

# Introductory Remarks on the Rights of People with Autism to Education and Employment: The Convention on the Rights of Persons with Disabilities & the European and National Perspectives

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Autism-Europe has the great honour of introducing this publication on the protection of the Rights of People with Autism in the fields of education and employment from international, European and national perspectives.

All families having children with autism as well as self-advocates have understood for quite a long time that dealing with autism and ensuring the defence of their fundamental rights requires international exchanges of good practices, under an evidenced based medicine approach, and an international advocacy initiative above purely national lobbying, under the so-called rights based approach.

## 1 Historic Perspective: Continuing Advocacy by Autism-Europe for Adapted Legal Instruments

From a historical perspective, we should recall the following steps which, during the last 20 years, undoubtedly permitted a better definition of the fundamental rights to education and to employment of people with autism.

As early as 1996, a Charter for persons with autism was drafted by Autism-Europe and adopted by the European Parliament as a written declaration. Although this Charter outlines the rights of people with autism in Europe, it is not legally-binding for the Member States of the European Union.<sup>1</sup>

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<sup>1</sup>European Parliament, Charter of Rights of persons with autism, Declaration, May 9, 1996. Charter available on the site of Autism-Europe, presented at the 4th Autism-Europe Congress, Den Haag, 10 May 1992, adopted as a written declaration by the European Parliament on 9 May 1996.

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Although, the European Social Charter of 1996 is a general human rights instrument, its Article 15 defines specific rights for people with disabilities. On the basis of this Article 15, the first collective complaint in Europe for the defence of the right to education of people with autism was lodged by Autism-Europe in 2002.<sup>2</sup>

The Committee of Social Rights of the Council of Europe rendered its decision on 4 November 2003. France was found to have failed to fulfil its educational obligations to people with autism under the European Social Charter.<sup>3</sup>

Subsequent to this landmark decision, the Committee of Ministers of the Council of Europe adopted in 2009 a Recommendation on the education and social inclusion of children and young people with autism spectrum disorders on the basis of the work achieved by an ad-hoc committee in which Autism-Europe actively participated.<sup>4</sup>

The 2002 collective complaint has also been at the origin of a second complaint lodged in 2012 by the European organisation *Action européenne du Handicap*.<sup>5</sup> The decision rendered by the Committee of Social Rights on 11 September 2013 confirmed and reinforced the decision issued 10 years previously.<sup>6</sup>

Finally, Autism-Europe was actively involved, along with the European Disability Forum, in the adoption of the UN Convention on the Rights of Persons with Disabilities. The UN Convention is the very first international treaty dedicated to people with disabilities.

This Convention was adopted on 13 December 2006 and opened for signature on 30 March 2007. It entered into force on 3 May 2008. Autism-Europe worked with the European Disability Forum to advocate for a European Disability Strategy 2010–2020 for ensuring the implementation of the Convention among the EU member states. In 2014, it was ratified by most of the European countries. The European Union itself also ratified the Convention. The States which have only signed the UN Convention are not legally bound thereby, but are obliged to refrain from acts that would defeat or undermine the treaty's objective and purpose. The States which have ratified the Convention are legally bound by it and must ensure that its national laws and policies comply with the Convention.

Regarding the rights of people with autism, and from both a European and an international perspective, we are of the opinion that should be taken into account not only the principles set forth by the UN Convention, but also the case law

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<sup>2</sup> Collective Complaint no. 13/2002, International Association Autism-Europe (IAAE) v. France.

<sup>3</sup> Council of Europe, European Committee of Social Rights, Decision on the merits, 4 November 2003. Decision available on the site of the Council of Europe.

<sup>4</sup> Council of Europe, Committee of Ministers, Recommendation CM/Rec (2009) 9 to Member States *on the education and social inclusion of children and young people with autism spectrum disorders*, 21 October 2009. Recommendation available on the site of the Council of Europe.

<sup>5</sup> Collective Complaint no. 81/2012, *Action européenne des handicapés* (AEH) v. France, available on the site of the Council of Europe.

