

Inclusion Europe's contribution to the mid-term review of the European Disability Strategy

Introduction

Inclusion Europe aisbl., the European Association of Persons with Intellectual Disabilities and their Families, is the European voice and representation of 69 member organisations of people with intellectual disabilities and their families in 37 European countries. The rights of persons with intellectual disabilities are often violated and their voice is neglected in policy and decision-making processes both at national and European level. Inclusion Europe is the only European-level organisation that represents the rights and interests of people with intellectual disabilities and their families in a democratic way. Since 1988, Inclusion Europe advocates for the full participation of children and adults with intellectual disabilities and their families in all spheres of life on an equal basis with others.

Inclusion Europe very much welcomes that on 23 December 2015, the European Commission published a public consultation on the mid-term review of the European Disability Strategy 2010-2020 (the Strategy). The launching of this review process follows the Concluding Observations that the UN CRPD Committee made earlier in 2015 regarding the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, or Convention) at EU level.¹ In these recommendations, the Committee particularly called the EU to:

'carry out the mid-term assessment of the European Disability Strategy 2010-2020 and establish clear guidelines for including the recommendations in the present concluding observations, with clear benchmarks and indicators, in close consultation with persons with disabilities and their representative organizations'.

Considering that the European Union ratified the Convention in 2010, all EU laws and policies, as well as the internal operations of EU administrative bodies must comply with the legal obligations of the CRPD. In order to achieve that, concrete steps should be taken to fulfil the recommendations made by the CRPD Committee after the first periodical review.

The European Disability Strategy covers eight main areas: Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health, and External action. The overall aim of the Strategy is to empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society and in the European economy.² As part of preparing Inclusion Europe's answer to the mid-term review of the European Disability Strategy,

¹ CRPD/C/EU/CO/1.

² European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe (COM/2010/0636 final).

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we have launched an online data collection between 19 January – 26 February 2016 to ask our members about two main questions:

1. What kind of barriers they face in the areas that are covered by the Disability Strategy?
2. What should the European Union do to improve the situation?

In this submission, we will provide a brief overview on the commitments that the EC made in the Disability Strategy to improve the lives of persons with disabilities, then discuss what the UN CRPD Committee recommended to the EU in order to improve the situation in the relevant areas. Furthermore, this submission summarizes the data we gathered from our membership on the seven areas of the Strategy that are most relevant for them. We would like to hereby thank to the large number of self-advocates and family members who filled out our online questionnaire.

The aim of this paper is twofold. On one hand, we would like to turn the European Commission's attention to the barriers that our members face in their everyday life, and on the other hand, we would like to address their recommendations to the EU on how could the situation be improved. We will discuss the seven policy areas that are covered in the European Disability Strategy and we hope that the EU will consider our recommendations when reviewing the Strategy and will develop benchmarks and indicators that can contribute to the socio-economic inclusion of all persons with disabilities.

1. Accessibility

Overview

The European Disability Strategy defines accessibility as people with disabilities having access, on an equal basis with others, to the physical environment, transportation, information and communications technologies and systems (ICT), and other facilities and services.³ The Strategy highlights that accessibility is an important pre-condition for participation in society and in economy. The European Commission committed itself to support activities that would remove barriers, increase the availability of assistive technologies, promote the incorporation of accessibility and 'design for all' in the education curricula of many professions. This wording is in line with the provisions of Article 9 of the CRPD.

Article 9 of the CRPD further indicates that barriers to accessibility must be eliminated in the areas of buildings, roads, transportation and other facilities, including schools, housing, medical facilities and workplaces, as well as information and communication, including electronic and emergency services. The CRPD Committee has developed a General Comment on Article 9 CRPD⁴ to provide a detailed explanation of the provisions on accessibility. States Parties to the

³ Ibid.

⁴ <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G14/033/13/PDF/G1403313.pdf?OpenElement>

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UN CRPD must ensure that they implement Article 9 CRPD fully and take the General Comment as the basis for interpreting its provisions.

