrawal: A proposal for diagnostic criteria of hikikomori. *World Psychiatry*, *19*(1), 116–117. <https://doi.org/10.1002/wps.20705>.
- Kato, T. A., Katsuki, R., Kubo, H., Shimokawa, N., Sato-Kasai, M., Hayakawa, K., ... Kanba, S. (2019). Development and validation of the 22-item Tarumi’s modern-type depression trait scale: Avoidance of social roles, complaint, and low self-esteem (TACS-22). *Psychiatry and Clinical Neurosciences*, *73*(8), 448–457. <https://doi.org/10.1111/pcn.12842>.
- Kato, T. A., Shinfuku, N., Sartorius, N., & Kanba, S. (2011). Are Japan’s hikikomori and depression in young people spreading abroad? *Lancet*, *378*(9796), 1070. [https://doi.org/10.1016/S0140-6736\(11\)61475-X](https://doi.org/10.1016/S0140-6736(11)61475-X).
- Kato, T. A., Shinfuku, N., Sartorius, N., & Kanba, S. (2017). Loneliness and single-person households: Issues of Kodokushi and Hikikomori in Japan. In N. Okkels, C. B. Kristiansen, & P. Munk-Jørgensen (Eds.), *Mental health and illness in the city* (pp. 205–219). Singapore: Springer Singapore.

- Kato, T. A., Suzuki, Y., Sato, R., Fujisawa, D., Uehara, K., Hashimoto, N., ... Otsuka, K. (2010). Development of 2-hour suicide intervention program among medical residents: First pilot trial. *Psychiatry and Clinical Neurosciences*, *64*(5), 531–540. <https://doi.org/10.1111/j.1440-1819.2010.02114.x>.
- Kato, T. A., Tateno, M., Shinfuku, N., Fujisawa, D., Teo, A. R., Sartorius, N., ... Kanba, S. (2012). Does the 'hikikomori' syndrome of social withdrawal exist outside Japan? A preliminary international investigation. *Social Psychiatry and Psychiatric Epidemiology*, *47*(7), 1061–1075. <https://doi.org/10.1007/s00127-011-0411-7>.
- Kato, T. A., Teo, A. R., Tateno, M., Watabe, M., Kubo, H., & Kanba, S. (2017). Can Pokemon GO rescue shut-ins (hikikomori) from their isolated world? *Psychiatry and Clinical Neurosciences*, *71*(1), 75–76. <https://doi.org/10.1111/pcn.12481>.
- Katsuki, R., Inoue, A., Indias, S., Kurahara, K., Kuwano, N., Funatsu, F., ... Kato, T. A. (2019). Clarifying deeper psychological characteristics of Hikikomori using the Rorschach comprehensive system: A pilot case-control study. *Frontiers in Psychiatry*, *10*, 412. <https://doi.org/10.3389/fpsy.2019.00412>.
- Kerepesi, A., Kubinyi, E., Jonsson, G. K., Magnusson, M. S., & Miklosi, A. (2006). Behavioural comparison of human-animal (dog) and human-robot (AIBO) interactions. *Behavioural Processes*, *73*(1), 92–99. <https://doi.org/10.1016/j.beproc.2006.04.001>.
- Kitayama, O. (1998). Transience: Its beauty and danger. *The International Journal of Psycho-Analysis*, *79*(Pt. 5), 937–953.
- Kitayama, O. (2010). *Prohibition of Don't look: Living through psychoanalysis and culture in Japan*. Tokyo: Iwasaki Gakujutsu Shuppansha.
- Kitchener, B. A., & Jorm, A. F. (2002). Mental health first aid training for the public: Evaluation of effects on knowledge, attitudes and helping behavior. *BMC Psychiatry*, *2*(1), 1.
- Kitchener, B. A., & Jorm, A. F. (2006). Mental health first aid training: Review of evaluation studies. *Australian and New Zealand Journal of Psychiatry*, *40*(1), 6–8.
- Kitchener, B. A., Jorm, A. F., & Kelly, C. M. (2013). *Mental health first aid manual* (3rd ed.). Melbourne: Mental Health First Aid Australia.
- Kondo, N., Kiyota, Y., Kitahata, Y., Kuroda, Y., Kurosawa, M., Sakai, M., ... Miyata, R. (2010). Shishunki hikikomori ni okeru seishin igakuteki shougai no jittai haaku ni kan suru kenkyuu (Research on the psychiatric disorders in adolescents with social withdrawal). *Kokoro no Kenkou Kagaku Kenkyuu (Japanese)*. pp. 67–86.
- Kondo, N., Sakai, M., Kuroda, Y., Kiyota, Y., Kitabata, Y., & Kurosawa, M. (2013). General condition of hikikomori (prolonged social withdrawal) in Japan: Psychiatric diagnosis and outcome in mental health welfare centres. *The International Journal of Social Psychiatry*, *59*(1), 79–86. <https://doi.org/10.1177/0020764011423611>.
- Koyama, A., Miyake, Y., Kawakami, N., Tsuchiya, M., Tachimori, H., Takeshima, T., & World Mental Health Japan Survey, G. (2010). Lifetime prevalence, psychiatric comorbidity and demographic correlates of "hikikomori" in a community population in Japan. *Psychiatry Research*, *176*(1), 69–74. <https://doi.org/10.1016/j.psychres.2008.10.019>.
- Kubo, H., Kato, T. A., & Kanba, S. (2017). Group psychotherapy for Hikikomori: Consideration of "difficulty in communicating with others" in the introduction period of group. *Japanese Journal of Adolescent Psychiatry (Japanese)*, *26*(2), 197–198.
- Kubo, H., Urata, H., Katsuki, R., Hirashima, M., Ueno, S., Suzuki, Y., ... Kato, T. A. (2018). Development of MHFA-based 2-h educational program for early intervention in depression among office workers: A single-arm pilot trial. *PLoS ONE*, *13*(12), e0208114. <https://doi.org/10.1371/journal.pone.0208114>.
- Kubo, H., Urata, H., Sakai, M., Nonaka, S., Saito, K., Tateno, M., Kobara, K., Hashimoto, N., Fujisawa, D., Suzuki, Y., Otsuka, K., Kamimae, H., Muto, Y., Usami, T., Honda, Y., Kishimoto, J., Kuroki, T., Kanba, S., & Kato, T. A. (2020). Development of 5-day hikikomori intervention program for family members: A single-arm trial. *Heliyon*, *6*(1), e03011. <https://doi.org/10.1016/j.heliyon.2019.e03011>.

- Kumazaki, H., Warren, Z., Swanson, A., Yoshikawa, Y., Matsumoto, Y., Takahashi, H., ... Kikuchi, M. (2018). Can robotic systems promote self-disclosure in adolescents with autism spectrum disorder? A pilot study. *Frontiers in Psychiatry, 9*, 36. <https://doi.org/10.3389/fpsyt.2018.00036>.
- Kumazaki, H., Yoshikawa, Y., Yoshimura, Y., Ikeda, T., Hasegawa, C., Saito, D. N., ... Kikuchi, M. (2018). The impact of robotic intervention on joint attention in children with autism spectrum disorders. *Molecular Autism, 9*, 46. <https://doi.org/10.1186/s13229-018-0230-8>.
- Lee, Y. S., Lee, J. Y., Choi, T. Y., & Choi, J. T. (2013). Home visitation program for detecting, evaluating and treating socially withdrawn youth in Korea. *Psychiatry and Clinical Neurosciences, 67*(4), 193–202. <https://doi.org/10.1111/pcn.12043>.
- Liu, L. L., Li, T. M., Teo, A. R., Kato, T. A., & Wong, P. W. (2018). Harnessing social media to explore youth social withdrawal in three major cities in China: Cross-sectional web survey. *JMIR Mental Health, 5*(2), e34. <https://doi.org/10.2196/mental.8509>.
- Malagon-Amor, A., Corcoles-Martinez, D., Martin-Lopez, L. M., & Perez-Sola, V. (2015). Hikikomori in Spain: A descriptive study. *The International Journal of Social Psychiatry, 61*(5), 475–483. <https://doi.org/10.1177/0020764014553003>.
- Malagon-Amor, A., Martin-Lopez, L. M., Corcoles, D., Gonzalez, A., Bellsola, M., Teo, A. R., ... Berge, D. (2018). A 12-month study of the hikikomori syndrome of social withdrawal: Clinical characterization and different subtypes proposal. *Psychiatry Research, 270*, 1039–1046. <https://doi.org/10.1016/j.psychres.2018.03.060>.
- Mandai, M., Kaso, M., Takahashi, Y., & Nakayama, T. (2018). Loneliness among mothers raising children under the age of 3 years and predictors with special reference to the use of SNS: A community-based cross-sectional study. *BMC Womens Health, 18*(1), 131. <https://doi.org/10.1186/s12905-018-0625-x>.
- Nakagami, Y., Kubo, H., Katsuki, R., Sakai, T., Sugihara, G., Naito, C., ... Kato, T. A. (2018). Development of a 2-h suicide prevention program for medical staff including nurses and medical residents: A two-center pilot trial. *Journal of Affective Disorders, 225*, 569–576. <https://doi.org/10.1016/j.jad.2017.08.074>.
- Nitta, M., Narita, T., Umeda, K., Hattori, M., Naitoh, H., & Iwata, N. (2008). Influence of negative cognition on the parental bonding instrument (PBI) in patients with major depression. *Journal of Nervous and Mental Disease, 196*(3), 244–246. <https://doi.org/10.1097/NMD.0b013e318165c116>.
- Pozza, A., Coluccia, A., Kato, T., Gaetani, M., & Ferretti, F. (2019). The ‘Hikikomori’ syndrome: Worldwide prevalence and co-occurring major psychiatric disorders: A systematic review and meta-analysis protocol. *BMJ Open, 9*(9), e025213. <https://doi.org/10.1136/bmjopen-2018-025213>.
- Prosser, M. (2018). *Searching for a cure for Japan's loneliness epidemic*. HUFFPOST. Retrieved from https://www.huffingtonpost.com/entry/japan-loneliness-aging-robots-technology_us_5b72873ae4b0530743cd04aa.
- Saito, T. (1998). *Shakaiteki Hikikomori-Owaranai Shishunki [Social withdrawal: A neverending adolescence]*. Tokyo: PHP Shinsho [in Japanese].
- Saito, K. (2010). *Hikikomori No Hyouka-Shien Ni Kansuru Gaido-Rain [Guideline of Hikikomori for their evaluations and supports]*. Tokyo: Ministry of Health, Labour and Welfare. http://www.ncgmkohnodai.go.jp/pdf/jidouseishin/22ncgm_hikikomori.pdf.
- Sakamoto, N., Martin, R. G., Kumano, H., Kuboki, T., & Al-Adawi, S. (2005). Hikikomori, is it a culture-reactive or culture-bound syndrome? Nidotherapy and a clinical vignette from Oman. *International Journal of Psychiatry in Medicine, 35*(2), 191–198.
- Shirahama, M., Terao, T., Ishii, N., Hatano, K., Hirakawa, H., & Kohno, K. (2018). Relationship between anxious temperament and harm avoidance in medical students and staff. *Psychiatry and Clinical Neurosciences, 72*(5), 322–328. <https://doi.org/10.1111/pcn.12633>.
- Subramanian, S. (2019). *A ‘modern’ depression is creeping into Japanese workplaces*. The Atlantic. Retrieved from <https://www.theatlantic.com/health/archive/2019/2010/modern-type-depression-japan/600160/>.

- Suzuki, Y., Kato, T. A., Sato, R., Fujisawa, D., Aoyama-Uehara, K., Hashimoto, N., ... Otsuka, K. (2014). Effectiveness of brief suicide management training programme for medical residents in Japan: A cluster randomized controlled trial. *Epidemiology and Psychiatric Sciences*, 23(2), 167–176. <https://doi.org/10.1017/S2045796013000334>.
- Tamura, T., Yonemitsu, S., Itoh, A., Oikawa, D., Kawakami, A., Higashi, Y., ... Nakajima, K. (2004). Is an entertainment robot useful in the care of elderly people with severe dementia? *Journals of Gerontology Series A, Biological Sciences and Medical Sciences*, 59(1), 83–85.
- Tarumi, S. (2005). The “new” variant of depression: The dysthymic type (in Japanese). *Japanese Journal of Clinical Psychiatry*, 34(5), 687–694.
- Tarumi, S., & Kanba, S. (2005). Sociocultural approach toward depression—Dysthymic type depression (in Japanese). *Japanese Bulletin Society of Psychiatry*, 13, 129–136.
- Tateno, M., Park, T. W., Kato, T. A., Umene-Nakano, W., & Saito, T. (2012). Hikikomori as a possible clinical term in psychiatry: A questionnaire survey. *BMC Psychiatry*, 12, 169. <https://doi.org/10.1186/1471-244X-12-169>.
- Tateno, M., Skokauskas, N., Kato, T. A., Teo, A. R., & Guerrero, A. P. S. (2016). New game software (Pokemon Go) may help youth with severe social withdrawal, hikikomori. *Psychiatry Research*, 246, 848–849. <https://doi.org/10.1016/j.psychres.2016.10.038>.
- Tateno, M., Teo, A. R., Shiraiishi, M., Tayama, M., Kawanishi, C., & Kato, T. A. (2018). Prevalence rate of Internet addiction among Japanese college students: Two cross-sectional studies and reconsideration of cut-off points of Young’s Internet Addiction Test in Japan. *Psychiatry and Clinical Neurosciences*, 72(9), 723–730. <https://doi.org/10.1111/pcn.12686>.
- Tateno, M., Teo, A. R., Shirasaka, T., Tayama, M., Watabe, M., & Kato, T. A. (2016). Internet addiction and self-evaluated attention-deficit hyperactivity disorder traits among Japanese college students. *Psychiatry and Clinical Neurosciences*, 70(12), 567–572. <https://doi.org/10.1111/pcn.12454>.
- Teo, A. R., Chen, J. I., Kubo, H., Katsuki, R., Sato-Kasai, M., Shimokawa, N., ... Kato, T. A. (2018). Development and validation of the 25-item Hikikomori Questionnaire (HQ-25). *Psychiatry and Clinical Neurosciences*, 72(10), 780–788. <https://doi.org/10.1111/pcn.12691>.
- Teo, A. R., Fetters, M. D., Stufflebam, K., Tateno, M., Balhara, Y., Choi, T. Y., ... Kato, T. A. (2015). Identification of the hikikomori syndrome of social withdrawal: Psychosocial features and treatment preferences in four countries. *The International Journal of Social Psychiatry*, 61(1), 64–72. <https://doi.org/10.1177/0020764014535758>.
- Twenge, J. M. (2017). *iGen: Why today’s super-connected kids are growing up less rebellious, more tolerant, less happy—and completely unprepared for adulthood (and what this means for the rest of us)*. New York: Atria Books.
- Watabe, M., Kato, T. A., Teo, A. R., Horikawa, H., Tateno, M., Hayakawa, K., ... Kanba, S. (2015). Relationship between trusting behaviors and psychometrics associated with social network and depression among young generation: A pilot study. *PLoS ONE*, 10(3), e0120183. <https://doi.org/10.1371/journal.pone.0120183>.
- Watanabe, T. (2005). Hikikomori heno houmon kaunseringu (Home counseling for hikikomori). *Rinshou Seishin Igaku (Clinical Psychiatry)*, 5, 289–291.
- Watanabe, K. (2011). Anxiety disorders especially related to Futoko (school refusal) and hikikomori. *Syonika Rinsyo (Japanese Journal of Pediatrics)* (Japanese), 64(5), 871–879.
- Winnicott, D. W. (1958). The capacity to be alone. *The International Journal of Psycho-Analysis*, 39(5), 416–420.
- Wong, P. W., Li, T. M., Chan, M., Law, Y. W., Chau, M., Cheng, C., ... Yip, P. S. (2015). The prevalence and correlates of severe social withdrawal (hikikomori) in Hong Kong: A cross-sectional telephone-based survey study. *The International Journal of Social Psychiatry*, 61(4), 330–342. <https://doi.org/10.1177/0020764014543711>.
- Wong, P. W. C., Liu, L. L., Li, T. M. H., Kato, T. A., & Teo, A. R. (2017). Does hikikomori (severe social withdrawal) exist among young people in urban areas of China? *Asian Journal of Psychiatry*, 30, 175–176. <https://doi.org/10.1016/j.ajp.2017.10.026>.

- Wong, P. W. C., Yu, R. W. M., Li, T. M. H., Lai, S. L. H., Ng, H. Y. H., & Fan, W. T. W. (2019). Efficacy of a multicomponent intervention with animal-assisted therapy for socially withdrawn youth in Hong Kong. *Society and Animals*, 27(5–6), 614–627. <https://doi.org/10.1163/15685306-12341462>.
- Wu, A. F. W., Ooi, J., Wong, P. W. C., Catmur, C., & Lau, J. Y. F. (2019). Evidence of pathological social withdrawal in non-Asian countries: A global health problem? *Lancet Psychiatry*, 6(3), 195–196. [https://doi.org/10.1016/S2215-0366\(18\)30428-0](https://doi.org/10.1016/S2215-0366(18)30428-0).

Further reading

- Kato, T. A., Hashimoto, R., Hayakawa, K., Kubo, H., Watabe, M., Teo, A. R., & Kanba, S. (2016). Multidimensional anatomy of ‘modern type depression’ in Japan: A proposal for a different diagnostic approach to depression beyond the DSM-5. *Psychiatry and Clinical Neurosciences*, 70(1), 7–23. <https://doi.org/10.1111/pcn.12360>.

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Gaming disorder in young people

Daniel L. King^a and Paul H. Delfabbro^b

^aCollege of Education, Psychology, and Social Work, Flinders University, Adelaide, SA, Australia, ^bSchool of Psychology, The University of Adelaide, Adelaide, SA, Australia

1 Introduction

Video gaming is a billion-dollar global industry that continues to expand and innovate. The popularity of online gaming reflects a major cultural shift in leisure and recreation preferences for screen-based entertainment over other pastimes. Individuals of all ages play games daily for enjoyment and socialization, and some people report finding deeper personal satisfaction and meaning in their virtual experiences than in the real world. For many young people, gaming may provide a 'hub' for social interaction and offer a place to explore and express their identity. Gaming provides an endless and constantly changing play experience, often involving other users, and there are new gaming products and innovative technologies (e.g. virtual reality and streaming services) continually entering the consumer market. Many new games include features that make them more immersive, socially integrated, and monetized than those before them (King, Koster, & Billieux, 2019). However, while there can be many benefits associated with gaming, including socializing, problem-solving, and creative applications, there is also growing recognition that unrestricted screen time, particularly for younger people, can lead to life disruption and harm or lost opportunities and that gaming can be highly time-consuming and addictive for some vulnerable individuals.

These developments have led to the recognition of *gaming disorder* (sometimes termed 'video game addiction')—a disorder characterized by persistent gaming, impaired control, and functional impairment. Gaming disorder not only is most similar in its features and description to gambling disorder but also resembles descriptions of substance-based disorders. The two major diagnostic systems for mental disorders, the DSM-5 and ICD-11, have recognized gaming as a disorder and advocated for the

need to better understand this condition. In the case of the DSM-5, gaming disorder is listed as a 'condition for further study', not an official disorder. Gaming disorder (GD) has recently been included in the ICD-11. For simplicity, this chapter will refer to gaming disorder to refer to the broad collection of terms used in the literature to refer to the most extreme patterns of gaming-related problems as described in the DSM/ICD systems.

2 Description of the problem

Prior to the nomenclatural recognition of gaming disorder, researchers had recognized the general phenomenon of 'problematic gaming'. Descriptions of problematic gaming first began to appear in the psychological literature in the early 1980s, and these were often formulated as a 'dependency' or addictive phenomenon that could vary in severity and course. Individuals who played video games excessively were often described as displaying many of the same symptoms as those with gambling and substance use disorders (Fisher, 1994). These early descriptions of problem players were also often focussed on younger individuals, between the age of about 15 and 20 years, and there was often an emphasis on delinquent aspects of behaviour, such as theft and aggression. The main problems that manifested from problematic gaming were conflict between parents and decreased school productivity or school absence.

At a behavioural level, engagement in excessive gaming can be associated with preoccupation, significant time spent away from other important activities, and a gradual intensification of gaming activity. However, video gaming differs, for example, from gambling or consuming alcohol, in terms of how it is consumed and the potential consequences for players. For example, a problem gambler often places larger bets and thus experiences *financial losses*, which cause emotional distress and major life difficulties (e.g. conflict with a partner, loss of material assets, legal issues, bankruptcy, or loss of employment) (Langham et al., 2015). An alcoholic will drink more frequently and experience similar interpersonal stressors and harms, in addition to *negative effects on health and well-being*, including heart disease, brain and liver damage, memory and attention problems, and the increased risk of physical injury while intoxicated (WHO, 2014). Such problems are rarely, if ever, reported by people affected by GD, aside from the general poor health consequences of prolonged sedentary behaviour.

An important question arises: How does problematic gaming and GD cause **harm** to players? Does this differ from other recognized addictive disorders? Gamers can often, just like gamblers, spend much of their time and income on gaming activities. For example, some gamers may spend too much on gaming-related purchases, including hardware and software

(including digital content, such as ‘microtransactions’), thereby accruing debts on credit cards (particularly in the case of adolescents with access to parents’ finances). Others may ‘chase losses’ in the sense of spending money impulsively on monetization features in games to improve their playing performance (Soroush, Hancock, & Bonns, 2014). However, such financial expenditure by gamers is usually relatively minor and unlikely to ever rival that expended by problem gamblers. In support of this view, gamers will often highlight the relatively low costs of their gaming compared with other activities, after the initial purchase of gaming equipment. Indeed, gaming may be seen as inexpensive when costs are expressed as a function of expenditure divided by time spent playing (King, Kaptsis, Delfabbro, & Gradisar, 2016).

Unlike substance misuse and addiction, the negative health effects of persistent gaming appear to be relatively mild. The most typically observed health-related ‘harms’ of gaming include loss of weight due to restricted diet (or weight gain due to overeating), physical pain issues due to poor posture and repetitive strain injuries (Macgregor, 2000), and restricted and poor sleep and/or reverse sleep–wake cycle that results in fatigue and lethargy (Männikkö, Billieux, & Käätäinen, 2015). In rare cases, gaming can produce photosensitive seizures (Chuang, 2006), but susceptible users may tend to avoid games that produce this reaction.

The primary way in which individuals with GD are negatively affected by their gaming relates to the extreme and inflexible time investment in gaming (i.e. 8–12 h per day on a consistent basis) (Baggio et al., 2016). Time spent gaming results in missed opportunities and the interference with, and displacement of, normal routine and functioning, including *basic activities* (i.e. sleep, eating, and personal hygiene), *real-world social interaction* (i.e. talking to people, meeting friends face-to-face, and visiting family), and *important responsibilities* (i.e. school, work, and care of pets and children). The recent ICD-11 description of gaming disorder emphasizes these elements (WHO, 2019). A gaming disorder markedly alters the user’s priorities, which results in diminished interest in, and capacity to, attend to nongaming-related information, people, and events. The affected individual becomes increasingly less able and less motivated to regulate gaming time. Consequently the user neglects the real world and his or her roles within it. A habitual pattern of gaming creates an expanding ‘void’ in the person’s life, where progression in important life areas, such as school or career, is stalled at the time at which gaming began. Over time the individual may find it increasingly more difficult to resume their involvement in other activities, due to loss of motivation or self-efficacy and/or deterioration of skills. For young people, for example, there may be a sense of shame or embarrassment in returning to school after a long absence (e.g. over 12 months). Such experiences appear to share some similarities with gambling, particularly on activities such as electronic gaming machines

where players can sometimes report entering into a ‘zone’ and wanting to stay in this immersive state for as long as possible (Schüll, 2012).

When not playing games an individual with GD is often preoccupied with gaming, consumed by thoughts of future gaming intentions and opportunities (King & Delfabbro, 2014a, 2014b, 2014c). The user may increasingly show less care about their present reality and attends less to nongaming concerns. Preoccupation reduces the availability of cognitive resources for nongaming tasks, which results in not learning at school, not completing work tasks efficiently or not completing them at all, and not interacting meaningfully with others. The lack of positive reinforcement and success in nongaming areas further leads the user to retreat into gaming activities. Within a short period of time (i.e. less than 3 months), the user may experience negative consequences such as failing at school, reprimands or lost productivity at work, and/or arguments with family or a partner. Negative mood states (i.e. usually irritability, sadness, and boredom) accompany the times when the individual is not playing or is less able to play (Dong & Potenza, 2014; Kaptsis, King, Delfabbro, & Gradisar, 2016). Such feelings may be amplified by other mood changes linked to poor diet and lack of sleep—which results in the user becoming more detached from the real world and seeking gaming for the relieving effects of play.

Thoughts of gaming for the user tend to be more automatic and require less mental effort and are more pleasant than thinking about real-world matters. For some gamers, having to think about oneself and the quality of life outside of gaming may be very painful and lead to suicidal ideation (Wu, Lee, Liao, & Chang, 2015). Such thoughts will often be ‘blocked out’ by gaming-related behaviour (e.g. browsing gaming websites). Individuals affected in this way can become less patient and respectful towards others and may come to view people as obstacles or interruptions to gaming. The user will regularly take ‘shortcuts’ (i.e. actions that require the lowest effort) to continue or maintain their gaming. The prioritization of gaming develops a pattern of behavioural avoidance (e.g. school truancy, ‘sick days’ from work, and avoiding social meals), not necessarily due to anxieties although they may also be present, but primarily with the intention of limiting the amount of time spent away from the gaming device. When unable to play the user experiences distress or *anhedonia*, as though experiencing a loss or deprivation of purpose.

3 Classification

Definitions of IGD/GD refer to ‘persistent and recurrent use of the Internet to engage in games, often with other players, leading to clinically significant impairment or distress’ (APA, 2013; p. 795). Table 1 presents a summary of the DSM-5 criteria for the classification of Internet gaming

TABLE 1 The DSM-5 and ICD-11 criteria for gaming disorder.

DSM-5 Internet gaming disorder	ICD-11 Gaming disorder
<p>Five or more of the following in a 12 month period</p> <ol style="list-style-type: none"> <i>Preoccupation.</i> Thinking about previous gaming activity or anticipation of playing the next game; Internet gaming becomes the dominant activity in daily life <i>Withdrawal.</i> Symptoms typically including irritability, anxiety, or sadness when Internet gaming is taken away, but there are no physical signs of pharmacological withdrawal <i>Tolerance.</i> The need to spend increasing amounts of time engaged in Internet games <i>Loss of control.</i> Unsuccessful attempts to control the participation in Internet games <i>Loss of nongaming interests.</i> Loss of interest in previous hobbies and entertainment as a result of, and with the exception of, Internet games <i>Gaming despite harms.</i> Continued excessive use of Internet games despite knowledge of psychosocial problems <i>Deception of others about gaming.</i> Deception of family members, therapists, or others regarding the amount of Internet gaming <i>Gaming for escape or mood relief.</i> Use of Internet games to escape or relieve a negative mood (e.g. feelings of helplessness, guilt, and anxiety) <i>Conflict/interference due to gaming.</i> Has jeopardized or lost a significant relationship, job, or educational or career opportunity because of participation in Internet games 	<p>Gaming disorder is characterized by a pattern of persistent or recurrent gaming behaviour ('digital gaming' or 'video gaming'), which may be online (i.e. over the Internet) or offline, manifested by the following:</p> <ol style="list-style-type: none"> <i>Impaired control over gaming</i> (e.g. onset, frequency, intensity, duration, termination, and context) <i>Increasing priority given to gaming</i> to the extent that gaming takes precedence over other life interests and daily activities <i>Continuation or escalation of gaming despite the occurrence of negative consequences.</i> The behaviour pattern is of sufficient severity to result in significant impairment in personal, family, social, educational, occupational or other important areas of functioning <p>The pattern of gaming behaviour may be continuous or episodic and recurrent. The gaming behaviour and other features are normally evident over a period of at least 12 months for a diagnosis to be assigned, although the required duration may be shortened if all diagnostic requirements are met and symptoms are severe</p>

disorder, which was included in [Section 3](#) as a condition for further study and is currently a provisional classification ([American Psychiatric Association, 2013](#)). Gaming disorder was officially adopted at the World Health Assembly in May 2019 as a diagnosis in the 11th edition of the International Classification of Diseases (ICD-11; [WHO, 2019](#)).

4 Epidemiology

Epidemiological research on problematic gaming and gaming disorder has improved greatly over the last decade. Studies of problematic

gaming in the early 2000s often involved self-selected samples, usually involving gamers recruited from online gaming forums or from students from a local secondary school. However, in recent years, there have been numerous high-quality population cohort studies designed to assess GD, as well as many large-scale studies (e.g. the Longitudinal Cohort Study on Substance Use Risk Factors [C-SURF] of young men in Switzerland) that have incorporated gaming-related questions. These developments have enabled much more precise estimates of the population-level harms related to gaming. By our count, there have been at least 30 longitudinal studies of problematic gaming and over 70 studies of prevalence conducted in large randomly selected or nationally representative samples. This growing evidence base has provided some insights into the course and outcome of this condition at its varying levels of severity.

4.1 Prevalence

Studies of prevalence have produced varied estimates, with these variations mainly due to differences in sample characteristics (e.g. age and gender), cultural and regional differences (e.g. Asian vs non-Asian countries and urban vs rural locales), choice of screening tools, and cut-off scores. In this section, we will highlight some of the larger, more robust studies which have informed current knowledge of prevalence of GD. Overall, these studies have reported rates of prevalence that generally fall between 1% and 2%.

Rehbein, Kliem, Baier, Mößle, and Petry (2015) conducted a large-scale, state-representative school survey of 11,003 adolescents (aged 13–18 years) using the DSM-5 criteria for GD. They reported that 1.2% of respondents may be classified as having GD. Individuals with GD played games for longer periods skipped school more often, had lower school grades, and had sleep problems. Another study by Müller et al. (2015) assessed the prevalence and correlates of GD in seven European countries based on a representative sample of 12,938 adolescents between 14 and 17 years. The authors reported that 1.6% of the sample met full criteria for GD, with a further 5.1% at risk for GD by meeting up to four criteria. GD was associated with psychopathological symptoms, including aggressive behaviour and social problems. Other high-quality studies have reported comparable figures, including 0.6% in a sample of 816 Norwegian adolescents (Mentzoni et al., 2011); between 0.3% and 1.0% in four international cohorts totalling 18,932 people (Przybylski, Weinstein, & Murayama, 2016); 2.0% in a sample of 1718 Chinese adolescents (Mak et al., 2014); 1.3% in a nationally representative panel of 902 Dutch gamers (Haagsma, Pieterse, & Peters, 2012); 1.5% of Dutch adolescents aged 13–16 years olds (van Rooij, Schoenmakers, Vermulst, Van Den Eijnden, & Van De Mheen, 2011); and 1.8% in a sample of 1287 Australian adolescents (King, Delfabbro, Zwaans, & Kaptis, 2013).

A metaanalysis by [Ferguson, Coulson, and Barnett \(2011\)](#) examined 33 published studies and doctoral dissertations. Although the authors noted that spuriously high rates were reported in some of these studies, they concluded that the most precise measures produced an overall prevalence rate of 3.1%. It bears noting that this analysis preceded the inclusion of GD in the DSM-5. [Przybylski et al. \(2016\)](#) presented an analysis of four survey studies ($N = 18,932$) with large international cohorts. They reported that, among those who played games, more than 2 out of 3 did not report any symptoms of gaming disorder. Further, their findings showed that only a very small proportion of the general population (up to 1.0%) might qualify for a potential acute diagnosis of GD. Comparison with gambling disorder revealed that Internet-based games may be significantly less addictive than gambling and similarly dysregulating as electronic games more generally. In addition the authors reported that links between GD and physical, social, and mental health outcomes were decidedly mixed. More recently, [Mihara and Higuchi \(2017\)](#) examined the prevalence of GD across 37 cross-sectional and 13 longitudinal studies. The main finding of their review was that the prevalence of GD ranged from 0.7% to 27.5%, with exceedingly high figures (i.e. >5%) tending to be reported in non-representative samples. GD prevalence was higher among males than females in the majority of studies and tended to be higher among younger rather than older people.

4.2 Comorbidity

Comorbidities have been examined across numerous studies of GD. Correlates such as anxiety and depression are often cited as evidence that GD has deleterious effects on individuals; however, this same evidence has also sometimes been interpreted as indicating that gaming may simply be a coping mechanism for other issues. In any case there is a substantial body of evidence that suggests that GD symptoms are strongly associated with other mental health conditions. For example, a large nationwide study in South Korea by [Kim et al. \(2017\)](#) surveyed 1401 adults aged between 18 and 74 years. They identified a subgroup of individuals with GD (7.7% of the sample). The GD group had higher rates of suicidal ideation, plans, and attempts than the non-GD group. GD was significantly associated with major depressive disorder, dysthymia, and depressive disorders after adjusting for all variables. [Marmet, Studer, Rougemont-Bücking, and Gmel \(2018\)](#) reported that gaming addiction was associated particularly strongly with depression, social anxiety, neuroticism, and aggressive behaviour.

Similar patterns of findings have been reported in adolescent samples. A study by [Strittmatter et al. \(2015\)](#) investigated 8807 European students (including 3% with GD) from randomly selected schools. Consistent with

studies of adults the adolescents with GD were at greater risk of internalizing symptoms than those without GD. In addition, adolescents with GD scored higher on measures of conduct disorder, hyperactivity/inattention, self-injurious behaviours, and suicidal ideation and behaviours. In summary, these studies suggest that GD may often be associated with multiple vulnerabilities and other symptoms of mental disorders, particularly mood symptoms.

4.3 Course and outcomes

The evidence on GD course and outcomes is currently mixed. A study by [Ko, Yen, Yen, Lin, and Yang \(2007\)](#) examined 517 students from three junior high schools in Southern Taiwan. The researchers examined gender, personality, mental health, self-esteem, family function, life satisfaction, and Internet activities as predictors of Internet addiction (which included gaming). Their results indicated that the 1-year incidence and remission rates for Internet addiction were 7.5% and 49.5%, respectively. Low self-esteem, low family functioning, and online (vs offline) game playing were predictive of the emergence of Internet addiction. Poorer social competence predicted remission of Internet addiction, demonstrating that difficulties in managing socially in the real world may contribute to 'relapse' or returning to the safety of the online world.

One of the largest longitudinal studies of adolescents by [Gentile et al. \(2011\)](#) was a two-year follow-up study involving 3034 school students in Singapore. Their study reported that increased gaming, lower social competence, and greater impulsivity were risk factors for becoming problematic gamers, whereas depression, anxiety, social phobias, and lower school performance seemed to be outcomes of problematic gaming. Notably the majority (84%) of youths who were initially identified as problematic gamers were still problematic gamers after 2 years. To our knowledge, this study shows the strongest support for the notion that problematic gaming can often be persistent or stable in the absence of intervention. Such work also aligns with the reported experiences of clinicians who manage referrals for complex cases of GD that we have conferred with at academic conferences and through other channels.

However, there is also evidence to suggest that problematic gaming may be relatively less stable over time. A study by [Scharkow, Festl, and Quandt \(2014\)](#) investigated 112 adolescents and 790 adults over a 2-year period. They reported generally low GAS scores which were very stable in yearly intervals. Only nine participants in total consistently exhibited symptoms of problematic game use across all waves, while no respondent could be classified consistently as being 'addicted'. Further, changes in problematic gaming were not related consistently to changes in psychosocial well-being.

An important limitation of Gentile et al. and Scharkow et al.'s studies is that they are based on general (i.e. nonclinical) samples and thus have very low base rates of actual GD or verified problems. Very few studies have examined how individuals with GD or problematic gaming who have sought treatment have tracked over time. One such study by [Han, Yoo, Renshaw, and Petry \(2018\)](#) involved a follow-up of 755 patients who received professional treatment for GD over a 5-year period. The authors reported that nearly two-thirds of patients who initiated treatment for GD completed the 8-week psychotherapy. Of these, about two-thirds who had not recovered completely by the end were offered additional care. Between 1 and 5 years later, 33.5% of the complete sample was considered to have recovered. Predictors of recovery from GD were older age, earlier admission to the clinic, and lower baseline levels of depression and attention deficit issues. The majority of the patients seeking treatment for GD continued to experience difficulties and sought treatment.

Taken together, this research evidence suggests that, while some individuals may report GD symptoms that are episodic or transient and have minimal relationship to lower mental health or quality of life, there is a substantial subgroup of more complex individuals who report persistent difficulties in managing severe GD and that their problems endure for many years, even after receiving treatment. Young people with significant problematic gaming issues are often referred to a psychologist or other help service at the point at which the problem has created major challenges or difficulties for the family, or the young person's life has reached a kind of 'crisis' point (e.g. failing grades or no longer at school despite attempts to reintegrate into education or home schooling, parents' relationship deteriorating due to frustration and disagreement on how to manage the problem, and/or teenager and parent regularly fighting about gaming leading to police involvement).

5 Causes

People play games differently and vary in their natural interest in gaming activities. These individual differences play an important role in the development of gaming disorder (GD). Some individuals are more at risk of GD due to personal characteristics, some of which may be modifiable (e.g. by intervention or other strategies), such as maladaptive beliefs or mood imbalances, whereas other risk factors may be fixed, such as genetics or upbringing. Risk factors for gaming disorder are usually related in some way. These factors influence how the individual tends to perceive and react to games and other gaming-related stimuli, including their perception of the costs and benefits of gaming. This section will summarize some of the known risk and protective factors for gaming disorder.

Males are generally understood to be at greater risk of developing GD (Andreassen et al., 2016). Studies have shown that GD prevalence favours males by a factor of at least 2 to 1 (Durkee et al., 2012; King, Delfabbro, & Griffiths, 2012). Males' greater risk of GD is not only due to their proportionately higher level of participation in gaming but also because males are more likely to engage in riskier games, such as competitive shooters and massively multiplayer online games. While many females also play these popular online games (including many of the same games), and the overall gender ratio in the gaming market is becoming more evenly balanced (Brand, Todhunter, & Jarvis, 2017), males tend to report playing games more frequently (i.e. on more days of the year) and intensely (i.e. for longer periods of time) than females.

Age is another well-documented risk factor in the addiction literature. Adolescence, usually defined for convenience as the period between 12 and 18 years, is the most vulnerable time for the acquisition of addictive disorders, including gaming (Gentile et al., 2017; Tejeiro, Gomez-Vallecillo, Pelegrina, Wallace, & Emberley, 2012). This vulnerability arises due to *neurological* (i.e. developing prefrontal cortex, which is responsible for decision-making and controlling impulses), *developmental* (i.e. resolving needs for social belonging and identity and challenging authority), and cultural (e.g. stressful transition to secondary school, new responsibilities, and greater independence) reasons. Gaming is typically more frequent during adolescence (Brand et al., 2017) and may therefore become relied upon as a means of coping with various physical and psychological changes and new role expectations. Gaming activities may be more likely to cause interference during periods of high stress and performance demands in middle-to-late adolescence (e.g. secondary school examinations) and into young adulthood (e.g. entering the workforce and formation of adult relationships).

Personality factors and psychological characteristics linked to GD have included impulsivity (Billieux, Schimmenti, Khazaal, Maurage, & Heeren, 2015; Billieux, Thorens, et al., 2015; Lee et al., 2012; Rho et al., 2017), neuroticism (Peters & Malesky, 2008), introversion (Cole & Hooley, 2013), lower agreeableness (Collins, Freeman, & Chamarro-Premuzic, 2012), lower conscientiousness (Braun, Stopfer, Müller, Beutel, & Egloff, 2016), low openness to experience (Wang, Ho, Chan, & Tse, 2015); boredom proneness (Liu & Peng, 2009), aggressiveness (Gervasi et al., 2017), rule breaking (Müller et al., 2015), trait anxiety (Mehroof & Griffiths, 2010), and narcissism (Stopfer, Braun, Müller, & Egloff, 2015). A study by Walther, Morgenstern, and Hanewinkel (2012) examined the Big Five personality traits and other characteristics across five different addictive disorders, including gambling, gaming, and use of tobacco, alcohol and cannabis, in a sample of 2553 people aged 12–25 years. They reported that problematic gaming was associated with irritability/aggression, social anxiety,

attention deficit issues, and low self-esteem. Protective factors include low impulsivity (Collins et al., 2012), high conscientiousness (Müller, Beutel, Egloff, & Wölfling, 2014), high extraversion (Kuss, Van Rooij, Shorter, Griffiths, & van de Mheen, 2013), and greater emotional regulation (Liau et al., 2015).

A major contributing factor for GD is comorbidity (Laconi, Pirès, & Chabrol, 2017; Sioni, Burlinson, & Bekerian, 2017; Wang, Cho, & Kim, 2018). Models of GD refer to mood symptoms and disorders, including depression and anxiety disorders, as a major vulnerability to the disorder (Brand, Young, Laier, Wölfling, & Potenza, 2016; Davis, 2001). Over the last two decades, there has been a great deal of research on the link between 'Internet addiction' and psychopathology (e.g., Ha et al., 2007; Ho et al., 2014; Ko et al., 2014; Yen, Ko, Yen, Wu, & Yang, 2007; Young & Rogers, 1998), with some of this work including online gaming activities (Andreassen et al., 2016; King et al., 2013). Links between comorbidity and GD have also been evaluated in treatment seekers. In a study of 263 patients with GD, Hyun et al. (2015) found that *individual factors* (sex and age), *cognitive factors* (IQ and perseverative errors), *psychopathological conditions* (ADHD, depression, anxiety, and impulsivity), and *social interaction factors* (family environment, social anxiety, and self-esteem) were significantly associated with GD, with psychopathological conditions emerging as the strongest risk factor.

Individuals with poor self-regulation and decision-making biases are more prone to developing addictive behaviours, including GD (Liu & Peng, 2009; Schiebener & Brand, 2017). Studies have reported that problem gamers tend to differ from controls on neurocognitive tasks of attention, processing, and decision-making. Problematic gamers have biases in how they interpret and process game-related information (Decker & Gay, 2011), they make poorer decisions under risky conditions (Yao et al., 2015), they fail to account for objective probabilities (Brand et al., 2016), and they are less able to delay gratification for a larger reward (Pawlikowski & Brand, 2011). These biases derive from a vulnerable neurobiological predisposition and are strengthened with repeated use of the activity (Brand et al., 2016). It is thought that the inability to self-regulate makes individuals' early experimentation with addictive activities a riskier or harmful prospect (Seay & Kraut, 2007).

Low self-esteem and self-efficacy are also important risk factors for GD. Individuals with low self-esteem have less confidence, are prone to self-criticism, and have difficulties in establishing and maintaining friendships. Gaming may therefore provide emotional comfort and offer 'safer' social avenues (Kowert, Domahidi, Festl, & Quandt, 2014; Lo, Wang, & Fang, 2005). Individuals who feel less certain in their own abilities and their place in the real world will be more at risk of using the Internet and playing online games to compensate (Davis, 2001; King & Delfabbro, 2014a, 2016; Turkle, 2017). Low self-esteem is also related to the cognitive

symptoms of many mental disorders (e.g. thoughts of hopelessness and uncertainty about the future) which are common risk factors for addiction. Similarly, individuals with low self-efficacy may be drawn to structured gaming activities that reinforce that the player is skilful or powerful (Jeong & Kim, 2011).

Another category of risk factors includes the social and environmental variables that impinge on individuals and direct them towards riskier participation in gaming activities. Many children are raised with access to gaming devices in the family home, according to studies where some participants have reported that their first gaming experience occurred at the age of 5 years (e.g. King et al., 2013; King, Delfabbro, et al., 2018; King, Herd, & Delfabbro, 2018). Young people may be introduced to gaming through their association with peers, in school, or other locales. Individuals who associate with frequent and probable problematic gamers will be at greater risk of GD due to having more gaming opportunities, having social incentives to play, and being invited to play regularly as part of a group. These social opportunities are also readily facilitated with online streaming services (e.g. twitch.tv) and online eSports events that draw large audiences in shared social arenas (e.g. live chat). Online gaming with 'friends' (i.e. real-world or online-only relationships) can give rise to social obligations to play regularly in teams (e.g. 'clans' and 'guilds'), which may become a significant and unpredictable time commitment.

Gaming behaviour is largely governed by the availability and accessibility of gaming activities (Weis & Cerankosky, 2010). Individuals with GD often modify their environment to centralize gaming so that it is easier to initiate and maintain. Studies show that individuals with greater access to gaming tend to play longer and more often. This connection is evident, for example, in the literature on electronic devices and sleep patterns in adolescent populations. Adolescents who have electronic media devices in the bedroom tend to report later bed times, shorter sleep duration, longer sleep-onset latency, and worse daytime functioning (e.g. worse memory or concentration), as compared with those without devices in their bedroom (Brunborg, Mentzoni, Molde, et al., 2011; Li et al., 2007; Schochat, Flint-Bretner, & Tzischinsky, 2010).

Family structures and relationships play a complex role in the development of problematic gaming (Choo, Sim, Liau, Gentile, & Khoo, 2015). Several familial influences, such as the parent-child relationship, parental restriction and monitoring of media use, and parents' marital and socio-economic status, may affect the likelihood that an adolescent becomes a problem gamer (Schneider, King, & Delfabbro, 2017). Adolescents from single-parent or blended families are reportedly at greater risk of problem gaming than those from two-parent families (Lam, Peng, Mai, & Jing, 2009). A 5-year longitudinal study by Rehbein and Baier (2013) reported that increased paternal devotion and higher parental supervision

in childhood predicted lower rates of problem gaming in adolescence. Individuals from less stable and less warm families may be more at risk of problematic gaming and other online activities that enable an 'escape'. Positive family functioning may be protective because more diligent family members are likely to direct the adolescent's attention away from games and towards other activities (Kim & Kim, 2015).

Relational trauma is another important risk factor for problematic gaming, although it has received less attention in the literature. Insecurely attached adolescents may seek out the security and emotional comfort of virtual worlds and relationships in online games (Milani, Osualdella, & Di Blasio, 2009). The use of gaming to satisfy relationship and emotional security needs may develop into a pattern of avoidance and/or heightened conflict with parents and peers. Research on adolescents with relational trauma histories has reported some young people may play online games as a way of dealing with painful memories related to early parent-child experiences. Schimmenti, Guglielmucci, Barbasio, and Granieri (2012) surveyed 250 players of MMO games to examine attachment profiles in relation to addiction symptoms. Almost half (47%) of the problematic gamers reported features of disorganized attachment and playing to escape from painful memories of abuse. Parental warmth and secure relationships are protective against addictive behaviours (Liau et al., 2015). Restoring or developing positive family relationships has been a feature of some interventions for young people with problematic gaming behaviours.

Finally, certain types and characteristics of games are associated with problematic gaming behaviours (Griffiths & Nuyens, 2017). A common feature of more addictive games is their never-ending nature (i.e. replayability and limitless rewards). Research has identified MMO games (Caplan, Williams, & Yee, 2009) and competitive shooters (Rehbein, Kleimann, & Mößle, 2010) as genres associated with GD. Online games are generally recognized as being more risky than offline games. Eichenbaum, Kattner, Bradford, Gentile, and Green (2015) surveyed 4744 university students and found that real-time strategy and role-playing games were more strongly associated with GD symptoms, as compared with action style and other games. Gaming reward systems that employ partial reinforcement, balancing the user's excitement and boredom or frustration levels (Wan & Chiou, 2006) with a mix of familiar and novel rewards, are likely to contribute to the development of problematic gaming in vulnerable users.

6 Treatment and prevention

The evidence base on interventions for GD has been developing steadily over the last decade but is still quite limited, particularly in relation to prevention. Most of the published research on treatment for GD has been

undertaken in South Korea, China, and Germany (King et al., 2017), where there are established treatment centres for GD and other online-related problems. The majority of referrals to these centres are for young people playing online games, although it is observed that many young people will not attend such services (i.e. treatment refusal) and parents or other caregivers will seek guidance on managing the problem. This section will summarize some of the recent international literature on treatment for gaming disorder, including some key treatment considerations, and note some of the methodological problems in this research. We will then provide a summary of prevention strategies proposed for problematic gaming, with an emphasis on harm reduction measures and then some practical guidelines for parents.