<sup>6</sup> Council of Europe, European Committee of Social Rights, Decision on the merits, 11 September 2013. Decision available on the site of the Council of Europe.

rendered by the Council of Europe applying the European Social Charter. To date, the Council of Europe is indeed the sole international organisation having enacted clear guidelines on the rights of people with autism and how they need to be applied in order to be effective.

The interaction between the UN Convention and the Council of Europe decisions and recommendations is an approach ensuring an effectiveness of the rights to education and to employment of all people with autism at the national level in Europe and outside Europe. Indeed, the rights to education and to employment of people with autism are in practice regulated by national legislations.

## **2 Scope of the Substantive Rules Set Forth by the European and International Instruments Targeted at the Defence of the Rights of People with Disabilities**

Indeed, as far as substantive law and effectiveness of rights are concerned, what are the rules to be retained in order to ensure the effectiveness of the rights of all people with autism?

As we know, the spectrum of autism is wide. At one end of the spectrum, people with autism are severely disabled. At the other end, we find people with Asperger syndrome who benefit from the highest capabilities. The UN Convention states that all people with disabilities are ‘entitled to all the rights and freedoms set forth therein, without distinction of any kind’. It emphasises the need to promote and protect the human rights of all people with disabilities, including ‘those who require more intensive support’ as might be the case for many low functioning people with autism. All people with autism deserve education and employment. Education and employment must be defined and adapted for each person with autism. The legal instruments, such as the UN Convention and the European Social Charter do provide and permit so.

Twenty years ago, Article 15 of the European Social Charter of 1996 already stated that for ‘ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community’, the States undertake, ‘to take the necessary measures’ to provide them 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’, and ‘to promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialised placement and support services (...)’. It is worth underlining that this Treaty is especially targeted at

responding to the needs of all and surely takes into account the wide variety of disabilities, as we know it in the world of autism.

Ten years later, Articles 24 and 27 of the UN Convention define the principles to be complied with for ensuring the full education and full employment of people with disabilities. Pursuant to Article 24 of the Convention on the right to education, the States must ensure that people with disabilities have equal access to education systems at all levels, including lifelong learning and vocational training. The States must also ensure that reasonable accommodation is provided to people with disabilities, not only through technical assistance, but also human assistance to enable access to education. Teachers must also receive specific training. Pursuant to Article 27 of the Convention, the States must enable people with disabilities to exercise their right to work and employment. This includes taking appropriate steps to ensure that reasonable accommodation is provided to people with disabilities in the workplace. The States must of course also employ people with disabilities in the public sector.

Notwithstanding certain approaches retained by some stakeholders or politicians, Articles 24 and 27 do not exclude special education and sheltered employment. Believing so is in fact a legal mistake. Articles 24 and 27 of the UN Convention must not be subject to a summary reading and its interpretation must not lead to a legal loophole. Retaining that pure inclusion is the sole solution promoted by Articles 24 and 27 would on the contrary exclude many people with severe mental disabilities to whom mainstream education or employment might not only be inadequate but also aggressive. Articles 24 and 27 of the UN Convention do not ban special educational services and sheltered and supported employment.

The scope of Articles 24 and 27 must be read in light of the whole UN Convention. In particular, Article 3 recalls the following principles:

- Non-discrimination: to reach non-discrimination, positive measures such as supported or sheltered employment can be implemented;
- Full and effective participation and inclusion in society: inclusion does not exclude the possibility for regular companies to subcontract work to sheltered services; such contracting processes between the companies and the sheltered services under fair commercial conditions do constitute effective participation and inclusion, as any other subcontracting; then, through supported and sheltered employment services, people with disabilities do effectively participate in the society;
- Equality of opportunity: does not mean “identity of opportunity”;
- Respect for difference: specific educational services and sheltered services positively respond to this respect;
- Accessibility: these services permit an effective and adapted access to society.

Article 5 on equality and non-discrimination stresses that: ‘In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided’. It also adds that ‘specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination’. What is meant

by ‘reasonable accommodation’? Pursuant to Article 2 of the UN Convention, ‘Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’.

