

EU Disability Strategy post 2020

Contribution to the European Commission Roadmap consultation

12 November 2020

Inclusion Europe is the European movement of people with intellectual disabilities. We fight for equal rights and full inclusion in all aspects of life of people with intellectual disabilities and family member. With member organisations in 40 European countries, we represent over 20 million people.

Inclusion Europe recognises the progress achieved in the EU for people with disabilities.

We believe the next EU disability strategy should foster change and have a concrete impact on the quality of life of people with intellectual disabilities and families.

Introductory remarks

Inclusion Europe believes¹ the next strategy should:

1. Address the importance of the right to make decisions;
2. Establish clear targets to end segregation;
3. Address violence against women with intellectual disabilities;
4. Recognise the role of families in fulfilling rights and providing support to their relatives with disabilities;
5. Connect to peoples' experiences and be easier to understand.

Throughout the strategy, particular attention needs to be paid to:

- Children with intellectual disabilities and their families;
- Women with intellectual disabilities;
- People with complex support needs and their families.

¹ <https://www.inclusion-europe.eu/wp-content/uploads/2020/07/11-Europead-disability-strategy-What-we-want.pdf>

Inclusion Europe

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The European Union should seize the opportunity the strategy presents to set a clear path to progress, to focus on areas where real improvement can be achieved and to lead by example.

There are many areas where the EU can and should implement direct and profound change, for example:

- Employment of people with disabilities in EU services and agencies;
- Education (Erasmus programmes, European schools);
- Accessibility of information and procedures.

The EU should position itself as a global leader in inclusive, accessible practice.

Contributions to the specific topics of the consultation:

Accessibility

Making information and decision-making process accessible is of critical importance for the European Union.

This Strategy as well as any other disability-related EU material should be available in easy-to-read, websites easy to navigate, online consultations, European funding (from call to submission to reporting) and events accessible. Funds should be used for projects that foster accessibility.

The strategy should also make sure access to public services is achieved.

Participation

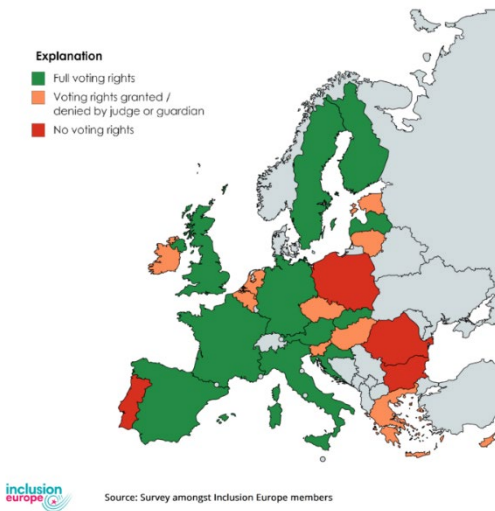
To be able to participate in public and political life, people with intellectual disabilities must not be deprived of their legal capacity. The Strategy should ensure the **transition to supported decision-making**.

A key element in participation is **the right to vote and to be a candidate** in an election. People under guardianship, which is often the case of people with intellectual disabilities, are excluded from those democratic processes². The EU must lead by example setting minimum standards recognising the right to vote for all for the elections of European deputies. The EU should give guidance to members states and monitor the accessibility of campaigns and voting..

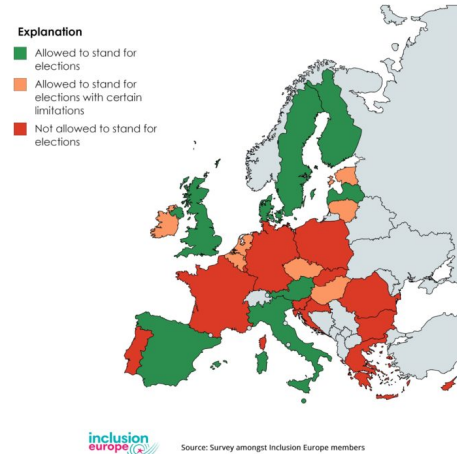
² <https://www.inclusion-europe.eu/wp-content/uploads/2015/03/Legal-capacity-and-citizenship-English.pdf>

Denying people with intellectual disabilities the right to vote, participate and the right to assembly should be covered under the EU's **rule of law reports**.

Voting rights for people under guardianship



Possibility to stand for elections for people under guardianship



People with disabilities and their representants must be involved in relevant initiatives, including children and women with intellectual disabilities, through funding and support for disability and self-advocacy organisations.

Employment³

The strategy should ensure that people with intellectual disabilities are employed in the open labour market, with an equal pay and have equal opportunities, by promoting solutions such as job carving or job coaching⁴ but also by setting the example creating those kind of job opportunities in the European institutions.⁵

When collecting data on employment, people working in segregated sheltered workshops should be taken into account to examine their working conditions.

³ How employment should be covered in the next EU Disability Strategy? <https://www.inclusion-europe.eu/employment-covered-in-the-eu-disability-strategy/>

⁴ My talents. For diversity. Videos supporting employment of people with intellectual disabilities <https://www.inclusion-europe.eu/videos-employment-people-with-disabilities/>

⁵ How could EU institutions make sure they are fostering the inclusion of people with intellectual disabilities? <https://www.inclusion-europe.eu/eu-institutions-employment-opportunities-people-with-intellectual-disabilities/>

Furthermore, the Strategy should recognise the role of families and carers, supporting part-time jobs, training and mentoring to contribute to their reinsertion in the labour market.

Skills

Access to vocational education and training is essential for people with intellectual disabilities to learn new skills, including digital skills and soft skills, such as social or interpersonal skills. . EU vocational skills initiatives must target and be accessible to people with intellectual disabilities.

