Reinforcing Social Europe:

European Pillar of Social Rights

Autism-Europe’s position on how to implement the European Pillar of Social Rights

November 2020
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Executive Summary

Autism-Europe welcomes the goals set out by the European Pillar of Social Rights and calls for a comprehensive and ambitious implementation plan of the “Pillar”. The plan should translate into concrete targets and timelines and clearly outline how the 20 principles announced will be implemented at every level of governance to set minimum social rights standards. Disability policies based on the principles set forth in the United Nations Convention on the Rights of People with Disabilities, should be mainstreamed into the practical application of all the existing principles as well as the European Semester process. Disability organisations should be involved in its implementation and monitoring, and ensure that the Action Plan urgently addresses the coverage of persons with disabilities in the Social Scoreboard.

Introduction

The European Pillar of Social Rights aims to deliver on new and more effective rights for European Union citizens and residents. It seeks to provide a framework for better assessing if countries’ social and employment policies are in line with EU recommendations, and for providing guidance on how to improve them.

On 14 January 2020, the European Commission presented a communication on building a “Strong Social Europe for Just Transition” that details the Action Plan on the Pillar. As an international association that represents autistic communities across the continent, Autism-Europe welcomes this announcement.

Shortly after the communication was published, COVID-19 spread across Europe and lead to the implementation of extraordinary measures. The COVID-19 pandemic caused disruption and uncertainty in the lives of people with disabilities, especially autistic people, and their families. COVID-19 has also shown that social issues such as loneliness, social isolation, relative poverty, lack of access to essential services, and loss of opportunity affected the quality of life of millions.

These are social challenges that autistic people and their families faced before the onset of COVID-19. However, they have been compounded by a lack of support that has been felt in many European countries. COVID-19 has brought a further fall in quality of life for autistic people and their families in 2020 and has also led to poorer outcomes related to health, social, financial, education, or employment issues for autistic people and their families.

Specifically COVID-19 has meant that autistic people and their families have often not been provided with accessible solutions for remote education, widening the digital gap between them and the rest of the population. Usual educational support services and the necessary reasonable accommodation have been widely disrupted, in particular school routines that are particularly important to many autistic children. People on the autism spectrum and their families have been particularly vulnerable to loss of opportunities in relation to employment during the pandemic. This situation has led to further income loss for many people on the autism spectrum and their families. Moreover, COVID-19 containment policies have made educational and employment mobility even more difficult.

Especially alarming is that COVID-19 related quarantines meant that that many people with disabilities, especially women and children, were institutionalised on a long term basis. The COVID-19 pandemic has also further emphasised healthcare inequalities for autistic people/ those with ID, likely contributing to disproportionate increases in morbidity and mortality in these groups.

Therefore, we welcome the commitments made by European Commissioner for Equality Helena Dalli to incorporate the lessons learned from COVID-19 in the Action Plan for the “Pillar”.
Equal Opportunities and Jobs for All

I. Empowering people through quality education, training and skills

The right to education is key to enable autistic people to develop to their full potential and be included in the community.

Education must be adapted to the needs of autistic people and their families. This also means that apart from teaching academic skills, education of people on the autism spectrum must include preparation for an independent life, adaptive behaviours and social skills. It means that inclusive education that take into account the accessibility and support needs of autistic people is necessary. However, inclusive education is limited across the European Union. There is little flexibility in curriculums, very little vocational educational training and people on the autism spectrum often face school exclusion.

Therefore, we recommend:

- Monitor the access to education of autistic learners and collect data and statistic across EU countries on their access to mainstream schools, to primary and secondary education, to vocational training and to employment
- Promote to access to universal, quality, affordable, inclusive education, and to individualised and specialised support for people requiring a higher level of support, taking into consideration their evolving capabilities
- Promote the use of EU Funding Programmes including EaSI, Erasmus+, ESF+ and InvestEU to fund the transition to fully inclusive education, notably training of staff on teaching and communication strategies for autistic people
- Uphol commitmment to ‘make lifelong learning and mobility a reality’ for all by making relevant programmes, such as Erasmus+, accessible to autistic people
- Establish common standards on the qualification of support teachers and assistants for autistic pupils and students
- Develop and adopt guidelines on the prevention of abuse and bullying against children on the autism spectrum in segregating and mainstream settings
- Support transition between the various education levels and employment
- Support the adoption of common standards for educational staff on the qualification of support teachers and assistants for autistic students and other types of disabilities
- Support the development of guidelines on the prevention of abuses and bullying
- Lead by example and improve the inclusiveness of European schools.

The proposal of the European Commission to reinforce the Youth Guarantee will help young people to get training; education and work. It also acknowledges the greater risks and barriers faced by young people with disabilities.

- To deliver on this objective, we recommend:
  - to acknowledge especially for young people with disabilities the need for flexibility when making paid work compatible with the eligibility of receiving disability entitlements, as a way of offsetting the additional costs they face in their daily lives
that funding to the Youth Guarantee helps cover other costs needed to facilitate the employment of certain young persons with disabilities, incl. supporting employers in providing reasonable accommodation for these young employee with disabilities

II. Supporting professional mobility and economic reconversion

We welcome that the European Commission wants all people to “have access to timely and tailor-made support; including training to improve chances of getting quality jobs or starting a business.”