In fact, said provisions do encourage positive measures which might be needed for highly mentally disabled people for whom pure inclusion in mainstream school or in the open labour market might be ineffective with no respect of their abilities and differences. The notion of equality does not mean identity of measures and does not impede having recourse to positive measures which in the meaning of the UN Convention are to be specific measures. The issue is not so much to retain or ban special education or sheltered employment services but to carefully determine to whom such services must be offered and to guarantee that such services must always remain positive and support measures.

Although the alternative of specific services must not be excluded, it remains imperative that States promote and develop opportunities for children and adults with autism to receive education in mainstream schools and to work in the open labour market, inclusive and accessible to all.

### **3 National Measures for the Rights to Education and Employment**

Because of the variety of the needs, and because of the obligation to guarantee the rights of each person with autism, Kari Steindal quite correctly underlined, ‘A society that can cope with autism can deal with all other forms of disability. If Europe cooperates in helping people with autism and helps to meet the huge demands of this disability, it will be better equipped to support all other forms of disability’.<sup>7</sup>

As a matter of fact, it is the responsibility of national legislations to implement the right to education and to employment of people with autism and severe disabilities. In practice, the latter do not always enjoy positive discrimination, in terms of the adequate or appropriate support they are entitled to, in order to enjoy the effectiveness of their rights.

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<sup>7</sup> Council of Europe, Interview of Kari Steindal, ‘A society that can cope with autism can deal with all other forms of disability’. Interview available on the site of the Council of Europe. Kari Steindal is educationalist and principal adviser to the Autism Unit of the National Autism Network of Norway, University of Oslo.

### ***3.1 Positive Measures and Effectiveness of the Right to Education***

The 2003 and 2013 decisions rendered by the European Committee on Social Rights<sup>8</sup> and the 2009 Recommendation of the Committee of Ministers of the Council of Europe<sup>9</sup> constitute an interesting guidance for ensuring, at the national level, the effectiveness of the right to education of people with autism.

The States must guarantee the right to education, at all ages, to children and adults with autism ‘in particular by providing for the establishment or maintenance of institutions and services sufficient and adequate for this purpose’.

The golden rule is that children with autism should be given regular and specific teaching in mainstream schools wherever possible.<sup>10</sup> Schooling options, in no specific order, should be available to meet the diverse needs of the children.

The specialised institutions must ensure, through their internal organisation and their working methods, that guidance, education and vocational training are given priority over the other functions and duties that they may be required to perform under national law.<sup>11</sup>

Education itself must be based on detailed assessments identifying the needs and strengths of each child or adult. In order to meet individual needs, personalised plans must be defined and regularly reviewed with the person, his/her family and the professionals at stake. Said plans must facilitate the transitions within the education system and to adulthood and the employment. Support and opportunities for social inclusion are to be provided in whatever situation best fits the current needs of the person with autism.

Training and continuing programs must also be introduced for professionals involved in the education of children and adults with autism. Finally, research must always be pursued in order to constantly retain the best and most adapted educational and inclusion strategies.

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<sup>8</sup> Decisions rendered in 2003 and 2013 subsequent to the Collective Complaint no. 13/2002, *International Association Autism-Europe (IAAE) v. France*, and to the Collective Complaint no. 81/2012, *Action européenne des handicapés (AEH) v. France*.

<sup>9</sup> As indicated above, this Recommendation was the result of the work achieved by the ad-hoc committee directed by Kari Steindal and which permitted an efficient exchange of good national practices. Recommendation CM/Rec (2009) 9 of the Committee of Ministers to Member States on *the education and social inclusion of children and young people with autism spectrum disorders* adopted by the Committee of Ministers on 21 October 2009. Recommendation available on the site of the Council of Europe.

<sup>10</sup> Article 15 of the European Social Charter of 1996.

<sup>11</sup> Collective Complaint no. 81/2012, *Action européenne des handicapés (AEH) v. France*, available on the site of the Council of Europe, para 111.

