

Recommendations for social inclusion policies in Ukraine

VGO Coalition and Inclusion Europe

**recommendation for full rights and inclusion of
people with intellectual disabilities and their
families**

Contents

Right to decide and right to vote	4
Housing and support.....	6
Right to live independently and to be included in the community.....	8
Education.....	10
Employment.....	12
Healthcare	13
Representation	14
About the authors	16
Inclusion Ukraine and VGO Coalition	16
Inclusion Europe.....	16

Inclusion Europe

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Ukraine prepares to join the European Union while defending from a war and dealing with the damage to social infrastructure by Russia. Ukrainian disability organisations and NGOs face the struggle of not only protecting and supporting people during the war, but also of overcoming the outdated policies that hold back inclusion of people with disabilities.

Inclusion Europe has been working with VGO Coalition (and now with Inclusion Ukraine, too) since the Coalition joined as member in 2019:

- We called together for changes in disability policies;
- Fundraised to help people with intellectual disabilities and families;
- Work together to develop self-advocacy, and improve policies for inclusion.

In this document, we provide recommendations to improve rights and inclusion of people with intellectual disabilities and their families in Ukraine. The recommendations are provided in the context of Ukraine's accession to the EU.

The recommendations concern in particular deinstitutionalisation, provision of community-based services, replacement of guardianship system with supported decision-making, involvement of persons with disabilities in decision-making processes in public policies, employment, and support for family carers.

The recommendations were developed by Inclusion Europe and the VGO Coalition.

In November 2023, Inclusion Europe published [Inclusion Indicators 2023](#) about rights and inclusion of people with intellectual disabilities in 29 European, including Ukraine.

Our recommendations are based on the 7 indicators. For each area, there is a brief explanation, the result of Ukraine, and explanation of our recommendations.

Right to decide and right to vote

The indicator examines the right to make decisions about one's life like any other person and the right to vote and stand for election.

Ukraine scores 1 out of 10:

- *Legal capacity can be fully removed, and this can limit the right to vote and the right to stand for elections. There is no easy-to-read information on elections available.*

The level of exclusion in this area is extreme and requires fundamental changes both in the relevant law, and in training of professionals and others involved.

Recommendations

1. Remove law that allows for deprivation of legal capacity.
Change relevant provisions in the Civil Code of Ukraine to replace substitute decision-making with the system of supported decision-making.
2. Create conditions for the practical application of supported decision-making mechanism within social services, banking, purchasing of goods and services.
3. Remove the law that prevents people under guardianship from voting and standing for election.
Change Article 70 of the Constitution of Ukraine, and the Electoral Code of Ukraine.
4. Provide election materials in easy-to-read format. Introduce appropriate regulations to the Electoral Code of Ukraine.
5. Set up a system of collecting data on the number of people who are deprived or limited in legal capacity and who use decision-making and/or legal support tools; publish and evaluate this data regularly.

6. Set up a training system for all relevant actors in the concept of supported decision-making.

Housing and support

The indicator focuses on assessing the availability of community-based social services for people with intellectual disabilities that enable them to live independent lives on an equal basis with other people.

Many live with their parents until they are unable to provide daily support. Many people with intellectual disabilities and families also do not have access to good disability support. Family members serve as disability support providers instead of being just a family. This indicator is about whether adults with intellectual disabilities are living with their family or if they are living on their own, and if the family receives support.

Ukraine scores 2.6 out of 10:

- *Most adults with intellectual disabilities live with their families, and they receive little support. Few live in their own place.*

The following measures are aimed at developing good services rooted in the community that enable people to live fully independent lives with individually tailored support and to have regular relationships with their families without relying solely on them for disability support. Availability of good support is key to prevent people from being institutionalised.

Recommendations

7. Make disability support available to everyone who needs it.
This includes those who live in rural areas.
Don't force more people to have to go into institutions; support their independence and inclusion in the community.
8. Find out the numbers of people with intellectual disabilities living in families, and what kind of disability support they need to live independently.