Persons with intellectual disabilities face significant challenges in accessing public goods and services as well as information in the EU. The lack of easy-to-read information and usability standards for persons with intellectual disabilities presents one of the greatest barriers to their full participation as European citizens. In line with the EU's competencies to act on issues relating to accessibility and towards the full implementation of the CRPD, it is necessary to make concrete steps that will provide genuine and consistent access to goods and services to adults and children with intellectual disabilities.

The European Commission has published the draft European Accessibility Act (EAA) in December 2015. Inclusion Europe has welcomed the proposal and published its position about the text with highlighting some necessary changes to ensure the rights of persons with intellectual disabilities will be fully covered by the Directive.⁵ We hope that the EAA will be soon adopted to remove many of the existing barriers that prevent persons with disabilities from participating in society.

Main challenges in the area of accessibility

Inclusion Europe's members reported that they face significant barriers to be included in the community and access the transport system, public websites, cultural programmes, or services. As one of them highlighted, **'persons with intellectual disabilities face significant challenges in accessing information, because of the lack of easy-to-read information and usability standards for persons with intellectual disabilities'**. We are convinced that accessible information would be beneficial for the whole population, but unfortunately the lack of accessible information in the area of education, training, employment, transport, community and political participation, health and access to justice presents a great barrier for most persons with intellectual disabilities across Europe. People with intellectual disabilities often do not receive accessible information about their human rights, and it leaves them in a particularly vulnerable situation.

What should the EU do to improve the situation?

Our members said that the EU must adopt swiftly the European Accessibility Act to ensure that persons with disabilities can access goods and services. However, it is necessary to strengthen the requirements to meet with the accessibility needs of persons with intellectual disabilities, as this group is one of the most marginalised. It is important to consider not only the **translation to easy-to-read**, as a necessary measure, but carry out actions to **simplify structures and processes** when developing new goods and services as part of 'Design for all' approach.⁶ **Mainstream protection mechanisms** and services, including banking system, health care, legal protection for tenants, rights of employees and consumer protection **should be more**

⁵ http://inclusion-europe.eu/wp-content/uploads/2015/03/IE_policypaper_EAA_final.pdf

⁶ See more about the necessary accessibility requirements for persons with intellectual disabilities at: http://easy-to-read.eu/wp-content/uploads/2014/12/EN_Information_for_all.pdf

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inclusive and accessible for persons with intellectual disabilities. Inclusion Europe's members also called the EU to adopt the Web Directive on the accessibility of the public sector bodies' websites. Furthermore, the EU should invest in training service providers, with special regard to staff of health care and social services about the accessibility needs of persons with disabilities. Furthermore, EU Funds should be spent only on projects and investments that contribute to increasing the accessibility and removing barriers for persons with disabilities.

2. Participation

Overview

'Participation' stands as a leitmotiv throughout the whole CRPD, guaranteeing inclusion in all areas of life. The Convention aims to achieve participation by eliminating discrimination and removing various types of barriers (legislative, environmental, attitudinal) as described in Article 5 of the CRPD.

The European Disability Strategy acknowledged that persons with disabilities face many obstacles to participate in society and practice their fundamental rights, including the rights as EU citizens. This includes the right to vote and stand as candidates at European elections, the involvement in policy and decision-making processes, the freedom movement, or the right to live in the community.

In its Concluding Observations, the UN CRPD Committee recommended the EU to develop a structural dialogue to consult with persons with disabilities in a meaningful way, to enable all persons with all types of disabilities, including those under guardianship, to enjoy their right to vote and stand for election, by providing accessible communication and facilities, and to ensure that EU funds will foster deinstitutionalization and the development of accessible support services in the community.

The European Commission has introduced the European Disability Card in 2015. Inclusion Europe welcomes this initiative that aims to improve the mutual recognition of the rights and benefits of people with disabilities in the European Union Member States in the areas of culture, leisure, transport and sport at home and abroad. However, we know that persons with intellectual disabilities face significant barriers in other matters related to free movement, such as accessing public services and information, education, employment, social and health services.

