## **CRPD - REGIONAL CONSULTATIONS**

## “From isolation, invisibility and segregation into inclusion of persons with disabilities in the community. Identifying and overcoming barriers to the successful process of deinstitutionalization”

#### [Committee on the Rights of Persons with Disabilities](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx)

**Outcome regional consultation**

**EASTERN EUROPE AND CENTRAL ASIA**

1. **ORGANIZATIONAL MATTERS**

The consultation took place online and the programme included two segments of one hour each of them, in which persons with disabilities, organizations of persons with disabilities, coalitions of persons with disabilities, and other civil society organizations and stakeholders intervened delivering testimonies and recommendations about the topics subject to the consultation.

Through the online consultations and the written submissions, persons with disabilities from the following countries and territories were represented: Albania; Armenia; Belarus; Bulgaria; Bosnia and Herzegovina; Georgia; Hungary; Kazakhstan; Kyrgyz Republic; Kosovo[[1]](#footnote-1); Moldova; Montenegro; North Macedonia; Russian Federation; Serbia; Slovakia; Ukraine; United Kingdom of Great Britain and Northern Ireland; United States of America.

1. **MAIN AREAS OF ACTION**

The regional consultation process includes the online consultation and review of written submissions. In many States, institutionalization, segregation and exclusion in different types of facilities remain the norm and the reality for persons with disabilities. Efforts to conduct deinstitutionalization have not lead to inclusion in the community but have perpetuated institutionalized living arrangements and lack of choice.

The regional consultation highlighted various areas of action:

1. Generally, **persons with disabilities, both children and adults, rely on families and/or institutions**. This especially concerns persons with intellectual or psychosocial disabilities, persons requiring higher levels of support or persons with autism. Such approach has harmful effects on the lives of persons with disabilities, leading them to social exclusion. It also has impacts on families of persons with disabilities facing poverty and social exclusion by association, and on communities and in society, which loose opportunity of social diversity and the contributions of persons with disabilities to the life of the community.
2. **The prevalence of different forms of institutionalization** (boarder special schools, small group homes, supported living houses), and negative impacts of institutionalization, including loss of agency for persons with disabilities living in regulated settings. Institutions, including those called small group homes exercise control and monitor life of persons with disabilities, including their social relations and daily decisions also through deprivation of their legal capacity. This is proven by the continuing and widespread forced placement of persons with disabilities in institutions.
3. **Child abuse and harm inflicted on children with disabilities within institutions**, and receiving little to no support or aid to enable them to stand up to those institutions.
4. **Prevailing disability stereotypes in families and in society** underpinning institutionalization.States must contribute to helping parents and families to accept the disability cultural identity of their children/adults with disabilities, including recognising that institutionalisation undermines persons with disabilities’ family relationships.
5. **Insufficient or not applied legal and regulatory frameworks, embedding the right of persons with disabilities to live independently and be included in the community.** Lack of implementation of legislation at different government levels (national, local, etc.). Lack of standards impinges on persons with disabilities’ rights and leads to poor, inconsistent services provision and the continuing of institutionalisation. Moreover, policies and regulations regarding persons with disabilities strongly rely on the medical model of disability through which a person with disability is considered as a deficient, lacking capacities to live independently.
6. **The supported decision making**, including the alternative and augmentative modes of information and communication should be applied, developed and regulated. The supported decision making should become a usual proceeding at the DI process.
7. **The concept of deinstitutionalization is not compatible with life in the community and full inclusion,** often replacing large scale institutions with smaller ones, and not comprising support for living independently. **Deinstitutionalisation should be conceived as a strategy aimed at providing persons with disabilities with genuine choices lo live in the community**, including through aid for social housing or rent subsidies. This requires **holistic transition pathways** which respond to the current context for persons with disabilities in a given country, identifying a role of different actors, requirements of legal reforms or measures at the State, the local and national level, and funding requirements. Deinstitutionalisation should be considered within the wider context of access to education and employment; include measures aimed at persons with disabilities who are both in institutions but also outside of institutions. Assessment of abilities of persons with disabilities for independent living “kills” the purpose of and support for independent living, is the key element to prevent the independent living to persons with high support requirements, thus, discredit the independent living and derive it from the CRPD standards.
8. **Need to reorient funding and eligibility to support.** Emphasis in State-funded-model of “care” of persons with disabilities, instead of support for inclusion. Human and financial resources continue being invested to sustain “care services” and rehabilitation revolving around institutions as main service-providers. Lack or insufficient budget allocation for support for living in the community and for forms of alternative care, such as foster care. All policies, laws and regulations regarding persons with disabilities must be revised at all levels and aligned with the provisions of the Convention herewith redirecting the financial flows from institutional to inclusive community-based facilities and provisions. Usually the support and provisions in line with the Convention come from civil society organisations and organisations of persons with disability, however such practices are rather rare and scarce, due to the lack of State support of them, who rather keeps on private sponsors and works on the bases of project thus are not sustainable.
9. **The human rights disability model**, including the concept of inclusive equality should be emphasized through highlighting the fundamental human rights such as **freedom of persons with disabilities** instead of control over their lives, equality instead of segregation, dignity instead of capacity-devaluation, personal support instead of institutional care, active participation instead of passive recipient role.
10. **Participation and involvement and participation of persons with disabilities** in deinstitutionalization processes, plans or programmes is crucial and should comprise participation in relation to the transitions and once people have been deinstitutionalized. Persons with disabilities, especially those with lived experience of institutionalisation should be entitled to participate in processes designing services and regulations. Access to legal documents is restricted for people with intellectual disabilities due to lack of accessible alternate formats.
11. **Recognising and defining the scope of community support services, including personal assistance.** Personal assistance and other forms of support must be recognised in legislation, developed and monitored with the aim to promote increased quality of life for persons with disabilities. (i.e. the goal can't just be getting out of the institutions and leave it at that). States should establish a human rights-based, not medicalised, eligibility criteria for support services; eligibility of support should not be restricted, such as by regulation linking independent living to independent decision-making capacity or living in supported housing or ability to access other funding allowances. There is a clear need to specify that community based services means the full inclusion in the community though the right to control over one’s life, personal assistance and access to services for general population.
12. **Access to inclusive education as a main driver of a life included in the community.** Consistent call to take comprehensive measures to dismantle special education and ensure inclusive education for all children with disabilities. The reported family resistance to leave special education schools arises from the lack of support at regular schools and communities since **special education schools became only way of support to children with disabilities and their families**, especially those requiring higher levels of support. Thus, it is necessary to differentiate strategies for
* Children with disabilities:

