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

Executive Summary

Inclusion international

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Executive Summary

Around the world, people with intellectual disabilities are being left behind by care systems, and their families are left to fill the gaps. Families propping up these care systems are seen as selfless and resilient, but as family member in Canada consulted for this report said it best - “I hate being called resilient - because if the supports were in place I wouldn't need to be called that.”

Momentum for care reform is growing around the world. The definition of “care” has recently been expanded to encompass the support that people with disabilities need to be independent and included in the community. As care and support reform moves in this new direction, why are the needs of people with intellectual disabilities and their families still not being met?

The views of people with intellectual disabilities and their families about gaps in care and support systems will be essential for policymakers to understand and address as approaches to care evolve.

To better document how they interact with care systems around the world, Inclusion International collected inputs and experiences from people with intellectual disabilities and their families from 42 countries through focus group discussions, a survey of family carers, and case studies from the Inclusion International network. This research considered experiences across the three pillars of care and support - formal care and support systems, semi-formal care and support from community networks, and informal care and support.

It highlighted a number of gaps in care and support systems that are failing people with intellectual disabilities and their families:

- The vast majority of people with intellectual disabilities cannot access care and support mechanisms that are sufficient to meet their needs. This holds true in all contexts around the world, including in countries considered to have robust care systems.

- Where formal care and support services exist, they are difficult to find, have accessibility barriers in place, and are often delivered in segregated settings in violation of the Convention on the Rights of Persons with Disabilities (CRPD).

- Lack of meaningful access to services results in families of people with intellectual disabilities filling the care and support gaps themselves - often at the expense of their livelihoods and physical and mental health.

- The fragmented, inaccessible systems and lack of support for family carers also create disproportionate challenges for people with intellectual disabilities who are care providers themselves.

The experiences of people with intellectual disabilities and their families accessing care and support make clear that the three core pillars of care systems for people with intellectual disabilities - formal services, community support, and family support - are not in balance. Under-resourced and inadequate services and community structures have shifted the care and support burden almost entirely to families.

Families are filling these gaps, but are cracking under the pressure.

Care and support systems need to change, and people with intellectual disabilities and their families have clear messages about what care and support systems in their countries should look like.

Inclusive care and support systems are based on **choice and autonomy**, provide **high-quality community-based services**, **take a whole family approach** to meeting needs, are **affordable and appropriately resourced**, and are **rooted in self-advocate and family leadership**.

While promising practices exist that incorporate these elements of an inclusive care and support system - like Kenya's Circles of Support model or Argentina's Layered Support model - there is an urgent need for governments to take action to remove barriers to care and support and re-imagine systems to be more inclusive.

This requires legislative and policy changes, investment in a transition from segregated to inclusive services, developing a strategy for improving service quality and monitoring, improving access and removing accessibility barriers, and embedding support for family carers at the heart of care systems.

Fully inclusive care and support systems that meet the needs of people with intellectual disabilities and their families are possible, and this report provides a roadmap for how to get there.

As governments review their care systems and develop strategies for reform, the voices of people with intellectual disabilities and their families must be central to the care reform process to ensure systems become fully inclusive.

Key Findings:

- Chronic underfunding and the use of outdated, segregated care models mean that formal support mechanisms around the world do not meet the needs of people with intellectual disabilities or their families.
- Formal care and support mechanisms are fragmented, difficult to identify, underresourced, and inaccessible.
- These gaps mean that formal support, semi-formal community support, and informal support as pillars of the system are out of balance, with the bulk of support provided by families without pay.
- The lack of support for families in their role as primary carers creates risks for families, including burnout, isolation, and institutionalisation of people with intellectual disabilities.
- People with intellectual disabilities are increasingly taking on care provider roles, but care and support systems are not responsive to their dual role as people requiring care and support and care providers.
- People with intellectual disabilities and their families will continue to be put at risk until care systems transition towards **affordable, appropriately resourced,** and **high-quality community-based services** that promote **choice and autonomy**, **take a whole family approach** to meeting needs, and are **rooted in self-advocate and family leadership**.