



Key Points from the Discussions at the Side-Event at 18th Conference of States Parties to the CRPD

‘Closing the revolving doors: A lifespan approach to deinstitutionalization’ June 9, 2025

Dorodi Sharma, Director Inclusive Development & Engagement, Keystone Human Services International

- Welcomed everyone to the side-event and outlined the context of the event.
- At Keystone, supporting persons with disabilities, especially those with high support needs to move out of congregate care and live meaningful lives in the community, have been the cornerstone for over 50 years. This experience, together with our work in Moldova the last 20 years and in India the last 10 years, show that community inclusion is possible and that there are models that can be scaled up.
- There has been a focus on deinstitutionalization through the CRPD and the Guidelines on Deinstitutionalization. But it is still considered to affect only a few groups of persons with disabilities.
- Deinstitutionalization is at the core of inclusion, there cannot be full and meaningful inclusion of children and persons with disabilities in the community without addressing institutionalization.
- The successes on deinstitutionalization are fragile, especially when resources are scarce.
- Community inclusion does not happen at a particular point in the lifetime of a person. Children with disabilities who are not supported to become part of society, they will not grow up to be adults who live independently in the community. When early intervention is not provided in the community, children with disabilities end up being abandoned or put into institutions because families feel that institution is where the best support can be provided to children with disabilities. Institutionalization becomes a default for them. Children with disabilities who live in institutions grow up to be adults who live in institutions. If adults with disabilities are able to find exit pathways out of institutions, their places are filled up quite fast. It becomes a revolving door with people moving from one institution to another.
- There is a growing focus on inclusive care reform to ensure that all children, including children with disabilities, grow up in safe, secure environments. There is not much convergence between the care reform movement and the disability movement, and these connections need to be created as the ‘how to’ of the deinstitutionalization cannot happen if the two movements are not talking to each other.



Miyeon Kim, Chair, UN Committee on the Rights of Persons with Disabilities (CRPD Committee)

- Miyeon Kim highlighted that the CRPD Committee, through General Comment 5 on Article 19 (Living independently and in the community) and the Guidelines on Deinstitutionalization including in Emergencies have provided a clear and comprehensive roadmap for community inclusion and building inclusive care systems.
- There is a need for bold and immediate actions and not incremental steps, by governments to close institutions.
- Placing children with disabilities in the name of care and welfare is not support. It is a systematic form of violence.
- The Sustainable Development Goals (SDGs) cannot be achieved without deinstitutionalization – it is the cornerstone of human rights-based approach to development.



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Genevieve Fitzgibbon, Vice President Global Programs & Advocacy, Keystone Human Services; CEO, Keystone Human Services International.

- Genevieve Fitzgibbon, in her remarks emphasized that there are great frameworks on deinstitutionalization but now is the time to focus on the 'how to'.
- From Keystone's work it is clear that deinstitutionalization is possible. Keystone's work in Moldova the last two decades is a great case study of how through collaboration, systems can change to provide sustainable solutions from a whole system and lifespan approach. Keystone has worked with governments on education, employment, and social protection which has created a continuum of support from children to adults to older persons with disabilities to live meaningful lives.
- Moldova is also a supporter of the UK government's Global Campaign on Care Reform which is another example of collaborative action.



Video statement from MANIRAFASHA Julienne, a young person with lived experience of care, survivor of institution, Rwanda

- MANIRAFASHA Julienne shared a powerful testimony of her experience of living in an institution where she faced hardships, verbal and physical abuse and felt unvalued losing hope and even wishing for death. Now she is back home, with affectionate parents, living with her siblings sharing a life together. She feels like any other child.
 - She wants to grow up to become a medical staff and support persons with disabilities to get better services.
- She called on leaders to support children with disabilities to be able to live at home and access education and other services.



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Mrs. Galina Nipomici, Deputy Permanent Representative, Counsellor, Permanent Mission of the Republic of Moldova to the UN

- Mrs. Nipomici in her remarks highlighted that leaving no one behind also applies to children and persons with disabilities.
- Since the ratification of the CRPD, government of Moldova has taken concrete steps towards deinstitutionalization. In 2017, there were 12500 children in residential care, which is a quite compelling number for a country like Moldova. Childcare protection reforms by the government, together with work with partners, helped the transition process. A UNICEF report from 2023 states that there were 677 children left in residential care, which although a concerning number is still a good success.
- The government has also worked with deinstitutionalization of adult persons with disabilities. Since 2009 about 700 adults have been deinstitutionalized. Many still remain in institutions because of the financial implications to implement community-based care, but Moldova is determined to pursue this agenda.

What worked:

- Putting in place normative frameworks including ratifying conventions, national laws and policies, national programs for social inclusion including of persons with developmental disabilities and psychosocial disabilities.
- Developing community based social services for children and persons with disabilities. There are now 316 social care services nationwide, including mobile team of services, personal assistance, foster care, parenting support services, and support for families.
- Actively investing in capacity building of social care services staff.
- Gatekeeping mechanisms helped prevent unnecessary institutionalization and promote community-based solutions.





