

# POSITION PAPER ON CARE FOR PERSONS WITH AUTISM SPECTRUM DISORDERS



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# POSITION PAPER

## ON CARE FOR PERSONS WITH AUTISM SPECTRUM DISORDERS

### A RIGHTS-BASED, EVIDENCE-BASED APPROACH

VIII INTERNATIONAL CONGRESS AUTISM-EUROPE  
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#### TABLE OF CONTENTS

##### ACKNOWLEDGEMENTS

- PREAMBLE THE RIGHTS-BASED APROACH TO DISABILITY
- A. AN APPROACH TO ASD BASED ON RIGHTS, PARTICIPATION AND QUALITY
1. A RIGHTS-BASED APPROACH TO AUTISM SPECTRUM DISORDERS
- 1.1 ACCESS TO (RE)HABILITATION AND HEALTHCARE
- 1.2 ACCESS TO LIFE-LONG EDUCATION
- 1.3 SOCIAL INCLUSION
2. A PARTICIPATION-BASED APPROACH TO ASD
3. A QUALITY-BASED APPROACH TO AUTISM SPECTRUM DISORDERS
- B. THE VIEW OF THE SCIENTIFIC COMMUNITY ON THE CARE OF AUTISM AND PERVERSIVE DEVELOPMENTAL DISORDERS
- C. THE ADDED VALUE OF THE EUROPEAN UNION IN THE FIELD OF CARE FOR ASD
- D. ETHICS AND RESEARCH IN THE FIELD OF ASD
- ANNEX 1 THE CORE INTERNATIONAL HUMAN RIGHTS INSTRUMENTS



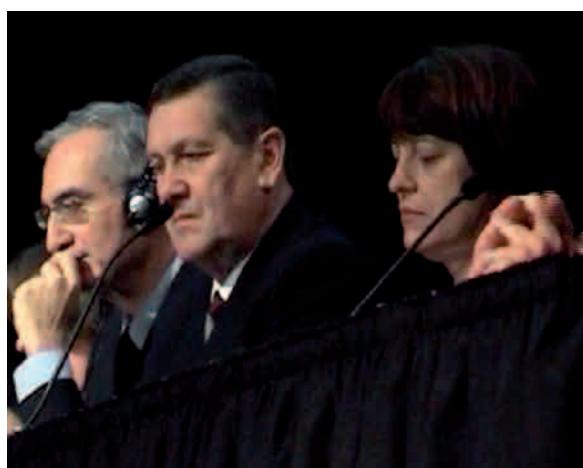
Cover : « Children of the World » by Fernando Jorge Seabra (APPDA)

This document includes the easy-to-read version and is also available in PDF format  
on the Autism-Europe web site  
[www.autismeurope.org](http://www.autismeurope.org)

# ACKNOWLEDGEMENTS

This position paper has been drafted by Autism-Europe, the International Association of Child and Adolescent Psychiatry and Allied Professions (IACAPAP) and the European Society for Child and Adolescent Psychiatry (ESCAP). It reflects the views of Autism-Europe, IACAPAP and ESCAP on the approach to Autism Spectrum Disorders.

It has been presented and officially adopted at the VIII International Congress of Autism-Europe (Oslo, September 2nd 2007) by the presidents of the three organisations:



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Autism-Europe is a European network which ensures effective liaison between approximately 80 member associations of parents of persons with autism in 30 European countries, governments and European and international institutions. In order to implement its objectives, Autism-Europe has built strategic alliances with social partners to maximise its impact on EU policies and to establish a structured dialogue with the European Institutions. Autism-Europe is a founding member of and cooperates closely with the European Disability Forum (EDF) and the Platform of European Social NGOs. European Union (EU), the Council of Europe (CoE) and the World Health Organisation (WHO). Autism-Europe's overarching statutory mission is to improve the quality of life of all persons with autism and their families by promoting and defending their rights. This is achieved through:

- Representing persons with autism towards all EU institutions
- Promoting awareness on the appropriate care, education, and well-being of persons with autism
- Promoting the exchange of information, good practices and experience.



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.



The European Society of Child and Adolescent Psychiatry (ESCAP), formerly the European Union of Child Psychiatrists, was founded in 1960 to further knowledge and understanding in the field of child and adolescent psychiatry. This field includes emotional, psychosomatic and behavioural disorders, (including depression, anxiety and conduct problems), developmental disorders, such as autism, learning difficulties, and alcohol and drug problems in this age group. ESCAP is the only scientific organisation bringing together all European psychiatrists who practice with children and adolescents.

# PREAMBLE: THE RIGHTS-BASED APPROACH TO DISABILITY



**The social model of disability says people with disabilities want to enjoy the same rights as others.**

**International laws state that people with disabilities have the right to be cured, educated and supported.**

**Ensuring these rights to people with disabilities can be expensive. But rights must be respected for all.**

**Lack of funds does not justify deprivation of rights.**

In the new millennium, the disabled persons' community is fighting for a new conception in the approach to disability. This new conception demands a paradigmatic shift from the so-called "medical" model towards a "social" model of disability. The "medical" model is an approach to disability that puts the impairment in the foreground whilst the person fades into the background. On the contrary, the rights-based approach to disability promotes a shift in values away from this model towards a social model that sees persons with disabilities as active subjects with rights and not passive objects of assistance.

According to a rights-based approach, and in relation to the available international and European legal framework (see Annex 1), access to fundamental rights, such as healthcare, (re)habilitation and life-long education, cannot be denied to any person on the grounds of disability or other conditions, including age.