Main challenges in the area of participation

Inclusion Europe's members clearly addressed in their responses that the **deprivation of legal capacity** for persons with intellectual disability presents the greatest barrier to participation in society on an equal basis with others. People who are placed under guardianship are denied the right to make their own decisions about where and with whom they want to live, they cannot marry, vote or stand as candidates at local, national or European elections, engage in financial

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matters, or enter the free labour market. Persons under guardianship cannot make their voice heard, or choose the support services they want to use. This can lead to **full exclusion from society, isolation in institutional settings**, where their fundamental rights are violated on a daily basis without effective remedy, or support. Independent living is still a great challenge for persons with intellectual disability, as they often **don't have access to personal budgets, allowances and personal assistance, which could contribute positively to their independence and choices**.

Since 2008, the financial crisis and recession hit European countries and impacted economies by growing deficits, rising unemployment, and less public income. As a result of that, EU Member States took austerity measures to stimulate economic growth by reducing public spending. Unfortunately, those **austerity measures had a disproportionately negative effect on benefits, provisions and support systems for persons with disabilities**.⁷ Austerity measures have reduced the budgets of local and regional authorities with direct consequences on the availability of social services and benefits for individuals.⁸ It is important to note that there have been far less budget cuts on institutional largescale provisions and support systems for people with disabilities such as residential institutions, or special schools. In line with Article 19 of the CRPD, segregating measures must be tackled and investment should only target forms of care that contribute to the inclusion of all persons with disabilities in the community. It is especially concerning, that persons with complex needs and elderly people with intellectual disabilities are regularly considered as unable to live outside of long-term institutional care.

What should the EU do to improve the situation?

In line with the recommendations of the CRPD Committee, the EU should take concrete actions to ensure that all persons with disabilities can enjoy their fundamental rights on an equal basis with others. This includes **promoting the abolishment of forms of substituted decision-making (guardianship)** in the Member States and **promote supported decision-making**.

The EU should also take concrete measures to promote the meaningful participation of persons with disabilities in law and policy-making processes, provide them with **accessible information about on-going initiatives** and invest in the **capacity building of the representative organisations of persons with disabilities**. EU Funds should be available to **develop support services for persons with disabilities** with special regard to those in a particularly vulnerable situation, such as prisons, institutional settings, or psychiatry etc.

Since the European Disability Card will only affect a small number of areas, we advise the European Commission to see the introduction of the Disability Card as only a first step, with a view to eventually expanding the scope of the Card and ensuring persons with disabilities can travel throughout the European Union on an equal basis with other European citizens.

⁷ <http://www.enil.eu/category/news/austerity-measures/>

⁸ Opinion of the European Economic and Social Committee on Long Term social care and deinstitutionalization (27/05/2015) <http://www.eesc.europa.eu/?i=portal.en.soc-opinions.33311>

3. Equality

Overview

In line with the Articles 10 and 19 of the Treaty on the Functioning of the European Union and Articles 1, 21 and 26 of the Charter of Fundamental Rights of the European Union, the EU shall promote the equal treatment of persons with disabilities. The European Disability Strategy aims to combat discrimination on the basis of disability by ensuring the full implementation of the Directive 2000/78/EC on equal treatment in the area of employment and promoting the conformity Member States' legislation on legal capacity with the UN CRPD.⁹ Unfortunately, still until today there are many examples of discrimination against people with intellectual disabilities in employment and occupation, as well as in other areas of life. Children and women with intellectual disabilities are in a particularly vulnerable situation due to multiple discrimination. Inclusion Europe's submission to the UN CRPD Committee to the draft General Comment on Article 6 (Women with disabilities) summarises our views on the various forms of discrimination that women with intellectual disabilities are facing.¹⁰

Under Article 5 of the CRPD, the EU has clear obligation to

‘...prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.’¹¹

The Convention also requires States Parties to provide reasonable accommodation and other measures to ensure de facto equality. During the review of the EU, the CRPD Committee called the EU to adopt its proposed horizontal directive on equal treatment, extending protection against discrimination to persons with disabilities, including by the provision of reasonable accommodation in all areas of competence.¹²

Currently, the EU anti-discrimination legislation does not protect against multiple or intersectional discrimination, based on age, disability, sexual orientation, gender identity, race, ethnic and social origin. While persons with disabilities are only protected against discrimination in employment and vocational training, protection for other grounds, like gender, ethnic origin or race goes much further. Inclusion Europe has been advocating for many years for the adoption of a horizontal Equal Treatment Directive. This new Directive should ensure that protection is guaranteed in other areas, such as social protection, social advantages, health, access to and supply of goods and other services available to the public, including housing, education and insurance. The proposal for the Directive has been on the table of the Council of the European Union since 2008 and the adoption is blocked due to the resistance of some Member States.