a) support to quality inclusive education at all levels, curriculum and extra-curriculum education, in providing teachers, trainings and reasonable accommodation;

b) support to the development of community-based early intervention.

* Adults with disabilities:

Independent housing in the community as a personal choice (provision of the article 19)

**Life-long perspective should be emphasized**, which means that inclusive early intervention and inclusive education are precondition of independent life in adult.

1. **Inclusive employment** in an open labour market is a key factor for independent living in the community. Persons in institutions, including in group homes, are usually employed inside institutions or in institutional framework outside mainstream employment settings, if they are employed at all. Specific incentives, including for personal assistance, training etc, are needed for both private and public employers.
2. **Impact of the COVID-19 pandemic on persons with disabilities in institutions.** Lack of public information about the impacts of the pandemic on persons with disabilities, and attitudes that tend to diminish or minimise the consequences of COVID-19 on persons with disabilities, including forced institutionalisations during the pandemic. Information about prohibition to visit institutions during the pandemic. States parties should develop accessible information for persons with disabilities concerning the pandemic, containment measures and measures to address the impacts. There is a **lack of emergency plans in the situations of crisis** and in refugee situations. the emphasis on the development of inclusive emergency plans for persons with disabilities in all life situations and settings should also be explicitly incorporated in the guidelines.
3. **CONCERNS AND RECOMMENDATIONS**

The following is a summary of concerns raised by participants that the Committee should include in the Zero Draft Guidelines for the Deinstitutionalization. To facilitate the reading, concerns and recommendations are grouped under headings related to the provisions of the Convention.

***Discriminatory policies and practices (art.1)***

***Concerns:***

* Most of the health and education professionals still push for old fashion soviet models of “defectology” and normalization of children with disabilities and their education within the specialized boarding school system.

***Legislation, including implementation (art.4)***

***Concerns:***

* Provide in legislation for the provision of free personal assistant services to everyone with a disability at risk group to the extent necessary to enable the person to lead an independent living.

