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

Inclusion international

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This work to collect the experiences of people with intellectual disabilities and their families in requiring and providing care and support was funded by the Sage Fund.

Inclusion International is the global network of people with intellectual disabilities and their families.

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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**.

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Introduction

Giving and receiving care and support are part of everyday life for people around the world.

From accessing health care or childcare to caring for aging relatives, we all interact with different formal and informal care systems throughout our lives – both as people requiring care and as a care provider.

Governments are beginning to reflect on the care systems that exist in their countries and how they can serve communities better. This care reform process is drawing together policymakers, care providers, those requiring care, and civil society to imagine care systems that are more effective and are better able to meet real needs.

But for people with intellectual disabilities and their families, "care" is only part of the picture. While people with intellectual disabilities interact with formal and informal care systems in different ways, "support" is also an essential part of the equation for being fully included in the community.

While care focuses on different ways to meet a person's basic needs – through health care, childcare, and other ways to ensure a person's well-being, "support" is the assistance that enables a person with a disability to actively participate in their community. Support can take the form of human support, assistive devices, or other forms of support that help a person live an inclusive life. It might look like a personal assistant, support for decision-making, assistance to get a job, or other forms of support that help a person do their daily activities.

This understanding of how support for people with disabilities fits into the broader care agenda is reflected in how the definition of "care" has evolved globally in recent years. In the most recent definition of care adopted by the United Nations, "care" refers broadly to all the activities that sustain daily life, human well-being and the sustainability of communities and the planet. This encompasses care for oneself and for others, including the provision of support and assistance to those who require it to enable their participation in society with dignity and autonomy.[1]

1. United Nations, 2025. Human Rights Dimension of Care and Support - Report of the United Nations High Commissioner for Human Rights.

For the purposes of this report, when the terms “care system” or “care reform” are used, this definition encompasses both care and support.

As people requiring care, people with intellectual disabilities access varying forms of care and support based on their needs. These range from medical and therapeutic services to decision-making support, support to manage money to employment support services, personal assistance to communication support or assistive technology. People with intellectual disabilities often need a combination of these different forms of support, and no two people with intellectual disabilities will require the exact same types of support - support depends on needs, interests, environment, and other factors. People with intellectual disabilities may also be providers of care, and may need to access forms of support to aid them in their family caring roles. It is not one or the other - providing and requiring care and support is a continuum in everyone’s life.

What care and support look like for people with intellectual disabilities varies significantly based on context – while some people with intellectual disabilities can access formal services staffed by professionals to receive these forms of support, far more people with intellectual disabilities are getting these forms of support from their family members. The vast majority of people with intellectual disabilities continue to live with their families as they age[2] and family members around the world are the largest provider of care and support for people with intellectual disabilities. Family members play the role of community support workers, therapists, care managers, decision-making supporters, and more – all while also playing the care and support roles that *all* families play for each other, regardless of disability.

Families of people with intellectual disabilities live and breathe care and support in their day-to-day lives, and often do so without any kind of meaningful support from their government. This level of care and support goes far beyond the standard that a parent of a child without an intellectual disability would be expected to provide, and continues into their adulthood and older age. Families are portrayed as resilient for taking on this role that they should never be doing without support in the first place. This report uses the terminology “care provider” to describe this intensive role that families of people with intellectual disabilities play. This language recognises the volume of care and support provided and how the roles they take on can be likened to professional services, distinguishing it from the standard “caregiver” role that all parents play for their children.

2. Inclusion International, 2012. Inclusive communities = stronger communities: A global report on Article 19.

In parallel, this report uses the terminology “those requiring care and support,” which includes not only the individuals receiving care and support but also those who need it but do not have access to it yet. In most instances in this report, people with intellectual disabilities are the primary people requiring care and support being discussed, but this language may also refer to family members in instances where people with intellectual disabilities themselves are in a care provider role.

Inclusion International spoke to people with intellectual disabilities and their families about what care and support does look like and should look like in their lives. Despite living in varied contexts, families around the world had consistent experiences of service gaps and financial barriers, gendered impacts of care, and a lack of help to deliver on their care and support roles. The experience of people with intellectual disabilities and their families accessing care and support is one of inequality and unmet needs - they report that service providers are often not equipped to deliver fully accessible and inclusive support that promotes living in the community. These gaps occur for a variety of reasons - geographic inequalities, understaffed services and underpaid care workers, and entrenched segregated approaches, among others.

Family members fill those gaps but receive little or no assistance (whether in the form of financial support, services, peer or mental health support, information or planning support, or other forms) to fulfil their role. People with intellectual disabilities who are care providers face new barriers as a result of interacting with these insufficient care systems. The message from people with intellectual disabilities and their families is clear: something needs to change.

As governments consider what care reform looks like in their national contexts, the voices of people with intellectual disabilities and their families as both care providers and people requiring care need to be part of the conversation. Strong care and support systems are an enabler for inclusion, and people with intellectual disabilities and their families know best what genuinely inclusive care systems should look like. Without their participation in the conversation about care reform, the reforms risk reproducing systems that consider care without embedding support, or reproducing systems that provide care and support where the individual is not in control of or directing the assistance they need.

Drawing on the voices of people with intellectual disabilities and their families from 42 countries, this report shares the challenges and realities they face accessing care and support - and their calls for change.

Through sharing the experiences of people with intellectual disabilities and their families navigating care and support systems and analysing how different care and support mechanisms impact them, this report gives policymakers the opportunity to bring the experiences of people with intellectual disabilities and their families into the care reform process.

Methodology

To document the experience of care and support for people with intellectual disabilities and their families, Inclusion International collected data from a variety of sources.

Building a nuanced picture of how families navigate within care and support systems requires both understanding their personal experiences, and the systemic factors that influence those experiences. To do this, Inclusion International collected information both from people with intellectual disabilities and their families in their own words, and from the organisations that represent them to supplement those individual experiences with national trends and information about the care and support mechanisms families engage with.

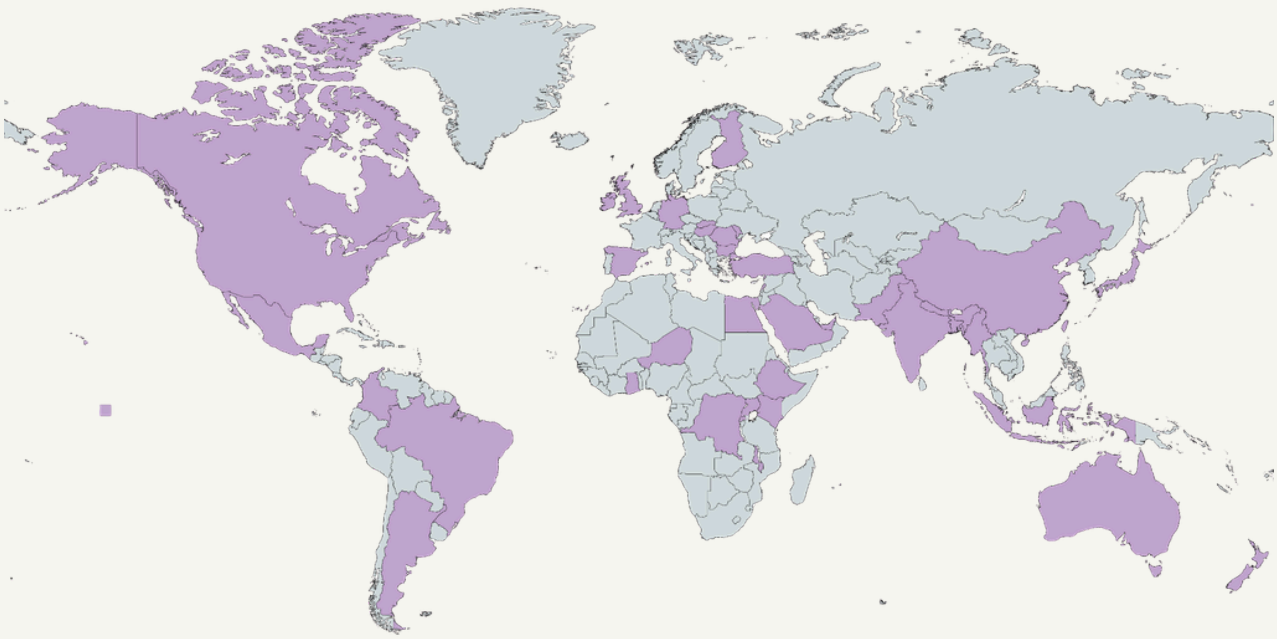
The information in this report was collected from three primary sources:

- Focus groups with family members of people with intellectual disabilities, and focus groups with people with intellectual disabilities who are self-advocates[3]
- A survey of family members of people with intellectual disabilities
- Case studies on formal and informal care and support mechanisms in different countries prepared by Inclusion International members

3. A self-advocate is a person with an intellectual disability who has been trained in human rights and speaks up for themselves and their peers. The self-advocates in Inclusion International's network do three important things: understand their rights, work as a team to support and learn from each other, and speak up about what would make life better for them and other people with intellectual disabilities.

