

Building an ecosystem that serves all children: Statement to the Day of General Discussion on Children's Rights and Alternative Care

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Introduction: Multiple UN conventions and statements proclaim the need to end institutionalization and uphold the right to family for all children. They include the Convention on the Rights of the Child (CRC), the UN Guidelines for the Alternative Care of Children, and the 2019 UNGA Declaration on the Rights of the Child. Article 19 of the Convention on the Rights of People with Disabilities (CRPD) states that people with disabilities have the right to live and participate fully in the community, and general comment No. 5 states the obligation of States to plan for deinstitutionalization, pushing for closure of all types of residential care institutions.

However, children with disabilities continue to be institutionalized in every region of the world and are often left out of efforts to provide high-quality alternative care. Care reform must develop a supportive ecosystem for children with disabilities and families to end institutionalization, provide high-quality alternative care, and facilitate better outcomes for all children.

Disability and institutionalization: There are an estimated 275 million children and youth with disabilities in low-and middle-income countries,ⁱ and 1,347 million family members impacted. Children with disabilities are over-represented in institutions,ⁱⁱ and are 17 times more likely to be institutionalized than their peers.ⁱⁱⁱ

The combination of institutionalization, poor early child development, and adverse childhood experiences contributes to disabilities and leaves children with disabilities at higher risk for negative outcomes.^{iv} Institutionalization is associated with significant developmental delays including poor physical and brain growth,^v and interrupts positive early child development, leaving children more vulnerable to future stressors.^{vi} For example, rates of malnutrition in residential institutions have been found to reach 70-90%,^{vii} and poor nutrition in childhood affects life-long brain function.^{viii} As stated by Marin Andronache, a self-advocate who grew up in an institution in Moldova, *"Institutions should be closed and more family-type services created, to help children be adopted, for children to grow up in families like everyone else. And in families where children with disabilities are born, to be offered support and to be explained how to raise a child with a disability."*

Parents of children with disabilities in resource-poor settings can experience significant stress, poverty, lower access to services, and a perceived inability to care for their child. In an informal survey, parents of children with disabilities in Azerbaijan described challenges accessing healthcare for their children including few rehabilitation centers, high costs for private care, lack of staff training, and long wait times. Shonaquip Social Enterprise estimated the additional costs to parents of a child with

disability in South Africa at R32,546 (\$2,400) per year, based on parent-led research.^{ix} Research shows that parents of children with disabilities also receive less social and practical support from their communities,^x and that coping strategies are often limited by poverty or logistical barriers.^{xi} This can make families more likely to place their child in an institution, less likely to transition a child back from institutional care, or less willing to foster or adopt a child with a disability.

Community, health and social services can prevent child abandonment, for example by identifying children who are at high risk for abandonment and offering intervention at birth.^{xii} Active parent networks can support parents to navigate their own and their children's rights and service provision.^{xiii} Once families access the knowledge, agency, and support to implement best care practices at home, they can be primary drivers of their child's care and success. As one parent in Shonaquip's parent network said, *"I have learnt to accept everything that is happening around me and my family, most importantly accepting my child's special needs, it's actually not that difficult, you just need people who understand what you are going through."*

Despite pledging a 'leave no one behind' approach, care reform movements often exclude children with disabilities. This is due to factors including poor inclusion of people with disabilities in decision making; stigma and assumptions; and insufficient research and data. The medical model of disability has led to a perspective that a disability needs to be 'fixed' by the medical profession, leading to tendencies to generalize, stereotype, and define a person by their disability.^{xiv} The medical model has historically guided child welfare and care systems for children with disabilities, including legislation and policies, higher education, and service provision.^{xv} As society has moved to the social model of disability, it is now well-recognized that the global community must welcome and accommodate people living with impairment; not change people to accommodate society.

Challenges and lessons from COVID-19: The pandemic has increased children's risks of illness, malnutrition, family separation, and other adverse outcomes, especially for children with disabilities.^{xvi} Emergency deinstitutionalization during the pandemic has demonstrated successful transitions of children with disabilities into family care, but in other cases showed that systems are unprepared to support children and families, or that children with disabilities were left in institutions while typically developing children transitioned to family care.

Some COVID-related adaptations have shown promise for inclusion. For example, in Azerbaijan, Child Development Specialists used online methods to guide parents and siblings to engage children with disabilities in activities, with families as key agents in the child's development. Many programs have moved to one-on-one settings, allowing service providers to focus on each child individually and to equip parents with skills and resources. Remote service delivery has reduced barriers, including wait times and transportation, and given some service providers a new avenue for professional development. These are often limited to places and families where internet is readily accessible, but low-bandwidth solutions like WhatsApp can be leveraged to expand access to support, training and resources.

An ecosystem approach: Successful care reform must create an enabling environment that allows each child to live a meaningful life with their family; adheres to the core principles of high-quality alternative care; and prioritizes the voiced needs, rights, and viewpoints of children and families. This cannot focus on one sector, but on a holistic network that allows children and their families to access individualized supports. This will be critical to addressing the root causes of institutionalization and supporting family reintegration and family-based care for all children.

Care reform systems must focus on the needs of children with disabilities and their families first, rather than designing for a hypothetical ‘typical’ child. In reality, every child in alternative care or at risk of family separation has individual strengths and needs. Adopting this perspective will lead to a system that can: adapt to serve any child including children with severe disabilities; respect parents, families, and other caregivers as leaders in a child’s care; support service providers to provide holistic, responsive care in communities; and hold all actors accountable for equitable care reform. Examples can come from other sectors. For example, inclusive education does not focus only on allowing children with disabilities into a classroom, but allows teachers to interact with students in a new way that responds to each child’s strengths, needs, and learning goals.