***Recommendations:***

* Family legislation restricting freedoms of persons with disabilities must be changed with a mind-set and philosophy of independent living as set out in the Convention;
* Repeal legal provisions authorising forced psychiatric placement and forced psychiatric treatment on the grounds of mental impairment;
* Need to increase the oversight of fulfilment of the Convention and the real situation of persons with disabilities.

***Public policies, including deinstitutionalization (art.4)***

***Concerns:***

* Create an individualized program of rehabilitation and treatment should be drawn up, as well as a plan for the provision of social services focused on empowerment, rather than restriction and control;
* Deinstitutionalization strategies are frequently poor, contain no timeframes and are rarely seeking universal scope.

***Recommendations:***

* Policies relating to disability must be changed to include persons with complex and rare diseases and acknowledge them as persons with disabilities under the Convention;
* Deinstitutionalisation necessarily requires a strategy;
* Create an assessment of needs for services, set comprehensive standards for their provision, provide a diversity of services and their sustainability;
* Enable public agencies and the private sector, civil society organizations and charities, national human rights defenders to work with families in the future involvement of adults with disabilities in the local community, prevention of institutionalization, re-institutionalization, isolation and coercion in general.
* States should deliver psychosocial support for persons with disabilities to aid in the DI process (e.g. supported decision-making);
* Persons with disabilities should have the opportunity to choose the type of support that suit them the best.

***Funding (art.4)***

 ***Recommendations:***

* Founding must be shifted to support community and families in order to allow a real inclusion for children with disabilities;
* Investments in small groups homes cannot be considered as a progressive realization of the right to be deinstitutionalized;
* Establish equate public organizations, state and municipal organizations in access to funding for the provision of social services for persons with disabilities.

***Participation of persons with disabilities (art.4)***

***Concerns:***

* The lack of legal capacity acts as a barrier because people being considered as “unable” to make decisions and therefore not ‘suitable’ for public administration.

***Recommendations:***

* The setting of a deinstitutionalization plan, with involvement of relevant stakeholders;
* It is crucial to ensure meaningful participation of persons with psychosocial disabilities;
* It is imperative to involve persons with intellectual disabilities in the preparation of legislative documents, information messages in an understandable format.
* Include OPDs in high level decision-making processes*.*

***Good practice:***

* Drafting laws on personal assistance with the involvement of the independent living movement.

***Reparations (art.4)***

***Concerns:***

* People who violate the rights of persons with disabilities are not subject to any punishment, attributing everything to the stigma of disability.

***Recommendations:***

* Reconciliation and transitional justice mechanism including reparations to deal with the human rights violation could play a vital role to leave institutionalization in the past;
* One of the most effective ways to abolish such malpractices is to hold the institutions accountable and make them pay compensations to the victims;
* Need to establish accountability mechanisms, including prosecution of perpetrators of violations of rights of persons with disabilities in the context of institutionalization. This includes specific oversight by independent ombudspersons.
* Institutions must be held accountable for malpractice such as child beatings and must be compelled to pay compensation to victims. This can only be done if legal aid is placed at the disposal of the inpatient at any time, this legal aid must be independent of the respective institution.

***Non-Discrimination (art.5)***

***Recommendations:***

* Persons with disabilities should have choices on an equal basis with others in all aspects of life;
* Persons with disabilities who have been deinstitutionalised must continue to be recognised.

***Women with disabilities (art.6)***

***Concerns:***

* Women with disabilities do not have access to adequate medical services; they are abused and excluded from the resources distribution in their communities and families;
* Women and girls with disabilities experience double discrimination, which puts them at higher risk of gender-based violence, sexual abuse, neglect, abuse and exploitation;
* In the current situation of COVID-19 pandemic and a subsequent crisis, women with disabilities suffering from intersectional forms of discrimination face even a greater risk of being left behind in COVID-19 response and recovery measures;
* Establish shelters, including in rural areas, and enhancing cooperation with non-governmental organizations that provide shelter and rehabilitation to victims of Gender-based violence;
* Women with disabilities who have children faced challenges to ensure online learning often in the situation of lack/limited access to computer equipment and Internet connection;
* Women with disabilities are almost completely excluded from decision-making processes at all levels.

