



Recommendations to mainstream disability in the future Pillar of Social Rights

Fostering equal opportunities for people
on the autism spectrum

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Introduction

In March 2016, the European Commission published the first outline of the European Pillar of Social Rights (the Social Pillar) and opened the consultation for inputs from stakeholders. The stated aim of the Social Pillar is to provide a reference framework to screen the employment and social performances of EU Member States and drive reforms, in order to promote decent employment and social protection. Autism-Europe welcomes the proposal for a European Pillar of Social Rights, and the opportunity to feed into the elaboration of this important initiative through a participatory approach. Autism-Europe, however, encourages the European commission to ensure that the consultation is made accessible for people with intellectual disabilities.

Following an analysis of the proposal, and after consultation with its members and partners, in particular the [European Disability Forum](#), Autism-Europe would like to make the following comments and recommendations to address the current challenges faced by people with disabilities, and in particular people on the autism spectrum who represent an estimated 1% of the population across the European Union.

Autism-Europe welcomes the initiative aimed at promoting the enforcement of social rights

Autism-Europe welcomes the proposal for a European Pillar of Social Rights, and the objective to help enforce existing rights by promoting common core principles in the field of employment and social policy. However, another key objective should be to restore “social upwards convergence”.

Mainstreaming UNCRPD provisions and promoting the social and human-right approach to disability

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) should be mainstreamed throughout the Social Pillar. When the EU became a party to the UNCRPD, it committed to mainstreaming the convention throughout EU policies. The EU should therefore take stock of the [specific recommendations of the CRPD Committee](#) issued following the review process that took place in 2014-2015 that constitute clear guidance on the way forward to implement the UNCRPD.

Disability is currently specifically mentioned in Chapter III on adequate and sustainable social protection, in relation to disability benefits. Autism-Europe considers that putting the focus on disability benefits fails to adequately reflect the paradigm shift intended by the UNCRPD from a “medical” to a “social” and “human-rights approach” to disability. People with disabilities should also be addressed in relation to supporting access to education, training and transition towards employment in order to enjoy their human rights and be included in society.

Beyond “long-term care”, special attention should be paid to long term “support” in the community and this initiative should be linked to the deinstitutionalisation process to support community-based services for people with disabilities.

The Pillar of Social Rights should integrate other existing relevant EU instruments, such as the [Strategic Engagement for Gender Equality 2016-2019](#), and pay particular attention to the **intersectional discrimination** experienced by certain groups, such as girls and women with disabilities.

Enlarging the scope of the Pillar and ensuring impact

The proposal is currently intended to apply to Eurozone countries and will be open for other Member States to join on a voluntary basis. AE recommends that the initiative apply to the whole European Union. In the current context, it should also apply not only to EU citizens and legally residing third country nationals, but also include undocumented migrants and other groups in vulnerable positions, such as refugees.

Autism-Europe calls on the Pillar of Social Rights to be an ambitious instrument that will foster better implementation of social rights and existing policies at the EU level.

Fostering equal opportunities for people with disabilities, including people on the autism spectrum, in accessing education and the labour market

1. Promoting access to skills, education and lifelong learning as well as facilitating transition

The consultation document highlights the need to ensure that EU citizens have equal access to education. **Persons with autism are still discriminated against in the field of education across the EU**, as autistic pupils and students, especially those in need of intensive support, do not have adequate access to education services. Irrespective of their age, children and people with autism spectrum disorders should enjoy equal opportunities for educational interventions that are appropriate to their needs and work towards social inclusion.

In a European survey across 11 EU countries¹, only 4 countries declared that all children with autism participated in public education programmes. In the rest of the countries, most children with autism are trained at home (54%) and some are also educated through social services and / or private therapies (27%). Most of the countries (81%) stated that they have an inclusion model within their SEN schooling systems.

People on the autism spectrum have unique educational needs that are qualitatively different from other special needs and require specific understanding and approaches in order to be

¹ European Autism Information System (EAIS) Report on the 'Autism Spectrum Disorders Prevalence Data and Accessibility to Services. Manuel Posada, Patricia Garcia Primo, Maria José Ferrari and Maria Concepción Martín-Arribas. Research Institute for Rare Diseases, Instituto de Salud Carlos III, Madrid. March 2007

met². For persons in need of intense educational support, such as persons with autism, the **effectiveness of education is heavily reliant on the skills and competences of the teachers and on adequate educational strategies** to respond to their major learning difficulties. A lack of training about autism for school staff disadvantages persons with autism and therefore constitutes discrimination.

It has been demonstrated that the **financial crisis has negatively influenced efforts towards inclusive education**. Budget restrictions in education are likely to place persons who need more support and accommodating measures to learn, such as persons with autism, at a disadvantage and thus result in a difference in treatment, i.e. discrimination based on disability. In some countries, Article 24 CRPD is used as a justification to cut funds for special schools without adopting adequate legislation, policies and measures and without providing sufficient funding to support this transition, nor to ensure appropriate support and accommodation for pupils and students with autism in mainstream schools.

