Don’t Call Me Resilient: How Care and Support Systems are Failing People with Intellectual Disabilities and their Families

Recommendations

Inclusion international

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Recommendations

The findings of this report make clear that care and support systems around the world are often fragmented, underfunded, and shaped by segregation and inequality, leaving persons with intellectual disabilities and their families with limited choices and inadequate services. Families are forced to fill these gaps with informal support, which creates substantial new challenges for both family carers and the people with intellectual disabilities they support.

At the same time, families and persons with intellectual disabilities have articulated a clear vision of what an inclusive care and support system should look like - one that is grounded in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Inclusive care and support systems ensure choice and autonomy, deliver high quality community-based options, are in line with a whole family approach, are affordable and adequately resourced, and embed meaningful self-advocacy and family leadership.

The recommendations below translate the calls from persons with intellectual disabilities, parents, siblings, and other family members to move towards care and support systems aligned with these values into concrete actions for governments, service providers, and civil society.

Many care and support systems around the world need to be built or re-built from the ground up in order to meet the needs of people with intellectual disabilities and their families. Significant reforms will take time, but in the meantime people with intellectual disabilities and their families will continue to fall through the gaps. The recommendations in the section below are organised into **immediate actions** which governments can take in the short time to improve existing care systems, and **progressive realisation** which identifies longer-term systems change goals that need to be embedded into care reform.

Care reform must be built on dignity, inclusion, shared responsibility, and meaningful participation, with persons with intellectual disabilities and their families at the centre of design, implementation, and monitoring - and governments have a responsibility to take action to make this a reality.

1 Choice and autonomy

People with intellectual disabilities want real control over the support they get, and families playing care provider roles want real choice in the services and support they access.

Choice and autonomy looks like legislative and policy environments that support people with intellectual disabilities and their families to make choices about services, and direct and manage their own support.

Immediate actions

- National Governments must reform laws and policies to recognise the full legal capacity of persons with intellectual disabilities, including persons with high support needs, replacing substitute decision-making with supported decision-making.
- National Governments must develop, fund, and fully recognise the authority of supported decision-making mechanisms, so that all people with intellectual disabilities can exercise choice and control over their lives.
- National Governments must make sure that existing formal services are person-centred, promote inclusion, independence, and self-determination.
- Donors must ensure the care and support related projects they fund are inclusive and in line with the CRPD.

Progressive realisation

- National Governments must ensure access to a diverse range of individualised support options that enable people with intellectual disabilities to choose where, how, and with whom they live and participate in their communities.

- Where formal services exist, National Governments must introduce flexible, self-directed funding schemes that allow individuals to choose support to their actual needs and preferences.

2 High quality community-based options

People with intellectual disabilities and their families want high quality support that is based in their community, not in segregated settings.

High quality community-based options look like legislative and policy environments that invest in fully funded and well monitored community-based models, ensuring equal access to all communities. This cannot be achieved without eliminating segregated settings.

Immediate actions

- National Governments must close institutions and other segregated services.

- Local and National Governments should scale up existing and successful community-based models led by organisations of persons with disabilities (OPDs) and community-based organisations (CBOs) that are in line with the CRPD.

- Local authorities must redirect funding used in segregated services to community-based support services such as personal assistance, community navigators, respite services, peer support, and supported employment.

- Service Providers must ensure mandatory training on human rights, inclusion, and person-centred approach for all support workers.

Progressive realisation

- National Government must make inclusive community-based services available in rural areas.

- National Governments must ensure accessible and affordable transportation so that people with intellectual disabilities can access all types of services, including health, employment and community activities.

3 Whole family approach

People with intellectual disabilities and their families want high quality support that is based in their community, not in segregated settings.

A whole family approach looks like legislative and policy environments that recognise the role of families, provide meaningful financial, psychological, and peer support for family carers.

Immediate actions

- National Governments must recognise families as key partners in care and support provision and reflect their needs within care and support policies and programmes.

- Service Providers should provide psychological support, counselling, and support the development of peer-support networks for family members, including parents and siblings.

- National Governments must put protections in place for workers who are family carers to prevent them from having to choose between work and their care and support responsibilities.

Progressive realisation

- National Governments must promote gender-responsive policies that address the disproportionate impact of care provision responsibilities on women and girls.
- Local authorities must support networks of families of persons with disabilities to deliver peer support through adequate funding.
- Local authorities must expand access to high-quality and accessible respite services to reduce care provider burnout and improve family well-being.
- Community-based organisations, including service providers should establish information, guidance, and navigation services to help families understand rights, access services, and plan for the future.
- Community-based organisations including family-based organisations should develop specific programmes for siblings, including training, peer networks, and involvement in future planning and decision-making.

4 Affordability and appropriate resourcing

People with intellectual disabilities and their families need support managing costs associated with disability, including both access to services and other financial impacts.

Affordability and appropriate resourcing looks like legislative and policy environments that fully fund care and support mechanisms to ensure needs are fully met, while also addressing the financial impacts of care and disability extra costs on people with intellectual disabilities and their families.

Immediate actions

- National governments must protect care and support funding from sudden cuts and ensure continuity of care and support throughout a person's life.
- National governments must consult with families on the financial impact of their role as family carers.
- National and local authorities must simplify eligibility procedures and reduce administrative barriers to accessing financial support and services.
- Service providers must compensate formal sector care workers appropriately to improve staff retention.

Progressive realisation

- National governments must ensure disability-related costs are fully recognised through adequate disability benefits, caregiver support, tax measures, and social protection schemes.
- National governments must guarantee that support services are affordable and available regardless of income level or geographic location.
- National governments must develop policies and allocate budgets that respond to the actual role of families who are care providers.

5 Self-advocate and family leadership

People with intellectual disabilities and their families know that the care and support system isn't working - and they know what needs to change to meet their needs.

Self-advocates and family leadership looks like governments and service providers listening to the advice of people with intellectual disabilities and their families, responding to feedback, and engaging service users in monitoring.

Immediate actions

- National Governments must ensure meaningful participation of people with intellectual disabilities and families in the design, implementation, monitoring, and evaluation of care and support policies and services.
- National and local authorities must establish formal consultation mechanisms to ensure that care reforms reflect the lived experiences of people with intellectual disabilities and their families.
- National Governments must promote existing family- and self-advocate-led peer support initiatives, circles of support, and community networks that strengthen inclusion and reduce isolation.

Progressive realisation

- Governments must equip organisations of persons with disabilities (OPDs) with the resources to support families and self-advocates to lead policy conversations.