This includes finding out about the support needs of today's students in collaboration with schools.

9. Establish assessment tools based on support needs instead of medical categories.

10. Build a system of supporting individual persons (case management) for inclusion in the community.

This needs to be person-centred, disability rights led approach.

11. Provide housing for people with intellectual disabilities that is accessible, placed in residential areas and does not lead to congregated living of people with disabilities.

12. Provide support for families caring for a member with an intellectual disability for a long time.

Find out about the needs of families and plan the development of social and other services accordingly.

Support families of (newborn) children through the system of early intervention and motivate them to provide family care and secure the right to grow up in a family environment for children with intellectual disabilities.

13. Develop a funding system with equal conditions for services provided by NGOs and government organisations.

Focus on stability of support services that support people with intellectual disabilities to live independently and be included in the community.

14. Reform the system of social services quality standards and their control to comply with human rights' protections, and disability rights requirements.

Right to live independently and to be included in the community

This indicator examines how many adults with intellectual disabilities are forced to live in segregated "care" facilities. The level of vulnerability/sense of urgency is reflected by the size and type of facility – facilities with more than 30 beds and psychiatric hospitals are considered to be at greater risk¹.

Ukraine scores 3.3 out of 10:

- *Some adults with intellectual disabilities live in larger institutions, few live in smaller institutions and psychiatric hospitals.*

The burden of the Soviet model of care based on congregation and segregation of people with disabilities and the creation of the illusion of a perfect society is a serious problem in Ukraine. This must be changed; institutions of all kinds must be substituted by good support in the community.

Recommendations

15. Stop immediately admitting more people into institutional care.
16. Provide community-based social services. Ensure equal financial provision of care services in the institution and in the community. Ensure every person with intellectual disabilities can make informed decisions about the type of support services they are going to use.

¹ Inspired by the report by reports by the European Expert Group on the transition from institutional to community-based care.

17. Set up a system of collecting data on intellectual disability statistics as determined by CRPD article 33 broken down by type of service. Introduce a system for regularly evaluating and publishing this data.
18. Prepare a clear strategy for the closure of institutions and their replacement by community services at national and regional level and for each individual institution.

Develop a strategy for the closure of institutions based on the assessed needs and preferences of people living in institutions.

Involve people with intellectual disabilities and their families in planning for change.
19. Move people out of harmful places and help them establish new lives according to their preferences and using community-based social services and support provided by the community and public services.
20. Redirect money from closing institutions to support people with disabilities.
21. Learn from what you (and others) are doing and create a system of training for change in disability support.

Education

The indicator examines how many children with intellectual disabilities are going to mainstream schools, special schools, or if they are not in school.

Ukraine scores 3.7 out of 10:

- *Most children with intellectual disabilities go to special schools, some children go to mainstream schools, and some receive no education.*

The following measures are aimed at ensuring that education is available to all children, regardless of their disability, and that education is available where they live, in a mainstream school. So called “special educational needs” must not be a reason for removing children from their family environment and placing them in a boarding school.

Recommendations

22. Support children to go to school where they live.

Close boarding schools that separate children from their families and communities. Provide targeted daily transportation for the students to avoid risk of institutionalisation.

23. Convert special education teams from boarding schools into special education support teams supporting education in mainstream schools. As a part of the support system, introduce plain language communication programs and procedures for education for children with intellectual disabilities, develop and introduce easy-to-read training materials, ensure training on plain language and easy-to-read format for the specialists involved in the education of children with intellectual disabilities.

24. Build a support system of training and consultation for teachers in regular, local schools to provide quality instruction to children with intellectual disabilities.

25. Remove architectural barriers in mainstream schools so that children with disabilities can attend.
26. Build a system of teaching assistants to help students and teachers create a good education environment.
27. Start preparing for transition from school to adulthood in advance and in partnership with students and their families, social services and other professionals as appropriate. Young people with intellectual disabilities must be prepared for independent living in the community, for which they will need good disability support.

