



Introduction

Autism Europe's Position Papers are published under the European Commission's non-discrimination programme "For Diversity. Against Discrimination" whose goal is to combat discrimination on the grounds of racial or ethnic origin, religion or belief, age, disability and sexual orientation.

Autism Europe's Position papers are drawn up on the basis of factual knowledge, informed opinion and the personal testimony of people with autism and their families. They address important areas of concern, represent an overview of the current situation within the field of autism and are underpinned by the most recent research developments and the universal declarations and charters of human rights and non-discrimination.

Moreover, the strategies and recommendations outlined in these position papers are essential since they act as a bridge between people with autism and their families and policy makers at all institutional levels, as well as raising awareness of autism among the general public.

As a qualified voice for autism, Autism Europe position papers play their part in the elaboration of Codes of Good Practice, and, together with these, in directing international and national legislations towards taking into account the needs of people with autism and their families, and consequently towards improving their well-being and quality of life.

The Position Papers published here have been approved by the Council of Administration of Autism Europe after consultation with every national member. Autism Europe wishes to take this opportunity to thank their members for their commitment, valuable knowledge and collaboration, without which these Position Papers could not have been realised.

TABLE OF CONTENTS

Autism and Inclusion	1
Autism and Health	3
Autism and Education	7
Autism and Employment	14
Autism and Ageing	18

This publication presents the views of Autism Europe and does not necessarily reflect the position or opinion of the European Commission. The European Commission and Autism Europe are not liable for any use that may be made of the information contained in this publication.

Brussels 2006.

Autism and Inclusion

Autism Europe adopts the Position on Inclusion held by the National Autistic Society

BACKGROUND

The term inclusion is used to describe an entitlement to education and support for all individuals with a disability within the mainstream of provision. It is a major plank of government policy at European level.

Inclusion differs from 'mainstreaming' or 'integration' in that the latter terms describe participation of disabled individuals when it is able to be demonstrated that they are able to benefit and that the mainstream setting will not be adversely affected by their presence within it.

Advocates of inclusion argue that segregation, either by disability, diagnosis or other factor or that having to 'earn' the right to be included is not in the interests of the child or adult. Over the past two decades, the impact of ideas; primarily from the USA and from Scandinavia around 'normalisation' have emphasised the importance of promoting valued social roles for those at risk of devaluation by reason of disability or other factors.

The development of policy around these ideas has largely reflected ideology rather than individual need. Segregation in large institutions has largely ceased and there has largely been an opening of the way for greater community presence and participation. There are however concerns that some individuals and their families have been seriously disadvantaged as a result of poorly resourced alternatives or the dilution of specialised expertise. In short, services have been based more on dogma than the needs of the disabled person.

Autism-Europe has been involved with advocacy on behalf of children and adults with autism and their families since 1985. It promotes good practice in the fields of education and educational approaches, in medical treatment and provision for the residential, support and vocational needs of adults.

Autism-Europe strongly advocates experiences for individuals with autism which will maximise their opportunities as citizens regardless of the nature and degree of their disability. These include an entitlement to education, support and freedom from abuse or exploitation. Autism-Europe believes that each individual with autism should receive such services and support within the mainstream of public provision unless this conflicts with their individual needs and requirements.

THE POSITION OF AUTISM-EUROPE

Autism-Europe believes that the cornerstone of effective provision is individualisation to ensure that each person receives appropriate education and support in order to achieve and sustain successful functioning as independently as possible and to exercise choice.

Autism and Health

Inclusion in the mainstream should be based on entitlement, not privilege and reflect the best interests and individual need of each person. Reasonable adjustments should be expected within educational or other facilities to provide better access and sustainable participation and benefit. The Policy of Inclusion should never be used to deny any service to any individual or to provide symbolic or token services which may give the illusion of provision whilst in reality denying opportunity.

The policy of inclusion must essentially ensure that appropriate learning or other positive experiences take place. It is not simply about 'where' an individual is educated or receives services or support; it is about its quality and relevance.

Autism-Europe emphasises the importance of skilled diagnosis and ongoing specialised assessment and a partnership between parents and professionals in order to determine appropriate educational or other programmes. Autism-Europe advocates that all such programmes be supported by professionals or other persons with acknowledged expertise in autism who can provide all of the necessary practical guidance and assistance, and who can evaluate the effects of such provision.

The policy of inclusion does not replace the need for sensitive, individual planning. This is particularly so in the case of complex individuals whose needs are especially difficult to accommodate in mainstream settings or who find such settings distressing.