According to the UNCRPD, **persons with disabilities must have access to all levels of education including life-long learning**. Nevertheless, the level of access to vocational training for young persons and adults with autism in EU countries is even lower than access to compulsory education, or indeed non-existent. As an example, even in Italy, where the inclusion of children with disabilities is granted by law, among students with autism only 6.7% have access to upper schools, and only 3.3% to vocational training.

Access to quality lifelong education and training should be enhanced across the European Union for people on the autism spectrum. Article 24 of the UNCRPD should be implemented, and particular attention should be paid to training professionals to respond to the specific educational needs of autistic people.

2. Fostering equal opportunities to access employment

It is estimated that 90% of people on the autism spectrum are currently unemployed.³ However, many people on the autism spectrum could be included in the world of work with the necessary reasonable accommodation and transition support.

Across Europe, there is a serious lack of services to assist adults with autism in making the transition from school to adult life. This transition includes not only receiving vocational training or a higher education qualification, but also developing skills for independent living and social and communication skills for employment that are not taught in mainstream education institutions because people who do not have autism usually learn these skills from context. As a consequence, long-term outcome studies of adults in the United Kingdom, Canada, the United States and Japan have consistently reported low levels of independence and poor employment prospects. Even for individuals who have autism and only require a low level of support, the proportion in work rarely exceeded 30 percent, and the majority of their jobs were

² Council of Europe, 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)

³ Aspiritech, Autism Speaks, Specialisterne / The National Autistic Society (NAS) via the Association of Graduate Careers Advisory Services.

unskilled and poorly paid.⁴ **Research suggests that the outcome, in terms of independence and employment amongst more independent individuals with autism, is likely to be determined as much by the services to which they have access as adults, as by their own innate abilities.** The lack of support for the transition to adult life is even greater among those adults with autism who require higher levels of support.

Reasonable accommodation plays an essential role in combating disability-based discrimination. According to Article 5 of the EU Employment Equality Directive, reasonable accommodation should be provided in order 'to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training'. The CJEU clarified the issue of "reasonable accommodation" with a reference to the CRPD in its decision in *HK Danmark*, stating that correct interpretation should aim at the 'elimination of the various barriers that hinder the full and effective participation of persons with disabilities in professional life on an equal basis with other workers'.⁵ The CRPD defines reasonable accommodation in Article 2 as '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'.

For persons with autism, reasonable accommodation might specifically entail adapting selection procedures during the recruitment phase, ensuring appropriate training, coaching or peer-support, adapting the workplace communication, access to assistive technology, accommodation for sensory overstimulation to light and sound, for example, and altering standard working hours, etc. Training should also be on hand for employers to heighten their understanding of the needs of employees with disabilities.

Autism-Europe recommends interpreting the denial of reasonable accommodation in the Employment Equality Directive 2000/78 in light of the [Article 5 of the CRPD](#), and therefore as a form of disability-based discrimination.

The Pillar of social Rights should support transitions throughout the life-cycle including the transition from education to employment. Labour market participation of people with disabilities, including people on the autism spectrum, shall be enhanced through awareness-raising and training to respond to their support needs and provision of adequate support. Denial of reasonable accommodation should be considered as a form of discrimination. Special attention shall also be paid to actively support people with disabilities in employment through the provision of person-centered services.

⁴ Howlin P, Alcock J & Burkin C (2005). 'An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome', *Autism*, December, pp.533-549.

⁵ CJEU joined cases C-335/11 and C-337/11, *HK Danmark (Ring and Skouboe Werge)*, para 54.

Fair working conditions

When they are not unemployed, people on the autism spectrum are more likely to be in underpaid jobs or in sheltered workshop.

Criticism of sheltered workshops is centred around the segregation and exploitation of people with disabilities and the denial of their rights that has taken place in some of these workshops. This refers to, for example, workshops in which people with disabilities work in jobs that are below their level of skill, for pay that is below minimum wage, for organisations that profit substantially from exploiting their labour and offer them little or no opportunity to develop their skills for the open labour market. The people with autism who work in these sheltered workshops are often those who have been institutionalised and their participation in sheltered workshops has not been a result of the free choice of the individual or their family members. Clearly, these practices cannot, under any circumstances, be considered acceptable.

Sheltered workshops can be an employment solution for people with autism who are in need of a high level of support, for whom the open labour market cannot meet their needs and where a sheltered environment is more suitable or better able to support their needs. **They can be a viable alternative to the open labour market when, and only when, they prioritise the rights and complex support needs of the individuals that they support. Whenever possible, they should also ensure the transition of people with autism to the open labour market.** Certainly, like all other organisations that aim to meet the needs of people with autism, sheltered workshops must strive to make continuous improvements as the field of autism and employment develops and new knowledge becomes available.

Chapter II of the Social Pillar should include a clear reference to the protection from exploitation and forced labour, particularly among persons with intellectual and psychosocial disabilities, or persons deprived of their legal capacity ([Article 12 of the CRPD](#)).

People with disabilities should be supported to take part in the social dialogue

People with autism or with intellectual disabilities should be fully included in social dialogue. In order to facilitate their participation, they need to receive accessible information and/or training on understanding their rights at work, recognising violations of their rights and developing their skills in self-advocacy. People with disabilities should receive the necessary support in exercising their trade union rights and receive assistance in participating in processes related to labour rights and trade union membership.