### ***3.2 Positive Measures and Effectiveness of the Right to Employment***

States must promote and develop opportunities for persons with disabilities to work in a labour market which is open, inclusive and accessible to them. Pursuant to Article 27 of the UN Convention, people with autism have the right to employment in inclusive settings and the right to reasonable accommodation and support to enable them to work effectively.

To enable people with autism to gain employment and fulfil their potential at work, adapted support is indispensable. This support should always be tailored to each person's individual needs and depends also on the nature of the enterprise concerned. Numerous approaches for providing this support exist. Innovative practices include work experience programmes, adapted recruitment processes and specific forms of support in the workplace. Support in the workplace means adjusting the job description, working hours, workplace communication practices and physical work environment. Providing assistance with transport to and from work and using assistive technologies are also support means to be retained. As underlined by Autism-Europe, 'one of the most significant emerging forms of support for people with autism at work is the practice of having identified support people such as 'job coaches' or other staff members who are designated to assist a person with autism with the difficulties they encounter (. . .) Given that like all other people, the needs and abilities of people with autism in relation to employment can change over time, support should also be provided on an ongoing and/or as required basis, from preparation for employment through to retirement'. Positive emphasis must be placed upon the abilities of people with autism rather than their disability.<sup>12</sup>

If the principle of inclusion in the open labour market must be the rule, sheltered employment services must not be excluded. As sensibly and realistically underlined by Arthur O'Reilly,<sup>13</sup> recalling the International Labour Organisations and the Council of Europe positions:

It is generally accepted that for some disabled persons, open employment may not be a practicable option, for various reasons. In calling for measures to promote employment opportunities for persons with disabilities, ILO Recommendation No. 168 states that such measures should include "appropriate government support for the establishment of various types of sheltered employment for disabled persons for whom access to open employment is not practicable". The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities states that while the aim should always be for persons with disabilities to obtain employment in the open labour market, 'for persons with disabilities

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<sup>12</sup> Autism-Europe (2014).

<sup>13</sup> O'Reilly (2007). Dr Arthur O'Reilly is the former Assistant Director General of the Irish National Training and Employment Authority (FAS), and former Chief Executive of the National Rehabilitation Board and National Disability Authority. He was the President of Rehabilitation International and former Chairman of CEDEFOP, the European Centre for the Development of Vocational Training. Dr Arthur O'Reilly has also worked as consultant to the European Commission, OECD, UNIDO and ILO.

whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative' (Rule 7 (7)).

As ILO Recommendation No. 168 implies, there are possibilities for different types of sheltered employment (...)

"When government officials are asked to present their system of sheltered employment to foreigners (...), they will sometimes refer exclusively to organizations providing productive work (in industry or services) to persons with disabilities who have an employment contract and receive a wage. Other officials (...) may want to include organizations where productive work is certainly not the only and often not even the main aim and where persons with disabilities have no employment contract and receive no wages, but only a bonus in addition to their disability pension. Other interested parties, such as workshop organizations or organizations of and for people with disabilities, may share this view or disagree." (...)

The Council of Europe (1992) also uses a broad definition of sheltered employment.

"Sheltered employment should be open to people who, because of their disability, are unable to obtain or keep a normal job, whether supported or not; it can cover a number of diversified situations, amongst which are sheltered workshops and work centres. Sheltered work should have a double purpose: to make it possible for people with disabilities to carry out a worthwhile activity and to prepare them, as far as possible, for work in normal employment. To this end, all ways of facilitating the passage from supported to ordinary employment should be devised, such as: the setting up of sheltered work sections in work centres or work centres in sheltered workshops; the setting up of sheltered work sections or work centres within ordinary firms; individual or collective detachment of workers in sheltered workshops or work centres to ordinary firms."

### ***3.3 National Duty in Response to the International Legal Instruments***

Despite the complexity and cost for enforcing the rights to education and employment of people with autism, the States must, in the name of positive discrimination, take measures that allow achieving the objectives pursued by the international and European legal instruments which prohibit all forms of discrimination, direct and indirect, the latter arising when people with autism are given 'inappropriate treatment'.

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