Autism is a spectrum condition requiring a range of individual sophisticated responses. It is hoped that increasingly these will occur within the mainstream of provision, for all or most of the time. There are however those individuals whose lifelong interests are best served by appropriately specialised services that provide the most appropriate and meaningful education and support.

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

"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,
- 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.

Autism and Education

EDUCATION FOR PERSONS WITH AUTISM SPECTRUM DISORDERS (ASD)

a) LEGISLATION

- a) 1. Rules and regulations should ensure equal enrolment and access for all to the education systems, regardless of the nature or severity of disability and prevent the school system and/or schools from having the legal freedom to refuse education to persons with ASD on the basis of the nature or severity of their disability (because they are “uneducable”) or of a lack of resources (because the school is not equipped to deal with their educational needs).
- a) 2. Rules and regulations should ensure equal opportunities to develop individual potential in every kind and level of education, regardless of the nature or severity of disability, by means of research-sound educational strategies and individually tailored educational programmes.
- a) 3. Rules and regulations should promote a user - centred educational approach, by means of Individual Education Plans (IEP) that are functional in order to achieve personal independence and dignity and social responsibility, according to individual needs, motivations and potentials.
- a) 4. Rules and regulations should define minimum standards in terms of the qualifications of the teachers for the staff enrolled in educational settings for children with ASD.
- a) 5. Rules and regulations should ensure access to life-long education for persons with ASD, from pre-school facilities to upper grade education and/or adapted facilities for adults, providing vocational training, as well as training for the maintaining and improvement of acquired communication, social and personal skills.

b) PUBLIC POLICIES

- b) 1. States should ensure resources and training centres with expertise in autistic spectrum disorders to provide training and technical support to schools.
- b) 2. States should provide a mechanism to evaluate the adequacy of support systems to schools in terms of training of personnel and technical assistance.
- b) 3. States should fund or support local facilities to provide upper and continuous education and vocational training for adults with ASD, after compulsory education.
- b) 4. States should monitor coordination among and transitions between the different levels of education for all ages, from pre-school educational services to upper grade schools and educational/vocational training facilities for adults

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 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%).

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

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.

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

- b) 5. States should provide training programmes for personnel with minimum standards of qualification in educational settings for persons with ASD. For example, at a minimum, teachers should have access to some special training (e.g. pre-service course work, equivalent in-service training, workshops), and to supervised practice in research-based practices in ASD. States should also provide continuous training and additional consultation by well-qualified, experienced support trainers.
- b) 6. States should develop a systematic strategy to fund the educational interventions that are necessary for persons with ASD in schools. Families should not be expected to fund or provide the majority of educational programming for their children.
- b) 7. Since levels of information about ASD vary greatly within the groups and agencies that make funding and policy decisions, it is crucial that persons knowledgeable in the range of needs and interventions associated with ASD be included in all decision-making activities.

c) IMPLEMENTATION

c) (i) DIAGNOSIS AND ASSESSMENT

- c) (i) 1. Because of their unique social difficulties, children with any ASD (autistic disorder, Asperger's disorder, atypical autism, PDD-NOS, childhood disintegrative disorder), regardless of their level of severity or functioning, should be eligible for special support in education.
- c) (i) 2. Autistic disorder, Asperger's disorder, atypical autism, PDD-NOS, childhood disintegrative disorder should be identified and classed by means of appropriate, reliable instruments following the International Classifications within the category of *autistic spectrum disorders (ASD)*, as opposed to other terminology used by school systems, such as social emotionally maladjusted, significantly developmentally delayed, etc.
- c) (i) 3. Identification of ASD should include a formal multidisciplinary evaluation of social behaviour, language and nonverbal communication, adaptive behaviour, motor skills, atypical behaviours, and cognitive status by means of appropriate reliable instruments, carried out by a team of professionals experienced with ASD. An essential part of this evaluation is the systematic gathering of information from parents on their observations and concerns. In order to carry out such an assessment, the local health services should collaborate with the education system.

c) (ii) TRAINING OF PERSONNEL

National Education Authorities should institute an agenda for upgrading the training of personnel who work with, and are responsible for, the education of children with autistic spectrum disorders, in collaboration with the already established infra-

structure of special needs education (Universities, reliable training centres, other relevant agencies).