When we collected data from people with intellectual disabilities and their family members directly – through survey responses and focus groups – we asked respondents to think about what care and support looks like in their own lives, and how the formal care and support system that exists in their country influences their lives and what they want to see change.

Across the three data sources, the experiences of people with intellectual disabilities and their families from 42 countries were collected to inform this report.



Focus group data

This report includes data from 5 focus groups with family members, and 9 focus groups with self-advocates. Perspectives from self-advocates and families from 28 countries were captured across the 14 focus groups. Focus groups with family members and focus groups with self-advocates were held separately, to make sure that both groups had a safe peer-only space to share their experiences.

A total of 18 family members from 14 countries took part in 2 international focus groups, which brought together family members from different countries to discuss experiences.

An additional 27 family members took part in single-country focus groups in their home country, hosted by Inclusion International members Inclusion Canada, ZPMPvSR Slovakia, and Disability Inclusion Rwanda.

A total of 25 self-advocates from 16 countries took part in 5 international focus groups, which brought together self-advocates from different countries to discuss experiences. An additional 51 self-advocates took part in single-country focus groups in their home country, hosted by Inclusion International members Plena Inclusion España, Tukena Foundation Finland, ZPMPvSR Slovakia, and Disability Inclusion Rwanda.

All focus groups run by Inclusion International, for both self-advocates and families, were run in line with the Listen Include Respect Guidelines. Participants received the focus group discussion questions and background information two weeks in advance, so that they had time to prepare.

Self-advocate participants were asked about the support they need to live independently and be included in the community, what good care and support looks like to them, how their families, organisations, and others provide them with care and support, and if they make choices about the care and support they get. Self-advocates were also asked about the roles they play as a carer and supporter themselves – to their families, friends, or others in their communities.

Family participants were asked about the care and support they provide, the care and support mechanisms offered in their country, and the support families need to help them in their role as a provider of care and support. They also spoke about what roles for families *should* look like – speaking about what the division of care and support work between families and government or service providers should look like, and whether they think that family carers and supporters should be compensated.

Survey data

Inclusion International also ran a survey for family members of people with intellectual disabilities to share written responses about their experiences providing care and support.

The survey collected 261 responses from family members in 21 countries around the world – with responses coming from all five of Inclusion International's regions – Africa, the Americas, Asia-Pacific, Europe, and the Middle East and North Africa (MENA).

Among the survey respondents, parents of people with intellectual disabilities made up 74% of responses – their strong representation a reflection of the key role that parents play in the provision of care and support for people with intellectual disabilities.

Siblings were the second largest group at 10% of responses, and the rest of the dataset was made up of grandparents, other family members of persons with intellectual disabilities, and a small number of people with intellectual disabilities who themselves are providers of care and support for others. The dataset was overwhelmingly made up of responses from women (79%), reflecting the gendered dynamics of family-based care and support.

Families were asked to identify and reflect on the care and support mechanisms that exist in their country and make recommendations about how they could be changed to better support their needs as carers. Families also shared their opinions on policy issues in care and support reform, and shared experiences of key moments as a family member of a person with an intellectual disability, including their experiences preparing for transitions of care and support as parents age.

Case studies

While focus groups and surveys are effective tools for hearing the individual voices and experiences of people with intellectual disabilities and their families, supplemental information from organisations was essential to understand the broader context in different countries.

These case studies aimed to document both formal and informal mechanisms for delivering care and support in a particular context – in particular, looking for models that provide key lessons that can inform future policy on effective care and support models.

Importantly, the case studies only documented care and support mechanisms that support people with intellectual disabilities to live full lives in their communities – while many care and support mechanisms exist that are provided in institutional or segregated settings, these mechanisms do not represent good practices to be replicated in care and support reform processes.

Inclusion International members Tukena Foundation (Finland), ZPMPvSR (Slovakia), Keystone Moldova (Moldova), Asociacion Azul (Argentina), SETI Caritas (Egypt), and KAIH (Kenya) contributed detailed case studies about care and support mechanisms that exist in their contexts. Some of these case studies are used as examples through the text of this report.

All of the personal experiences shared by people with intellectual disabilities through focus groups or survey data have been anonymised. Quotes or vignettes used throughout this report will be attributed only to the speaker by their role (family member or self-advocate) and their home country.

A group of family members of people with intellectual disabilities talking about care and support in Kenya.

The State of Care and Support

As governments around the world look towards reforming their care systems, the momentum for the new care agenda provides an important opportunity to reflect on how the current system is working - or not working - for people with intellectual disabilities and their families.

Presenting the current state of care and support, this section will provide top-level findings about the care and support systems that people with intellectual disabilities are accessing, and where the gaps in the care and support ecosystem exist.

Inclusion International's research found that regardless of where a person lives, the care and support needs of people with intellectual disabilities are not being met.

Current care and support models are failing people with intellectual disabilities around the world for a number of reasons, which intersect with and amplify each other.

Lack of Government Responsibility

In many contexts, governments failing to take responsibility for care and support is a key driver of unmet needs. In countries without robust social protection systems, people with intellectual disabilities and their families are left with no access to publicly-funded care and support - whether that takes the form of financial support to cover extra costs associated with disability or funded hours for support services. This leaves people with intellectual disabilities and their families to choose between often unaffordable privately run care and support providers or having no access to care and support outside the family.

Care and support is not only a private family matter - it is a public responsibility that requires investment, coordination, and long-term planning. The state of care and support cannot improve until governments around the world recognise this reality and take responsibility for the provision of inclusive and effective care and support.

Outdated and Rights-violating Delivery Models

In countries where care and support systems do exist, these are often being delivered in line with outdated service models that fail to meet the needs and uphold the human rights of people with intellectual disabilities.

In high-income countries where substantial budgets may be allocated to disability care and support, funding is frequently directed toward segregated models instead of CRPD-compliant support models. Governments continue to fund segregated services such as residential institutions (including group homes), segregated (special) schools, and other service settings that isolate people with disabilities from their community, in violation of their rights under the Convention on the Rights of Persons with Disabilities (CRPD).

Governments that have ratified the CRPD continue to use and praise the effectiveness of these segregated models, which people with intellectual disabilities and their families have been clear do not meet needs or support inclusive lives. Services delivered in segregated settings remove people from community life, limit individual choice, and reinforce the idea that persons with disabilities are merely recipients of care rather than persons requiring support through rights-based inclusion.

In addition to the negative outcomes that these outdated segregated service models create in the lives of people who interact with them, they are also not a cost-effective service delivery model. Governments in high-income countries spend significant portions of annual budgets on care and support for people with disabilities - but much of this budget goes towards models that people with intellectual disabilities and their families say do not meet needs.

How much are governments spending on care and support models?

Governments in high-income countries fund care and support in national budgets, but portions of these budgets are being used to deliver care and support models that violate rights and fail to meet needs.

- In Australia, about 1.9% of GDP is spent on the National Disability Insurance Scheme (NDIS).
- In Canada, around 0.7% of federal and public spending directly targets disability across government levels.
- In Europe, most EU countries spend about 1% to 2% of GDP on disability.

Due to how these budgets are reported on, it can be challenging to tell what percentage of allocated funding supports segregated vs. inclusive service models. Availability of segregated services in these places tells us that large portions of care budgets continue to be spent on outdated models.

Care and support services for persons with disabilities may be relatively well resourced in some countries, but testimonies from persons with intellectual disabilities and their families make clear that investments in segregated or medicalised service delivery models are not meeting their needs - indicating an ineffective use of resources that could be better spent on more effective, inclusive models.

Given the large budgets at stake, it is urgent that governments invest in inclusive models that *do* work for people with intellectual disabilities. People with intellectual disabilities, families, and experts are clear that community-based approaches that combine inclusion, support, and family and community involvement are the most effective care and support models. Effective systems do not treat these three elements - inclusion, support, and family engagement - as separate or competing options; rather, they bring them together so that people with intellectual disabilities can live in their communities, access tailored support, and remain connected to family and social networks.