Gaming disorder (GD) is a complex phenomenon with several characteristics that require attention in treatment. While researchers have debated the validity of GD as an addictive disorder, in particular the validity of tolerance and withdrawal symptoms (Billieux et al., 2017; Starcevic, 2017), treatment approaches to GD have generally been adapted from methods used with established addictions. Similar to the logic applied in the treatment of pathological/disordered gambling, psychological approaches to GD view individuals as having cognitive biases that arise in and relate to gaming activities and impaired control over motivational drives for reward seeking (Dong & Potenza, 2014). Accordingly, two crucial components of effective treatment for GD are thought to include strategies that (i) modify clients' maladaptive beliefs about gaming behaviour and (ii) help reduce withdrawal and other unpleasant mood states when not gaming. The ultimate aim of treatment is to reduce or eliminate gaming behaviours that interfere with self-care, relationships, and other life responsibilities and foster new, productive, and healthy patterns of thinking, routines and other behaviours, and social relationships.

6.1 Individualized treatment

Treatment must take into consideration the unique needs of the client, including his or her GD symptom profile and risk/protective factors and gaming-related beliefs and motivations. Some therapies will be more appropriate and necessary for some clients than others. For example, an individual with GD who holds strong maladaptive beliefs about the social function of gaming in the context of social anxiety may benefit from behavioural activation that includes real-world socialization, monitoring the social functions of gaming (e.g. the 'pros' and 'cons' of online relationships); strengthening social supports and building healthy real-world relationships, and cognitive therapy for specific beliefs about others (e.g. addressing themes of rejection or abandonment).

6.2 Treatment aims

For many seeking help for GD, the ultimate goal may not be to ‘quit’ gaming but rather to maintain a gaming schedule that is compatible with life responsibilities. This is likely to be the case for many young people whose social network may be largely composed of others who play games. Gaming in moderation may often be the most realistic and achievable outcome (e.g. [McLean, 2013](#)), but this may also present some challenges given the continual opportunities to play excessively. In a 2014 review, which included studies of adolescents, all eight studies reported that participants’ long-term aim was controlled use of games rather than abstinence ([King & Delfabbro, 2014c](#)).

6.3 Drugs versus psychotherapy

Psychotherapy studies for GD outnumber pharmacological treatment studies by a factor of about 3 to 1. The most recent metaanalysis to compare drug-based (specifically, escitalopram, bupropion, and methylphenidate) and psychotherapy interventions was conducted by [Winkler, Dörsing, Rief, Shen, and Glombiewski \(2013\)](#), who assessed 16 studies of ‘Internet addiction’ treatment, which included but was not limited to gaming-related problems. This review reported that there were no significant differences in the efficacy of drugs versus psychotherapy for improving Internet addiction (IA) symptoms (which primarily involved gaming) or reducing time spent online. However, psychotherapy for IA was reported to be more effective for reducing comorbid depression. Although Winkler et al. reported that treatment effect size estimates were ‘high, robust, unrelated to study quality or design, and maintained over follow-up’ (p. 317), it is important to remember that the studies rarely administered follow-up measures.

6.4 Effectiveness of CBT

CBT is often advocated to be a first-line therapy for many mental health conditions, including addictions. A metaanalysis by [Stevens, King, Dorstyn, and Delfabbro \(2019\)](#) examined 12 independent CBT studies of GD. CBT demonstrated high efficacy in reducing GD symptoms and depression and showed moderate efficacy in reducing anxiety at posttest. However, there was insufficient power to determine whether CBT was capable of reducing time spent gaming. Further, treatment gains at follow-up were nonsignificant. The pooled findings suggested that CBT for GD may be an effective short-term intervention for reducing GD and depressive symptoms, but more studies with follow-ups are needed to assess long-term gains.

6.5 Research limitations

Many GD treatment studies have fundamental design and reporting limitations. Many studies do not have control groups, and there is a general lack of compliance with the CONSORT statement (King et al., 2017). Recommendations to improve studies include (1) extending follow-up assessment from 1 month to at least 3–6 months; (2) including an assessment of diagnostic (i.e. clinical) change, rather than differences in mean symptom score; (3) conducting a broader assessment of treatment outcomes, including quality of life, and measuring cognitions in CBT studies (King & Delfabbro, 2014b); and (4) examining posttreatment adjustment, including social and environmental changes. The field lacks published treatment manuals which would be a valuable resource for clinical practice.

7 Cognitive-behavioural treatment strategies

7.1 Self-monitoring

Self-monitoring involves asking the client to record all the times of the day when gaming occurs, the duration of each gaming session, and the basic outcomes of each session (e.g. change in mood state, game progress, and other consequences). This exercise requires the client to stop regularly to record their behaviour, which may curb impulsive decisions and allow time for reflection. This may be particularly useful for young people, at the initial stages, because it assumes a more neutral stance in the intervention that avoids making assumptions about the function and extent of gaming behaviour.

7.2 Activity scheduling

Activity scheduling can be a useful behavioural technique, particularly for clients with greater willingness to reduce gaming. Activity scheduling involves identifying ‘high-risk’ times of the day at which gaming usually occurs and scheduling an alternative activity. For young people, this might be at unstructured times of the day, such as after school times. Scheduled activities must be specific, practical, and appropriate to the capability of the client (i.e. achievable without difficulty). Activities and the steps involved should be operationalized (i.e. time of day and types of eligible activities) and include guidelines (i.e. the use of rating scales to monitor consequences) to avoid any potential confusion.

7.3 Contingency management

Gaming is one of the most positively reinforcing leisure activities, relative to the effort required to play. Games are designed to reward players in some way each time they play. Contingency management (CM) may be a useful behavioural technique to ensure that the client is 'rewarded' (e.g. using money or privileges) for not gaming. CM is based on operant conditioning principles that assume that an alternative schedule of reinforcement may help to override the addictive schedule. CM involves stimulus control (i.e. limited gaming activity) and the administration of an alternative reinforcer in exchange for gaming abstinence or controlled use. This approach, while simple, has been shown to be effective for addictive behaviours, by improving clients' ability to remain abstinent and therefore engage with other components of therapy (Petry, Martin, Cooney, & Kranzler, 2000; Prendergast, Podus, Finney, Greenwell, & Roll, 2006).

7.4 Exposure and response prevention

Exposure therapy for GD involves the client entering gaming situations that elicit the urge to play and then the client does not engage in gaming to relieve this urge (i.e. response prevention). The aim is to provide a supported experience where the client learns that gaming urges will naturally decrease and become controllable without having to play. Exposure therapy may proceed *gradually* by working through a hierarchy of situations that are increasingly more urge provoking, to overcome urges and other negative mood states (e.g., anxiety or apprehension) in the most manageable and least confronting way.

7.5 Socratic questioning

The Socratic method is a guided form of self-discovery that is facilitated by the therapist. The aim of the method is to help the client develop greater insight into their thought processes and how these influence their emotions and behaviour. Accordingly the client becomes aware of maladaptive beliefs and is assisted to challenge them and change the behaviour. The guided questioning approach should involve clarification and feedback based on the theme of the discussion. Once the client's negative thinking styles and maladaptive beliefs about gaming have been identified, the therapist and client can begin to explore the validity and utility of the client's thoughts.

7.6 Daily thought records

The purpose of the exercise is to systematically examine thoughts that pertain to gaming that maintain the pattern of persistent gaming behaviour. This is achieved practically with the aid of a physical record, usually a table referring to (1) *situation* (i.e. the event or trigger for gaming), (2) *automatic thoughts* (i.e. thoughts triggered by the event), (3) *emotions* (i.e. list of feelings that followed the thought); (4) *behaviour* (i.e. the actions taken in response to the feeling), (5) *outcome* (i.e. what happened next, including changes in thoughts), and (6) *rational or adaptive response* (i.e. strategies that may help and other ways of considering the situation). The aim of completing thought records is to assist the client in recognizing that their internal states (thoughts/feelings) are separate but related to their behaviours and consequences.

7.7 Behavioural experiments

An active behavioural experiment can be a powerful therapeutic technique to achieve positive change. The purpose of a behavioural experiment is to test unhelpful or maladaptive cognitions and encourage critical thinking and problem-solving that leads to emotional and behavioural change. This involves a series of steps akin to applying the basic scientific method: (1) developing a hypothesis that relates to the client's beliefs, (2) planning a way of testing this belief, (3) conducting the 'experiment', and (4) reflecting on the findings of the experiment and reevaluating the tested belief. For example, one such experiment may involve testing the client's belief that he or she is unable to cope without playing video games at an identified 'risky' time of day. This experiment may involve monitoring urges to play during a period of time when not playing (e.g. engaged in another activity that prevents gaming) and then reassessing the belief related to coping.

8 Prevention

From a public health perspective, participation in gaming activities may be viewed along a spectrum, where most individuals tend to engage in 'safe' levels of gaming (i.e. gaming that does not produce any significant negative consequences for the user or others and has a largely positive influence on the individual's life or state of well-being, such as promoting feelings of satisfaction and happiness) (King, Delfabbro, et al., 2018; King, Herd, & Delfabbro, 2018). A small proportion of individuals may 'misuse' gaming products and services in different ways and to varying degrees of regularity. Misuse refers to gaming that has negative consequences for

the user or others, due to excessive use or the displacement of other activities or important responsibilities. At the other end of the spectrum are a very small proportion of the gaming population who could be considered 'pathological' users (i.e. individuals with GD) and who frequently display patterns of statistically abnormal gaming behaviour that generate harms. Effective prevention strategies aim to cater and respond to the unique needs of these different risk groups, with the overarching goal of preventing the onset of new gaming-related problems and preventing the progression of existing problems to more severe manifestations.

Prevention may be conceptualized as including one or more of the following:

- (1) Preventing a problem behaviour from ever occurring
- (2) A delay in the onset of a problem behaviour
- (3) A reduction in the impact of a problem behaviour
- (4) Strengthening knowledge, attitudes, and behaviours that promote emotional and physical well-being
- (5) Promoting institutional, community, and government policies that further physical, social, and emotional well-being of the larger community (Romano & Hage, 2000)

Unlike some public health problems (e.g. the use of tobacco products) with clearly defined levels of harm, defining the levels or types of gaming use that are detrimental to users is less straightforward. Although many gaming activities, including those occurring online and offline, may be considered 'addictive' for some users (Griffiths, 2009), these activities would not be classified as inherently harmful, or incrementally harmful according to level of use. Gaming can be adaptive, productive, socially significant, and increase the psychological well-being of users (Sublette & Mullan, 2012). GD prevention should therefore not intend to reduce population-level gaming to its lowest possible point, nor impose restrictions upon those who play games at healthy levels or with little apparent harm.

9 Harm reduction strategies

Harm reduction strategies are informed by a public health approach that views gaming as a health behaviour (rather than an addiction per se) where gaming is safe at certain low to moderate levels but can become incrementally harmful with increasing use. Addictions require a lifelong commitment to self-management, rather than a 'once-off' intervention. The main purpose of harm reduction is to reduce negative consequences by taking practical steps to address the conditions of use and the use itself. Some strategies include the following:

9.1 Environmental modifications

Gaming activities usually take place in the home. Therefore the home environment may be modified to reduce the ease or accessibility of use, or reducing the likelihood of long gaming sessions. This may involve shifting living room furniture so that it is not facing the gaming device, removing gaming devices from the bedroom, and keeping gaming paraphernalia to a minimum or to a single room in the house. Keep gaming equipment unplugged and stored away in a box when not in use may be helpful in making gaming a less available or automatic routine.

9.2 Limit setting

This approach involves setting a time limit on a gaming device by accessing the parental lock controls on a gaming system (e.g. *PlayStation* and *Xbox* consoles), or setting alarms that signal a break in play, or scheduling gaming at times when it is more likely to end at the intended time due to external interruption. These strategies aim to give gaming activities an endpoint given that many types of games are essentially endless.

9.3 Increase reality awareness

This approach refers to strategies that reduce gaming immersion that contributes to experiences of losing track of time. Practical ideas include keeping the lights on in the room where gaming occurs, having a clock above the gaming screen, having an outside window in the field of view when gaming, having a mirror that enables the individual to see himself, and playing the game with lower audio volume or without use of noise-cancelling headphones.

9.4 Avoiding risky games

Certain games or gaming conditions may be more likely to lead to pre-occupation and planning and longer sessions of gaming (King, Delfabbro, et al., 2019; King, Koster, & Billieux, 2019). Avoiding massively multiplayer online (MMO) games (e.g. *World of Warcraft*) and other competitive online games (e.g. battle arena games and first-person shooters) and deleting of apps and shortcuts on supporting devices (e.g. smartphones and stored website links) linked to these games may be a helpful step towards achieving moderate levels of gaming. Another consideration might be avoiding playing certain game modes that tend to require much more time (e.g. 'raids' and similar group-based activities in online games). Players may also wish to consider deleting a game account to reduce the temptation of returning to play the game in future. For some players, avoiding game-related sites, including streaming and news sites, may reduce the temptation to play.

9.5 The role of parents

A common refrain is that parents should simply remove or turn off gaming devices and disconnect the Internet service (i.e. the *'just turn it off'* approach). To be fair, this approach will usually be effective in some cases of problematic gaming, such as when problems are minor, the user is younger and the parent or carer has a history of successfully establishing boundaries. However, in some other cases, the sudden removal of gaming devices by a parent or carer may compound any existing relational conflict with the risk of physical retaliation and violence.

Research studies on parental restriction and monitoring of gaming have generally produced mixed findings concerning the effectiveness of these methods in curbing problematic behaviour (Choo et al., 2015; Kwon, 2011; Liao et al., 2015; Rehbein & Baier, 2013). Inconsistent findings may be related to difficulties in isolating the influence of a single variable on problem gaming behaviour. Studies indicate that the effectiveness of restriction may depend on whether it was implemented *before* or *after* the gaming problem began. Wu et al. (2016) found that media restriction was nearly twice as high for adolescents who used the Internet excessively compared with other adolescents. Restriction may therefore have a 'forbidden fruit' effect (see Bijvank, Konijn, Bushman, & Roelofsma, 2009), meaning that gaming becomes more desirable when unavailable. Removing devices also denies children opportunities to learn to self-regulate gaming. The manner in which devices are removed (e.g. by a parent in anger vs with empathy) will have some bearing on the consequences.

Although parental restriction of gaming activities will be necessary in practice, particularly for children, parents should not rely on this approach as the primary means of protecting against overuse. It will likely become less effective as the child gets older. The effectiveness of media restriction is influenced by other individual and contextual factors. The greater use of restriction may be a sign of the need for alternative approaches. Parents who encourage alternative interests, self-regulation, and problem-solving may be more successful in restricting gaming activities. Children who can stay calm and reflect on their actions, who have multiple hobbies, will likely not need to be told 'no' as often as other children and thus will be less likely to develop gaming problems.

9.6 Parent guidelines

Recognizing that not all parents can (or wish to) remove gaming devices to prevent the occurrence of gaming misuse, some health organizations and expert bodies (Dooley, Cross, Hearn, & Treyvaud, 2009; Lim, 2012; McLean, 2013; RANZCP, 2011) have developed guidelines to assist

parents to make more informed decisions about gaming activities in the home environment. Together, these guidelines suggest that parents should

- (1) learn about the types of games available on the market and the gaming preferences of their children to determine the suitability of game products;
- (2) model healthy use of electronic media and avoid enabling excessive use;
- (3) know the warning signs of problematic gaming, such as mood changes (e.g. the child is only happy when gaming), loss of sleep due to gaming, diminished interest in other activities, and lying about gaming and refusal to stop playing when asked;
- (4) set limits on gaming time in advance and encourage playing games as a family activity;
- (5) be familiar with who the child or adolescent plays with online and ensure that personal information is not shared with strangers by discussing cyber safety;
- (6) negotiate how gaming devices are used and then employ the parental controls on gaming consoles (e.g. content restriction and time limits) and lock the option to spend money on games using credit cards and similar options;
- (7) support other interests and activities, especially nonscreen-based activities such as sports or physical exercise.

10 Conclusions

While only recently recognized as an addictive disorder in the ICD-11, gaming disorder (and less severe forms of problematic gaming) has been the topic of research for several decades. Many studies have focussed on young people who display symptoms of the condition, but there is still some uncertainty among researchers as to the prevalence, severity, and course of the condition. Despite some very high prevalence estimates, in reality only very few (<1%) young people may meet the criteria for gaming disorder. Young problematic gamers tend to be more likely to be male, play online social (rather than offline, single-player) games, and have higher levels of impulsivity and comorbid psychopathological conditions, low self-esteem, and limited alternative interests. In addition, many problematic gamers may come from chaotic and insecure families, who have less structure in their daily routine and have more access to games and more opportunities to play, and develop a social network of peers who game at high levels. A challenge for interventions has been young people's insight and willingness to participate in treatment, in addition to general uncertainties regarding 'best practice' given the limited evidence

base. Research on gaming disorder is likely to continue to grow in the context of global interest in the study of behavioural addictions, particularly those related to online technologies. The field would benefit from more robust studies on the nature and consequences of gaming disorder, including longitudinal and clinical studies involving young people, as well as independent support from the gaming industry which has been limited to date.

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References

- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)* (5th ed.). Washington, DC: American Psychiatric Association.
- Andreassen, C. S., Billieux, J., Griffiths, M. D., Kuss, D. J., Demetrovics, Z., Mazzoni, E., & Pallesen, S. (2016). The relationship between addictive use of social media and video games and symptoms of psychiatric disorders: A large-scale cross-sectional study. *Psychology of Addictive Behaviors, 30*, 252–262.
- Baggio, S., Dupuis, M., Studer, J., Spilka, S., Daeppen, J. B., Simon, O., ... Gmel, G. (2016). Reframing video gaming and internet use addiction: Empirical cross-national comparison of heavy use over time and addiction scales among young users. *Addiction, 111*, 513–522.
- Bijvank, M. N., Konijn, E. A., Bushman, B. J., & Roelofsma, P. H. (2009). Age and violent-content labels make video games forbidden fruits for youth. *Pediatrics, 123*, 870–876.
- Billieux, J., Schimmenti, A., Khazaal, Y., Maurage, P., & Heeren, A. (2015). Are we overpathologizing everyday life? A tenable blueprint for behavioral addiction research. *Journal of Behavioral Addictions, 4*, 119–123.
- Billieux, J., Thorens, G., Khazaal, Y., Zullino, D., Achab, S., & Van der Linden, M. (2015). Problematic involvement in online games: A cluster analytic approach. *Computers in Human Behavior, 43*, 242–250.
- Billieux, J., Van Rooij, A. J., Heeren, A., Schimmenti, A., Maurage, P., Edman, J., ... Kardefelt-Winther, D. (2017). Behavioural Addiction Open Definition 2.0—Using the Open Science Framework for collaborative and transparent theoretical development. *Addiction, 112*, 1723–1724.
- Brand, J. E., Todhunter, S., & Jervis, J. (2017). *Digital Australia 2018 (DA18)*. <http://www.igea.net/wp-content/uploads/2017/07/Digital-Australia-2018-DA18-Final-1.pdf>.

- Brand, M., Young, K. S., Laier, C., Wöfling, K., & Potenza, M. N. (2016). Integrating psychological and neurobiological considerations regarding the development and maintenance of specific internet-use disorders: An interaction of person-affect-cognition-execution (I-PACE) model. *Neuroscience & Biobehavioral Reviews*, *71*, 252–266.
- Braun, B., Stopfer, J. M., Müller, K. W., Beutel, M. E., & Egloff, B. (2016). Personality and video gaming: Comparing regular gamers, non-gamers, and gaming addicts and differentiating between game genres. *Computers in Human Behavior*, *55*, 406–412.
- Brunborg, G. S., Mentzoni, R. A., Molde, H., et al. (2011). The relationship between media use in the bedroom, sleep habits and symptoms of insomnia. *Journal of Sleep Research*, *20*, 569–575.
- Caplan, S., Williams, D., & Yee, N. (2009). Problematic Internet use and psychosocial well-being among MMO players. *Computers in Human Behavior*, *25*, 1312–1319.
- Choo, H., Sim, T., Liau, A. K. F., Gentile, D. A., & Khoo, A. (2015). Parental influences on pathological symptoms of video-gaming among children and adolescents: A prospective study. *Journal of Child and Family Studies*, *24*, 1429–1441.
- Chuang, Y. C. (2006). Massively multiplayer online role-playing game-induced seizures: A neglected health problem in Internet addiction. *Cyberpsychology & Behavior*, *9*, 451–456.
- Cole, S. H., & Hooley, J. M. (2013). Clinical and personality correlates of MMO gaming: Anxiety and absorption in problematic internet use. *Social Science Computer Review*, *31*, 424–436.
- Collins, E., Freeman, J., & Chamarro-Premuzic, T. (2012). Personality traits associated with problematic and non-problematic massively multiplayer online role playing game use. *Personality and Individual Differences*, *52*, 133–138.
- Davis, R. A. (2001). A cognitive-behavioral model of pathological Internet use. *Computers in Human Behavior*, *17*, 187–195.
- Decker, S. A., & Gay, J. N. (2011). Cognitive-bias toward gaming-related words and disinhibition in World of Warcraft gamers. *Computers in Human Behavior*, *27*, 798–810.
- Dong, G., & Potenza, M. N. (2014). A cognitive-behavioral model of internet gaming disorder: Theoretical underpinnings and clinical implications. *Journal of Psychiatric Research*, *58*, 7–11.
- Dooley, J. J., Cross, D., Hearn, L., & Treyvaud, R. (2009). *Review of existing Australian and international cyber-safety research*. Perth: Child Health Promotion Research Centre, Edith Cowan University.
- Durkee, T., Kaess, M., Carli, V., Parzer, P., Wasserman, C., Floderus, B., ... Brunner, R. (2012). Prevalence of pathological internet use among adolescents in Europe: Demographic and social factors. *Addiction*, *107*, 2210–2222.
- Eichenbaum, A., Kattner, F., Bradford, D., Gentile, D. A., & Green, C. S. (2015). Role-playing and real-time strategy games associated with greater probability of Internet Gaming Disorder. *Cyberpsychology, Behavior and Social Networking*, *18*, 480–485.
- Ferguson, C. J., Coulson, M., & Barnett, J. (2011). A meta-analysis of pathological gaming prevalence and comorbidity with mental health, academic and social problems. *Journal of Psychiatric Research*, *45*, 1573–1578.
- Fisher, S. (1994). Identifying video game addiction in children and adolescents. *Addictive Behaviors*, *19*(5), 545–553.
- Gentile, D. A., Bailey, K., Bavelier, D., Brockmyer, J. F., Cash, H., Coyne, S. M., ... Markle, T. (2017). Internet gaming disorder in children and adolescents. *Pediatrics*, *140*, S81–S85.
- Gentile, D. A., Choo, H., Liau, A., Sim, T., Li, D., Fung, D., & Khoo, A. (2011). Pathological video game use among youths: A two-year longitudinal study. *Pediatrics*, *127*, e319–e329.
- Gervasi, A. M., La Marca, L., Costanzo, A., Pace, U., Guglielmucci, F., & Schimmenti, A. (2017). Personality and Internet gaming disorder: A systematic review of recent literature. *Current Addiction Reports*, *4*, 293–307.
- Griffiths, M. D. (2009). Online computer gaming: Advice for parents and teachers. *Education and Health*, *27*, 3–6.

- Griffiths, M. D., & Nuyens, F. (2017). An overview of structural characteristics in problematic video game playing. *Current Addiction Reports*, 4, 272–283.
- Ha, J. H., Kim, S. Y., Bae, S. C., Bae, S., Kim, H., Sim, M., ... Cho, S. C. (2007). Depression and Internet addiction in adolescents. *Psychopathology*, 40(6), 424–430.
- Haagsma, M. C., Pieterse, M. E., & Peters, O. (2012). The prevalence of problematic video gamers in the Netherlands. *Cyberpsychology, Behavior and Social Networking*, 15, 162–168.
- Han, D. H., Yoo, M., Renshaw, P. F., & Petry, N. M. (2018). A cohort study of patients seeking Internet gaming disorder treatment. *Journal of Behavioral Addictions*, 7, 930–938.
- Ho, R. C., Zhang, M. W., Tsang, T. Y., Toh, A. H., Pan, F., Lu, Y., ... Watanabe, H. (2014). The association between internet addiction and psychiatric co-morbidity: A meta-analysis. *BMC Psychiatry*, 14, 183.
- Hyun, G. J., Han, D. H., Lee, Y. S., Kang, K. D., Yoo, S. K., Chung, U. S., & Renshaw, P. F. (2015). Risk factors associated with online game addiction: A hierarchical model. *Computers in Human Behavior*, 48, 706–713.
- Jeong, E. J., & Kim, D. H. (2011). Social activities, self-efficacy, game attitudes, and game addiction. *Cyberpsychology, Behavior and Social Networking*, 14, 213–221.
- Kaptsis, D., King, D. L., Delfabbro, P. H., & Gradisar, M. (2016). Withdrawal symptoms in internet gaming disorder: A systematic review. *Clinical Psychology Review*, 43, 58–66.
- Kim, K., & Kim, K. (2015). Internet game addiction, parental attachment, and parenting of adolescents in South Korea. *Journal of Child & Adolescent Substance Abuse*, 24, 366–371.
- Kim, D. J., Kim, K., Lee, H. W., Hong, J. P., Cho, M. J., Fava, M., ... Jeon, H. J. (2017). Internet game addiction, depression, and escape from negative emotions in adulthood: A nationwide community sample of Korea. *Journal of Nervous and Mental Disease*, 205, 568–573.
- King, D. L., & Delfabbro, P. H. (2014a). Is preoccupation an oversimplification? A call to examine cognitive factors underlying Internet gaming disorder. *Addiction*, 109, 1566–1567.
- King, D. L., & Delfabbro, P. H. (2014b). The cognitive psychology of Internet gaming disorder. *Clinical Psychology Review*, 34, 298–308.
- King, D. L., & Delfabbro, P. H. (2014c). Internet gaming disorder treatment: A review of definitions of diagnosis and treatment outcome. *Journal of Clinical Psychology*, 70, 942–955.
- King, D. L., & Delfabbro, P. H. (2016). The cognitive psychopathology of Internet gaming disorder in adolescence. *Journal of Abnormal Child Psychology*, 44, 1635–1645.
- King, D. L., Delfabbro, P. H., Doh, Y. Y., Wu, A. M. S., Kuss, D. J., Mentzoni, R., ... Sakuma, H. (2018). Policy and prevention approaches for disordered and hazardous gaming and Internet use: An international perspective. *Prevention Science*, 19, 233–249.
- King, D. L., Delfabbro, P. H., Gainsbury, S. M., Dreier, M., Greer, N., & Billieux, J. (2019). Unfair play? Video games as exploitative monetized services: An examination of game patents from a consumer protection perspective. *Computers in Human Behavior*, 101, 131–143.
- King, D. L., Delfabbro, P. H., & Griffiths, M. D. (2012). Clinical interventions for technology-based problems: Excessive Internet and video game use. *Journal of Cognitive Psychotherapy: An International Quarterly*, 26, 43–56.
- King, D. L., Delfabbro, P. H., Wu, A. M. S., Doh, Y. Y., Kuss, D. J., Mentzoni, R., ... Sakuma, H. (2017). Treatment of Internet gaming disorder: An international systematic review and CONSORT evaluation. *Clinical Psychology Review*, 54, 123–133.
- King, D. L., Delfabbro, P. H., Zwaans, T., & Kaptsis, D. (2013). Clinical features and axis I comorbidity of Australian adolescent pathological Internet and video-game users. *Australian and New Zealand Journal of Psychiatry*, 47, 1058–1067.
- King, D. L., Herd, M. C. E., & Delfabbro, P. H. (2018). Motivational components of tolerance in Internet gaming disorder. *Computers in Human Behavior*, 78, 133–141.
- King, D. L., Kaptsis, D., Delfabbro, P. H., & Gradisar, M. (2016). Craving for internet games? Withdrawal symptoms from an 84-h abstinence from massively multiplayer online gaming. *Computers in Human Behavior*, 62, 488–495.
- King, D. L., Koster, E., & Billieux, J. (2019). Study what makes games addictive. *Nature*, 573, 346.

- Ko, C. H., Liu, T. L., Wang, P. W., Chen, C. S., Yen, C. F., & Yen, J. Y. (2014). The exacerbation of depression, hostility, and social anxiety in the course of internet addiction among adolescents: A prospective study. *Comprehensive Psychiatry*, *55*, 1377–1384.
- Ko, C. H., Yen, J. Y., Yen, C. F., Lin, H. C., & Yang, M. J. (2007). Factors predictive for incidence and remission of internet addiction in young adolescents: A prospective study. *Cyberpsychology & Behavior*, *10*, 545–551.
- Kowitz, R., Domahidi, E., Festl, R., & Quandt, T. (2014). Social gaming, lonely life? The impact of digital game play on adolescents' social circles. *Computers in Human Behavior*, *36*, 385–390.
- Kuss, D. J., Van Rooij, A. J., Shorter, G. W., Griffiths, M. D., & van de Mheen, D. (2013). Internet addiction in adolescents: Prevalence and risk factors. *Computers in Human Behavior*, *29*, 1987–1996.
- Kwon, J.-H. (2011). Toward the prevention of adolescent Internet addiction. In K. Young & N. de Abreu (Eds.), *Internet addiction: A handbook and guide to evaluation and treatment* (pp. 223–243). John Wiley & Sons, Inc.: Hoboken, NJ.
- Laconi, S., Pirès, S., & Chabrol, H. (2017). Internet gaming disorder, motives, game genres and psychopathology. *Computers in Human Behavior*, *75*, 652–659.
- Lam, L. T., Peng, Z., Mai, J., & Jing, J. (2009). Factors associated with Internet addiction among adolescents. *Cyberpsychology & Behavior*, *12*, 551–555.
- Langham, E., Thorne, H., Browne, M., Donaldson, P., Rose, J., & Rockloff, M. (2015). Understanding gambling related harm: A proposed definition, conceptual framework, and taxonomy of harms. *BMC Public Health*, *16*, 80.
- Lee, H. W., Choi, J. S., Shin, Y. C., Lee, J. Y., Jung, H. Y., & Kwon, J. S. (2012). Impulsivity in internet addiction: A comparison with pathological gambling. *Cyberpsychology, Behavior and Social Networking*, *15*(7), 373–377.
- Li, S., Jin, X., Wu, S., Jiang, F., Yan, C., & Shen, X. (2007). The impact of media use on sleep patterns and sleep disorders among school-aged children in China. *Sleep*, *30*, 361–367.
- Liau, A. K., Choo, H., Li, D., Gentile, D. A., Sim, T., & Khoo, A. (2015). Pathological video-gaming among youth: A prospective study examining dynamic protective factors. *Addiction Research & Theory*, *23*, 301–308.
- Lim, S. S. (2012). Regulatory initiatives for managing online risks and opportunities for youths—The East Asian experience. In M. Walrave (Ed.), *E-youth: Balancing between opportunities and risks?* (pp. 271–290). Brussels: Peter Lang.
- Liu, M., & Peng, W. (2009). Cognitive and psychological predictors of the negative outcomes associated with playing MMOGs (massively multiplayer online games). *Computers in Human Behavior*, *25*, 1306–1311.
- Lo, S. K., Wang, C. C., & Fang, W. (2005). Physical interpersonal relationships and social anxiety among online game players. *Cyberpsychology & Behavior*, *8*, 15–20.
- Macgregor, D. M. (2000). Nintendonitis? A case report of repetitive strain injury in a child as a result of playing computer games. *Scottish Medical Journal*, *45*, 150.
- Mak, K. K., Lai, C. M., Watanabe, H., Kim, D. I., Bahar, N., Ramos, M., ... Cheng, C. (2014). Epidemiology of internet behaviors and addiction among adolescents in six Asian countries. *Cyberpsychology, Behavior and Social Networking*, *17*, 720–728.
- Männikkö, N., Billieux, J., & Kääriäinen, M. (2015). Problematic digital gaming behavior and its relation to the psychological, social and physical health of Finnish adolescents and young adults. *Journal of Behavioral Addictions*, *4*, 281–288.
- Marmet, S., Studer, J., Rougemont-Bücking, A., & Gmel, G. (2018). Latent profiles of family background, personality and mental health factors and their association with behavioural addictions and substance use disorders in young Swiss men. *European Psychiatry*, *52*, 76–84.
- McLean, S. (2013). *Advice sheets: Problematic Internet use*. Department of Education and Training. Retrieved from education.vic.gov.au/Documents/about/programs/bully-stoppers/smproblematic.pdf.

- Mentzoni, R. A., Brunborg, G. S., Molde, H., Myrseth, H., Skouverøe, K. J. M., Hetland, J., & Pallesen, S. (2011). Problematic video game use: Estimated prevalence and associations with mental and physical health. *Cyberpsychology, Behavior and Social Networking, 14*, 591–596.
- Mihara, S., & Higuchi, S. (2017). Cross-sectional and longitudinal epidemiological studies of Internet gaming disorder: A systematic review of the literature. *Psychiatry and Clinical Neurosciences, 71*, 425–444. <https://doi.org/10.1111/pcn.12532>.
- Milani, L., Osualdella, D., & Di Blasio, P. (2009). Quality of interpersonal relationships and problematic Internet use in adolescence. *Cyberpsychology & Behavior, 12*, 681–684.
- Müller, K. W., Beutel, M. E., Egloff, B., & Wölfling, K. (2014). Investigating risk factors for Internet gaming disorder: A comparison of patients with addictive gaming, pathological gamblers and healthy controls regarding the big five personality traits. *European Addiction Research, 20*, 129–136.
- Müller, K. W., Janikian, M., Dreier, M., Wölfling, K., Beutel, M. E., Tzavara, C., ... Tsitsika, A. (2015). Regular gaming behavior and internet gaming disorder in European adolescents: Results from a cross-national representative survey of prevalence, predictors, and psychopathological correlates. *European Child & Adolescent Psychiatry, 24*, 565–574.
- Pawlowski, M., & Brand, M. (2011). Excessive Internet gaming and decision making: Do excessive World of Warcraft players have problems in decision making under risky conditions? *Psychiatry Research, 188*, 428–433.
- Peters, C. S., & Malesky, L. A. (2008). Problematic usage among highly-engaged players of massively multiplayer online role playing games. *Cyberpsychology & Behavior, 11*, 481–484.
- Petry, N. M., Martin, B., Cooney, J. L., & Kranzler, H. R. (2000). Give them prizes and they will come: Contingency management for treatment of alcohol dependence. *Journal of Consulting and Clinical Psychology, 68*(2), 250.
- Prendergast, M., Podus, D., Finney, J., Greenwell, L., & Roll, J. (2006). Contingency management for treatment of substance use disorders: A meta-analysis. *Addiction, 101*, 1546–1560.
- Przybylski, A. K., Weinstein, N., & Murayama, K. (2016). Internet gaming disorder: Investigating the clinical relevance of a new phenomenon. *American Journal of Psychiatry, 174*, 230–236.
- RANZCP. (2011). *The impact of media on vulnerable children and adolescents [position statement 72]*. Faculty of Child and Adolescent Psychiatry. Retrieved from https://www.ranzcp.org/Files/Resources/College_Statements/Position_Statements/ps72-pdf.aspx.
- Rehbein, F., & Baier, D. (2013). Family-, media-, and school-related risk factors of video game addiction: A 5-year longitudinal study. *Journal of Media Psychology-Theories Methods and Applications, 25*, 118–128.
- Rehbein, F., Kleimann, M., & Mößle, T. (2010). Prevalence and risk factors of video game dependency in adolescence: Results of a German nationwide survey. *Cyberpsychology, Behavior and Social Networking, 13*, 269–277.
- Rehbein, F., Kliem, S., Baier, D., Mößle, T., & Petry, N. M. (2015). Prevalence of Internet gaming disorder in German adolescents: Diagnostic contribution of the nine DSM-5 criteria in a state-wide representative sample. *Addiction, 110*, 842–851.
- Rho, M. J., Lee, H., Lee, T. H., Cho, H., Jung, D. J., Kim, D. J., & Choi, I. Y. (2017). Risk factors for internet gaming disorder: Psychological factors and internet gaming characteristics. *International Journal of Environmental Research and Public Health, 15*, 40.
- Romano, J. L., & Hage, S. M. (2000). Prevention: A call to action. *The Counseling Psychologist, 28*, 854–856.
- Scharkow, M., Festl, R., & Quandt, T. (2014). Longitudinal patterns of problematic computer game use among adolescents and adults—A 2-year panel study. *Addiction, 109*, 1910–1917.
- Schiebener, J., & Brand, M. (2017). Decision-making and related processes in Internet gaming disorder and other types of Internet-use disorders. *Current Addiction Reports, 4*, 262–271.

- Schimmenti, A., Guglielmucci, F., Barbasio, C., & Granieri, A. (2012). Attachment disorganization and dissociation in virtual worlds: A study on problematic internet use among players of online role-playing games. *Clinical Neuropsychiatry*, 9, 195–202.
- Schneider, L. A., King, D. L., & Delfabbro, P. H. (2017). Family factors in adolescent problematic Internet gaming: A systematic review. *Journal of Behavioral Addictions*, 6, 321–333.
- Schochat, T., Flint-Bretner, O., & Tzischinsky, O. (2010). Sleep patterns, electronic media exposure and daytime sleep-related behaviours among Israeli adolescents. *Acta Paediatrica*, 99, 1396–1400.
- Schüll, N. D. (2012). *Addiction by design: Machine gambling in Las Vegas*. Princeton University Press.
- Seay, A. F., & Kraut, R. E. (2007, April). *Project massive: Self-regulation and problematic use of online gaming*. In: *Proceedings of the SIGCHI conference on Human factors in computing systems* (pp. 829–838): ACM.
- Sioni, S. R., Burlleson, M. H., & Bekerian, D. A. (2017). Internet gaming disorder: Social phobia and identifying with your virtual self. *Computers in Human Behavior*, 71, 11–15.
- Soroush, M., Hancock, M., & Bonns, V. K. (2014, October). Self-control in casual games: The relationship between Candy Crush Saga™ players' in-app purchases and self-control. In *Games Media Entertainment (GEM), 2014 IEEE*. <https://doi.org/10.1109/GEM.2014.7048099>. Retrieved from https://touchlab.uwaterloo.ca/testing/wordpress/wp-content/uploads/ieee-gem2014_submission_56.pdf.
- Starcevic, V. (2017). Internet gaming disorder: Inadequate diagnostic criteria wrapped in a constraining conceptual model: Commentary on: Chaos and confusion in DSM-5 diagnosis of Internet Gaming Disorder: Issues, concerns, and recommendations for clarity in the field (Kuss et al.). *Journal of Behavioral Addictions*, 6, 110–113.
- Stevens, M. W. R., King, D. L., Dorstyn, D., & Delfabbro, P. H. (2019). Cognitive-behavioral therapy for Internet gaming disorder: A systematic review and meta-analysis. *Clinical Psychology and Psychotherapy*, 26, 191–203.
- Stopfer, J. M., Braun, B., Müller, K. W., & Egloff, B. (2015). Narcissus plays video games. *Personality and Individual Differences*, 87, 212–218.
- Strittmatter, E., Kaess, M., Parzer, P., Fischer, G., Carli, V., Hoven, C. W., ... Bobes, J. (2015). Pathological Internet use among adolescents: Comparing gamers and non-gamers. *Psychiatry Research*, 228, 128–135.
- Sublette, V. A., & Mullan, B. (2012). Consequences of play: A systematic review of the effects of online gaming. *International Journal of Mental Health and Addiction*, 10, 3–23.
- Tejeiro, R. A., Gomez-Vallecillo, J. L., Pelegrina, M., Wallace, A., & Emberley, E. (2012). Risk factors associated with the abuse of video games in adolescents. *Psychology*, 3, 310–314.
- Turkle, S. (2017). *Alone together: Why we expect more from technology and less from each other*. UK: Hachette.
- van Rooij, A. J., Schoenmakers, T. M., Vermulst, A. A., Van Den Eijnden, R. J., & Van De Mheen, D. (2011). Online video game addiction: Identification of addicted adolescent gamers. *Addiction*, 106, 205–212.
- Walther, B., Morgenstern, M., & Hanewinkel, R. (2012). Co-occurrence of addictive behaviors: Personality factors related to substance use, gambling and computer gaming. *European Addiction Research*, 18, 167–174.
- Wan, C. S., & Chiou, W. B. (2006). Psychological motives and online games addiction: A test of flow theory and humanistic needs theory for Taiwanese adolescents. *Cyberpsychology & Behavior*, 9, 317–324.
- Wang, H. R., Cho, H., & Kim, D. J. (2018). Prevalence and correlates of comorbid depression in a nonclinical online sample with DSM-5 internet gaming disorder. *Journal of Affective Disorders*, 226, 1–5.
- Wang, C. W., Ho, R. T., Chan, C. L., & Tse, S. (2015). Exploring personality characteristics of Chinese adolescents with internet-related addictive behaviors: Trait differences for gaming addiction and social networking addiction. *Addictive Behaviors*, 42, 32–35.

- Weis, R., & Cerankosky, B. C. (2010). Effects of video-game ownership on young boys' academic and behavioral functioning: A randomized, controlled study. *Psychological Science, 21*, 463–470.
- Winkler, A., Dörsing, B., Rief, W., Shen, Y., & Glombiewski, J. A. (2013). Treatment of internet addiction: A meta-analysis. *Clinical Psychology Review, 33*, 317–329.
- World Health Organization (WHO). (2014). *Global status report on alcohol and health, 2014*. Geneva: World Health Organization. ISBN: 978 92 4 069276 3.
- World Health Organization (WHO). (2019). *6C51 gaming disorder*. Retrieved from <https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/1448597234>.
- Wu, C. Y., Lee, M. B., Liao, S. C., & Chang, L. R. (2015). Risk factors of internet addiction among internet users: an online questionnaire survey. *PLoS One, 10*, e0137506.
- Wu, C. S. T., Wong, H. T., Yu, K. F., Fok, K. W., Yeung, S. M., Lam, C. H., & Liu, K. M. (2016). Parenting approaches, family functionality, and internet addiction among Hong Kong adolescents. *BMC Pediatrics, 16*, 130.
- Yao, Y. W., Wang, L. J., Yip, S. W., Chen, P. R., Li, S., Xu, J., ... Fang, X. Y. (2015). Impaired decision-making under risk is associated with gaming-specific inhibition deficits among college students with Internet gaming disorder. *Psychiatry Research, 229*, 302–309.
- Yen, J. Y., Ko, C. H., Yen, C. F., Wu, H. Y., & Yang, M. J. (2007). The comorbid psychiatric symptoms of Internet addiction: Attention deficit and hyperactivity disorder (ADHD), depression, social phobia, and hostility. *Journal of Adolescent Health, 41*, 93–98.
- Young, K. S., & Rogers, R. C. (1998). The relationship between depression and Internet addiction. *Cyberpsychology & Behavior, 1*, 25–28.

Further reading

- King, D. L., & Delfabbro, P. H. (2019). *Internet gaming disorder: Theory, assessment, treatment, and prevention*. Cambridge, MA: Elsevier Academic Press.
- Petry, N. M., Rehbein, F., Gentile, D. A., Lemmens, J. S., Rumpf, H. J., Mößle, T., ... Auriacombe, M. (2014). An international consensus for assessing internet gaming disorder using the new DSM-5 approach. *Addiction, 109*, 1399–1406.
- Saunders, J. B., Hao, W., Long, J., King, D. L., Mann, K., Fauth-Bühler, M., ... Chan, E. (2017). Gaming disorder: Its delineation as an important condition for diagnosis, management, and prevention. *Journal of Behavioral Addictions, 6*, 271–279.

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Common challenges and pitfalls in the treatment of paediatric OCD using CBT and medication

*Georgina Krebs^{a,b}, Dominic Cottrell^a,
Angela Lewis^a, and Bruce Clark^{a,c}*

^aOCD, BDD and Related Disorders Clinic, South London and Maudsley NHS Trust, London, United Kingdom, ^bSocial, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, United Kingdom, ^cDepartment of Child and Adolescent Psychiatry, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, United Kingdom

1 Introduction

Obsessive-compulsive disorder (OCD) is characterized by persistent and unwanted intrusive thoughts, images, and urges (obsessions) and/or repetitive behaviours or mental acts (compulsions) ([American Psychiatric Association, 2013](#); [World Health Organization, 2018](#)). The disorder has an estimated prevalence of approximately 2% among children and adolescents ([Douglass, Moffitt, Dar, McGee, & Silva, 1995](#)) and is associated with marked functional impairment in multiple domains ([Piacentini, Bergman, Keller, & McCracken, 2003](#)). In the absence of treatment, symptoms typically follow a chronic course ([Stewart et al., 2004](#)) and predict a range of other psychiatric disorders in adulthood ([Micali et al., 2010](#)). Over the last two decades, increasing empirical attention has been given to the treatment of paediatric OCD. There is robust evidence for cognitive behaviour therapy (CBT) and selective serotonin reuptake inhibitors (SSRIs) as being efficacious treatments for OCD in youth ([McGuire et al., 2015](#); [Watson & Rees, 2008](#)). These treatments are effective as stand-alone interventions, but in combination their effect may be superior to either treatment alone

(POTS, 2004). Clinical guidelines recommend CBT as the first-line treatment for young people with OCD but specify that SSRIs should be offered in conjunction with CBT to youth who have not adequately responded to a previous attempt at CBT (Geller & March, 2012; NICE, 2005).

Despite being highly effective treatments for OCD, there are a wide range of obstacles that clinicians can encounter when delivering CBT and SSRIs to young people with OCD, which can hinder compliance and undermine effectiveness. This chapter outlines some of the common challenges and offers strategies on how to manage these issues to optimize outcomes (see Tables 1 and 2 for an overview).

TABLE 1 Common obstacles when delivering CBT to young people with OCD.

Domain	Obstacles	Strategies
Refusal to engage in ERP	Anxious avoidance	<ul style="list-style-type: none"> • Ensure thorough psychoeducation to dispel any erroneous beliefs • Break exposure tasks down until 'transition zone' is reached
	Poor insight	<ul style="list-style-type: none"> • Anchor tasks in functional goals • Use contingency management • Consider working exclusively with parents
Mental rituals	Difficult to identify	<ul style="list-style-type: none"> • Ask directly about presence of mental rituals • Give a range of examples to aid recognition • Use behavioural observations
	Difficult to control	<ul style="list-style-type: none"> • Once recognized, label mental ritual as a compulsion and put on hierarchy • Usually more effective to 'mess up' ritual as opposed to attempted to stop it initially • During E/RP, verbalize the mental ritual and/or write it down
Family accommodation	Can easily be overlooked	<ul style="list-style-type: none"> • Assess using comprehensive measure • Consider all family members, not just primary caregiver
	Attempts to reduce family accommodation can be met with resistance	<ul style="list-style-type: none"> • Be clear that family accommodation is a maintaining factor in OCD • Identify and address individual reasons for engaging in accommodation (e.g. guilt and fear)

TABLE 1 Common obstacles when delivering CBT to young people with OCD—cont'd

Domain	Obstacles	Strategies
Reassurance	May not be recognized as a compulsion	<ul style="list-style-type: none"> • Explicitly label as a compulsion • Be clear that reassurance seeking is counterproductive and will fuel OCD • Put examples of reassurance seeking on hierarchy • Gradually reduce reassurance seeking, as guided by hierarchy
	Young person unable resist asking for reassurance	<ul style="list-style-type: none"> • Agree that reassurance will not be provided if sought • Agree an appropriate alternative response to providing reassurance • Ensuring a consistent approach among relevant family members and friends
Distraction	Unclear whether it should be encouraged or discouraged during exposure tasks	<ul style="list-style-type: none"> • Priority is to promote engagement with exposure tasks. Ideally this would be without distraction, but if necessary distraction can be used as a short-term coping strategy
	Distraction becoming a ritual	<ul style="list-style-type: none"> • Encourage young person to frequently vary the form of distraction • Monitor beliefs about function of distraction. If they view distraction as being <i>necessary</i> as opposed to <i>helpful</i>, it is advisable to reduce distraction
Constantly changing symptoms	Compulsions are difficult to pin down, and ERP can feel like constant firefighting	<ul style="list-style-type: none"> • Identify whether new compulsions relate to same obsession or different obsession • If new compulsions relate to same obsession, be vigilant to 'ritual replacement' during ERP. Establish obsession hierarchy and directly confront obsessional fear • If new compulsions relate to new obsession, add to hierarchy but do not become sidetracked and attempt to tackle new symptoms as soon as they occur. Instead, continue to follow hierarchy and promote generalization of ERP principles to other domains

Continued

TABLE 1 Common obstacles when delivering CBT to young people with OCD—cont'd

Domain	Obstacles	Strategies
Challenging the core fear	Core fears are difficult to identify	<ul style="list-style-type: none"> • Ensure detail is elicited and avoid making assumptions • Normalize obsessions to facilitate disclosure
	Thought-action fusion inhibits disclosure of thoughts	<ul style="list-style-type: none"> • Consider use of cognitive strategies to tackle thought-action fusion
	Resistance to exposure tasks that seem extreme	<ul style="list-style-type: none"> • Use metaphors to convey rationale for these tasks
Ethical considerations in ERP	Therapist and parental anxiety about ethics of exposure tasks	<ul style="list-style-type: none"> • Ensure family are closely involved in therapeutic work • Make sure exposure tasks are grounded in clear rationale with discernible link between the task and the target obsession

TABLE 2 Common obstacles when using medication to treat youth with OCD.