- c) (ii) 1. The States should establish a plan to provide priority funds for pre-service and in-service training of teachers, paraprofessionals, and other personnel providing educational programmes for persons with autistic spectrum disorders, including children under 3 years of age and adults.
- c) (ii) 2. The need for a comprehensive approach involving many professions should be addressed during personnel training and practical work within multidisciplinary organizations and teams.
- c) (ii) 3. A special emphasis should be placed on the training of trainers and special attention should be paid to rapidly increase the capabilities of the trainers in the special skills and practices for children with autistic spectrum disorders.
- c) (ii) 4. The existing support systems that provide training to teachers should include people with special expertise in autistic spectrum disorders on their staff.
- c) (ii) 5. The content of the curriculum for children with autistic spectrum disorders should be based on sound research.

c) (iii) EDUCATIONAL GOALS

The IEP should be the vehicle for planning and implementing educational objectives.

- c) (iii) 1. Appropriate educational objectives for children with autistic spectrum disorders should be observable, measurable behaviours and skills, functional for self-independence and social responsibility. These objectives should be able to be accomplished within 1 year and expected to affect a child's participation in education, the community, and family life. They should include the development of:
 - a. Social skills to enhance participation in family, school, and community activities (e.g., imitation, social initiations and response to adults and peers, parallel and interactive play with peers and siblings);
 - b. Expressive verbal language, receptive language, and nonverbal communication skills;
 - c. A functional communication system;
 - d. Increased engagement and flexibility in developmentally appropriate tasks and play, including the ability to attend to the environment and respond to appropriate motivational requests;
 - e. Fine and gross motor skills used for age-appropriate functional activities, as needed;
 - f. Cognitive skills, including symbolic play and basic concepts, as well as academic skills;

- g. Replacement of problem behaviours with more conventional and appropriate behaviours; and
- h. Independent organizational skills and other behaviours that underlie success in regular education classrooms (e.g. completing a task independently, following instructions in a group, asking for help).

- c) (iii) 2. Ongoing measurement of educational objectives must be documented in order to determine whether a child is benefiting from his individual educational plan. Every child's response to the educational programme should be assessed after a short period of time. Progress should be monitored frequently and objectives adjusted accordingly.

c) (iv) EFFECTIVE EDUCATION

Recommendations for effective education are made on the basis of empirical findings from representative programmes and findings in general education and developmental literature

- c) (iv) 1. Skilled diagnosis and ongoing specialised assessment should be implemented in partnership with parents and health professionals in order to determine appropriate educational programmes
- c) (iv) 2. Specialized educational support based on a set of individualized objectives and plans should begin as soon as a child is suspected of having an autistic spectrum disorder. Taking into account the needs of an individual child and its family, the child's schedule and educational environment, both in and out of the classroom, should be adapted as needed in order to implement the IEP. Specialized educational support should be provided up to 25 hours a week, 12 months per year, especially when considering young children with ASD and/or students with complex educational needs, during which time the child is engaged in systematically planned, developmentally appropriate educational activity aimed towards identified objectives. Wherever the educational activity takes place (in ordinary school or specialized educational facilities), the content of the activity should be determined on the basis of the child's best interest, motivation, strengths and needs, depending on the characteristics of both the child and the family.
- c) (iv) 3. A child must receive sufficient individualized attention on a daily basis so that individual objectives can be effectively implemented; individualized attention should include individual teaching, small group instruction with peers, and direct one-to-one contact with teaching staff.
- c) (iv) 4. Assessment of a child's progress in meeting objectives should be used on an ongoing basis to further refine the IEP. A lack of objective documentary evidence of progress over a 3-month period should be taken to indicate a need to increase intensity by lowering student/teacher ratios, increasing programming time, reformulating curricula, or providing school staff with additional training and consultation.

- c) (iv) 5. To the extent that this leads to the specified educational goals (e.g. peer interaction skills, independent participation in regular education), children should receive specialized education in inclusive settings in which ongoing interactions regularly occur with typically developing children.

c) (v) AREAS OF EDUCATION

Six areas of education should have priority:

- c) (v) 1. Functional, spontaneous communication should be the primary focus of education. For very young children, programming should be based on the assumption that most children can learn to speak. Effective teaching techniques for both verbal language and alternative modes of functional communication, drawn from the empirical and theoretical literature, should be vigorously applied across settings.
- c) (v) 2. Social education should be delivered throughout the day in various settings, using specific activities and support planned to meet age-appropriate, individualized social goals (e.g., cooperative activities with peers, social routines, flexibility in applying social rules, ...).
- c) (v) 3. The teaching of play skills should focus on play with peers, with additional learning in the appropriate use of toys and other materials.
- c) (v) 4. Other education aimed at goals for cognitive development should also be carried out in the context in which the skills are expected to be used, with generalization and maintenance in natural contexts being as important as the acquisition of new skills.
- c) (v) 5. Specialized strategies that address problem behaviours should incorporate:
 - information about the contexts in which the behaviours occur;
 - positive, proactive approaches; and
 - a range of techniques that have empirical support (e.g. functional assessment, functional communication training, reinforcement of alternative behaviours).
- c) (v) 6. Functional academic skills should be taught when appropriate to the ability and needs of a child.

c) (vi) ROLE OF FAMILIES

Families are co-educators of the child and should be actively involved in and help to shape educational planning and the educational process. Specifically:

- c) (vi) 1. In order for a family to be effective members of the Individualized Education Plan (IEP) team, the school should take into account the family's knowledge and awareness of their child, their concerns and perspectives as part of the assessment process and IEP programming.