From this perspective, healthcare, social care and school systems cannot, in any event, restrict or violate any individual right recognised by international and national normative sources. Access for all to (re)habilitation programmes and to education systems should be recognised as a priority and ensured, regardless of the nature or severity of the disability.

Moreover, eventual financial claims invoked by national or local Authorities cannot, in any event, justify a restriction to fundamental rights. Following existing ordinances issued by presiding judges on these matters, public authorities are obliged to allocate adequate support to children with severe disabilities because the concept of damage to the person not only includes the physical and mental integrity of the person but also damage caused by infringement of an inalienable and fundamental human right.

The justification adopted by public authorities concerning the insufficiency of available financial resources is therefore irrelevant in the face of inviolable individual rights.

## A - AN APPROACH TO ASD BASED ON RIGHTS, PARTICIPATION AND QUALITY

### 1. A rights-based approach to autism spectrum disorders



**Persons with autism have life-long, severe disability and complex needs, but they have the same value as other people.**

**Their complex needs make difficult for them to get their rights to healthcare, education and to the proper support to live with other people.**

**Nevertheless, denying healthcare, education and proper support to them is a violation of their rights.**

It is recognised that Autism Spectrum Disorders result in a significant lifelong disability, and that persons with ASD form an especially vulnerable group even among persons with disabilities because of the complexity of their needs. Nevertheless, they should not be considered nor treated as an exception to the rules among persons with disabilities, nor as a population that is NOT ABLE to achieve goals such as independence, self-determination and dignity. People with Autism Spectrum Disorders have the same human value as anyone else and, as such, have the same human rights. The right not to be discriminated against in the enjoyment of fundamental rights is also violated when persons whose situations are significantly different fail to be treated differently without reasonable justification.

Nonetheless, the needs of persons with ASD in terms of health-care and rehabilitation, education and inclusion are not always sufficiently taken into account. Many persons with ASD do not have access to (re)habilitation and education programmes and facilities on the grounds of the severity of their impairments. Thus, human rights violations against them take place daily throughout the world.



Pedro A. Martin del Pino



## The support people with autism and their families need is:

- Doctors and staff in hospitals who know what autism is and how to treat it,
- Easy to understand information,
- Adapting schools and the places they live and work in to their needs,
- Experts to help them to live their everyday lives, to work and to have fun,
- Experts to draw, put in practice and check their personal plans,
- to use the same services as other people.

**The lack of proper support and services make life harder for persons with autism and their families.**

**Families are very concerned about the future of their children with autism after their death.**

**Ensuring proper services relieves their concern.**

**Families do not want places where to put their children with autism. They want rights and chances for them to enjoy their lives with others.**

Healthcare and education systems and services often plead budget restrictions to deny the support needed to cope with the particular difficulties of ASD, which include major communication impairments, cognitive impairments and challenging behaviours.

### Support is needed in terms of:

- skilled healthcare professionals in the field of proper diagnosis, assessment and treatment of ASD;
- correct and suitable information on ASD conditions, general/individual needs and individual intervention plans for the persons concerned or for the parents of those who are unable to represent themselves;
- reasonable adjustments of the environment in order to foster social inclusion and full participation of persons with ASD;
- skilled individual support in any life setting, including employment and leisure
- skilled practitioners to properly implement individual (re)habilitation/ educational plans;
- mainstreaming of provision in inclusive settings.

Failure to provide this support generates additional impairments, preventing persons with ASD from achieving the maximum of their unique potential and independence or their capacity for informed choice and self-advocacy, which are the key to achieving a dignified life and full participation in society.

A paucity of healthcare and/or educational provision has an impact not only on the persons with heightened vulnerabilities, such as persons with ASD, but also on the other persons affected, and in particular their families, on whom disproportionate pressure is put in the event of institutional shortcomings.

Moreover, due to the normal life expectancy of persons with ASD, the future that awaits them when her/his parents are too old, ill or dead is a major concern for their parents. A network of services ensuring continuity of quality care, needed to achieve a dignified adulthood, also provides the most effective emotional support for the family's concerns.

One perspective still considers persons with ASD as objects of pity and their families as objects of charity. According to this perspective, the support provided, if any, is aimed at relieving parents of their "burden" more than at ensuring their children's rights and dignity and improving the quality of life of all the family members. Policies inspired by this misconception still speak about and plan for "places" for persons with ASD.

In contrast, parents of persons with ASD are not demanding places. What they are demanding for their children are rights and opportunities in order to achieve their unique potential and live as fulfilling and dignified a life as anyone else's. The burden they want to be relieved of is not their children's disability but their unjustified exclusion from full participation in society.

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In 2002, Autism-Europe launched a survey amongst its members, in co-operation with the COFACEH Europe, the French National Council for Europe, and other interested European organisations. A questionnaire was prepared in collaboration with the Council of Administration of Autism-Europe and partner organisations dealing with the question of the situation of persons with autism or other complex dependency needs disability in the field of access to proper healthcare. The questionnaire was circulated throughout the network of our member associations across Europe and was also accessible on the Web page of Autism-Europe in several European languages. About 300 replies were received from 14 different countries (of which 11 EU member states) within a few months.

Given the limited means at our disposal, this investigation does not claim to be scientific<sup>1</sup>. However, the analysis of these replies highlighted, at least at a qualitative level, the key elements of the situation of the group of people that we represent. The main themes arising from the results of this investigation are set out below :

A- The first important element that arose from this study is that, whilst most families (73%) contacted the healthcare services before their child was 2 years of age, the vast majority (71%) only received a proper diagnosis after the child was 3 years of age or older. Directly linked to this result, we noted that the diagnosis was made mainly by a private specialist (31%), while parents seemed to be more capable of making the diagnosis themselves (18,4%) than either paediatricians (12%) or family doctors (2,4%).

