

FIGHTING FOR THE RIGHT TO EDUCATION OF PERSONS WITH AUTISM SPECTRUM DISORDERS

Tool-Kit For Parents And Self-Advocates



Supported by the European Commission









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Autism Europe AISBL

is a European network regrouping nearly 80 associations of parents of persons with autism in 30 countries. Its principal objective is to promote and defend the rights of people with autism and their families and to improve their quality of life.

Autism-Europe is a founding member of and strictly collaborates with the European Disability Forum (EDF), with the Platform of European Social NGOs and the European Coalition for Community Living (ECCL)



This document includes the easy-to-read version and is also available in PDF format on the Autism-Europe web site

http://www.autismeurope.org



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FIGHTING FOR THE RIGHT TO EDUCATION OF PERSONS WITH AUTISM SPECTRUM DISORDERS (ASD)

TOOL-KIT FOR PARENTS AND SELF-ADVOCATES

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FIGHTING FOR THE RIGHT TO EDUCATION OF PERSONS WITH AUTISM SPECTRUM DISORDERS (ASD)

TOOL-KIT FOR PARENTS AND SELF-ADVOCATES

1. RIGHT TO EDUCATION FOR ALL

1.1 A rights-based approach to disability

Persons with disabilities do not want pity. They want rights.

The rights-based approach to disability promotes a shift of values away from a medical approach to disability towards a social approach. This approach sees persons with disabilities as subjects with rights, not as objects of assistance. Rules and regulations and provisions are established in order to secure human and fundamental rights and to meet individual needs. According to this approach and to the international legal framework, access to an adapted education programme cannot be denied to any pupil on the grounds of disability.



1.2 European legal framework

Persons with disability are different from other persons. This must be taken into account.

Article 14 of the European Convention on Human Rights¹ states that the principle of equality means treating equals equally and providing different adapted measures for people in a different situation. In particular,² "the right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different." In other words. human difference in a democratic society should be viewed positively and should be responded to with discernment in order to ensure real and effective equality.

European Convention on Human Rights Article 14

¹ **The European Convention on Human Rights**: was adopted in 1950 and contains a number of fundamental rights and freedoms of a political nature such as the right to life, prohibition of torture, right to liberty and security, right to a fair trial, the right to respect for private and family life, freedom of thought, conscience and religion, freedom of expression, and the prohibition of discrimination.

² Thlimmenos case [Thlimmenos c. Grèce [GC], n o 34369/97, CEDH 2000-IV, § 44)

Persons with disabilities have the right to live, study and work with other people.

Article 15 of the Revised Social Charter³ states the right to independence, social integration and participation in the life of the community. To this end, States which have signed up to and ratified the Charter) have an obligation:

Revised Social **Charter (1996)** Article 15

1. to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private; 2. to promote their full social integration and participation in the life of the community in particular through measures, ...

It should be noted that Article 15 applies to all persons with disabilities regardless of the nature and origin of their disability and irrespective of their age. It thus clearly covers both children and adults.

Services must provide education to persons with disabilities.

Article 17 is predicated on the need to ensure Revised Social that children and young persons grow up in an environment which encourages the "full development of their personality and of their physical and mental capacities". approach is just as important for children with disabilities as it is for others and arguably more in circumstances where the effects of ineffective or untimely intervention are ever likely to be undone. Article17§1, in particular, requires the establishment and maintenance of sufficient and adequate facilities and services for the purpose of education.

Charter (1996) Article 17

Discrimination means treating someone badly. **Discrimination** of persons with disabilities is prohibited.

Article E of the Revised Charter establishes the principle of non-discrimination with respect to the achievement of the various substantive rights contained therein. Although disability is not explicitly listed as a prohibited ground of discrimination under Article E, it is adequately covered by the reference to "other status".