- c) (vi) 2. The school should provide each family with:
 - the written results of their child's assessment on which the IEP will be based,
 - a contact person to explain the findings and discuss their concerns
 - the opportunity to participate in the IEP meeting to voice their questions, concerns, and perspectives about their child's development and educational programming
- c) (vi) 3. The IEP should be approved by the parents/legal representative of the child and the school should provide the opportunity to discuss their child's progress and changes to the IEP at regular intervals (see point c) (iv) 4).
- c) (vi) 4. The local education authority/local school should provide the parents with written information concerning the best practices in education for autistic spectrum disorders, sources of support (e.g. a support guide and bibliography), and their child's rights, as well as information and training that enables them to continue the educational process outside the school (at home, in the community...).

c) (vii) INCLUSION

Like all society, education systems should be inclusive. Whilst Autism is a spectrum condition requiring a range of sophisticated individual responses, it is hoped that increasingly these responses will occur within the mainstream of provision, for all or most of the time, under the following conditions:

- c) (vii) 1. Inclusion in the mainstream should be based on entitlement, not privilege, and reflect the best interests and individual need of each person.
- c) (vii) 2. Appropriate adjustments should be expected within educational facilities to provide better access and sustainable participation and benefit for persons with ASD.
- c) (vii) 3. The Policy of Inclusion should never be used to deny any support or access to education to any individual or to provide symbolic or token services which may give the illusion of provision whilst in reality denying opportunity.
- c) (vii) 4. The policy of Inclusion should essentially ensure that appropriate learning or other positive experiences take place in an environment as inclusive as possible. It is not simply about 'where' an individual is educated or receives services or support: it is about its quality and relevance.

c) (viii) LIFELONG EDUCATION

- c) (viii) 1. Adults with ASD should be eligible for appropriate support to continuous education and vocational training in terms of specific educational strategies, adapted educational settings, specialized teachers, individualized attention and job coaching, regardless of level of severity or functioning.
- c) (viii) 2. After compulsory education, adults with ASD should have access to regular upper secondary school, when appropriate to their individual needs and ability, or to special courses aimed at enhancing and maintaining acquired individual skills and knowledge in functional areas (see point c) (v) - Areas of educational support)

- c) (viii) 3. Adults with ASD should have access to vocational training based on the person's individual motivation, ability and needs that can lead to employment or to a more or less protected form of occupation, depending on prior individual training, skills and experience, and which provides continuous education in an occupation.
- c) (viii) 4. Whatever the kind or level of adult education, facilities should provide individually tailored programmes, based on the person's individual strengths, motivation and priorities, and on continuous functional assessments by means of reliable instruments

AKNOWLEDGEMENTS

International Classification of Diseases and Disorders - ICD 10, (1992)
World Health Organization

Diagnostic and Statistical Manual of mental Disorders and Diseases- DSM IV - Revised (2000)
American Psychiatric Association

Education of Children and Young People with Autism (1997)
Rita Jordan, Birmingham University, United Kingdom
Guides for Special Education No. 10, UNESCO

Educating Children with Autism (2001)
Commission on Behavioral and Social Sciences and Education - USA

Inclusive Schooling: Children with Special Educational Needs (2001)
DfES Publications, Department for Education and Skills - UK

The Distribution of Resources to Support Inclusion (2001)
DfES Publications, Department for Education and Skills – UK

Comprehensive and Integrative Schooling – Improvements to be made in the Educational System for Students with Special Needs (1989)
Report of the Special Committee Vitoria-Gasteiz, December 1988
Basque Government - ES

Charter of Rights for Persons with Autism (1992)
Autism – Europe AISBL
Adopted as a Written Declaration by the European Parliament on May 9th, 1996

Code of Good Practice for the Prevention of Violence and Abuses against People with Autism (1998)
Autism – Europe AISBL, EU Daphne Programme

The Needs of People with Autism and their Families – Position Paper (2001)
Autism-Europe AISBL

Awareness on Autism - Position Paper and Leaflet
Autism-Europe AISBL, European Year of People with Disabilities 2003

Autism and Education - Position Paper
Autism-Europe AISBL, European Year of People with Disabilities 2003

Autism and Employment

Autism-Europe supports the measures launched by the European Union in the field of the fight against discrimination and in particular the Directive in favour of “Equal Treatment in Employment and Occupation” adopted by the Council in November 2000.