⁹ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>

¹⁰ http://inclusion-europe.eu/wp-content/uploads/2015/03/IE_submission_GC_Art.6-CRPD.pdf

¹¹ UN CRPD, Article 5.

¹² CRPD/C/EU/CO/1.

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Main challenges in the area of equality

Legislation, policy and current practice fail to promote the equal rights of persons with intellectual disabilities, particularly in the areas of education and training, employment, private and family life, access to justice, political participation, living in the community and health. **People who are under guardianship are denied to be recognised before the law** on an equal basis with others. The process in which one is losing his/her legal capacity is often discriminatory, as the decision is automatically made if someone has an intellectual impairment. Women and children with intellectual disabilities often suffer from **multiple discrimination**.

In line with the UN CRPD, the **denial of reasonable accommodation** constitutes discrimination, however persons with intellectual disabilities often do not receive reasonable accommodation to enable them to study in mainstream education, take up a job in the open labour market, live in the community, or participate in political and public life.

Finally, an aspect of discrimination that is very important to us is often overlooked in discussions about discrimination: the “**discrimination by association**” that especially family members of people with intellectual disabilities face. In many countries in Europe they are denied equal opportunities, either in economic terms or in terms of full participation in society.¹³

What should the EU do to improve the situation?

The **legal protection against discrimination on the basis of disability should be strengthened**. Persons with intellectual disabilities need **adequate protection** and **reasonable accommodation** in all areas of life to be able to participate in society on an equal basis with others. Inclusion Europe calls the EU to swiftly **adopt the horizontal Equal Treatment Directive** in order to implement the provisions of the CRPD in the area of non-discrimination across all EU Member States. Our members encountered that the lack of awareness and knowledge about the rights of persons with disabilities at National and EU level also amounts in direct and indirect discrimination.

The EU should **promote the introduction of supported decision-making** in all EU Member States and realise that the denial of legal capacity has a negative impact in all aspects of life and undermines the fundamental principle of equality. **Training** should be provided and good practices should be exchanged across all EU Member States **to support governments** in drafting new, more CRPD compliant legislation.

¹³ http://inclusion-europe.eu/wp-content/uploads/2015/03/Discrimination_by_association_position_paper_inclusion_europe.pdf

4. Employment

Overview

“States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.” With its special competences in the area of employment, the European Union has also a specific responsibility to guard and implement this principle of the UN CRPD.

While employment rates of people with disabilities are generally low in Europe, the situation for people with intellectual disabilities is even worse. Figures from Member States suggest that in some countries more than 80% of people with intellectual disabilities remain unemployed¹⁴. In other countries, the employment rate is higher due to the provision of sheltered workplaces, but here the majority of workers have no employee status. The employment rate of people with intellectual disabilities in the open labour market is extremely low in all EU countries.

Despite its competencies, the European Union does not protect people with intellectual disabilities from discrimination on the basis of disability “with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions”. It also does not contribute sufficiently to the implementation of all other obligations of States Parties in the area of employment that are enshrined in the Convention.

Main challenges in the area of employment

Discrimination of people with intellectual disabilities in access to employment takes many forms. One of the most current barriers in access to work is still the **outdated legal capacity legislation** in many European countries. Without the capacity to sign work contracts, people with intellectual disabilities cannot legally work. If they live in residential institutions or work in sheltered workplaces, they often **do not earn a real salary** or their salary is kept by the institution.

Indirect discrimination against people with intellectual disabilities in recruitment is extremely common. School leaving certificates are requested even if there is little or no connection to the job in question. Thus, people with intellectual disabilities are excluded from jobs they could perform with little or no support. This is increased by the lack of knowledge about reasonable accommodation measures and a lack of support services. Even where job coaches or other support services exist, they are virtually unknown to potential employers.