In the majority of cases (63%), the parents received only verbal information concerning the diagnosis and its consequences for their child's condition, whilst only 11,3% received a written report, and 15,7% received no information at all. Finally, the majority (57,7%) were not informed about parents associations or other non-profit organisations advocating and/or providing information in the field of their child's disorder.

B- A significant number of families (40,4%) never received a functional assessment of their child's real skills and potential. Moreover, more than one third (37,9%) of persons with autism or another complex dependency needs disability have never had access to a re-education program, whilst a large number (61%) received medications. In this group, only 15% enjoyed a regular follow-up of the effects of the medication, whilst in 16,9% the service/doctor that prescribed the medication did not provide any follow-up at all. Moreover, the healthcare services did not provide any continuity of care after childhood in more than half the cases (53,6%).

C- More than one third of the families believes that the staff of specialised healthcare services are not motivated (35,9%) nor take into account the family's needs (43,9%) or priorities (43,9%). Moreover, 28% of the families have never had meetings with the staff and more than half (57,77%) have never received any information from the service on the rights of their child in terms of access to healthcare.

D- Finally, concerning access to general healthcare services by persons with autism or a complex dependency needs disability for medical problems other than their specific impairments, the replies show that a significant portion of general healthcare services lack competence in the special needs of their children (38,16%), and fail to provide appropriate reception (35%), continuity of care (46,9%), easy access to the service (39,1%), information to parents (43,4%) and prevention (46,3%).

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1- The percentages indicated represent only the responses received in the sample. It cannot be extrapolated to the total population of the persons concerned.

## 1.1 Access to (re)habilitation and healthcare



**Every person with autism must have support to develop their abilities and live independently.**

**Healthcare system must provide:**

- **early diagnosis of autism and the assessment of the individual needs,**
- **life-long treatment to get skills and live with other people,**
- **access to care for illnesses.**

**Without this help families of children with autism must meet themselves their children needs. To do so, they have to neglect other children and may lose their friends and their work.**

**The diagnosis of autism helps parents to understand the strange behaviour of their children.**



Gonzalo Rodrigo Palacios

No person with ASD should be deprived of the freedom to develop his or her own way of life in as independent a way as possible. The development of their unique potential depends more on the availability of suitable, proper, early, comprehensive and lifelong support than on the degree of individual impairment.

Positive actions and active measures should therefore be put in place by healthcare systems in order to ensure that persons with ASD have:

- Access to appropriate, early, multi-disciplinary diagnosis and assessment, "in accordance with internationally accepted medical standards"<sup>2</sup>,
- Access to appropriate, early, multi-disciplinary and continuous treatment, including social rehabilitation, in accordance with internationally accepted medical standards,
- Access to the ordinary healthcare services that do exist and receive the care that is appropriate to their health needs, in accordance with the same standards afforded to other ill persons.

The parents of children with autism encounter, on a daily basis, the difficulties of inaccurate diagnoses, inadequate care settings, a shortage and/or lack of well-trained staff and a general unwillingness to engage with autism. Meeting these parents' needs (risk of social isolation, disregard for the needs of siblings...) should therefore be an important issue in any comprehensive treatment and guidance plan.

### Access to Screening and Diagnosis

Early, skilled diagnosis is the first step to ensure early, adapted intervention that is aimed at supporting the development of the person, their social inclusion and participation in the community.

The concerns of parents about their child's "strange" behaviour should be seriously taken in account by paediatricians and physicians, who should receive continuing training in the use of specific screening instruments.

Developmental surveillance should be performed on all children from infancy through school age, and at any age thereafter if concerns are raised about social behaviour, communication or learning difficulties. Screening for autism should be performed on all children failing routine surveillance developmental procedures using validated instruments.

2- As stated in the UN «Principles for the protection of persons with mental illness and the improvement of mental health care», adopted by General Assembly resolution 46/119 of 17 December 1991.



**Parents of children with autism realise very soon that their children have strange behaviour.**

**Doctors must listen to parents and take in account their concerns. They should also watch the child playing and use special tests for autism when visiting toddlers. They should send children which are likely to have autism to the specialist for a diagnosis as soon as possible.**

**The diagnosis should help the child. It should not lead to his/her isolation or rejection.**

**The social approach to disability considers persons more important than their diagnosis. Treatment must focus the individual needs.**

**Many different experts are needed to check how a child with autism understands, thinks and functions. This assessment helps to understand the individual needs and to draft a personalised plan of intervention. Individual plans must be checked. If the child does not make progress, the plan must be changed.**

**Parents know their children better than anyone else. They must participate in the assessment.**

The diagnosis of autism should be implemented by means of specific autism sensitive diagnostic instruments administered by trained and qualified professionals and should include standardised parent interviews regarding current concerns and behavioural history, as well as direct, structured observation of social and communicative behaviour and play.

Nowadays, trends in predictive genetic diagnosis and the pressure of society tend to focus on stigmatisation and may lead in the near future to a rejection of disability. Screening and diagnosis must foster the inclusion of persons with ASD in society, not their exclusion or isolation. Healthcare services should detect and identify the disability in order to relieve and support persons with ASD, not to select, split up and isolate them and their families.