To deliver on this objective, we recommend:
- To fund programs that ensure that people with disabilities can transition from education to employment and from one employment to another
- To support awareness-raising of employers about the potential of workers with disabilities to fight stigma and avoid the workplace discrimination they are subjected to
- To harmonise disability assessments recognition between EU member states to allow for the freedom of movement of people with disabilities

III. Creating more jobs

It is estimated that less than 10% of autistic people are in employment (mostly employed in low-paid jobs or in sheltered settings), this is significantly lower than the average employment rate of people with disabilities as a whole.

We acknowledged that on the occasion of a written parliamentary question on the integration into the workforce of people on the autism spectrum by Members of the European Parliament on the Committee on Employment and Social Affairs, the Commission regarded the future Strategy on Disability, the “Pillar” and the EU Directive 2000/78/EC on discrimination in employment, as policy frameworks for actions to help autistic people get into employment. Therefore, we remind the European Commission to follow up on proper implementation of each of these.

We welcome that the European Commission acknowledges that “socially responsible procurement can ensure that existing funds are spent in a way that support inclusion by for example providing jobs for people with disabilities”.

However, we also recommend:
- To improve EU-wide data collection on employment rate with a human rights-based approach, disaggregated by gender, age, disability type, ethnic origin, sexual orientation, etc., including people with disabilities who have until now been left out of the statistics
- To commit to step up the efforts to create an inclusive, accessible and non-discriminatory EU labour market for people with disabilities
- To push EU Member states to ensure reasonable accommodation for all people with disabilities in the workplace and to provide relevant training in accessible formats for employers and persons with disabilities
- To support social investment and initiatives for all people with disabilities
- To develop guidelines on sheltered workshops providing people with disabilities with skills to gain employment in the open labour market
- To use the European Social Fund Plus (ESF+) to foster employment of persons with disabilities
IV. **Fostering equality**

It is key to acknowledge the intersectionality of discrimination. We welcome that the European Commission aims at strengthening the inclusion of people with disabilities and create a fairer society. Moreover, we call on the to be particularly mindful of the situation of women and girls with disabilities who face particularly high levels of poverty, social exclusion and violence in the EU. Autistic women and girls can be especially vulnerable as they tend to be underdiagnosed due to a range of factors, which often equates to a lack of adequate support.

Therefore, we recommend:

- to adopt the proposed horizontal anti-discrimination directive, thereby extending protection to people with disabilities outside employment
- to consider the difficulties women and girls with disabilities face accessing education and employment, and other areas of life
- to explicitly address the gender pay gap, pension gap and care gap of parents, especially mothers (with or without disabilities) of children with disabilities
- Fully implement the Work-Life Balance Directive and strive to go beyond the minimum requirements established in the Directive and make use of infringement procedures if Member States do not comply with the provisions in the Directive.
- To promote adequate support in the community and assistance so that families can raise their children at home and prevent institutionalisation
- to address the situation faced by women and girls locked in institutions due to their disability, who are at even greater risk of violence, cannot access empowerment initiatives and are segregated from their communities
- to ratify the Istanbul Convention

Moreover, we welcome the European Commission commitment to the **European Accessibility Act**. However, while the EAA is a step in the right direction, its scope remains restricted as it covers computers and operating systems, ATMs, ticketing and check-in machines, smartphones, TV equipment related to digital television services, telephony services and related equipment, access to audio-visual media services such as television broadcast and related consumer equipment, services related to air, bus, rail and waterborne passenger transport, banking services, e-books and e-commerce. However, the EAA does not explicitly address important areas, such as the built environment.

To deliver on this objective, we recommend:

- An ambitious transposition and implementation of the European Accessibility Act (EAA) in the member states
- to complement the limited scope of the EAA via other legislative instruments, with accessibility requirements that take into account access needs of autistic people
- Availability of documents in easy-to-read/understand or other alternative-augmentative formats.
- to address accessibility needs for all types of invisible disabilities to ensure a holistic approach to accessibility
- to expand the scope of the EU disability card
- the creation of an EU Access Board
Furthermore, we welcome the commitment to adopt an ambitious European disability strategy.

**And we recommend:**

- that the UNCRPD is mainstreamed across all actions of the Pillar, and other equality strategies
- to ensure coherence and appropriate links between the different strategies that are foreseen in the field of equality
- to pay particular attention to the intersectional discrimination experienced by certain groups such as women as well as ethnic and sexual minorities with disabilities
- help drive a change of mind-set in society to support the active participation and inclusion of people with disabilities
- the next European disability strategy to take into account the full diversity of disability, support and accessibility needs with clear benchmarks and indicators as well as adequate data collection, disaggregated by types of disabilities, gender and age
- a well-resourced monitoring mechanism, with CPRD focal points in all EU institutions and agencies, and an efficient coordination mechanism within and between the institutions
- that persons with disabilities and their representative organisations are supported to meaningfully participate in the implementation up to the evaluation of the Pillar and the strategy

**Fair Working Conditions**

We welcome that the European Commission wants every worker to have a fair minimum wage to allow for a decent living.