¹⁴ Of the 26.786 adults with a Learning Disability known to local authorities in Scotland in 2014 only 1.782 were listed as in employment with only 875 listed as being in open, paid employment. The majority of adults with intellectual disabilities in Cyprus are rather unemployed (84%) or underemployed.

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An important problem for the employment of people with intellectual disabilities is also the “**benefit trap**”. Legislation about social benefits in most Member States does not allow people to return to a disability benefits scheme after they have worked in open employment. This creates a huge barrier for persons with intellectual disabilities who may want to try working in the open labour market. The European Disability Strategy states as one of its objectives to “fight those disability benefit cultures and traps that discourage them from entering the labour market”. Unfortunately, the past 5 years have not seen many successes in this direction.

In many countries, adults with intellectual disabilities can hardly join the open labour market because they lack the appropriate skills and because there are **not enough accessible work places**. As for the smooth transition from school to working life, weaknesses exist in relation to the acquisition of professional and social skills. In addition, there is still a **pay gap among persons with intellectual disabilities and other workers**.

What should the EU do to improve the situation?

At the level of the European Commission, Inclusion Europe proposes **to take action against discrimination of people with intellectual disabilities who are involved in European projects**. Secondly, the Commission should develop **non-discriminatory recruitment methods** and enforce those also in the procurement of external services to end the indirect discrimination of people with intellectual disabilities in accessing the European institutions as employees. Finally, it is absolutely essential to **recognise all legal capacity legislation that hinders access to employment as direct discrimination against people with intellectual disabilities**.

5. Education and training

Overview

Inclusion Europe's submission to the CRPD Committee regarding the General Comment No.4 on Article 24 summarises our views on access to inclusive education in the European Union.¹⁵ It shows that most children and adults with intellectual disabilities do not have access to inclusive education of a sufficient quality. Acknowledging the lack of EU competencies in this sector, even the targets set by the European Disability Strategy have so far not been achieved, such as promoting inclusive education and lifelong learning for pupils and students with disabilities.

Statistics show that segregation of students with disabilities increased in Europe since 2008 from 2,0 % to 2,25 % in 2012¹⁶. There is evidence suggesting that mostly students with intellectual disabilities and complex needs are being segregated. This is considered to be a result of implicit policies regarding children with intellectual disabilities and complex needs as too difficult or too expensive to be included in the general educational system.

Main challenges in the area of education and training

There is **not enough awareness and training for mainstream school staff** regarding the needs of students with intellectual disabilities. Students are often wrongly labeled by teachers. In addition, a number of students with specific learning difficulties are not being identified and subsequently fail as they are not provided with reasonable accommodation. A very serious issue is the **transition from school to work**. Some efforts have been made for appropriate training of educational personnel on the approach of students with disabilities who are integrated into mainstream schools but are still in early stages. As regards inclusive education there is a **lack of personalized approach of students** and their preparation about developing individual skills, mobility skills and skills for their integration in the open labour market. Unlike their integration in mainstream schools, children with intellectual disabilities after the age of 21 are forced either to join institutional forms of day care or stay at home.

Inclusion Europe's members report a **discrepancy between the displayed policy orientation towards inclusive education and the lack of political will to overhaul the school system accordingly**. Mainstream schools are not sufficiently inclusive (lack of adaptation to the learning needs of each child, lack of training for teachers, lack of assistants in the classroom, lack of adapted methods and programmes, lack of resources, etc.). Special schools are not given enough means to work in partnership with mainstream schools and to transform themselves into resource centres. There is a lack of support to ensure access to day care

¹⁵ www.e-include.eu/images/PDF_files/Inclusion_Europe_Submission_GC4_Art24.pdf

¹⁶ Based on Special Needs Education Country Data 2008, 2010 and 2012 by the European Agency for Development in Special Needs Education. https://www.european-agency.org/sites/default/files/special-needs-education-country-data-2008_SNE-Data-2008.pdf / https://www.european-agency.org/sites/default/files/special-needs-education-country-data-2010_SNE-Country-Data-2010.pdf / https://www.european-agency.org/sites/default/files/sne-country-data-2012_SNE-Country-Data2012.pdf

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activities before and after school. As a result of all this, the right to education is not effective for all children with intellectual disabilities.