Revised Social **Charter (1996)** Article E

2. **EUROPEAN POLICIES IN THE FIELD OF DISABILITY**

³ The European Social Charter: was adopted in 1961 and guarantees a number of economic and social rights including employment related rights, the right to education, the right to social security and health related rights. The ESC was revised in 1996 to introduce new rights such as the right to protection against poverty and social exclusion, the right to housing and the right to protection in cases where employment is terminated. Additionally, the revised ESC amended certain rights and improved the protection for disabled people (see further below).

States must help people with disabilities. The European institutions tell States how to do this. Disability policies are essentially the responsibility of member States. Nevertheless, although the policy instruments of the European Institutions are not binding on member States, European policies impact the situation of people with disabilities at national level because they are taken into account by the Member States as guide—lines in developing national disability policies.



2.1

The European Union says that disabled people must be treated like other people

European Union policy on disability

Equality of opportunity is the objective of the European Union⁴ strategy on disability, which aims to enable disabled people to enjoy their right to dignity, equal treatment, independent living and participation in society.

European Union

2.1.1

The European Union tells States how people with disabilities must be treated

European Union policy instruments

The EU Disability Action Plan (DAP), established by the European Commission⁵ to mainstream disability issues into relevant Community policies and develop concrete actions in crucial areas to enhance the integration of people with disabilities, provides a framework to develop the EU disability strategy. The DAP identifies operational objectives and actions, focusing on the active inclusion of people with disabilities and on mainstreaming disability issues in relevant Community policies. Incorporating disability issues into the lifelong learning concept and processes is one of the priority actions of the EU Disability Action Plan 2006-2007.

European Commission Disability Action Plan

2.2 Council of Europe's policy on disability

⁴ In 1957 six Western European countries established an international organisation to promote economic cooperation. This organisation was originally called the European Economic Community (EEC). Over the years the EEC evolved and obtained greater powers. It also changed its name, becoming firstly the European Community (EC), and now the European Union (EU). Today the EU is not only concerned with economic matters, but also with social policy and human rights. In addition the EU has significantly expanded its membership, being made up of 25 Member States as of 1 May 2004. Further expansion eastwards is to be expected.

⁵ The Commission is the executive and the main administrative body of the EU. The Commission is headed by 25 Commissioners, each nominated by a Member State. The Commission has two main tasks:

to propose legislation and policy. The Commission is the only institution which can propose new legislation. It is then up to the Council and the Parliament to adopt, amend or reject that legislation.

⁻ to monitor compliance with the law by Member States. The Commission has the task of ensuring that Member States comply with EU law. If the States do not do this, the Commission can take them to the European Court of Justice.

The Council of Europe says that the rights of persons with disabilities must be respected. The Council of Europe⁶ has adopted a number of initiatives aimed at securing and strengthening the position of persons with disabilities in society as well as fighting discrimination against persons with disabilities. To this end, the Committee of Ministers⁷ has adopted a number of resolutions and recommendations with the aim of establishing policies directed towards persons with disabilities. In 1992, for example, the Committee of Ministers adopted Recommendation no. R(92)6 on a coherent policy for people with disabilities.

Council of Europe

2.2.1

Council of Europe policy instruments

The Council of Europe says that people with disabilities must live among other people The Council of Europe Action Plan 2006-2015 establishes the policy agenda of the Council of Europe to promote the rights and full participation of people with disabilities in society (Recommendation Rec(2006)5) under the authority of the Directorate General of Social Cohesion.

European
Directorate
General of Social
Cohesion

The Council of Europe says that pupils with Autism need special help in their education The Report of the CoE's Committee of Experts on Education and Integration of Children with Autism⁸ recognises that pupils with Autism Spectrum Disorders need a very specific educational approach and strategies and has issued recommendations to the State Parties aimed at implementing their rights in the field of education.