Domain	Obstacles	Strategies
Refusal to trial a medication	Parental attitudes	<ul style="list-style-type: none"> • Emphasize that medication is an evidence-based treatment for OCD • Discuss OCD in 'biological' and psychological terms
	Patient attitudes	<ul style="list-style-type: none"> • Emphasize the role of medication in 'assisting' the fight back against OCD • Discuss the evidence base for tackling OCD pharmacologically
Fear of addiction	Perception of 'addictiveness'	<ul style="list-style-type: none"> • Explain withdrawal syndrome is not universally experienced • Discuss the difference between 'withdrawal symptoms' and drug dependency
	Withdrawal symptoms	<ul style="list-style-type: none"> • Counsel the potential effects of withdrawing from an SSRI before this happens • When switching/stopping a medication, cross-taper and reduce slowly, especially towards the end of the course

TABLE 2 Common obstacles when using medication to treat youth with OCD—cont'd

Domain	Obstacles	Strategies
Suicidality	Concerns regarding increased suicidality	<ul style="list-style-type: none"> • Discuss suicide as part of the consultation, both related to and independent of medication usage • Normalize discussions of self-harm and suicide and accept that they may be a part of the experience of OCD, even without treatment • Form a safe and clear management plan with both patient and caregivers • Reassure that SSRIs are more likely to reduce suicidal thoughts, by reducing the distress from OCD
Side-effects	GI side effects	<ul style="list-style-type: none"> • Reassure that these are typically self-limiting and will pass on their own • Minimize GI side effects through split doses or taking medication with meals
	Sexual side effects	<ul style="list-style-type: none"> • Discuss these before starting an SSRI and normalize discussion of sexual function as part of the consultation • If sexual side effects appear, consider dose reduction or switch to an alternative agent
	Activation syndrome	<ul style="list-style-type: none"> • If evident, consider using slower titration schedules, reduction of dose, or switch to an alternative agent • Consider this if symptoms appear to be worsening without obvious trigger
Failure to improve	Early phase	<ul style="list-style-type: none"> • Explain that SSRIs tend not to be a 'quick fix' and that an adequate trial to assess response is typically at least a few months
	Later phase	<ul style="list-style-type: none"> • Consider switching to an alternative SSRI; if doing so, carefully cross-taper with an alternative agent and be aware of the risks of discontinuation syndrome
Withdrawing treatment	Choosing the best time to stop treatment	<ul style="list-style-type: none"> • Taper slowly • Choose times of reduced stress/low symptom burden • Offer frequent reviews • Counsel regarding risk of relapse and potential need to restart medication

2 Obstacles to the delivery of CBT

CBT for paediatric OCD is a relatively short-term, psychological treatment which generally encompasses psychoeducation about OCD and anxiety, exposure with response prevention (ERP), and relapse prevention (Turner, Volz, & Krebs, 2019). The core active component is ERP, and clinical guidelines specify that this should be a key focus of CBT for OCD (NICE, 2005). ERP involves gradually confronting feared situations (e.g. touching door handles) and refraining from carrying out compulsions (e.g. handwashing) in an attempt to neutralize anxiety or a feared outcome. Through this process the anxiety gradually subsides, and with repeated exposure, it extinguishes altogether (i.e. habituation). ERP tasks are set up in graded way, as guided by a hierarchy, and are carried out in sessions with the therapist and in between sessions as homework. Despite the relatively straightforward principles underlying CBT for OCD in young people, the treatment can nevertheless be challenging to implement.

2.1 Refusal to engage in ERP

Refusal to engage in exposure tasks is a frequently encountered obstacle when carrying out CBT for OCD with young people. Refusal can occur for a variety of reasons, and understanding the driving factors is crucial to informing treatment strategies. The most common reasons for refusal to engage with CBT for OCD are anxious avoidance and poor insight.

Young people often refuse to engage in exposure work because they are simply too anxious about the possible consequences of experiencing high levels of distress. They may have specific beliefs about what can happen if a person gets 'too anxious', or they might just find the feeling far too overwhelming. It is crucial that any young person engaged in CBT for OCD has received thorough psychoeducation to dispel any unhelpful, erroneous beliefs about anxiety. When anxious avoidance persists, tasks should be broken down as much as possible until the 'transition zone' has been reached (March & Mulle, 1998). This is the point at which the child feels able to resist compulsions whilst still generating some degree of anxiety so that the child can learn the principles of anxiety habituation at an experiential level.

Poor insight is a common feature of paediatric OCD, particularly in young children (Lewin et al., 2010). Young people who do not recognize the irrational nature of their obsessions and compulsions are typically less likely to engage in ERP, and poor insight has been associated with poorer response to CBT in children (Garcia et al., 2010). However, CBT can still be effective where insight is limited and should be offered. When insight is poor, it is especially important that the young person's functional goals

are identified at the outset of CBT, and ERP tasks should be anchored in achieving these goals to promote engagement. Therapists might also consider the use of contingency management to promote compliance (e.g. rewards for attendance and/or completion of tasks), or even working exclusively with parents (Lebowitz, 2013).

2.2 Tackling mental rituals

Therapists often describe mental rituals as being challenging to tackle in CBT (Gillihan, Williams, Malcoun, Yadin, & Foa, 2012). Mental rituals are a form of covert compulsion that can involve repeatedly thinking of certain 'safe' words or phrases, counting, praying, mentally reassuring oneself, or mentally checking. As with overt compulsions, mental rituals are performed in an attempt to neutralize anxiety or prevent a feared outcome from occurring but have the unintended consequence of reinforcing obsessional thoughts and maintaining anxiety. Mental rituals have been estimated to affect approximately a third of adolescents with OCD, although they may be less common in children under the age of 13 (Mancebo et al., 2008). They can cooccur with any other OCD symptoms but have been particularly linked with sexual, aggressive, and religious obsessional thoughts (Abramowitz, Franklin, & Schwartz, 2003; Williams et al., 2011).

Mental rituals can be difficult to identify because they are not visible to others, and young people may not recognize mental rituals as being a compulsion, instead confusing them with obsessions or viewing them as helpful 'self-talk'. It is therefore crucial for clinicians to directly ask about the presence of mental rituals and to provide a range of concrete examples to aid recognition. Behavioural observations can also be helpful in identifying mental rituals. Young people with mental rituals often appear distracted or slowed down. For example, they may be delayed in responding to questions, speak in a disjointed manner, or forget their train of thought halfway through a sentence. Again, if such behaviours are observed, clinicians should ask directly about mental rituals.

Even when mental rituals are identified, they can still present a challenge in treatment. Mental rituals can feel harder for the young person to control compared with overt compulsions and are often described as being performed automatically or involuntarily (Gillihan et al., 2012). Attempting to simply stop performing a mental ritual can often be counterproductive and is analogous to the paradoxical effect of thought suppression (Wegner, Schneider, Carter, & White, 1987). A better approach is to expose the young person to an obsessional thought to trigger the mental ritual and encourage them to gradually 'mess up' the ritual over successive attempts (e.g. changing the order of numbers in a counting ritual).

When tackling mental rituals with young people in this way, in the early stages, it can often be helpful to say the ritual aloud and/or write it down. This can create a cognitive load that interferes with the almost involuntary nature of mental rituals and gives the young person greater control over the process. It can also make it easier for therapist to monitor compliance with ERP tasks and progress.

2.3 Dealing with distraction

In the context of CBT for OCD, distraction can involve physical behaviours (e.g. looking away) or mental processes (e.g. singing a song in one's head) which serve the function of enabling the young person to avoid facing their fears and/or anxiety head-on. There has been some debate about whether distraction helps or hinders exposure-based CBT. On the one hand the ultimate goal of exposure-based CBT is to fully confront fears without any attempts to avoid or neutralize anxiety. Thus distraction is often discouraged and is considered to diminish the effect of exposure techniques by interfering with anxiety habituation (Gillihan et al., 2012). On the other hand, it has been suggested that *judicious* use of distraction techniques during CBT for anxiety might be helpful in certain circumstances, for example, if they promote engagement with exposure tasks and/or a sense of self-efficacy (Parrish, Radomsky, & Dugas, 2008).

In our view the key to effective CBT for OCD is to encourage and promote engagement with ERP tasks. Ideally, this would be done without distraction techniques, and therapists should be vigilant to physical and mental distraction during ERP. However, if the young person is unwilling to carry out any ERP tasks, due to difficulty tolerating anxiety, then distraction techniques might be indicated. If distraction is used, it should be explicitly labelled as a temporary strategy that the young person will utilize in the early stages of treatment until they gain more confidence in carrying out ERP tasks. It can also be helpful to encourage the young person to vary the distraction strategy to reduce the risk of it becoming a ritual.

2.4 Managing reassurance

Reassurance seeking is a common behaviour among youth with OCD. Studies have estimated that over half of children and teenagers with OCD seek reassurance from their parents about perceived threats on a daily basis (Peris et al., 2008). The process of seeking reassurance can become highly ritualized in OCD, with young people repeatedly asking the same question and requiring a very specific response before they can desist. Although OCD sufferers most commonly ask for reassurance from family members and friends, reassurance seeking can spill over into CBT

sessions (Kobori & Salkovskis, 2013). In some instances reassurance seeking in therapy sessions might be obvious, but in other cases it can be subtle and emerge gradually during the course of treatment. Thus therapists can find themselves inadvertently providing reassurance to a young person, especially during ERP tasks.

Although reassurance provides the patient with some temporary relief from their anxiety and may even appear to bolster their confidence during an ERP task, it is nevertheless counterproductive in the long run. On a behavioural level, reassurance seeking typically leads to an immediate reduction in anxiety, thereby interfering with the process of anxiety habituation. Thus, instead of learning that their anxiety naturally reduces over time when they confront a feared situation, they instead learn that reassurance alleviates their distress and as such can become increasingly reliant on this as a means of coping. On a cognitive level, reassurance prevents the young person from having to tolerate uncertainty and being exposed to the possibility that a negative outcome *could* occur when their obsessional fears are triggered.

If reassurance seeking is identified during CBT, it should be placed on the hierarchy and tackled in a gradual way like any other compulsion. Whilst the ultimate goal is for the young person to refrain from asking for reassurance, it should be acknowledged that this might be too difficult for the young person initially. The therapist should therefore explicitly discuss and agree with the young person a response to reassurance seeking. Parents and close others should be aware of this agreement so that they can respond in a consistent manner.

2.5 Reducing family accommodation

The term ‘family accommodation’ refers to the involvement and participation of family members in an individual’s OCD rituals. This can entail direct participation in routines (e.g. helping a young person to wash), providing items for rituals (e.g. excessive quantities of soap), facilitating avoidance, and providing reassurance. Family accommodation has received increasing empirical attention over the last decade, and it is now recognized as being a widespread phenomenon in the context of OCD. Indeed, studies have demonstrated that 60%–96% of relatives assist or modify their behaviour to accommodate their child’s OCD symptoms (Monzani et al., n.d.). Moreover, family accommodation is also predictive of poorer response to CBT (Garcia et al., 2010; Torp et al., 2015).

Family accommodation of OCD can easily be overlooked during CBT, with therapists focussing exclusively on the young person’s symptoms. To optimize treatment response, it is important that the full extent of family

accommodation is identified and subsequently targeted during CBT. Assessment of family accommodation can be aided by use of the Family Accommodation Scale, a 13-item questionnaire designed to provide a comprehensive assessment of current accommodation of OCD-related behaviours (Flessner et al., 2010).

Importantly, effective reduction of family accommodation has been shown to lead to better CBT outcomes (Merlo, Lehmkuhl, Geffken, & Storch, 2009). Thus relevant family members should be directly included in CBT, and the various facets of family accommodation should be labelled as rituals, placed on the symptom hierarchy, and gradually tackled in a collaborative manner. In practice, reducing family accommodation can often be met with resistance. Few studies have explored the reasons why family members are motivated to accommodate OCD-related avoidance and compulsions. In some cases it may simply reflect a lack of understanding that accommodating behaviours are counterproductive and fuel OCD. However, many parents recognize that accommodation of OCD is unhelpful yet continue to support their child's rituals. In such cases it is crucial to identify the individual factors driving accommodation so that these can be managed appropriately. For example, anxious parents may find it particularly hard to withdraw from rituals, in part because they struggle to tolerate the feeling that they are causing distress in their child. In support of this a number of studies have shown a positive association between parental anxiety and accommodation of OCD (Monzani et al., n.d.). Some parents are reluctant to reduce their accommodation of OCD because, when they do, their child displays aggression or extreme temper outbursts. Indeed, temper outbursts often occur in the context of OCD when rituals are thwarted and the child's propensity for temper outbursts is positively associated with maternal accommodation of OCD (Krebs et al., 2013). This issue can generally be addressed by explaining that temper outbursts are a normal part of the anxiety 'fight-or-flight' response, reassuring parents that outbursts will improve as OCD symptoms reduce, and encouraging parents to praise their child in instances where they challenge OCD without having an outburst. In cases where temper outbursts are part of broader range of externalizing symptoms (e.g. stealing, lying, and vindictiveness), CBT outcomes may be improved by including parent management training (PMT) as an adjunct to CBT for OCD (Sukhodolsky, Gorman, Scahill, Findley, & McGuire, 2013).

2.6 Coping with constantly changing symptoms

OCD is a highly heterogeneous condition, encompassing a wide range of possible obsessions and compulsions. Factor analytic studies

have found that paediatric OCD symptoms fall into at least four dimensions, namely, hoarding/checking, taboo obsessions, contamination/cleaning, and symmetry/ordering (Mataix-Cols, do Rosario-Campos, & Leckman, 2005). Several studies have examined the temporary stability of OCD symptoms in young people. The main finding from these investigations is that it is relatively common for OCD symptoms to change over time *within* symptom dimension but changes *between* symptoms dimensions are rare (Delorme et al., 2006; Fernandez de la Cruz et al., 2013; Rettew, Swedo, Leonard, Lenane, & Rapoport, 1992). Nevertheless, frequently changing compulsions are commonly reported by clinicians as being an obstacle in CBT for OCD (Keleher, Jassi, & Krebs, *in press*). The therapist might find it hard to construct or adhere to a hierarchy, and treatment can feel like a constant process of firefighting of new symptoms.

In our experience the most common type of change in OCD symptoms occurs when one form of ritual is replaced with another. For example, handwashing may decrease but be replaced by excessive use of antibacterial hand gel. This type of 'ritual replacement' will hinder progress in CBT as it will prevent the child from fully confronting their feared outcome and experiencing anxiety habituation. The child and their parents should therefore be encouraged to remain vigilant for new and emerging compulsions during ERP tasks and to respond to these using the skills that they have learnt in treatment. In cases where compulsions appear to be frequently morphing from one form to another, the therapist might decide to base the symptom hierarchy on the child's key obsessions (e.g. an obsessional fear of bodily fluids) rather than compulsions (e.g. varying forms of washing, cleaning, and avoidance), since the former are likely to be more stable.

Alternatively, new obsessions and compulsions can emerge entirely unrelated to ERP tasks; they are not replacing a preexisting ritual, but instead, they are additional symptoms. In such scenarios, new symptoms can be acknowledged and added to the hierarchy. However, it is important that the therapist is not sidetracked by new symptoms; although it can feel tempting to try to 'nip them in the bud', this approach often leads to a pattern of tackling symptoms in a rather haphazard way. Instead, it is usually advisable for the therapist to remain focussed on systematically working through the symptom hierarchy. As the child's confidence in ERP grows and their obsessional beliefs and anxiety reduce, they will usually generalize their learning and use of ERP techniques. When this occurs, they will typically start to spontaneously tackle symptoms, including any new ones that have emerged during treatment. Thus it is generally not necessary to tackle every obsession and associated compulsion in formal ERP tasks as some will naturally abate.

2.7 Challenging the core fear

To be fully effective, exposure tasks must adequately challenge the young person's *core fear*. However, core fears are often difficult to identify, especially in younger children. When eliciting a young person's core fear, detail is key, and assumptions should be avoided. For example, a child might engage in cleaning compulsions which appear to be based on a fear of germs in general, but which are in fact associated with a very specific fear of urine in particular. Understanding this will determine the design of the exposure tasks. Even when the clinician asks directly, obsessional fears may be withheld due to shame. Normalizing obsessions demonstrates to the young person that the therapist will not be shocked to hear their disclosure; however, abhorrent it may seem. A useful resource for this is a survey which demonstrates how common intrusive thoughts are among students (Purdon & Clark, 1993). Thought-action fusion can also inhibit a young person's ability to fully disclose their obsessions for fear of the possible consequences of doing so. Thought-action fusion is the belief that thinking about something is either morally equivalent to doing it or increases the likelihood of its occurrence (Shafran & Rachman, 2004). Thus, when a young person appears reticent to disclose their obsessional fears, therapists should be vigilant to thought-action fusion beliefs and use cognitive techniques to challenge them if necessary.

Once identified, core fears should be placed at the top of the hierarchy, and the young person encouraged to gradually work towards confronting them, often in the latter stages of treatment. Exposure to core fears can seem relatively extreme and involve doing something out of the norm, such as eating off a toilet seat to challenge a fear of contamination. Where in vivo exposure is not possible (e.g. a fear of going to hell), imaginal exposure can be used instead. The rationale for carrying out extreme exposure tasks can be difficult to convey to young people, but metaphors can be helpful (Krebs & Lewis, 2018). For example, extreme exposure tasks can be likened to baseball players using heavier bats during their practice, so that when they go back to using their standard bat during matches it feels easier. It is crucial to make the young person aware that tackling core fears is essential to maximize their chance of full recovery and reducing the risk of relapse (Eisen et al., 2013).

2.8 Ethical considerations in ERP

Exposure tasks in the context of CBT for OCD necessarily involve encouraging people to do something anxiety provoking. This can sit uncomfortably with many therapists, who consider their role in treatment to be one of distress reduction. However, given that ERP is a key active component in CBT for OCD, it is paramount that clinicians adopt

the ethos of the model and tolerate their own anxieties about exposure work to ensure they are able to deliver treatment in its most efficacious form. Parents may also harbour anxieties about the risks involved in an exposure task or about the consequences of their child experiencing high levels of distress. Families, in particular parents, should be closely involved in sessions throughout CBT (Barrett, Healy-Farrell, & March, 2004; Freeman et al., 2014). Involving parents in the course of treatment ensures they are clear about the rationale for exposure tasks and that they are able to consent to the work being carried out. Parents may need to be supported to identify their own beliefs about anxiety and to understand the role that they inadvertently play in the maintenance of their child's OCD.

Most exposure tasks will involve encouraging a young person to confront 'normal' and developmentally appropriate situations or materials. However, this is not always the case. A young person with aggressive obsessions might be asked to hold a sharp knife, someone with contamination obsessions might eat food that has been placed on a bin, or a child with sexual obsessions might record a script of their most terrifying thoughts about sex and listen to these on a loop tape. Such obsessional thoughts and/or related ERP tasks can raise concerns about risk among family members and indeed clinicians. It is essential to hold in mind that individuals with OCD do not act on their obsessional fears (Veale, Freeston, Krebs, Heyman, & Salkovskis, 2009), and ERP tasks aimed at triggering such thoughts are vital for the young person to challenge their obsession in its entirety. There is no clear right or wrong when it comes to how far is 'too far' with exposure tasks, but the guiding principle is that the rationale should always be clear, with a discernible link between the task and the obsession that it targets (Krebs & Lewis, 2018).

3 Obstacles to the use of medication

The first-line medication option for OCD is a selective serotonin reuptake inhibitor (SSRI) (NICE). Although the tricyclic antidepressant clomipramine has also demonstrated efficacy in paediatric OCD, it is not the drug of choice due to (i) toxicity in overdose, (ii) significant side-effect profile (with pronounced anticholinergic effects), and (iii) risk of cardiotoxicity (requiring ECG monitoring) (Cook et al., 2001). Whilst all SSRI medications appear to have similar efficacy in treating paediatric OCD, the recommended first choices are fluoxetine (which has a license in paediatric depression and, due to its long half-life, fewer concerns regarding adherence) and sertraline. Paroxetine is especially unfavourable because of a short half-life, which increases the risk of discontinuation symptoms, alongside concerns regarding suicidality.

Despite the clear efficacy of such medications, research suggests that only a small proportion of young people treated with psychotropic medication stay on their medication for an adequate length of time (Haege et al., 2016). One of the most consistently identified factors in adherence among young people is parental attitudes towards pharmacotherapy (Dean, Wragg, Draper, & McDermott, 2011), and so it is vital that all involved are given sufficient and accurate information to inform decisions about their treatment. The aim of the discussion in the succeeding text is not to lead to a clinician ‘convincing’ anyone to start a trial of treatment but to ensure that the prescriber feels comfortable and informed to discuss the matter fully with their patient and caregivers.

3.1 Addressing ambivalence about medication

When initiating a pharmacological agent, it is key to ensure that there is a shared expectation that any medication is likely to have a therapeutic effect. However, parents often have a solely psychological account of OCD, as opposed to a ‘neurobiological’ one, with a resulting low perceived efficacy of medication (Furnham & Buck, 2003). It is important, therefore, to point out that there is extensive evidence confirming that SSRIs are effective in reducing obsessive-compulsive symptoms. Furthermore, whilst both psychological and pharmacological interventions are similarly effective, they are most powerful in combination (POTS, 2004).

An important consideration when treating OCD is the young person’s sense of self-efficacy in managing their symptoms. CBT for OCD puts great emphasis on the importance of ‘fighting back’ against the disorder and how practising exposure tasks is integral in achieving this. For those in combination therapy (CBT and medication), it can be useful to describe pharmacotherapy as a ‘helping hand’ in this fight, making it easier to perform exposures (especially in the often-challenging early part of therapy). For those treated only with medication, it is necessary to emphasize both that medication alone is a valid, evidence-based treatment for OCD and that persisting with medication, despite potential side effects and other challenges, is itself part of the ‘fightback’. NICE guidelines encouraged a stepped care approach to treatment where psychological therapy is encouraged before the introduction of medications (NICE, 2005). It is important, however, to be mindful that one can encounter rare clinical scenarios where a young person refuses to engage with psychological therapy. In these circumstances, it is possible to offer medication as a sole treatment with a view to revisit the commitment to CBT at a later stage.

3.2 Dealing with concerns that SSRIs are addictive

The perceived addictive quality of antidepressants, especially SSRIs, has been identified as a factor in poor adherence in young people (Dean et al., 2011). The belief that SSRIs are addictive appears to partly stem from the fact that abrupt discontinuation of these medications can lead to sudden emergence of a cluster of symptoms of varying severity, which include dysphoria, sleep disturbance, gastrointestinal upset, and 'electric shock'-like sensations (Black, Shea, Dursun, & Kutcher, 2000; Coupland, Bell, & Potokar, 1996).

Given the significant social stigma associated with being an 'addict', it is important to explain that SSRIs are not considered to be addictive: they are not associated with cravings, a build-up of tolerance or increased time spent seeking/taking the medication. However, whilst stressing that antidepressants are not 'addictive' per se, it is important not to minimize the potential side effects that can be experienced alongside SSRI discontinuation. Before beginning a course of SSRIs, it is important to explain that switching or stopping may be difficult but is achievable with support. When changing to a new medication, or ending a course of treatment, it is advisable to monitor for any signs of discontinuation. For those who find a standard tapering course of SSRIs challenging, it has been suggested that a more 'hyperbolic' (i.e. moving down to very small increments) regime be used (Horowitz & Taylor, 2019).

3.3 Tackling concerns about suicidality

Concerns have been raised regarding the risk of antidepressants increasing suicidal thoughts and behaviours (henceforth, 'suicidality') since the early 1990s (Jick, Kaye, & Jick, 2004). In 2004 the US Food and Drug Administration (FDA) released a 'black box' warning about the risk of suicide among young people taking SSRIs, which led to a dramatic reduction in their use in routine clinical practice (Cheung, Sacks, Dewa, Pong, & Levitt, 2008). Similarly, in 2003, the UK's Medicines and Healthcare products Regulatory Agency (MHRA) released a warning that SSRIs should be used with caution in children and adolescents and, ideally, by a specialist (i.e. not within primary care) (Cheung, Emslie, & Maynes, 2004). Discussions regarding suicidality are therefore a necessary component of medication counselling in OCD, and, once medication has commenced, suicidality should be monitored along with other side effects.

However, it is important to see the aforementioned in a broader context. Much of the data on suicide in people who take SSRI medication focus on those with a depressive illness; there are no clear data on increased suicide rates in those with OCD taking SSRIs. Furthermore, it is unclear

what impact medication has on this preexisting risk, with studies suggesting that starting an SSRI does not increase rates of suicide in young people (March, Klee, & Kremer, 2006). When considering the risks and benefits of SSRI medication, it is important to keep in mind that OCD itself is known to be associated with a notable increased risk of suicidality (de la Cruz et al., 2017), and thus effective treatment of OCD is likely to lower risk of suicide.

When discussing suicide with young people and their carers, it is important to be open and honest and to encourage young people to express when they are having such thoughts. One can be reassuring that there is little evidence that treating with an SSRI in young people with OCD increases the risk of suicide, but there are likely to be clear benefits in terms of mood and overall functioning. In any case, given that OCD is itself distressing and often comorbid with other mental health problems, a robust and sensible safety plan is an integral part of managing any young person with OCD.

3.4 Dealing with side effects

The side-effect profile of SSRIs is broadly similar to those seen in adults. However, there are some specific and important side effects to consider when counselling young people with OCD about medication. Roughly 15% of young people complain of gastrointestinal (GI) side effects (nausea, abdominal pains, and diarrhea) (Murphy, Segarra, Storch, & Goodman, 2008). These side effects tend to develop early and are typically self-limiting; to mitigate these symptoms, one can advise that medication be taken with meals or split into smaller doses. Some OCD patients' fears of illness or vomiting may lead them to particularly struggle with discussions regarding GI side effects. In these instances it is important to strike a balance between ensuring the patient is informed and not dwelling on side effects, which are experienced by a minority of patients.

It is known that sexual side effects (loss of libido, delayed or loss of orgasm, and loss of physical arousal) occur in over one-third of patients prescribed SSRIs (Murphy et al., 2008). Despite this and the importance of sexual function in adolescents, this is a poorly researched area (Scharko, 2004) and one not routinely assessed clinically (Levine & McGlinchey, 2015). As this is a symptom that is rarely volunteered, it is important to directly ask about this on clinical review. It is also important to be aware that these side effects affect male and female patients and to counsel all patients about them. Whilst roughly 10%–20% of patients with sexual side effects appear to improve spontaneously (Montejo, Llorca, Izquierdo, & Rico-Villademoros, 2001), the majority do not, and this may pose a significant barrier in medication adherence.

Agitation or ‘activation’ is the tendency for young people especially to develop increased impulsive and overactive behaviour, typically within the first few weeks of treatment or around the time of a dose increase (Murphy et al., 2008). This syndrome is poorly characterized, and so exact prevalence rates are hard to find; one review estimates the prevalence of such symptoms in youth recently prescribed an SSRI at around 22% (Luft, Lamy, DelBello, McNamara, & Strawn, 2018). A review of this phenomenon found it more common at higher doses and during rapid titration schedules. In the OCD population, it may manifest as a worsening of compulsions and can potentially interfere with psychological treatment (Reid et al., 2015). Should this develop, it is advisable to either reduce the medication dose or change to another agent. An important differential for such behaviour is the development of a manic episode, which can be triggered by the introduction of SSRI medication.

3.5 Managing expectations and knowing when to switch

A significant factor in poorer compliance with medication is the perception that the treatment is not working. Prior to commencing an SSRI, it is important that the young person and their parents’ expectations for medication are appropriately managed. In particular, it should be emphasized that medication will not be a ‘quick fix’ and that benefits may appear very gradually and only become apparent after weeks or even months. Clinical guidelines recommended a three-month trial at the maximum tolerated dose (NICE, 2005) for this reason. Only after this period, if there has been no adequate response, is it then worth considering switching to a different SSRI, or augmenting with a low-dose atypical antipsychotic (NICE, 2005). If it has been agreed that there will be a trial of another SSRI, a cross-tapering schedule can be adopted (though ensure this is monitored closely, to minimize the risk of serotonergic side effects or, at worst, serotonin syndrome).

3.6 Deciding when to discontinue medication

The optimal duration of SSRI treatment is an area that has historically been poorly researched, but there have been increasing efforts to address this important question in recent years. There is evidence to suggest that young people with OCD benefit from relatively long-term SSRI treatment, with continued improvements being observed over 52 weeks (Cook et al., 2001). Furthermore, approximately a third of OCD patients who have responded to SSRIs relapse following discontinuation, whereas those who remain on medication in the longer term are less likely to relapse (Romano, Goodman, Tamura, Gonzales, & Group, 2001). There does not appear to be

a completely 'safe' period of medication treatment, after which the risk of relapse is not increased when treatment is withdrawn. Recommended periods of continuing medication range from 6 to 18 months (Bushnell et al., 2018; Cook et al., 2001) after a good clinical response is seen. Young people and parents will have differing views about the longer-term use of SSRI medication. If the decision is taken for medication to be withdrawn, the following principles should be followed: (i) if possible, taper the medication slowly (to mitigate risk of discontinuation symptoms or relapse); (ii) reduce medication during low stress periods; and (iii) offer frequent reviews, to monitor clinical progress. For those who choose to stop medication, it is important that the risk of relapse is made clear and that provision is made for the young person to quickly return to treatment should relapse occur.

4 Conclusions and future directions

The treatment of OCD is both rewarding and highly efficacious. Internationally regarded practice parameters attest to the clear benefits of evidence-based treatments. Outcomes in specialist clinics show that close adherence to standard protocols of treatment very typically also delivers good treatment responses in many patients previously deemed to be treatment resistant or unresponsive (Krebs et al., 2015). Some common pitfalls in treatment, if thoughtfully addressed as earlier, can very often unlock significant treatment responses and even symptom remission. This positive message is an important one to share with young people and their families in treatment.

In spite of being able to give a hopeful message to many young people and their families in treatment, there is still a clear need to better understand mechanisms underpinning nonresponse to treatment, which occurs in a significant minority, and to develop improved interventions for this subgroup. In particular, further research is needed in a range of patient groups that can prove more challenging to treat including young people with comorbid autism spectrum disorders and those who are significantly underweight (Jassi, Patel, Lang, Heyman, & Krebs, 2016; Murray, Jassi, Mataix-Cols, Barrow, & Krebs, 2015). There will also be new medications regimes that will require close attention to detail both for their efficacy in treating OCD generally but importantly in treating children and young people. Lessons of the past have taught us that children and young people's clinical response to medications can differ significantly to that of adults. It is important therefore that we do not view children and young people simply as 'small adults', who will therefore respond in a similar manner to all treatments.

Going forward, clarity will be required about the optimum lengths of treatment. This includes both with psychological and pharmacological therapies. Our understanding of the role of both aspects of treatment

to maintain remission and prevent relapse is still poor, and long-term follow-up studies are still needed.

Finally, there will be novel assessment techniques and therapies that will require testing and careful research in paediatric populations. This may include the role of genetic testing in all aspects of clinical care and outcome modelling. New technologies will also continue to emerge, which will take their place in assessment, treatment, and follow-up of OCD. These will include the use of digital and other online platforms, in addition to novel interventional strategies, such as transcranial magnetic stimulation. Research in these areas is still in its infancy and will require careful and systematic evaluation in children and young people.

Exciting new prospects for treatment of OCD lie ahead. Treating practitioners can enjoy and should promote therapeutic optimism with their patients. OCD is already one of the most treatment responsive mental health presentations, and perhaps the most common pitfall to avoid is one of therapeutic despondency.

References

- Abramowitz, J. S., Franklin, M. E., & Schwartz, S. A. (2003). Symptom presentation and outcome of cognitive-behavioral therapy for obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology, 71*(6), 1049–1057.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Barrett, P., Healy-Farrell, L., & March, J. S. (2004). Cognitive-behavioral family treatment of childhood obsessive-compulsive disorder: A controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry, 43*(1), 46–62.
- Black, K., Shea, C., Dursun, S., & Kutcher, S. (2000). Selective serotonin reuptake inhibitor discontinuation syndrome: Proposed diagnostic criteria. *Journal of Psychiatry and Neuroscience, 25*(3), 255.
- Bushnell, G. A., Compton, S. N., Dusetzina, S. B., Gaynes, B. N., Brookhart, M. A., Walkup, J. T., et al. (2018). Treating pediatric anxiety: Initial use of SSRIs and other antianxiety prescription medications. *The Journal of Clinical Psychiatry, 79*(1), e1–e19.
- Cheung, A., Emslie, G. J., & Maynes, T. L. (2004). Efficacy and safety of antidepressants in youth depression. *The Canadian Child and Adolescent Psychiatry Review, 13*(4), 98.
- Cheung, A., Sacks, D., Dewa, C. S., Pong, J., & Levitt, A. (2008). Pediatric prescribing practices and the FDA Black-box warning on antidepressants. *Journal of Developmental and Behavioral Pediatrics: JDBP, 29*(3), 213–215.
- Cook, E. H., Wagner, K. D., March, J. S., Landau, P., Wolkow, R., et al. (2001). Long-term sertraline treatment of children and adolescents with obsessive-compulsive disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 40*(10), 1175–1181.
- Coupland, N. J., Bell, C. J., & Potokar, J. P. (1996). Serotonin reuptake inhibitor withdrawal. *Journal of Clinical Psychopharmacology, 16*(5), 356–362.
- de la Cruz, L. F., Rydell, M., Runeson, B., D'Onofrio, B. M., Brander, G., Rück, C., et al. (2017). Suicide in obsessive-compulsive disorder: A population-based study of 36 788 Swedish patients. *Molecular Psychiatry, 22*(11), 1626.
- Dean, A. J., Wragg, J., Draper, J., & McDermott, B. M. (2011). Predictors of medication adherence in children receiving psychotropic medication. *Journal of Paediatrics and Child Health, 47*(6), 350–355.

- Delorme, R., Bille, A., Betancur, C., Mathieu, F., Chabane, N., Mouren-Simeoni, M. C., et al. (2006). Exploratory analysis of obsessive compulsive symptom dimensions in children and adolescents: A prospective follow-up study. *BMC Psychiatry*, 6(1), 1.
- Douglass, H. M., Moffitt, T. E., Dar, R., McGee, R., & Silva, P. (1995). Obsessive-compulsive disorder in a birth cohort of 18-year-olds: Prevalence and predictors. *Journal of the American Academy of Child & Adolescent Psychiatry*, 34(11), 1424–1431.
- Eisen, J. L., Sibrava, N. J., Boisseau, C. L., Mancebo, M. C., Stout, R. L., Pinto, A., et al. (2013). Five-year course of obsessive-compulsive disorder: Predictors of remission and relapse. *The Journal of Clinical Psychiatry*, 74(3), 233–239.
- Fernandez de la Cruz, L., Micali, N., Roberts, S., Turner, C., Nakatani, E., Heyman, I., et al. (2013). Are the symptoms of obsessive-compulsive disorder temporally stable in children/adolescents? A prospective naturalistic study. *Psychiatry Research*, 209(2), 196–201.
- Flessner, C. A., Sapyta, J., Garcia, A., Freeman, J. B., Franklin, M. E., Foa, E., et al. (2010). Examining the psychometric properties of the family accommodation scale-parent-report (FAS-PR). *Journal of Psychopathology and Behavioral Assessment*, 33(1), 38–46.
- Freeman, J., Sapyta, J., Garcia, A., Compton, S., Khanna, M., Flessner, C., et al. (2014). Family-based treatment of early childhood obsessive-compulsive disorder: The pediatric obsessive-compulsive disorder treatment study for young children (POTS Jr)—A randomized clinical trial. *JAMA Psychiatry*, 71(6), 689–698.
- Furnham, A., & Buck, C. (2003). A comparison of lay-beliefs about autism and obsessive-compulsive disorder. *International Journal of Social Psychiatry*, 49(4), 287–307.
- Garcia, A. M., Sapyta, J. J., Moore, P. S., Freeman, J. B., Franklin, M. E., March, J. S., et al. (2010). Predictors and moderators of treatment outcome in the Pediatric Obsessive Compulsive Treatment Study (POTS I). *Journal of the American Academy of Child and Adolescent Psychiatry*, 49(10), 1024–1033. quiz 86.
- Geller, D. A., & March, J. (2012). Practice parameter for the assessment and treatment of children and adolescents with obsessive-compulsive disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(1), 98–113.
- Gillihan, S. J., Williams, M. T., Malcoun, E., Yadin, E., & Foa, E. B. (2012). Common pitfalls in exposure and response prevention (EX/RP) for OCD. *Journal of Obsessive-Compulsive and Related Disorders*, 1(4), 251–257.
- Haeghe, A., Weymann, L., Bliznak, L., Maerker, V., Mechler, K., & Dittmann, R. W. (2016). Non-adherence to psychotropic medication among adolescents—A systematic review of the literature. *Zeitschrift für Kinder- und Jugendpsychiatrie und Psychotherapie*, 46, 69–78.
- Horowitz, M. A., & Taylor, D. (2019). Tapering of SSRI treatment to mitigate withdrawal symptoms. *The Lancet Psychiatry*, 6, 538–546.
- Jassi, A., Patel, N., Lang, K., Heyman, I., & Krebs, G. (2016). Ritualised eating in young people with obsessive compulsive disorder; clinical characteristics and treatment outcomes. *Journal of Obsessive-Compulsive and Related Disorders*, 8, 1–8.
- Jick, H., Kaye, J. A., & Jick, S. S. (2004). Antidepressants and the risk of suicidal behaviors. *JAMA*, 292(3), 338–343.
- Keleher, J., Jassi, A., & Krebs, G. (in press). Clinician-reported barriers to using exposure with response prevention in the treatment of paediatric obsessive-compulsive disorder. *Journal of Obsessive-Compulsive and Related Disorders*.
- Kobori, O., & Salkovskis, P. M. (2013). Patterns of reassurance seeking and reassurance-related behaviours in OCD and anxiety disorders. *Behavioural and Cognitive Psychotherapy*, 41(1), 1–23.
- Krebs, G., Bolhuis, K., Heyman, I., Mataix-Cols, D., Turner, C., & Stringaris, A. (2013). Temper outbursts in paediatric obsessive-compulsive disorder and their association with depressed mood and treatment outcome. *Journal of Child Psychology and Psychiatry*, 54(3), 313–322.
- Krebs, G., Isomura, K., Lang, K., Jassi, A., Heyman, I., Diamond, H., et al. (2015). How resistant is ‘treatment-resistant’ obsessive-compulsive disorder in youth? *British Journal of Clinical Psychology*, 54(1), 63–75.

- Krebs, G., & Lewis, A. (2018). *Relapse prevention strategies for young people with OCD (After CBT)*. In *The clinician's guide to cognitive-behavioral therapy for childhood obsessive-compulsive disorder* (pp. 185–202): Elsevier.
- Lebowitz, E. R. (2013). Parent-based treatment for childhood and adolescent OCD. *Journal of Obsessive-Compulsive and Related Disorders*, 2(4), 425–431.
- Levine, A., & McGlinchey, E. (2015). Assessing sexual symptoms and side effects in adolescents. *Pediatrics*, 135(4), e815–e7.
- Lewin, A. B., Bergman, R. L., Peris, T. S., Chang, S., McCracken, J. T., & Piacentini, J. (2010). Correlates of insight among youth with obsessive-compulsive disorder. *Journal of Child Psychology and Psychiatry*, 51(5), 603–611.
- Luft, M. J., Lamy, M., DelBello, M. P., McNamara, R. K., & Strawn, J. R. (2018). Antidepressant-induced activation in children and adolescents: Risk, recognition and management. *Current Problems in Pediatric and Adolescent Health Care*, 48(2), 50–62.
- Mancebo, M. C., Garcia, A. M., Pinto, A., Freeman, J. B., Przeworski, A., Stout, R., et al. (2008). Juvenile-onset OCD: Clinical features in children, adolescents and adults. *Acta Psychiatrica Scandinavica*, 118(2), 149–159.
- March, J. S., Klee, B. J., & Kremer, C. M. (2006). Treatment benefit and the risk of suicidality in multicenter, randomized, controlled trials of sertraline in children and adolescents. *Journal of Child and Adolescent Psychopharmacology*, 16(1–2), 91–102.
- March, J. S., & Mulle, K. (1998). *OCD in children and adolescents: A cognitive-behavioral treatment manual*. New York: Guilford Press.
- Mataix-Cols, D., do Rosario-Campos, M. C., & Leckman, J. F. (2005). A multidimensional model of obsessive-compulsive disorder. *American Journal of Psychiatry*, 162(2), 228–238.
- McGuire, J. F., Piacentini, J., Lewin, A. B., Brennan, E. A., Murphy, T. K., & Storch, E. A. (2015). A meta-analysis of cognitive behavior therapy and medication for child obsessive-compulsive disorder: Moderators of treatment efficacy, response, and remission. *Depression and Anxiety*, 32(8), 580–593.
- Merlo, L. J., Lehmkuhl, H. D., Geffken, G. R., & Storch, E. A. (2009). Decreased family accommodation associated with improved therapy outcome in pediatric obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology*, 77(2), 355–360.
- Micali, N., Heyman, I., Perez, M., Hilton, K., Nakatani, E., Turner, C., et al. (2010). Long-term outcomes of obsessive-compulsive disorder: Follow-up of 142 children and adolescents. *The British Journal of Psychiatry*, 197(2), 128–134.
- Montejo, A. L., Llorca, G., Izquierdo, J. A., & Rico-Villademoros, F. (2001). Incidence or sexual dysfunction associated with antidepressant agents: A prospective multicenter study of 1022 outpatients. *The Journal of Clinical Psychiatry*, 62, 10–21.
- Monzani B, Vidal-Ribas P, Turner C, Krebs G, Stokes C, Heyman I, et al. The role of paternal accommodation of paediatric OCD symptoms: Patterns and implications for treatment outcomes, n.d., submitted.
- Murphy, T. K., Segarra, A., Storch, E. A., & Goodman, W. K. (2008). SSRI adverse events: How to monitor and manage. *International Review of Psychiatry*, 20(2), 203–208.
- Murray, K., Jassi, A., Mataix-Cols, D., Barrow, F., & Krebs, G. (2015). Outcomes of cognitive behaviour therapy for obsessive-compulsive disorder in young people with and without autism spectrum disorders: A case controlled study. *Psychiatry Research*, 228(1), 8–13.
- NICE. (2005). *Obsessive-compulsive disorder: Core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder*. London: NICE.
- Parrish, C. L., Radomsky, A. S., & Dugas, M. J. (2008). Anxiety-control strategies: Is there room for neutralization in successful exposure treatment? *Clinical Psychology Review*, 28(8), 1400–1412.
- Peris, T. S., Bergman, R. L., Langley, A., Chang, S., McCracken, J. T., & Piacentini, J. (2008). Correlates of accommodation of pediatric obsessive-compulsive disorder: Parent, child, and family characteristics. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(10), 1173–1181.

- Piacentini, J., Bergman, R. L., Keller, M., & McCracken, J. (2003). Functional impairment in children and adolescents with obsessive-compulsive disorder. *Journal of Child and Adolescent Psychopharmacology*, 13(2, Suppl. 1), 61–69.
- POTS. (2004). Cognitive-behavior therapy, sertraline, and their combination for children and adolescents with obsessive-compulsive disorder: The Pediatric OCD Treatment Study (POTS) randomized controlled trial. *The Journal of the American Medical Association*, 292(16), 1969–1976.
- Purdon, C., & Clark, D. A. (1993). Obsessive intrusive thoughts in nonclinical subjects. Part I. Content and relation with depressive, anxious and obsessional symptoms. *Behaviour Research and Therapy*, 31(8), 713–720.
- Reid, A. M., McNamara, J. P., Murphy, T. K., Guzik, A. G., Storch, E. A., Geffken, G. R., et al. (2015). Side-effects of SSRIs disrupt multimodal treatment for pediatric OCD in a randomized-controlled trial. *Journal of Psychiatric Research*, 71, 140–147.
- Rettew, D. C., Swedo, S. E., Leonard, H. L., Lenane, M. C., & Rapoport, J. L. (1992). Obsessions and compulsions across time in 79 children and adolescents with obsessive-compulsive disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 31(6), 1050–1056.
- Romano, S., Goodman, W., Tamura, R., Gonzales, J., & Group, C. R. (2001). Long-term treatment of obsessive-compulsive disorder after an acute response: A comparison of fluoxetine versus placebo. *Journal of Clinical Psychopharmacology*, 21(1), 46–52.
- Scharko, A. M. (2004). Selective serotonin reuptake inhibitor-induced sexual dysfunction in adolescents: A review. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43(9), 1071–1079.
- Shafraan, R., & Rachman, S. (2004). Thought-action fusion: A review. *Journal of Behavior Therapy and Experimental Psychiatry*, 35(2), 87–107.
- Stewart, S., Geller, D., Jenike, M., Pauls, D., Shaw, D., Mullin, B., et al. (2004). Long-term outcome of pediatric obsessive-compulsive disorder: A meta-analysis and qualitative review of the literature. *Acta Psychiatrica Scandinavica*, 110(1), 4–13.
- Sukhodolsky, D. G., Gorman, B. S., Scahill, L., Findley, D., & McGuire, J. (2013). Exposure and response prevention with or without parent management training for children with obsessive-compulsive disorder complicated by disruptive behavior: A multiple-baseline across-responses design study. *Journal of Anxiety Disorders*, 27(3), 298–305.
- Torp, N. C., Dahl, K., Skarphedinsson, G., Compton, S., Thomsen, P. H., Weidle, B., et al. (2015). Predictors associated with improved cognitive-behavioral therapy outcome in pediatric obsessive-compulsive disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(3), 200–7.e1.
- Turner, C., Volz, C., & Krebs, G. (2019). *OCD-tools to help young people fight back!: A CBT manual for therapists*. Jessica Kingsley Publishers.
- Veale, D., Freeston, M., Krebs, G., Heyman, I., & Salkovskis, P. (2009). Risk assessment and management in obsessive-compulsive disorder. *Advances in Psychiatric Treatment*, 15(5), 332–343.
- Watson, H. J., & Rees, C. S. (2008). Meta-analysis of randomized, controlled treatment trials for pediatric obsessive-compulsive disorder. *Journal of Child Psychology and Psychiatry*, 49(5), 489–498.
- Wegner, D. M., Schneider, D. J., Carter, S. R., & White, T. L. (1987). Paradoxical effects of thought suppression. *Journal of Personality and Social Psychology*, 53(1), 5.
- Williams, M. T., Farris, S. G., Turkheimer, E., Pinto, A., Ozanick, K., Franklin, M. E., et al. (2011). Myth of the pure obsessional type in obsessive-compulsive disorder. *Depression and Anxiety*, 28(6), 495–500.
- World Health Organization. (2018). *The ICD-11 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: WHO.