Doing away with outdated segregated models in favour of inclusive care and support delivery ensures that people with disabilities are not isolated from ordinary community life, that they have the practical and personalised assistance people need to exercise choice and participate fully, and that their family involvement helps sustain relationships, especially where formal services remain limited. When these three elements are balanced well, they reduce reliance on segregated services and create more sustainable, rights-based responses that can adapt to ageing populations and growing demand.

Chronic under-resourcing

While some governments are dedicating resources to segregated delivery models, others are under-resourcing care and support systems entirely. In higher income countries this often looks like insufficient availability of services and unstable workforces due to underpaid care workers. In low- and middle-income countries necessary budgets are often not available at all, making the development of formal services nearly impossible.

This resourcing challenge will become even more pressing as populations age. With growing demand, care and support providers will become less available as more older people with and without disabilities require support. Without a deliberate commitment to resourcing care and support, the gap between need and available support will continue to widen, leaving families to absorb responsibilities that should be shared by the state and the community.

It is important to recognise that as governments cut costs that result in insufficient care and support being provided by the state, the cost savings of governments come at the expense of families. By filling in gaps and providing informal care and support where formal services are underfunded or unavailable, families are subsidising national care budgets with their unpaid labour.

This is where semi-formal support including community networks can provide alternatives. Many local initiatives led by families and communities (circles of support, peer support, etc) have shown positive results. In addition, the more governments invest in inclusive communities, fewer special services will be needed.

The state of care and support globally is one of urgent need - a need for governments to take responsibility for supporting populations, a need for service models to move from segregated to inclusive models, and a need for real investment in care and support systems.

The lack of government ownership over care and support, pervasive outdated models, and chronic under-resourcing have resulted in a care and support system that is failing to meet the needs of people with intellectual disabilities and their families.

As governments fail to provide adequate support, parents, siblings, and other family members are expected to continue providing the majority of care and support for their family member with an intellectual disability well into older age, often without recognition of this role, without respite, or without sufficient support.

Despite the lack of availability and access to services for people with intellectual disabilities around the world, people with intellectual disabilities do continue to get the care and support they need - primarily from their family members. Families of persons with disabilities are the primary providers of care and support, regardless of where they live or the level and type of support services available in their countries. The proportion of care that family members provide is particularly high in low- and middle-income countries (LMICs) where formal services are less likely to exist[4], with one study finding that 94.3% of carers were family members.[5] For people with intellectual disabilities specifically, research by Inclusion in 2012 revealed that families in both high- and low- and middle-income contexts are the primary providers of care and support.[6]

Although families around the world are providing the bulk of care and support, they are compensating for insufficient care and support systems without the resources they need to play this role. Among the survey respondents, 70% of family members reported that they do not receive meaningful support - this trend held true both in places where formal support services exist and in places where families had no access to services at all.

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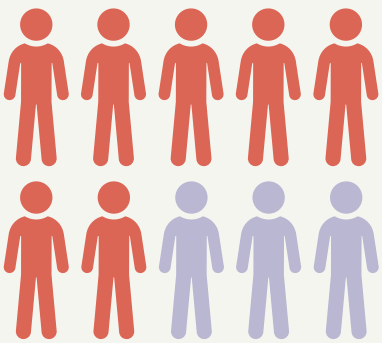
family members do not receive meaningful support for their care role



4. Hunt, Xanthe et al. "Community Support for Persons with Disabilities in Low- and Middle-Income Countries: A Scoping Review." International journal of environmental research and Public Health vol. 19,14 8269. 6 Jul. 2022, doi:10.3390/ijerph19148269
5. Bernabe-Ortiz, A., et al. "Disability, caregiver's dependency and patterns of access to rehabilitation care: results from a national representative study in Peru." Disability and rehabilitation, 2016. 38(6): p. 582-588.
6. Inclusive communities = stronger communities: A global report on Article 19. Inclusion International.

Trends in the data point to many different reasons for the lack of support - while a tiny fraction of families (1%) reported that no services or support mechanisms existed in their community at all, a much larger percentage of the respondents pointed to system-wide failures of care and support that result in a lack of access. Families highlighted that care and support mechanisms from governments, organisations, and formal service providers were bureaucratic, slow, confusing, fragmented, and not designed with families in mind - with 24% of families explicitly mentioning these system failures in their responses.

The absence of support as a trend comes from a variety of sources, with 42% of respondents reporting that they are not able to access any support from their government and 32% reporting they aren't able to access any support from organisations. Importantly, 61% of these families live in contexts where families are presumed to be the default care providers, justifying the lack of investment in inclusive care and support systems in the eyes of institutions.

The data made clear that this lack of investment in care and support results in families paying the price for filling those gaps - with 67% of survey respondents reporting exhaustion, burnout, and the need for relief. 62% of families who responded to the survey specifically cited respite as a key unmet need, with only 47% of the respondents reporting getting any respite support at all. Anecdotal evidence across global focus groups reinforced this point, with family members sharing stories about the many roles they are forced to play simultaneously and how that responsibility has negatively impacted their relationships with others, their mental health, their livelihoods, and their broader well-being.

When family carers and supporters do get a break, this often comes in the form of informal support from another person in their life. Families reported that in 77% of cases, any respite being provided is from another member of their family - often someone with similar caring responsibilities like a spouse, sibling, or parent. Only 23% of the families who reported having access to respite indicated that this support was coming from outside the family - either being provided by a friend, neighbour, or other member of the community.

Despite navigating a challenging lack of support - both for their family members with an intellectual disability and a lack of support for their own caring responsibilities, many families also make a point to report the positive side of their care and support role.

In the survey results and across focus groups, many families framed the experience of being a family carer as holding deep love at the same time as holding deep exhaustion from playing care and support roles and navigating broken systems.

We asked families how they would summarise the experience of being the family member of a person with an intellectual disability, and positive experiences shone through:

"A wonderful experience. I feel pride and daily accomplishment in my life for supporting my daughter with an intellectual disability and helping her understand the complexities of life while instilling confidence in herself."

A mother from the UAE

"I would choose the sleepless nights, the quiet tears, the exhaustion, the carrying and lifting and the whispers of courage on the days that let us both down. I would do it all again and I would choose my daughter in a heart beat"

A mother from Canada

"It is also an experience that has opened my perspective and world view in a way I would not change."

A sibling from Ireland

"It has been a journey of love, responsibility, learning, and growth. Through this experience, I have gained deep empathy, resilience, and a strong commitment to defending the rights and dignity of persons with intellectual disabilities."

A sibling from Ethiopia

"It is a daily act of love, patience, and presence."

A mother from Brazil

Ultimately, 72% of families shared in the survey that despite the challenges they face, they still see family as the core carers and supporters of people with intellectual disabilities, with many noting that families need to continue to play a key role in a broader ecosystem of inclusion and better support.

Families are driven by love and want to play a key role in supporting people with intellectual disabilities - but they are struggling under the weight of failing systems. The messages from people with intellectual disabilities and their families through survey results, focus groups, and inputs from their representative organisations make clear that access to care and support at present is insufficient, inaccessible, and not inclusive. Care and support systems are failing to meet the needs of people with intellectual disabilities, and their family members are forced to step in and fill those gaps.

Like their family members, people with intellectual disabilities are also driven to provide care and support for their family members. They may be parents themselves and caring for a child, they may be adults with aging parents who need their support, and they may provide informal support to their family and friends in other ways. Care and support are a continuum, with many people with intellectual disabilities simultaneously being a care provider and requiring care and support themselves.

As we mark the 20th Anniversary of the CRPD in 2026, people with intellectual disabilities are taking on roles that were far less visible 20 years ago - including as care providers. Many people now have access to support services that enable them to live independently, as well as self-directed budgets, and other forms of individualised support that allow them to participate in society and fulfil roles they were previously unable to take on. But even in cases where people with intellectual disabilities are getting support in their capacity as a person requiring care, they are impacted by the gaps in support available for care providers and additional barriers navigating their experience as a care provider.

As this report documents the ways that family members support each other, this also includes the ways that people with intellectual disabilities take on care and support roles in their own lives.

"I try and help people how I get helped. I live with two other people. I try to help with their support needs as best I can. It's about caring for one another."

A self-advocate from the UK

"I support my family financially. I am independent. I support members of my [extended] family to pay their children's school fees."

A self-advocate from Malawi

With care reform on the horizon in countries around the world, people with intellectual disabilities and their families are calling for access to care and support systems that meet their needs (as both care providers and people requiring care) and enable them to live a full, inclusive life.

Governments have an important opportunity to reflect on how people with intellectual disabilities and their families are being left behind by current care and support mechanisms, and move towards inclusive systems that align with the needs and human rights of persons with intellectual disabilities.