However, Autism-Europe believes that, at this point in time, the general framework defined by this Directive does not sufficiently take into account the needs of persons with autism or a complex dependency needs disability and their families.

The particularly complex situation of persons with autism or a complex dependency needs disability and their families and the discrimination that they suffer from in terms of accessing or remaining in the labour market calls for the following recommendations:

A - PERSONS SUFFERING FROM AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY

The severity of their disability means that they require life-long training, adapted to their specific needs in the fields of:

education, to develop not only work competencies, but also the social and personal skills needed to access professional training and a job, albeit a protected one.

professional training, continuous teaching.

Those that are lucky enough to enjoy adapted training are subsequently able to work. Conversely, the absence of early, individualised and continuous training has irreparable consequences on the development of the person and their ability to gain employment at an adult age.

Adequate support at the workplace (adaptation of the environment, supervision by professionals, tasks appropriate to their disability...) is an essential condition for people with autism or a complex dependency needs disability to benefit from the services that do exist for people with disabilities, such as sheltered workshops.

The lack of training and of adapted support, explains to a large extent why people with autism or a complex dependency needs disability are almost entirely absent from the labour market and remain totally dependent on the support of their families in the long-term. This is independent of their ability or otherwise to work, even though the discrimination that they suffer from, as people with disabilities and through lack of support, should be fought against by the Directive 2000/78/CE.

B- FAMILIES OF PERSONS WITH AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY

families need measures aimed at preventing them from being forced to modify their professional situation and/or ambition in order to assure the care of their child, even when this child has reached adult age. The lack of care services adapted to the needs of their

child, hours of care services incompatible with a job and the unavailability of facilities during the school holidays mean that, in the vast majority of cases, one or other of the parents, very often the mother, is driven to give up his/her job indefinitely. An indirect consequence of this can then be that the partner is forced to increase their working hours to make up for this loss of income or to meet the extra financial costs incurred.

Families need to be supported and informed of the existing provisions that can help them, notably in terms of flexible working hours, from the moment their child receives its diagnosis.

For these reasons, Autism-Europe is calling for complementary measures to the Directive in favour of “Equal Treatment in Employment and Occupation” and to EU policy in terms of employment and social protection to be taken, in order to fight against the barriers to the employment of people with complex dependency needs disabilities and their families.

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

Reinforcing life-long training of persons with autism or a complex dependency needs disability, notably professional training.

Strengthening and adapting support at the workplace to the needs of persons with autism or a complex dependency needs disability .

Putting in place quality care services for all dependent persons (children, the elderly, people with disabilities).

Improving the existing indicators on the care of children in order to be able to measure the proportion of children with disabilities benefiting from these services

Developing flexible working hours whilst maintaining the social rights of the families (parental leave, career breaks....).

Systematically informing families on the legislation and provisions already in place which allow the reconciliation of family and professional life.

DISCRIMINATION IN EMPLOYMENT OF PERSONS SUFFERING FROM AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY

ANNEX: INVESTIGATION ON THE ACCESS TO WORK OF PERSONS WITH AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY AND OF THEIR FAMILIES

During the course of the year 2001-2, Autism Europe launched a survey¹ amongst its members and any interested European organisations via the European Disability Forum and the Platform of European Social NGOs. A questionnaire, prepared in dialogue with the Council of Administration of Autism-Europe, and treating the question of the situation of persons with autism of working age and that of their families, was circulated throughout the network of our member associations across Europe. The questionnaire, translated into 8 European languages, was also accessible on the Web page of Autism-Europe. We received more than 400 replies from 19 different countries (of which 11 EU member states) within two months.

The survey was made up of two parts, one concerning the employment of the persons

with autism themselves and with the difficulties that they meet, the second part concerning the employment of the families of people with autism (mainly their parents), whose professional situation is very often affected by the presence of the person with autism.

Although this investigation does not pretend to be scientific², given the limited means at our disposal, the analysis of these replies highlighted, at least on a qualitative level, the key elements of the situation of the group of people that we represent. The main ideas of the results of this investigation are set out below:

A- PERSONS SUFFERING FROM AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY

The first important element that comes out of this study is that, in the vast majority of cases, persons with autism or another complex dependency needs disability **do not want to or cannot work** (61.5% of cases).