Developmental perspectives on ADHD, treatment implications, and achieving good outcomes

David Coghill^{a,b,c,d} and Sarah Seth^d

^aDepartment of Paediatrics, University of Melbourne, Melbourne, VIC, Australia, ^bDepartment of Psychiatry, University of Melbourne, Melbourne, VIC, Australia, ^cMurdoch Children's Research Institute, Melbourne, VIC, Australia, ^dRCH Mental Health, Royal Children's Hospital, Melbourne, VIC, Australia

Attention deficit hyperactivity disorder (ADHD) is characterized by a developmentally inappropriate, pervasive (across different situations such as home and school/work), and persistent pattern of significant inattention and/or hyperactivity/impulsivity. Onset is typically in childhood, and the core ADHD symptoms are associated with substantial impairment in social, academic, and/or occupational functioning. The formal definition of ADHD in DSM-5 is based upon a set of 18 core symptoms covering two dimensions, inattention (9 symptoms) and hyperactivity/impulsivity (9 symptoms). DSM-5 distinguishes three presentations of ADHD: predominantly inattentive presentation (at least six symptoms of inattention and less than six of hyperactivity/impulsivity), predominantly hyperactive/impulsive presentation (\geq six hyperactivity/impulsivity and $<$ six inattention), and combined (\geq six hyperactivity/impulsivity and \geq six inattention). The core symptoms must have persisted for at least 6 months and must be pervasive across at least two situations (e.g. home, school, work, and/or social life), and several must have been present before 12 years of age. A recent systematic review of ADHD prevalence during childhood and adolescence based on 102 studies from across all world regions calculated an overall prevalence of ADHD of 5.3%. The prevalence of children was 6.5% dropping to 2.7% for adolescents (Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007). Differences between countries are largely accounted for by differences in the methods used to assess and

the criteria required for diagnosis. Despite concerns that the prevalence of ADHD might be increasing worldwide in recent years, this was not supported by a recent meta-analysis that found no evidence for an increased prevalence over the past three decades when standardized diagnostic criteria and procedures are followed (Polanczyk, Willcutt, Salum, Kieling, & Rohde, 2014).

The criteria for ADHD have evolved over time. Until relatively recently, most people would have defined attention deficit hyperactivity disorder (ADHD) as ‘a neurodevelopmental disorder that starts early in life and certainly before the age of 7 years’. However, several recent lines of research have led us to question this received wisdom and indeed opened up the possibility that ADHD can also have an onset later in life and, perhaps, even arise *de novo* in adulthood (Coghill, Asherson, Faraone, & Rohde, 2018). From a clinical perspective, this and the recognition that ADHD frequently persists into adulthood have increased the importance of considering the various developmental trajectories that are seen in those with ADHD and considering their implications for treating and managing ADHD across the lifespan. This chapter will focus on developmental perspectives on ADHD from early childhood to adolescence and early adulthood with a particular focus on the aspects of treatment and management that can be harnessed to optimize outcomes for those with ADHD.

1 Developmental perspectives

1.1 How early in life can we diagnose ADHD?

Whilst much of the recent discussion and debate about the age of onset of ADHD has focused on whether ADHD can present for the first time beyond early childhood and even in adulthood, it is important to acknowledge that most individuals who will meet criteria for ADHD at some point in their life do in fact have at least some ADHD symptoms that are recognizable from very early in life. The diagnostic process for ADHD during the school years, whilst not always straightforward, is relatively well described and is a part of core business for many child psychiatrists, child psychologists, and paediatricians. During this process, it often becomes clear that symptoms were apparent during the preschool period and, not uncommonly, during infancy. Whilst these differences may be easy to identify with hindsight, it is more difficult to define the boundaries of normal levels of activity, inhibitory control, and attention during the preschool years. Population-based studies show that these symptoms are common amongst typically developing preschoolers (Smidts & Oosterlaan, 2007) and that this makes it challenging to define extreme levels and the boundaries between normal and clinical presentations. It is, however, generally

agreed that it is, in some cases at least, possible to make a clinical diagnosis of ADHD during the preschool period, at least for those aged 4 years and older. This is supported by studies that have demonstrated that cases diagnosed in their preschool years have ADHD symptom levels 4–8 times higher during the preschool period than age-matched, non-ADHD peers (Kadesjo, Kadesjo, Hagglof, & Gillberg, 2001) and levels of impairment reported in preschoolers with a diagnosis of ADHD are similar to that for school-age children with ADHD (Wilens et al., 2002). Preschoolers with an ADHD diagnosis are also reported to be less academically ready for school entry, have poorer fine motor skills, and are to be less socially skilled relative to healthy controls (DuPaul, McGoey, Eckert, & VanBrakle, 2001). Preschool ADHD also has a significant impact on family functioning with increased levels of expulsion from preschool care, greater difficulty maintaining babysitters and childcare with higher levels of parents missing work, and less personal time (Barkley, 2006).

Studies of the stability and predictive validity of preschool diagnoses of ADHD with almost all children who met full diagnostic criteria for ADHD at 4 years continue to meet full criteria and show marked functional impairment over the next 3 years (Lahey et al., 2004). Whilst there was a clear continuity of overall ADHD status, this was not true for ADHD subtypes, which often changed over time. This was one of the major reasons for DSM-5 shifting the focus from ‘subtypes’ of ADHD to ‘presentations’ of ADHD.

Evidence-based clinical guidelines have started to include guidance on the assessment and management of ADHD in preschoolers, and there are specialist sections in the most recent versions of both the UK NICE (NICE, 2018) and American Academy of Pediatrics (Wolraich et al., 2019). Both of these guidelines not only highlight the validity of diagnosing preschool ADHD but also note the particular challenges associated with determining the presence of key symptoms during this period of rapid development and the need to try and access good-quality and reliable collateral information when there is no teacher to provide a report. Studies looking at the heritability of ADHD symptoms in preschoolers suggest a strong continuity of aetiological influences across the lifespan with estimates of heritability similar to those seen in older children, adolescents, and adults (around 0.78) (Price et al., 2005). These findings also reinforce the fact that, even in children as young as 2 years of age, ADHD can be measured in a reliable way, since heritability estimates cannot, by definition, be greater than the reliability of test-retest reliability of the phenotype. Interestingly, studies conducted across different developmental periods show not only a continuity across the lifespan but also evidence for new genetic effects appearing at different ages, consistent with the effects of maturational processes on ADHD, and potentially leading to individual differences for age of onset and different levels of compensatory mechanisms being active at different stages of development (Faraone et al., 2015).

1.2 When does ADHD start?

Although the earliest descriptions of the constellation of symptoms and difficulties that were later to become known ADHD all emphasized an early onset, it was not until 1980 when attention deficit disorder was defined in DSM-III that specific age-of-onset criteria were first specified. These were based solely on clinical experience and required symptoms to be present before the age of 7 years. At this time a significant factor in defining the age of onset was a desire to avoid the potential misdiagnosis of those children who presented with hyperactivity, impulsivity, and inattention arising as a reaction to the stresses associated with starting school (Applegate et al., 1997; Barkley & Biederman, 1997). With the publication of DSM-IV, these criteria were modified to require the presence of impairment and symptoms before age 7 years. Again, no empirical evidence was put forward to support this amendment. Barkley and Biederman publicly questioned the selection of 7 years as the age-of-onset criterion as far back as 1997 and argued that, whilst there was general agreement that ADHD typically starts early in life, there was no empirical support for 7 years to be the designated cut-off (Barkley & Biederman, 1997). This position was supported by evidence from a systematic review of the literature that recommended raising the age-of-onset criterion from 7 to 12 years, which is exactly what was recommended by the DSM-5 committee. The DSM-5 committee also dropped the impairment requirement from the age-of-onset criterion (but not the overall diagnostic criteria). It is, therefore, now only required that 'several symptoms' (with or without impairment) are present before the age of 12 years for a diagnosis to be made. Some believe that this change will help minimize the number of false-negative diagnoses, which are particularly likely to occur for cases where assessment is conducted later in life, whilst at the same time reaffirming ADHD as a disorder of childhood onset. Other authors have voiced concerns that extending the upper limit could increase the prevalence of ADHD and result in children whose problems are a reaction to the increased demands and stresses associated with school entry, rather than as a consequence of a neurodevelopmental disorder per se, receiving a diagnosis of ADHD (Polanczyk et al., 2010). Although an initial study using UK data suggested that increasing the criterion from 7 to 12 years was unlikely to result in significant changes for childhood ADHD (Polanczyk et al., 2010), a subsequent study which assessed the impact of these changes in a US sample found an increase of almost 50% in those meeting criteria with prevalence rising from around 7% up to 11% (Vande Voort, He, Jameson, & Merikangas, 2014).

From a clinical perspective the dropping of the impairment requirement from the age-of-onset criterion does seem sensible. Clinicians working in the ADHD field will be very familiar with the adolescent or adult who had, at least some, very clear ADHD symptoms from an early age (often

with more emerging over time) but for whom these were not impairing until later in life when, as the demands of life increase, for example, with a change from primary to high school or from high school to college, university, or work. In such cases the usual clinical formulation is to recognize that, until the change in situation, there was adequate scaffolding to prevent the ADHD symptoms from causing significant impairment. Such scaffolding could be a result of a strong family, a supportive school environment, high intelligence, or a combination of these or other positive factors in the person's life. Under the DSM-IV criteria such a person would not have been eligible for a diagnosis of ADHD even though the available data suggest that they would be indistinguishable from those with similar current symptoms and impairments but who had a diagnosis by virtue of their impairment starting earlier in life.

As noted earlier, dropping the impairment requirement from the age-of-onset criterion in no way diminishes the importance of impairment to the diagnostic process. Indeed, in view of the many studies that support a dimensional perspective of ADHD (Coghill & Sonuga-Barke, 2012) and the continuous nature of ADHD symptoms across the population (Kuntsi et al., 2014; Levy, Hay, McStephen, Wood, & Waldman, 1997), it is clear that the key determinant of caseness is the presence of clinically significant impairment. Whilst the presence of impairment is a defining characteristic of many mental disorders, it is particularly important for trait-like disorders such as ADHD, where the symptoms are not necessarily a reflection of a change from a premorbid state (Asherson, Buitelaar, Faraone, & Rohde, 2016).

Impairment is also key to recent debates about whether or not we should be treating those with subthreshold ADHD (Kirova et al., 2019). Although there are still many aspects of this debate that remain contentious, most clinicians seem to agree that it is appropriate to at least consider treating an individual who does not quite meet the DSM-5 symptom criteria for ADHD but who is significantly impaired as a consequence of ADHD symptoms.

1.3 What is the developmental course of ADHD?

Across the different life stages, ADHD is associated with negative outcomes across a wide range of different functional domains and environments. Sometimes, these arise as a direct consequence of the ADHD, and sometimes, they relate to associated comorbid conditions. Particular aspects of life commonly affected by ADHD include school problems and academic underachievement; low self-esteem; difficulties in parent-child interactions, sibling interactions, and peer relationships; and poorer psychosocial adjustment. Children with ADHD are often rejected by peers even after only brief interactions they have fewer friends and tend to choose other ADHD youths as playmates. Some of these social difficulties

relate to their difficulties in regulating their emotions. They are also at increased risk for all types of accidents from early childhood to adulthood. Social difficulties are often more extensive if the child also has oppositional defiant disorder (ODD) or conduct disorder (CD). ADHD is a strong risk factor for later psychiatric diagnosis, antisocial behaviour, and social and peer problems, even after allowing for a coexistent CD. Poor self-esteem is also recognized as a mediating factor of several longer-term adverse outcomes, including depression, deviant peer choices, and substance abuse in children with ADHD. Academic deficits, school-related problems, and peer neglect tend to be most associated with symptoms of inattention, whereas peer rejection is more strongly linked to hyperactivity or impulsivity (Willcutt et al., 2012).

Outcomes over the lifespan differ widely. Changes in symptoms across childhood and adolescence may be a consequence of natural developmental processes seen in all children but may also improve as a result of learned skills, coping strategies, and environmental restructuring. Most children diagnosed with ADHD whilst in primary school continue to have significant manifestations of the disorder throughout adolescence. Adolescents with ADHD are often emotionally immature and tend to feel more comfortable interacting with younger children.

ADHD symptoms, as a whole, decline with age, and hyperactivity/impulsivity symptoms tend to diminish after puberty or present differently with age; symptoms of inattention do not; and symptoms of other disorders, such as CD and anxiety disorders, increase with age (Faraone, Biederman, & Mick, 2006). A very large majority (60%–85%) of children with ADHD will continue to meet criteria for the disorder during the teenage years. Longitudinal studies have documented that ADHD persists into adulthood in many cases. The extent to which ADHD persists depends on how it is defined, but about 65% of children with ADHD will still experience significant clinical impairment as adults, and the full ADHD diagnosis is met in approximately 15% at age 25 (Faraone et al., 2006).

The risk factors determining the persistence of ADHD into adulthood remain unclear. However, some studies suggested that higher persistence is associated with family history of ADHD; adversities during childhood, including family adversity; increased severity of ADHD symptoms during childhood; and presence of comorbidities [e.g. major depressive disorder, high comorbidity, paternal (but interestingly not maternal) anxiety mood disorder, and parental antisocial personality disorder] (Lara et al., 2009).

2 Treatment and management of ADHD

Treatments for ADHD have been extensively studied, and the supporting evidence for the various pharmacological and non-pharmacological

approaches will be summarized here. Less well studied and described are the approaches to managing ADHD, the *how* of treatment, that guides treatment decision-making. This understanding is key to delivering treatments for ADHD in ways that can optimize clinical outcomes. Understanding the *how* is extremely important in view of the fact that, whilst we have access to some of the most efficacious treatments available in medicine, the real-world outcomes for those with ADHD are not good (Langley et al., 2010) and, despite the publication of various evidence-based clinical guidelines for ADHD, there continues to be a significant ‘voltage gap’ between the outcomes from research and day-to-day clinical practice (Coghill, 2019; Swanson, 2019). This will be the focus of the last section of this chapter.

3 Developmental aspects of treatments for ADHD

3.1 Pharmacological treatments

Stimulant medications have been known to be efficacious for many years, and more recent studies have demonstrated efficacy for several non-stimulant medications (Cortese et al., 2018). Whilst most of these medications have been demonstrated to be effective across the lifespan, there are differences in response at different stages of development (Cortese et al., 2018).

Clinical guidelines generally suggest caution in the use of ADHD medications in pre-schoolers although recommendations about how early one should routinely consider medication differ somewhat between different guidelines. The most recent NICE (NICE, 2018) and AAP (Wolraich et al., 2019) guidelines, for example, suggest that medication should not routinely be given to children aged 4 years or younger, whilst the German guidelines (Banaschewski et al., 2017) suggest 6 years and younger. The basis for this caution reflects evidence from clinical trials that, whilst psychostimulants can be effective at reducing ADHD symptoms in pre-schoolers, there is a significantly higher risk of adverse effects in this group. The largest study to date was the NIMH-funded Preschool ADHD Treatment Study (PATS), which investigated the short-term (5 weeks) efficacy and longer-term safety (40 weeks) of methylphenidate in children aged 3–5.5 years who met criteria for ADHD. One-third of the children enrolled in the study did not in fact receive medication as they improved considerably during a 10-week behavioural intervention. Compared with controls, those that received medication had significant reductions in ADHD symptoms. The mean effective total daily dose of methylphenidate MPH was 14.2 mg/day which is considerably lower than seen in similar trials of school-age children (Greenhill et al., 2006). Thirty percent of

parents reported moderate-to-severe adverse effects, including emotional outbursts, insomnia, repetitive behaviours and thoughts, loss of appetite, and irritability. Eleven percent of children in this phase discontinued MPH. For those that stayed on medication for the full 40 weeks, annual growth rates were 20% lower than expected for height and 55% lower for weight. Interestingly the presence of coexisting disorders had a significant impact in response. Children with fewer coexisting disorders were most likely to respond to methylphenidate treatment, whereas those with three or more coexisting disorders, who in a clinical setting may be those most likely to be offered medication at an early age, did not respond to the treatment (Ghuman et al., 2007).

For school-age children and adolescents, the picture is rather different. Cortese and colleagues in the European ADHD Guidelines Network (EAGG, Cortese et al., 2018) carefully conducted a network meta-analysis (NMA) that investigated the short-term efficacy and tolerability of ADHD medications in children, adolescents, and adults. They included published and unpublished double-blind randomized controlled trials that compared amphetamines (including lisdexamfetamine), atomoxetine, bupropion, clonidine, guanfacine, methylphenidate, and modafinil either with each other or with placebo. In children and adolescents, all included drugs were superior to placebo. Standardized mean difference (SMD) for core ADHD symptoms rated by clinicians ranged from -1.02 [95% confidence intervals (CI) -0.19 to -0.85] for amphetamines, to -0.78 (95% CI -0.93 to -0.62) for methylphenidate, to -0.56 (95% CI -0.66 to -0.45) for atomoxetine. By contrast, for available comparisons based on teachers' ratings, only two medications methylphenidate (SMD -0.82 , 95% CI -1.16 to -0.48) and modafinil (-0.76 , 95% CI -1.15 to -0.37) were more efficacious than placebo. With respect to tolerability, amphetamines were less well tolerated than placebo in children and adolescents [odds ratio (OR) 2.30, 95% CI 1.36–3.89] as was guanfacine (2.64, 95% CI 1.20–5.81). For the head-to-head comparisons, only differences in efficacy (based on clinicians' ratings) were found. These favoured amphetamines over modafinil, atomoxetine, and methylphenidate in both children and adolescents (SMDs -0.46 to -0.24). Importantly, there were not enough data on studies longer than 12 weeks to make any comment on longer-term efficacy. Unfortunately, it was not possible in this study to give separate outcomes for children and adolescents primarily because most studies did not report results separately by age group. This is unfortunate because the findings from the EAGG network meta-analysis for adults differed to those for children and adolescents. In adults the amphetamines were clearly more efficacious than methylphenidate, atomoxetine, and modafinil, but amphetamines were less well tolerated than placebo. There is therefore clearly a change at some point in development, but it is not clear at what stage this occurs. The EAGG concludes that, based on the NMA,

the balance of evidence supports methylphenidate as the first-choice treatment for children and adolescents, whilst amphetamines are preferred in adults (Cortese et al., 2018). Whilst this is important evidence, it is of little clinical relevance in many countries outside of North America and Northern Europe, especially low- and middle-income countries, where there is limited access to ADHD medications and in particular stimulant medications. On the positive side however, it is important to recognize that the strength of effect of all ADHD medications including non-stimulants stands up well against not only other psychiatric medications but also many treatments in physical medicine (Leucht, Hierl, Kissling, Dold, & Davis, 2012), so even where availability is limited, if there is access to one of these medications, they should be considered.

3.2 Non-pharmacological treatments

A wide range of non-pharmacological treatments have also been proposed for ADHD. These were also reviewed in detail by the EAGG in a series of systematic reviews and meta-analyses (Cortese et al., 2015, 2016; Daley et al., 2014; Sonuga-Barke et al., 2013; Stevenson et al., 2014). In the first of these treatments, they reviewed the effects of a broad range of treatments on ADHD core symptoms. Treatments evaluated were three dietary interventions (food additive exclusions, restricted elimination diets, and supplementation with fatty acids), cognitive training, neurofeedback, and behavioural parent training (Sonuga-Barke et al., 2013). In addition to the broad scope of this review, a key contribution was the introduction of a more nuanced approach to the issue of blinding that is a potential compromising factor in many clinical trials of psychological interventions. The EAGG compared the outcomes for the rating considered to be *most proximal (mprox)* with the outcome on the rating considered the *most likely to be blind (pblind)*. This distinction proved to be important as most of the interventions that showed positive efficacy on the mprox (usually unblinded) outcomes (restricted elimination diets, cognitive training, neurofeedback, and behavioural parent training) were no longer significant when assessed using the pblind outcomes. Only food additive exclusions and supplementation with fatty acids remained efficacious at reducing core ADHD symptoms when assessed using probably blinded outcomes. The most unexpected finding was that behavioural parent training, which had an SMD of 0.40 in the mprox analysis, dropped almost to zero under pblind (SMD 0.02). Subsequent systematic reviews and meta-analyses by the same group which have assessed efficacy not only for ADHD outcomes but also at the broader outcomes have largely supported the findings of the original study. For parent training, there continues to be a lack of effect on pblind ratings of ADHD symptoms (Daley et al., 2014). There are, however, clear effects for parent training on several blinded outcomes,

increased positive and reduced negative parenting, and a reduction in oppositional behaviours (Daley et al., 2014).

It should be noted that there has been intense debate about the importance of the pblind findings with several experts arguing that, if parents are reporting a positive effect, then this, in itself, is an important indication of benefit, whilst others argue, equally forcefully, that blinded ratings are the gold standard and should be respected (Daley et al., 2017). European evidence-based clinical guidelines have also come to different conclusions despite having considered identical evidence. The German ADHD guidelines have continued to recommend parent training as a first-choice treatment for children with mild to moderate ADHD (Banaschewski et al., 2017). NICE, on the other hand, now recommends that, after considering any environmental modifications and psychoeducation, medication should be considered as a first-choice treatment for all children and adolescents with ADHD (NICE, 2018). This reverses their previous recommendation that parent training should be considered as the first treatment for all children with ADHD unless it was severe, when medication could be considered as a first treatment. NICE reserves parent training as a first option only for pre-schoolers and those school-age children presenting with coexisting ODD or CD. North American guidelines, mostly consensus driven rather than evidence based, have always suggested that medication is the first-line treatment for ADHD (CADDRA, 2018; Wolraich et al., 2019).

None of the current evidence-based guidelines endorse or recommend dietary manipulations, neurofeedback, or cognitive training as treatments for ADHD. It is important to acknowledge that, whilst there is currently no strong evidence to support these approaches to treatment, we also cannot say that they do not work. The most appropriate interpretation of the evidence for both cognitive training and neurofeedback is that the studies and meta-analyses to date have failed to demonstrate an effect but have not proved no effect.

Parent training is clearly aimed at modifying parenting and behaviour of younger children. Indeed the evidence suggests larger effects in pre-schoolers compared with school-age children (Daley et al., 2014). For adolescents (and adults), there is increasing evidence to support some beneficial effects for more formal cognitive behavioural therapy focussed on the individuals with ADHD rather than their parents (Solanto et al., 2010; Solanto, Marks, Mitchell, Wasserstein, & Kofman, 2008; Young & Amarasinghe, 2010). This work is at a much earlier stage of development and testing compared with most other approaches; however, in their most recent guidance, NICE recommends that we should 'consider a course of cognitive behavioural therapy (CBT) for young people with ADHD who have benefited from medication but whose symptoms are still causing a significant impairment in at least one domain' (NICE, 2018). Because

of the lack of good-quality research in this area, the NICE guideline development groups used their clinical experience, rather than evidence, to suggest that CBT programmes for ADHD should address social skills with peers, problem-solving, self-control, active listening skills, and dealing with and expressing feelings.

3.3 ADHD and comorbidities

It is also very important that clinicians managing ADHD are aware of, and actively manage, any coexisting or comorbid disorders. This has clear implications for assessment protocols. An assessment focussed solely on ADHD is likely to miss important comorbidities which, if not assessed and identified accurately, are unlikely to be treated. For comorbid mental health problems, this is perhaps more likely to happen in a paediatric setting than in mental health (Efron, Davies, & Sciberras, 2013) (although the converse—missed diagnoses of ADHD in those with mental health problems—is also common, particularly in, but not limited to, youth and adult mental health services). In many countries the bulk of care for ADHD is delivered by paediatricians. This is due to a combination of almost universal shortages of child and youth psychiatrists with a reluctance on the part of specialist mental health providers to recognize ADHD as a mental disorder. This might not be a problem if paediatricians were able to receive adequate training in managing mental disorders (including ADHD). Unfortunately, these opportunities are not available in many regions. Whilst the solution seems obvious, for paediatric and mental health services to work more closely together within multidisciplinary settings where they can support each other, examples of such services are few and far between (Coghill, 2017). As discussed later where integrated services have been developed and successfully implemented, outcomes are significantly improved (Coghill & Seth, 2015).

A full discussion of the management of comorbidities in ADHD is beyond the scope of this chapter; however, some basic principles should be considered. Most important is to decide which condition should be treated first. In some situations (e.g. severe depression, the presence of suicidal ideation or behaviors, and an acute psychotic episode), it is clear that the coexisting disorders will usually take precedence over the ADHD. In others (e.g. the presence of significant anxiety, tics, the sequelae of trauma, ODD, or CD), there is no clear rule. On the one hand, it can be best to identify which disorder is the most impairing and focus on that first; on the other, it is often the case that psychological therapies are more effective once the ADHD has been effectively treated with medication. For anxiety as an example, whilst it used to be thought that ADHD medications were less effective in the presence of comorbid anxiety, this has now been shown not to be the case, although those with both disorders do respond

much better to a combination of medication and behavioural treatment than medication alone (March et al., 2000). One perennial clinical concern, particularly in mental health settings, centres around 'is it trauma or is it ADHD?' Whilst there will certainly be cases at one or other end of this spectrum, it should be recognized that those with ADHD are more likely to suffer from all forms of trauma including abuse, neglect, and accidents, because of the heritable nature of ADHD and the fact that many parents of children with ADHD suffer themselves from ADHD, often not diagnosed or treated, and experienced suboptimal parenting which impacted on the knowledge and understanding that they themselves brought to parenting. Whilst this cycle of disadvantage has an inevitable impact on parent-child relationships and makes attachment difficulties extremely common for those with ADHD, it also should help recognize that it is much more likely to be ADHD *and* attachment than ADHD or attachment.

The Canadian ADHD Resource Alliance (CADDRA) ADHD Practice Guidelines (CADDRA, 2018) have a strong focus on managing comorbidities and provide useful guidance for clinicians across a wide range of disorders. Whilst their recommendations are, in general, supported by evidence, they are not strictly evidence-based being developed through clinical consensus. As NICE has developed specific guidance for many of the most common comorbid disorders and as the recommendations for treating most disorders in the presence of ADHD are the same as those when it occurs independently, an alternative approach is to consult these disorder-specific guidelines when looking to manage these disorders. There are of course some caveats. Whilst SSRI antidepressants are considered safe in combination with stimulants, drug/drug interactions for those drugs metabolized through the CYP450/2D6 system, for example, fluoxetine and paroxetine, require additional caution and monitoring when combined with amphetamines or atomoxetine.

The family of disorders that typically generate the most clinician's anxiety is the substance use disorders. CADDRA guidelines recommend that the best approach to treatment sequencing in individuals with ADHD and comorbid substance use disorder is the concurrent interventions with specific interventions for each disorder (CADDRA, 2018). There is some, although far from conclusive, evidence that treatment of ADHD may facilitate earlier quitting and increase the overall likelihood of quitting. Depending on the type of substance being used, prescribing psychostimulants in the presence of active substance abuse requires careful monitoring for medical interactions and should take into account the potential risk of misuse and abuse. It is, however, important to remember that psychostimulants taken orally do not have the same abuse liability as illicit stimulants (e.g. cocaine and metamphetamine) due to a longer half-life, slower dissociation from the dopamine transporter, and slower uptake into the striatum. Long-acting stimulant preparations are associated with

significantly less abuse potential than the immediate-release preparations, and lisdexamfetamine can be dissolved in water to ensure that it is swallowed when given. Where the risk of stimulants is considered clinically to be too high, atomoxetine and guanfacine XR can be considered as they do not have abuse potential.

4 Organizing care and managing ADHD in a clinical setting

4.1 General principles

Our personal mantra is 'ADHD, easy to treat, but hard to treat well'. Even the best guidelines struggle to clearly describe how to deliver this care within routine clinical practice, and clinicians themselves struggle to follow them in day-to-day clinical practice ([Gordon et al., 2016](#)). Perhaps as a consequence of these challenges, routine clinical care varies considerably not only from country to country but also between clinicians practicing in the same town or from the same offices. As previously highlighted, clinical outcomes are disappointing, and when asked, clinicians are more likely to report that they are content to reduce symptoms rather than optimize outcomes ([Kovshoff et al., 2013](#)). The purpose of this final section is to package key messages from research into a more usable format that will help the clinician develop and implement clinical pathways in their everyday practice. Important differences in the funding and organization of healthcare across the world mean that there can be no one optimal model of service delivery that will fit all systems of care. This does not, however, mean that we should not look for common elements of care that can be generalized and adapted to these different contexts.

Because most people with ADHD present at clinical services with multiple problems in addition to their core ADHD symptoms and impairments, the first challenge facing the clinician is to decide which problem or problems should be tackled first. Sometimes the decision is simple (e.g. child protection concerns or significant suicidality clearly outweigh most other problems), but in many circumstances the choice depends on a combination of severity (actual and perceived), relative importance (to the child, their parents, the school, and the clinician), the availability of an evidence-based treatment, and a combination of rational and pragmatic clinical decision-making. Where the key impairments are judged to be secondary to ADHD symptoms (e.g. poor peer relationships and academic functioning with low self-esteem), it would seem sensible to treat the ADHD symptoms first and observe the impact of this on the other difficulties. It is always important for the treatment plan to be explicit about the overall goals of treatment, what order they will be tackled and to identify when expectations may not be realistic. It is very important that children

and adolescents, as well as their parents, are involved in this process. The more sense of ownership they have, the more they will be motivated to comply with the proposed treatment.

Psychoeducation forms the cornerstone of treatment and should be offered to all those given a diagnosis and their families. The approach to psychoeducation should include giving accurate information about ADHD, including causes, consequences, and approaches to treatment; facilitate skill development in understanding and managing the behaviours associated with ADHD; and empower patients and their families to seek appropriate community and academic help and support and avoid stigma. Whilst a sole focus on reduction of core symptoms of ADHD would be short-sighted, it is also the case that, unless there is a significant reduction in symptoms, other aspects of life will be much more difficult to manage. For this reason, symptom reduction is usually prominent amongst our early treatment targets.

4.2 Using medication

If the decision has been made to start a medication and this has been agreed with the patient and family, it is then necessary to decide which medication to start first. It is generally agreed that the first medication will usually be a stimulant. There are, however, occasions when a non-stimulant would be considered. These include a current or past history of substance misuse, the presence of tics, the presence of anxiety, and a strong family preference to avoid stimulants.

These are, however, relative preferences for non-stimulants, rather than absolute contraindications to stimulants, and their presence does not mean that stimulant medications should necessarily be avoided.

Whilst the EAGG network meta-analysis suggested that, for children and adolescents, methylphenidate is slightly preferred than amphetamines/lisdexamfetamine, this recommendation was based on better tolerability for methylphenidate rather than efficacy. It is, therefore, not a strong recommendation, and there is room for clinical preference allowed by local regulations or dictated by cost considerations. Whilst generally more expensive the long-acting stimulant preparations can help to reduce stigma, increase privacy, improve compliance, and reduce the risk of diversion.

Optimal outcomes require an individual to be treated with the right medication at the right dose. Not every patient will respond to every medication, and for the stimulants at least, it is important to recognize that it is not possible to predict the most effective dose from consideration of the patient's age or weight or the severity or type of symptoms or comorbidities. It is, therefore, important to titrate patients onto each new medication whilst carefully measuring both their response and any adverse effects.

Key to this process is the routine use of standardized instruments to measure treatment response and the routine assessment of adverse effects. There are several reliable and valid measures available to assess treatment response. In our clinic, we favour the use of freely available measures and have chosen the SNAP-IV rating scale (Coghill & Seth, 2015). We use this as a clinician-rated semistructured interview with parents and patients, as our main measure of ADHD symptoms and response to treatment. We adopted the clinician-rated approach as it is somewhat more reliable than the parent-rated measure and allows the clinician to make more detailed enquiries about particular symptoms when it is not clear how persistent and pervasive they are in day-to-day life. We find that the easiest way to interpret the SNAP-IV is to calculate the mean score per item. Table 1 provides guidance about the clinical interpretation of the SNAP-IV rating scale. Teacher ratings, using the 10-item SKAMP questionnaire, are also helpful and in our clinic are also collected at each appointment (Coghill & Seth, 2015). SKAMP scores can also be converted to mean score per item and interpreted in the same way as the SNAP-IV. For the adverse effects, it is helpful to have a standardized set of questions to rate the presence or

TABLE 1 Clinical interpretation of scores from the SNAP-IV rating scale.

SNAP-IV rating scale score				Post-treatment monitoring
Total score (range 0–54)	Mean item total score ^a	Subscale ^b score (range 0–27)	Mean item subscale score ^a	Clinical interpretation
0–18	≤1	0–9	≤1	Very good/optimal response: symptoms well within normal range
19–26	<1.5	10–13	<1.5	Good response: symptoms within normal range but may be improved
27–36	1.5–2	14–18	1.5–2	Response still clinically significant: symptoms just outside normal range and response probably inadequate. Need to assess other factors
37–54	>2	19–27	>2	Inadequate response: many symptoms still observed. Need to assess other factors

^a Calculated by dividing the total/subscale score by the number of items (18 for the total; 9 for each subscale).

^b Inattention or hyperactivity/impulsivity subscales.

SNAP-IV, Swanson, Nolan, and Pelham-IV rating scale.

absence of common adverse effects and to note whether or not these are impairing. Pulse, blood pressure, height, and weight should be measured and charted against age- and gender-matched norms. We have previously published documentation from the Dundee ADHD Care Pathway which contains a sample pro forma for collecting and recording this type of information and gives access to the scales mentioned earlier (Coghill & Seth, 2015). Whilst most guidelines emphasize the importance of titration when initiating medication treatments for ADHD or when switching from one class of drug to another, few if any of them give advice as to how to do this in a real-world clinic setting. There are several different approaches to titration onto methylphenidate, and which one you choose will depend on several factors. Most recommended approaches suggest aiming for the maximum benefit at minimum dose with the least adverse effects. This means continuing to titrate until there is no further room for improvement, until there are significant adverse effects, or until the maximum routine dose is reached (usually the equivalent of 20-mg methylphenidate three times daily immediate release). Dose increases can be as frequent as weekly, and symptoms, adverse effects, and vital signs are measured at every review. A common issue is halting the titration before the optimum dose has been identified. This is an issue because when, as frequently occurs, the family returns some months later to say that the medication is not working and it was previously, it is not possible to be sure whether this is because, now that they have got used to the improved symptoms and behaviour, they realize that the strong response to medication was not quite as complete as it seemed or it is because the patient has become tolerant to the medication. If tolerance has developed increasing the dose, the usual response in this situation would appear to resolve the situation but only for a short period, whereas stopping the medication for a short period would allow the tolerance to resolve and full response to return when medication was restarted.

In our clinic, we titrate over a 4- or 8-week period with weekly/bi-weekly dose increases. By the end of this period, the clinician will have decided that the patient (1) has responded best to a particular dose; (2) has responded but cannot tolerate the optimal dose due to adverse effects, either shows an acceptable response, with no or tolerable adverse effects at a lower dose, or does not show an acceptable response at a lower dose; and (3) has not responded at any dose.

This plan is designed for titration onto methylphenidate with four doses (5 mg tids up to 20 mg tids or equivalent extended-release doses) but can easily be adapted for amphetamines or lisdexamfetamine.

For atomoxetine the standard protocol is to initiate treatment at a dose of 0.5 mg/kg for 7 days (to accommodate adverse effects), then increase to 1.2 mg/kg, and continue at this dose (with a maximum dose of 100 mg/day). Whilst many of those who are going to show a response will report

some positive effects after 4 or so weeks, we have found that, in our clinical experience, there is a small but significant group of patients who, whilst showing no response at around 8 weeks, report significant benefits at around 12 weeks. We, therefore, recommend that patients are made aware of this and that treatment is continued for 12 weeks before a decision about non-response is made. When there is a response to 1.2 mg/kg but there remains room for improvement, it is acceptable to increase the dose up to 1.8 mg/kg (up to the maximum of 100 mg/day). If there is no response after 12 weeks at 1.2 mg/kg, we usually conclude that the patient is an atomoxetine non-responder and switch to an alternative treatment.

For extended-release guanfacine the starting dose is 1 mg/day for 1 week, 2 mg/day for 1 week (again to allow identification and adjustment to early adverse effects, with little expectation of clinical response), and then increase to 3 mg/day for around 6 weeks. If there is no response at this point, we would consider the patient a non-responder and discontinue. If there is a response but with clear room for improvement, we consider increasing the dose to 4 mg/day. Whilst the dose can increase to 7 mg in adolescents, we have rarely needed to increase to this dose. Following discontinuation of guanfacine, it is possible for patients to experience an increase in blood pressure and heart rate. It is, therefore, important to instruct patients and their caregivers not to discontinue their medication abruptly or without consulting their doctor. Pulse and blood pressure should be monitored when reducing the dose or discontinuing this medication. Good practice is to taper the dose down in decrements of no > 1 mg every 3–7 days to avoid possible rebound hypertension.

Having established and stabilized effective and optimized treatment, we should put systems in place to monitor ongoing treatment. Whilst a proportion of patients will probably continue to do well with minimal intervention, many will require more careful monitoring either to ensure continued clinical response or to minimize the impact of adverse effects such as sleep and appetite difficulties, common with stimulants. Based on the findings of the multimodal treatment of ADHD (MTA) study ([The MTA Cooperative Group, 1999](#); [Vitiello et al., 2001](#)), we adopted the same measurement-based care approach used during titration to monitor longer-term outcome. The MTA results suggested that the key differences between the MTA medication protocol and routine clinical care were a structured titration, 12-h medication cover, higher overall doses (10 mg/day higher), ongoing support, and a structured approach to monitoring care and adjusting treatment ([Vitiello et al., 2001](#)). These benefits, seen at the end of the 14-month trial, did not continue once treatment was transferred back to the community. We based our clinic on a streamlined version of the MTA medication protocol and continued with the measurement-based care approach using the same protocol during titration over the long-term treatment. Using this approach, we were able to

replicate the 14-month MTA outcomes, within a community clinic setting and, perhaps even more importantly, demonstrate that, with careful clinical care, these outcomes could be sustained into the long term (Coghill & Seth, 2015).

Of course not every patient responds well to any one particular medication, and even when they have had a strong clinical response, they may have adverse effects that make it necessary to consider changing medication. Whilst the need for change may have been recognized within primary care, such alterations to the treatment plan should usually be carried out by specialists within child and mental health services or paediatrics. This is particularly the case where the issue is suspected non-response. Here, there are several general issues that should be considered before making a decision about what will be the best and most appropriate response. These include reviewing dosage (always ensure an adequate dose has been applied before switching treatment), addressing compliance issues (motivational interviews may help compliance and if on an immediate-release preparation, try an extended-release one), and assessing whether the apparent non-response is actually due to a coexisting disorder or problem that is not currently being treated. These and other questions that should be considered before switching treatments are summarized in Box 1.

For those who have either failed to respond or have had intolerable adverse effects to the first stimulant they have tried, it is usually acceptable to consider switching to the other family of drugs (i.e. from methylphenidate to amphetamine or from amphetamine to methylphenidate). Whilst it is sometimes the case that a patient who has adverse effects to one will

BOX 1

Questions you could ask before changing to a different drug

1. Have I titrated properly?
2. Is the patient at the maximum dose?
3. Is this drug/preparation working well at any times during the day?
4. Have I got good enough information from school?
5. Are parents and school in agreement about the effects of the drug?
6. Am I targeting the right symptoms?
7. Is there a behavioural explanation for the drug 'wearing off'?
8. What else is going on in patient's life/family life?
9. Is the medication working but effects limited by side effects?
10. Have I missed any comorbidity?
11. Is the diagnosis right?

have similar problems with the other, this is by no means always the case. Of course, some patients and families will be uncomfortable about such a switch, and their wishes should always be taken into account. We have found, however, that a clear discussion of the evidence can allay many of these worries along with a strong reassurance that, if there are further problems, they should communicate these quickly so that further changes can be discussed and implemented without delay. For further suggestions about the management of adverse effects, there are several comprehensive high-quality reviews with clear clinical recommendations (Cortese et al., 2013; Graham et al., 2011).

For those who have failed both stimulant classes, a switch to one of the non-stimulants should be considered. Atomoxetine is the most accessible; extended-release guanfacine is also now available in many countries (and extended-release clonidine is available in the United States) and would often be the appropriate choice. There are no data to help predict who will respond to any of the ADHD medications, so switching is something that has to be tried and tested one drug at a time. For those who have a partial response to a stimulant, it may be appropriate to consider adding in an alpha-2 agonist (guanfacine or clonidine). These drugs have a very different adverse event and safety profile to the stimulants and atomoxetine. Whilst we would not recommend combining stimulants or combining them with atomoxetine on the grounds of safety, it does appear to be safe to combine stimulants with an alpha-2 agonist. Indeed, this combination is within label in several jurisdictions. These recommendations about switching medications and augmenting treatment are one aspect of treatment that is likely to change over time as new evidence about existing medications and new treatments and preparations become available. It is, therefore, important that the clinician stays up to date with new advances in the field and current guideline recommendations.

4.3 Treatment adherence

One further issue particularly relevant to adolescents is adherence to treatment. Using data gathered from a large UK primary care database, we found that very few adolescents were remaining on their ADHD medications past early adolescence with almost none continuing into adulthood (McCarthy et al., 2009). This is despite clear evidence that most of these young people will continue to suffer from at least some ADHD symptoms and significant ADHD-related impairments (Faraone et al., 2015). There are clearly many reasons why adolescents in general and those with ADHD, in particular, find it more difficult to comply with treatment. At the most general level, adolescents herald a shift towards questioning values held by others and a desire to take control of one's own life circumstances. Whilst the 'patient' during childhood is more broadly defined to include

the parent/child dyad, this is changing during adolescence, and the need to respect and account for these changes can catch the clinician and the parents and adolescents by surprise. Adolescents with ADHD have also been shown to have a positive illusory bias (i.e. an overestimation of their own performance or competence relative to an objective criterion) and also to underreport their impairments. This can lead to distortion and underestimation of the need for treatment. There are also a range of condition related (e.g. those with ADHD are more forgetful), patient related (e.g. feelings of stigma and worries about teasing and bullying by peers), therapy related (e.g. adverse effects or being on suboptimal doses), socio-economic and demographic factors (e.g. rural locations with poor access to care and unable to afford treatment), and health system factors (e.g. institutional stigmatization, lack of knowledge about ADHD, and a drive to discharge those not taking medication). Thankfully, there are also a range of factors that can be used to improve adherence to treatment (Table 2).

TABLE 2 Potential approaches to improve adherence in ADHD.

Focus	Intervention
Patient (youth and parent) education	Targeting knowledge and skills about <ul style="list-style-type: none"> • Etiology • Course • Adverse effects (short and long term) Elicit and address misconceptions/misinformation about ADHD and ADHD medications Information needs to be current, unbiased, and accurate
Individualized approaches for tailoring medication	Identify out what outcomes are important for each patient Aim for maximal therapeutic benefit and minimal adverse effects Target the right times of the day Use titration protocols Simplify dosing Allow for flexibility Educate about time to response
Behavioural strategies	May require work with parents and/or young person <ul style="list-style-type: none"> • target environmental constraints, to adherence • improve the salience of taking medication • address habitual and automatic processes that may influence adherence behaviour • improve patient self-efficacy in taking medication Technology-based approaches <ul style="list-style-type: none"> • alerts and reminders to refill scripts and take meds • pill reminder boxes • alarms to remind parents/youth to take medication Parent training to improve positive parenting Pill swallowing training Behavioural approaches to reducing ODD and improve overall compliance

TABLE 2 Potential approaches to improve adherence in ADHD—cont'd

Focus	Intervention
Peer support strategies	<p>Peers are often effective at engaging similarly situated individuals into services because they are viewed as credible role models who provide hope, empower participants, and enhance satisfaction with services</p> <p>Peer-delivered services decrease isolation, normalize feelings of distress, and destigmatize views about mental illness and seeking treatment</p> <p>Family advocates—to help parents</p> <p>Youth advocates—to help adolescents</p> <p>ADHD coaches can play a big role in improving all aspects of care</p>

Unfortunately, but very important to acknowledge, there is no one recipe for change that will work in every healthcare setting. ADHD care is delivered in very diverse clinical environments each with its own history and barriers to change (Sayal, Prasad, Daley, Ford, & Coghill, 2018) and within a wide range of healthcare systems that require and often demand that the clinician organizes their care in very different ways and with huge variation in access to both pharmacological and non-pharmacological treatments. It is, however, possible to present some general guidelines that will facilitate the development of evidence-based care pathways. One effective strategy is to address the need for change with a positive problem-solving approach and utilize the concepts of clinical audit to monitor and inform cycles of change. A detailed description of how these issues were addressed in one particular service along with the supporting clinical documentation can be found in the work by Coghill and Seth (2015).

5 Conclusions

In this chapter, we have reviewed current knowledge about developmental trends in ADHD and the evidence about treating and managing ADHD across childhood and adolescence. We have also provided a framework for developing evidence-based protocols for managing ADHD. Whilst translating evidence into routine clinical practice is never easy, it is possible. It requires dedication, willingness to self-reflect critically about things that could be done better, and a team that can work together as a unit and who are willing to embrace change. Whilst it does require time and some resources, it does not necessarily require either a significant investment of money or huge numbers of staff. It is often quite daunting to take the first steps along this path; however, it is also very satisfying to practice in the knowledge that you are doing all that you can to ensure each patient receives the right treatment at the right time. We hope that

this chapter and the supporting texts will stimulate further changes in clinical practice and look forward to hearing about the next generation of change from others in the future.