Accessible information and support to take part in consultation should be granted to workers with disabilities in order for them to take part in social dialogue. People with intellectual disabilities shall have access to information in an alternative / augmentative format, such as easy-to-read.

Adequate and sustainable social protection

1. Enhancing access to social benefits and services and preserving freedom of movement

Social protection systems, poverty reduction programmes and access to disability related social security benefits fall under the shared competencies between the EU and Member States. Adequate and sustainable social protection and access to services are key to live one's life in dignity and autonomy (Article 28 of the CRPD).

Social services are important tools for the implementation of public policies in the field of social protection, non-discrimination, the fight against poverty and exclusion. Austerity measures have affected social services for persons with disabilities, enhancing the burden their support and assistance place on their families, as well as the risk of poverty because of the high financial contributions requested to access services. Because of the complexity and intensity of their support needs, the increase in personal contributions to be paid to services may exclude many persons with autism from enjoying them.

The Social Pillar should make reference to preventing and reversing the adverse and retrogressive effects of the austerity measures on the adequate standard of living of persons with disabilities, including through the provision of a minimum social protection floor in compliance with the recommendations of the CRPD committee to the European Union.

Persons with disabilities and their families should be able to enjoy their right to freedom of movement on an equal basis with others, including the portability of social security benefits in a coordinated manner across its Member States.

Restrictions in transferring social security benefits from one's Member State of origin when moving to a different EU Member State temporarily, difficulties in getting one's disability status recognised and additional bureaucratic burdens when moving to a different Member State permanently, particularly affect the freedom of movement of persons with autism within the EU, because of their needs for intensive and qualified support to move around.

Disparities in definitions of autism across the EU Member States⁶ and their medical approach undermine the right to freedom of movement of persons on the autism spectrum and of families with autistic children, as they determine inequalities in the recognition of disability-specific and individual needs of persons with ASD and in the provision of appropriate early intervention and quality services across the EU Member States.

The social pillar should tackle inequalities related to intra-EU mobility, including fostering the harmonisation of diagnosis and intervention protocols for person with autism across the EU. The Social Pillar should also promote the mutual recognition and provision of benefits, reasonable accommodation, individually-tailored support, education and habilitation programmes which are absolutely needed by persons with autism to be included and to participate in society.

⁶ European Commission Health & Consumer Protection, Directorate C - Public Health and Risk Assessment, C2 - Health information "Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union", 2005

2. Access to life-long support and long-term care

The section on long-term care in Chapter three of the Social Pillar should also make reference to the EU's and EU Member States' engagement towards deinstitutionalisation, in line with Article 19 of the UNCRPD. This chapter should not focus exclusively on the older people, but equally on persons with disabilities, and include "long-term support".

Because of the high prevalence of autism and the complexity of the associated support needs, coherent policies and measures are needed at the EU level to empower persons with autism to live independently and participate in the community. Because of the challenging behaviour they may exhibit, and due to existing prejudices about their capacity to live independently, autistic people, are at higher risk of institutionalisation. **Timely and ongoing access to appropriate and adequate individualised support is a precondition for them to develop the choice skills, independence skills and self-determination needed to live independently.** Lack of support and adequate childcare available for children on the autism spectrum, as well as lack of information and training for families on how to meet the specific and complex needs of children, also contribute to institutionalisation.

The Pillar of social rights should therefore promote a dignified life for all – including people who are not able to work - and consider the entire life-cycle.

What is the European Social Pillar?

In March 2016, the European Commission put forward a preliminary outline of what should become the European Pillar of Social Rights, otherwise referred to as the “Social Pillar”. A wide public consultation is taking place until the end of 2016 to allow Member States’ Authorities, social partners and European citizens to give feedback on the outline of the Pillar.

The Pillar will identify a number of essential social principles common to euro area Member States, focusing on their needs and challenges in the field of employment and social policies. The current proposal is that the Social Pillar will cover 20 domains, and will build on and complement the EU social “acquis” - the European legal order which is made up of treaty provisions, regulations, directives, policies, European Court decisions and other non-binding legal measures.

The Pillar touches on both on areas where the EU is competent to legislate, and on others where Member States are primarily responsible, and where the EU has a more supportive and complementary role. The Pillar does not, however, re-state or modify existing rights, which remain valid. Instead it aims to complement them by detailing a number of essential principles which should become common to participating Member States for the conduct of their employment and social policy

About Autism-Europe

Autism-Europe is an international association whose main objective is to advance the rights of people with autism and their families and to help them improve their quality of life. We ensure effective liaison among more than 80 member autism organisations throughout 30 European countries, including 25 Member States of the European Union, governments and European and international institutions. We also play a key role in raising public awareness, and in influencing the European decision-makers on all issues relating to the rights of people with autism and other disabilities involving complex dependency needs.

More information: <http://www.autismeurope.org/>

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or undersensitivity to sounds, touch, tastes, smells, light or colours. It is currently estimated that around 1% of the European Union is on the autism spectrum.



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