**Yet we recommend to:**

- Pay particular attention to the risk of in work poverty for people with disabilities, as they face additional costs due to their disability
- Ensure minimum wage for people with disabilities in sheltered workshops
- Set the minimum threshold for adequate minimum wages at least 60% of the national median wage to enable people a life of dignity;
- Use reference budgets to ensure adequate minimum wages are actual living wages in all Member States
- Ensure increases in adequate minimum wages go hand in hand with increased funding for social service providers to avoid the quality of services and the availability of staff being undermined by minimum wage requirements.

**Social Protection and Inclusion**

I. **Securing high social protection**

The European Commission wants to ensure the protection and inclusion of all people in the European Union. They plan to do this through programs such as the European Unemployment Benefit Reinsurance Scheme aimed at protecting EU citizens and residents by reducing the pressure on public finances during external shocks.

The European Commission has planned initiatives for the Health Union and affordable health care. We welcome that the European Commission makes the connection between poverty and health pointing out that on average people who live in poverty live 6 years less. We would like to remind the European Commission that there is also a link between disabilities and health. In fact, autistic people die on
average 16 years earlier than the non-autistic population. A study in the UK found that “autistic adults with a learning disability are 40 times more likely to die prematurely due to a neurological condition, with epilepsy being the leading cause of death”.

We acknowledge the fight against cancer by the European Commission. Yet we like to remind the Commission that cancer and other health issues can be experienced differently by people with disabilities and can be less obviously recognized by health professionals. This is especially true for the mental health problems of autistic people. Finally, we welcome the initiatives taken by the European Commission on aging.

**Recommendations:**

- Ensure that people with disabilities can fully benefit from the European Unemployment Benefit Reinsurance Scheme.
- Foster accessibility and reasonable accommodation of healthcare services (including somatic health, mental health, dental care, emergency and preventive services)
- Promote training in autism and accessible communication in the curricula of all healthcare professionals and other relevant staff
- Ensure that EU funds are not invested in the construction or refurbishment of institutional care settings
- EU funds to be dedicated to the transition towards community-based care ensuring self-determination and social inclusion of autistic people and their families – and ensure proper monitoring
- Support the development of services to support transition
- Support the adoption of quality assessment systems for support services which are centred on outcomes in terms of inclusion, employment, participation and quality of life
- Address the specific needs of elderly people with disabilities.

**II. Fighting poverty and exclusion**

We welcome the initiative to fight poverty and exclusion in the EU.

**We recommend:**

- to adopt a European initiative on long-term care that is compliant with the UNCRPD and promote evidence-based recommendations for the development of long-term care and support services across the EU and the key quality principles to be ensured
- to fund availability of affordable, flexible, quality and comprehensive community-based services leading to deinstitutionalisation for people with disabilities, while following a right-based approach to disability
- to ensure access to individualised support focusing on positive outcomes for people with disabilities, and involve them in designing and improving the care they receive to inclusion and support for autonomy and self-determination of people with disabilities
- to improve support at transitional stages of life, e.g. for the transition within different stages of education and from education to employment for people with disabilities
- Improve the working conditions in the long-term care sector, including the support for informal and family carers
- Reduce the overreliance on informal long-term care and the overburdening of informal carers

More concretely as **children with disabilities** are more excluded and prone to poverty, we welcome the encouraging focus on social provisions contained in the **Child Guarantee**, namely free education, adequate nutrition, accessing healthcare, having decent housing and early intervention provision for all
children in the EU.

We also recommend:

- Adequately addressing the needs of children with disabilities where these services exist
- to working towards a more inclusive society where the rights of children with disabilities can be fully realized
- to mainstreamed disability in the future Child Guarantee scheme, while also mainstreaming the rights of children with disabilities in all relevant EU policies
- drafting or reviewing specific frameworks for children with disabilities
- helping EU Member States to properly implement the United Nations Convention for the Right of the Child (UNCRC) to advance the rights of children with disabilities in the EU
- providing funding for projects on rights of children with disabilities inside the EU
- capacity-building and training for professionals dealing with children with disabilities
- to address children with disabilities in institutions by enabling funding for their transition to community-based case

Promoting European values in the world

We welcome that the European Commission wishes to promote the European Union values throughout the world.

Recommendations:

- The European Commission should promote the ratification and proper implementation of the UNCRPD in European third countries (e.g. Liechtenstein) and around the globe through international cooperation and EU aid
- The European Commission should call out against international agreements violating the text and spirit of the UNCRPD (e.g. the additional protocol on forced treatment of the Council of Europe Oviedo Convention against which we campaign ["Withdraw Ovideo"] together with other ENGOs)

Working together

We work together by sharing our recommendations during the consultation process. This position paper is our contribution to this process. Beyond this we continue to work together with the European Commission on all issues pertaining people with disabilities. We welcome the cooperation with the European Commission.

Published with the support of the DG EMPL — Directorate-General for Employment, Social Affairs and Inclusion of the European Commission, under the European Community Programme – Rights, Equality and Citizenship. The information contained in this publication does not necessarily reflect the views or opinion of the European Commission.