Committee of Experts on Education and Integration of Children with ASD

3. IMPLEMENTING DISABILITY POLICIES IN THE FIELD OF EDUCATION

⁶ The Council of Europe (CoE) is a regional political organisation established in 1949 by a number of West European countries with the aim of "safeguarding and realising the ideals and principles which are their common heritage and facilitating their economic and social progress." Among these ideals and principles is the maintenance and further realisation of human rights and fundamental freedoms (Article 2 Statute of the Council of Europe). Since its beginning, the CoE has enlarged its membership so that currently 45 countries are now a part of the organisation. The CoE should not be confused with the European Union (or one of the European Union's institutions, the European Council), while in some respects the activities of the European Union and the CoE overlap and converge (for example on the area of human rights). Nevertheless, the CoE's core activities are centred around the protection of human rights, the promotion of democracy and the rule of law, and the strengthening of social cohesion and cultural diversity.

⁷ The Committee of Ministers is the CoE's decision-making body and is made up of the Ministers of Foreign Affairs of all the Member States. The Committee's main tasks are the encouragement of political dialogue, the conclusion of new conventions/treaties and agreements, and the supervision of Member States' compliance with their treaty obligations. The Committee may make recommendations to Member States.

⁸ The CoE's Committee of Experts on the Education and Integration of Children with Autism consisted of delegates from member and observer States. Its aim was to produce recommendations for a realistic policy of education and inclusion for children with ASD, to promote a comprehensive approach and to specify which parties are involved in providing care and their respective roles.

3.1

Pupils with disabilities have the right to study, just like all other pupils

Schools cannot refuse students with disabilities because their education is difficult and expensive

Ensuring access to education

School systems must be able to accept any pupil, whatever the degree of their learning impairment. The school system organisation cannot, in any event, restrict or violate any right of the person recognised by international and national sources.

Equal enrolment and access for all to the Education systems, regardless of the nature or severity of disability, should be guaranteed. The school system and/or schools should not be allowed to refuse education to pupils with severe learning impairments or complex dependency needs on the grounds of the nature or severity of their disability (because they are "uneducable") or because of a lack of resources (because the school is not equipped to deal with their educational needs).



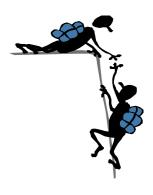


3.2

Pupils with a severe disability need support to be able to learn

Ensuring adequate support

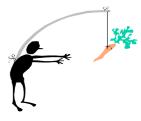
Education can represent a challenge for children with severe learning disabilities if adapted support is not ensured. The right not to be discriminated against in the enjoyment of rights is also violated when persons whose situations are significantly different fail to be treated differently without an objective and reasonable justification. As a consequence, a child with severe disability must receive sufficient individualized attention on a daily basis so that educational objectives can be effectively implemented.



Each pupil with a disability needs his/her own programme

A user - centred educational approach should be adopted and implemented by means of Individual Education Plans (IEP) that are

functional in achieving independence, dignity and social participation, according to individual needs, motivation and potential.



If the pupil does not make progress, his/her programme must be changed

3.3

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, reformulating curricula, increasing programming time, or providing school staff with additional training and consultation.



Promoting inclusive education

Inclusion occurs when a pupil with a disability is educated with other children Like all society, education should be inclusive. 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.



Inclusion of pupils with disabilities at school requires support

Inclusion in the mainstream should be based on entitlement, not privilege, and should reflect the best interests and needs of each person. The policy of Inclusion should essentially ensure that appropriate learning or other positive experiences take place in as inclusive an environment as possible. It should never be used to deny 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.

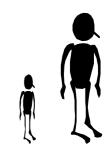


3.4

Ensuring lifelong education

The right to education is for both children and adults.

Any person with a disability shall receive multidisciplinary provision catering for his or her specific needs and difficulties. The age of the disabled person is irrelevant in relation to the right to education. Access to life-long education should be ensured on the same basis as anybody else's, from pre-school facilities to upper grade education and/or adapted facilities for adults.



Adults with disabilities need education to get a job.

After compulsory education, adults with disabilities 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 and at providing vocational training.



4. IMPLEMENTING THE RIGHT TO EDUCATION FOR PERSONS WITH ASD

4.1 Learning impairments in autism

Education of pupils with autism requires knowledge of the characteristics of autism

Autism is a developmental disorder, ranking from severe to moderate and featuring significant impairments social interaction in and communication. In most cases, Autism results in a significant lifelong learning disability. Autism is different from all other disabilities and its particular characteristics and learning style require very specific educational approaches.