References

- Applegate, B., Lahey, B. B., Hart, E. L., Biederman, J., Hynd, G. W., Barkley, R. A., ... Shaffer, D. (1997). Validity of the age-of-onset criterion for ADHD: A report from the DSM-IV field trials. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(9), 1211–1221. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9291722>.
- Asherson, P., Buitelaar, J., Faraone, S. V., & Rohde, L. A. (2016). Adult attention-deficit hyperactivity disorder: Key conceptual issues. *Lancet Psychiatry*, 3(6), 568–578. [https://doi.org/10.1016/S2215-0366\(16\)30032-3](https://doi.org/10.1016/S2215-0366(16)30032-3).
- Banaschewski, T., Bauer, M., Bea, M., Dopfner, M., Gelb, M., & Grosse, K. P. (2017). Langfassung der interdisziplinären evidenz- und konsensbasierten (S3) Leitlinie. In *Aufmerksamkeitsdefizit-/Hyperaktivitätsstörung (ADHS) im Kindes-, Jugend- und Erwachsenenalter*. Retrieved from <https://www.awmf.org/leitlinien/detail/II/028-045.html>.
- Barkley, R. A. (2006). ADHD in adults: Developmental course and outcome of children with ADHD, and ADHD in clinic-referred adults. In R. A. Barkley (Ed.), *Attention-deficit hyperactivity disorder, a handbook for diagnosis and treatment* (3rd ed., pp. 248–253). New York: Guilford Press.
- Barkley, R. A., & Biederman, J. (1997). Toward a broader definition of the age-of-onset criterion for attention-deficit hyperactivity disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(9), 1204–1210. <https://doi.org/10.1097/00004583-199709000-00012>.
- CADDRA. (2018). *Canadian ADHD practice guidelines*. Toronto, ON: CADDRA.
- Coghill, D. (2019). Debate: Are stimulant medications for attention-deficit/hyperactivity disorder effective in the long term? (for). *Journal of the American Academy of Child and Adolescent Psychiatry*, 58(10), 938–939. <https://doi.org/10.1016/j.jaac.2019.07.002>.
- Coghill, D., Asherson, P., Faraone, S. V., & Rohde, L. A. (2018). The age of onset of attention-deficit hyperactivity disorder. In G. De Girolamo, P. D. McGorry, & N. Sartorius (Eds.), *Age of onset of mental disorders: Etiopathogenetic and treatment implications* (pp. 217–236). New York, NY: Springer.
- Coghill, D., & Seth, S. (2015). Effective management of attention-deficit/hyperactivity disorder (ADHD) through structured re-assessment: The Dundee ADHD Clinical Care Pathway. *Child and Adolescent Psychiatry and Mental Health*, 9, 52. <https://doi.org/10.1186/s13034-015-0083-2>.
- Coghill, D., & Sonuga-Barke, E. J. (2012). Annual research review: Categories versus dimensions in the classification and conceptualisation of child and adolescent mental disorders—Implications of recent empirical study. *Journal of Child Psychology and Psychiatry*, 53(5), 469–489. <https://doi.org/10.1111/j.1469-7610.2011.02511.x>.
- Coghill, D. R. (2017). Organisation of services for managing ADHD. *Epidemiology and Psychiatric Sciences*, 26(5), 453–458. <https://doi.org/10.1017/S2045796016000937>.
- Cortese, S., Adamo, N., Del Giovane, C., Mohr-Jensen, C., Hayes, A. J., Carucci, S., ... Cipriani, A. (2018). Comparative efficacy and tolerability of medications for attention-deficit hyperactivity disorder in children, adolescents, and adults: A systematic review and network meta-analysis. *Lancet Psychiatry*, 5(9), 727–738. [https://doi.org/10.1016/S2215-0366\(18\)30269-4](https://doi.org/10.1016/S2215-0366(18)30269-4).
- Cortese, S., Ferrin, M., Brandeis, D., Buitelaar, J., Daley, D., Dittmann, R. W., ... European, A. G. G. (2015). Cognitive training for attention-deficit/hyperactivity disorder: Meta-analysis of clinical and neuropsychological outcomes from randomized controlled trials. *Journal*

- of the American Academy of Child and Adolescent Psychiatry, 54(3), 164–174. <https://doi.org/10.1016/j.jaac.2014.12.010>.
- Cortese, S., Ferrin, M., Brandeis, D., Holtmann, M., Aggensteiner, P., Daley, D., ... European, A. G. G. (2016). Neurofeedback for attention-deficit/hyperactivity disorder: Meta-analysis of clinical and neuropsychological outcomes from randomized controlled trials. *Journal of the American Academy of Child and Adolescent Psychiatry*, 55(6), 444–455. <https://doi.org/10.1016/j.jaac.2016.03.007>.
- Cortese, S., Holtmann, M., Banaschewski, T., Buitelaar, J., Coghill, D., Danckaerts, M., ... European, A. G. G. (2013). Practitioner review: Current best practice in the management of adverse events during treatment with ADHD medications in children and adolescents. *Journal of Child Psychology and Psychiatry*, 54(3), 227–246. <https://doi.org/10.1111/jcpp.12036>.
- Daley, D., Van Der Oord, S., Ferrin, M., Cortese, S., Danckaerts, M., Doepfner, M., ... Sonuga-Barke, E. J. (2017). Practitioner review: Current best practice in the use of parent training and other behavioural interventions in the treatment of children and adolescents with attention deficit hyperactivity disorder. *Journal of Child Psychology and Psychiatry*. <https://doi.org/10.1111/jcpp.12825>.
- Daley, D., van der Oord, S., Ferrin, M., Danckaerts, M., Doepfner, M., Cortese, S., ... European, A. G. G. (2014). Behavioral interventions in attention-deficit/hyperactivity disorder: A meta-analysis of randomized controlled trials across multiple outcome domains. *Journal of the American Academy of Child and Adolescent Psychiatry*, 53(8), 835–847. e831–835. <https://doi.org/10.1016/j.jaac.2014.05.013>.
- DuPaul, G. J., McGoey, K. E., Eckert, T. L., & VanBrakle, J. (2001). Preschool children with attention-deficit/hyperactivity disorder: Impairments in behavioral, social, and school functioning. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40(5), 508–515. <https://doi.org/10.1097/00004583-200105000-00009>.
- Efron, D., Davies, S., & Sciberras, E. (2013). Current Australian pediatric practice in the assessment and treatment of ADHD. *Academic Pediatrics*, 13(4), 328–333. <https://doi.org/10.1016/j.acap.2013.03.009>.
- Faraone, S. V., Asherson, P., Banaschewski, T., Biederman, J., Buitelaar, J. K., Ramos-Quiroga, J. A., ... Franke, B. (2015). Attention-deficit/hyperactivity disorder. *Nature Reviews Disease Primers*, 1, 15020. <https://doi.org/10.1038/nrdp.2015.20>.
- Faraone, S. V., Biederman, J., & Mick, E. (2006). The age-dependent decline of attention deficit hyperactivity disorder: A meta-analysis of follow-up studies. *Psychological Medicine*, 36(2), 159–165. <https://doi.org/10.1017/S003329170500471X>.
- Ghuman, J. K., Riddle, M. A., Vitiello, B., Greenhill, L. L., Chuang, S. Z., Wigal, S. B., ... Skrobala, A. M. (2007). Comorbidity moderates response to methylphenidate in the Preschoolers with attention-deficit/hyperactivity disorder treatment study (PATS). *Journal of Child and Adolescent Psychopharmacology*, 17(5), 563–580. <https://doi.org/10.1089/cap.2007.0071>.
- Gordon, M. K., Baum, R. A., Gardner, W., Kelleher, K. J., Langberg, J. M., Brinkman, W. B., & Epstein, J. N. (2016). Comparison of performance on ADHD quality of care indicators: Practitioner self-report versus chart review. *Journal of Attention Disorders*. <https://doi.org/10.1177/1087054715624227>.
- Graham, J., Banaschewski, T., Buitelaar, J., Coghill, D., Danckaerts, M., Dittmann, R. W., ... Taylor, E. (2011). European guidelines on managing adverse effects of medication for ADHD. *European Child & Adolescent Psychiatry*, 20(1), 17–37. <https://doi.org/10.1007/s00787-010-0140-6>.
- Greenhill, L., Kollins, S., Abikoff, H., McCracken, J., Riddle, M., Swanson, J., ... Cooper, T. (2006). Efficacy and safety of immediate-release methylphenidate treatment for preschoolers with ADHD. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(11), 1284–1293. <https://doi.org/10.1097/01.chi.0000235077.32661.61>.

- Kadesjo, C., Kadesjo, B., Hagglof, B., & Gillberg, C. (2001). ADHD in Swedish 3- to 7-year-old children. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(9), 1021–1028. <https://doi.org/10.1097/00004583-200109000-00010>.
- Kirova, A. M., Kelberman, C., Storch, B., DiSalvo, M., Woodworth, K. Y., Faraone, S. V., & Biederman, J. (2019). Are subsyndromal manifestations of attention deficit hyperactivity disorder morbid in children? A systematic qualitative review of the literature with meta-analysis. *Psychiatry Research, 274*, 75–90. <https://doi.org/10.1016/j.psychres.2019.02.003>.
- Kovshoff, H., Vrijens, M., Thompson, M., Yardley, L., Hodgkins, P., Sonuga-Barke, E. J., & Danckaerts, M. (2013). What influences clinicians' decisions about ADHD medication? Initial data from the influences on prescribing for ADHD questionnaire (IPAQ). *European Child & Adolescent Psychiatry, 22*(9), 533–542. <https://doi.org/10.1007/s00787-013-0393-y>.
- Kuntsi, J., Pinto, R., Price, T. S., van der Meere, J. J., Frazier-Wood, A. C., & Asherson, P. (2014). The separation of ADHD inattention and hyperactivity-impulsivity symptoms: Pathways from genetic effects to cognitive impairments and symptoms. *Journal of Abnormal Child Psychology, 42*(1), 127–136. <https://doi.org/10.1007/s10802-013-9771-7>.
- Lahey, B. B., Pelham, W. E., Loney, J., Kipp, H., Ehrhardt, A., Lee, S. S., ... Massetti, G. (2004). Three-year predictive validity of DSM-IV attention deficit hyperactivity disorder in children diagnosed at 4–6 years of age. *The American Journal of Psychiatry, 161*(11), 2014–2020. <https://doi.org/10.1176/appi.ajp.161.11.2014>.
- Langley, K., Fowler, T., Ford, T., Thapar, A. K., van den Bree, M., Harold, G., ... Thapar, A. (2010). Adolescent clinical outcomes for young people with attention-deficit hyperactivity disorder. *The British Journal of Psychiatry, 196*(3), 235–240. <https://doi.org/10.1192/bjp.bp.109.066274>.
- Lara, C., Fayyad, J., de Graaf, R., Kessler, R. C., Aguilar-Gaxiola, S., Angermeyer, M., ... Sampson, N. (2009). Childhood predictors of adult attention-deficit/hyperactivity disorder: Results from the World Health Organization World Mental Health Survey Initiative. *Biological Psychiatry, 65*(1), 46–54. <https://doi.org/10.1016/j.biopsych.2008.10.005>.
- Leucht, S., Hierl, S., Kissling, W., Dold, M., & Davis, J. M. (2012). Putting the efficacy of psychiatric and general medicine medication into perspective: Review of meta-analyses. *The British Journal of Psychiatry, 200*(2), 97–106. <https://doi.org/10.1192/bjp.bp.111.096594>.
- Levy, F., Hay, D. A., McStephen, M., Wood, C., & Waldman, I. (1997). Attention-deficit hyperactivity disorder: A category or a continuum? Genetic analysis of a large-scale twin study. *Journal of the American Academy of Child and Adolescent Psychiatry, 36*(6), 737–744. <https://doi.org/10.1097/00004583-199706000-00009>.
- March, J. S., Swanson, J. M., Arnold, L. E., Hoza, B., Conners, C. K., Hinshaw, S. P., ... Pelham, W. E. (2000). Anxiety as a predictor and outcome variable in the multimodal treatment study of children with ADHD (MTA). *Journal of Abnormal Child Psychology, 28*(6), 527–541. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11104315>.
- McCarthy, S., Asherson, P., Coghill, D., Hollis, C., Murray, M., Potts, L., ... Wong, I. C. (2009). Attention-deficit hyperactivity disorder: Treatment discontinuation in adolescents and young adults. *The British Journal of Psychiatry, 194*(3), 273–277. <https://doi.org/10.1192/bjp.bp.107.045245>.
- NICE. (2018). *Attention deficit hyperactivity disorder: Diagnosis and management*. NICE guideline [NG87]. Retrieved from <https://www.nice.org.uk/guidance/ng87>.
- Polanczyk, G., Caspi, A., Houts, R., Kollins, S. H., Rohde, L. A., & Moffitt, T. E. (2010). Implications of extending the ADHD age-of-onset criterion to age 12: Results from a prospectively studied birth cohort. *Journal of the American Academy of Child and Adolescent Psychiatry, 49*(3), 210–216. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/20410710>.
- Polanczyk, G., de Lima, M. S., Horta, B. L., Biederman, J., & Rohde, L. A. (2007). The worldwide prevalence of ADHD: A systematic review and meta-regression analysis. *The American Journal of Psychiatry, 164*(6), 942–948. <https://doi.org/10.1176/appi.ajp.164.6.942>.

- Polaczyk, G. V., Willcutt, E. G., Salum, G. A., Kieling, C., & Rohde, L. A. (2014). ADHD prevalence estimates across three decades: An updated systematic review and meta-regression analysis. *International Journal of Epidemiology*. <https://doi.org/10.1093/ije/dyt261>.
- Price, T. S., Simonoff, E., Asherson, P., Curran, S., Kuntsi, J., Waldman, I., & Plomin, R. (2005). Continuity and change in preschool ADHD symptoms: Longitudinal genetic analysis with contrast effects. *Behavior Genetics*, *35*(2), 121–132. <https://doi.org/10.1007/s10519-004-1013-x>.
- Sayal, K., Prasad, V., Daley, D., Ford, T., & Coghill, D. (2018). ADHD in children and young people: Prevalence, care pathways, and service provision. *Lancet Psychiatry*, *5*(2), 175–186. [https://doi.org/10.1016/S2215-0366\(17\)30167-0](https://doi.org/10.1016/S2215-0366(17)30167-0).
- Smidts, D. P., & Oosterlaan, J. (2007). How common are symptoms of ADHD in typically developing preschoolers? A study on prevalence rates and prenatal/demographic risk factors. *Cortex*, *43*(6), 710–717. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17710823>.
- Solanto, M. V., Marks, D. J., Mitchell, K. J., Wasserstein, J., & Kofman, M. D. (2008). Development of a new psychosocial treatment for adult ADHD. *Journal of Attention Disorders*, *11*(6), 728–736. <https://doi.org/10.1177/1087054707305100>.
- Solanto, M. V., Marks, D. J., Wasserstein, J., Mitchell, K., Abikoff, H., Alvir, J. M., & Kofman, M. D. (2010). Efficacy of meta-cognitive therapy for adult ADHD. *The American Journal of Psychiatry*, *167*(8), 958–968. <https://doi.org/10.1176/appi.ajp.2009.09081123>.
- Sonuga-Barke, E. J., Brandeis, D., Cortese, S., Daley, D., Ferrin, M., Holtmann, M., ... European, A. G. G. (2013). Nonpharmacological interventions for ADHD: Systematic review and meta-analyses of randomized controlled trials of dietary and psychological treatments. *The American Journal of Psychiatry*, *170*(3), 275–289. <https://doi.org/10.1176/appi.ajp.2012.12070991>.
- Stevenson, J., Buitelaar, J., Cortese, S., Ferrin, M., Konofal, E., Lecendreux, M., ... Sonuga-Barke, E. (2014). Research review: The role of diet in the treatment of attention-deficit/hyperactivity disorder—An appraisal of the evidence on efficacy and recommendations on the design of future studies. *Journal of Child Psychology and Psychiatry*, *55*(5), 416–427. <https://doi.org/10.1111/jcpp.12215>.
- Swanson, J. M. (2019). Debate: Are stimulant medications for attention-deficit/hyperactivity disorder effective in the long term? (against). *Journal of the American Academy of Child and Adolescent Psychiatry*, *58*(10), 936–938. <https://doi.org/10.1016/j.jaac.2019.07.001>.
- The MTA Cooperative Group. (1999). A 14-month randomized clinical trial of treatment strategies for attention-deficit/hyperactivity disorder. The MTA Cooperative Group. Multimodal Treatment Study of Children with ADHD. *Archives of General Psychiatry*, *56*(12), 1073–1086. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10591283>. <http://archpsyc.jamanetwork.com/article.aspx?articleid=205525>.
- Vande Voort, J. L., He, J. P., Jameson, N. D., & Merikangas, K. R. (2014). Impact of the DSM-5 attention-deficit/hyperactivity disorder age-of-onset criterion in the US adolescent population. *Journal of the American Academy of Child and Adolescent Psychiatry*, *53*(7), 736–744. <https://doi.org/10.1016/j.jaac.2014.03.005>.
- Vitiello, B., Severe, J. B., Greenhill, L. L., Arnold, L. E., Abikoff, H. B., Bukstein, O. G., ... Cantwell, D. P. (2001). Methylphenidate dosage for children with ADHD over time under controlled conditions: Lessons from the MTA. *Journal of the American Academy of Child and Adolescent Psychiatry*, *40*(2), 188–196. <https://doi.org/10.1097/00004583-200102000-00013>.
- Wilens, T. E., Biederman, J., Brown, S., Tanguay, S., Monuteaux, M. C., Blake, C., & Spencer, T. J. (2002). Psychiatric comorbidity and functioning in clinically referred preschool children and school-age youths with ADHD. *Journal of the American Academy of Child and Adolescent Psychiatry*, *41*(3), 262–268. <https://doi.org/10.1097/00004583-200203000-00005>.
- Willcutt, E. G., Nigg, J. T., Pennington, B. F., Solanto, M. V., Rohde, L. A., Tannock, R., ... Lahey, B. B. (2012). Validity of DSM-IV attention deficit/hyperactivity disorder symptom dimensions and subtypes. *Journal of Abnormal Psychology*. <https://doi.org/10.1037/a0027347>.

- Wolraich, M. L., Hagan, J. F., Jr., Allan, C., Chan, E., Davison, D., Earls, M., ... Subcommittee on Children and Adolescents With Attention-Deficit/Hyperactive Disorder. (2019). Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics*, *144*(4). <https://doi.org/10.1542/peds.2019-2528>.
- Young, S., & Amarasinghe, J. M. (2010). Practitioner review: Non-pharmacological treatments for ADHD: A lifespan approach. *Journal of Child Psychology and Psychiatry*, *51*(2), 116–133. <https://doi.org/10.1111/j.1469-7610.2009.02191.x>.



P A R T IV

Child and adolescent
mental health policy
and services—Asian
perspectives

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Starting small: Developing child-centric mental health policies

Daniel Shuen Sheng Fung and Daniel Poremski

Department of Developmental Psychiatry, Institute of Mental Health,
Singapore, Singapore

1 Introduction

There is a Chinese saying that says the highly skilled doctor prevents illness, the mediocre doctors treat impending illness, and the least skilled doctor treats actual illness. While it is difficult to capture the nuances of the original meaning, it echoes Benjamin Franklin's axiom that 'an ounce of prevention is worth a pound of cure'. These types of axioms underscore the importance and potential of child psychiatrists and the health policies based upon their practices.

1.1 What is policy?

The word policy has its origins from Latin, Greek, and French, meaning 'prudence or wisdom in the management of affairs' according to the Merriam-Webster's dictionary. The WHO defines mental health policy as an official statement that provides overall direction for mental health services (World Health Organization, 2007). It should have vision, values, principles, and objectives that we would like to see in today's healthcare system. In other words, it is a big picture for what a country's mental health system would like to be and a basis for action towards these goals. This approach includes the financing, the coordination, and the legislation needed to achieve the objectives. What is the purpose of public policy? On the one hand the answer can be relatively simple in that policies are developed for the good of the public. On the other hand the answer can just as easily be complicated by how people describe what is 'good' for the people. Good could be seen as developing equality, mitigating disparities,

and translating knowledge into meaningful action (Harper, 2012), or it could just be administering the political views of a particular era.

1.2 What is good policy?

A good policy must be rooted in the evidence base, be supplemented by a strategic actionable plan, and generate clear measurable outcomes. Well-devised mental health policies take into consideration the need for services to be flexibly organized to adapt and respond to foreseen and unforeseen changing demand. However, services must achieve this structure and responsiveness in a cost-effective manner not only in the short term but also in the long term. In this way policies consider not only an immediate need but also the needs of subsequent generations.

1.3 What is the problem with current approaches to policy?

Psychiatrists can be in a quandary. Our clinical training puts us at risk of adopting a reductionist approach in determining what must be done for the identified patient and their family. It makes us reduce problems into categories called diagnoses, which then can be solved with a series of interventions. When you place a child psychiatrist in a situation that requires them to plan services, the same reductionist approach is seldom successful. Systems cannot be simplified or reduced to a series of independent components. Attempting to do so, which is the tendency of those who adopt a reductionist approach, has resulted in the siloed systems existing in most nations. Complex systems (such as families with multiple needs) require a more global approach to allow for the interrelational dynamics of the family and the various systems to work together. While such dynamics, when recognized, are increasingly being addressed, most of the components of the complex systems (social work, forensic services, and medical services) have habitually forced them apart to divide various superficial manifestations into manageable and consequentially disjointed problems. This may be at the expense of addressing the root cause which led to the superficial manifestations. Tasking a child psychiatrist with developing mental health policy may result in anarchy and chaos because of the reductionist clinical mindset. This is not to condemn physicians to policymaking mediocrity but rather to highlight that, if physicians are tasked with roles in policymaking, they must be mindful of the way in which their medical training might influence their strategies. Indeed, physicians who are aware of the limitations of seeing the healthcare system through the reductionist lens and who adopt an approach that is public health driven can accomplish meaningful reform. A review of 29 physicians who became politicians and heads of state (Lass, Szarszewski,

Gaworska-Krzemińska, & Sławek, 2012) suggested that they were capable administrators with a penchant for driving public health policies (and by inference upstream policies).

1.4 Why are children a key population?

When it comes to children, a number of issues exist. As many adulthood illnesses trace their origins to the ‘sensitive periods of childhood’ (Andersen & Teicher, 2008), policies about children are focused on the future. Any undetected aberrations that develop during these periods become risk markers for health problems if not managed appropriately (Teicher et al., 2003). Policies about children tend to cross sectoral boundaries and become too complex to manage because aberrations in one sector can have repercussions in another. For example, a policy on children’s health requiring regular exercise and fitness training would certainly overlap with educational policies and curriculum development. Much as we want the child to sit in a classroom for a number of hours to develop literacy and numeracy skills, that child may also need to be outdoors in the sun and eating well and have sufficient activity and rest. If not, physical health may be affected both in childhood and adulthood in the form of obesity and subsequent sequelae. To develop good policies, one may therefore need to work across different sectors to identify the needs and focus on intersectoral collaboration to achieve the intended outcomes, in the present and future. Ideally, such policies must have a population-based, upstream perspective that recognizes that risks and strengths emerge during sensitive periods of development. Additionally the policies must recognize that, once the period has passed, risks are harder to reverse and strengths are harder to develop. Several countries have started to look towards national policies focusing on childhood, the most prominent perhaps is Scotland and their governmental plan to give every child their best start in life (Scottish Government, 2010).

We would like to apply the traditional principles of mental health policy development but take a child-oriented perspective. Instead of planning services, as one would in creating a mental healthcare system, we would like to propose a transformation of existing mental healthcare services towards a child-focused, family strength-based integrated ecosystem. This will involve not only the healthcare system but also other sectors. The arguments that support the proposal fall into eight sections presented in the succeeding text in a logical sequence. Each section impacts other sections, so to ease understanding, we quickly set forth the sections and our rationale for their order. Each section is accompanied, where possible, with examples of existing initiatives (Fig. 1).

Collaboration and coordination appear as a logical starting point. Since the sectors that could benefit from collaboration are already mature,



FIG. 1 Chapter sections and organization.

it may be preferable that, early on, connections and collaboration be established to share knowledge and understanding of the various challenges encountered by each system. While some collaborations already exist, we wish to underscore the importance of this activity precisely because many subsequent sections depend on successful collaboration. **Promotion, prevention, and treatment** are amongst the elements that the various sectors have already developed as part of their maturation stage, and it therefore becomes relevant for intersectoral collaborations to explore how their current practices may be altered as a result of the collaborations. We acknowledge that arguments could be made to place content related to prevention and treatment at a later stage, once other issues related to collaboration have been settled, but keeping it early highlights that much of the subsequent sections are necessary in support of healthcare promotion, disease prevention, and treatment. Following closely on the establishment of key collaborations comes the need to understand the way the **organization of services** may alter as a result. Sharing and sifting knowledge may help reduce duplication and provide a clearer consistent message to service seekers. While **legislation** often provides the bedrock on which practice is built, it is also relevant to have a clear understanding of the systems' practices for legislation to be written to support the collaborations. **Financing** is an issue that underlies several activities throughout our proposal, but as financial mechanisms may be slow to change, it is challenging to suggest that it should be addressed at the forefront. Once collaborations are established, service organization planned out, and responsibilities distributed, funding

should flow to sectors where it is needed. The technology required to support **information systems** will likely surpass our expectation for development, but as an important part for information sharing, the developments related to these technologies should be acknowledged. Building **human resources** like many other sections we discuss could be placed at multiple spots along our cycle. However, we would argue that its placement may largely depend on finance and depend on the method chosen to project the need for resources. A system can be developed to fit available resources, or resources can be made available to attempt to meet the requirements of a system based on need. While the latter option is likely what many systems strive to accomplish, the reality, as detailed in the succeeding text, may more resemble the former. Finally, we would like to highlight the role of **research and evaluation** in providing continuous impetus for documenting and sharing initiatives to facilitate the dissemination of knowledge between sectors that may not have direct lines of communication.

2 Coordination and collaboration

The traditional concept of coordination of care in child and adolescent mental health (CAMH) services started with the concern that existing services could not cope with the scope of work that was needed. In healthcare the concept of primary care (seen as frontline services) linking within secondary care (specialist-referred services) and tertiary care (multidisciplinary services with specialized centres such as hospitals) provides a degree of collaboration, but it may still be bound by the limitations of healthcare service providers. Similar tiered approaches are being adopted by child mental health services, but the limitations of the structure will also be inherited (Sayal, 2006). This tiered organizational strategy is best articulated in the WHO Mental Health Gap Action Programme (mhGAP), which puts forth a coordinated plan for integrating primary care services for supporting mental health issues (World Health Organization, 2008). The essence of the plan is to balance the ‘insufficient, inequitably distributed, and inefficiently used’ services (World Health Organization, 2008). The mhGAP initially focused on eight areas, of which only one is childhood focused and initially gave the impression that childhood disorders were distinct from adult conditions. The mhGAP focuses mainly on health agencies and therefore lacks a developmental perspective that considers the lifelong impact of early life social environmental or health experiences. These components may be outside of the realm of influence of services organized within the tiered system if no provisions are made to connect the tiers to their analogue systems in other sectors, such as social educational or forensic services.

There is a need to develop systems of care that cross sectors. Much of this will require different agencies in public, private, and people (non-governmental) sectors to work together. Singapore has a school mental health system that works within the educational system that took 10 years to realize (Fung & Lim-Ashworth, 2017). This system is made of school partnership with health services integrated with assisting social service agencies. Many countries have been developing this type of ecosystem with varying degrees of success. The reason for doing this is linked to the concept that children and their needs exist in various sectors (be it education, health, or social) and that these domains have difficulties collaborating and integrating.

In an ideal world, policy will need to consider (1) shared funding where cross sectoral work needs a common budget; (2) shared human resource meaning that transdisciplinary training and expertise is developed so that, regardless of professions, the mental health worker will need to function at various levels of care; (3) population acceptability of such a concept so that access to services is seen across the primary, secondary, and tertiary sectors as needed and not have people access services unnecessarily.

3 Promotion, prevention, and treatment

As noted earlier the superior doctor prevents illness, and this is best accomplished by understanding and addressing upstream processes and illness aetiologies. The importance of problem-oriented approaches towards treatments and interventions are well established. Consequently, many clinical services focus on early detection and risk amelioration but have focused less on identifying practically what works in their population. Family- and community-based approaches often look at resiliency and strengths as means of helping. This is especially true for children where focussing on what works can create opportunities for coping. A strength-based approach towards healthcare system development is therefore important (Swartz, 2017).

At the same time the need to identify the best yet cost-effective treatments is an ongoing task that sometimes gets sidelined in the search for preventive psychiatry and population mental health (Saraceno et al., 2007). It is necessary not only to measure clinician-rated outcomes but also to measure person-reported outcomes and social outcomes, as these tend to be the outcomes that produce the most value. Value-based medicine will mean that the evidence of efficacy and effectiveness must be measured against cost and the wider value society accords to the improvements (Lee et al., 2016).

The evidence base that exists for psychopharmacological interventions is well developed. This can be attributed to the rigour with which such

interventions need to be tested to pass safety certification and licencing. Such interventions therefore feature prominently in clinicians' treatment arsenal. Psychosocial interventions contrarily do not need to undergo such rigorous testing to receive governmental approval. Therefore they are generally lacking in comparable evidence base. This imbalance must be re-addressed with additional research (Beecham, 2014). The use of randomized controlled trials may be less feasible in children; as such, experimental interventions carried out in a rapidly developing child are akin to trying to shoot a moving target. Clinicians and policymakers should therefore adjust their expectations for acceptable standard of evidence and must supplement the existing experimental evidence with other, more accessible, forms of evidence. Other means of research using cohorts and measuring multiple informant outcomes across time may shed light into this complex system.

Once we know which interventions work, the next question is how to create accessibility to the interventions and ensure treatment gaps do not form for children and adolescents. This would require that sufficient and relevant resources be obtained to ensure that every child receives the necessary help early.

Advocating the rights of children and acting accordingly should be a priority for any good government. Today the United Nations Convention on the Rights of the Child has been ratified by 196 of the 197 countries (United Nations, 1989). It is the most widely ratified human rights treaty in history. However, when it comes to acting accordingly, the development of services for children continues to lag behind.

Improvements and innovations need to be encouraged to reconsider how we organize health and mental health services. To move upstream in promotion and prevention will require a mindset change to prioritize community- and school-based interventions and resiliency building initiatives. These interventions can no longer be based solely within health-care systems but must embrace cross sectoral work to leverage the various points of intervention across the development of the child, and eventually, family-based self-care systems will become predominant.

4 Organization of services

Services are traditionally organized by age, but there is an increasing realization that age-specific organization has created its own problems particularly in transitions of care for chronic illnesses. Many chronic mental illnesses actually have their onset in childhood or late adolescence, and service provision should be patient centred rather than age specific. Organization based on disorders risks creating silos of care, unnecessary barriers (such as exclusion of comorbidities), and subspecialisation. This type of organizational strategy leads to multiple points of contact

that may duplicate supportive services, taking up unnecessary resources, and exposing service users to unnecessary activities. Left on their own, many systems have evolved in very diverse ways. For example, a recent survey in Europe showed that services have developed very differently amongst 28 European Union member countries, despite their close geographic proximity to one another (Signorini et al., 2017). The study found that the way various child and adolescent mental health services were designed in terms of infrastructure, human resources, and processes varied considerably between countries. This variation also occurred in terms of funding and access to services. There was no relationship between disease prevalence, burden, and the resources allocated. How should services be organized? Existing specialist tertiary services are only the tip of the iceberg (Fig. 2). It is crucial to ensure not only that services are well run and able to deal with acute problems but also that resources are flexible enough to shift in response to emerging efficiencies and needs. The savings generated by efficient primary care can be moved elsewhere, perhaps towards specialist-empowered primary and secondary care. These areas need training and skills development so that not only physicians and allied professionals but also families and children themselves are able to obtain the tools and develop the abilities necessary to maintain good health. Creating links between hospitals, which for now have the greatest concentration of experts, and communities and homes will require a technological evolution of the interfaces between them. Today the Internet and mobile devices represent a potential digital solution for establishing such a connection. This may be especially true in lower-income regions where the speed with which mobile networks can be erected outpaces the speed with which traditional bricks-and-mortar infrastructure can be constructed.

As healthcare sectors shift further away from institutionalized modes of care, healthcare providers must consider which relationships and transdisciplinary expertise must be developed to support children and their families in the community. Professions have developed skills and expertise that are based on their qualities and roles within a specialized hospital setting, where multidisciplinary teams work hand in hand. This changes when services move into the community, where separate professions work in greater isolation. This change in the work structure leads to a need to develop transdisciplinary expertise within singular individuals. Expertise can be formalized with the development of tools (such as treatment algorithms, referral checklists, or care provider maps), which in turn may allow the expertise to be shared. Eventually, developing these skills and expertise may become mandatory and may be integrated into continuing education. In fact, it may become an essential part of the maintenance of certification for professional development across time. For example, a community-based nurse may need competencies that might traditionally

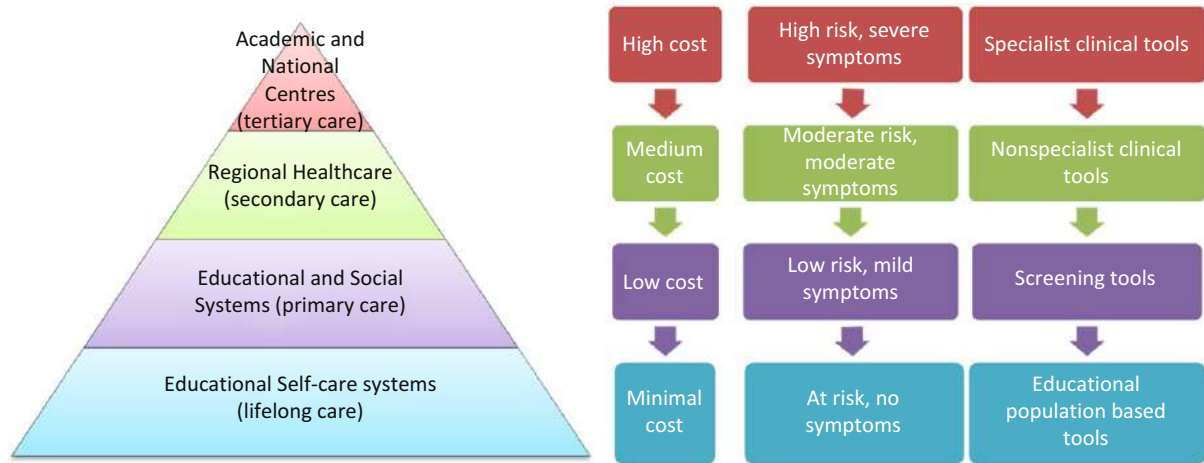


FIG. 2 Organization of services and corresponding costs, needs, and tools.

be within the domain of a social worker or occupational therapist as these specialized service providers may not be immediately accessible during community visits. Within a hospital a nurse may defer questions about financial support or therapy paradigms to the relevant professional, but when visiting service users within the community, it may be expected that the nurse has knowledge of such matters.

As the organization of services evolves, policymakers must not neglect the need for services to be able to show cost-effectiveness and value. This requires that services not only be organized with clear measurable outcomes in mind but also that services have the resources to take measurements at key stages of their development (Lee et al., 2016). With this added layer of organization, policymakers can obtain and monitor the value of their services. Funding should be based on service performance towards achieving their stated outcomes.

5 Legislation

Legislation is an important instrument for countries and their governments to organize society, protect its citizens, and articulate the way culture define acceptable behaviour. Policies use legislation to create rules for society. Health legislation is often enacted to protect the population against various diseases and their sequela, including mental illnesses. The aim of mental health legislation is to protect persons with mental illness by setting out a framework that allows others, namely, service providers, to intervene for the sake of the safety of the individual and the safety of those around them. There is a worry that people who experience mental illness have lost the ability to care for themselves due to ‘lack of insight’ which is part of the symptom pathology in serious mental illness. This worry has a long history of driving legislation and the way society behaves towards such people, for better or worse (Table 1).

TABLE 1 Concerns at the centre of policies that have driven legislation and subsequent practices.

Purpose and concerns	Legislation	Examples
Protection of society	Mental health laws	Mandatory assessment and treatment Manage dangerous behaviours to self and others
Protection of children	Prevention of child abuse laws	Define child abuse Reporting of child abuse
Mental capacity	Mental capacity laws	Assessment of capacity Age of consent and culpability

With regard to children, apart from protecting society against the risks of mental illnesses, legislation also serves to protect children from abuse and neglect. Such child protection legislation is widespread (Cutland, 2012). Much of the legislation arose in response to empirical evidence that child maltreatment is widespread in every studied country and that this maltreatment is strongly correlated with adverse adult mental and physical health outcomes (Collin-Vézina, Daigneault, & Hébert, 2013; Tran et al., 2018). However, child and adolescent-specific mental health legislation remains relatively absent (Shatkin & Belfer, 2004; World Health Organization, 2005), ineffectively incorporated into the general mental health legislation (Bailey & Davis, 2012) or poorly coordinated (Bringewatt & Gershoff, 2010). In child protection laws, most laws focus on physical and sexual abuse but do not address the significant effects of emotional abuse (Dunne, Chen, & Choo, 2008). In some countries, legislation is also lacking due to the cultural sensitivity of sexual abuse and shame within families (Wismayanti, O'Leary, Tilbury, & Tjoe, 2019). This absence may perpetuate the lack of specific policies and consequently a lack of action. This is troubling, especially in the light of strong evidence that supports the link between the presence of CAMH-specific policy and lower adolescent aggressive behaviours in European countries (Hendriks et al., 2019).

There are certain difficulties legislating child protection laws that adequately cover the various sources of childhood trauma (Cutland, 2012), despite the global evidence of its negative impact (Tran et al., 2018). For example, it is reasonable to legislatively prohibit violence against children (a step taken by many countries) or to oblige the reporting of abuse. However, enforcement remains problematic (Lukefahr, Kellogg, Anderst, Gavril, & Wehner, 2011). Crafting legislation that supports preventative actions has also been elusive. Strategies implemented to overcome the challenges include extending professional capacity to intervene, implementing mandatory reporting and data collection, and monitoring systems (such as child death review teams Palusci & Covington, 2014). While addressing trauma resulting from sexual abuse by enforcing offender management registries may be considered one preventative measure (Collin-Vézina et al., 2013), preventing emotional abuse and child neglect may be much more challenging given the isolating impact of the abuse and because the target of abuse is within the family (Morelen & Shaffer, 2012). Educational programmes that target schools and parents are potential avenues to increase awareness, facilitate early detection, and offer preliminary intervention in all forms of abuse. Such programmes have been shown to be effective in the reduction of sexual abuse when they are of sufficient duration and provide repeated exposure to important concepts (Collin-Vézina et al., 2013). Such strategies may be effective in preventing other forms of abuse as well in a multitude of cultural contexts (Dunne et al., 2008; Saini, 2013; Tran et al., 2018).

All professionals dealing with children should be mindful of their potential role as advocates (Cutland, 2012). It is interesting to note that, to a certain degree, professional ethical guidelines can support vulnerable populations in the absence of adequate legislation (Cukovic-Bagic, Welbury, Flander, Hatibovic-Kofman, & Nuzzolese, 2013; Morelen & Shaffer, 2012). This suggests that professional bodies can play an important role by adopting measures that have yet to be legislated (provided they do not contravene existing legislation), despite having marginal influence on legislators.

Although mental health laws are increasingly common in many countries, most laws do not address children and adolescents. Despite the lack of youth-relevant laws, existing legislation has evolved in response to advocacy and changing evidence (Law Reform Commission, 2011). More recent reviews in many countries have focussed on individual rights especially in adults with mental illness who have capacity to negotiate their rights. For example, in the new Indian Mental Healthcare Act 2017, admissions and treatment are regarded as 'supported' rather than involuntary (Namboodiri, George, & Singh, 2019), and there is more advocacy for psychiatric advance directives or psychiatric wills in psychiatric care. However, this specific act, taken as an example, has some notable differences concerning the degree to which an adolescent is able to govern what is done to them. For example, Acts governing the legal sector may recognize an individual below the legal age as someone who can be tried as an adult in certain circumstances, thereby recognizing the individual's decision-making capacity. The Indian Mental Healthcare Act of 2017 however does not make this recognition and does not address the degree to which adolescents should be consulted on matters of their care. Rather, it transfers the full responsibility of making care decisions to them only when they turn 18 (Sharma & Kommu, 2019). This age-based concept is a common, although not universal, standard internationally, with the legal age of consent to medical treatment typically 2 years older than the legal age for criminal responsibility (Noroozi, Singh, & Fazel, 2018). This discrepancy demonstrates that legislators continue to disagree about the pivotal age at which people become capable of making decisions about their lives. As our understanding of capacity advances, our legislation and policies must follow (Cave, 2014; Noroozi et al., 2018).

By arguing that more legislation is needed to recognize and protect the decision-making capabilities of mature minors, we do not intend to argue that the treatments suitable for adults are suitable for adolescents. This point of clarification is necessary because it may result in the lowering of the age of people eligible for admission to adult wards, which would have deleterious effects. Child and adolescent wards are still necessary, and admissions of children to adult wards must be avoided. What we intend is that legislators around the world must be mindful of the developments in

our understanding of capacity to consent. Structured recommendations exist to lower the age of consent to medical treatment to 14 in certain circumstances ([Law Reform Commission, 2011](#)), and mental health acts currently being written or rewritten should incorporate these advances in a culturally sensitive way.

Once these questions have been addressed, it is likely that others will surface, for which no debate exists. For example, under current practice, where people below the age of majority have no capacity to make a medical decision, their legal guardians are automatically designated as the decision-makers. But this automatic decision is not equivalent in adults who lose capacity. If, as we have argued, the age at which the ability to make medical decision is lowered, should the individual's legal guardians remain as the substitute decision-makers? Or is additional legislation required for protection, as in the case of independent mental healthcare advocates?

6 Financing

A good financial support system is the bedrock for good mental health policy. However, the proportion of the healthcare budget devoted to mental health services varies considerably and remains relatively low ([World Health Organization, 2017](#)). The WHO reports in their *2017 Mental Health Atlas* that on a global level a median of 2% of governmental expenditure on healthcare is directed to mental health. This proportion not only varies in accordance with a country's wealth but also likely varies depending on the degree to which the individual is responsible for the funding of their own mental health services. Out-of-pocket expenditures account for a greater portion of mental health expenditure in Africa and the South East Asian region than the global average ([World Health Organization, 2017](#)). The proportion of mental health funding devoted to hospitals also hints at the type of care provided by regions. In countries with higher GDP, the proportion of funds routed to hospitals is lower than in area of low or middle income. This distribution likely indicates that areas with higher hospital spending likely also have a higher reliance on institutionalized sources of care. Psychiatrists earn in the lower third of medical specialists, slightly better than the paediatrician ([Kane, 2019](#)). While the circumstances of resource allocation are complex ([Penno, Gauld, & Audas, 2013](#)), given that mental health issues contribute significantly to the global burden of disease and that illnesses may be the most prevalent in younger age groups, we may expect funding to be more proportionate.

Child mental health services across the globe are often funded in a mixture of methods. Across Europe, studies have suggested that great variation in payment systems exists, including public tax-based funding

distributed by the government, such as universal coverage, child disability benefits, and social insurance, and private health insurances, such as those purchased by private individuals and those purchased by employers (Signorini et al., 2017). There may be no single payment system that can work, but a combination will be needed when working with children, always bearing in mind the developmental nature that funding for children entails. The source of the funding is an important consideration, given that funders (the branch of the government or the underwriter of the policies) must be able to account for spending and show concrete results. Given that the causal chain between life and ill health contains various steps, various organizations play a role at each step. And because these organizations are compartmentalized in various ministries and agencies, financing an intervention that might positively influence one element in the causal chain may not be reflected in the returns of that financing body (Scott, Knapp, Henderson, & Maughan, 2001). For example, funding an antisocial treatment by means of family-based therapy administered through a medical practice may cost the practice and healthcare system a considerable sum of money but may return important future savings for the ministry of justice in the form of crimes avoided (Scott et al., 2001). In this scenario the health ministry invests an important sum of money, but savings are generated elsewhere. On a societal level, those transfer payments are not important, but when it comes to budget negotiation and practical fund allocation, arguing for such investment can be difficult. The intersectoral collaborations required to finance mental health multiply if we consider the added complexity of private insurance mechanisms.

Another point at which policy may exert considerable financial pressure is the way in which policymakers choose to allow certain services and items to be covered under public insurance schemes, pharmaceutical schedules, or drug and device formularies. Health ministries often have health technology assessment units to help them determine the cost-effectiveness of new strategies or treatment alternatives. If a new drug or intervention demonstrates cost-effectiveness, it may be introduced into the list of allowed expenses, encouraging public healthcare providers to administer the treatment. While there are obvious benefits for such a system and a glaring need for expenses to be vetted in an efficient method, the process is relatively focussed on interventions that traditionally fall under the domain of physicians. In psychiatry, there is a perverse incentive to see patients in the clinic rather than preventing illness in the community (Lavigne, Brown, & Matzke, 2017), possibly because, under the former treatment modality, expenses can be billed, but under the latter, services may fall outside permitted expenses. If a potential intervention falls outside the list of permitted expenses, a market does not develop, and the service is underutilized. Policymakers must carefully consider the way in which various health technologies are approved for remuneration

and assess whether their list might be neglecting treatment alternatives that indirectly impact health via other intervention modalities outside the domain of the physician.

Alongside the healthcare financing is the need to consider how other sectors work with children and adolescents. Selected components of education and social budgets may need to be combined to pay for supporting children and adolescents as there is a long-term opportunity cost. Despite challenges that exist here, it has long been shown that intersectoral cooperation at an early stage can have long-term financial windfalls (Scott et al., 2001). Estimates of healthcare spending by age group reveal that spending increases with age, something linked to the increase in multiple comorbidities (Dieleman et al., 2016). However, what estimations also highlight is the distribution of the spending: on treatments for risk factors versus treatments for the immediate condition. Considering that the most expensive conditions have a high degree of modifiability due to their aetiology in modifiable behaviours, we would expect to see growing proportions of resources being devoted to the remediation of these modifiable behaviours. This is not the case (Dieleman et al., 2016). This illustrates that healthcare systems are still struggling to shift their focus to preventative medicine. What is relevant specifically to this discussion on child psychiatry is the amount of spending devoted to treating risk factors in childhood and adolescence. Between 1996 and 2013 the amount of money dedicated to treating risk factors in the elderly above 65 grew 18.5%, while the amount of money devoted to treating those below 20 rose only 3.7% (Dieleman et al., 2016).

Such a disparity can be due to the nature of medicine, which tends to avoid initiating pharmacological treatment in children as much as possible, especially in psychiatry. The tendency to adopt a ‘vigilant waiting’ strategy may also explain why the medical professional is more prepared to intervene in older individuals. However, this disparity can also be due to political will. While studies documenting healthcare spending preference globally are not common, those that do exist support the idea that, within a specific country, those who tend to vote tend to sway policy. Surveys of willingness to dedicate finite public resources to social assistance, education, unemployment insurance, healthcare, or pensions reveal a polarization between different age groups. Retired individuals are far more in favour of reducing spending on education than of boosting spending on pensions (Busemeyer, Goerres, & Weschle, 2009). Pair this with voter demographics, which tend to be older (Dautovic, 2018), and it is reasonable to conclude that society and political action tend to favour spending on the elderly. This is especially problematic given the projected cost of untreated clinical and subclinical mental disorders (Fatori et al., 2018; Rivenbark et al., 2018) and the cost-effectiveness of early interventions (Beecham, 2014; Murphy & Fonagy, 2012; Scott et al., 2001). Society’s

time preference, which favours the present, is the reason economists discount benefits that occur in the future. It is therefore, methodologically speaking, harder to show cost-effectiveness for interventions that have implications several decades down the road because people generally prefer to obtain benefits now and incur costs later. Incurring costs today for a possible benefit next year, let alone in 5 or 10, is politically unpopular, and therefore implementing new services of this nature or expanding existing ones is generally not easy. This is in part why several mental health advocates are calling for budget cuts to education and child social services to be reversed (Knapp et al., 2016).

In CAMH, this preference for the present time has important implications. As spending may depend on political clout, children are intrinsically vulnerable to neglect. It therefore falls on the shoulders of advocates to take the necessary steps to lobby for resources. Other sectors representing voiceless stakeholders and vulnerable populations have succeeded in gaining traction, such as in environmental law. While it is beyond us to call for such militancy, as has been seen in the realm of environmentalist lobbying, it behoves all professionals working in child health (and mental health) services to place themselves in a position to be involved and consulted when taxpayer money is divided. To effectively lobby for a proportionate share of the resources, we must be armed, not with placards or chains, but with research and figures. While the fact that figures in defence of our argument have long existed, recent reviews show that this domain, the economic analysis of the impact of treating childhood mental disorders, is lagging behind others (Beecham, 2014). Furthermore, being sure that existing figures are properly consumed by society may represent an important step in swaying popular opinion and gaining more funding.

7 Information systems and service digitization

The shift towards digitization of information and services represents an important direction for services, arguably in any country, regardless of their level of economic development. While this is true for many disciplines in medicine (Ali, Shah, & Tandon, 2011), psychiatry and child services especially can accelerate their service coverage and access via the expanding access of digital networks (Aboujaoude, Salame, & Naim, 2015; Hilty et al., 2013). This is predominantly due to the nature of psychiatry as a discipline that does not necessarily require physical intervention. While pharmacological interventions are a staple of treatment, psychiatry does not require operating theatres or sophisticated imaging infrastructure. Furthermore, as information relevant to psychiatric monitoring and treatment is often reliant on self-report or noninvasive observation, it can

be done remotely. While certain differential diagnostics may require imaging to rule out biological causes and certain medications require routine blood tests, at least at the beginning of treatment, much of the routine follow-up work can be accomplished without requiring in-person contact (Aboujaoude et al., 2015). Therefore telehealth, electronic remote data collection, and even automated treatment programmes can be seen as having great potential in psychiatry.