Directly linked to this result, we notice that these people **only rarely receive professional and/or continuous training** (37%), which can probably explain, at least partially, the impossibility or non-willingness to work.

Finally, their **participation in social life remains difficult, if not non-existent** in the majority of cases (57%). Unfortunately, barriers to this participation are still numerous, mainly due to a failure to adapt the environment (36%), lack of adequate services (24%) or negative attitudes from the general public (18.3%). Although out of the area of this investigation, it can be pointed out that the lack of educational services in the childhood, not allowing a preparation for social life, is an aggravating factor of the disability.

These two factors combined, lack of training and of adapted support, explain to a large extent why people with autism or a complex dependency needs disability are almost entirely absent from the labour market and remain totally dependent on the support of their families in the long-term.

B- FAMILIES OF PERSONS WITH AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY

With regard to the families who have a person with autism or another complex dependency needs disability to look after, it is noticed that their employment situation changes significantly after the arrival of their disabled child. The main elements that come out of the report are: **a total cessation of work, a reduction in hours worked or conversely an increase in the hours worked**. Only a minority have not been led to change their employment situation (26%).

But, what is doubtless particular to the sector that we represent is that these **changes have been brought about through necessity** (54%) much more than through choice (36%).

Another important point is that there is a lack of information on the existing measures at national level in favour of families of people with disabilities. A vast majority of the people that replied to the questionnaire think that there are none (46%) or do not know if there are any (22%).

Finally, concerning the support of families of persons with autism or a complex dependency needs disability, the replies show that care services outside of the home only provide **partial, occasional or even no aid** (50% of the people during the school year and 63.5% of the people during school holidays have partial, occasional or no access to care services outside of the home.) and that help within the home is very rarely provided by a social service but rather through family solidarity.

The families almost inevitably have to change their professional situation and/or ambition in order to be able to ensure the care of their child, even when this child has reached adulthood. The lack of care services adapted to the needs of their child, hours of care services incompatible with a job and the unavailability of facilities during the school holidays mean that, in the vast majority of cases, one or other of the parents, very often the mother, is driven to give up his/her job indefinitely. An indirect consequence of this can then be that the partner is forced to increase their working hours to make up for this loss of income or to meet the extra financial costs incurred.

OBSERVATIONS

In the light of these different results, one cannot help but notice that the area covered by the current Directive is still not sufficient to respond to the needs of persons with autism or a complex dependency needs disability and their families. The different elements of this study back up the recommendations that the members of Autism-Europe have been making for many years.

The issue here is not their ability or otherwise to work, but the discrimination that, through lack of support, persons with autism or another complex dependency needs disability suffer from as people with disabilities, a form of discrimination nevertheless fought against by the Directive 2000/78/CE.

These elements highlight the particularly complex situation of the families of people with autism or a complex dependency needs disability and the discrimination that they suffer from in terms of accessing or remaining in the labour market.

Autism-Europe hopes to have contributed to a better understanding of the situation of persons with autism or a complex dependency needs disability and their families at the European level, thanks to the contributions of its members, and in so doing, to have participated in the fight against the discrimination of the most vulnerable groups, for a Europe that is more just for all its citizens.

¹ The full results of the investigation are available at the secretariat of Autism Europe.

² The percentages indicated represent only the responses received in the sample. It can not be extrapolated to the total population of the persons concerned.

Autism and Ageing

Towards a better quality of life

In the last decade several conferences and seminars have been devoted to the problems of ageing persons but few have approached the problem of ageing persons who also happen to be disabled for different reasons than those resulting from ageing.

Persons with disabilities have:

- Problems resulting from ageing
- Problems resulting from their disabilities.

The International Association Autism-Europe is developing a campaign using an holistic approach to raise awareness in the importance of studying the **common problems** these two populations face as well as the **specific problems of persons with autism**.

Autism-Europe invites persons with autism, their families and all those who are directly or indirectly involved in the subject to raise questions and to demand solutions.

BACKGROUND

• Ageing people with disabilities in Europe and in the world

People are living longer and in better health conditions in both developed and developing countries. By 2050 the ratio of older people in society will have doubled from 1 in 10 to 1 in 5. These figures are also true of persons with intellectual disabilities. According to the WHO (World Health Organisation) the social and medical factors leading to this increase in longevity have also increased the life span of people with intellectual disabilities.