#### **Access to Individual Assessment**

The social approach to disability focuses on the person. Ongoing, specialised assessment is the milestone of person-centred intervention. Immediate and long-term evaluation and monitoring of persons with ASD require a comprehensive multi-disciplinary approach, involving different professions (child psychiatrists, psychologists, speech therapists, special educators), in order to provide comprehensive, adequate assessment in multiple areas, such as verbal and non-verbal communication, cognitive functioning and adaptive behaviour.

Assessment should identify realistic objectives to be implemented by means of individually tailored plans that are functional in achieving independence, dignity and social participation, according to individual needs, motivation and potential. Assessment of a child's progress in meeting the scheduled objectives should be used on an ongoing basis to further refine the individual plans. A lack of objective documentary evidence of progress should be taken to indicate a need to increase the intensity and quality of intervention by reducing child /carer ratios, reformulating individual programmes, increasing programming time, or providing staff with additional training and consultation.

Parents should be actively involved in their child's evaluation process. Involving parents means they are active participants in the various steps which lead to the identification and continuing redefinition of their child's abilities and rehabilitation needs, and work as qualified members of the team carrying out the agreed rehabilitation project.



**In many countries experts in autism are not sufficient to ensure treatment to all persons who need it. Many persons with ASD do not get treatment and cannot develop skills.**

**There is no cure for autism yet, but proper intervention can improve very much the life conditions of persons with autism.**

**Persons with autism need a personal plan as soon as possible.**

**Early intervention can help them better to practice how to live independently, make choices and take decisions.**

**Proper intervention improves also the lives of adults and of persons with severe autism.**

### **Access to treatment**

In many countries, the availability of expertise in the field of autism within the healthcare services is widely insufficient to ensure early, adapted and life-long care to all the people in need.

Many persons with ASD do not have access to (re)habilitation programmes and facilities, on the grounds of their age or the severity of their impairments, and are deprived of the opportunity to develop their unique potential.

Nevertheless, although to date there is no cure for ASD, it is widely recognised that early intervention is crucial for fostering the development of social and communication skills. Adapted, individually-tailored intervention programmes should be designed and implemented as soon as possible in order to maximise the opportunities to develop functional skills, independence, and capacity of choice and self-determination.

However, the age of the person cannot be invoked as justification in denying proper intervention. Adapted, individualised and continuous care, as well as a range of sophisticated, individual responses and sufficient individualized attention, should be guaranteed for all people with ASD, regardless of the severity of their condition or age, in order that they may enjoy equal opportunities in every field and period of their lives, and achieve as high a degree as possible of independence, social inclusion and participation.

Moreover, much can be done at any age to prevent and/or improve the impact of the primary impairments of ASD on behavioural features, which often represents a major source of discrimination and exclusion for these persons. Individual (re)habilitation plans should continue at every age and be adapted to the needs and age of the person in terms of social, communication and functional skills in order to maintain and improve their abilities and quality of life to the highest possible degree.

## 1.2 Access to life-long education



**Education is a right, but for persons with autism it is more. It helps them to understand the world.**

**Education for persons with autism must start early. It must be adapted to their way of thinking and understanding.**

**Every child with autism should have an individual plan of education. The individual plan should fit the interests of the pupil and the wishes of his/her family.**

**Also adults must have education to learn new skills to get a job and to live independently.**

**Persons with severe autism must not be excluded from education.**

For people with ASD, education represents a lot more than a basic right. Education is necessary to compensate for the great difficulties that people with autism have in extracting meaning from simple experiences, something most other people are capable of without specific educational support. Equal opportunities to develop individual potential in every kind and level of education, regardless of the nature or severity of disability, should be ensured for pupils with ASD by means of research-sound educational strategies.

Children with ASD should be referred for free appropriate education from pre-school age. A specialized educational approach should engage the pupil in systematically planned, developmentally-appropriate educational activities, according to identified objectives on the basis of the child's best interest, motivation, strengths and needs, whilst also taking into account the priorities of the family.

According to the international legal framework on discrimination, the age of a disabled person is irrelevant in relation to the right to education. After compulsory education, adults with disabilities should have access to regular upper secondary school, when appropriate to their individual needs and abilities, or to special courses aimed at enhancing and maintaining acquired individual skills and knowledge in functional areas and providing vocational training. Adults with Autism Spectrum Disorders should be eligible for appropriate support in continuing education and vocational training in terms of specific educational strategies, adapted educational settings, specialized teachers, individualized attention and job coaching, regardless of their degree of severity or level of functioning.



Rafael Cabezón García

## 1.3 Social inclusion



**Persons with autism must not live hidden away or isolated from other people. They should have the rights to live with others. Education also should not be provided in isolated settings. Nevertheless, it should be adapted to their needs.**

**Persons with autism must get all the support they need to live with others. Inclusion does not mean that families have to give to their children all the support they need. This would lead to the exclusion of the family and their children with autism.**

As for all society, education and any other provision should be inclusive. Children should receive specialized education in inclusive settings in which ongoing interactions regularly occur with typically developing children. Inclusion in the mainstream of all persons with ASD, including leisure activities and employment, should be based on entitlement, not privilege, and should essentially ensure that appropriate learning or other positive experiences take place in an environment as inclusive as possible.

However, a policy of inclusion should never be used to deny support or access to education or treatment to any individual or to provide symbolic or token services that may give the illusion of provision whilst in reality denying opportunity. Moreover, it should not be forgotten that withdrawal of adequate support to a person with ASD puts disproportionate pressure on their families, who are expected to take upon themselves all the responsibilities and care for their relative with ASD, whilst seeing their moral and economic efforts totally thwarted. Leaving families alone to face all the complex needs of their relatives does not foster the inclusion of persons with ASD. On the contrary, it extends the exclusion and the isolation to all family members. A network of qualified, skilled support services is therefore crucial to ensure the social inclusion of persons with ASD and their families.