Health information technologies (HIT) and electronic health and medical records (EMR) are ubiquitous in most healthcare systems. They have several benefits concerning access to care, the quality of care, and our fundamental understanding of health. However, concerns remain about security, access, and ownership of the information contained in such systems. In certain systems where public insurance may cover most medical services, such as in Canada and Scandinavian countries, health records remain the property of the branch of the government responsible for medical services like the ministries of health. In such systems, these EMR can be harnessed to produce powerful cohort studies that alter our understanding of health (Frank, 2000) and improve programme quality (Jones, Talebi, Littlejohn, Bosnic, & Aprile, 2018). In fragmented systems that consist of private and public services or subsidized services, EMR may be institute specific, making the aggregation of records for research or information management purposes more complicated.

In CAMH services the implementation of health information technologies, including EMR, can facilitate key elements of the services, including collaborative care team communication, multiinformant clinical assessment, and collaborative and additive treatment provision (Coffey, Vanderlip, & Sarvet, 2017). Information systems can help with system integration and consequently access to services by allowing primary care physicians to play a greater role in the care of children with mental health concerns (Sarvet, Gold, & Straus, 2011).

Implementing EMR with mental health-specific modules in tertiary mental health institutes can have several positive benefits (Riahi, Fischler, Stuckey, Klassen, & Chen, 2017). Introducing patient-centred care planning and restraint and seclusion modules within the EMR helped reduce adverse drug reactions and improved control and restraint monitoring (Riahi et al., 2017). These important achievements followed quality improvement initiatives that included the introduction of simpler alert prompts programmed into the EMR that could be automated according to the circumstances of the case. Such simple prompts may help staff handle multiple tasks without having to remember monitoring schedules and adverse medication interactions but may lead to information overload (Colicchio, Cimino, & Del Fiol, 2019). These systems also have 'patient portals' via which service users can access their personal health information. This capability empowers

service users to communicate and disseminate their health information as necessary, even in notorious systems where health information has historically been heavily restricted (Essén et al., 2018; Riahi et al., 2017). In Singapore, for example, parents can now access their child's health records in this manner (Luk, 2018).

The shift towards digitization of records and services has an important role to play in the development of services, even more so in low- and middle-income countries (Hagg, Dahinten, & Currie, 2018). As most children live in lower- and middle-income countries, the absolute cost of EMR systems may need adjustment to deliver cost-effective solutions. Given the nature of digital software and the low marginal cost of producing another licence, it is reasonable for developers to have a sliding scale for licencing products, which would allow affordable access, while maintaining security and medical confidentiality. Therefore digital solutions may be attainable in regions where bricks-and-mortar services are lacking. This is due to the way in which access to the Internet has significantly outpaced access to bricks-and-mortar services. Access to digital networks and cell phones has expanded in low-income countries and will likely continue to expand (Poushter, Bishop, & Chwe, 2018; Samarthya-Howard & Rogers, 2018). While this expanded access to the World Wide Web likely serves many medical disciplines, the expansion can be greater in mental health where treatments can be delivered via automated online systems (Aboujaoude et al., 2015; Marzano et al., 2015). Furthermore the development of online games that address issues of concentration and other psychological domains specifically targeted to youth can be made readily available without requiring bricks-and-mortar establishments. While there is a limit to what such modes of treatment can treat, they would expand access to many people.

The shift away from hard records to electronic systems is accompanied by several concerns (Colicchio et al., 2019), including cybersecurity (Sittig, Wright, Ash, & Singh, 2016). Another concern about using electronic systems relates to data entry into such systems and the change management for clinicians who are used to making records using pen and paper. This paradigm shift and its impact on provider wellbeing cannot be underestimated (Krishna, 2017), and there is a need to consider technology enablers that facilitate this process and still allow adequate clinician–patient interaction and development of therapeutic alliance. For children the need for the interaction to go beyond language and the importance of nonverbal cues may also increase the burden for clinicians in terms of keeping records, as such cues and nonverbal interactions by their very nature fit poorly into the written word. With the miniaturization of video technology, video logs can be produced without interfering with intruding on the interaction.

8 Human resource and training

There is a worldwide shortage of child and adolescent psychiatrists (Thomas & Holzer, 2006). To illustrate this, Fig. 3 shows the number of psychiatrists per 100,000 people in the WHO regions. Child psychiatrists only account for 1.19/100,000 in high-income countries and on a global level account for a fraction lower than 0.1/100,000 people (World Health Organization, 2017). This shortage is also true for other mental health professionals including psychologists, social workers, and other members of the multidisciplinary teams (Segal et al., 2018). Such shortages depend on upstream decisions about expected workforce requirements and shifts in care management paradigms (Faulkner & Goldman, 1997). Decisions about the quality and quantity of care that should be supplied to a population influence the resource projections that in turn inform university training programme enrolment quotas. The typical supply and demand approach does not work well in healthcare systems because clinical work can be driven up when there are perverse incentives. This is particularly so in a fee-for-service model of financing. Most healthcare systems typically use three methods to determine workforce requirements. While several taxonomies exist to characterize the various approaches (Jeon & Hurley, 2010; Rafiei, Mohebbifar, Hashemi, Ezzatabadi, & Farzianpour, 2016; Sharma, Zodpey, Gaidhane, & Quazi, 2014), the three main methods are briefly described in the succeeding text and illustrated in Fig. 4.

- (1) Service target approach. This approach compares the current number of doctors per capita population (and every other professional within the specific healthcare system) with a regional or economic benchmark (Sharma et al., 2014). Presumably the benchmark is

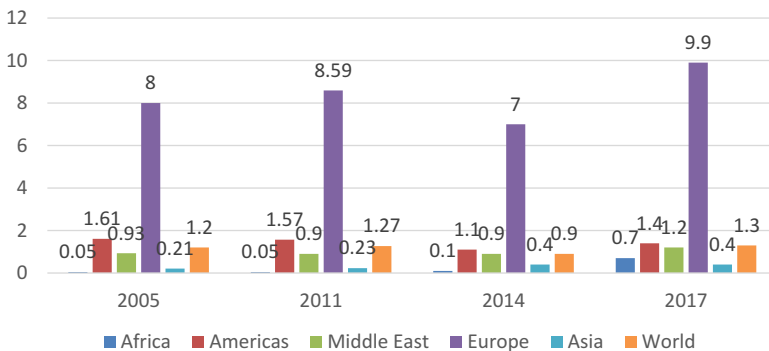


FIG. 3 Number of psychiatrists per 100,000 people per WHO region, extracted from each years' WHO Mental Health ATLAS.

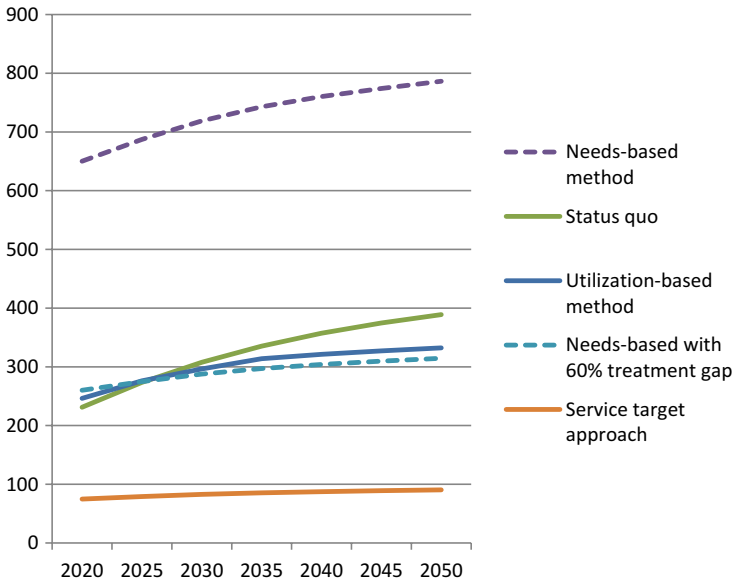


FIG. 4 Three main approaches to human resource projections, along with one modified approach, and a status quo projection. Vertical axis: number of psychiatrists needed to meet the demands of the Singapore population.

recognized as being adequate to provide reasonable care. The problem with such an approach is that it assumes that a particular formula that has worked in one area can be translated to others. The WHO-AIMS method of measuring service delivery uses such an assumption that, by increasing the density of mental health professionals, overall care and outcomes will improve (World Health Organization, 2009). The obvious problem is that, as shown in Fig. 3, most lower- and middle-income countries do not have the capacity or the resources to build up such numbers (World Health Organization, 2017).

- (2) **Utilization-based approach.** This method of workforce planning takes into account existing labour resources and estimates growth based on capacity to train and generic growth that can result from the pipeline that is established (Jeon & Hurley, 2010). This is a realistic approach that depends on expected growth in the prevalence of mental illness. The problem with such an approach is that the growth is slow and may not necessarily meet demands or needs if the prevalence of the disorder rises within the population (Sharma et al., 2014; Sutherland, 2015).
- (3) **Needs-based approach.** This systematic approach has received greater attention in recent years (MacKenzie, Murphy, & Audas, 2019; Segal et al., 2018; Segal & Leach, 2011). It utilizes a formulaic approach

that first defines the population and its needs and then specifies roles, skill sets, and competencies required for clinicians to deliver care according to the needs defined in the first step. The approach then calculates the full-time equivalent employees required. Such an approach takes into account the specific burdens of illnesses as well as the use of evidence-based practice guidelines to determine care. It also allows analysts to model task shifting and test how such activities affect the workload of various types of service providers. However, this approach is data intensive and requires a firm understanding of the capabilities of the labour force for the results of the hypothetical models to translate into actual service provision levels.

To illustrate their variability a hypothetical example is provided in Fig. 4. The figure includes the projection of a population of 5.5 million, roughly the size of Singapore. The service target approach is pegged at the WHO world average for number of psychiatrists per 100,000 illustrated in Fig. 3. The utilization-based approach considers a hypothetical availability of 30 psychiatrists per 100,000 and considers 3% prevalence for severe mental illness and 12% for other forms of mental illness. The needs-based approach relies on various guidelines to determine how much care is needed and projects the number of psychiatrists required to provide the standard of care to all those with a mental illness in the population. Adjusting this approach to account for a 60% treatment gaps aligns this method's estimates with the utilization-based approach. Finally a status quo projection can be calculated to show what may be expected if only the current supply of psychiatrists is considered without considering growth in the population, other benchmarks, or the needs of the population.

Apart from articulating a coherent human resource development target, it is also necessary to consider staff wellbeing, especially when training and establishing a mental health service workforce. Physicians, including psychiatrists, are also susceptible to mental health disorders, and studies have suggested that help seeking is often delayed (Puthran, Zhang, Tam, & Ho, 2016) and suicides are not uncommon (Collier, 2017). Despite the nature of the subject matter dealt with by psychiatrists, it is necessary to make specific provisions for addressing their self-care and ameliorating their resilience to stressors. Consequently the needs to understand work stress, reduce burnout, and create work/life balance are important aspects of human resource development. The need to include aspects of self-care and relationship building within training frameworks in both undergraduate and postgraduate programmes as well as on the job training should not be underestimated. The Institute of Healthcare Improvement has been advocating a healthcare initiative to improve provider satisfaction as the fourth aim of what used to be called the triple aims of improving the patient experience of care, improving the health of populations, and reducing the per capita cost of healthcare (Perlo et al., 2017).

The development of appropriate competencies in healthcare provider training needs to undergo review if the goal is a model that focusses on upstream and population-based work. It would require the establishment of relevant skills (and mindsets) preservice and in service. Models of care that involve health promotion and illness prevention must be taught and prioritized (Weisz, Sandler, Durlak, & Anton, 2005). Apart from the role of physician and other healthcare professions, coaching and patient activation roles should be developed. Transdisciplinary approaches, defined as ‘an approach to curriculum integration which dissolves the boundaries between the conventional disciplines and organizes teaching and learning around the construction of meaning in the context of real-world problems or themes’ (OECD, 2019) is probably needed in mental healthcare.

9 Research and evaluation

No amount of policy planning can proceed without adequate research and programme evaluation. However, there are significant barriers to developing good research programmes in child mental health, especially when it comes to global health and cross cultural research (Atilola, 2015). The most important is the lack of funding. Few countries designate funding for mental health research, and when there is funding, it often represents a small portion in comparison with research funding in other areas, despite the clear burden of mental illnesses (Graham, Phelps, Nhung, & Geeves, 2014; Hazo et al., 2016; MQ Transforming Mental Health through Research, 2018). This is even more difficult when it comes to upstream research (Beecham, 2014). The lack of research in childhood areas is obvious in the way mental health research funding goes, towards neuroscience and diseases that plague adults (Lewis-Fernández et al., 2016). Apart from government funding, philanthropic funding of mental health research is very limited and may, at least in part, be attributed to stigma and lack of mental health literacy in these areas. As noted earlier, certain groups have more political clout, which translates into more funding to address their needs for services and service development (Busemeyer et al., 2009).

While the lack of funding is one aspect that impedes the generation of knowledge, issues of ethics also discourage certain types of research activities (Hein et al., 2015; Powell, Fitzgerald, Taylor, & Graham, 2012). The ethical issues can be divided into main dilemmas related to compensation for participation, confidentiality and anonymity, informed consent, and most importantly the protection of participants. Policies exist to help guide researchers, but these guidelines may have unintended consequences, which often include exclusion.

Research may be impeded by the challenge of obtaining consent from parents, (Coyne, 2010). The issues of compensation closely follow the issue of

consent and the degree to which individuals other than the child may benefit from their participation (Powell et al., 2012). In these scenarios too, it is possible that research simply excludes children and youth because they may require more effort to reach.

The consequence of this practice of exclusion has led to significant gaps in the literature that is only now beginning to be filled (Weisz et al., 2017). Increasingly, funding agencies and ethics committees are beginning to adapt their policies to accommodate or even mandate the inclusion of habitually excluded participants. Some have argued that the violations of the rights of children and youth are so problematic that the only solution would be a fundamental alteration in the way knowledge is produced. Such advocates call for the inclusion of youth and children to be included in the research teams (Oates, 2019). Indeed, in some jurisdictions, policymakers have gone as far as to include children as copolicymakers to ensure their voice was heard (Scottish Government, 2010). Such efforts are not without their own inherent challenges (Graham et al., 2014), but represent an important step in the right direction.

10 Examples from Singapore and plans for the future

We have given you, the gentle reader, a rapid review of the issues on developing a child centric mental health policy with many of the challenges that the world faces. We believe that opportunities exist here, and we would like to demonstrate some of the efforts that have emerged from a tiny island state called Singapore. This is by no means a finished product, and a caveat is that Singapore has rather unique characteristics.

Policy development in Singapore, since its independence in 1965, has been consistently based on developing free, open multilateral trading systems based on being a regional business hub (Mondeja, 2017). This means that ideas are gleaned across the globe and implemented rapidly yet systematically. Singapore has been financially and politically stable, which helps in the development of cogent policies across the system. This has allowed policymakers to follow long-term methods of evaluating impacts critical to meaningful development of an evidence base (Centers for Disease Control and Prevention, 1999; Shroff et al., 2016; Wilson & Harrison, 2002). The principles of policymaking is based on evidence and very familiar to clinicians in mental healthcare (Fig. 5).

10.1 Coordination and collaboration

The past 50 years of Singapore's development has been characterized by an ideological shift from a system of hierarchical order in which the leaders instruct the people on what needs to be done to a system of working with



FIG. 5 Key steps in programme, policy, or clinical practice evaluation and improvement.

the people for common good. This difficult step is now commonly known as cocreation, an intimate form of collaboration between a government and its people to create value for all (Loong, 2013). This idea of having conversations and listening more to people with mental illness created a platform for sharing that included peers who have lived experiences (Seow, 2016). In child and adolescent mental health, this translates to opening conversations about stigma and myths surrounding mental illness (Pang et al., 2017). In 2018 the National Council for Social Services started a 5-year anti stigma campaign called 'Beyond the Label' (<https://www.ncss.gov.sg/Our-Initiatives/Beyond-The-Label>). The campaign will move onto the subject of youths in 2020, and the idea is to first create awareness of stigma, improve mental health literacy, and then cocreate solutions on how to understand, support, and help those who have mental illness. Alongside this national campaign, specific strategies to bring community partners together for mental health started with the National Mental Health Blueprint in 2007 (Healthy Minds, Healthy Communities. National Mental Health Blueprint, 2010) and the Community Mental Health Masterplan in 2016 (Mind Matters, a special supplement on community mental health, 2016). These initiatives help to drive a coordinated approach across sectors and bring many different professionals together for a common cause.

10.2 Promotion, prevention, and treatment

The need for moving upstream is often understated and the recognition of having a nationally concerted effort unrealized until a crisis emerges. In Singapore the recognition of the potential unexpected financial impact of health issues led to a clarion call in 2016 to develop a plan to address the lifelong health in our young called Nurture SG (Lam & Puthuchear, 2016). The task force along with a public consultation developed three main focus areas: (1) encouraging good nutrition and physical activity, (2) promoting mental wellbeing, and (3) promoting sleep health with two enablers: parent engagement and fostering healthy and active living. The action plan was then laid out for implementation across all sectors of government working with children and adolescents in eight actionable items with specified drivers and designated responsible champions. Interestingly, only three of the eight items were specific to mental wellbeing. All were upstream efforts with good evidence base in their health promotion effects. If these strategic initiatives achieve their goals, they will likely have long-term effects on the current health of the youth, but also on their health later in life.

10.3 Organization of services

The move from tertiary hospital services to community clinics was started in the 1980s, but waiting times in all clinics continued to rise. By 2005, it took 3 months for a child to be reviewed by the small number of child psychiatrists (Lim, Ong, Chin, & Fung, 2015). A major reorganization of child and adolescent services was undertaken in 2005 as part of the development of the National Mental Health Blueprint (Fung, 2012). This sets a population health agenda of developing school-based mental health services for children rather than a primary care physician-based programme. Using school counsellors as the foundation for providing early identification and intervention services in schools and drawing health and social services into the school ecosystem, this multitiered, severity stratified service was able to be rapidly implemented nationwide in a cost-effective scale (Cai & Fung, 2016). This school-based community programme has been implemented nationally and involve five hospitals and three health-care clusters and has been recognized for its contribution in a National Medical Excellence Award presented by the Minister of Health in 2018.

10.4 Legislation

In terms of policies towards child protection, the most significant has to be the pro family slant of all policies. This is based on the principle that children develop best in the presence of a strong family unit. Laws are then weaved into creating the essential safeguards for these policies (Pathy, Yuxuan Cai, How Ong, Fung, & Shuen, 2014).

Singapore has progressively developed its legislation to focus on protecting children. This means that, apart from reducing the risk of harm through neglect or abuse, it has also looked into how a child can develop holistically. To do so, proactive and preventative efforts must take precedence. For example, marriage between minors (those aged 18–21) requires mandatory marital preparation. Several pieces of legislation exist that have focused on child protection ([Protecting Children in Singapore, 2016](#)) including the Children and Young Persons Act which determines what constitutes child abuse and how to handle delinquency and misdemeanours. The Women's Charter protects women's rights and protects them against intimate partner and family violence. The Guardianship of Infants Act focuses on care and wellbeing of children in the face of marital divorce. The penal code prevents sexual exploitation. The Adoption of Children Act protects adopted children. The Employment Act limits the employment of minors and their exploitation in the workplace. As policies evolve, legislation continues to change along with times ([Singapore: Family Law 2020, 2019](#)).

10.5 Financing

Singapore has focused on a principle of individual responsibility as a mainstay of healthcare policies ([Haskins, 2011](#)). This means that developing any system focused on children should incorporate family-based support. Educational and healthcare needs are provided through a co-payment system in which families are required to pay according to their means, and in situations where they are not able, a means-testing system then provides for the deficits. Schools are allocated specific funding for low-income families, and there is also direct funding to families through financial assistance schemes ([Singapore: Governance and Accountability, 2019](#)). This means that the lower-income population receives almost free services in both education and healthcare but progressively would need to pay for services as their incomes increase.

If parents are working, there is compulsory savings for medical care (Medisave) with contributions by both the worker and the employer, which can then be used to pay for healthcare services ([Ministry of Health, 2015](#); [Ministry of Health, n.d.](#)). This form of copayment creates individual responsibility focussed on self-reliance yet allowing for a social safety net that maintains equity and social responsibility.

10.6 Information systems

Singapore envisages itself to become a smart nation, a concept to encompass a life that is enabled, seamlessly by technology ([Balakrishnan, 2019](#); [Ng, 2019](#)). In such a technologically enabled system, healthcare is expected to allow for sharing of information and the use of such information

to (i) passively and actively collect data for predictive analytics, (ii) develop automated interventions at the health promotion and primary prevention level of care, and (iii) allow the use of self-learning systems (artificial intelligence) to enable pushing out self-help and help promotion activities. These information systems form a foundation upon which medical information whether in the form of electronic medical records and other health records sits on and interacts with that will allow predictive data analytics to help inform not only healthcare professionals but also children and their families on taking care of their own health. Singapore's SMART nation initiative will have an immense impact of the development of population health initiatives including those that focus on public education and self-care.

10.7 Research and evaluation

The importance of developing a research culture in Singapore cannot be underestimated (Poh, 2016). The government of Singapore has placed large tranches of funding to stimulate research in the last 30 years with increased spending in the last 10 years from S\$16 billion from 2011 to 2015 and S\$19 billion from 2016 to 2020 (Research Innovation Enterprise 2020 Plan, 2019). Not only has this resulted in an increase in research across many fields, but it has also increased the quality and impact of the research (Fig. 6).

Moving ahead, efforts are being made in the following areas:

- (1) Focus on pregnant mothers, the neonatal period, and childhood as important intervention points for policy change. All aspects of policy in these sensitive periods should receive the greatest attention and cross sectoral cooperation to ensure maximum benefit. For example, family-based care and specialized mother child and even family-based units will be common place in hospitals. For example, the policies on the first 1000 days of life (Moore, Arefabid, Deery, & West, 2017).
- (2) Develop mental health literacy as part of school curriculum for overall health promotion. This would be achievable if systems establish clear relationships and intersectoral collaborations. Teaching students about their own health and mental health will create a generation of knowledgeable individuals who can better understand themselves, others, and their world. This can be followed by stigma reduction strategies at a population level creating inclusive policies that allow population to recognize the narratives of mental illness from a recovery perspective. Peer support systems and sharing of lived experiences are particularly useful for children and adolescents as these are developmentally appropriate and introduce normalcy at an early age.

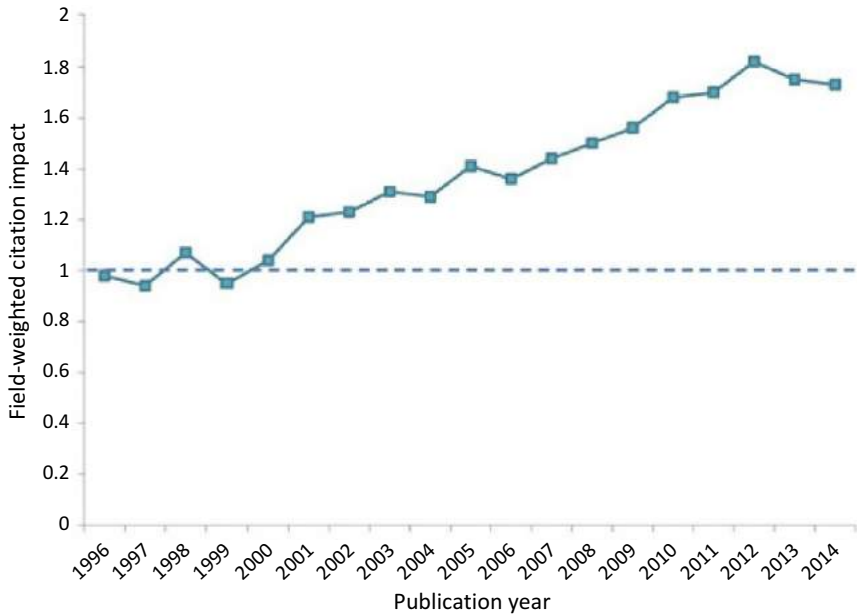


FIG. 6 The citation impact factor of Singapore-based publications compared with the global average. From Research Innovation Enterprise 2020 Plan. (13 May, 2019). Retrieved from <https://www.nrf.gov.sg/rie2020>.

- (3) Attracting good talent into the area of service. With reduced stigma and increasing knowledge, passionate individuals may take up the challenge of entering the mental health profession. Current systems must ensure that the next generation continues advocacy initiatives and drives new improvements and innovations to create care models for mental health.

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References

- Aboujaoude, E., Salame, W., & Naim, L. (2015). Telemental health: A status update. *World Psychiatry, 14*(2), 223–230. <https://doi.org/10.1002/wps.20218>.
- Ali, M. K., Shah, S., & Tandon, N. (2011). *Review of electronic decision-support tools for diabetes care: A viable option for low-and middle-income countries?* SAGE Publications.
- Andersen, S. L., & Teicher, M. H. (2008). Stress, sensitive periods and maturational events in adolescent depression. *Trends in Neurosciences, 31*(4), 183–191.

- Atilola, O. (2015). Cross-cultural child and adolescent psychiatry research in developing countries. *Global Mental Health (Cambridge, England)*, 2, e5. <https://doi.org/10.1017/gmh.2015.8>.
- Bailey, B. C., & Davis, T. S. (2012). Mental health parity legislation: Implications for children and youth with serious emotional disturbance. *Social Work in Mental Health*, 10(1), 12–33.
- Balakrishnan, V. (2019). *Smart nations: The way forward*. In: *Paper presented at the Smart City Expo World Congress, Barcelona*.
- Beecham, J. (2014). Annual research review: Child and adolescent mental health interventions: A review of progress in economic studies across different disorders. *Journal of Child Psychology and Psychiatry*, 55(6), 714–732.
- Bringewatt, E. H., & Gershoff, E. T. (2010). Falling through the cracks: Gaps and barriers in the mental health system for America's disadvantaged children. *Children and Youth Services Review*, 32(10), 1291–1299.
- Busemeyer, M. R., Goerres, A., & Weschle, S. (2009). Attitudes towards redistributive spending in an era of demographic ageing: The rival pressures from age and income in 14 OECD countries. *Journal of European Social Policy*, 19(3), 195–212.
- Cai, S. Y., & Fung, D. S. S. (2016). Community mental health as a population-based mental health approach. *The Israel Journal of Psychiatry and Related Sciences*, 53, 33–39.
- Cave, E. (2014). Goodbye Gillick? Identifying and resolving problems with the concept of child competence. *Legal Studies*, 34(1), 103–122.
- Centers for Disease Control and Prevention. (1999). Framework for program evaluation in public health. *MMWR: Vol. 48(No.RR-11)*.
- Coffey, S., Vanderlip, E., & Sarvet, B. (2017). The use of health information technology within collaborative and integrated models of child psychiatry practice. *Child and Adolescent Psychiatric Clinics of North America*, 26(1), 105–115.
- Colicchio, T. K., Cimino, J. J., & Del Fiol, G. (2019). Unintended consequences of nationwide electronic health record adoption: Challenges and opportunities in the post-meaningful use era. *Journal of Medical Internet Research*, 21(6), e13313.
- Collier, R. (2017). Physician suicide too often “brushed under the rug”. *CMAJ: Canadian Medical Association Journal*, 189(39), E1240.
- Collin-Vézina, D., Daigneault, I., & Hébert, M. (2013). Lessons learned from child sexual abuse research: Prevalence, outcomes, and preventive strategies. *Child and Adolescent Psychiatry and Mental Health*, 7(1), 22–30.
- Coyne, I. (2010). Research with children and young people: The issue of parental (proxy) consent. *Children & Society*, 24(3), 227–237.
- Cukovic-Bagic, I., Welbury, R. R., Flander, G. B., Hatibovic-Kofman, S., & Nuzzolese, E. (2013). Child protection: Legal and ethical obligation regarding the report of child abuse in four different countries. *The Journal of Forensic Odonto-Stomatology*, 31(1), 15–21.
- Cutland, M. (2012). Child abuse and its legislation: The global picture. *Archives of Disease in Childhood*, 97(8), 679–684.
- Dautovic, E. (2018). The weight of the median voter ageing on public debt. *Constitutional Political Economy*, 29(1), 69–92.
- Dieleman, J. L., Baral, R., Birger, M., Bui, A. L., Bulchis, A., Chapin, A., ... Joseph, J. (2016). US spending on personal health care and public health, 1996–2013. *JAMA*, 316(24), 2627–2646.
- Dunne, M. P., Chen, J. Q., & Choo, W. Y. (2008). The evolving evidence base for child protection in Chinese societies. *Asia-Pacific Journal of Public Health*, 20(4), 267–276.
- Essén, A., Scandurra, I., Gerrits, R., Humphrey, G., Johansen, M. A., Kierkegaard, P., ... Ross, P. (2018). Patient access to electronic health records: Differences across ten countries. *Health Policy and Technology*, 7(1), 44–56.
- Fatori, D., Salum, G., Itria, A., Pan, P., Alvarenga, P., Rohde, L. A., ... Conceição do Rosário, M. (2018). The economic impact of subthreshold and clinical childhood mental disorders. *Journal of Mental Health*, 27(6), 588–594.

- Faulkner, L. R., & Goldman, C. R. (1997). Estimating psychiatric manpower requirements based on patients' needs. *Psychiatric Services, 48*(5), 666–670.
- Frank, L. (2000). When an entire country is a cohort. *Science, 287*(5462), 2398–2399.
- Fung, D. S. (2012). *REACH chronicles: A community mental health model for children and adolescents in Singapore*. Singapore: World Scientific.
- Fung, D. S., & Lim-Ashworth, N. S. (2017). Child psychiatry without psychiatrists: A new model for old problems. *Annals Academy of Medicine Singapore, 42*(2), 42–43.
- Graham, A. P., Phelps, R. A., Nhung, H. T. T., & Geeves, R. (2014). Researching with children in Vietnam: Cultural, methodological and ethical considerations. *Qualitative Research, 14*(1), 37–60.
- Hagg, E., Dahinten, V. S., & Currie, L. M. (2018). The emerging use of social media for health-related purposes in low and middle-income countries: A scoping review. *International Journal of Medical Informatics, 115*, 92–105.
- Harper, G. (2012). Child and adolescent mental health policy. In J. M. Rey (Ed.), *e-Textbook of child and adolescent mental health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions.
- Haskins, R. (2011). Social policy in Singapore: A crucible of individual responsibility. *Ethos, 9*, 73–80.
- Hazo, J. B., Gervais, J., Gandré, C., Brunn, M., Leboyer, M., & Chevreur, K. (2016). European Union investment and countries' involvement in mental health research between 2007 and 2013. *Acta Psychiatrica Scandinavica, 134*(2), 138–149.
- Healthy Minds, Healthy Communities. (2010). *National mental health blueprint*. Singapore: Ministry of Health, Institute of Mental Health. Retrieved from <https://www.imh.com.sg/uploadedFiles/Publications/IMH%20National%20Mental%20Health%20Blueprint.pdf>.
- Hein, I. M., De Vries, M. C., Troost, P. W., Meynen, G., Van Goudoever, J. B., & Lindauer, R. J. (2015). Informed consent instead of assent is appropriate in children from the age of twelve: Policy implications of new findings on children's competence to consent to clinical research. *BMC Medical Ethics, 16*(1), 76–79.
- Hendriks, A. M., Bartels, M., Stevens, G. W., Walsh, S. D., Torsheim, T., Elgar, F. J., & Finkenauer, C. (2019). National child and adolescent health policies as indicators of adolescent mental health: A multilevel analysis of 30 European countries. *The Journal of Early Adolescence, 1*–29. <https://doi.org/10.1177/0272431619858413>.
- Hilty, D. M., Ferrer, D. C., Parish, M. B., Johnston, B., Callahan, E. J., & Yellowlees, P. M. (2013). The effectiveness of telemental health: A 2013 review. *Telemedicine Journal and e-Health, 19*(6), 444–454.
- Jeon, S.-H., & Hurley, J. (2010). Physician resource planning in Canada: The need for a stronger behavioural foundation. *Canadian Public Policy, 36*(3), 359–375.
- Jones, M., Talebi, R., Littlejohn, J., Bosnic, O., & Aprile, J. (2018). An optimization program to help practices assess data quality and workflow with their electronic medical records: Observational study. *JMIR Human Factors, 5*(4), e30.
- Kane, L. (2019). *Medscape physician compensation report 2019*. Retrieved from <https://www.medscape.com/sites/public/physician-comp/2019>.
- Knapp, M., Ardino, V., Brimblecombe, N., Evans-Lacko, S., Lemmi, V., King, D., ... Wilson, J. (2016). *Youth mental health: New economic evidence*. Available from <https://imsva91-ctp.trendmicro.com:443/wis/clicktime/v1/query?url=http%3a%2f%2fwww.pssru.ac.uk&umid=160AC8ED-9009-B705-AE4E-C6F56D8D2B2C&auth=6e3fe59570831a389716849e93b-5d483c90c3fe4-73ab32e9d1a948c91d7bc3f6af9b78f0034e87f0publication-details.php?id=5160>.
- Krishna, R. (2017). The impact of health information technology on the doctor-patient relationship in child and adolescent psychiatry. *Child and Adolescent Psychiatric Clinics of North America, 26*(1), 67–75.
- Lam, P. M., & Puthuchear, J. (2016). *Nurturing SG: Action plan report*. [Singapore].

- Lass, P., Szarszewski, A., Gaworska-Krzemińska, A., & Sławek, J. (2012). Medical doctors as the state presidents and prime ministers—A biographical analysis. *Przegląd Lekarski*, 69(8), 642–646.
- Lavigne, J. E., Brown, J., & Matzke, G. R. (2017). Population health and medicine: Policy and financial drivers. *American Journal of Health-System Pharmacy*, 74(18), 1413–1421.
- Law Reform Commission. (2011). Children and the law: Medical treatment (LRC 103-2011). Dublin. Retrieved from <https://www.lawreform.ie> (Accessed August 15, 2019).
- Lee, V. S., Kawamoto, K., Hess, R., Park, C., Young, J., Hunter, C., ... Horton, D. J. (2016). Implementation of a value-driven outcomes program to identify high variability in clinical costs and outcomes and association with reduced cost and improved quality. *JAMA*, 316(10), 1061–1072.
- Lewis-Fernández, R., Rotheram-Borus, M. J., Betts, V. T., Greenman, L., Essock, S. M., Escobar, J. I., ... Druss, B. G. (2016). Rethinking funding priorities in mental health research. *The British Journal of Psychiatry*, 208(6), 507–509.
- Lim, C. G., Ong, S. H., Chin, C. H., & Fung, D. S. S. (2015). Child and adolescent psychiatry services in Singapore. *Child and Adolescent Psychiatry and Mental Health*, 9(1), 7–11.
- Loong, L. H. (2013). To listen, labour and Lead: Building a better Singapore together. *Ethos*, 12, 6–11.
- Luk, C. Y. (2018). *The impact of digital health on traditional healthcare systems and doctor-patient relationships: The case study of Singapore*. In *Innovative perspectives on public administration in the digital age* (pp. 143–167): IGI Global.
- Lukefahr, J. L., Kellogg, N. D., Anderst, J. D., Gavril, A. R., & Wehner, K. K. (2011). Pediatric response to a large-scale child protection intervention. *Child Abuse & Neglect*, 35(8), 574–581.
- MacKenzie, A., Murphy, G. T., & Audas, R. (2019). A dynamic, multi-professional, needs-based simulation model to inform human resources for health planning. *Human Resources for Health*, 17(1), 42–54.
- Marzano, L., Bardill, A., Fields, B., Herd, K., Veale, D., Grey, N., & Moran, P. (2015). The application of mHealth to mental health: Opportunities and challenges. *The Lancet Psychiatry*, 2(10), 942–948.
- Mind Matters, a special supplement on community mental health. (2016). *Singapore agency for integrated care*.
- Ministry of Health. (November 4, 2015). https://www.moh.gov.sg/content/moh_web/home/costs_and_financing/schemes_subsidies/Medifund.html.
- Ministry of Health. (n.d.). <https://www.chas.sg/content.aspx?id=303>.
- Mondeja, M. (2017). *Notes on Singapore's development strategy*. University of Chicago Law School Chicago. Retrieved from http://chicagounbound.uchicago.edu/international_immersion_program_papers/54_23/11/2019.
- Moore, T., Arefabid, N., Deery, A., & West, S. (2017). *The first thousand days: An evidence paper*. Parkville, VIC: Murdoch Children's Research Institute.
- Morelen, D., & Shaffer, A. (2012). Understanding clinical, legal, and ethical issues in child emotional maltreatment. *Journal of Aggression, Maltreatment & Trauma*, 21(2), 188–201.
- MQ Transforming Mental Health through Research. (2018). Retrieved from <http://www.joinmq.org/research/pages/mental-health-researchfunding-landscape-report>.
- Murphy, M., & Fonagy, P. (2012). *Mental health problems in children and young people*. In *Annual report of the chief medical officer* (pp. 1–13).
- Namboodiri, V., George, S., & Singh, S. P. (2019). The Mental Healthcare Act 2017 of India: A challenge and an opportunity. *Asian Journal of Psychiatry*, 44, 25–28.
- Ng, C. K. (2019). *Digital government, smart nation: Pursuing Singapore's tech imperative*. Retrieved from <https://www.csc.gov.sg/articles/digital-government-smart-nation-pursuing-singapore%27s-tech-imperative>.
- Noroozi, M., Singh, I., & Fazel, M. (2018). Evaluation of the minimum age for consent to mental health treatment with the minimum age of criminal responsibility in children and

- adolescents: A global comparison. *Evidence-Based Mental Health*, 21(3), 82–86. <https://doi.org/10.1136/ebmental-2018-300032>.
- Oates, J. (2019). Research ethics, children, and Young people. In R. Iphofen (Ed.), *Handbook of research ethics and scientific integrity*. (pp. 1–13). Springer International Publishing. https://doi.org/10.1007/978-3-319-76040-7_28-1.
- OECD. (2019). *OECD future of education and skills 2030 conceptual learning framework*. OECD. Retrieved from www.oecd.org/education/2030-project.
- Palusci, V. J., & Covington, T. M. (2014). Child maltreatment deaths in the US national child death review case reporting system. *Child Abuse & Neglect*, 38(1), 25–36.
- Pang, S., Liu, J., Mahesh, M., Chua, B. Y., Shahwan, S., Lee, S. P., ... Chong, S. A. (2017). Stigma among Singaporean youth: A cross-sectional study on adolescent attitudes towards serious mental illness and social tolerance in a multiethnic population. *BMJ Open*, 7(10), e016432.
- Pathy, P., Yuxuan Cai, S., How Ong, S., Fung, S., & Shuen, D. (2014). Child protection and children's rights in Singapore. *Adolescent Psychiatry*, 4(4), 242–250.
- Penno, E., Gauld, R., & Audas, R. (2013). How are population-based funding formulae for healthcare composed? A comparative analysis of seven models. *BMC Health Services Research*, 13(1), 470. <https://doi.org/10.1186/1472-6963-13-470>.
- Perlo, J., Balik, B., Swensen, S., Kabcenell, A., Landsman, J., & Feeley, D. (2017). *IHI framework for improving joy in work* (pp. 3–41). Cambridge, MA: Institute for Healthcare Improvement.
- Poh, L. (2016). *From research to innovation to enterprise: The case of Singapore* (pp. 133–139). Cornell University, INSEAD, and WIPO, The Global Innovation Index.
- Poushter, J., Bishop, C., & Chwe, H. (2018). *Social media use continues to rise in developing countries but plateaus across developed ones* (p. 22). Pew Research Center.
- Powell, M. A., Fitzgerald, R. M., Taylor, N., & Graham, A. (2012). *International literature review: Ethical issues in undertaking research with children and young people*. Dunedin, Lismore: University of Otago, Centre for Research on Children and Families, Southern Cross University.
- Protecting Children in Singapore. (2016). *Singapore: Ministry of Social and Family Development*. Retrieved from <https://www.msf.gov.sg/publications/Pages/Protecting-Children-in-Singapore.aspx>.
- Puthran, R., Zhang, M. W., Tam, W. W., & Ho, R. C. (2016). Prevalence of depression amongst medical students: A meta-analysis. *Medical Education*, 50(4), 456–468.
- Rafiei, S., Mohebbifar, R., Hashemi, F., Ezzatabadi, M. R., & Farzianpour, F. (2016). Approaches in health human resource forecasting: A roadmap for improvement. *Electronic Physician*, 8(9), 2911–2917.
- Research Innovation Enterprise 2020 Plan. (13 May, 2019). Retrieved from <https://www.nrf.gov.sg/rie2020>.
- Riahi, S., Fischler, I., Stuckey, M. I., Klassen, P. E., & Chen, J. (2017). The value of electronic medical record implementation in mental health care: A case study. *JMIR Medical Informatics*, 5(1), e1.
- Rivenbark, J. G., Odgers, C. L., Caspi, A., Harrington, H., Hogan, S., Houts, R. M., ... Moffitt, T. E. (2018). The high societal costs of childhood conduct problems: Evidence from administrative records up to age 38 in a longitudinal birth cohort. *Journal of Child Psychology and Psychiatry*, 59(6), 703–710.
- Saini, N. (2013). Child abuse and neglect in India: Time to act. *Japan Medical Association Journal*, 56(5), 302–309.
- Samarthya-Howard, A., & Rogers, D. (2018). *Scaling mobile technologies to maximize reach and impact: Partnering with mobile network operators and governments*. In *Affordability issues surrounding the use of ICT for development and poverty reduction* (pp. 193–211): IGI Global.
- Saraceno, B., van Ommeren, M., Batniji, R., Cohen, A., Gureje, O., Mahoney, J., ... Underhill, C. (2007). Barriers to improvement of mental health services in low-income and middle-income countries. *The Lancet*, 370(9593), 1164–1174.

- Sarvet, B., Gold, J., & Straus, J. H. (2011). Bridging the divide between child psychiatry and primary care: The use of telephone consultation within a population-based collaborative system. *Child and Adolescent Psychiatric Clinics of North America*, 20(1), 41–53.
- Sayal, K. (2006). Annotation: Pathways to care for children with mental health problems. *Journal of Child Psychology and Psychiatry*, 47(7), 649–659.
- Scott, S., Knapp, M., Henderson, J., & Maughan, B. (2001). Financial cost of social exclusion: Follow up study of antisocial children into adulthood. *BMJ*, 323(7306), 191–194. <https://doi.org/10.1136/bmj.323.7306.191>.
- Scottish Government. (2010). *Getting it right for every child*. Retrieved from <https://www.gov.scot/policies/girfec/>.
- Segal, L., Guy, S., Leach, M., Groves, A., Turnbull, C., & Furber, G. (2018). A needs-based workforce model to deliver tertiary-level community mental health care for distressed infants, children, and adolescents in South Australia: A mixed-methods study. *The Lancet Public Health*, 3(6), e296–e303.
- Segal, L., & Leach, M. J. (2011). An evidence-based health workforce model for primary and community care. *Implementation Science*, 6(1), 93–97.
- Seow, H. H. (2016). *Discovering eldercare and mental health needs*. Singapore: Singapore Centre for Social Enterprise.
- Sharma, E., & Kommu, J. V. S. (2019). Mental Healthcare Act 2017, India: Child and adolescent perspectives. *Indian Journal of Psychiatry*, 61(Suppl 4), S756–s762. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_126_19.
- Sharma, K., Zodpey, S. P., Gaidhane, A., & Quazi, S. Z. (2014). Methodological issues in estimating and forecasting health manpower requirement. *Journal of Public Administration and Policy Research*, 6(2), 25–33.
- Shatkin, J. P., & Belfer, M. L. (2004). The global absence of child and adolescent mental health policy. *Child and Adolescent Mental Health*, 9(3), 104–108.
- Shroff, A., Thia, J. P., Tan, E., Do, H. V. K., Tham, S., Leong, W. Y., ... Liow, E. (2016). *Evidence-based policymaking in Singapore: A policymaker's toolkit*. Singapore: Civil Service College Singapore. Retrieved from <https://www.csc.gov.sg/docs/default-source/resources/evidence-based-policymaking.pdf>.
- Signorini, G., Singh, S. P., Boricevic-Marsanic, V., Dieleman, G., Dodig-Ćurković, K., Franic, T., ... McNicholas, F. (2017). Architecture and functioning of child and adolescent mental health services: A 28-country survey in Europe. *The Lancet Psychiatry*, 4(9), 715–724.
- Singapore: Family Law 2020. (2019). Retrieved from <https://iclg.com/practice-areas/family-laws-and-regulations/singapore>.
- Singapore: Governance and Accountability. (2019). Retrieved from <http://ncee.org/what-we-do/center-on-international-education-benchmarking/top-performing-countries/singapore-overview-2/singapore-governance-and-accountability/>.
- Sittig, D. F., Wright, A., Ash, J., & Singh, H. (2016). New unintended adverse consequences of electronic health records. *Yearbook of Medical Informatics*, 25(01), 7–12.
- Sutherland, J. M. (2015). Pricing hospital care: Global budgets and marginal pricing strategies. *Health Policy*, 119(8), 1111–1118.
- Swartz, M. K. (2017). A strength-based approach to care. *Journal of Pediatric Health Care*, 31(1), 1. <https://doi.org/10.1016/j.pedhc.2016.10.008>.
- Teicher, M. H., Andersen, S. L., Polcari, A., Anderson, C. M., Navalta, C. P., & Kim, D. M. (2003). The neurobiological consequences of early stress and childhood maltreatment. *Neuroscience & Biobehavioral Reviews*, 27(1–2), 33–44.
- Thomas, C. R., Holzer, C. E., III. (2006). The continuing shortage of child and adolescent psychiatrists. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45(9), 1023–1031.
- Tran, B., Pham, T., Ha, G., Ngo, A., Nguyen, L., Vu, T., ... Tran, T. (2018). A bibliometric analysis of the global research trend in child maltreatment. *International Journal of Environmental Research and Public Health*, 15(7), 1456.

- United Nations. (1989). *United Nations convention on the rights of the child*. Retrieved from <https://www.unicef.org/sites/default/files/2019-04/UN-Convention-Rights-Child-text.pdf>.
- Weisz, J. R., Kuppens, S., Ng, M. Y., Eckshtain, D., Ugueto, A. M., Vaughn-Coaxum, R., ... Fordwood, S. R. (2017). What five decades of research tells us about the effects of youth psychological therapy: A multilevel meta-analysis and implications for science and practice. *The American Psychologist*, 72(2), 79–117. <https://doi.org/10.1037/a0040360>.
- Weisz, J. R., Sandler, I. N., Durlak, J. A., & Anton, B. S. (2005). Promoting and protecting youth mental health through evidence-based prevention and treatment. *American Psychologist*, 60(6), 628.
- Wilson, R., & Harrison, B. (2002). What is clinical practice improvement? *Internal Medicine Journal*, 32(9–10), 460–464.
- Wismayanti, Y. F., O’Leary, P., Tilbury, C., & Tjoe, Y. (2019). Child sexual abuse in Indonesia: A systematic review of literature, law and policy. *Child Abuse & Neglect*, 95, 104034.
- World Health Organization. (2007). *Mental health policies and action plans*. Geneva: World Health Organization.
- World Health Organization. (2008). *Mental Health Gap Action Programme: Scaling up care for mental, neurological and substance use disorders*. Geneva: World Health Organization.
- World Health Organization. (2005). *Atlas: Mental health resources in the world 2005*. Geneva: WHO.
- World Health Organization. (2009). *Mental health systems in selected low-and middle-income countries: A WHO-AIMS cross-national analysis*.
- World Health Organization. (2017). *Mental Health Atlas 2017*.

Chinese policy and practice in child and adolescent mental health

Yi Zheng

Beijing Anding Hospital, Capital Medical University, Beijing, PR China

1 Introduction

With socioeconomic development and the acceleration of the proportion of the population that is ageing, the incidence rates of mental disorders have become higher and higher worldwide. So far the disease burden caused by mental disorders has ranked second in the world. In China, it accounts for 13% of all noncommunicable disease burden (Que, Lu, & Shi, 2019). Hence, mental health has become a major public health problem and social problem. In particular the mental health problems of children and adolescents are fundamentally linked to the development of the country and the future of the world.