4.2

Without

education, the life of persons with autism and their families is hard

Public Authorities must be particularly mindful of the impact that a lack of educational provision will have on groups with heightened vulnerabilities as well as on the other persons affected including,

especially, their families, on whom the heaviest burden falls in the event of institutional

Access to education for autism

shortcomings.



Education helps people with autism to understand the world

For people with autism, 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.

Autism must be identified to begin education and help children with autism to be with others

Skilled diagnosis and ongoing specialised assessment should be implemented in partnership with parents and health professionals in order to determine appropriate educational programmes. Individual education programmes must be available as early as possible in order to support the development of the person, their social inclusion and participation in the community.



4.3

Persons with autism need support for all their lives.

Teachers of pupils with autism must have skills.

Support to education for autism

No person with autism 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 and lifelong support than on the degree of individual impairment.



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 researchsound educational strategies. Minimum standards should be defined in terms of teaching

qualifications for staff employed in educational settings for children with Autism Spectrum Disorders.



The setting for the education of pupils with autism should be adapted Specialized educational support should be provided in order to implement an individually tailored educational plan (IEP), based on a set of individualized objectives. Whilst taking into account the needs of the individual child and his/her family, the child's schedule and educational environment, both in and out of the classroom, should be adapted as required in order to implement the IEP.



The education programmes should fit the interests of the pupil and the wishes of his/her family.

A specialized educational approach should engage the pupil in systematically planned, developmentally-appropriate educational activities, according to identified objectives. Wherever the educational activity takes place, the content of the activity should be determined on the basis of the child's best interest, motivation, strengths and needs and in keeping with both the characteristics of the child and the priorities of the family.



Pupils with autism should be educated in schools for all. Whilst Autism is a spectrum condition requiring a range of sophisticated individual responses, it is hoped that increasingly these responses will be found within the mainstream of provision.



Adults with autism need support and education to get a job.

Adults with Autism Spectrum Disorders should be eligible for appropriate support in continuous education and vocational training in terms of specific educational strategies. adapted educational settings. specialized teachers. individualized attention and job coaching, regardless of their level of severity or functioning.



- 5. STRATEGIC LITIGATIONS
- 5.1 Individual complaints

Many families of pupils with severe disabilities have asked for more support for their children to the Courts of Justice. Individual complaints can be lodged by persons with disabilities or their parents and representatives before the national courts of justice. Many families in EU countries have lodged petitions with the Public Administration in order to obtain the right to education for their disabled children. They claim the right to appropriate support at school and, in this respect, appeal to the inviolability of the right to education and training, to the full development of the child's personality as recognised by national and international normative texts. On these premises, they demand the adoption of suitable measures to guarantee the full enjoyment of their disabled children's rights on the grounds of National Legislation, the European Convention on Human Rights, Article 14, and the European Social Charter, Articles 15, 17 and E.



Lack of support to pupils with disabilities causes damage to the child and family. On the basis of existing rules and regulations, the presiding judges issue ordinances of allocation or reinstatement of adequate teaching support as claimed by the petitioners, whilst observing that not only damage to the physical and mental integrity of the person but also damage caused by lesion of an inalienable and fundamental human right fall within the concept of damage to the person. Withdrawal of the adequate educational support to the disabled child does not encourage teaching or learning. It unjustifiably jeopardises a fundamental right of the person to an education, to inclusion and to the development of his/her personality as guaranteed by the national and international legislation and causes serious and irreparable damage to the child and his/her family, whose moral and economic efforts are totally thwarted.



Support cannot be denied to any student because of its cost. The justification adopted by schools and Public Authorities concerning the insufficiency of available financial resources or the current support needs of other pupils are irrelevant in the face of inviolable subjective rights. Eventual financial claims invoked by the Authorities cannot, in any event, justify the restriction of the right to education.