Key Takeaways:

- Care and support systems are not meeting the needs of people with intellectual disabilities.
- Lack of government responsibility, reliance on outdated segregated delivery models, and chronic under-resourcing have all contributed to the current state of care and support.
- When formal systems fail to meet needs, families are forced to be the sole provider of care and support.

- 70% of family members caring for people with intellectual disabilities report that they do not receive any kind of meaningful support to enable their caring role. Fewer than half of family carers are getting access to respite or other breaks to help them avoid burnout.

- Families want to be a core part of the care and support that people with intellectual disabilities receive - and 72% of family carers want to be a primary carer - but they cannot fulfil this role without better support.

- People with intellectual disabilities are also increasingly taking on care provider roles in their families, while also requiring support - and care and support systems are not designed to respond to this dual role.

What does care and support for people with intellectual disabilities look like?

People with intellectual disabilities interact with care and support in different ways - for their own care and support needs, they may interact with formal support services or receive informal care and support from their families, friends, or organisations. People with intellectual disabilities also may interact with care and support as care providers.

People with intellectual disabilities who are self-advocates from 15 countries around the world came together to talk about care and support, and shared examples of what care and support look like in their own lives.

What forms of support are most important to people with intellectual disabilities? Self-advocates said....

- Support to handle daily tasks, like cooking, cleaning, or using the internet
- Support with tasks outside of the home, like going shopping
- Support to build connections with people in the community
- Support to find a job, and support at work
- Support to get around through reliable and accessible transportation
- Support to manage money
- Support to make decisions about our lives
- Support to move out of our family homes and get our own housing
- Support to maintain our homes
- Emotional support
- Getting advice, encouragement, and celebrating with me when things go well
- Support with managing schedules and appointments

This section looks at how these forms of support people with intellectual disabilities use most often are provided across the different pillars of care and support systems - through formal sector care and support services, through semi-formal community support, and through informal support primarily delivered by families.

This report uses the term “formal” to refer to paid services delivered by professionals, and the term “informal” to refer to support provided by families, friends, and personal networks who are not employed to deliver that support. While in some cases families may receive some compensation for their caring role, such as a caregiver allowance, this type of support is still delivered outside of professional settings and is considered informal.

Different terms are used in different contexts – the distinction between formal and informal support may also be called paid vs. unpaid support, formal vs. natural support, or may be referred to by other terminology. There is not one agreed or correct set of terminology to discuss these distinctions in the forms of support.

Formal supports

Many people with intellectual disabilities and their families access formal support services - referring to paid services delivered by professionals.

Formal support can be delivered by governments or by organisations or businesses, ranging from professional service providers (in some cases, regulated by governments) to organisations of persons with disabilities (OPDs).

Formal support can also take a variety of different forms - ranging from cash transfers that enable people to get the support they need through to human support provided on a one-to-one basis like personal assistance. Formal supports generally fall into one of four categories - social protection benefits, disability-specific services, mainstream services, and segregated services.

Service category	Examples of services
Social protection benefits	Disability allowance, caregiver allowance, cash incentives (like tax incentives or tax credits) and other forms of financial support
Disability-specific services	Support workers, personal assistance, CBR/CBID programmes, assistive devices, personalised budgets
Mainstream services	Health services including mental health, public transportation services, vocational training and job match services
Segregated services	Day care centres, sheltered workshops, camps, special schools

In some contexts formal support may be available across multiple categories and families can access a combination of formal services. In other contexts, families may be forced to access segregated services for their family member with an intellectual disability due to lack of other options. In other contexts still, none of these forms or formal support exist, leaving families to provide all care and support independently.

Social protection benefits

Social protection benefits provide financial assistance to vulnerable people, often provided by governments as part of a larger social safety net.

For people with disabilities, social protection programmes often take the form of cash transfers that are usually used to cover the person's disability related costs, enabling them to pay for their own access to formal support services.

This type of formal support aims to reduce inequalities between persons with disabilities and persons without disabilities by ensuring the extra cost of disability support services does not disadvantage people with disabilities and their families.

Cash transfers may be delivered to the person with a disability directly, or to their family member who may help them navigate using that funding to purchase support. Families report using these benefits to pay for access to therapy, for health related costs, to pay for personal support workers, or to pay for support in school.

> ***"I am grateful to our government for providing financial support for my child, as well as assistance with transportation, electricity bills, and food expenses."***
>
> A mother from the UAE

Access to this type of formal support is particularly important for families of children with disabilities, who are more likely to be facing poverty and who are expected to bear the additional costs for the support their family member needs. Many family members of persons with intellectual disabilities, mothers in particular, have had to leave the workforce in order to provide care and support full time, and access to financial support from their government is essential for ensuring that families can make ends meet.

Many people with intellectual disabilities and families report that they cannot access these mechanisms. Eligibility criteria and entry points to access these mechanisms differ significantly, and are inaccessible and complicated to navigate. Many people with intellectual disabilities and families find navigating this form of financial support bureaucratic and confusing.

> ***"Applying to public housing needs documents, and I don't know how to handle those documents."***
>
> Self-advocate from Hong Kong

When people with intellectual disabilities and their families can overcome the barriers to get access these benefits, they do not always meet needs.

People with intellectual disabilities and their families report that they find these measures insufficient, inflexible and unsustainable.

> ***"I had to leave my job due to the responsibility of caring for a child with a disability and no accommodation for my family situation. Now my household has one less income"***
>
> A mother from Canada

> ***"The pension is not enough; I have to work at the same time as being a single mother. I live alone, the government does not help with rent payments."***
>
> Self-advocate from Mauritius

The result is that many primary care providers still do not have access to a care allowance, which impacts the family's overall economic situation and means that their family member with a disability is less able to pay for other formal support services they may need to be included in their community.

Between contexts where social protection mechanisms do not exist and contexts where families struggle to get access to support that does exist, these challenges have left many families without any benefits to help them cover the added costs of disabilities. 42% of family members who responded to Inclusion International's survey reported that they do not get any support from their government.

These experiences using social protection mechanisms help identify the pressure points in current systems where reform is urgently needed. Families face challenges both identifying what support is available to them, and navigating bureaucracy to apply for support. This points to the need for care and support reform to ensure that social protection mechanisms are designed based on user-friendly systems with single entry points for applicants.

Disability-specific community-based services

Disability-specific services include a broad range of targeted support directly linked to disability-related needs. These are services that only people with disabilities would use. Examples include personal assistance, support workers, or other professional support persons, who may have different titles and roles depending on their training and qualifications.

This form of support can be provided by OPDs or by other service providers. They can be funded by governments, which may cover a certain number of hours per week of support per person from disability-specific services. In other schemes, families use disability-related benefits to pay for disability-specific services directly.

Many of the good practice models for supporting independent living and inclusion in the community fall under the category of disability-specific services. This includes programmes and mechanisms that support access to housing in the community for people with intellectual disabilities and provide access to personal assistance. Well-funded and reliable disability-specific services are the key for independent lives in the community for many people with disabilities.

While these types of services in theory are designed to meet the specific needs of people with intellectual disabilities, families who try to access these services report major gaps that prevent their family members from getting the support they need. Families report that disability-specific services are not available everywhere, and are mostly concentrated in urban areas and large cities. While persons with disabilities living in rural areas may, in principle, be eligible to use them, transport is often unavailable or inaccessible. As a result, families must cover transport themselves and absorb all related costs if they want to access these forms of support.

"We receive no support services as we live in a small rural town. We could drive 45 minutes to the nearest city that provides some programming but with how expensive everything is, it does not fit within our budget."

A mother from Canada

"My son receives some hours of personal assistance and some hours of care, which are extremely low in salary. We have to supplement the payment with private money for the support people to get a decent amount of money."

A mother from Argentina

For those who do have access to personal assistance or other support workers through a disability-specific service provider, many families described these services as unreliable, inconsistent, and insufficient. Funding amounts often don't cover the real cost of meaningful support from these disability-specific services, or support is provided in such small quantities that it doesn't begin to cover the real need.

For people with intellectual disabilities who want to move out of their family home, insufficient access to personal assistance and other independent living support prevents people from making this transition, leaving people with intellectual disabilities with less choice and leaving families in primary care and support roles through adulthood.

Navigating disability-specific service transition points across the life course also creates real challenges for people with intellectual disabilities and their families, who often see their access to these formal support services disappear upon turning 18, with little or no support to help them navigate the new adult services that may be available.

"Once he became an adult, the coordinating medical/social work type care provided through the hospital disappeared and I feel adrift."

A mother from Canada

In line with the experience accessing social protection measures, another gap mentioned by families is the administrative process to receive these services which is complex and very long - families struggle to figure out what support they can access, and once they have identified a programme often need to go through long and bureaucratic processes to begin accessing that particular service.