Despite of the commitment in the European Disability Strategy to “increase knowledge on levels of education and opportunities for people with disabilities”, there are still **no reliable and comparable data about inclusive education of people with (intellectual) disabilities**. Especially concerning is the fact, that there is also no data available about school-age students in so-called “home-school programs” or in long-term residential institutions, who are not attending regular schools. Disaggregated statistics of the reasons for their non-attendance are essential for educational planning.

What should the EU do to improve the situation?

While recognizing the limited competences of the European Union in the area of education, the European Disability Strategy should fully be aligned with and support the implementation of the CRPD General Comment No.4. It has a specific responsibility in the areas of **data collection, monitoring, exchange of experiences and professional training**.

Students with disabilities must have appropriate training and assistance. Furthermore, staff members of mainstream schools must receive capacity building training to be able to help students and their parents. As far as actions for education and vocational training, there should be a conclusive plan for the programming of educational programmes and developing skills and capacities from the early stage, at which the child enters primary education. **Guidelines should be published** about the smooth transition from one level of education to another based on **individualized programmes**.

It is also essential that the European Union promotes, develops and enforces the **compulsory inclusion of comprehensive special education units of learning in all university courses** that lead to a degree **in teaching**. The EU should also promote **research on inclusive education** as well as the dissemination of the results of this research.

6. Social Protection

Overview

Direct and indirect discrimination, financial disadvantages and social isolation are the main reasons that persons with intellectual disability and their families are more vulnerable than others to social exclusion. This is a reality in all Member States of the European Union as well as in accession countries. Lower participation in general education and in the open labour market lead to income inequalities for people with disabilities and further amounts in social exclusion and isolation. The European Disability Strategy addressed that persons with disabilities need to be able to benefit from social protection systems and poverty reduction programmes, disability-related assistance, public housing programmes and other enabling services, and retirement and benefit programmes. The Commission committed itself to assess

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the adequacy and sustainability of social protection systems for persons with disabilities. As we mentioned earlier in this submission, austerity measures hit this group disproportionately and in many countries there have been cuts on the social benefits and allowances for persons with disabilities. This unfortunately affected a lot of services that supported people in the communities and caused a human rights crisis for many people.

The UN CRPD Committee noted in their Concluding Observations that the austerity measures had a retrogressive effect on the adequate standard of living of person with disabilities. The Committee therefore called the EU to take urgent measures to avoid further effects by setting a social protection floor that respects the core content of the right to an adequate standard of living and to social protection.

Main challenges in the area of social protection

In some countries the **minimum income scheme remains below the poverty line**. Furthermore, there are often territorial disparities concerning the grant of the special allowance designed to cover the expenses linked to disability. We know from our membership that people who are entitled to receive this allowance are entitled to less and less since the economic crisis. In countries where current policies grant allowances and benefits for persons with disabilities, measures do not go further than securing the minimum standard of living and **there is no comprehensive strategy to develop more sustainable inclusive policies**. Most persons with intellectual disabilities **live in poverty and cannot afford to live independently in the community**. They often have to choose between taking up a job or receiving disability benefits, which prevents many from taking a risk and potentially losing the benefit as a stable income. However, this situation keeps them away from the labour market and they will continue to be dependent on social benefits throughout their lives.

What should the EU do to improve the situation?

The EU should ensure the **inclusion of all persons with disabilities in the mainstream education system** to provide people with the opportunity to receive training and obtain the necessary certificates to apply for jobs in the open labour market. **Enterprises and employers should be motivated to employ persons with disabilities**, through tax exemption or other measures and further provide them with the necessary adjustments or reasonable accommodation to support them to perform in their full potential.

European Social Funds should help EU Member States that face economic problems to spend on **maintaining the social protection system** and do not cut the benefits of the most vulnerable parts of society, with special regard to families who raise children with profound intellectual disability and complex needs.