All persons of all ages have a right to education

The fact that the disabled child attends the kindergarten or upper secondary school, which are not included within compulsory education, is deemed entirely irrelevant in relation to the right to education.



5.2

Collective Complaints

Only some organisations can

The collective complaints mechanism was introduced in 1995 through an additional protocol to

European Social

make collective complaints. People cannot make them for themselves. the European Social Charter. It is a recent, direct **Charter** and efficient procedure. **Addition**

Additional protocol

Collective complaints must have a collective scope and may be lodged with the European Committee of Social Rights⁹ of the Council of Europe. The CSR issues a judicial decision that is transmitted to the Committee of Ministers¹⁰, which issues a policy statement.

Only certain organisations are allowed to file (or make) such complaints. These include a number of trade unions and NGOs that:

- are International non-governmental organisations with participatory status
- have been recognised as being an observer (observer status) at the meetings of the Council of Europe
- have particular competence in respect to matters that are the object of the complaint.

National organisations can file collective complaints only in the case of a declaration by the State. Until now, only Finland has made this declaration

On the basis of the conclusions of the European Committee of Social Rights, the Committee of Ministers adopts resolutions. If a violation is found by the European Committee of Social Rights, the Committee of Ministers issues a recommendation to the violating State. The State then has to provide information on the measures taken to comply with the recommendation.

⁹ The European Committee of Social Rights is a body composed of independent experts that examines reports submitted by States that have accepted to be bound by the ESC. The Committee decides whether or not the situations in the countries concerned are in conformity with the Charter. Its decisions, known as "conclusions", are published every year. Additionally, under the collective complaints procedure, the European Committee of Social Rights may receive collective complaints from organisations (not individuals) that have been recognized to make such complaints. In both cases the Committee concludes whether or not a State has complied with the Charter.

¹⁰ The Committee of Ministers is the CoE's decision-making body and is made up of the Ministers of Foreign Affairs of all the Member States. The Committee's main tasks are the encouragement of political dialogue, the conclusion of new conventions/treaties and agreements, and the supervision of Member States' compliance with their treaty obligations. The Committee may make recommendations to Member States. Additionally, the Committee is responsible for ensuring that judgments of the European Court of Human Rights are enforced and the conclusions of the European Committee for Social Rights are acted upon by adopting resolutions and/or recommendations.

5.2.1

Autism Europe's Collective Complaint

Autism Europe defended the right to education of people with autism in France In 2002, Autism Europe, an organisation that has the required observer status, submitted a collective complaint to the European Committee of Social Rights on the ground of Articles 15, 17 and E of the European Social Charter, dealing with insufficient educational provision for persons with autism in France. The complaint was declared admissible and in 2003 the European Committee heard the complaint.



Many people with autism in France do not have education

According to Autism Europe, France failed to satisfactorily apply its obligations under the Revised ESC with regard to the right to education of children and adults with autism. In this respect, Autism Europe argued that France did not provide sufficient education opportunities, facilities and services of an adequate standard or quality to children and adults with autism. Additionally, Autism Europe claimed that France discriminated against children and adults with autism because France did not manage to ensure that children and adults with autism enjoyed the right to education in the same way that all other children and adults did. This lack of action by the French government also resulted in discrimination because children and adults with autism did not enjoy the same level of education as other people.



5.2.2

The Decision of the ECSC

France is guilty because it does not provide education to persons with autism.

The European Committee of Social Rights concluded by 11 votes to 2 that the situation in France constituted a violation of Articles 15§1 and 17§1, whether alone or read in combination with Article E of the revised European Social Charter because:

- the proportion of children with autism being educated in either general or specialist schools in France is much lower than in the case of other children, whether or not disabled
- there is a chronic shortage of care and support facilities for autistic adults.



Autism Europe, Brussels 2006



The contents of these pages do not necessarily reflect the position or views of the European Commission



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 can affect 6:1000 of the 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 form а 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.



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One million for Disability make disability discrimination history



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