While families value access to disability-specific services to support people with intellectual disabilities to live an independent life in their community, the gaps in access and in service provision are failing to ensure that people with intellectual disabilities are getting the support they need.

> ***"I'm 80. I'm negotiating for in-home support, but it's taking forever to become reality. The process started in January, 2025 when I gave notice that I planned to quit caring full time."***
> A mother from Canada

The experiences of families accessing mainstream services give clear directives for future reform for care and support systems. People with intellectual disabilities and their families report challenges accessing enough disability-specific service provision to meet their needs, which points to the need for greater investment in these services. This encompasses both sufficient access to disability-specific support in both urban and rural areas. Until people with intellectual disabilities across countries are able to access enough hours of personal support or other services to meet their needs and facilitate their inclusion in the community, families will continue to bear the brunt of care and support provision.

Future reform also needs to consider eligibility for services across the lifespan, ensuring that access to funded services does not end at adulthood and that children's services and adult services are in dialogue to make transitions smooth for families.

Mainstream services

As a complement to disability-specific services, people with intellectual disabilities also are able to access mainstream services.

Mainstream services refer to inclusive services that are available to everyone in the community, including being open and accessible to persons with intellectual disabilities. These include health services, inclusive education, transportation, employment services, and other community services. When mainstream services are inclusive, they significantly ease barriers in families' daily lives by reducing the need to search for separate, specialised services they may not know about.

Inclusive mainstream services are also essential to ensuring that persons with disabilities are fully included in the community, recognised as full citizens, and able to exercise their rights.

While very few countries restrict people with intellectual disabilities from accessing mainstream services, in practice many of these services around the world remain inaccessible to persons with disabilities - in many cases, people with disabilities experience overt discrimination that effectively excludes them from using these services. This might look like children with disabilities being turned away from schools, employment support or job match services encouraging people with disabilities to use a specialised service instead, or even medical professionals not knowing how to engage with people with intellectual disabilities.

"When you go to the doctor you don't understand what the doctor is saying, so you need them to speak slowly and easy to understand."

Self-advocate from Romania

"They don't know what intellectual disability is and they don't know how to deal with people with intellectual disability. So when we try to get assistance, they don't understand us or they give the wrong treatment."

Self-advocate from Malawi

Facing discrimination from mainstream services or dealing with service providers who don't know how to work with people with intellectual disabilities pushes people towards segregated options, such as special schools and sheltered workshops, rather than inclusive, community-based services.

"We need inclusion in all schools and kindergartens, and for the procedures for this to be made easier"

A father from Egypt

As is the case with disability-specific services, access remains a challenge for families who live outside of major cities. Even mainstream services have very limited availability in rural areas, where people often face significant barriers to accessing them. Absence or lack of accessible and affordable transportation is a major gap to inclusion mentioned by family members when trying to access mainstream services.

"I would like support services to be more regular and closer to my home. More home visits would be helpful to avoid frequent trips to the medical centre."

A mother from Niger

"There's no public transportation, and I don't have a driver's license to drive her there and back, and they won't give me the transportation stipend"

A mother from Spain

Access to mainstream services on an equal basis with others in the community needs to be a core part of the formal support that people with intellectual disabilities can access - but reports from families indicate that their access to and inclusion in these services around the world is still not a reality.

The experiences of families accessing mainstream services indicates that inaccessibility is a chronic issue across services in different sectors. To address this issue, care and support reforms cannot be limited solely to improving disability-specific services - providers of mainstream services need training and support to deliver their services in a way that is accessible to everyone. Without care reform specifically addressing barriers in mainstream services, people with intellectual disabilities and their families will still be forced to seek out segregated services if they are not accepted in mainstream inclusive service provision spaces.

Segregated services

As the gaps in access to social protection programmes, disability-specific services, and mainstream services detailed above indicate, for many people with intellectual disabilities and their families, the only form of support outside of the family available in their community may be segregated services.

Segregated services are services that are provided for people with intellectual disabilities that separate them from their community - for example, residential institutions instead of supported community living, or day centres instead of access to education or employment. These services are provided to persons with disabilities in separate settings that do not enable meaningful participation, inclusion, or choice.

Families described many examples of the segregated services that were available to them as their sole support options - the most commonly cited examples were special schools, day care centres, sheltered workshops, and camps. Although segregated settings are known by many different names around the world, they share a common feature: groups of persons with disabilities are brought together, away from their community, to do the same activities according to a predetermined schedule or agenda, without or with limited choice.

Although most parents reject these types of services and say they would prefer inclusive options, in practice they often have no real alternative.

"There is no inclusive school. They refuse to take the children. The quality of special school is bad, I don't want to put him there."

A mother from Indonesia

"My 10 year old is living in a group home 400 kilometers away from us because the supports we begged for are unavailable in our area"

A mother from Canada

The position of families on segregated services is clear: families want their children with intellectual disabilities to have access to inclusive education and supports in their community. People with intellectual disabilities echo this call, and want to be able to live with support and access services in their communities - not in segregated spaces.

"I spent 25 years in different institutions and from 2012 I have lived in the community. For me, the community is important because it is my right and every person with a disability has the right to live in the community... I work, I am paid and I have where I live. And I have the freedom which I didn't have in institutions."

Self-advocate from Romania

As care reforms move forward, these calls from self-advocates and families to detach access to care and support from segregated spaces in favour of inclusive, community-based models must be an essential pillar of new and improved care systems.

"We need to be included everywhere - like in schools."

Self-advocate from Malawi

What all four of these types of formal support have in common is that people with intellectual disabilities are struggling to access the formal support they need to be fully included in their communities.

Across contexts, families reported that formal supports – when they exist – rarely cover the full range of needs for people with intellectual disabilities. Even in countries with comprehensive social protection systems and progressive laws, where a wide range of support services exist, families reported that access varies across regions, and access to support can depend on the resources of the local government body and the person's ability to advocate for their needs. Gaps in availability, accessibility, quality and coordination mean that informal support from families remains the backbone of care and support systems, even in high-income countries.

As reflected in the section on the state of care and support, a variety of factors have resulted in the fragmented, insufficient care and support systems that families describe.

To begin to respond to these challenges, governments must take legislative and policy action to address the prevalence of segregated service delivery models, close the gaps in social protection systems that limit access, address the inaccessibility of mainstream services, and increase investment to improve availability of inclusive disability-specific services.

Key Takeaways:

- Where services exist, they are insufficient.
- Formal services are bureaucratic, inaccessible, and unevenly available.
- Mainstream services remain inaccessible to people with intellectual disabilities, and segregated services are often presented as the only option, despite families wanting inclusive settings.
- Formal services are not functioning as a key pillar of care and support systems, which leaves families without support options.
- For care and support systems to begin to meet needs, governments must take action to shift from segregated delivery models to inclusive models and increase investment in formal services and social protection mechanisms to improve availability and accessibility.

Support from local organisations and communities

While formal services are typically delivered by professionals, local family groups and community networks also play an important role in supporting people with intellectual disabilities to be included and participate in community life. These forms of support are organised, but not typically delivered by professionals. Community respite services are a common example of this type of support that falls between formal and informal support on the spectrum, where it is likely to be coordinated by a local organisation or a community network, but is not delivered by professionals.

Often, it is organisations of persons with disabilities (OPDs) led by the family members of people with intellectual disabilities who are coordinating these services. In the case of respite provided by local organisations, this form of support is a lifeline for family members, stepping in when parents or siblings are unavailable, exhausted, or when formal services are missing, helping to sustain both the person with a disability and their family.

Family-based organisations play a key role in supporting families, and their impact is not limited to these semi-formal services like respite care. In many communities, family-based OPDs are often the only support that exists for families of persons with intellectual disabilities. OPDs might deliver support services themselves, like respite, referral services, or facilitating peer support groups. Peer support, including models like circles of support, is recognised by many families as a major source of relief and encouragement in their day-to-day care provision role.

In addition, provision of information, training, guidance and referrals by OPDs are cited as important support for families, especially for young parents when they are new in the disability world.

"What I learned from my own mom is that parents and families need training about care and support because at the end of the day, even though they love and care, they do everything. They need a lot of training and tools and resources to know what to do with their own children with disabilities. So that way we can work together."

Self-advocate from Uganda

Following diagnosis or when the child is school-aged, families often have many questions about their family member's future that they do not get answers to from doctors or from the school professionals. Family members, typically parents, start to navigate what support for their family member with an intellectual disability should look like on their own, and often find that the only available options to them are inaccessible or segregated forms of support. OPDs have an important role in providing families with information about the rights of their children with a disability, and helping families understand what rights-based support and services look like. When this information comes from another parent or another sibling who has been through this process themselves, the peer-led vision building helps families build stronger and more inclusive care and support mechanisms for their family members.