***Recommendations:***

* Given the disproportionate adverse impacts that the crisis has on women and girls with disabilities, it is imperative that gender equality concerns are embedded in not only crisis response but also mid- and long-term socio-economic recovery measures;
* Create gender inclusive policies to protect women with disabilities.

***Children with disabilities (art.7)***

***Concerns:***

* Children with disabilities face considerable barriers accessing education opportunities;
* Prevailing negative social norms and attitudes towards disability;
* limited understanding and capacity of education professionals to work in an inclusive environment;
* Lack of a mechanism of targeted state funding based on non-medical criteria and limited disability friendly school infrastructure;
* Culture of institutionalization of children with disabilities in special boarding schools and child care institutions is persistent;
* Child poverty is increasing, and in the longer run, it will trigger further demand for institutional care;
* Families of persons with disabilities are worried because children are forced to be institutionalized after a certain age;
* Any person with disabilities with movement, self-service, self- realization or education, work, family creation issues is facing high risk of being forced inside closed boarding-type institutions;
* Parents, especially of children requiring higher levels of support, were strongly opposed to the closure of the boarding school, as it was the only institution where their child could receive appropriate educational, rehabilitation and social services.

***Recommendations:***

* Accelerate the development of family support services for families with children with disabilities, as well as family-based alternative care options for children with disabilities deprived of parental care;
* Strengthen control over the observance of the rights of “clients” of psycho-neurological boarding schools.

***Awareness Rising (art.8)***

***Concerns:***

* Charity driven and exclusion oriented attitudes to persons with disabilities is going on at all levels, creating a vicious circle of marginalization and re-enforcement of traditional and medical charity approach;

***Recommendations:***

* Focus on triggering political will;
* Management and staff of the inclusive educations should receive training in the basic principles of the Convention on the Rights of Persons with Disabilities;
* Rise the awareness on disability rights in the decision making positions, in order to have decision making processes based on human-rights based model of approach to disability, instead of medical, functional, or charity model;

***Effect of the Covid-19 Pandemic or other emergencies (art.10-11)***

***Concerns:***

* Although been part of a community living project some persons with disabilities have been isolated and discriminated because resulted positive to the virus without adequate support**;**
* Persons with disabilities also at a greater risk of institutionalisation due to the pandemic, as it has limited their capacity to live independently.
* Persons with disabilities resulted positive have been isolated and left without the possibility to access hospitals**;**
* There was no provision of special support for persons with disabilities to deal with the lockdown restrictions, leaving their families or friends alone in providing for their needs**;**
* In the territories affected a the conflict many cases of forced repatriation have been reported;
* By lacking systematic reporting of COVID-19 testing, infection, mortality or outcomes by disability, it is not possible to measure the magnitude of pandemic’s impact on persons with disabilities;
* NGOs not receiving sufficient operating funds for advocacy and services during the pandemic;
* Minimisation of the consequences of COVID-19 on persons with disabilities, including forced institutionalisation, and inability to visit institutions;

***Recommendations:***

* Reform policies laws and practices should be adopted to assure the protection of person with disabilities during conflicts;
* Provide with free personal protective equipment and testing for service users and their providers instead of temporary stopping of the services due to physical contact;
* States affected by an armed conflict should pay special attention to rights of persons with disabilities and take into account special needs of persons with disabilities in developing measures to guarantee enjoyment of human rights by the conflict-affected population.
* Need for consultation and participation of persons with intellectual disabilities;
* Need to develop accessible information in relation to the pandemic;
* National legislation should include persons with disabilities as a protected category in the case of emergencies like pandemics;

***Equal recognition before the law (art.12)***

***Recommendations:***

* Introducing supported decision-making would allow to abolish substituted decision-making and to develop a comprehensive strategy on deinstitutionalization;
* Establish a commission in each region to review the diagnoses of persons with disabilities and facilitate the filing of a lawsuit in order to change the legal status of the boarding school clients.