## 2. A PARTICIPATION-BASED APPROACH TO ASD



**Like other people, persons with autism must take part to all the decisions concerning them.**

**Parents must take part in the decisions concerning persons who are not able to decide themselves.**

**Parents should participate also in the diagnosis, assessment and treatment of their children, as parents know their children better than anyone else.**

**Many years ago, people thought that bad parents caused autism.**

**As a consequence, parents were not involved in the treatment of their children with autism.**

**Now we know that parents are not responsible for autism.**

**Doctors should tell that clearly to parents and avoid them to feel guilty.**



Rafael Cabezon Garcia

Like any other person, disabled people should be actively involved in any decision concerning their life, including the objectives of the intervention and any form of support, according to their desires and priorities. For persons with ASD who are not able to represent themselves or to express their consent, families should be involved in all decisions concerning their children, in their role as the best experts of their child's needs and behaviours.

All individuals with autism are unique in their way of being and in how they react and families should be recognized for the invaluable knowledge they possess of their relative. In their everyday encounters, parents are in a position to help other people overcome their preconceptions and fears, accept their own social responsibilities and explore the potential of viewing life from another perspective, the perspective of a person with autism. The views of families should therefore be taken into account during the diagnostic procedure, the evaluation process and the tailoring and implementation of the intervention programmes.

In the past, parents of persons with ASD were considered responsible for their autistic child's impairments because, it was claimed, they were unable to develop positive parental relationships. Nowadays, although the early belief the parental practices are responsible for autism has been definitively disproved, some professionals still blame parents and cultural prejudices on their culpability still exist among the public at large.

These prejudices generate much suffering and prevent parents from contributing to their child's development. As a consequence, it is unacceptable, on the basis of current knowledge, that parents be blamed or that silence reigns in relation to their blamelessness. This attitude only encourages those superseded assumptions that still survive in the collective consciousness of the uninitiated and in the prejudice of some professionals.

Parents should be explicitly relieved of any sense of guilt on the first suspicion of diagnosis so that their rehabilitation potential is fully recognized and adequately supported. Moreover, as ASD affect all family members, including brothers and sisters, the family should receive all and every form of support needed in order that they may themselves enjoy equal opportunities, full citizenship and effective participation in society.

### **3. A QUALITY BASED APPROACH TO ASD**



**Quality means that persons with autism must enjoy good intervention and good life.**

**A good intervention does not mean that treatment must cure autism. It means that it must improve the well-being and skills of persons with autism. Quality care improves the quality of life of persons with autism.**

**A big deal of support is not sufficient to ensure quality care. Quality care must also rely on reliable intervention.**

**Scientific knowledge gives information on reliable intervention for autism. Bad intervention can prevent persons with autism to learn skills and live independently.**

**Healthcare professionals need training programmes in autism to provide quality care and support.**

**Lack of training can lead to bad intervention or to use drugs instead of proper treatment.**

When speaking about quality-based approaches, we have to consider two different aspects of quality: the quality of life of the person as the primary goal of the intervention and the quality of the intervention itself as a means of ensuring best possible outcomes in terms of the highest degree of independence and self-determination.

According to the “medical” approach to disability, a cure for impairments is the main goal of intervention. As a consequence, adequate intervention was often denied to persons with ASD because of the high cost of provision in the face of their impossibility of being cured. Quality of life, free choice and dignity were not considered to be sufficient reasons for ensuring the expensive support and services needed to implement adequate, ongoing treatment programmes. On the contrary, according to the “social” approach to disability, the first goal of care should focus on the achievement of a better quality of life. Any human being, regardless of the nature or severity of their impairments, can improve their living conditions and achieve some extent of social participation with adequate support.

Intensity of intervention is not sufficient to ensure equal opportunities for persons with ASD. Intervention should also meet quality criteria in terms of research-sound, evidence-based approaches. The scientific reliability of the intervention is not an extraneous or a secondary factor in combating discrimination and in fostering the social inclusion and participation of persons with ASD. Bad practices that are based on misconceptions of autism or on unproven theories and dubious efficacy can lead to serious problems in the well-being or physical health of persons with ASD and have irreparable consequences on the development of the person and their ability to achieve independence, social inclusion and a dignified life at an adult age.

Reliable training programmes in the field of ASD based on correct, early diagnosis, appropriate treatment and the rights of persons with disabilities should therefore be available for specialized healthcare professionals in order to ensure quality intervention. A lack of trained staff can lead not only to inadequate intervention but also to improper or inappropriate use of pharmaceutical drugs and to pharmacological abuse, often without the informed consent of parents or against their will.



**Parents also can need training to deal with their children's difficulties and to improve the family life.**

**Parent training should help parents to better understand and meet the needs of their child.**

**Families and professionals can work together and share their knowledge during training programmes.**

**Professionals should provide parents with support and information on rights of the child and available services.**

Not only professionals but also families may need greater understanding of the rights and specific needs of their children with ASD. All parents are concerned with bringing up their children but this task is much more difficult when parents have a son or daughter with an ASD and the information and tools to understand and act, and "special" help is not forthcoming. Individually tailored training programmes should also be available for families in order to maximise their "rehabilitation potential" and improve the quality of life of all the family including the quality of life and participation in family life of their child with ASD.