Although families report that these forms of support are essential, few families are able to access them. Among survey respondents, 32% of family members reported that they do not have access to any form of support from local organisations, including OPDs. While these semi-formal support mechanisms delivered through community networks are an essential pillar of the care and support system, they remain underdeveloped.

While they do provide people with intellectual disabilities with some forms of care and support and can be an invaluable source of respite for families, without significant investment they are unable to provide a level of support that people with intellectual disabilities and families need.

Governments considering reform should look at embedding this type of programming into broader care and support systems. Sustained funding for community groups will create more options and better availability of support for families, and with support from governments to scale up community support they can form a key pillar of improved care and support systems.

Key Takeaways:

- Community networks and other semi-formal support mechanisms can play a key role in supporting people with intellectual disabilities and their families when available.

- Organisations of persons with disabilities (OPDs) are a key source for these semi-formal supports, particularly delivering peer support for families and providing access to information and training.

- Community organisations are significantly under-resourced and not sufficient to replace well-functioning formal systems.

Informal support

In the previous sections, this report presented the current reality of availability of and access to formal and community-based services. People with intellectual disabilities and their families are not able to access formal and community-based supports that meet their needs, which leaves informal support as the third pillar of care and support systems to absorb all of the unmet need.

Informal support constitutes all of the care and support that people with intellectual disabilities get that does not come from formal service providers or community organisations. With major gaps accessing formal support services alongside the limited resources for community support options, most care and support for people with intellectual disabilities globally is informal.

Informal support can come from families, friends, neighbours, and personal networks, but the vast majority of informal support is provided directly by the family members of a person with an intellectual disability. While the bulk of support tends to be delivered by parents, siblings, grandparents and the extended family also often play key roles. People with intellectual disabilities are also commonly providers of informal care, in addition to requiring care and support themselves.

This reliance on families to provide most of the care and support that people with intellectual disabilities need happens for a variety of reasons - as explored in previous sections, formal services are fragmented, under-resourced, slow to respond to need, difficult to access, or simply not available in many communities. When they observe gaps in the care and support their family member needs, families step in to provide a wide range of informal support that keep people with disabilities alive, safe, included, and in control of their own lives.

Importantly, families do this alone - 70% of family members who responded to Inclusion International's survey reported that they do not receive any kind of meaningful support (from governments, communities, or others) to deliver on their informal care support role.

Informal support will look different from person to person, but the below examples detail the most common forms of informal support that people with intellectual disabilities and their families told us that they provide for each other.

Meeting basic needs

Basic needs encompasses providing care including feeding, support with hygiene, support with mobility, support with dressing or toileting, help with medication, and a variety of other ways that families ensure that the basic needs of their family member with an intellectual disability are met.

The support a person needs in these areas will vary significantly from person to person, with some families needing to provide very little support with basic needs and others providing full time support if their family member has complex disabilities or additional health needs.

In contexts where formal services are not available or not accessible, many family members, particularly mothers, shared how helping their family member meet basic needs such as eating, bathing and staying safe is often a 24/7 responsibility that falls entirely on them.

"I take care of him by providing food, drink, helping him get around, and assisting him with his daily needs"

A mother from the UAE

"As a caregiver of a family member with an intellectual disability, I play an essential role in their daily life. I regularly accompany them to the medical centre for appropriate care and consultations with their doctor. I closely monitor adherence to their treatments and their overall well-being. On a daily basis, I ensure their needs are met, whether for nutrition, hygiene, or comfort."

A daughter from the Democratic Republic of Congo

This can be the case for children or for adults with intellectual disabilities, and providing this kind of care becomes increasingly challenging both as the person with an intellectual disability grows and as family members age. For family members providing significant basic needs support for their adult children with disabilities, they expressed concern about decreasing capacity to provide more physical aspects of care like supporting mobility and toileting as they age.

For people with intellectual disabilities who are providers of care, they may be providing for these same basic needs, particularly for aging parents. Across global consultations, self-advocates reported different ways that they provided for the basic care needs of their aging parents - ranging from health needs like supporting parents take their medication each day or accompanying them to their medical appointments through to more physically demanding support, like carrying aging parents who are unable to walk to help them get around the house.

> ***"[My mom] has a severe illness. She needs help walking, getting up stairs, going to the toilet, needs someone to carry her, and has vision and mobility issues."***
>
> Self-advocate from Taiwan

Providing for basic needs of another person as an informal carer is a particularly intense role, and 47% of family members reported that they are providing this form of care and support without access to any respite services that would allow them to take a break.

Mental health and psychological support

Beyond physical care, another form of informal support that family members report providing is emotional support, reassurance, strengthening self-confidence, and support dealing with societal challenges.

When mental health services are unavailable or inaccessible, family members become the main, and sometimes only, source of psychological support. This is true from the early childhood of the person with an intellectual disability through their adulthood.

Mental health support and support navigating challenges is not unique to people with disabilities - most people will get this type of informal support from their family at some point in their lives. But because people with intellectual disabilities are systemically excluded from their communities and as a result tend to have fewer connections outside the family and less access to formal mental health services, the degree of support required by families is significantly larger.

"I see myself as his support; I'm there for him through every detail of his life, big and small. My role isn't limited to caregiving; it includes teaching, encouraging him, and building his self-confidence step by step."

A sibling from Saudi Arabia

"Many people here are isolated, because it's not safe to go out. I'm a counsellor, so I counsel my family members. But it's difficult because we don't have any support."

A sibling from Myanmar

One particularly valuable form of mental health support for people with intellectual disabilities is peer support, which often happens through participation in self-advocacy groups.

"Peer support is very important. Self-advocates and people with intellectual disabilities can help each other."

Self-advocate from Taiwan

Planning and coordination

Many family members, especially parents, describe themselves as "*doing everything,*" often reporting that they feel like they are playing the role of a manager in the life of their family member with an intellectual disability.

Informal support with planning and coordinating might look like organising their family member's calendars and booking their appointments, researching opportunities or services available to them, overseeing the support they are getting from formal service

providers, helping them to find work, making sure their family member gets where they need to go, supporting them with future planning, and other forms of informal support that require coordination and planning across the areas of a person's life.

"I believe that my role has been to gain a thorough understanding of my son's needs and become the manager of his support system."

A mother from Colombia

"I coordinate all the support that is required. I organise, direct and supervise staff that we hire directly."

A mother from Canada

"Families act as 'pathfinders', helping their loved one find information and preparing them with the skills to live an inclusive life (for example, financial literacy skills to prepare for living on their own)."

A family member from Canada

Coordination support is also essential for people with intellectual disabilities who are care providers. For example, in their role as a care provider they may need to navigate calendars and appointments for others, which can be challenging without support. In these cases, getting support for their support role enables people with intellectual disabilities to deliver on their role as a family care provider.

"I have some neighbors who help by accompanying my mother to some appointments. One of them, for example, comes to my house every night and organises both my medications and the ones I need to give my mother the next day. They also help by scheduling appointments, checking them on the computer, and printing a list with the appointment dates so I can accompany them and not miss any."

A son with an intellectual disability from Spain

Social inclusion support

Many people with intellectual disabilities need support to build connections and take part in their communities.

Many families described the work they do to support community-based activities, whether that means getting their relatives to school or employment, helping them to build relationships with neighbours, contributing to local activities, or attending events in community spaces alongside their family member as a support person.

This role is a key component of building an inclusive life in the community, and in some countries such as Spain and Canada, support with community connections also exists as a formal service provided by OPDs, often called a community navigator or connector - although most families explain that they are the primary supporters in this area.

People with intellectual disabilities also play this social inclusion support role for each other, particularly people who are leaders in OPDs or are associated with self-advocacy groups that they can connect other community members to.

"... I help others and him engage meaningfully with each other even though he is nonverbal. I helped him grow a network of meaningful, safe, fulfiling social connections."

A father from Canada

"I arrange social meetings so that he has relationships beyond us"

A sibling from India

"I helped a new member join our self-advocacy group. [...] I met this person at the gym."

Self-advocate from Taiwan

"In my community, I give education. I teach other people about me, about people with intellectual disabilities. To show that when they see us, they accept us - they don't see us as a burden or a curse."