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Kemi Williams, Head of Gender, Equalities and Rights, FCDO

- The Global Campaign on Care Reform launched in January by the Foreign Secretary of the Government of UK brings a personal commitment from the Foreign Secretary.
- Globally, over 5 million children live in care of which 80% have a living parent and one in three of them have a disability. There is overwhelming evidence that institutional care impacts physical and mental health, causes developmental setbacks, and increases vulnerability to violence.
- Foreign Secretary David Lammy launched this campaign to advocate for family-based care for ALL children and calling for an end to institutionalization including for children with disabilities. At the heart of the campaign is the belief that ALL children should grow up in safe and secure environments.
- Later in the year, Secretary Lammy will launch a Global Charter and call for governments to make ambitious commitments towards care reform, to strengthen support to families and to help them look after their children at home where it is safe to do so. The call is also to provide alternative family-based care where needed.
- This is an initiative to unite all countries for a shared commitment to end institutionalization and ensure that no child is left behind. This would need efforts across borders, and also across sectors and across all levels, from supporting local expertise to finding locally led solutions and sharing knowledge and good practices at the global level. Only by working together in the best interest of the child will we achieve the changes that we so desperately need.



- Meaningful participation of persons with disabilities and their representative organizations is fundamental. At the Global Disability Summit in April, the UK committed to ensuring the full and meaningful participation of young people with disabilities and their representative organizations so that their voices are heard and their opinions reflected in the campaign. Children and young people with lived experience of alternative care have informed early development of the draft of the Global Charter. The UK, alongside other countries, has committed to addressing the systemic and specific barriers faced by children with disabilities and their families in the care campaign.
- The care campaign is grounded in the principles of the CRPD, and the Global Charter has built in a multi-sectoral approach bringing in children, young adults and families, especially children with lived experience of alternative care and Organizations of Persons with Disabilities (OPDs), communities, faith leaders, donors, national governments – the whole canopy of partnerships. The aim is to commit to urgent, decisive and coordinated actions to ensure a safe, nurturing and loving home for every child.



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Fatma Wangare, Secretary General of the Kenya Association of the Intellectually Handicapped (KAIH) and Regional Coordinator for Inclusion Africa

- It is an exciting time in Africa with the coming into force of the African Disability Protocol (ADP). But momentum without an actionable roadmap will not realize our goals: we all belong in our communities, that is where we need to be.
- Fatma Wangare highlighted the following points that OPDs and families consider critical in the realization of deinstitutionalization:
 - Strengthening legal and policy frameworks: Article 14 of the African Disability Protocol (ADP) aligns with Article 19 of the CRPD, and it is very clear about community participation and inclusion in all aspects of life. Quite a number of national laws are the drivers of the institutionalization of persons with disabilities, laws that deprive them of their legal capacity. Governments are investing in child care reform laws and policies, but these are often not CRPD compliant and therefore not compliant with the ADP. When it comes to inclusive social protection policies, there is no clear implementation of programs that recognize disability related costs of people with disabilities. Strengthening laws is a critical step in the process of deinstitutionalization.
 - Need for a complete transformation of investments from institutionalization to supporting community living in the form of inclusive community services starting from inclusive education, inclusive health, inclusive employment, and inclusive social protection. Most importantly, community mental health programs must be inclusive of people with disabilities.
 - Increased government investment in awareness raising: In Africa persons with disabilities face persistent stigma and discrimination especially people with intellectual and psychosocial disability. This also leads to institutionalization which in the African context can include prayer camps, shackling, healing centres where persons with intellectual and psychosocial disabilities live for months to years in the name of 'driving away demons'.
 - Increased government investment in data: The ADP mandates African states to collect and disaggregate data. There is a need for clear data not only on the number of people with disabilities in institutions but also on systemic barriers that people with disabilities face, and importantly on the support and accommodations to be provided to them from a very person-centered approach to live in their own communities.
 - Strengthening of weak monitoring mechanisms and follow up mechanisms including periodic reporting on the implementation of the Guidelines on Deinstitutionalization and a clear roadmap of how governments are going to involve persons with disabilities and their representative organizations to work on deinstitutionalization.



In terms of what OPDs and families would like to draw further attention to, Fatma Wangare laid out the following points:

- While many African states have placed moratoriums on registration of new charitable children's institutions, those with less than 20 children are not affected by it. This coupled with quite a couple of unregistered institutions for children means that children with high support needs, especially children with intellectual and multiple disabilities, are still being institutionalized. Statistics from government of Kenya states that 40% of children with disabilities are in institutions, which is a very high number. Segregated schools have become institutions in their own way.
- Children with high support needs are often not registered at birth and are therefore not counted. Without government papers, children with disabilities cannot avail services.
- In Africa, infanticide is still a risk for children with disabilities. Sometimes mothers find institutions are the only way to have their child with disability survive and live. This narrative that institutions are the best place for children with disabilities needs to change.
- There must be community based early intervention and support services. Even in Nairobi, families have to travel 3-4 hours to access services. There must be respite care at the community level. Families must be supported so that children with disabilities can grow up in their homes and communities.