Training should not be just a simple list of procedures but guidance in the evaluation of situations and identification of the best solution to tackle them, help parents understand their child in all his/her manifestations and teach them how to help him/her by demonstrating how to behave with the child and how to put into practice the procedures which will be carried out by the staff of the school or centre the child attends. In any event, a minimum of training should be guaranteed to each family.

Training programmes can constitute an excellent basis for collaboration between professionals and parents, help to remove the question of parental 'inadequacy' and concentrate attention on the most appropriate ways to interact with the child both at an adequate therapeutic level and a more fulfilling psychological level. The sharing of knowledge and 'made-to-measure' training in each individual case are the most valuable elements in creating a relationship of trust between parents and professionals. Moreover, professionals working in the field of ASD should also be able to provide parents with more practical support in relation to their rights, to the services they should be guaranteed and how to obtain and achieve the integrated care without which the child would have little opportunity to develop.

## B - THE VIEW OF THE SCIENTIFIC COMMUNITY ON THE CARE OF AUTISM AND PERVERSIVE DEVELOPMENTAL DISORDERS



**Autism is a serious disorder. 1 person every 150 have autism or a similar disorder. It can be seen in very young children everywhere in the world, and lasts through the life span.**

**It creates big difficulties in relationships with others, in speaking, understanding and thinking.**

**Children with autism show strange behaviours and interests.**

**The most have learning difficulties, many are mute.**

**Scientific studies help to understand and treat autism.**

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 150. 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 behavioural 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 behavioural and emotional symptoms including over-activity, stereotypy, repetitive and restricted range of activities, anxiety, and self-injurious behaviour.

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 behavioural 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.





**More studies are needed to improve the diagnosis of autism.**

**The scientists think that the difficulty in relating with others is the core problem of autism.**

**We do not know the cause of autism. Studies have shown problems in understanding information.**

**Genes have also a crucial role in causing autism.**

**Intervention should start as soon as possible. It should be performed by skilled professionals and parents working together. It should be adapted to the age of the person with autism.**

**Treatment should address:**

- Behaviour**
- Skills to relate and communicate with others**
- support and training for families**
- leisure activities**
- practice in life-skills**
- training to get a job**
- going to school**
- psychiatric help for anxiety**
- medicines if needed.**

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 used 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 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;
- psychotherapy for promoting social and emotional competence and help cope with anxieties and other troubles;
- medication for specific areas of symptomatology, as needed.



**Treatment should help persons with autism to live in the community.**

**Services must give each person with autism the possibility to choose what is best for them.**

**Treatments for autism and their outcomes will be improved by further scientific studies on the brain, its functioning, medicines and genes.**

**Many different specialists must work together to study and treat autism. They should work as a team with persons with autism and their families.**

**Centres with special expertise in autism and service organisation and management are 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 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 centres of excellence in autism and PDD to engage in:

- systematic, multidisciplinary research;
- training specialists;
- disseminating information; and
- evaluating, treating and supporting individual children, adolescents and adults, and their families .



## IACAPAP recommends:

- 1. Medical centres with expertise in the diagnosis and assessment of young children with autism,**
- 2. Starting treatment as early as possible, and going on through the life span,**
- 3. Choice of the best treatment for each person with autism,**
- 4. Collaboration between professional and parents to draw personal planning based on individual needs and wishes,**
- 5. Treatment, education and care based on valid scientific studies,**
- 6. Training for professionals,**
- 7. Respect for the person with autism.**

**IACAPAP says that treatment and education of persons with autism are very important and must be provided.**

## 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 continue 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.
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, neuroimaging, neurochemistry, neuropharmacological 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.

## C - THE ADDED VALUE OF THE EUROPEAN UNION IN THE FIELD OF CARE FOR ASD



**Autism is an important issue for Europe. Countries of the European Union need to work together on autism.**

**Countries of European Union can put together what they know on and what should be done for autism. This collaboration will improve the understanding and treatment of autism.**

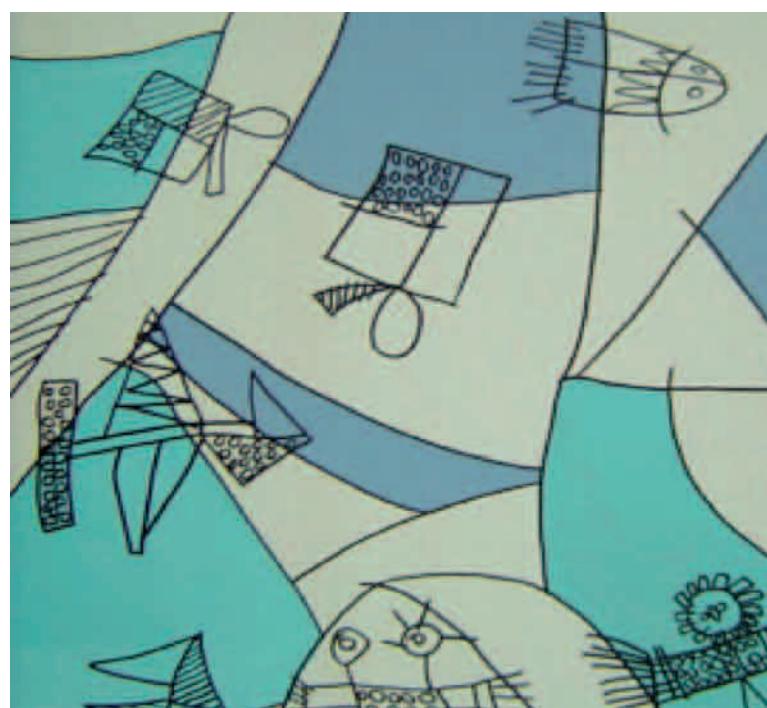
**International associations can help to put in place this collaboration and to improve the condition of persons with autism across Europe.**

Autism represents one of the priorities for Child Psychiatry in Europe today. There is an urgent need for sharing knowledge and best practices between countries in Europe and for integrating the different cultural backgrounds.