Self-advocate from Ghana

Support for decision-making

While “supported decision-making” was not cited explicitly during the survey or consultations, families’ descriptions of the care and support they deliver clearly illustrate that support for decision-making is a key part of how they support their family members. Families explained how they support their relatives with intellectual disabilities to choose and make decisions about daily life, work, and their future - for example, explaining complex information in accessible ways to their relatives. For family members of those with little or no speech, this might look like communicating that person’s likes and dislikes, preferences, needs, and behaviours to others.

> ***“... I also gather information about welfare services in order to help him choose the way of living that will make him happier.“***
>
> A mother from Japan

This form of support that people with intellectual disabilities get from their families is essential for helping people build decision-making skills that will support them to live independently in the long term. For many families, the mechanisms for supported decision-making are something they had to figure out on their own, building an understanding of how to balance information, support, and guidance while preserving choice for their family member, ultimately making their own decision.

> ***“I make my own decisions. That does not mean that I don’t disagree when they give me advice. I seek support, but not permission.”***
>
> Self-advocate from the UK

> ***“Support we need from parents is protection, but not over-protection. This makes us not open up, we don’t go out.”***
>
> Self-advocate from Bangladesh

Advocacy

Families report that they have to advocate for all of their family members' rights as a person with a disability to be fulfilled, and advocate for their family members to be able to access everything they can and should benefit from.

Families are navigating systems that were not designed for people with intellectual disabilities and often have to fight for inclusion over the course of many years - especially in systems where basic rights such as education, healthcare and employment are denied.

Families have to challenge discriminatory attitudes in schools, services, the community and even sometimes within their own extended family. They have to push for their family members to be included in spaces, to access services, and to get to make their own decisions.

"The expectations from others throughout his life are that of low expectations and segregation from early childhood education, schooling and post-secondary school life. As his family we have advocated very strongly for my son to have an inclusive life in every regard and opportunities post school that allow him to be an engaged and active citizen."

A mother from Australia

"I would like the community to accept people with intellectual disabilities to eliminate marginalization. We need full inclusion. Most of the time they are segregated - which makes them lack confidence."

A mother from Rwanda

"As a sibling of a person with an intellectual disability, my role has been both personal and purposeful. I provide emotional support, advocate for inclusion and equal opportunities, and help navigate systems that are often not designed with accessibility in mind."

A sibling from Ethiopia

"I advocate on her behalf with some members of the family who still have old vocabulary. Members of the family who have outdated ways of thinking. We want to make sure that everybody is using language that is encouraging and supportive and not disabling for her."

A mother from Canada

Experienced self-advocates also report that they provide support to other people with intellectual disabilities in their advocacy journey - either through participation or leadership in self-advocacy groups or through mentorship.

Self-advocates shared examples of recruiting other people with intellectual disabilities to self-advocacy groups, helping others speak up for the first time, supporting each other with decision-making, or helping people think through if their support is meeting their needs.

"As a self-advocate I also support others to speak up for themselves and say no. I do training and workshops about these topics."

Self-advocate from Hungary

"We have to show good examples. We know that we're not only asking for support, we're supporting others."

Self-advocate from Malawi

"We have just started a new programme about peer support at People First New Zealand. We visit group homes and people who live with their families. We check in to see if they are okay. We ask if they need different support."

Self-advocate from New Zealand

This form of support from one person with an intellectual disability to another often occurs with the support of an organisation of persons with disabilities (OPD) or other community group that supports self-advocacy.

Financial support

In addition to the unpaid hours of care and support they provide, families also report that they frequently shoulder both the direct and indirect financial costs of disability. This ranges from paying for therapies and medication to absorbing lost income when someone has to reduce or leave paid work.

Where social protection schemes are weak, insufficient, or highly conditional, these costs can push families into poverty or deepen existing poverty.

"I had to stop working to care for my family. We live on only my wife's and boys' disability checks that are 35% below poverty. A caregiver income for caring for my family would be nice and having it non clawed back from other benefits and non taxable would be good. Like a UBI would be the thing."

A father from Canada

"I help with matters related to the family and, when necessary, with financial support when social security does not cover or provide medication."

A sibling from Mexico

All of these forms of informal support - ranging from providing support for basic needs to helping someone plan their life to being their primary advocate - are significant investments of time.

People with intellectual disabilities and their family members report that in the vast majority of cases, it is members of the immediate family, namely primarily parents and siblings, that are providing this support. This is true both of people with intellectual disabilities receiving care and support from family members, and of family members receiving care and support from people with intellectual disabilities.

Informal support can also be provided by others in the community, like friends and neighbours, although their informal support contributions tend to be much lighter than the role family members play, or the role that people with intellectual disabilities play supporting each other. Many family members shared that friends or neighbours provide them with respite by taking over their care provider role for a few hours, helping to spread the workload of playing an informal support role.

Importantly, families share that they *want* to provide this informal care and support to their family members with an intellectual disability - 72% of family members who responded to Inclusion International's survey told us that they want to be playing a key role in their family member with a disability's care and support. Where this preference and the reality diverge is in the volume of informal support that families are required to provide because formal and community support options are insufficient to meet needs.

Reforms taken by governments to develop inclusive services, strengthen formal services and scale up semi-formal community supports will have an impact on the degree of informal support that people are required to provide - with inclusive mainstream services, including inclusive education, employment, health and transport, and more effective formal care and support mechanisms, the amount of informal support the families need to provide can decrease.

Until those reforms happen and families are able to stop filling the gaps, all of these informal support roles that families and people with intellectual disabilities who are care providers play, which are documented in this section, also have real consequences in the lives of these carers, which is explored in the next section of this report.

Key Takeaways:

- Families are the backbone of care and support, making up the vast majority of care and support provided to people with intellectual disabilities.
- Informal support requires families to deliver care and support across many areas of a person with an intellectual disability's life, playing a number of roles at once - personal assistant, nurse, therapist, manager, advocate, teacher, psychologist, among others.
- Informal support requirements can be demanding and require 24/7 work.
- Reliance on informal support from families is a response to failures in care and support systems, not a choice.
- People with intellectual disabilities are increasingly playing care provider roles in their own lives, and require support to deliver on their support roles.

A self-advocate attending a conference with his supporter.

Consequences of care and support system gaps

As explored in the section above, care and support systems are failing people with intellectual disabilities and their families. They encounter formal services and community support systems and services that are underdeveloped, inaccessible, or completely absent in many contexts, meaning families are expected to be the main, if not only, source of care and support - with little or no support from governments.

These systemic failures to provide inclusive, accessible, and adequate care and support around the world have real consequences for people with intellectual disabilities and for their families. This section explores these consequences, in the words of the family members forced to fill the gaps.

Impact on families

In contexts where formal services don't exist or are not accessible, many families describe their primary role as being a long-term care provider, delivering numerous daily tasks related to basic needs provision or support for living independently.

In contexts where formal services exist and people with intellectual disabilities are able to access them, families tend to play a "support provider role." Being a support provider might entail helping their family member choose the support services they want to access, supporting the process of navigating complex procedures, making sure their family member is getting the support they need, and acting as a watchdog for the service providers.

This results in family members providing a complex ecosystem of support and playing a wide variety of roles that under many circumstances would be played by professionals. This responsibility often comes at the expense of their professional careers, particularly for mothers, at the expense of their relationships with members of their family and community without disabilities, and often at the expense of their own physical and mental health.

Instead of getting just to be a parent, or just to be a sibling, family members are acting as nurses, personal assistants, therapists, advocates, managers, and more through the lifespan of their family member with an intellectual disability.

Family members are often required to assume full responsibility for both care and support. Many families characterise their roles as unpaid professionals - they cite the different jobs they do and that should be done by professionals, including “teacher, educator, therapist, nurse, manager, psychologist” and other jobs as among the roles they play. Families are being pushed into playing these roles without the training or the compensation normally associated with delivering this kind of professional support.

“I have been the nurse, psychologist, educator, coach, behavior therapist, nutritionist, companion, stylist, partner and very rarely parent of a person labeled with an intellectual disability “

A mother from Canada

“My role is of a well-trained provider of health, educational, basic and social needs. Not disregarding economic provision. Someone who is alert 24/7.”

A mother from Argentina

Families are shouldering the responsbility of providing care and support, without sufficient support or recognition for themselves in their own caring role. Family members of people with intellectual disabilities, especially parents, and mothers in particular, shared their experiences about tiredness and the overwhelming sense of responsibility, often accompanied by anxiety about the future, as well as the financial burden they bear for disability-related costs, especially in contexts where governments do not or do not sufficiently provide financial support.

We heard from families how the lack of support impacts their lives as individuals and as families.

Exhaustion and Burnout

Many family members describe their journey as care and support providers using terms like “hard,” “tiring,” “intense,” and “a struggle with no limits.” They describe this experience as reshaping their own lives. Most of those expressing these fears and feelings are family members living in contexts where support services are missing and expectations placed on families are very high.