***Access to justice (art.13)***

***Concerns:***

* The COVID-19 pandemic affected court proceedings on legal capacity of persons with intellectual and psychosocial disabilities;
* Courts were not always able to complete proceedings without psychiatric examinations, mandatory in such cases, because psychiatric hospitals suspended their operations in this regard due to the COVID-19 crisis;

***Recommendations:***

* Provide legal aid when people undergo forced interventions and other human rights violations, including beatings in institutions;
* In cases where substitute decision-making continues to exist, relatives of persons with disabilities should have access to effective non-judicial mechanisms allowing for representation of rights and interests of persons with disabilities.

***Persistence to institutionalization and need to prevent it (art.14, 19, 28)***

 ***Concerns:***

* Any person with disabilities with movement, self-service, self- realization or education, work, family creation issues is facing high risk of being forced inside closed boarding-type institutions;
* Institutions such as boarding schools being the only option where children could receive appropriate educational, rehabilitation and social services;

 ***Recommendations:***

* *Create stronger social and economic programmes to help persons with disabilities avoid institutionalisation.*

***Violence against persons with disabilities in institutions (art. 15-16-17)***

***Concerns:***

* Children with disabilities face abuses**,** cruel treatment are recorded - beatings, sexual violence and harassment;
* Were noted cases of sterilization, compulsion to use contraception in the form of intrauterine devices;
* The system of psycho-neurological boarding schools is archaic, inhuman and is one of the risk zones where human rights are often violated spending whole days in a confined space, virtually without connections with the outside world.

***Recommendations:***

* End the practice of using isolation wards and other restrictive measures, including the use of psychotropic drugs such as chlorpromazine, and training staff in modern methods of managing aggression;
* End the practice of restricting contacts of boarding school clients with the outside world, the over-custody of clients; excessive regulation of their lives such as mandatory getting up and going to bed at a certain time.

***Understanding of Independent Living (art.19)***

***Concerns:***

* Deinstitutionalization means that persons with disabilities have access to the right of employment and social payments.

***Recommendations:***

* The guideline should clarify that provision of the right to live independently is a precondition to the deinstitutionalization;
* Clearly establish that group homes built for children with disabilities contravene the rights of children with disabilities to live in the community;
* Prohibit the building, developing or investing in new institutions for persons with disabilities, either by the State or by private entities;
* Re-allocate resources budgeted per person for living in residential facilities and distribute them individually.

***Institutionalization negatively impacts on choice and self-determination (art.19)***

***Concerns:***

* The life of institutionalized persons is often fully controlled by the guardian in the person of the director of the closed institution in which he is located**;**

***Recommendations:***

* “I would like to have more freedom. I would like to be independent, to live as I want”.

***Range of choice for persons with disabilities (art.19)***

***Concerns:***

* The majority of residents of large institutions are only provided the options of moving to smaller institutions;

***Individualized support (art.19 (b))***

***Concerns:***

* No support services are put in place once a person transitions from institutionalised living into the community as the focus has been in closing institutions without thinking about the support required to ensure this is successful;
* The legislation for mobile aids and orthopaedic devises is discriminatory. People who were de-institutionalised are often facing with the barriers to access to mobile aids and wheelchairs and medications.

***Recommendations:***

* Ensure the creation and expansion of individual support for the family of a child with disabilities, starting with early intervention, in the social security system, not only the form of material support and financial payments;
* Persons with disabilities who are deinstitutionalised must receive support to access education, employment, and support for decision-making.

***Personal assistance (article 19 (b))***

***Concerns:***

* Personal Assistants are often confused with home care and in other cases the assistance is not really personal;
* Personal assistants are often former staff members of institutions retrained to support people living in the community but keeping the control over the daily lives of person with disabilities;
* The lack of legal capacity impedes persons with disabilities to have any control over personal assistance;
* Lack of adequate funding for personal assistance.

***Recommendations:***

* Focus on the role of personal assistants after the closure of institutions;
* Develop personal assistance programmes especially during emergencies;
* Enable assistants to move without restrictions while the state of emergency and curfew.
* Rise awareness about what personal assistance is, how it could help person with disabilities and ensure that the governments provide legislation on this matter.
* During emergencies such as COVID, personal assistances should receive special passes to allow them to remove without restrictions. Personal assistance should also get priority in accessing transportation if restrictions are imposed on transport due to pandemics. Furthermore, personal assistants and persons with disabilities should receive sufficient amount of PPI. It’s important not to restrict support services for persons with disabilities in local communities; these should be kept to pre-pandemic time’s levels of support.

