

IACAPAP Declaration of Venice

Autism and Pervasive Developmental Disorders

The International Association of Child and Adolescent Psychiatry and Allied Professions (IACAPAP) is the international organization of national societies committed to child and adolescent psychiatry, psychology and allied professions. For more than sixty years, IACAPAP has been an international advocate for children and families and for the professions that serve them. Major goals are to facilitate the provision of preventive and treatment services, to enhance the training and the work of mental health professionals, and to promote the advancement of knowledge and the sharing of information across nations to improve the quality of care and treatment that is available. Autism and pervasive developmental disorders (PDD) are the most serious child psychiatric disorders. Autism affects one child in every 1,500 and associated pervasive developmental disorders affect one child in every 200 or 300. Individuals with autism and PDD 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 and pervasive developmental disorders affect the vital areas of psychological and behavioral development, generally through the life span. Children with autism and associated disorders 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 intellectually disabled (mentally retarded) 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.

Advances in scientific and clinical research during the past decade have resulted in major advances in understanding and treatment. The International Classification of Diseases, tenth edition (ICD 10) and the Diagnostic and Statistical Manual of the American Psychiatric Association, fourth edition (DSM IV) provide a reliable diagnostic system and criteria for autism, Asperger Syndrome, Rett's Syndrome, and Disintegrative Disorder. This internationally utilized system enhances international collaboration and sharing of knowledge. Further phenomenological and biological research is

needed on the diagnosis of children with other types of pervasive developmental disorders, including conditions such as Multiple Complex Developmental Disorder/Psychotic Disharmony. 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 on communication demonstrates disturbances in various areas of language use and communication. There is no single, known cause for autism and PDD. Neurochemical findings have implicated the role of serotonergic systems; neuro-imaging studies have indicated possible alterations in brain structures and differences in the ways in which individuals with autism process social information; and genetic research has provided evidence for contributions of genetic vulnerability and perhaps specific genes. Intervention strategies should start as soon as possible, during the first years of life, based on careful, individual assessment of strengths and problems. 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 menu 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 programs 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; psychotherapy for promoting social and emotional competence and help cope with anxieties and other troubles; and medication for specific areas of symptomatology, as needed. The goal of intervention should be to allow the individual with autism to remain within the family and community, to the extent possible, and to have his or her autonomy, individuality, and dignity respected. Communities and nations should be able to provide individuals with autism and PDD with a range of options for education, treatment, and living situation. The spectrum of services 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 treatment, the vast majority of individuals with autism remain impaired in social, communicative, emotional and adaptive functioning throughout their lives. The future prognosis for these individuals will depend on advances in basic and clinical neuroscience and their applications to treatment. 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 with 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 PDD to engage in systematic, multidisciplinary research; train specialists; disseminate information; and evaluate, treat and support individual children, adolescents and 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 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. Treatment should be initiated as early as possible, and continued throughout the life-span, as needed.

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.

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.

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.

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.

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.