Education

Segregated education must stop, starting at EU level: provide inclusive education in European schools, Erasmus+ programs reaching out to people with disabilities, and inclusive research and teaching (through European agencies and think tanks)

Social protection

Proper monitoring is necessary, with statistics on disability and poverty, that take into account extra costs of disability to map the quality of life of people with intellectual disabilities.⁶

As mentioned previously, mutual recognition of the disability status is essential to allow people with disabilities to access social protection when they are in another Member State.

The strategy should ensure that people with disabilities can keep their disability benefits when entering the open labour market. Minimum wage or income schemes should not replace those, as disability benefits are attributed to cover the extra costs of disability – so there is no link with employment.

Financial independence must be ensured through the elimination of substituted decision-making.

Disability is a cross cutting issue, it must be included in all action plans targeted to specific groups, such as the 2020-2030 EU Roma Strategic Framework, the Youth Guarantee or the Child and Youth Guarantee should reach out to children with intellectual disabilities.⁷

⁶ <https://www.inclusion-europe.eu/wp-content/uploads/2020/09/Briefing-on-minimum-income-and-social-protection.pdf>

⁷ <https://www.inclusion-europe.eu/paper-eu-child-rights-strategy/>

The Strategy should have a dedicated section on families, supporting them in having an active role in fulfilling the rights of people with intellectual disabilities. Poverty protection and pensions for carers should be encouraged.

Finally, social policies regarding housing must take into account accessibility of housing for people with intellectual disabilities and statistics should reflect housing accessibility for people with intellectual disabilities.

Social services

Victim support services must be made accessible and professionals trained to talk to women with intellectual disabilities, including in institutions⁸.



Social services must be widely available and accessible to people with intellectual disabilities to support their inclusion in the community. Social services must have quality inspections, with the direct participation of service users as evaluators and with the results being published in a clear and easy-to-understand way. The Strategy can support this via financial means (EU funding) and via facilitation of the development of these practices among member states.

⁸ <https://www.inclusion-europe.eu/violence-against-women-with-intellectual-disabilities/>

Independent living

The Strategy must be firm in its aim to end segregation, and allocate resources make independent and community-based living a reality. This transition must start and be lead by children with disabilities and adults with intellectual disabilities, esp. those with complex support needs.

There are still at least 1,438,696 persons living in institutions;

the number of people in institutions does not seem to have substantially changed over the past 10 years;

in many countries, and especially those who started the process of deinstitutionalisation some time ago persons with intellectual disabilities and complex needs are most likely to still live in institutional settings.⁹

Support needs to be provided for people who were victims of violence in institutions.¹⁰

The strategy should establish a mechanism for direct collaboration between member states, EU and DPOs to develop clear steps and measures to advance deinstitutionalisation. A lot of progress has been achieved thanks to the role of the EU and activities in member states; further progress can be achieved by better collaboration and exchange of ideas through a mechanism.

The strategy should also aim to establish support for actions at national level (training, mentoring programmes, long-term support) for deinstitutionalisation advocates.

A mechanism to measure and monitor progress on ending segregation should be established at EU level.¹¹

Access to health

Member States must provide people with intellectual disabilities the same range, quality and standard of free or affordable health care as everyone else. This also

⁹ <https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf>

¹⁰ <https://www.inclusion-europe.eu/letter-eu-funding-stop-violence-against-women-girls/>

¹¹ A possible inspiration <https://stateofthestates.org/>

applies to family members, who should have access to respite care to be able to have access to healthcare.

Healthcare services and equipment must be accessible to people with intellectual disabilities. Healthcare coverage should include early childhood education, rehabilitation and care, extra costs of medical care and health. The Strategy must ensure that women and girls with intellectual disabilities have access to sexual and reproductive health and rights, and that they have information in easy-to-read. In addition, prevention and health campaigns should also be addressed at people with disabilities.

Regarding health professionals, the strategy should encourage Member States to offer training on the principles of dignity, autonomy, non-discrimination and respect of difference. Finally, The European Union should set up monitoring schemes to evaluate quality of life.¹²

Access to justice

A prerequisite is legal capacity, which must not be denied to anyone as there are safeguards and support supported-decision making mechanisms.

The Strategy must ensure accessibility of procedures, complaint mechanisms and support services to people with intellectual disabilities, through reasonable accommodations and easy-to-read information.

Civil rights

Key rights for participation, such as the right to assembly, association, and freedom of expression, must be ensured.

Forced sterilisation of women with disabilities have to end, and so do stereotypes on women with disabilities' sexual lives, to enable discussions around reproductive rights and the right to form a family.¹³

The Strategy should further encourage accessibility of nationality procedures for people with intellectual disabilities (easy-to-read and understand tests).

¹² EU should set up monitoring mechanism health situation, quality of life and health care like there is in England with the LeDeR (Learning disability mortality review program in the UK (<https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/who-is-involved/>))

¹³ Life after Violence report https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication_web.pdf

Mobility

Mutual recognition of the disability status is key to achieve freedom of movement as it enables people to perceive social security and disability benefits.

The European Union must make the European Disability Card and parking card for people with disabilities, and their carers, available and valid in all Member States.

The Erasmus+ and the European Solidarity Corps should reach out to people with intellectual disabilities, be accessible and provide support.

Data collection and monitoring

The Strategy must promote a human rights-based approach to the collection of data, including data on people with disabilities who are living in segregated settings (“special” education, sheltered workshops, residential institutions) and that would reflect their quality of life.

People with intellectual disabilities and their representants must be involved in the monitoring of the Strategy.

The EU should establish a mechanism for close collaboration with the member states and DPOs to monitor and evaluate progress on key areas of the strategy, focus on the quality of life of people with disabilities and on how their rights are being fulfilled.