***Equal access to services in the community (art.19 (c))***

***Recommendations:***

* Social services should be placed at level of the community;
* Establish regional centres to take over the management of “community based social services”;
* The access to services should be universal, guaranteed as a right and people living in rural and remote areas should not be deprived of it;
* Prevent the isolation, marginalization of people with disabilities or their placement in specialized institutions and provide them with affordable and high-quality medical, social and educational services at the level of the local community;
* Every website, primarily sites of state and local authorities, should have a version for people with visual and hearing impairments.

***Access to information (art.21)***

***Concerns:***

* Information and guidance were not shared in accessible formats during the pandemic, restricting the right to information, placing them at additional risks of contracting virus and face greater inequalities.

***Respect for home and the family (art.23)***

***Concerns:***

* Relatives of persons with disabilities grew old, lose physical and mental strength to support persons with disabilities, die and others are forced to send a person with a disability to local government institutions.

***Recommendations:***

* Create parenting clubs at centres for the provision of services for children with disabilities about topics of child development, such as feeding, physical rehabilitation, genetic characteristics of development, sex education;
* Ensure accessible communication of children with disabilities with their parents, relatives and friends through the creation of safe and accessible conditions, special mechanisms, infrastructure and services;
* Assure parental leave twice a year to restore the physical and psychological state;
* Accelerate the development of family support services for families with children with disabilities, as well as family-based alternative care options for children with disabilities deprived of parental care.

***Education (art.24)***

***Concerns***

* Lack Inclusive education;
* Boarding schools prevail as a form of special segregated education system, and sometimes represent the only option for children with disabilities to access education;
* Life in closed boarding schools is built on a basis of a strict schedule, a person has no right to choose an alternative;
* Children with psychosocial disabilities face many troubles accessing inclusive education and many of them is relegated at home;
* Offenses, corruption crimes related to embezzlement of funds from accounts and cards of persons with disabilities, theft of budget funds aimed at providing food, maintenance of persons living in LSG;
* Lack of inclusive education for children requiring higher levels of support, and institutions such as boarding schools being the only option where children could receive appropriate educational, rehabilitation and social services;

***Recommendations:***

* Management and staff of the inclusive educations should receive training in the basic principles of the Convention on the Rights of Persons with Disabilities;
* Accelerate the development of family support services for families with children with disabilities, as well as family-based alternative care options for children with disabilities deprived of parental care;
* All girls and boys must have access to an inclusive education;
* Improving the accessibility of online education, which is a vital tool in order to permit an equal access to the school system;
* In the event of schools closing and students having to restore to home education, staff that supported students with disabilities in school settings should continue providing such support at student’s household if students and their families agree to that;
* Use services based on chat technologies, where children have the opportunity to exchange opinions, carry on correspondence, participate in the discussion of a problem during the implementation of, for example, a project;
* Strengthen the development of cognitive and communicative competence, the ability to carry out interpersonal and intercultural communication with all members of society.

***Health (art.25)***

***Concerns:***

* Volunteer staff members trying to help people with spinal cord injury have been repeatedly banned from provide their services due to the COVID-19 pandemic prevention measures;
* There are no minimum sanitary conditions in the infections department of the hospital to properly host people with spinal cord injury who have been directly banned from the hospitals or left on the floor in the corridors.

***Work and employment (art.27)***

***Recommendations:***

* Promote the employment of persons with disability, the adjustment of employment conditions and the open labour market which is strongly favouring the employment of “fully able-bodied” workers;
* The state should compensate labour costs through protected social jobs for persons with disabilities;
* Prevent further isolation of people with intellectual disabilities creating a daytime employment environment.

***Housing (art. 19-28)***

***Recommendations:***

* Separate social services from housing otherwise persons with disabilities risk to end up on a street just because their refusal to certain services in institutions or “supported houses”.

***Data (art.31)***

***Concerns:***

* Data as well as analysis of existing information, on persons with disabilities are generally lacking on all levels.

***Recommendations:***

* Strengthen data collection and analysis system across all sectors, using unified definitions and standards.

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1. The reference to Kosovo in the present document should be understood to be in compliance with [Security Council resolution 1244 (1999)](https://undocs.org/S/RES/1244%281999%29). [↑](#footnote-ref-1)