Worldwide, about 20% of children and adolescents experience mental disorders (Belfer & Saxena, 2006). Half of all mental disorders begin by the age of 14 and three-quarters by mid-20s (Kessler, Chiu, Demler, Merikangas, & Walters, 2005). Neuropsychiatric conditions are the leading cause of disability in young people in all regions. If untreated, these conditions severely influence children's development, their educational attainments, and their potential to live fulfilling and productive lives. Children and adolescents with mental disorders face major challenges with stigma, isolation, and discrimination, as well as lack of access to health care and education facilities, in violation of their fundamental human rights (WHO, 2019). Obviously, children and adolescents are vulnerable groups, they have no political

power, and their mental health problems are more complicated in view of their rapid development and dependency needs. The mental health of children and adolescents requires multisectoral cooperation and requires the attention of the whole society. In particular, ensuring government actions and policies is crucial. Such policies must be designed to ensure that children and adolescents are able to access even the most basic mental health care. However, few countries worldwide have policies specifically designed to address the mental health needs of children and adolescents (Shatkin, Balloge, & Belfer, 2008).

China has a large population of children (238 million under age 15). The social reforms that have taken place in recent years and the rapid economic development have had a great influence on child and adolescent mental health. Increasing social stress, the growing migration of workers and the historically enforced family planning with one-child policy have changed the traditional family structures and social support systems (Zheng & Zheng, 2015). With the development and progress of China, to promote mental health, the Chinese government has promulgated a series of policies and regulations, especially some policies aimed at promoting the mental health of children and adolescents, such as 'Law of the People's Republic of China (PRC) on the Protection of Minors', 'Mental Health Law of the PRC', and 'Technical Criterion for Child Mental Health Care'. Moreover the upcoming 'China Brain Project' will also focus on some mental disorders such as autism, depression, and dementia to improve mental health research in China (Que et al., 2019).

This chapter will focus on the key points of these policies and the effects of their practices. This will help peer experts discuss and exchange experiences about the impact of children's mental health policies on children's health. These policies and their practical effects also help to provide a positive reference model for people around the world who care about children's mental health.

2 The development of mental health policy for children and adolescents in China

The development of child and adolescent psychiatry is the result of social progress and development. The formulation of mental health policies for children and adolescents was promoted by the development of child and adolescent psychiatry and a result of Chinese society's pursuit of a better life. The development of social and economic resources was, of course, a catalyst for policy implementation.

2.1 The current state of child and adolescent mental health in China

At present, there are many mental health problems and their influencing factors for Chinese children and adolescents. However, the most important challenge at present is the gap between the increasing number of mental disorders and the shortage of child psychiatrists. Therefore it is urgent for national governments to formulate policies to resolve this challenge.

2.1.1 Prevalence of child and adolescent mental disorders in China

China has a population of 1.3 billion of which 238 million are children under the age of 15 (National Bureau of Statistics of China, 2011). With social and medical development, the physical health of children has improved significantly and has reached the level of high-income countries. For example, child mortality has declined significantly; neonatal mortality, infant mortality, and under-five mortality have fallen from 33.1 per thousand, 50.2 per thousand, and 61.0 per thousand in 1991 to 3.9 per thousand, 6.1 per thousand, and 8.4 per thousand in 2018, respectively, representing reduction of 88.2%, 87.8%, and 86.2%, respectively (Department of Maternal and Child Health, the National Health Commission of the People's Republic of China, 2019).

However, with the accelerated pace of life, intense social competition, changes in family structure, and changes in diet and living environment, the incidence of mental disorders in children has increased significantly. For example, the detection rate of behavioural problems rose from 12.9% (Xin, Tang, Zhang, et al., 1992) in 1991 to 18.7% (Yan, Ling, Zheng, et al., 2019) in 2015. Though a nationwide prevalence study is lacking, some regional epidemiological studies show that the prevalence of mental disorders in children is close to the worldwide prevalence of 20% (Zheng & Zheng, 2015). Studies from different time periods demonstrate an increasing trend in the overall prevalence of child mental disorders. The preliminary results of a nationwide epidemiological study suggest that 15% of Chinese children suffer from mental health problems and the prevalence of some disorders, such as anxiety disorders, are increasing (Zheng & Zheng, 2015).

2.1.2 Scarcity of child and adolescent psychiatrists

Chinese child and adolescent psychiatry, like the field in many countries in the world, has gradually evolved from general psychiatry. In the early days, children with mental disorders were basically treated as 'small adults'. Since the beginning of the 1950s, Dr. Guotai Tao began the development of child psychiatric services in Nanjing, and the development of child

psychiatry in China has gradually developed and expanded. In particular, it has grown rapidly since Dr. Shiji Zhang, Dr. Yi Zheng, and Dr. Linyan Su attended the International Association for Child and Adolescent Psychiatry and Allied Professions Congress and joined the IACAPAP in 1998.

Today, in spite of considerable effort, children and adolescents with mental disorders still lack access to treatment due to the dearth of service providers and lack of child and adolescent psychiatrists. The total number of qualified child and adolescent psychiatrists in China is < 500 (Zheng & Zheng, 2015). This small group of doctors certainly cannot provide adequate service for > 200 million children, and most of these doctors practice in big cities. In China, medical students usually receive approximately 20h of lectures on clinical psychiatry and practical training in psychiatry wards for approximately 2 weeks. Child and adolescent psychiatry is hardly taught in medical school. This means that primary care physicians do not have adequate training in child psychiatry. Tertiary care centres usually don't have child psychiatric clinic, and even specialized mental hospitals do not have a child and adolescent psychiatric ward. For children with mental disorders, only 5.8% sought help in a child psychiatric clinic, and 9.1% went to paediatric clinics (Tao, 2006). Outpatient clinics are the most common form of service for children with mental disorders. A survey done in a mental health centre in Shanghai analysed outpatient data from 1985 to 1999. The result showed that children 6–12 years old were more likely to seek help but with a trend towards younger patients (0–3 years). Among the disorders seen in outpatient clinics, ADHD, intellectual disability, learning disorders, and emotional problems were the most common (Du, Xin, & Xu, 2001).

A multidisciplinary approach could contribute to better service provision. It could take the form of a child and adolescent psychiatrist, for instance, working with or supervising social workers or creating positions for social workers within child and adolescent psychiatry departments. In China, traditional social workers are older women from the neighbourhood, but now, more colleges and universities are offering degree courses for social workers in clinical psychology and childcare. Also, with the creation of more primary care centres in the community, primary care physicians can play the role of screening and follow up doctors for children with mental disorders. However, more education and training tailored to the need of primary care providers are needed. To address this problem, we are advocating a new form of multilevel collaboration. Paediatricians across the country and primary care physicians are now being trained in early diagnosis and basic treatment for common child mental disorders. They are being taught to screen patients for signs of developmental disorders such as 'Does the three-month-old baby's eyes follow moving objects?' or 'At 18 months, can she make eye contact?' (Department of Maternal and Child Health, the National Health Commission of the People's Republic of China, 2013).

2.2 Problems in modern Chinese society

Opportunities and challenges coexist. China's reform and opening up and the rapid development of social economics have conflicted with traditional social culture and customs. Therefore it also brings many problems. Support and management of national policies are needed.

2.2.1 Changes in family planning

The family planning policy, otherwise known as the one-child policy, was introduced in 1979 (Zheng, 2010). The Chinese government introduced this policy as a response to the growing social, economic, and environmental issues caused by overpopulation. The policy, which rewards couples that agree to have just one child, has proved so successful that the birth rate has fallen to only 1.4 children per woman, which is below the replenishment rate (2.1 children per woman) needed to maintain a stable population (Zheng, 2010).

However, this successful birth control measure has resulted in new problems, key of which is the problem of an ageing population and a skewed sex ratio at birth. From a mental health perspective, the one-child policy meant that children did not have to compete with siblings for attention. This could partially explain why overprotection or lack of autonomy was not viewed as negatively in most studies with Chinese samples (Zheng, 2010). Another common phenomenon for the only child is the overemphasis on school performance. This is reflected in research showing that, while interpersonal conflicts are important stressors for 'Western' adolescents, poor academic performance predicts higher levels of depression in Chinese children as young as 8 years of age (Chen, Rubin, & Li, 1995). In addition, poor academic performance predicts suicidal ideation in Chinese adolescent samples (Hesketh, Ding, & Jenkins, 2002). This could partly be explained by the high expectation families have for the only child.

As the first 'only child' generation was born in the 1980s, more and more people became concerned with the way these children were raised. The 4, 2, and 1 family structure was also seen as a potential problem (4 refers to the grandparents, 2 to the parents, and 1 to the child). In 1984 research was conducted in six kindergartens in Beijing with 138 only children and 127 children with siblings, focusing on the personality trend of these two groups. The result showed no significant differences in empathic, supportive, and aggressive behaviours, but children with siblings scored slightly higher in those domains (Chen & Zheng, 2006). Another study led by Tao and colleagues studied the impact of one-child policy on child development in 697 preschool children using CBCL (Tseng et al., 1988). Girls who were only children scored slightly higher on the factors of depression, moodiness, and temper. Zheng and

colleagues conducted several studies on the development of personality and psychological problems of only children. One study of 911 only children in Beijing aged 6–12 years showed that the prevalence of social adaptation problems was 23%—similar to the average in high-income countries (Zheng & Chen, 2001). A 6-year multicentre controlled trial of psychosocial development tried to explore the effect of an early systemic intervention on psychosocial development in only children. The behaviour problems of intervention group were significantly lower than that of control group ($P < .01$). The psychosocial development, the average IQ, the temperament, and the adaptability of intervention group were significantly better than control group ($P < .05$ or $.01$) (Chen & Zheng, 2006). This study showed that early systemic intervention benefits the psychosocial development of the only child.

The one-child policy is now undergoing a review. Experts are concerned that China's low birth rate, combined with its ageing population, will damage its future economic development. As a result the once strict birth control policy is starting to loosen up. Since 2011, if both parents have no siblings, they are allowed to have two children. As of November 2014 the policy also allowed for a family to have two children if either of the parents has no siblings. So far the problem of having a second child for an older couple has become a new problem in family planning. As can be expected the long-term effect of these changes on the psychological well-being of children will become a new focus of studies in the coming years.

2.2.2 Migration workers and left-behind children

With the rapid urbanization the economic gap between cities and rural areas has widened, and rural workers have started to seek better employment and opportunities in the cities. These often consist of young men and women in their 20s to 40s. Given that China's 'household registration' system (the Chinese have two identity registration and management systems, ID cards and household registration books) is very rigid, migrated workers are not registered as 'residents' in the cities. As a result, their children struggle to get services such as education and health service in the cities. Furthermore, rural workers often have lower income, live in more crowded living conditions, and cannot afford to bring children with them. For these reasons the children are often left behind to live in their rural hometowns. This results in the 'left-behind' children phenomenon. Left-behind children are defined as children living in their rural home with one or both of their parents working outside their registered resident area (Cheng & Duan, 2005).

Based on a national survey in 2012, the total number of left-behind children had reached 58 million, making up nearly 30% of rural children population (China Women's Federation, 2013). More than half of these left-behind children had both parents working in other cities. A sizeable

minority of left-behind children (32.67%) are raised by their grandparents. Others (20.70%) are left with other relatives, and a small number of them (3.37%) do not have any designated guardian. Compared with 2005 the number of left-behind children in 2012 has grown by 2.4 million. The left-behind children phenomenon and the fast-growing number of this potentially vulnerable group have raised concerns about their physical and mental wellbeing. Though rural–urban migration is not a phenomenon unique to Chinese society, the scale of migration is unprecedented, and the social and economic implications of this phenomenon warrant more attention and research.

In a study assessing the overall quality of life in left-behind children, the mean scores of Pediatric Quality of Life Inventory were lower in the left-behind children than the non-left-behind children (Jia, Shi, Cao, Delancey, & Tian, 2010). While mean physical health subscale scores did not differ significantly, the psychosocial summary, emotional functioning, social functioning, and school performance scores of left-behind children were significantly lower (Jia et al., 2010). Results of the majority of existing studies show that left-behind children are prone to psychological stresses and have more mental health problems. A metaanalysis including six controlled studies compared 1465 left-behind children and 1401 children in normal family environment. The findings from this and several other studies suggest that left-behind children have significantly higher scores in anxiety, loneliness, fear, and self-blame (Jia & Tian, 2010; Zhao et al., 2014; Zhen, Song, & Shi, 2013). Other studies found that, although no significant differences in the overall mental outcomes between the left-behind children and other children existed, certain subgroups of left-behind children were at potential risk (Tao, Guan, Zhao, & Fan, 2014). Being raised by grandparents and going to boarding schools were identified as two independent risk factors for psychological problems, while higher education levels of mothers were a protective factor (Wu, Lu, & Kang, 2014). More psychological problems were seen in boys aged 12–16 years, with oppositional defiant disorder, hyperactivity disorder, and poor social interaction being the most troubling problems (Wu et al., 2014). A study focused on left-behind adolescents revealed a higher level of internet addiction, suicide ideation, and thoughts of running away from home along with other social behavioural issues such as smoking and binge drinking (Gao et al., 2010).

2.2.3 The financial burden of mental disorders

Children with mental disorder bring a high burden both financially and emotionally to the family. Families of disabled children received more economic assistance than families of typically developing children. The burden of raising children with disabilities is the highest in children with ASD (Xiong et al., 2011). Such families have a heavier burden, and they need more help in many aspects (Xiong et al., 2011). Prior to 2005, China's mental

health services were provided in the same manner as all health services in the country. The hospital was the centre of the service delivery network, and there was little continuity between hospital services and community services. From the beginning of this century, China has invested much in building an effective and functional public health system which was launched as the 'Central Government Support for the Local Management and Treatment of Severe Mental Illnesses Project' (also referred to as the '686 Project') (Ministry of Health of the People's Republic of China, 2006).

The components of the intervention included patient registration and initial assessment, free medication, regular follow-up in the community, management for community emergencies, and free emergency hospitalization for certain mental disorders. By the end of 2010, a total of 280,000 persons with serious mental disorders had been registered in the system, 200,000 follow-up visits of registered patients had been conducted, free medication was provided on 94,000 occasions, and free treatment had been provided 12,400 times (Ma, Li, & Yu, 2009).

For other child mental disorders, most are paid by national medical insurance for registered residents of the area [individuals spend a small amount of money (about 20 US dollars per year) to buy child medical insurance, and the government pays part of the medical expenses when sick]. Some children's medical insurance is covered by their parents' insurance. Additional commercial medical insurance is also available. Most families buy national medical insurance for their children, and a small number of families buy commercial insurance in addition to national medical insurance.

2.3 The value and role of mental health policy for children and adolescents

Few countries worldwide have policies specifically designed to address the mental health needs of children and adolescents. Yet policies are essential to guide the development of systems of care, training programmes for practitioners, and research endeavours. Without policy, there is no clear pathway for programme development, no specific commitment from government, no expression of governance, no guide to support funding, and no clarification of who exactly is responsible for providing services to children and adolescents.

The WHO defines a policy as a guide that dictates actions, such as programme development, financing, and access to care. Policy can be formally enacted by law or adopted by decree. Regardless of the level of detail, in all cases, policy provides a recognizable document with the presumed force of law. Although there is great discrepancy in the way various countries execute mental health policy in general, the near absence of policies designed specifically to address the mental health care needs of children and adolescents, combined with poor execution of those

TABLE 1 The value and role of mental health policy for children and adolescents.

-
- Conducive to eliminating prejudice, discrimination, and stigma and raising awareness and understanding of mental disorders in children and adolescents
 - Conducive to strengthening multisectoral cooperation and improving the level of diagnosis and treatment of mental disorders in children and adolescents
 - Conducive to standardizing mental health services, strengthening funding and management
 - Conducive to promoting early care and healthy parenting, promoting children's mental health and overall development
 - Conducive to improving the overall quality of the people and preventing mental disorders
 - Conducive to scientific management and deepening scientific research, to overcome the problem of unclear causes of mental illness
-

few policies that are currently in existence, is an evergrowing concern. Given that children and adolescents have no political power, policies must be designed to ensure that they are able to access even the most basic mental health care (Skokauskas et al., 2018).

At present the Chinese government attaches great importance to mental health work and has created a standardized and regularized science and policy management system. Especially after the promulgation of the Mental Health Law, Chinese child and adolescent psychiatry has entered a new phase of science and policy management (see Table 1).

In 2013 the implementation of the 'Mental Health Law in China' (NPC, 2012) made a legal framework for clinical research and medical services for mental disorders. In 2014 China established the National Clinical Research Center for Mental Disorders which raised the priority of mental and psychological development to the national strategic level for the first time. In addition, the 'Healthy China 2030 Planning Outline', the '13th Five-Year Hygiene and Health Plan', the 'China's Long-Term Plan for Prevention and Treatment of Chronic Diseases 2017–2025', and the 'National Mental Health Work Plan 2015–2020' are all being announced gradually (<http://en.nhc.gov.cn/laws&policies.html>). These announcements have indicated the urgent need for strengthening mental health research, service, and management in China and have put forth new requirements for the future development of psychiatry.

3 Overview of Chinese mental health policy for children and adolescents

The Chinese government was one of the first countries to commit to the implementation of the United Nations' 1989 Convention on the Rights of the Child and was one of the first countries to support the use of ICD-11. Since the reform and opening up, China has not only integrated with

the world but also formulated a series of documents and policies in line with the national conditions of high-income countries. This has allowed Chinese child and adolescent psychiatry to develop and grow rapidly.

3.1 Ongoing improvements in the legal and policy system for child and adolescent mental health

The mental health of children and adolescents is included in three distinct but related policy frameworks in China: One is the inclusion of children's and adolescents' mental health in the national policy; the second is the child and adolescent mental health component in the maternal and child health policy; the third is a dedicated policy for child and adolescent mental health.

3.1.1 *Strengthening the legal system for maternal and child health*

Article 49 of the Constitution of the People's Republic of China states that 'marriage, family, mothers and children are protected by the State'. 'The Maternal and Child Health Care Law' (NPC, 1995), 'The Population and Family Planning Law' (NPC, 2002), 'the Women's Rights and Interests Protection Law' (NPC, 1992), 'Law on the Protection of Minors' (NPC, 1991), and the 'Mental Health Law' (NPC, 2012) have been promulgated, and the protection of women's and children's health rights has, as a result, been enshrined in national law. The State Council formulated regulations on the implementation of the Maternal and Infant Health Law and on the Management of Family Planning Technical Services. The Council's work includes special provisions for the protection of female employees, refining policies and measures, promoting the support of government departments at all levels and the whole society, guaranteeing the health of women and children, and protecting the mental health of children and adolescents (NPC, 2018).

3.1.2 *Continuing to improve the maternal and child health policy system*

Women's and children's health has been incorporated into important policies and plans of the party and the state, in the Outline of Chinese Women Development, Chinese Child Development Program, the 13th Five-Year Plan for National Economic and Social Development, and the Outline of Healthy China 2030. In the important documents such as the 'Decision of the CPC Central Committee and the State Council on Achieving the Poverty Alleviation', it puts forward clear target requirements and policy measures, incorporates the core indicators of maternal and child health and key policy measures into the assessment of government targets at all levels, and promotes the implementation of various tasks. For instance, these documents formulated and improved maternal

and child health norms and standards, strengthen management across the industry, towards the gradual formation of a systematic and complete maternal and child health policy system.

3.1.3 Utilizing national policies to promote the development of mental health policies for children and adolescents

In 1985 a committee consisting of five senior psychiatrists started to draft a national mental health law. Several key government departments were involved in the process. The draft was revised and released for public consultation only in 2011. Further amendments were made, and the ‘Mental Health Law of the People’s Republic of China’ (referred to as the Mental Health Law in the succeeding text) was finally enacted in May 2013 (NPC, 2012).

Despite its limitations the Mental Health Law is a great step forward in the protection of psychiatric patients’ civil rights. It aims to promote mental health, improve the quality of mental health services, and protect the human rights of patients with mental disorders during the process of hospital admission, treatment, and discharge. In the newly implemented Mental Health Law, many items have been added concerning child and adolescent mental health. Given that China has implemented a 9-year compulsory education programme for all school-aged children, primary schools have become important functional entities for advocating and improving child mental health and the ideal place to provide related services. Research has shown programmes promoting mental health are among the most effective of health promoting school efforts. The Mental Health Law mandates that all levels of school be equipped with psychologists and counsellors for mental disorders and psychological problems. Preschool educational institutions must carry out relevant forms of mental health education. In the face of traumatic and other stressful events, the school must gather specialists and provide psychological counselling and mental health rescue to children in need.

With the implementation of the ‘Work Plan for Mental Health in China (2011–2020)’ (National Health and Family Committee of the People’s Republic of China, 2008), China is further promoting the mental health and wellbeing of children and adolescent. The mental health plan required that by 2015 mental health education in primary school should have reached 85% of schools in the city and 70% in rural areas. The prevalence of mental disorders should be managed, while the awareness of child and adolescent mental health should be further promoted (from 30%–40% of awareness in 2005 to 80% in 2015). The plan also emphasized that relevant information on the prevention and screening of mental disorders should be accessible and distributed by primary care physicians. The ‘Developing Outline for Chinese Women and Children’ in 2010 (National Health and Family Committee of the People’s Republic of China, 2010) also emphasized the

importance of child mental health and stated that multiple forms of psychological counselling and treatment programmes should be provided to the public.

On 30 December 2016 the National Health and Family Planning Commission and the Central Propaganda Department, the Central Comprehensive Management Office, the National Development and Reform Commission, the Ministry of Education, the Ministry of Science and Technology, the Ministry of Public Security, the Ministry of Civil Affairs, the Ministry of Justice, and the Ministry of Finance, a total of 22 ministries and commissions, jointly issued 'Guiding Opinions on Strengthening Mental Health Services' (abbreviated as 'Opinions'). The 'Opinions' pointed out that mental health is a major public health problem and social problem affecting economic and social development. To strengthen the requirements of mental health services, according to the 'Mental Health Law', 'Health China 2030 Planning Outline', and related policies, specific guidance was given to strengthen health services and to develop sound social psychological service systems ([State Council of the PRC, 2016](#)).

The 'Opinions' emphasized the need for multisectoral cooperation of the government. Health, education, media, justice, and social services should work together to provide comprehensive protection from prenatal and postnatal care, early education, and mental health guidance at all times. In addition, prevention and early detection of mental health problems and early treatment should be offered. At the same time, it identified special populations of those in need of additional care—the mental health of the elderly, women, and disabled children. In particular, it proposed strengthening the mental health services for migrants, left-behind women, and children.

Chapter 5 of the 'Opinions' focused on improvements required in the mental health service system and proposed that each college or university should establish a mental health education and counselling centre. Primary and secondary schools should be equipped with counselling rooms and have full-time or part-time psychologists. Preschool and special education schools must have specialized (part-time) mental health workers.

In the 15th section of Chapter 5, proposals to strengthen the mental health service capacity of hospital and medical institutions were made. Maternal and child health care centres should carry out mental health education for women and children, improve mental health counselling and guidance, conduct screening for mental illness, and provide referral services.

In particular, in 2013, the National Health Commission of the People's Republic of China formulated a special document for child mental health, 'Technical Criteria for Child Mental Health Care' ([National Health Commission, 2013](#)). This is outlined in [Table 2](#).

TABLE 2 Outline of the technical criterion for child mental health care.

Subject	Technical criteria for child mental health care
Purpose	Based on the principles of children’s psychological development and their psychological and behavioural characteristics at different ages, periodical evaluation should be performed of the psychological and behavioural development of children, timely assessments of the psychological and behavioural development level of children of different ages, create good environments, and scientifically promote the healthy development of children. Early detection; timely intervention; elimination of biological, psychological, and social adverse factors affecting children’s psychological and behavioural development; early identification of children’s psychological and behavioural abnormal development; targeted follow-up; intervention; and health management should all be performed
Service recipients	Children aged 0–6 years in the jurisdiction include healthy children, high-risk children, and children with abnormal psychological and behavioural development
Contents and methods	<ul style="list-style-type: none"> • Healthy children <p>Children’s psychological and behavioural development is monitored and guided at the same time as their physical health examination</p> <ol style="list-style-type: none"> 1. Monitoring methods <ol style="list-style-type: none"> (i) Child growth and development monitoring charts (ii) Early warning signs of psychological problems: According to the early warning signs of children’s psychological and behavioural development problems, check whether there is deviation of development at the corresponding age, and any early warning signs should be registered and referred at that time (iii) Standardized scale: The National Standardized Child Development Screening Scale, such as the Children’s Intelligence Development Screening Scale (DDST) and the 0–6-old Development Screening Scale (DST), should be used to screen and evaluate children’s psychological and behavioural development problems 2. Referral <p>If the results of screening are suspicious or abnormal, they should be registered and referred to the relevant specialized clinics (higher maternal and child health institutions or other medical institutions) for follow-up</p> 3. Proactive developmental guidance <p>As part of children’s regular health examination, clinicians should give scientifically valid guidance about children’s psychological and behavioural development based on the pattern of a specific child’s psychological and behavioural development, based on the principle of individualization</p>

Continued

TABLE 2 Outline of the technical criterion for child mental health care—cont'd

Subject	Technical criteria for child mental health care
	<ul style="list-style-type: none"> • High-risk children 1. Target population <p>Premature or low birth weight. Maternal and foetal abnormalities during pregnancy and childbirth. Abnormal neonatal period. Suffering from hereditary metabolic diseases</p> 2. Management methods <ul style="list-style-type: none"> (i) Registration management: registration, referral, and follow-up (ii) Project management: increase the number of monitoring, strengthen diagnosis and evaluation, provide timely consultation and guidance (iii) Closing and referral: Two consecutive assessments of normal high-risk children over the age of 1 year can be completed. Those with suspicious or abnormal screening results are referred to the relevant specialized clinics of maternal and child health institutions or other medical institutions for diagnosis and early intervention • Children with abnormal psychological and behavioural development 1. Target population <ul style="list-style-type: none"> (i) General psychological and behavioural development problems: inappropriate sucking behaviour, fingernail-biting, dietary behaviour problems, sleep problems, enuresis, excessive dependence, withdrawal behaviour, breath holding, anger attacks, habitual friction syndrome, etc. (ii) Common psychological and behavioural developmental disorders: intellectual disability, speech and language disorders, autism spectrum disorders, stuttering, sleep disorders, separation anxiety disorders, attention deficit hyperactivity disorder, tic disorder, oppositional defiant disorder, posttraumatic stress disorder, etc. Psychological disorders of children also include schizophrenia, bipolar disorder, depression, anxiety disorder, phobia, obsessive-compulsive disorder, anorexia nervosa, bulimia, and so on. Children who experience such disorders should be referred to psychiatric clinics or specialist hospitals in a timely manner 2. Management methods <p>Children with abnormal psychological and behavioural development found during child health examination in community health service centres and township health centres are referred to the mental and behavioural development clinic of maternal and child health institutions at the district (county) level. The psychobehavioural development clinics are in charge of children with general psychobehavioural development problems and common psychobehavioural development disorders for evaluation, preliminary diagnosis, and counselling guidance. Those with difficulty in diagnosis should be referred to psychiatric clinics or hospitals in time and assist in rehabilitation treatment</p>

Service process	The service process is mainly to provide comprehensive mental health care for children through concise guidance referral process map which can guide health examination, consultation, registration, information management, two-way referral, follow-up, and so on
Service requirements	<ol style="list-style-type: none"> 1. On the basis of children’s health examination, community health service centres and township health centres carry out children’s psychological and behavioural development monitoring and guidance, early detection of high-risk children, and timely registration and referral. District (county) level maternal and child health institutions set up high-risk children monitoring and management clinics and children’s psychological and behavioural development clinics, responsible for the special management of high-risk children within their jurisdiction and the evaluation, identification, counselling, guidance, and referral of children with abnormal psychological and behavioural development 2. Medical and nursing personnel engaged in child mental health care should receive regular technical training in child mental health care and psychiatry and obtain training certificates 3. Professionals engaged in child mental health care should master the monitoring methods of psychological and behavioural development, pay attention to individual differences, correctly interpret test results, and emphasize the principle of confidentiality. Give scientific guidance according to the results 4. Maternal and child health institutions at the district (county) level or above should monitor and manage high-risk children in an appropriate environment and provide outpatient rooms for children’s psychological and behavioural development with scales and tools for children’s psychological and behavioural development
Evaluation index	The coverage rate of psychological and behavioural development screening for children aged 0–3 years = the number of children aged 0–3 years who received one or more psychological and behavioural development screening in the jurisdiction in that year / the number of children aged 0–3 years who should receive child health care services in that jurisdiction in that year * 100%

The National Health Commission of the People's Republic of China and the Chinese Society for Child and Adolescent Psychiatry also issued guidelines for the prevention and treatment of mainly child and adolescent mental disorders, for example, Guidelines for the Prevention and Treatment of Attention Deficit Hyperactivity Disorder (in 2007, 2015) (Zheng, 2007, 2015) and Guidelines for the Diagnosis, Treatment and Rehabilitation of Autism (in 2010) (National Health and Family Committee of the People's Republic of China, 2010).

3.2 Strengthening the construction of the legal and policy implementation system for child and adolescent mental health

The formulation and promulgation of policies are very important, but without good policy implementation system and measures, policies are just empty talk.

3.2.1 Continue to strengthen the establishment of culturally appropriate maternal and child health service network with for the Chinese population

Ongoing efforts are required to strengthen the establishment of urban and rural maternal and child health service networks and to integrate different levels of care with maternal and child health care institutions as the core and grassroots medical and health institutions, large- and medium-sized general hospital specialist hospitals, and related research and teaching institutions as steps in the care pathway.

Maternal and child health service network

By 2018, there will be 3080 maternal and child health care institutions, 807 maternity hospitals, 129 children's hospitals, nearly 640,000 employees, 400 million outpatient visits a year, 13.79 million hospitalizations, 338,000 beds, and various types of medical care. The number of obstetrics and gynaecology and paediatric beds in institutions has continued to increase. Five national clinical medical research centres and 15 key research laboratories were established in the field of obstetrics and gynaecology diseases and children's health (Department of Maternal and Child Health, the National Health Commission of the People's Republic of China, 2019).

Child and adolescent mental health is integrated into the entire child and adolescent care system. The 'Technical Criteria for Child Mental Health Care' formulated by the National Health and Wellness Committee is the best embodiment of the implementation of the national child and adolescent mental health policy.

3.2.2 Increase the protection of maternal and child health investment

The state takes into account its economic and social development and the health needs of women and children, adheres to the principle of prevention and prevention, adheres to the principle of maternal and child health and public welfare, and aims to increase the investment and protection of maternal and child health, with the goal of establishing a relatively complete investment guarantee policy and mechanism.

Since 2009, the implementation of the national basic public health service project, the subsidy for each person has gradually increased, from the initial average of 15 yuan per person to 55 yuan (US\$8) in 2018, and provides free access for all residents including the establishment of health records, health education, vaccination, pregnancy, maternal health management, and health management for children aged 0–6. In 2018 the central government invested 41.55 billion yuan (US\$ 5.91 billion), and local governments at all levels were allocated sufficient subsidies to effectively guarantee the project's implementation. This included a total of 14 categories of 55 basic public health services. It is an important institutional arrangement for the Chinese government to protect people's health ([Department of Maternal and Child Health, the National Health Commission of the People's Republic of China, 2019](#)).

A medical security system covering the entire population has been established. Basically a medical insurance system covering the whole people has been established, and a 'safety net' for residents to seek medical care for medical treatment has been formed. The participation rate of basic medical insurance in China is stable at over 98%, and the number of people with access to basic medical insurance is > 1.35 billion. Governments at all levels have increased the basic medical insurance subsidy standards for urban and rural residents year by year, and the proportion of residents' payments has decreased year by year ([Department of Maternal and Child Health, the National Health Commission of the People's Republic of China, 2019](#)).

Another key component of recent developments included provision of scientific and technological support for the development of maternal and child health. There are efforts to organize the implementation of 'major new drug creation', key research projects, focusing on key diseases of children's physical and mental health, including autism, attention deficit hyperactivity disorder, and other research. At present a total of 50 projects have been launched, and the central government has supported about 1.1 billion yuan ([Department of Maternal and Child Health, the National Health Commission of the People's Republic of China, 2019](#)).

4 Conclusions and future perspectives

There is a Chinese saying that ‘children are strong while the country is strong’. Children’s health is the cornerstone of national health, the yardstick to measure the progress of social civilization, and the foundation and premise of human sustainable development.

The mental health of children and adolescents needs the attention of the whole society, multidisciplinary cooperation, and international support. The development and practice of China’s mental health policy for children and adolescents shows that discipline development and policy formulation require the political support of the state. There are new practical demands, and there are also new driving forces and new goals, such as (1) the state attaches great importance to providing political guarantee for the development of children’s and adolescents’ mental health, (2) it has put forward new requirements for the development of children’s and adolescents’ mental health, (3) there has been a comprehensive deepening reform that provides a new impetus for the development of mental health for children and adolescents, and (4) the realization of the 2030 sustainable development agenda ([The CPC Central Committee and State Council, 2016](#)) provides new coordination and goals for the development of mental health for children and adolescents.

As the largest developing country in the world, China has the largest group of children and adolescents. Comprehensive protection of child and adolescent mental health is also facing many challenges such as uneven development and inadequate services. It is still unable to meet the growing mental health needs of children and adolescents.

With China’s reform and opening up and the rapid development of society and economy, the mental health of children and adolescents has a very strong legal system to protect and promote. Nevertheless, the shortage of Chinese child and adolescent psychiatrists is expected to continue for some time. To solve this problem a new form of multilevel collaboration is being implemented. Paediatricians and primary health care doctors are being trained in child and adolescent psychiatry. Officials also recruited foreign psychologists to help train psychologists and raise awareness. China is exploring all possible ways to strengthen multilevel cooperation to promote children’s physical and mental health. It reflects the great opportunity in ‘opening up’ of paediatric psychiatry in China from big cities to villages and from research institutions to communities ([Zheng, 2015](#)).

In this area the demand for international cooperation is also growing. From the beginning of Dr. Guotai Tao, founder of Chinese Pediatric Psychiatry, trained in the United States, more and more child and adolescent psychiatrists participate in overseas education and training programmes. China is an active member of the Asian children and adolescent psychiatry and related professional association (ASCAPAP) and of the

International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP). It is hoped that, with the efforts of the government, society and international cooperation, a public mental health framework with appropriate policies and programmes will be established to educate and advocate for change and to provide systematic and targeted solutions (Belfer, 2013). We are working hard to accelerate the training of child and adolescent psychiatrists and establish a professional registration and certification system for child and adolescent psychiatrists, instead of having only a general psychiatric licence and education and training certificate. At the same time, China is also actively attracting more foreign child and adolescent psychiatrists to work and develop their career in this part of the world.

Entering a new era and embarking on a new journey, child and adolescent mental health workers must comply with the requirements of the times, strive to meet the needs of the people, seize opportunities, work hard, and realize a new vision for the development of mental health for children and adolescents.

In line with the UN 2030 Sustainable Development Agenda, in accordance with the 'Healthy China 2030 Planning Outline', we will focus on key points of the programme of change, strengthen systems and enhance capacity, optimize services, manage innovation, and comprehensively improve adaptation to diverse contexts. The new era needs new ideas, new policies, and new impetus. Let's work together to achieve new goals.

Conflict of interest

The authors declare no competing interests.

References

- Belfer, M. L. (2013). Global child health. *Journal of Paediatrics and Child Health*, 49(9), 355–356.
- Belfer, M. L., & Saxena, S. (2006). WHO child atlas project. *Lancet*, 367, 551–552.
- Chen, X., Rubin, K. H., & Li, B. S. (1995). Depressed mood in Chinese children: Relations with school performance and family environment. *Journal of Consulting and Clinical Psychology*, 63(6), 938–947.
- Chen, X. S., & Zheng, Y. (2006). Multi-center study of early systemic intervention on psychosocial development in non-sibling children. *Chinese Journal of Behavioral Medical Science*, 2(12), 1126–1128.
- Cheng, R., & Duan, F. (2005). Studies on "left behind" children in rural China. *Population Research*, 29(1), 29–36.
- China Women's Federation. (2013). *National survey of left-behind children in rural areas and migrant children in urban and rural areas*. <http://acwf.people.com.cn/n/2013/0510/c99013-21437965.html>.
- Department of Maternal and Child Health, the National Health Commission of the People's Republic of China. (2013). *Outline of the technical criterion for child mental health care*. <http://www.nhc.gov.cn/wjw/gfxwj/201304/23623f839ce64d0498e3d372115ecef8.shtml>.

- Department of Maternal and Child Health, the National Health Commission of the People's Republic of China. (2019). *Report on the development of maternal and child health in China*. <http://www.nhc.gov.cn/fys/s7901/201905/bbd8e2134a7e47958c5c9ef032e1dfa2.shtml>.
- Du, Y., Xin, R., & Xu, T. (2001). Development of child and adolescent psychiatry during the last 15 years in Shanghai. *Shanghai Archives of Psychiatry*, 13(1), 8–11.
- Gao, Y., Li, L. P., Kim, J. H., Congdon, N., Lau, J., & Griffiths, S. (2010). The impact of parental migration on health status and health behaviours among left behind adolescent school children in China. *BMC Public Health*, 10, 56.
- Hesketh, T., Ding, Q. J., & Jenkins, R. (2002). Suicide ideation in Chinese adolescents. *Social Psychiatry and Psychiatric Epidemiology*, 37(5), 230–235.
- Jia, Z., Shi, L., Cao, Y., Delancey, J., & Tian, W. (2010). Health-related quality of life of “left-behind children”: A cross-sectional survey in rural China. *Quality of Life Research*, 19(6), 775–780.
- Jia, Z., & Tian, W. (2010). Loneliness of left-behind children: A cross-sectional survey in a sample of rural China. *Child: Care, Health and Development*, 36(6), 812–817.
- Kessler, R. C., Chiu, W. T., Demler, O., Merikangas, K. R., & Walters, E. E. (2005). Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62, 617–627.
- Ma, H., Li, J., & Yu, X. (2009). Important mental health policy documents and speeches in recent years in China. *Chinese Mental Health Journal*, 23(12), 840–843.
- Ministry of Health of the People's Republic of China. (2006). *Notice to implement national continuing management and intervention program for psychoses in 2006*. <http://www.moh.gov.cn/publicfiles/business/htmlfiles/mohjbyfkzj/pgzdt/200804/19191.htm>.
- National Bureau of Statistics of China. (2011). <http://data.stats.gov.cn>.
- National Health and Family Committee of the People's Republic of China. (2008). <http://www.nhfpc.gov.cn/jkj/s5888/200805/81047a30f3c34141b12481de35930d78.shtml>.
- National Health and Family Committee of the People's Republic of China. (2010). *The Developing Outline for Chinese women and Children in 2010*. <http://www.nhfpc.gov.cn/zhuzhan/wsbmgz/201304/c08b60d54ca44d68e180926be1ef6a8.shtml>.
- NPC. (1991). *Law on the protection of minors* (p. 9). China Legal Publishing House.
- NPC. (1992). *The women's rights and interests protection law* (p. 4). China Legal Publishing House.
- NPC. (1995). *The maternal and child health care law* (p. 6). China Legal Publishing House.
- NPC. (2002). *The population and family planning law* (p. 9). China Legal Publishing House.
- NPC. (2012). *Mental health law of the People's Republic of China* (p. 10). China Legal Publishing House.
- NPC. (2018). *Mental Health Law of the People's Republic of China (latest revised in 2018)*. China Legal Publishing House. April.
- Que, J., Lu, L., & Shi, L. (2019). Development and challenges of mental health in China. *General Psychiatry*, 32, 1–4.
- Shatkin, J. P., Balloge, N., & Belfer, M. L. (2008). Child and adolescent mental health policy worldwide: An update. *International Psychiatry*, 5(4), 81–84.
- Skokauskas, N., Lavelle, T. A., Munir, K., Sampaio, F., Nystrand, C., McCrone, P., et al. (2018). The cost of child and adolescent mental health services. *Lancet Psychiatry*, 5(4), 299–300.
- Tao, G. (2006). Challenges of Chinese child psychiatry. *Chinese Journal of Child Health Care*, 14(2), 109–111.
- Tao, X. W., Guan, H. Y., Zhao, Y. R., & Fan, Z. Y. (2014). Mental health among left-behind preschool-aged children: Preliminary survey of its status and associated risk factors in rural China. *The Journal of International Medical Research*, 42(1), 120–129.
- The CPC Central Committee and State Council. (2016). *The Outline of the “Healthy China 2030” Plan* (p. 8).

- Tseng, W. S., Kuotai, T., Hsu, J., Chiu, J. H., Yu, L., & Kameoka, V. (1988). Family planning and child mental health in China: The Nanjing survey. *The American Journal of Psychiatry*, 145(11), 1396–1403.
- WHO. (2019). *Child and adolescent mental health*. https://www.who.int/mental_health/maternal-child/child_adolescent/en/.
- Wu, Q., Lu, D., & Kang, M. (2014). Social capital and the mental health of children in rural China with different experiences of parental migration. *Social Science & Medicine*, 10, 46–50.
- Xin, R., Tang, H., Zhang, Z., et al. (1992). Epidemiological investigation on mental problems in child and adolescents in 22 cities in China. *Shanghai Archives of Psychiatry*, 4(1), 47–55.
- Xiong, N., Yang, L., Yu, Y., Hou, J., Li, J., Li, Y., et al. (2011). Investigation of raising burden of children with autism, physical disability and mental disability in China. *Research in Developmental Disabilities*, 32(1), 306–311.
- Yan, J., Ling, W., Zheng, Y., et al. (2019). Epidemiological characteristics of primary school students in Beijing city based on 2015 survey data. *Chinese Mental Health Journal*, 33(1), 52–57.
- Zhao, X., Chen, J., Chen, M. C., Lv, X. L., Jiang, Y. H., & Sun, Y. H. (2014). Left-behind children in rural China experience higher levels of anxiety and poorer living conditions. *Acta Paediatrica*, 103(6), 665–670.
- Zhen, L., Song, A., & Shi, J. (2013). Meta analysis of mental health in left behind children. *Chinese Journal of Child Health Care*, 21(1), 68–70.
- Zheng, Y. (2007). *Guideline for the diagnosis and treatment of ADHD* (1st ed.). Peking University Medical Press.
- Zheng, Y. (2010). *One-child policy and child mental health. Increasing awareness of child and adolescent mental health*. 2010 (pp. 49–70). Jason Aronson Press.
- Zheng, Y. (2015). Development and prospect of Chinese children's psychiatry. *Chinese Journal of Psychiatry*, 48(3), 147–150.
- Zheng, Y., & Chen, X. (2001). Analysis of social adaptive behavior and correlative factors in Chinese children. *Chinese Journal of Health Education*, 2(17), 392–396.
- Zheng, Y., & Zheng, X. (2015). Current state and recent developments of child psychiatry in China. *Child and Adolescent Psychiatry and Mental Health*, 13(9), 2–10.

Further reading

- Department of Disease Control, the National Health Commission of the People's Republic of China. (2016). *Guiding opinions on strengthening mental health services*. <http://www.nhc.gov.cn/jkj/s5889/201701/10ea6b89740344199bfb24e891ca5564.shtml>.
- Department of Medical Affairs, the National Health Commission of the People's Republic of China. (2010). *Chinese guideline for autism diagnosis, treatment and rehabilitation*. http://www.gov.cn/zwgk/2010-08/16/content_1680727.htm.
- Zheng, Y., & Liu, J. (2015). *Guideline for the diagnosis and treatment of ADHD* (2nd ed.). China Medical Electronic Audio and Video Publishing House.

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Child and adolescent mental health needs, services, and gap in East and Southeast Asia and the Pacific Islands

*Tomoya Hirota^a, Anthony P.S. Guerrero^b,
and Norbert Skokauskas^c*

^aDepartment of Psychiatry, University of California San Francisco, San Francisco, CA, United States, ^bDepartment of Psychiatry, University of Hawai'i John A. Burns School of Medicine, Honolulu, HI, United States, ^cCentre for Child and Youth Mental Health and Child Protection, Faculty of Medicine, Norwegian University of Science and Technology, Trondheim, Norway

This chapter highlights themes related to child and adolescent mental health (CAMH) in East Asia, Southeast Asia, and Pacific Islands world regions. In the first two sections, we will provide general information about the CAMH needs, services, and the treatment gap across the world. In the third section, we will provide a narrative review of prevalence studies conducted in the regions targeted in this chapter, emphasizing the increasing needs for the CAMH. Then, we will describe the changes in CAMH needs, services, and training systems in the East and Southeast Asia over 5 years (2012–17) based on findings from surveys. In the fifth section, we will highlight factors that possibly contribute to challenges in CAMH service delivery in these regions, including workforce shortages and stigma. Recent progress in CAMH services in these regions will be described next, highlighting the community outreach program in Singapore as an example. In the last two sections, we will discuss the

importance of considering and addressing the acculturative and socio-economic challenges that lead to CAMH disparities and provide solutions and recommendations for the future.

1 The importance of child and adolescent mental health

The World Health Organization (WHO) reported that approximately 10%–20% of children and adolescents experience mental disorders ([World Health Organization, 2001](#)). Furthermore, other studies indicate that 70% of mental disorders have their onset before the age of 25 years ([Kessler et al., 2005](#)) and that untreated mental problems/disorders in childhood can persist into adolescence and adulthood ([McEwan, Waddell, & Barker, 2007](#)). Given the brain plasticity during childhood and adolescence, mental problems and disorders that occur in these periods can alter their developmental trajectories and, therefore, significantly impact young people's wellbeing and ability to succeed in school and society. Costs associated with childhood mental disorders include medical expenses, special education needs, the burden to the criminal justice system, and social services. One study in the United States estimated that a child with attention deficit hyperactivity disorder (ADHD) has annual medical costs of US\$4306 compared with \$1944 for children without ADHD and that conduct disorder has been found to be even more costly at \$14,000 compared with \$2300 for children without conduct disorder ([Hsia & Belfer, 2008](#)). Costs associated with childhood mental disorders include medical expenses, and costs borne by other agencies, including educational needs, the criminal justice system, and social services, may be very high ([World Health Organization, 2010](#)). Taken together, there has been an increased awareness of need for child mental health services in both developing and developed countries.

2 Mental health needs, services, and a gap across the world

Lack of adequate child and adolescent mental health (CAMH) services across the world was reported in the WHO Child and Adolescent Mental Health Atlas ([World Health Organization, 2005](#)). In the WHO Atlas, key informants of countries were contacted and asked to provide data on CAMH. The response rate was 34% (66 among 192 countries in which informants were contacted); this low response rate was considered in part attributable to a lack of available resources in those countries. In this report, providers who generally treat adults, such as general psychiatrists, paediatricians, and general practitioners often cared for youth with mental illness and contributed to CAMH in countries where there was a significant scarcity of workforce. Although the WHO Atlas provided

comprehensive information, updated data are needed to map more recent CAMH needs and available services given that the Atlas was published in 2005. Worldwide, there are very few child and adolescent psychiatrists; in high-income countries the number of child psychiatrists is 1.19 per 100,000 youth, but in low- and middle-income countries (LMICs), where the preponderance of the world's children and adolescents live, the number is <0.1 per 100,000 population (Skokauskas et al., 2019).

Additionally a study conducted by Morris et al. revealed a higher rate of unmet needs in CAMH training and a wider gap between CAMH needs and available CAMH services in low- and middle-income countries compared with high-income countries (Morris et al., 2011). It is also reported that, in comparison with Europe and North America, there have been substantial unmet needs for CAP resources in Asia, in view of the rapidly growing numbers of youngsters who require mental health evaluation and ongoing care (Srinath, Kandasamy, & Golhar, 2010).

This chapter strives to highlight themes related to CAMH care in the East Asia, Southeast Asia, and Pacific Islands world regions. The authors fully acknowledge the inherent challenges and imperfections in ambitiously trying to describe a large and diverse section of the globe. The chapter cannot comprehensively review all that is known about child and adolescent mental health in the scores of nations that comprise these regions. Instead, this chapter focuses on issues that are especially important in addressing child and adolescent psychiatric care needs in places that include large populations; that reflect a blending of urban and rural, modern and traditional, and foreign and indigenous influences; and that—in many of the areas—reflect adaptations to life near or within an ocean and with strong connections to the natural environment.