International collaboration 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<sup>3</sup>. Europe represents a richness and a resource in the field of the treatment of ASD. Each country has its own peculiarities, represented in clinical practice and by national cultures.

International associations, such as Autism-Europe, the European Society for Child and Adolescent Psychiatry and the European Academy of Child and Adolescent Psychiatry, have an important role in acting as a bridge between countries in Europe and as a starting point for a new approach to research into and treatment of ASDs. These perspectives focus on the right to treatment, with attention to the family. International policies and research (multicenter studies, international research seminars) help to reach this goal.

The challenge is to bridge the multiple dimensions surrounding the child with ASD and his/her family with the aim to integrate research, clinical practice and different professions and services – also taking into account policies and legislation initiated by the European institutions.



3- From the Venice Declaration, IACAPAP, 1998.



**Scientific research on autism can improve our knowledge in many other fields.**

**Scientific studies can improve diagnosis, treatment, education and care for persons with ASD.**

**Studies should also help to understand the difficulties of families of persons with ASD.**

**There is not enough research on autism at the moment. Persons with autism and their families need research to improve their lives, as they are vulnerable persons.**

**Research must be serious and respect the persons which are involved in studies.**

**Children and adults with ASD should only take part in research if they want to. To decide to take part in a study, they must be informed on what the research is about and how it will be performed.**

**The Council of Europe says that persons with autism must be involved in studies only if they have a benefit.**

Research on autism and associated disorders will help to develop concepts, research methodologies, and treatment approaches that can be used in relation to other, early onset and emergent developmental, psychiatric, and serious emotional disorders<sup>4</sup>.

Scientific research is much needed in the fields of neurobiology, as well as in psychological functioning and cognitive processes which are specifically impaired in autism, in order to develop new reliable instruments for early detection, diagnosis and individual assessment, more adapted education strategies and more efficient and effective intervention. Because of the severity and complexity of the disability resulting from ASD and the intensity of care needed, controlled studies are also essential in order to identify, spread awareness and support the implementation of effective comprehensive care models. Moreover, studies should be performed on the human, social and financial costs of the impact of ASD on families, especially when they are alone in meeting their children's needs.

Biomedical research should reach citizens with Autism Spectrum Disorders (ASD) since they are currently underrepresented or absent in the research efforts made in most countries. Newer and more effective ways of counteracting the negative consequences of these disorders on the quality of life of persons with ASD are needed. Discovering better ways of treating and perhaps preventing these disorders should be made a health priority. But the substantial needs of this group of citizens do not imply that all research proposals should be carried out. Research programs need to be carefully assessed. Most people with ASD fall into the category of vulnerable persons, those for whom fair informed consent is a challenge – as happens with minors, older citizens with disabilities or people with restricted freedom of choice. Ethical committees must assure, with special care in these cases, that the potential benefit is much greater than the risk involved and that a fair due process has taken place.

The Council of Europe has established that it is essential that research conducted with vulnerable subjects is guided by the likelihood of direct benefit for the individual person<sup>5</sup>. In exceptional cases, significant improvement in the scientific understanding of an individual's condition, disease, or disorder, justifies research that has the aim of conferring benefit to the person concerned or to other people in the same age category or having the same condition. It is widely accepted that when a vulnerable person is an adult, he or she should participate in the consent procedure in the best possible way.

4- From the Venice Declaration, IACAPAP, 1998.

5- Council of Europe, Additional protocol to the convention on human rights and biomedicine concerning biomedical research, Article 15.2. ETS N° 195 - Strasbourg: Council of Europe; 2005.



**Children also should be asked their opinion, and their opinion should be taken in account.**

**Images, sign language and other communication tools should be used to support the decisions of persons with autism. These tools should be used depending on their individual communication skills.**

**Their reactions during the studies should also be observed and taken in account.**

**Autism-Europe affirms that persons with autism should be involved only in serious research.**

**Special groups of experts (Ethical Committees) should evaluate and approve any project of research before involving persons with autism.**

**Ethical Committees should also ask the opinion of the associations of persons with autism and their parents. Experts, professional and parents together could get more funds for the research on autism.**

The positive opinion of minors (defined as "assent") should be taken into account, always considering their age and maturity. Visual aids, augmented communication systems, "easy reading texts" and systematic observation of their reactions by legally authorized representatives are of paramount importance in this population.

**Autism-Europe supports the application of the following seven ethical requirements for clinical research in ASD as defined by Chen and col<sup>6</sup>:**

1. social or scientific value
2. scientific validity
3. fair subject selection
4. favourable risk-benefit ratio
5. independent review
6. informed consent
7. respect for potential and enrolled research participants.

These requirements do not apply only to clinical trials of new medications but also to complex neuroscience studies, ASD screening procedures in the general population, and genetic testing.

In conclusion, research in this field is necessary and parent associations should encourage participation in scientifically solid projects, but only on the condition that they have been approved by appropriate bioethical committees.

To ensure adequate consideration of the characteristics and needs of persons with autism, the contribution of field experts and representatives from ASD associations should be sought by Ethical Committees reviewing research projects with these subjects.

