



With the support of the European Commission, DG EMPL.

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Autism and Health

A POSITION PAPER ON THE DISCRIMINATION OF PERSONS SUFFERING FROM AUTISM OR OTHER COMPLEX DEPENDENCY NEEDS DISABILITY IN THE FIELD OF HEALTHCARE

Autism is a complex lifelong disability, identifiable in very early childhood, which is due to multiple medical causes interfering with the normal development and functioning of the brain¹. Although the exact mechanisms involved in this neurological dysfunction are not yet clear, autism profoundly affects the way a person communicates and interacts with his or her environment and requires life-long care, adapted to each person's specific needs.

In spite of the available good models of service delivery, very few persons affected by autism actually have access to the scientific, medical, educational and social progress made in reference to this condition in recent decades. This deprivation generates much suffering and additional handicaps, and constitutes a form of discrimination.

Though there is to date no cure for autism, persons with autism can really improve if a multidisciplinary life-long care is provided, including early diagnosis and assessment followed by personalised, specific treatment. The best-studied therapies include educational/behavioural and medical intervention. While reducing the severity and frequency of disruptive behaviours, individualised educational programmes (IEP) based on individualised assessments can significantly enhance the capacity to learn, communicate and relate to others and are to date the only means of re-education for people with autism supported by the international scientific community. Medications cannot cure autism, but prescribing appropriate medication can enhance attention, reduce troublesome symptoms and, thus, facilitate the access to other forms of intervention. As a consequence, medications should never be prescribed instead of a re-habilitation programme but only in the best interests of the person, within a comprehensive individualised programme of intervention, and, if possible, for a limited period of time.

Many other forms of intervention are available but few, if any, scientific studies support their use.

The lack of early, adapted, individualised and continuous care, as well as inadequate intervention, based on misconceptions of autism (such as treatments aimed at improving parental relationships or at "braking the autistic shell", e.g. Psychoanalytic Therapy), or on unproven theories and efficacy (e.g. Facilitated Communication, or Auditory Integration Training, just to quote two), 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.

In the light of:

- the right to *accessible, effective, health care facilities for the entire population*, established in the European Social Charter,
- the UN Declaration on the Rights of Disabled Persons, Proclaimed by General Assembly resolution 3447 of 9 December 1975, stating that

¹ See the Awareness Document on Autism, Autism Europe, EYPD 2003, the Description of Autism, Autism Europe, 2000, and the International Classification of Diseases and Disorders, ICD 10, World Health Organisation

" Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthetic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration",

- and the UN Declaration on the Rights of Mentally Retarded Persons , proclaimed by General Assembly resolution 2856 (XXVI) of 20 December 1971, stating that :
" The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential",

Autism-Europe believes that the needs of persons with autism in the field of health care are not sufficiently taken into account, and human rights violations against people with autism take place daily in this field across EU countries.

The discrimination that they suffer from in terms of accessing health care calls for active measures that will enable them to achieve the maximum of their unique potential, independence, and capacity for informed choice and self-advocacy by providing:

- Access to appropriate, early, multi-disciplinary diagnosis and assessment, *in accordance with internationally accepted medical standards*²,
- Access to appropriate, early, multi-disciplinary and continuous treatment, including social rehabilitation, *in accordance with internationally accepted medical standards*,
- Access to the ordinary health services that do exist³ and receive the care that is appropriate to his or her health needs⁴, in accordance with the same standards afforded to other ill persons

Autism-Europe particularly recommends the development of the following measures:

- Put in place quality care services for people with autism, as well as for all dependent persons
- Improve the existing indicators on specific health care services in order to be able to measure the proportion of children with autism or a complex dependency needs disability benefiting from adequate re-education programmes
- Reinforce the initial and continuous training of health professionals on the internationally accepted diagnostic systems and evidence based treatments,
- Integrate the specific behavioural and communication features and needs of persons with autism or a complex dependency needs disability into the standard education systems by means of the continuous training of health professionals at all levels and not only as part of specialised training,
- Strengthen and adapt general healthcare services to the needs of persons with autism or a complex dependency needs disability, by providing specific support and facilities,
- In co-operation with parents associations, design and create international consensus documents for a medical care guide specific to autism, comprising protocols for the diagnostic process and medication as well as guide-lines for rehabilitative intervention,
- Systematically inform families on the health condition of their child and on the existing legislation and provisions that entitle them to ensure the best care for their children,

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.

³ Accessibility problems often encountered by people with autism include noisy waiting rooms, aggressive medical tests

⁴ Epilepsy, neurological problems, stomach and teeth-related problems, gynaecology, etc.

- Systematically disseminate reliable information on state-of-the-art medical standards in relation to autism and other complex dependency needs disabilities.

DISCRIMINATION IN THE HEALTH CARE OF PERSONS SUFFERING FROM AUTISM OR OTHER COMPLEX DEPENDENCY NEEDS DISABILITY

**ANNEX
INVESTIGATION INTO DISCRIMINATION IN THE FIELD OF THE PUBLIC HEALTH CARE SYSTEM OF PERSONS WITH AUTISM OR OTHER COMPLEX DEPENDENCY NEEDS DISABILITY**

In 2002, Autism Europe launched a survey amongst its members, in co-operation with the COFACEH Europe, the French National Council for Europe, and any 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 health care. 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 scientific⁵. 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 health service 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 amount (61%) receive medications. In this group, only 15% enjoy a regular follow-up of the effects of the medication, whilst in 16.9% the service/doctor that prescribed the medication does not provide any follow-up at all. Moreover, the health care service does 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 health care 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 health care.

D - Finally, concerning access to general health 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 health services lack competence in the special needs of their

⁵ The percentages indicated represent only the responses received in the sample. It cannot be extrapolated to the total population of the persons concerned.

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%).