

Declaration on Autism Spectrum Disorders

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Autism Spectrum Disorders (hereafter termed 'autism') are the most serious child psychiatric disorders. Autism affects one child in every 800 and associated pervasive developmental disorders affect one child in every 150 to 200. Individuals with autism are found in every nation, in all ethnic groups, in all types of families, and in every social class. Arising during the first years of life, autism affects the vital areas of psychological and behavioral development, generally throughout the lifespan.

Children affected by autism are impaired in the development of their social relations, communication, and emotional functioning, and are burdened in their adaptation to life in the family, in school, and in the community. They suffer from serious behavioral and emotional symptoms including over-activity, stereotypy, repetitive and restricted range of activities, anxiety, and self-injurious behavior. Most individuals with autism, although not all, are also affected by intellectual disability and many are non-verbal (mute). Social disturbances, however, exceed intellectual difficulties and social, emotional, and behavioral problems of autistic individuals cannot be explained solely as a result of intellectual disability.

Autism assessment is a complex task. A multi-professional approach to assessment needs to be resourced and supported for all patient age groups. A diagnosis of autism is usually regarded as life-long, although with early detection and intervention, more individuals are able to lead lives of independence and self-sufficiency as adults. Therefore, it is of equal importance that autism is diagnosed and, where appropriate, not diagnosed, accurately. Claims are increasingly being made that, in the foreseeable future, autism will be diagnosed by brain scanning or similar technology. This seems unlikely. Instead, further research into optimal clinical assessment needs to be supported, to further enhance the 'patient journey'.

During the past two decades, advances in scientific and clinical research have resulted in major advances in understanding and intervention and have provided a reliable diagnostic system and criteria for autism spectrum disorders. This internationally utilized system enhances international collaboration and sharing of knowledge.

Further phenomenological and biological research is needed on the assessment and diagnosis of children with presentations on the 'broader autism phenotype'. Psychological research has substantiated the centrality of social impairments in autism. Developmental and neuropsychological research suggest that individuals with autism have an inborn or early appearing impairment in the understanding and use of social information and in the formation of reciprocal social relations. Research demonstrates disturbances in various areas of language use and communication.

There is no single, known cause for autism, although the very strong role of genetic factors has been increasingly appreciated with multiple genes likely to be involved. Neurochemical findings have implicated the role of serotonergic and other neurotransmitter systems; neuro-imaging studies have indicated possible alterations in brain structures and differences in the ways in which individuals with autism process social information.

Intervention should start as soon as possible during the first years of life, based on careful, individual assessment of strengths and problems. Various methods have now been established based on peer-reviewed scientific research and these evidence-based treatments should be the first line of intervention. Specially trained professionals, working in collaboration with parents, should develop a comprehensive treatment plan. As the child develops, a lifetime perspective should be devised that will change with maturation and changes in the individual's strengths and needs.

Components of a comprehensive treatment plan include individual behavioral therapies to remediate specific symptoms; education to promote social, emotional, and language development; family support and guidance to help sustain the child in the family; recreational programming to enhance emotional maturation; life-skill programs to promote adaptation; vocational training to allow for community-based work; adequate schooling to facilitate participation in age-appropriate groups and cultural values; as well as, when needed, psychotherapy for promoting social and emotional competence and help in coping with anxiety, as well as pharmacological interventions when appropriate.

There is increasing awareness that a significant number of adults with autism have not been diagnosed as children and are entering adult life with significant, often unrecognized difficulties. In some cases, such individuals may have been incorrectly diagnosed with other psychiatric conditions, such as schizophrenia. There may be insufficient awareness of their mental health and social needs within adult psychiatric care (including forensic settings and general prison populations). Therefore, there is a concomitant need to increase autism awareness for general adult and psychogeriatric mental health practitioners and primary care practitioners, so that adults not yet diagnosed with autism can receive the special care which they require. It is therefore incumbent on all child and adolescent mental health practitioners to improve early recognition, assessment and diagnosis of autism and to share knowledge with adult mental health colleagues, to improve assessment for cases that have not been recognized in earlier years.

The goal of intervention should be to allow the individual with autism to remain within the family and community to the fullest extent possible, and to have his or her autonomy, individuality, and dignity respected. Communities and nations should be able to provide individuals with autism with a range of options for

education, treatment, and living situations. The spectrum of services provided should allow an individual to receive treatment and education that is suitable for his or her specific needs and strengths, age, and family situation.

Even with optimal intervention, the vast majority of individuals with autism remain impaired in social, communicative, emotional and adaptive functioning throughout their lives. There is no 'cure' for autism, as such. The future prognosis for people with autism will depend on advances in basic and clinical neuroscience and their treatment applications. Promising areas include studies of the molecular biology of brain development; the biological basis of socialization and communications; neuropharmacology; neuro-imaging; and genetics .

Many disciplines must be involved in the care and treatment of individuals with autism and in the advancement of scientific knowledge. These professions include child and adolescent psychiatry, psychology, speech and language, special education, genetics, developmental neuroscience, pharmacology, and the full range of biomedical specialties concerned about brain development and function. In addition, special expertise is needed in the organization and management of programs, financing systems, and lifetime planning. Within nations, there should be centers of excellence in autism and the broader phenotype to engage in systematic, multidisciplinary research; train specialists; disseminate information; and evaluate, treat and support individual children, adolescents, adults and older adults, and their families.

International collaborations can serve important functions in promoting high quality research; sharing information, methods, and data; developing and testing treatment methods; and experimenting with different systems for early assessment and diagnosis, intervention, and delivery of care and education.

Research on autism and associated disorders will help to develop concepts, research methodologies, and treatment approaches that can be utilized in relation to other, early onset and emergent developmental, psychiatric, and serious emotional disorders.

IACAPAP firmly endorses the following principles:

1. Nations and communities should develop clinical systems for early diagnosis and evaluation of young children with serious developmental and psychiatric disorders such as autism.
2. Interventions and treatment should be initiated as early as possible, and continue throughout the lifespan as needed and should be based on solid scientific evidence.
3. Children and their families should be provided with a range of treatment and care options, with the major goal of improving adaptation, reducing symptoms,

promoting maturation, and maintaining the individual with autism within the family and community. All intervention should be specifically related to individual needs and strengths, and treatments should be carefully evaluated for effectiveness and safety, with due consideration of family and cultural values.

4. Treatment planning should be based on collaborations between professionals from various disciplines and the family; treatment and care should also consider the wishes of the individual with autism and PDD, to the extent that this is possible, and respect the individuality, autonomy, and dignity of the individual and family.

5. A broad range of biological and behavioral research is needed to understand the biological basis of autism and associated conditions, neuropsychological features, and effective behavioral and biological (including pharmacological) interventions. Genetic research, molecular biological research, neuro-imaging, neurochemistry, neuro-pharmacological studies, and cognitive neuroscience studies are especially promising. Research is also needed on behavioral, educational and psychological interventions.

6. Programs of training - both in clinical care and research - are needed to ensure the highest levels of science and research. Standards for clinical care should be developed to guide such training.

7. All interventions and research studies must conform to the highest level of ethical considerations; also, there is an ethical responsibility by professionals to test their methods and to promote the advancement of knowledge.

IACAPAP asserts the importance to nations of well-funded, high quality, ethically delivered education and treatment for individuals with autism and PDD, and to all children and adolescents with serious psychiatric and developmental disorders. To assure the creation and maintenance of optimal systems of mental health and special education, government, private organizations, professionals, families, and advocates need to work together.

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