Figure 1: Potential components of an ecosystem of support^{xvii}



Elements of an inclusive system: Four areas can accelerate progress towards an inclusive system: inclusive leadership, policy and funding, provider training and skills, and community-based services.

Inclusive leadership: Care reform must support leadership of people with disabilities and their families and networks as change agents. Empowered families acting together can shape inclusive and sustainable supports, policies, and practices at community and national levels. This must include services that respond to families’ and children’s needs and requests; ensuring that services and service

providers focus on supporting families; reflecting their leadership in policies; and ensuring that children with disabilities, their families, and other members of their networks are meaningfully engaged in policy development.

Policy and funding: Governments and partners must prioritize the rights, needs, and viewpoints of children with disabilities in care reform policies. A systems approach combining bottom-up and top-down initiatives is recommended to address the causes and consequences of institutionalization.^{xviii} Existing guidelines, research, and commitments should inform this process.

There is a clear need to increase funding for care reform in nearly all countries. This represents a significant lost opportunity, as residential care is significantly more costly than supporting family-based care.^{xix} However, budget constraints cannot be accepted as a reason to exclude children with disabilities from existing progress. In Burkina Faso, ISS supports child welfare authorities to develop family reintegration and family based-care for children with disabilities. A major challenge is ensuring sustainability of the system by reducing over-reliance on external funding and advocating for greater involvement of the State and stakeholders at all levels. Care reform is a long-term commitment requiring sustained financing, continuous advocacy, and sustainable policies.^{xx} Policies and budgets must reflect the principle of “the money follows the child”. Stakeholders must collaborate to generate needs-based cost estimates of inclusive deinstitutionalization, preventive services, and alternative services, while informing how to allocate resources saved from institutionalization.

Provider skills and training: As countries expand policies to protect the right to family care for all children, limited workforce capacity may mean that these policies exist only on paper. Many service providers in health, education, and social work have no training on disability rights or early childhood development for children with disabilities. This leads to gaps in the knowledge and skills necessary to keep children in families or facilitate successful transitions to family care.

Currently, many trainings are limited in scope, are not adapted to context, perpetuate the medical model, or provide limited opportunity to transfer knowledge into practice. Through a multi-sectoral effort, our consortium of NGOs is working with universities to develop a global training package grounded in a rights-based approach that combines learning in health, education and social development for children with disabilities. It will contain practical and skills-based modules on foundational knowledge such as child development, understanding disability, building on a child’s strengths, working with families, social inclusion, and nutrition. It will improve professionals’ skills and knowledge, serve as a foundation for further learning, and allow professionals to work hand-in-hand with families to support children with disabilities and support the inclusive planning of services.

Inclusive community-based services: Provider skills alone will not provide children the support they need. Without quality community services and support for parents, kin, and foster families, institutions are seen as a ‘way out’ or the only option to care for children with disabilities. Existing services too often focus on one sector, are fragmented, lack capacity, or discriminate against children with disabilities. In

an informal survey, parents of children with disabilities in Azerbaijan recommended services including care centers, financial support, mental health support, extracurricular events for children, more and better trained staff, and increased rehabilitation services as examples of community-based services that would help them. Parent networks can also extend support, advice, and resources to parents in remote areas.

There is an urgent need to develop and improve community-based social care services with clear referral pathways. Much of this can be accomplished by eliminating barriers that prevent families impacted by disability from benefiting from existing supports and services. Such services are also necessary as children integrate into their communities, families, and schools. Marin Andronache states, *“People who leave residential institutions are afraid of the unknown, they do not know what living in the community is. It is very important that when they leave alternative care they have a support person to explain to them what it means to live in the community... what convinced and helped me the most was that I went to a lady's house and saw the difference between living in an institution and living in a community.”*

Summary of recommendations: All children deserve to grow up in a family, and children with disabilities have the right to be fully participating citizens, equal with others. As countries seek to uphold their obligations to the CRC and the CRPD, deinstitutionalization will only succeed if there is a supportive ecosystem for children with disabilities and their families, including family strengthening efforts and inclusive community-based services. Delegates should take these actions to move this agenda forward:

- Create services to help children grow up in families, and enforce quality standards in alternative care.
- Advocate for inclusive care reform that prioritizes the needs, rights, and viewpoints of children with disabilities and values voices from families.
- Ensure that alternative care policies and strategies reflect the CRC and CRPD and are supported with appropriate resources and accountability measures.
- Create and use a standardized foundational course on family care for children with disabilities for service providers in low- and middle-income countries, building on existing capacities and resources and increasing collaboration.

ⁱ Olusanya BO, et al., Global Research on Developmental Disabilities Collaborators (GRDDC). Global Burden of Childhood Epilepsy, Intellectual Disability, and Sensory Impairments. *Pediatrics*. 2020 Jul;146(1):e20192623. doi: 10.1542/peds.2019-2623. Epub 2020 Jun 17. PMID: 32554521.

ⁱⁱ van Ijzendoorn, M.H., et al. 2020. Institutionalisation and deinstitutionalisation of children 1: a systematic and integrative review of evidence regarding effects on development. *The Lancet Psychiatry*. Vol 7 Issue 8, P 703-720. DOI:[https://doi.org/10.1016/S2215-0366\(19\)30399-2](https://doi.org/10.1016/S2215-0366(19)30399-2)

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^v van Ijzendoorn, M.H., et al. 2020.

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- xvii Adapted from Burchell, 2021
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