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Aminul Islam, Global Technical Lead on Child Protection System Strengthening and Child Care Reform, UNICEF

Aminul Islam in his remarks highlighted the following:

- The Convention on the Rights of the Child (CRC) mandates that every child should grow up in a family environment and when we say every child it includes children with disabilities. The CRPD takes this a bit forward and under Article 23 (2) mandates State Parties to ensure that children with disabilities have equal rights with respect to family life, and emphasizes that where the immediate family is unable to care for a child with disability, States must undertake every effort to provide alternative care within the wider family and failing that, within the community in a family setting. The message is very clear from both the Conventions.
- UNICEF supports governments around the world in sharing lessons and to also adapt care reform initiatives. The care reform approach at UNICEF is three pronged:
 - Preventing family separation
 - When separation is inevitable, focus should be on family-based alternative care.
 - Ending institutionalization of children and promoting family intervention.
- To deliver work on these 3 areas, child protection systems must be strengthened to support and empower families in all contexts. When it comes to children with disabilities and their families, there are barriers that prevent their access to the benefits of the system. These barriers also extend to other system related services such as education, social protection, health services, etc.
- Strengthening child protection services requires it to be both effective and inclusive. To make it inclusive for children with disabilities, UNICEF's approach is informed by its experience and practices in different countries.
- Among the different components of child protection, legal and policy frameworks are very important. These must include specific provisions for children with disabilities and their equal right to family-based care. Another important component is governance and coordination. Governance and coordination mechanisms on care system reform must be connected to those mechanisms that exist for children with disabilities. Additionally, services for children must be inclusive – with targeted funding of services for children with disabilities while also making mainstream child services inclusive.
- Another aspect of the child protection system is the social service workforce, which is often under-resourced and lacks capacity. UNICEF has developed a competency framework for social service workforce on disability inclusion. This must be part of the training of social service workers.
- There must be a focus on data for monitoring using the UNICEF Washington Group Child Functioning Module. UNICEF is now working on integrating this into its child protection information system which is being piloted in countries.



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Video of Diana Zgherea (member of self-advocacy group) and Ludmila Jalbă (coordinator of the self-advocacy group) from Moldova

- Diana Zgherea had lived in an institution for 20 years but is now living in the community. She works as a janitor at a kindergarten. She shared that she feels free now, she sees her friends, goes to the grocery store, get involved in food preparations, etc. – she is her own guide.
- Simple things that she was not able to do before like watering the flowers, communicating with friends, going for a walk and making her own food were impossible earlier.
- Today, she enjoys listening to music, reading books, and watching television. She has also traveled to the United States and to Austria.
- Her message to world leaders is that living in the community is much better.
- This story is about community life, dignity and respect. Diana Zgherea proves that community living for people with disabilities is possible.

Waqar Puri, Director of Programs and Operations, Transforming Communities for Inclusion (TCI)

- Children with disabilities are at most heightened risk of being institutionalized, especially children with high support needs, including children with intellectual and psychosocial disabilities. It is important to highlight realities like shackling and forced psychiatric diagnosis of children with disabilities for being slow learners, autistic, having attention deficit, etc. and many childhoods have been lost due to these treatments.
- Often families push their children into institutions for rehabilitation treatments, and they remain confined there for many years. There are still massive investments being made in various types of institutions. Institutionalization is not care, it is segregation. It removes children from family, culture, love and belonging.



- Even facilities like independent living centers, small group homes, rehabilitation centers - they reproduce institutional dynamics, such as rigid routines, lack of personal agency, no bonds of permanence, and these are not acceptable as alternatives to live in the community.
- The CRPD and the Guidelines on Deinstitutionalization are clear that no child should be placed in an institution under any circumstances. And hence, states must cease any further investments being made which segregates children with disabilities from their families and communities. Rather strategies must be developed to support State Parties to transition from institutionalization to community-based settings by investing in community inclusion and recognizing community support systems as a viable social entity and core component of deinstitutionalization that ensure communities and families are empowered and prepared.
- Establishing and strengthening community support systems that are responsive to the lived experiences of children with psychosocial disabilities and children with diverse disabilities. This includes actively engaging communities and families, building inclusive and responsive community networks, reinforcing peer support structures and promoting informal peers, informal support mechanisms rooted within the communities. These systems are essential, not only to prevent institutionalization, but also enable children with disabilities to live and thrive in the mainstream community settings with dignity and autonomy.





Video of Marin Andronache (survivor of institution) and Ludmila Malcoci (Regional Director of Keystone Human Services International, Executive Director of Keystone Moldova) from Moldova

- Marin Andronache shared that he had never expected to ever have a family or children. He and his wife believed they would be stuck in an institution all their lives and eventually die there. But this was not true. Today he has a family, a house, and a job. He interacts with many friends, and people – a lot has changed. People with disabilities living in residential institutions do not know if they have a future.
- Marin Andronache and his wife will be celebrating 7 years together and have two children. Marin did not have a family, a mother or a father. Today they feel lucky to have children who they are raising with love. The children love them and are loved and together they wish to be a happy family.