3 The importance of CAMH in Asia: Prevalence of mental health problems and disorders

In low- and middle-income countries, children and adolescents constitute 35%–50% of the population, and there is a vast gap between child and adolescent mental health (CAMH) needs and the availability of resources (Patel, Flisher, Nikapota, & Malhotra, 2008). Such is the case in the majority of countries in Asia, in view of the rapidly growing numbers of children and adolescents who require mental health evaluation and ongoing care, except for Japan, Korea, and Taiwan (Srinath et al., 2010). Paradoxically, fewer epidemiological studies have been conducted in Asia compared with countries in Europe and North America. The studies that have examined the prevalence of mental problems and disorders in youth in Asia would deepen our understanding of needs for CAMH in this region; thus, we will summarize the findings from these epidemiological studies in the succeeding text.

In a study conducted in school-age children (age 6–12) in Singapore, researchers used the Child Behavior Checklist (CBCL) to examine the frequency of emotional and behavioural problems (Woo, Ng, & Fung, 2007), where 12.5% of children were found to have either or both internalizing (emotional) and externalizing (behavioural) problems. Another survey study of 5988 school students aged 12–19 years in China reported the lifetime prevalence of substance use and suicidal ideation in these students; 17.6% of students had tried cigarette smoking, 63.1% had had at least one drink of alcohol, 1.7% of students had used cannabis/marijuana, 17.6% of students had planned suicide, and 3.2% had attempted suicide (Wang, Deng, Wang, Wang, & Xu, 2009). In this study the authors examined the correlates of the substance and alcohol use and psychiatric problems and found that male sex was positively associated with substance use and negatively associated with sadness, hopelessness, and suicide ideation.

Several studies conducted in Asia have reported the prevalence of specific mental disorders. In an epidemiological study conducted in South Korea, a two-stage procedure consisting of a screening phase and a subsequent standardized clinical assessment phase through Attention-deficit Diagnosis System and the Korean version of the modified computerized test of variables of attention (Cho, Chun, Hong, & Shin, 2000) was used to estimate the prevalence of ADHD in a community sample of elementary school students aged 7 and 12 and found an overall prevalence of 8.5% (Kim et al., 2017). Additionally a systematic review of a total of 67 ADHD prevalence studies reported that the overall prevalence of ADHD in children and adolescents in China was 6.3% (Wang et al., 2017). Although lower than the prevalence of ADHD reported in the United States, where approximately 9.4% of children 2–17 years of age had ever been diagnosed with ADHD, according to the parent report (Danielson et al., 2018), findings from these studies corroborated the high prevalence of ADHD in Asian countries. With regard to the prevalence of paediatric depression in Asian countries, a small community study in Singapore revealed the prevalence estimate of depression in adolescence to be between 2% and 2.5% (Woo et al., 2004). A pooled prevalence of paediatric depression in China was reported to be 1.3% in a systematic review and a metaanalysis (Xu et al., 2018). Differences in the prevalence of paediatric depression between these studies would be mainly due to different screening and diagnostic tools used in those studies. The prevalence rate of posttraumatic stress symptoms (PTSS) among earthquake-affected children and adolescents of the Kathmandu districts of Nepal ranged from 10.7% to 51% (Chaulagain, Kunwar, Watts, Guerrero, & Skokauskas, 2019). There are also prevalence studies of autism spectrum disorder (ASD) conducted in China, Japan, and South Korea (Honda, Shimizu, Misumi, Niimi, & Ohashi, 1996; Kim et al., 2011; Sun et al., 2019), all of which ascertained cases using methodologically rigorous research designs and thus provided reliable findings.

The recent national survey of child mental disorders from Taiwan is reported in detail in this volume (Gau and Chen, this volume, [Chapter 1](#)).

Very few longitudinal studies have been conducted in Asia to examine the development of mental disorders in youth. Among them, Gau et al. conducted a 3-year longitudinal assessment of youth mental disorders in school-aged children (between 13 and 15 years old) in Taiwan (Gau, Chong, Chen, & Cheng, 2005), revealing the prevalence of each mental disorder and persistency/discontinuation of those disorders over 3 years. Investigators administered a semistructured interview [the Chinese version of the Schedule for Affective Disorders and Schizophrenia for School-Age Children—Epidemiologic Version (K-SADS-E) in screen-positive children]. The retention rate was excellent in this study (96.7% at the third time point for data collection). The overall rates of mental disorders were higher in children aged 13 and 14 years than those aged 15 years, specifically in child-onset disorders, including ADHD, specific phobia, social phobia, and separation anxiety disorder. Most findings of this study were consistent with those of studies previously conducted in North America and Europe, suggesting similar high needs for CAMH in Asia.

4 CAMH needs, services, and training systems in East and Southeast Asia

Historically, child and adolescent psychiatry has been the principal medical specialty focusing on the mental health of children and adolescents and their families. As it developed, child and adolescent psychiatry integrated elements from many disciplines, including general psychiatry, developmental psychology, neuroscience, and others. Child and adolescent psychiatry also contributed to adding developmental perspectives into diagnostic classifications of psychiatric disorders. Given the historical role of child and adolescent psychiatry in CAMH, several countries have established postgraduate training systems to foster child and adolescent psychiatrists. The quality of training systems are standardized and accredited in those countries by agencies, such as the Accreditation Council for Graduate Medical Education in the United States and the European Union of Medical Specialties in Europe, respectively. Compared with these countries, however, there has been limited data available regarding training systems in child and adolescent psychiatry in Asia.

Therefore, to examine CAMH needs and map training systems in child and adolescent psychiatry (CAP) in this region, members in the Consortium on Academic Child and Adolescent Psychiatry in the Far East (CACAP-FE), supported by the World Psychiatry Association, Section on Child and Adolescent Psychiatry Group on Teaching and Learning, conducted the first study in 2012 and obtained data from the following

TABLE 1 Contents of the questionnaire used in the original survey research in 2012.

1. How many qualified (board-certified) general psychiatrists are there?
2. How many of the general psychiatrists treat child and adolescent populations?
3. Is there a national guideline for postgraduate general psychiatry training?
4. What is the duration of general psychiatry training?
5. Is there any Child and Adolescent Psychiatry (CAP) exposure during general psychiatry training? If so, how long?
6. Is child and adolescent psychiatry recognized as a separate specialty (subspecialty)?
7. Is there a specialized postgraduate training program in CAP? If so, how long?
8. Is there a national guideline for postgraduate CAP training?
9. Are overseas CAP electives available for trainees? If so, in which countries?
10. Is there a need for more child and adolescent psychiatrists (and/or child adolescent mental health specialists)?
11. If so, what are the estimated numbers of required child and adolescent mental health professionals?
12. How many CAP departments affiliated to universities are there?
13. Is there a CAP society?
14. Is there a national CAP journal?
15. Is there a national child and adolescent mental health policy?

From Hirota, T., Guerrero, A., Sartorius, N., Fung, D., Leventhal, B., Ong, S. H., ..., Skokauskas, N. (2019). Child and adolescent psychiatry in the Far East: A 5-year follow up on the Consortium on Academic Child and Adolescent Psychiatry in the Far East (CACAP-FE) study. Psychiatry and Clinical Neurosciences, 73(2), 84–89.

17 countries/functionally self-governing or specially administered areas: Brunei, Cambodia, People's Republic of China (China), Hong Kong (technically a Special Administrative Region of the People's Republic of China), Indonesia, Japan, Lao People's Democratic Republic (Lao PDR), Malaysia, Myanmar, Mongolia, Philippines, Russian Far East Region (Russia), Singapore, South Korea, Taiwan, Thailand, and Vietnam (Hirota et al., 2015). The questionnaire including the 15 questions is listed in Table 1.

Findings from this survey study are summarized in Table 2. The key findings were as follows: First, child and adolescent psychiatry rotations were available for trainees during general psychiatry residency training in 12 out of 17 countries and areas (median, 3 months; range, 2–6 months). Second, child and adolescent psychiatry was recognized as a subspecialty in 12 out of 17 countries. Third, child and adolescent psychiatry postgraduate training was available in 10 countries, whereas national guidelines for child and adolescent psychiatry training existed only in four countries. Fourth, among 10 countries that provided data, the duration of child and adolescent psychiatry training varied from 12 to 48 months (median: 30 months). Fifth, national guidelines for child and adolescent psychiatry postgraduate training existed only in 4 out of 17 countries (Malaysia, Philippines, Taiwan, and Thailand). Lastly, shortage of CAMH specialists was apparent, despite local needs, from the data of 16 out of 17 countries.

Based on the aforementioned findings, the authors of this chapter and colleagues carried out a follow-up survey in 2017 to identify whether

TABLE 2 Summary of data from the original (the year 2012) and the follow-up (the year 2017) studies.

Year	Number (N) of qualified psychiatrists		N of qualified CA psychiatrists		N of psychiatrists treating children and adolescents		National guidelines for postgraduate training in psychiatry		CAP recognized as a discrete specialty		CAP exposure during general psychiatry training	
	2012	2017	2012	2017	2012	2017	2012	2017	2012	2017	2012	2017
Brunei	4	4	NA	1	1	1	NA	Y	Y	Y	N	Y
Cambodia	41	46	NA	NA	NA	12	Y	Y	Y	N	N	N
China	20,808	28,000	NA	500	2800	8000	Y	Y	Y	Y	Y	Y
Hong Kong	300	357	NA	40	30	200	N	N	Y	N	Y	Y
Indonesia	600	850	NA	55	40	55	N	N	Y	Y	Y	Y
Japan	13,534	14,793	NA	316	Most	Most	Y	Y	N	N	Y	Y
Lao PDR	2	0	NA	NA	NA	2	N	N	N	N	N	N
Macau	NA	0	NA	0	NA	0	NA	NA	NA	N	NA	NA
Malaysia	275	360	NA	24	25	NA	Y	Y	Y	Y	Y	Y
Myanmar	80	200	NA	0	80	200	Y	Y	N	N	Y	Y
Mongolia	135	154	NA	0	2	45	Y	Y	Y	N	Y	Y
Philippines	400	400	NA	30	20	Most	Y	Y	Y	Y	Y	Y
Russia	509	486	NA	NA	72	55	Y	Y	N	N	Y	Y
Singapore	150	229	NA	NA	NA	35	Y	Y	N	N	Y	Y
South Korea	2900	3600	NA	400	400	100	N	Y	Y	Y	Y	Y
Taiwan	1400	2018	NA	195	400	21	Y	Y	Y	Y	Y	Y
Thailand	150	750	NA	220	120	250	Y	Y	Y	N	Y	Y
Vietnam	700	900	NA	10	10	30	N	N	Y	Y	Y	Y

Continued

TABLE 2 Summary of data from the original (the year 2012) and the follow-up (the year 2017) studies—cont'd

Year	Specialized CAP postgraduate training program		National guidelines for CAP training		Need for more CAMH specialists and CA psychiatrists		The national CA mental health policy		Number of academic CAP departments/divisions		CAP society	
	2012	2017	2012	2017	2012	2017	2012	2017	2012	2017	2012	2017
Brunei	N	N	N	N	Y	Y	N	N	0	0	N	N
Cambodia	N	N	N	N	Y	Y	N	N	0	0	Y	N
China	Y	Y	N	N	Y	Y	Y	Y	15	10	Y	Y
Hong Kong	N	Y	N	N	Y	Y	N	Y	2	2	N	Y
Indonesia	Y	Y	N	N	Y	Y	N	N	0	9	Y	Y
Japan	Y	Y	N	Y	Y	Y	Y	Y	1	10	Y	Y
Lao PDR	N	N	N	N	Y	Y	N	N	0	0	N	N
Macau	NA	N	NA	N	NA	Y	NA	N	NA	N	NA	N
Malaysia	Y	Y	Y	Y	Y	Y	Y	Y	0	4	Y	Y
Myanmar	N	N	N	N	Y	Y	N	N	0	0	N	N
Mongolia	N	N	N	N	Y	Y	Y	Y	0	2	N	N
Philippines	Y	Y	Y	N	Y	Y	Y	N	1	2	Y	Y
Russia	Y	Y	N	N	Y	Y	N	N	0	6	Y	Y
Singapore	Y	Y	N	N	Y	Y	N	N	2	2	Y	Y
S. Korea	Y	Y	N	Y	Y	Y	Y	Y	30	20	Y	Y
Taiwan	Y	Y	Y	Y	Y	Y	Y	Y	10	15	Y	Y
Thailand	N	Y	Y	Y	Y	Y	Y	Y	0	10	Y	Y
Vietnam	N	Y	N	N	Y	Y	N	N	0	20	N	N

CAP, child and adolescent psychiatry.

From Hirota, T., Guerrero, A., Sartorius, N., Fung, D., Leventhal, B., Ong, S. H., . . . , Skokauskas, N. (2019). *Child and adolescent psychiatry in the Far East: A 5-year follow up on the Consortium on Academic Child and Adolescent Psychiatry in the Far East (CACAP-FE) study. Psychiatry and Clinical Neurosciences, 73(2), 84–89.*

changes in CAMH needs, services, and training systems have been made over 5 years in these countries (Hirota et al., 2019). In the follow-up survey, we added Macau to the 17 countries/functionally self-governing or specially administered areas above and obtained data from key informants. Key informants were official CAP representatives affiliated with academic universities, research facilities, or specialty societies in all identified countries and areas. In the original CACAP-FE study, a 15-item questionnaire regarding CAP training systems was sent to all representatives; questions about the CAP Training program contents were not included as it was assumed that limited numbers of included countries and areas had structured training systems. For the follow-up survey, in addition to the 15 questions used in the original survey study, questions about contents of CAP training were introduced to collect data to identify progress in the CAP training in several countries in East and Southeast Asia. The survey questionnaire for this study is in Table 3, and the findings of this follow-up survey are summarized in Table 4.

The major findings of the follow-up survey study in comparison with those of the original survey study were as follows: (1) The number of psychiatrists providing CAMH services varied from 0 in Macau to 8000 in China; (2) CAP postgraduate training was available in 12 countries/areas (the number of such countries in the follow-up survey increased by 2 from that in the original survey 5 years before); (3) of 12 countries with CAP training, CAP is recognized as a subspecialty in seven countries with national guidelines for CAP training in five countries (the number of such countries in the follow-up survey increased by one from that in the original survey); (4) all informants from participating countries reported a persisting need for more CAMH specialists and child and adolescent psychiatrists; and (5) a national CAMH policy was available in eight countries.

In terms of contents of child and adolescent psychiatry training, data were obtained from 12 countries: China, Hong Kong, Indonesia, Japan, Malaysia, Philippines, Russia, Singapore, South Korea, Taiwan, Thailand, and Vietnam (see Table 4), and findings are as shown in the succeeding text: (1) Among countries where national guidelines for child and adolescent psychiatry training exist, the duration of CAP training varied from 12 to 48 months; (2) principal rotations included in most countries were inpatient and outpatient child and adolescent psychiatry rotations (12/12 countries), consultation-liaison psychiatry (10/12 countries), school consultation (8/12 countries), paediatric neurology (7/12 countries), forensic psychiatry (4/12 countries), and general paediatrics (2/12 countries); and (3) in 6 out of 12 countries, there is a board certification system for CAP trainees following the completion of training.

The two surveys in the preceding text did not report data on types of CAMH services (e.g. inpatient unit treatment, outpatient clinic treatment,

TABLE 3 Contents of the questionnaire for a 5-year follow-up survey study.

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1. How many qualified (board-certified) general psychiatrists are there in your country?
 2. How many of the general psychiatrists treat child and adolescent populations?
 3. Is there a national guideline for postgraduate general psychiatry training? Choose YES or NO
 4. What is the duration of general psychiatry training?
 5. Is there any CAP exposure during general psychiatry training? If YES, answer question 5 (a)
 - 5 (a). What is the duration of CAP exposure during general psychiatry training?
 6. Is child and adolescent psychiatry recognized as a separate specialty (subspecialty)? Choose YES or NO
 7. Is there a specialized postgraduate training program in CAP? If Yes, please answer questions 7 (a)—7 (i). If No, please skip to question 8
 - 7 (a). Is the completion of general psychiatry training is required before entering CAP training? Choose YES or NO
 - 7 (b). Is inpatient child and adolescent psychiatry unit rotation available for trainees? Choose YES or NO
 - 7 (c). Is child and adolescent psychiatry outpatient rotation available for trainees? Choose YES or NO
 - 7 (d). Is consultation-Liaison (psychosomatic medicine) rotation available for CAP trainees? Choose YES or NO
 - 7 (e). Is paediatric neurology rotation available for CAP trainees? Choose YES or NO
 - 7 (f). Is general paediatrics rotation available for CAP trainees? Choose YES or NO
 - 7 (g). Is school consultation rotation available for CAP trainees? Choose YES or NO
 - 7 (h). Is forensic training rotation available for CAP trainees? Choose YES or NO
 - 7 (i). Are there exit exams in CAP training? Choose YES or NO
 8. Is there a national guideline for postgraduate CAP training? Choose YES or NO
 9. Are overseas CAP electives available for CAP trainees? Choose YES or NO
 - 9 (a). If YES to question 9, in which countries?
 10. Is there a need for more child and adolescent psychiatrists? Choose YES or NO
 - 10 (a). If YES to question 10, what are the estimated numbers of required child and adolescent? Choose YES or NO
 11. Is there a need for more child and adolescent mental health specialists other than child and adolescent psychiatrists? Choose YES or NO
 - 11 (a). If YES to question 11, what are the estimated numbers of required child and adolescent mental health specialists other than child and adolescent psychiatrists? Choose YES or NO
 12. Is there board certification system for child and adolescent psychiatrists? Choose YES or NO
 13. How many qualified (board-certified) child and adolescent psychiatrists are there in your country?
 14. How many CAP departments affiliated to universities are there in your country?
 15. Is there a CAP society? Choose YES or NO
 16. Is there a national CAP journal? Choose YES or NO
 17. Is there a national child and adolescent mental health policy? Choose YES or NO
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TABLE 4 Contents of specialized child and adolescent psychiatry (CAP) training in 12 countries.

	Is completion of general psychiatry training required before entering CAP training?	Inpatient unit rotation	Outpatient clinic rotation	Consultation-liaison (psychosomatic medicine) rotation	Paediatric neurology rotation	General paediatrics rotation	School consultation rotation	Forensic training rotation	Board certification system for CAP
China	Yes (Y)	Y	Y	Y	Y	No (N)	Y	N	N
Hong Kong	N	Y	Y	Y	N	N	N	N	N
Indonesia	Y	Y	Y	Y	Y	N	Y	N	N
Japan	N	Y	Y	Y	N	N	N	N	Y
Malaysia	Y	Y	Y	Y	Y	Y	Y	Y	Y
Philippines	Y	Y	Y	Y	Y	N	Y	Y	Y
Russia	Y	Y	Y	N	N	N	N	N	N
Singapore	Y	Y	Y	Y	Y	Y	Y	N	N
S. Korea	Y	Y	Y	Y	N	N	Y	N	Y
Taiwan	Y	Y	Y	Y	Y	N	Y	Y	Y
Thailand	Y	Y	Y	Y	Y	N	Y	Y	Y
Vietnam	N	Y	Y	N	N	N	N	N	N

and community outreach), types of treatment modalities (medication, therapy, etc.), or types of professionals (e.g. physicians, psychotherapists, social workers, and nurses) available in the countries and areas included. Thus, further research is needed to collect such information. Additionally, we are not aware of any research that systematically examined training systems across countries in Asia for other professionals besides child and adolescent psychiatrists (e.g. child psychologists), who also play critical roles in CAMH.

5 Factors accounting for CAMH gap

Among the many reasons that could account for a tremendous gap between CAMH needs and available services, as described earlier, the shortage of child and adolescent psychiatrists was acknowledged by informants in all 18 countries included in the study (Hirota et al., 2019). Such a gap is even true of countries where there are many more CAMH professionals. For example, in the United States, there are approximately 8300 practicing child and adolescent psychiatrists for over 15 million children and adolescents who need CAMH services. There the average delays between the onset of symptoms and intervention are reported to be 8–10 years, delays of which are in part attributable to the lack of access to trained CAMH professionals (American Academy of Child and Adolescent Psychiatry, 2019). Difficulty with access to CAMH services may be due to a severe maldistribution of CAMH services. That is, children in rural areas, and also areas with low socioeconomic status, have significantly reduced access.

Stigma has been identified as a possible key factor preventing individuals from access to CAMH services, leading underutilization of existing services (Thompson, Noel, & Campbell, 2004). Stigma consists of three key components: stereotypes (learned, oversimplified, and often negative attitudes embedded in society), prejudice (endorsed stereotypes that are accompanied by negative emotional reactions), and discrimination (Kaushik, Kostaki, & Kyriakopoulos, 2016). For younger children the stigma that parents have towards mental illness or experience from others may affect their utilization of CAMH services given that young children require parental support to receive services (e.g. initiating the referral, providing consent, and transportation to the clinic). On the other hand, for adolescents, the stigma that youths own or experience from others can affect how they utilize CAMH services. Although stigma research has been underdeveloped in child and adolescent mental health compared with adult mental health, research has shown that child and adolescent mental issues are more stigmatized than physical illness in children and that stigmatizing views and behaviours can develop from early childhood (Wilkins & Velicher, 1980).

To understand the underutilization of mental health services, we need to consider cultural factors as they play important roles in influencing service use (Lonner, Dinnel, Forgays, & Hayes, 1999). For example, Lau and Takeuchi summarized three general explanations for the underutilization among Asians and Asian Americans: (1) conflict between traditional Asian values and the Western psychotherapy process, (2) cognitive appraisal of psychological problems, and (3) shame and stigma associated with mental illness (Lau & Takeuchi, 2001). In some Asian cultures, self-restraint is valued rather than seeking professional help or expressing personal emotions. Individuals are also expected to control and suppress their emotional problems (Tracey, Leong, & Glidden, 1986). Therefore, some strategies recommended for seeking mental health services can seem unnatural for many individuals. In a study conducted in Hong Kong, it is reported that Chinese Americans and Europeans are more likely to seek professional help for their mental illness than Hong Kong and Mainland Chinese (Chen & Mak, 2008).

Cultural aspects can also impact on individuals' perceptions about the aetiology of mental illness. Individuals in cultures where collectivism is valued such as Asian cultures are considered more likely to attribute mental health problems to internal and personal causes, whereas individuals residing in cultures where Western-based mental health treatment is the mainstay perceive mental illness as stemming from interactions between the person and the environment (Mallinckrodt, Shigeoka, & Suzuki, 2005). Such cultural differences may influence the perceived efficacy of Western-based mental health treatments.

6 Recent progress in CAMH services in East and Southeast Asia

There have been dramatic shifts in mental health services over the last decades—in particular, promoting deinstitutionalization is one important trend. This led to increased awareness of the importance of prevention and early identification and intervention. Subsequently, mental healthcare has been shifting from hospitals and clinics to community-based care for providing integrated mental health and social care services (World Health Organization, 2013). This shift has also been occurring in Asia, represented by the establishment of the Asia–Pacific Community Mental Health Development project comprising 14 member nations (Ng, Herrman, Chiu, & Singh, 2009).

Such a shift to community-based care is also true in CAMH, supported by increased funding and support from governments. For example, in Singapore, Response, Early Intervention, and Assessment in Community Mental Health (REACH) was developed to support school-age students

with mental health problems. The four main goals of REACH (Lim, Loh, Renjan, Tan, & Fung, 2017) are to improve the mental health of youth via early assessment and intervention; to build the capacity of schools and community partners; to detect and manage mental health problems through support and training; and to build a community mental health support network for children and adolescents in the community, comprising schools, general practitioners, and voluntary welfare organizations.

The REACH team, which is a mobile multidisciplinary team of child and adolescent psychiatrists, clinical psychologists, social workers, occupational therapists, and psychiatric nurses, provides services primarily to schools. Lim and colleagues examined the effectiveness of the REACH program comparing data obtained at an intake assessment and at a 6-month time point after the intervention (Lim et al., 2017). The results showed improvements in the illness severity assessed by the Clinical Global Impression Severity (Guy, 1976) and in the symptoms of conduct problems, emotional problems, hyperactive behaviours, peer problems, and prosocial behaviours assessed by the Strengths and Difficulties Questionnaire (Goodman, 1997). There have been increased community mental health services provided specifically to children and adolescents in other Asian countries. For example, in South Korea, Hong reported that 24 community mental health centres participated in school mental health programs, and 500 community child centres provided various programs for protection, education, and cultural activities as of 2004 (Hong, 2006).

Similar to community outreach services, CAMH plays an important role in the school system given that there is a small percentage of school-age children who seek professional mental health services despite relatively high rates of the prevalence of psychological problems in this population (Tateno, Inagaki, Saito, Guerrero, & Skokauskas, 2017). In some countries in Asia, there are tremendous needs for school counsellors and/or psychologists and other CAMH providers to address school-related and peer-related issues, such as school refusal and bullying. For example, in Japan, school counsellors are deployed in over 75% of all junior high schools (Tateno et al., 2017).

7 Specific opportunities and challenges in the Southeast Asia/Pacific region

In addition to the challenges with mental health workforce and financial, cultural, and stigma-related barriers to available care, there are specific stressors that are of interest in Southeast Asia and in the Pacific region, where there are cultural, historical, and linguistic similarities. As reviewed by Guerrero and colleagues (Guerrero, Fung, Suaalii-Sauni, & Wiguna, 2013), many countries in this larger region have faced colonization and cultural trauma, resource depletion and poverty, and relatively recent war and conflict—all of which can increase psychiatric risk spanning generations. Furthermore, this world region includes coastal areas

and islands, where geographic isolation can limit access to healthcare and especially mental healthcare and where there is particular vulnerability to ocean-related natural disasters and climate change.

In many of the Southeast Asian and Pacific Island nations described in Guerrero et al.'s review (Guerrero et al., 2013), shared themes included inadequate infrastructures for mental healthcare, a dearth of subspecialty and inpatient psychiatric services, over-representation of specific populations in juvenile justice and inpatient settings, elevated suicide rates in specific populations, and urbanization-associated stress. There were also other possible biological considerations relevant to psychiatric care in this broader world region; some examples included dietary neurotoxins and increased susceptibility to metabolic syndrome (a possible side effect of psychotropic medication treatment).

In nations that have experienced colonization, cultural trauma and socioeconomic disadvantage are important causes of youth mental health disparities, which exist even in well-resourced nations. These disparities result from differential exposures, throughout development, to poverty, trauma, discrimination, and barriers to accessing mental healthcare, and they significantly impact indigenous and other vulnerable populations (Guerrero, Chock, Lee, Sugimoto-Matsuda, & O'Kelly, 2019). Based on their review and an analysis of mental health challenges in a world region roughly approximating to Southeast Asia and the Pacific, Guerrero and colleagues (Guerrero et al., 2013) recommended culturally relevant and primary care-integrated mental healthcare delivery models to systematically address acculturative stressors and related barriers to care, financing of universal health and mental healthcare to mitigate the effects of poverty and socioeconomic challenges in accessing care, and video-conferencing technology to increase access to services and education in the context of geographic isolation. Furthermore, in view of the large populations residing near the ocean and other areas that are susceptible to global warming, rising sea levels, and natural disasters, the strong culturally rooted connections between the ocean and indigenous people in this region, and the increasingly apparent reality that climate change has profound impacts on mental health (Coverdale et al., 2018), we believe that addressing mental health needs in the Asia/Pacific region must responsibly include carbon footprint reduction, support for resource-sustaining indigenous practices, and care for climate change-affected populations.

Additionally, it is important to pay attention to the potential influence of a growing number of migrant workers on their children's mental health. Migration trends are on the rise in this region (UN Women Asia and the Pacific, 2017); more workers seek better employment and opportunities and migrate to countries like Singapore. These trends lead to children of migrant workers being left in their countries of origin and taken care of by their grandparents or other relatives. Fragmented contact with

their parents could increase psychological challenges. In China where migrant trends within a country have been more common recently due to a broader economic gap between cities and rural areas, studies indicate that children who are separated from their parents who migrated to cities for work (“left-behind” children) reported a higher level of anxiety, loneliness, fear, and self-blame (Zhao et al., 2014; Zheng, 2016).

Of interest, this world region includes several population centres that are diverse and that are at the crossroads of other world regions (e.g. the Pacific region is situated between the Asia and North America world regions). Certain places in this world region, such as Hawai‘i, are examples of social environments that, with integrative and multicultural models of cultural interfacing, may promote the development of healthy cultural identity (McDermott & Andrade, 2011), a potentially important component of optimal mental health throughout the lifespan.

8 Future perspectives

Child and adolescent psychiatry and mental health are in a unique position to respond to the growing public health challenges associated with a large number of mental disorders arising early in life, but some changes may be necessary to meet these challenges. In 2018 the future of child and adolescent psychiatry was considered by the Section on Child and Adolescent Psychiatry of the World Psychiatric Association (WPA CAP), the International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP), the World Association for Infant Mental Health (WAIMH), the International Society for Adolescent Psychiatry and Psychology (ISAPP), the UN Special Rapporteur on the Right to Health, representatives of the WHO Department of Mental Health and Substance Abuse, and other experts. There, three consensus priorities for child and adolescent psychiatry over the next decade were highlighted: increasing the workforce necessary for providing care for children, adolescents, and families facing mental disorders; reorienting child and adolescent mental health services to be more responsive to broader public health needs; and increasing research and research training while also integrating new research findings promptly and efficiently into clinical practice and research training (Skokauskas et al., 2019).

To conclude, the shortage of professionals in the CAMH workforce is a long-standing challenge. Developing more standardized training systems to foster next-generation workforce and professionals is an important task in East and Southeast Asia and the Pacific. Such training opportunities need to be available not only for physicians (child and adolescent psychiatrists, paediatricians, and general psychiatrists) but also for other CAMH professionals, including psychologists, social workers, nurses, and possibly school teachers. Developing such systems requires sufficient

funding sources, time, and inputs from professionals in the countries where those systems have already been established. International collaborations through regional or international meetings would be helpful particularly for countries where resources and funding are very more scarce in this region. International professional associations, such as the Asian Society for Child and Adolescent Psychiatry and Allied Professions, the IACAPAP, and the WPA CAP, are good resources. Online textbooks in CAMH, such as the IACAPAP textbook (IACAPAP, 2019) can also be an excellent educational resource and contribute to improving the quality of CAMH services across the world. In addition to the development of professional training, it is also important to scale up services for mental disorders in nonspecialized health settings. This is the primary aim of the WHO Mental Health Gap Action Programme (mhGAP) (World Health Organization, 2019). The current version of the mhGAP Intervention Guide has one module for child and adolescent mental and behavioural disorders.

The shortage of workforce can be partially mitigated with the advancement of telemedicine. Telemedicine refers to the practice of caring for patients remotely when the provider and patient are not physically present with each other. Modern technology can safeguard patients' medical information. It is reported that telemedicine can fill gaps in care that result from the shortage of providers and reducing patient and family travel burdens (Tuckson, Edmunds, & Hodgkins, 2017). While the use of telemedicine can solve the scarcity of providers in rural areas in countries where most providers based their practice in major cities, however, different strategies are needed in countries or areas where the scarcity of CAMH providers is prevalent. In such countries, developing systems where local providers can consult professionals who have expertise in CAMH in other countries may be a strategy in the future while acknowledging obstacles to the growth of telemedicine across countries, such as licensure and national laws governing the provision of telemedicine. Guerrero et al. have described successful use of telemedicine in providing clinical services and education across large, transoceanic distances in the Pacific region (Guerrero, Alicata, Haack, & Rehuher, 2019).

Lastly, it is important that a multisector child and adolescent mental health policy be reflected in all levels of the government and community. Without policy, there is no security for the plan of action, system development, financing, and account access for CAMH services. A previous study did not identify any countries that had a national mental health policy or action plan specifically for children and adolescents (Shatkin & Belfer, 2004). As delineated by Skokauskas and colleagues (Skokauskas et al., 2019), such mental health policies need to include human rights, service organization and delivery, development of human resources, sustainable financing, civil society and advocacy, quality improvement, information systems, program evaluation, and plans to address stigma.

References

- American Academy of Child and Adolescent Psychiatry. (2019). *AACAP workforce issues*. https://www.aacap.org/AACAP/Resources_for_Primary_Care/Workforce_Issues.aspx. (Accessed 15 November 2019).
- Chaulagain, A., Kunwar, A., Watts, S., Guerrero, A. P. S., & Skokauskas, N. (2019). Child and adolescent mental health problems in Nepal: A scoping review. *International Journal of Mental Health Systems*, 13, 53. <https://doi.org/10.1186/s13033-019-0310-y>.
- Chen, S. X., & Mak, W. W. S. (2008). Seeking professional help: Etiology beliefs about mental illness across cultures. *Journal of Counseling Psychology*, 55(4), 442–450. <https://doi.org/10.1037/a0012898>.
- Cho, S.-Z., Chun, S.-Y., Hong, K.-E., & Shin, M.-S. (2000). A study of the development and standardization of ADHD diagnostic system. *Journal of the Korean Academy of Child and Adolescent Psychiatry*, 11(1), 91–99.
- Coverdale, J., Balon, R., Beresin, E. V., Brenner, A. M., Guerrero, A. P. S., Louie, A. K., & Roberts, L. W. (2018). Climate change: A call to action for the psychiatric profession. *Academic Psychiatry: The Journal of the American Association of Directors of Psychiatric Residency Training and the Association for Academic Psychiatry*, 42(3), 317–323. <https://doi.org/10.1007/s40596-018-0885-7>.
- Danielson, M. L., Bitsko, R. H., Ghandour, R. M., Holbrook, J. R., Kogan, M. D., & Blumberg, S. J. (2018). Prevalence of parent-reported ADHD diagnosis and associated treatment among U.S. children and adolescents, 2016. *Journal of Clinical Child and Adolescent Psychology: The Official Journal of the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53*, 47(2), 199–212. <https://doi.org/10.1080/15374416.2017.1417860>.
- Gau, S. S. F., Chong, M. Y., Chen, T. H. H., & Cheng, A. T. A. (2005). A 3-year panel study of mental disorders among adolescents in Taiwan. *The American Journal of Psychiatry*, 162(7), 1344–1350. <https://doi.org/10.1176/appi.ajp.162.7.1344>.
- Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 38(5), 581–586.
- Guerrero, A., Alicata, D., Haack, S., & Rehuher, D. (2019). Connections at the crossroads of the Pacific: Hawaii's experiences with video teleconferencing for education, collaboration, and services. In *Innovations in global mental health*. Springer.
- Guerrero, A. P. S., Chock, S., Lee, A. K., Sugimoto-Matsuda, J., & O'Kelly, A. S. (2019). Mental health disparities, mechanisms, and intervention strategies: Perspective from Hawai'i. *Current Opinion in Psychiatry*, 32(6), 549–556. <https://doi.org/10.1097/YCO.0000000000000551>.
- Guerrero, A. P. S., Fung, D., Suaalii-Sauni, T., & Wiguna, T. (2013). Care for the seafarers: A review of mental health in Austronesia. *Asia-Pacific Psychiatry: Official Journal of the Pacific Rim College of Psychiatrists*, 5(3), 119–140. <https://doi.org/10.1111/appy.12031>.
- Guy, W. (1976). *Clinical global impressions*. In *ECDEU, assessment manual for psychopharmacology, revised* (pp. 218–222). Rockville: National Institute of Mental Health.
- Hirota, T., Guerrero, A., Sartorius, N., Fung, D., Leventhal, B., Ong, S. H., ... Consortium on Academic Child and Adolescent Psychiatry in the Far East (CACAP FE). (2015). Child and adolescent psychiatry in the Far East. *Psychiatry and Clinical Neurosciences*, 69(3), 171–177. <https://doi.org/10.1111/pcn.12248>.
- Hirota, T., Guerrero, A., Sartorius, N., Fung, D., Leventhal, B., Ong, S. H., ... Skokauskas, N. (2019). Child and adolescent psychiatry in the Far East: A 5-year follow up on the Consortium on Academic Child and Adolescent Psychiatry in the Far East (CACAP-FE) study. *Psychiatry and Clinical Neurosciences*, 73(2), 84–89. <https://doi.org/10.1111/pcn.12800>.
- Honda, H., Shimizu, Y., Misumi, K., Niimi, M., & Ohashi, Y. (1996). Cumulative incidence and prevalence of childhood autism in children in Japan. *The British Journal of Psychiatry: The Journal of Mental Science*, 169(2), 228–235.

- Hong, S. D. (2006). Community mental health system for children and adolescents in Korea. *Psychiatry Investigation*, 3(1), 32–38.
- Hsia, R. Y., & Belfer, M. L. (2008). A framework for the economic analysis of child and adolescent mental disorders. *International Review of Psychiatry (Abingdon, England)*, 20(3), 251–259. <https://doi.org/10.1080/09540260802002434>.
- IACAPAP. (2019). *JM Rey's IACAPAP e-textbook of child and adolescent mental health*. <https://iacapap.org/iacapap-textbook-of-child-and-adolescent-mental-health/>. (Accessed 15 November 2019).
- Kaushik, A., Kostaki, E., & Kyriakopoulos, M. (2016). The stigma of mental illness in children and adolescents: A systematic review. *Psychiatry Research*, 243, 469–494. <https://doi.org/10.1016/j.psychres.2016.04.042>.
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62(6), 593–602. <https://doi.org/10.1001/archpsyc.62.6.593>.
- Kim, M. J., Park, I., Lim, M. H., Paik, K. C., Cho, S., Kwon, H.-J., ... Ha, M. (2017). Prevalence of attention-deficit/hyperactivity disorder and its comorbidity among Korean children in a community population. *Journal of Korean Medical Science*, 32(3), 401–406. <https://doi.org/10.3346/jkms.2017.32.3.401>.
- Kim, Y. S., Leventhal, B. L., Koh, Y.-J., Fombonne, E., Laska, E., Lim, E.-C., ... Grinker, R. R. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, 168(9), 904–912.
- Lau, A., & Takeuchi, D. (2001). Cultural factors in help-seeking for child behavior problems: Value orientation, affective responding, and severity appraisals among Chinese-American parents. *Journal of Community Psychology*, 29(6), 675–692. <https://doi.org/10.1002/jcop.1042>.
- Lim, C. G., Loh, H., Renjan, V., Tan, J., & Fung, D. (2017). Child community mental health services in Asia Pacific and Singapore's REACH model. *Brain Sciences*, 7(10), <https://doi.org/10.3390/brainsci7100126>.
- Lonner, W., Dinnel, D., Forgays, D., & Hayes, S. (1999). *Merging past, present, and future in cross-cultural psychology: Selected papers from the Fourteenth International Congress of the International Association for Cross-Cultural Psychology*. Lisse, Netherlands: Swets & Zeitlinger Publishers.
- Mallinckrodt, B., Shigeoka, S., & Suzuki, L. A. (2005). Asian and Pacific Island American students' acculturation and etiology beliefs about typical counseling presenting problems. *Cultural Diversity and Ethnic Minority Psychology*, 11(3), 227–238. <https://doi.org/10.1037/1099-9809.11.3.227>.
- McDermott, J., & Andrade, M. (2011). *People and cultures of Hawai'i: The evolution of culture and ethnicity*. Honolulu, United States: University of Hawai'i Press.
- McEwan, K., Waddell, C., & Barker, J. (2007). Bringing children's mental health "out of the shadows". *CMAJ: Canadian Medical Association Journal*, 176(4), 471–472. <https://doi.org/10.1503/cmaj.061028>.
- Morris, J., Belfer, M., Daniels, A., Flisher, A., Villé, L., Lora, A., & Saxena, S. (2011). Treated prevalence of and mental health services received by children and adolescents in 42 low-and-middle-income countries. *Journal of Child Psychology and Psychiatry*, 52(12), 1239–1246. <https://doi.org/10.1111/j.1469-7610.2011.02409.x>.
- Ng, C., Herrman, H., Chiu, E., & Singh, B. (2009). Community mental health care in the Asia-Pacific region: Using current best-practice models to inform future policy. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)*, 8(1), 49–55.
- Patel, V., Flisher, A. J., Nikapota, A., & Malhotra, S. (2008). Promoting child and adolescent mental health in low and middle income countries. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 49(3), 313–334. <https://doi.org/10.1111/j.1469-7610.2007.01824.x>.

- Shatkin, J. P., & Belfer, M. L. (2004). The global absence of child and adolescent mental health policy. *Child and Adolescent Mental Health*, 9(3), 104–108. <https://doi.org/10.1111/j.1475-3588.2004.00090.x>.
- Skokauskas, N., Fung, D., Flaherty, L. T., von Klitzing, K., Pūras, D., Servili, C., ... Guerrero, A. (2019). Shaping the future of child and adolescent psychiatry. *Child and Adolescent Psychiatry and Mental Health*, 13, 19. <https://doi.org/10.1186/s13034-019-0279-y>.
- Srinath, S., Kandasamy, P., & Golhar, T. S. (2010). Epidemiology of child and adolescent mental health disorders in Asia. *Current Opinion in Psychiatry*, 23(4), 330–336. <https://doi.org/10.1097/YCO.0b013e32833aa0c1>.
- Sun, X., Allison, C., Wei, L., Matthews, F. E., Auyeung, B., Wu, Y. Y., ... Brayne, C. (2019). Autism prevalence in China is comparable to Western prevalence. *Molecular Autism*, 10, 7. <https://doi.org/10.1186/s13229-018-0246-0>.
- Tateno, M., Inagaki, T., Saito, T., Guerrero, A. P. S., & Skokauskas, N. (2017). Current challenges and future opportunities for child and adolescent psychiatry in Japan. *Psychiatry Investigation*, 14(5), 525–531. <https://doi.org/10.4306/pi.2017.14.5.525>.
- Thompson, V. L. S., Noel, J. G., & Campbell, J. (2004). Stigmatization, discrimination, and mental health: The impact of multiple identity status. *The American Journal of Orthopsychiatry*, 74(4), 529–544. <https://doi.org/10.1037/0002-9432.74.4.529>.
- Tracey, T., Leong, F. T. L., & Glidden, C. (1986). Help seeking and problem perception among Asian Americans. *Journal of Counseling Psychology*, 33(3), 331–336. <https://doi.org/10.1037/0022-0167.33.3.331>.
- Tuckson, R. V., Edmunds, M., & Hodgkins, M. L. (2017). Telehealth. *The New England Journal of Medicine*, 377(16), 1585–1592. <https://doi.org/10.1056/NEJMSr1503323>.
- UN Women Asia and the Pacific. (2017). *Women migrant workers in the Asean economic community*. <https://asiapacific.unwomen.org/digital-library/publications/2017/06/women-migration-workers-in-asean>. (Accessed 15 November 2019).
- Wang, J., Deng, X.-J., Wang, J.-J., Wang, X.-W., & Xu, L. (2009). Substance use, sexual behaviours, and suicidal ideation and attempts among adolescents: Findings from the 2004 Guangzhou Youth Risk Behaviour Survey. *Public Health*, 123(2), 116–121. <https://doi.org/10.1016/j.puhe.2008.10.013>.
- Wang, T., Liu, K., Li, Z., Xu, Y., Liu, Y., Shi, W., & Chen, L. (2017). Prevalence of attention deficit/hyperactivity disorder among children and adolescents in China: A systematic review and meta-analysis. *BMC Psychiatry*, 17(1), 32. <https://doi.org/10.1186/s12888-016-1187-9>.
- Wilkins, J. E., & Velicher, W. F. (1980). A semantic differential investigation of children's attitudes toward three stigmatized groups. *Psychology in the Schools*, 17(3), 364–371. [https://doi.org/10.1002/1520-6807\(198007\)17:3<364::AID-PITS2310170315>3.0.CO;2-F](https://doi.org/10.1002/1520-6807(198007)17:3<364::AID-PITS2310170315>3.0.CO;2-F).
- Woo, B., Ng, T., & Fung, D. (2007). Emotional and behavioral problems in Singaporean children based on parent, teacher and child reports. *Singapore Medical Journal*, 48(12), 1100–1106.
- Woo, B. S. C., Chang, W. C., Fung, D. S. S., Koh, J. B. K., Leong, J. S. F., Kee, C. H. Y., & Seah, C. K. F. (2004). Development and validation of a depression scale for Asian adolescents. *Journal of Adolescence*, 27(6), 677–689. <https://doi.org/10.1016/j.jadolescence.2003.12.004>.
- World Health Organization. (2001). *The world health report 2001*. http://www.who.int/whr/2001/en/whr01_en.pdf?ua=1. (Accessed 15 November 2019).
- World Health Organization. (2005). *WHO Atlas: Child and adolescent mental health resources*. https://www.who.int/mental_health/publications/atlas_child_ado/en/. (Accessed 15 November 2019).
- World Health Organization. (2010). *The world health report 2010*. <https://www.who.int/whr/2010/en/>. (Accessed 15 November 2019).
- World Health Organization. (2013). *WHO mental health action plan 2013–2020*. http://www.who.int/entity/mental_health/publications/action_plan/en/index.html. (Accessed 15 November 2019).

- World Health Organization. (2019). *WHO mental health gap action programme (mhGAP)*. http://www.who.int/mental_health/mhgap/en/. (Accessed 15 November 2019).
- Xu, D.-D., Rao, W.-W., Cao, X.-L., Wen, S.-Y., Che, W.-I., Ng, C. H., ... Xiang, Y.-T. (2018). Prevalence of major depressive disorder in children and adolescents in China: A systematic review and meta-analysis. *Journal of Affective Disorders, 241*, 592–598. <https://doi.org/10.1016/j.jad.2018.07.083>.
- Zhao, X., Chen, J., Chen, M.-C., Lv, X.-L., Jiang, Y.-H., & Sun, Y.-H. (2014). Left-behind children in rural China experience higher levels of anxiety and poorer living conditions. *Acta Paediatrica (Oslo, Norway: 1992), 103*(6), 665–670. <https://doi.org/10.1111/apa.12602>.
- Zheng, Y. (2016). Psychological consequences of parental migration for left-behind children. In M. Hodes, S.S.-F. Gau, & P. J. de Vries (Eds.), *Positive mental health, fighting stigma and promoting resiliency for children and adolescents* (pp. 141–157). London: Academic Press.

Further reading

- Jia, Z., & Tian, W. (2010). Loneliness of left-behind children: A cross-sectional survey in a sample of rural China. *Child: Care, Health and Development, 36*(6), 812–817. <https://doi.org/10.1111/j.1365-2214.2010.01110.x>.

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Starting at the Beginning

Laying the Foundation for Lifelong Mental Health

Edited by **Matthew Hodes, Susan Shur-Fen Gau, and Petrus J. de Vries**

Starting at the Beginning: Laying the Foundation for Lifelong Mental Health coincides with a series of web-based events that replace the 24th International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) Congress in Singapore. As a result of the COVID-19 pandemic the face-to-face congress was replaced by an introductory webinar in July 2020, and a virtual congress in December 2020. This book examines epidemiological and cultural perspectives in Child and Adolescent Mental Health (CAMH), risk, prevention, and intervention opportunities in developmental neuropsychiatry, new perspectives on problems and disorders, and Asian Perspectives in CAMH policy and services.

It addresses the ways in which interventions and mental health services can be developed and shaped to address the individual differences amongst children in different contexts. Additional topics include environmental hazards and mental health, cultural psychiatry as a basic science to address mental health disparities, and disease burden, risk, and costs in Asian countries.

Chapters dive deeper into hikikomori, gaming disorder, pitfalls of treatment in OCD, developmental perspective on ADHD, prevention of neuropsychiatric disorders, and ASD interventions in low-resource settings. Given the location of the IACAPAP congress, one section focusses on mental health services and policy developments in China, Oceania, and East Asia.

Key Features:

- Emphasizes cultural, social, and environmental influences
- Focuses on early developmental processes
- Covers a range of illustrative psychiatric disorders and problems
- Reviews CAMH Policies with an emphasis on Asia
- Addresses the resourcing and training of child and adolescent psychiatrists in Asia
- Works towards the goal of producing a mental health workforce with internationally recognized competencies



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