Europe has been one of the first regions in the world to be confronted with the problem of ageing people. According to the documentation produced by the European Union the number of ageing people in Europe has increased so dramatically since 1950 that measures have had to be taken at a level of economic, political, social and employment legislation and directives.

At the same time the European Union has become aware of a reality often forgotten. Nowadays there is an increasing ratio of 1 disabled citizen to 10 other European citizens. Dependency and disability are directly linked with ageing. Europe must improve the quality of life of disabled and ageing people.

The fight against the exclusion of older people with disabilities implies that laws and directives must be put into practice. At the employment level, for instance, jobs must be adapted to ageing persons; at the social and economic level, retirement pensions have to be raised; quality health services must be implemented and/or extended; transportation and communication systems must be adequate for their users; housing facilities must be provided.

• Ageing people with autism and other complex dependency needs

Autism was first referred to scientifically in the '40s (Leo Kanner in 1943, Asperger in 1944) and the first children studied at that time are now adults and many of them are in their sixties. The world is faced with the ageing process of persons with autism.

Statistics on ageing people with autism are not available. We may infer that they are similar to those of other people with intellectual disabilities. Empirical data show that persons with autism die of the conditions associated with autism, mostly epilepsy. There are also deaths caused by accident and in the case of high functioning persons there are reports of suicide. However we have reason to believe that persons with autism are also living longer. In the last 30 years, according to incidental reports, fewer people with autism have died before the age of 50 years than was previously the case.

Within the group of ageing persons with disabilities ("double vulnerability"), persons with autism and other persons with high complex dependency needs are the most excluded and the most difficult to include in society. This is a fact recognised by the European Disability Forum in the reference document "Excluded among the Excluded" (2000).

When a person has autism, the whole family is being discriminated.

This statement brings us to "*associated discrimination*" as defined in a conference recently organised by the Danish Presidency in 2002. The fight against discrimination should include the discrimination a person experiences through his or her association with another person who is discriminated against.

Ageing persons with autism have older parents who are also in a situation of vulnerability

• Specific problems of ageing people with autism

The needs of ageing people with autism are the same as those of other ageing people: economic, social, residential and affective, but aggravated by the neurological, physiological and psychological factors linked to their specific condition.

Moreover they face additional problems like:

- **Health problems** due to associated diseases, secondary effects of medical drugs;
- **Communication and interaction problems** that can lead to isolation;
- **Behaviour problems** that may arise or be aggravated by communication and interaction problems.
- **Residential problems:**
 - **Living at home** – no longer possible without a carer because of the ageing parents of persons with autism.
 - **Staying in the same day centres or workshops** – ageing persons with autism must sometimes leave their day centres and go to inadequate places such as hospitals or ordinary residences for older people not specifically adapted to people with autism.
- **Lack of a lifelong learning environment** - Persons with autism have considerable learning disabilities and in most cases are very slow learners. Often they must leave their usual structured learning environment, therefore losing the visual cues they need.
- **Lack of trained staff** for ageing persons with autism or with complex dependency needs
- **Lack of realistic and appropriate financial support in most European countries**

THE RIGHTS OF AGEING PEOPLE WITH AUTISM PLAN FOR ACTION

Persons with autism, their families or representatives, organisations and governments must establish a plan for action based on European laws and directives.

The right to an independent life and self determination

Persons with autism and other complex dependency needs or their representatives have the right to decide their future and to ask for the implementation of the principles stated in the Madrid Declaration and in the Charter of Rights for Persons with Autism. Principles are also present in the treaties and directives issued by the European Union on the rights of ageing persons and persons with disabilities, in particular those with complex dependency needs.

The right to maintain or improve the quality of health

- Prevention of health problems related with ageing
- Accurate diagnosis and accurate information on their specific health condition
- Prevention of problems related to specific health conditions
- Treatment of specific health conditions

The right to maintain and improve communication and social interaction

Access to alternative means of communication, visual information

If possible, foster inter-generational dialogue by:

- Involving young people through their participation in cultural events and other games or sports activities with persons with autism in the community
- Facilitate contacts between schools, youth organisations and institutions.

The right to appropriate intervention

Multidisciplinary assessment and co-ordination of interventions while taking into account:

- The functional abilities of the person.
- The interests and wishes of the person and his/her family

Design and put into practice an individualised support plan with the main objective of:

- Improving and maintaining autonomy skills in the home or residence
- Improving and maintaining social skills in community activities

The right to have services to provide a good quality of life

Services should be the result of a dialogue. Diversity of choice of accredited services must be available.

This will enable family and staff members to identify the individual needs of the person with disabilities. It will also be a way of reducing the risk of isolation and consequently exclusion.