7. Health

Overview

“We have a lower life expectancy than others within Scotland, on average we die 20 years younger”. This sentence of a self-advocate from Scotland summarises the health situation of people with intellectual disabilities in the whole of the European Union. Various reports focus on the blatant discrimination in access to and within health services in all European countries that is experienced by people with intellectual disabilities. The implementation of Article 25 CRPD that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” is thus dramatically lacking with the result of suffering and early death of many individuals.

The Commission failed to support – as foreseen in the Disability Strategy - policy developments for equal access to healthcare or to effectively pay attention to people with disabilities when implementing policies to tackle health inequalities.

Main challenges in the area of health

In general, there is a **lack of knowledge and awareness about the medical concerns that accompany disability issues**. The difficulties of individuals to express themselves, or use verbal communication often results in the hesitation of medical professionals to carry out screening tests, or other examinations.

There are numerous reports of **medical treatment being denied or withdrawn**, resulting in death with the reason intellectual disability as the common factor. Health or prescription information produced is mostly inaccessible. People with intellectual disabilities are often **deprived from legal capacity and thus cannot decide anything related to their health** and well-being. It is often the legal guardian who chooses the doctors and agrees to the treatment for them. This causes extreme vulnerability and this is why persons with intellectual disability are often exposed to involuntary or forced treatment, or harmful, unwanted medication.

In many countries the **health system is not adapted to the specific needs of persons with intellectual disabilities** due to an insufficient coverage by social security of the specific health care they need, **the lack of prevention and training of health professionals** and the **lack of coordination between health services and support services for persons with disabilities**. Territorial disparities and austerity measures even worsen the situation.

What should the EU do to improve the situation?

The European Commission should finance **guidelines for family members and care givers to become more familiar with the medical concerns** and the difficulties that are present or likely to be experienced by the person with disability. Medical practitioners should discuss the communication strategies of the individual with people who know the person well so as to be better equipped on how to handle various situations. The European Union should develop a

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programme against the deprivation of legal capacity. People with disabilities should **enjoy their right to choose a doctor, receive information about the medication** they are taking and be allowed to make an informed decision whether they want to use it or not. Residential homes should be monitored frequently to discover human rights violations. The EU should fully implement the recommendation of the Committee on the rights of persons with disabilities concerning Article 25 UN CRPD. The EU should also **promote research on the specific health needs of persons with intellectual disabilities**, diagnosis, training of health professionals, therapeutic education and accessible prevention campaigns.

Conclusion

Since the adoption of the European Disability Strategy in 2010, the European Union was hit by the economic crisis and recession. While the economic crisis in the EU affected all European citizens, the most severely and disproportionately hit were and unfortunately still are persons with disabilities. Austerity measures and cuts have been primarily affecting services aimed at promoting and facilitating independent living and inclusion of persons with disabilities in society. We call the European Commission to ensure that the European Disability Strategy will be fully implemented in the next 5 years and that no economic factors can hinder the enjoyment of human rights for persons with disabilities.

Persons with intellectual disabilities face significant barriers that prevent them from participating in society on an equal basis with others. Current practices that deprive the legal capacity of persons with intellectual disability and place them under substituted decision-making regimes are the main cause for social exclusion. Without carrying out effective changes in the national legislations of EU Member States and introducing supported decision-making, the European Disability Strategy will not bring real changes in the lives of all persons with intellectual disability. The UN CRPD Committee stated in the General Comment on Article 12 and in the Concluding Observations on the EU report, that effective measures must be taken to give back the voice and decision-making power to all people with disabilities, including those with intellectual and psychosocial impairment. The deprivation of legal capacity affects all areas of life, and prevents people from voting at elections, participating in the community, deciding where and with whom to live, studying in mainstream education system together with others, taking up an employment contract, or opening a bank account. **Therefore, we call the European Union to include 'legal capacity' as a new area of action in the European Disability Strategy as a result of this review process** and by that manifest its commitment to significantly improve the human rights situation of persons with intellectual disability in the EU. The Commission must take concrete steps to promote supported decision-making and further develop benchmarks and indicators that are suitable to measure the improvement in the areas that are covered by the European Disability Strategy.

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