Employment

This indicator examines the employment rate of people with intellectual disabilities in the open labour market, their wages and whether they are at risk of losing their disability pension if they earn their own wages.

Ukraine scores 3.3 out of 10:

- *Very few people with intellectual disabilities have a job on the open labour market. They do not risk to lose their disability benefits when they earn their own salary.*

The following measures are aimed at removing barriers to entry into the open labour market and providing support in finding and keeping a job.

Recommendations

28. Remove barriers to access to the open labour market. In particular, abandon the medical approach to employing people with intellectual disabilities based on doctors' judgements about whether a person can work. Replace this system with an assessment of the support needed to find and keep paid employment.
29. Strengthen employment in open labour market by incentives for businesses and the public sector to employ persons with disabilities in order to streamline quotas for employing people with disabilities.
30. Create support programmes for disadvantaged jobseekers such as "supported employment" for people with intellectual disabilities who need help to find work, to acquire the necessary skills in the workplace and to keep a job in the open labour market.
31. Remove legal provisions leading to a person with disabilities losing disability benefits when in paid employment.

Healthcare

The indicator examines equal access to healthcare for people with intellectual disabilities, equal treatment and the availability of information in an easy-to-read format.

Ukraine scores 4.9 out of 10:

- *People with intellectual disabilities have access to a general practitioner, but only some have a dentist or physiotherapist.*

The recommendations focus on equal access to health care, including dental care, and the provision of health care in the community rather than in institutional settings, and people's right to information and the ability to make decisions about their health.

Recommendations

32. Set up a state compensation system for dentists treating patients with intellectual disabilities and/or autism.
33. Develop a training program for dentists in treating patients with intellectual disabilities, autism, etc.
34. Create a training system for therapists focused on the mental health of people with intellectual disabilities.
35. Support health service providers to produce easy-to-read information on health care.
36. Abolish the practice of forced sterilisation (performing sterilisation without informed and free consent of the person with disability).

Representation

The indicator examines if people with intellectual disabilities are represented nationally and if organisations advocating for the rights of people with intellectual disabilities get funding from the government.

Ukraine scores 4.5 out of 10:

- *People with intellectual disabilities are represented in the national cross-disability organisation. VGO Coalition does not receive government funding for their advocacy work.*

The recommendations focus on ensuring conditions for effective involvement of people with intellectual disabilities (self-advocates) in decisions that affect them.

Recommendations

37. Create a system of state financial support for organisations of people with intellectual disabilities and their families representing the rights of people with intellectual disabilities which enable regular functioning of these organisations including self-advocacy groups.
38. Remove from law and policy terminology based on limitations and incompetence. Replace terms like “invalids”, “persons with limited abilities”, or “defectology” with terms based respecting people’s dignity and rights in all legal and policy documents and other communication regarding people with disabilities.
39. Use plain language as the primary means of clear communication from the authorities to people with intellectual disabilities.
Provide people with intellectual disabilities with the training and assistance they need to participate effectively in the decision-making processes that affect them.

40. Ensure that people with intellectual disabilities can effectively participate in planning the development of community-based services at all levels of government and in all legislative, financial and policy decisions that may affect them including of strategy planning of the Ukraine recovery and reconstruction.

About the authors

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Inclusion Ukraine and VGO Coalition

All Ukrainian NGO Coalition for People with Intellectual Disabilities (VGO Coalition) represents and supports people with intellectual disabilities and their families in Ukraine. VGO Coalition is a network of 85 parental organizations from all regions of Ukraine set up in 2004.

Inclusion Ukraine is a new non-governmental organization set up in 2023 to unite the groups of self-advocates with intellectual disabilities from all over Ukraine.

Inclusion Europe

Inclusion Europe speaks up for people with intellectual disabilities and their families since 1988.

We advocate for equal rights and full inclusion in all aspects of life representing 20 million people with intellectual disabilities and their families.

We are a European organisation with members in over 30 countries representing in a democratic way the rights and interests of all people with intellectual disabilities and their families in Europe.

www.inclusion.eu



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