The right to education and lifelong learning

Services must provide a learning environment and education facilities

The right to employment for persons with disabilities and their families

Employment must be adapted to persons with autism and their families so they will not risk exclusion. Professional training must be provided.

The right to housing facilities

Persons with autism must remain in their own homes as long as they can, like other ageing people, or go to places where they were used to living before retiring from "active life". Preparation for the changes in placement and ways of living must be carefully planned. New environments must be adapted to the specific needs of the persons with autism.

• Living at home

Provision of special help (medical, technical resources, house keeping, adaptation of the environment, etc)

Support for the ageing members of the family.

• **Living in small apartments** with the permanent assistance of carers.

• **Living in institutions:** keep people with autism in the same institutions they are used to living in with no age limit. Or place them in a nearby structure.

Provide complementary medical and health support: nurses, other support staff, hospital care, technical aids, accessibility, etc

• **Living in an institution while maintaining family contacts** with their ageing relatives: Staff can take an active role in preserving relationships by enabling persons with autism to visit their parents at home or by making arrangements for the parents to visit residences.

• **Living in a special structure for ageing people with disabilities**

New types of special residences with medical care for ageing persons with disabilities, complex dependency needs and serious need of medical care.

• Training of professional staff

On taking into account research results, comparing experiences in developed countries and considering the needs of Northern, Southern and East European countries, it is urgent to implement:

- Staff training, co-ordinated and prepared according to a systematic plan and with an holistic approach.
- Programmes for home assistance for ageing persons with autism and their families

• The right to realistic and adequate financial support

Persons with autism and other populations with complex dependency needs should be able to live independently in the country of Europe where they were born or reside and have the same rights to realistic and appropriate funding:

- To have access to a good quality of life in terms of physical, emotional, social and material wellbeing
- To have an environment that fosters communication and is adapted to the problems of behaviour faced by persons with autism
- To live a healthy and inclusive life in the community
- To choose a way of living either at home or in a residential setting with adequate support from health and education services.

AUTISM

Autism is a complex lifelong disability, due to multiple medical causes, interfering with the normal development and functioning of the brain, sometimes identifiable in very early childhood. Although the exact mechanisms involved in the neurological dysfunction are not yet clear, autism deeply affects the way the person communicates and relates with his or her environment.

Despite initial beliefs to the contrary, autism is not a rare condition. We know that, if the whole spectrum of autistic disorders is considered, the disability may affect almost 1/1000 of population.

Autism can affect any family, regardless of ethnic or social class, and it is four times more frequent in males than in females. Often, but not always, autism is combined with other disabilities, especially general learning difficulties of varying degrees, as well as behavioural problems.

Persons with autism can really improve if early diagnosis is followed by personalised specialised education and treatment but the vast majority of them, and their families, need intensive and sustained support throughout their lives to fulfil their potential and make the difficult task of living with autism easier.

In spite of the availability of good models of service delivery, most persons affected by autism do not have access to them nor are they able to benefit from scientific, medical, educational and social progress made during the last decades in reference to this condition. This deprivation generates much suffering and additional difficulties, and constitutes a form of discrimination which Autism-Europe is strongly committed to fight against.

AUTISM-EUROPE a.i.s.b.l.

Autism-Europe ensures effective liaison between approximately 85 member associations of parents of persons with autism in 31 European countries, including 20 Member States of the European Union, governments and European and international institutions.

Autism-Europe plays a key role in raising public awareness, and in influencing the European decision-makers on all issues relating to autism, including the promotion of rights of people with autism and other disabilities involving complex dependency needs:

- **through its publications:**
 - "LINK" MAGAZINE published and circulated in English, French and Portuguese
 - CHARTER FOR PERSONS WITH AUTISM formally adopted by the European Parliament as a Written Declaration (May 1996)
 - CODE OF GOOD PRACTICE on the prevention of violence against persons with autism
 - DESCRIPTION OF AUTISM drafted by an international team of experts
 - POSITION PAPERS on health, ageing, inclusion, education and family needs
 - AWARENESS LEAFLET
- **by organising events and actions at European level:**
 - An international Congress in Europe every three/four years
 - Awareness campaigns
- **by promoting actions and initiatives (client oriented service delivery, scientific research, etc.) aimed to improve the quality of life of persons with autism and their families.**



Autism-Europe
a.i.s.b.l.

Rue Montoyer 39 bte 11 • 1000 Brussels • BELGIUM
Tel.: + 32(0) 2.675.75.05 • Fax: + 32(0) 2.675.72.70
Email: secretariat@autismeurope.org
Web site: www.autismeurope.org