Moreover, joint lobbying by experts, professional and parent associations in national and European agencies should facilitate the allocation of appropriate resources for research in ASD.

6- Chen DT, Miller FG, Rosenstein DL. Ethical aspects of research in the etiology of autism (review). *Ment Retard Dev. Disabil Res Rev* 2003;9(1):48-53.

# ANNEX 1

## THE CORE INTERNATIONAL HUMAN RIGHTS INSTRUMENTS

UNITED NATIONS

GA res. No.	Title	Adopted /Open to sign.	Entry into force
217 A (III)	Universal Declaration of Human Rights	10/12/1948	
2200A (XXI)	International Covenant on Economic, Social and Cultural Rights	16/12/1966	3/1/1976
2200A (XXI)	International Covenant on Civil and Political Rights	16/12/1966	23/3/1976
2200A (XXI)	Optional Protocol to the International Covenant on Civil and Political Rights	16/12/1966	23/3/1976
2856 (XVI)	Declaration on the Rights of Mentally Retarded Persons	20/12/1971	
3447 (XXX)	Declaration on the Rights of Disabled Persons	9/12/1975	
34/180	Convention on the Elimination of All Forms of Discrimination against Women	18/12/1979	3/9/1981
39/46	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	10/12/1984	26/6/1987
44/25	Convention on the Rights of the Child	20/11/1989	2/9/1990
46/119	Principles for the protection of persons with mental illness and the improvement of mental health care	17/12/1991	
48/96	Standard Rules on the Equalization of Opportunities for Persons with Disabilities	20/12/1993	
A/54/4	Optional Protocol to the Convention on the Elimination of Discrimination against Women	10/12/1999	22/12/2000
A/54/263	Optional protocol to the Convention on the Rights of the Child on the involvement of children in armed conflict	25/5/2000	12/2/2002
A/57/199	Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	18/12/2002	4/2/2003
A/61/611	Convention on the Rights of Persons with Disabilities and Optional Protocol	Adopted by UN GA on 13/12/06	3/5/2008

COUNCIL OF EUROPE

No.	Title	Open to signature	Entry into force
005	Convention for the Protection of Human Rights and Fundamental Freedoms	4/11/1950	3/9/1953
009	Protocol to the Convention for the Protection of Human Rights and Fundamental Freedoms	20/3/1952	18/5/1954
035	European Social Charter	18/10/1961	26/2/1965
044	Protocol No. 2 to the Convention for the Protection of Human Rights and Fundamental Freedoms, conferring upon the European Court of Human Rights competence to give advisory opinions	6/5/1963	21/9/1970
045	Protocol No. 3 to the Convention for the Protection of Human Rights and Fundamental Freedoms, amending Articles 29, 30 and 34 of the Convention	6/5/1963	21/9/1970
046	Protocol No. 4 to the Convention for the Protection of Human Rights and Fundamental Freedoms, securing certain rights and freedoms other than those already included in the Convention and in the first Protocol thereto	16/9/1963	2/5/1968
055	Protocol No. 5 to the Convention for the Protection of Human Rights and Fundamental Freedoms, amending Articles 22 and 40 of the Convention	20/1/1966	20/12/1971
114	Protocol No. 6 to the Convention for the Protection of Human Rights and Fundamental Freedoms concerning the Abolition of the Death Penalty	28/4/1983	1/3/1985
117	Protocol No. 7 to the Convention for the Protection of Human Rights and Fundamental Freedoms	22/11/1984	1/11/1988
118	Protocol No. 8 to the Convention for the Protection of Human Rights and Fundamental Freedoms	19/3/1985	1/1/1990
126	European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment	26/11/1987	1/2/1989
128	Additional Protocol to the European Social Charter	5/5/1988	4/9/1992
140	Protocol No. 9 to the Convention for the Protection of Human Rights and Fundamental Freedoms	6/11/1990	1/10/1994
142	Protocol amending the European Social Charter	21/10/1991	
146	Protocol No. 10 to the Convention for the Protection of Human Rights and Fundamental Freedoms	25/3/1992	
151	Protocol No. 1 to the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment	4/11/1993	1/3/2002
152	Protocol No. 2 to the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment	4/11/1993	1/3/2002
155	Protocol No. 11 to the Convention for the Protection of Human Rights and Fundamental Freedoms, restructuring the control machinery established thereby	11/5/1994	1/11/1998
158	Additional Protocol to the European Social Charter Providing for a System of Collective Complaints	9/11/1995	1/7/1998
160	European Convention on the Exercise of Children's Rights	25/1/1996	1/7/2000
161	European Agreement relating to persons participating in proceedings of the European Court of Human Rights	5/3/1996	1/1/1999
163	European Social Charter (revised)	3/5/1996	1/7/1999
164	Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine	4/4/1997	1/12/1999
168	Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, on the Prohibition of Cloning Human Beings	12/1/1998	1/3/2001
177	Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms	4/11/2000	1/4/2005
186	Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin	24/1/2002	1/5/2006
187	Protocol No. 13 to the Convention for the Protection of Human Rights and Fundamental Freedoms, concerning the abolition of the death penalty in all circumstances	3/5/2002	1/7/2003
194	Protocol No. 14 to the Convention for the Protection of Human Rights and Fundamental Freedoms, amending the control system of the Convention	13/5/2004	
195	Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research	25/1/2005	



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European Society for Child and Adolescent Psychiatry  
(ESCAP)  
<http://www.escap-net.org>