In both the survey results and in the focus group consultations, family members spoke about burnout like a foregone conclusion - an experience that any family member who is providing continuous care and support will experience at some point. Among family members who responded to the survey, 67% reported experiencing exhaustion or burnout.

“Long, Tiring, Isolating, unrelent[ing] and I hate being called resilient because if the supports were in place I wouldn't need to be called that.”

A mother from Canada

“I am the main and only caregiver 24 hours a day. I have no support and/or help from other relatives or from any public and/or private entity.”

A mother from Spain

“When you're looking for support, you probably need more than one support person. So that person doesn't burn out.”

Self-advocate from the United States

Burnout not only results in mental health consequences for family carers, it also impacts the quality of care they are able to provide for their family members, which creates risks of additional gaps in care and support for people with intellectual disabilities. Access to respite services to allow care providers to take a break from their care role and have time to themselves is an essential element for care systems that aim to prevent burnout and exhaustion. Among survey respondents, 62% of families cited access to respite services as a key unmet need.

Isolation

For many family members, becoming a primary care and support provider is an isolating experience. Family care providers report feeling disconnected from their community and becoming isolated from the people who were in their lives prior to taking on increased care needs of their family members.

Particularly for family members who are not connected to an organisation of persons with disabilities (OPD), they might have no one in their life who has a similar caring experience who they can relate to and seek peer support from. In many cases, family carers are also forced to leave the workforce to provide full time support, further isolating them from others in the community.

"It is the most lonely piece of who I am. Since my children were diagnosed all of our friends and almost all our family have backed out of our lives. We no longer receive invites to events and gatherings."

A mother from Canada

"I and my husband were usually left alone, even blamed by some teachers or grandparents from time to time."

A mother from Turkey

"As an older sibling (13 year age gap) I have had a prominent caring role for my sister her whole life... To describe the experience, especially as a young teenager, I would say it was very isolating. I didn't have anyone to really speak to about my experience or relate to. "

A sibling from Ireland

Families highlighted how this isolation leads to loneliness and broader mental health impacts for family carers, which in turn, also impacts their ability to provide effective care and support.

Anxiety about the future

Families do all that they can to ensure their family member with an intellectual disability can have a happy and inclusive life. But for parents in particular, family care providers around the world report a fear for the future of their children after they pass away.

"People with intellectual disabilities do not have the right to legal capacity. My son cannot inherit my money when I die, even though he is an adult. [He] is working, he has his own cafe, but he's not allowed a bank account, it's all under my name."

A mother from Indonesia

"As I am aging, I get more anxious about the future of my disabled son."

A mother from Hong Kong

"It keeps me up at night worrying what will become of her when we are gone."

A mother from Canada

Very few programmes supporting families to transition to "life after parents" exist.

Most families of children with disabilities report that while they often think about the question, they don't have the capacity to find solutions, occupied with struggling with the current challenges they face around education, and accessing health care and early childcare. However, for families of adults with intellectual disabilities, families report that the future of their family member is a constant source of anxiety.

In many families, there are often assumptions that siblings of people with intellectual disabilities will take on full time care and support roles after parents pass away, which can create challenging dynamics within families and create new mental health and lifestyle impacts for the next generation.

Impacts on Siblings

Siblings contribute to the care and support of their brothers and sisters with intellectual disabilities in many ways and at different levels over time. Their experience changes across the lifespan, with roles shifting from providing emotional support and acting as "protectors of rights and dignity" in childhood and adolescence, to contributing financial support, taking on direct care tasks, and offering temporary support to give parents respite, particularly when siblings are adults with their own work and family responsibilities.

> ***"Some parents don't want their children to get married, have a partner. They want us to be a perpetual carer for our siblings. We want our own lives as well."***
>
> A sibling from Myanmar

> ***"There should be more support networks for siblings. Parents need to know not to expect us to do care without giving us all the information. They often place demand on older siblings. We need trust, loyalty and acceptance within the family. When everyone contributes, it's balanced. The responsibility comes on the mothers and older sisters."***
>
> A sibling from Pakistan

Many siblings criticise the lack of recognition of their support role from parents and the wider community, noting that they are often not involved in key decisions about their brother or sister with intellectual disabilities, despite an implicit expectation that they will ensure continuity of care and support in the future.

Taking on a support role in particular can also create challenging dynamics within the family, putting parents and siblings in a position to disagree about care and support, impacting their own relationships.

Across the survey and focus groups, many siblings shared concerns about the overprotective attitudes of some parents and described tensions when they try to promote more autonomy and space for their brother or sister.

> ***"[My mother] always wants to be the one to support him, she wants to be with him all the time. I argue with her - you can't be everywhere, give him time and space!"***
>
> A sibling from Ethiopia

> ***"It's rewarding, but very exhausting, especially dealing with my parents when I see them overprotecting my brother"***
>
> A sibling from Spain

Siblings from England.

Gendered care impacts

Worldwide, care provision falls disproportionately on the shoulders of women and girls, including the care of persons with disabilities. Inclusion International's survey reflected this disproportionate care burden, with 78% of the responses from family members coming from women and the vast majority of focus group participants also being women.

When it comes to disability, this dynamic is exacerbated because women and girls with disabilities are also more likely to be care and support providers to another family member - often resulting in female care providers who are the primary carer and supporter to a person with an intellectual disability while also simultaneously caring for aging parents or children.

Female care providers report usually being expected to be the one to make the "big sacrifice," abandoning their careers in order to support their family member with a disability. This puts female care providers in a fragile economic situation, particularly for single mothers, who may be depending only on pensions and government support when they exist.

"The responsibility comes on the mothers and older sisters. This is challenging. I try to push my older brother, but it's difficult. It's not easy to ask your partner, your father, your brother to step in."

A sibling from the UAE

"All the burden of being a carer is to the woman. To the mother. Society sees it as our obligation, so it's free. This is the hardest part. When you cannot perform you feel like a bad mother, a bad woman. I can't be everywhere at once. If I choose my career it takes my time to take care of him. No one considers what I want."

A mother from Indonesia

Impact on people with intellectual disabilities

Care and support systems are meant to ensure that people with disabilities get what they need to live independent, inclusive lives. But people with intellectual disabilities shared through focus group consultations that this is not a reality.

Broken care systems are impacting people with intellectual disabilities as both providers of care and support and as recipients of care and support.

This section highlights some of the key ways that people with intellectual disabilities report being impacted by gaps in care and support systems.

Challenges as a care provider

Many people with intellectual disabilities are themselves a provider of care and support in adulthood - providing care for their aging parents, being part of the care and support ecosystem for siblings or other family members with higher support needs, or providing care for their own children.

For people with intellectual disabilities who are the primary care or support provider to another person - which may be a person with or without a disability - they face the same negative impacts as other family carers do. People with intellectual disabilities who are in care provider roles are at risk of facing that same loneliness, isolation, and burnout - on top of the additional barriers they face.

For care providers with intellectual disabilities, navigating the complex and bureaucratic systems associated with formal sector care is a significant barrier. Systems are fragmented, and it can be difficult to understand what services are available for a person without an intellectual disability - as is the experience of many family members.

Once a care provider with an intellectual disability does identify a form of support they want to access, perhaps on behalf of the person they are providing care and support for, they encounter complicated jargon and forms and application procedures that aren't user-friendly.

When systems are not designed to be inclusive and easy to understand for people with intellectual disabilities, self-advocates note that there is also lack of support to understand what services and forms of support that exist.

> ***"I need accessible information to make decisions. Information is power! We have the right to understand the world around us."***
>
> A self-advocate from Hungary

Other negative impacts that care providers face are compounded for people with intellectual disabilities in a care role. Families of people with intellectual disabilities reported in the previous section that there are significant economic impacts of caring - including additional costs of care and less available time for work or other livelihood activities. People with intellectual disabilities around the world are less likely to be in paid work and are more likely to be in poverty - and taking on the additional economic impact of a care provider role can create even more significant financial barriers.

Other barriers in the community create additional challenges for people with intellectual disabilities. Self-advocates around the world shared in consultations that they often support their family members with tasks that require them going out in the community - examples shared by self-advocates included grocery shopping for a sick family member, going to the health centre to pick up medication, or running errands for aging parents. When people with intellectual disabilities have to navigate barriers in the community like inaccessible transport this makes fulfiling the care needs of others more challenging - and means that people may need to find their own supporter to support them in their role as a care provider.

Navigating family dynamics

For people with intellectual disabilities who are receiving support from their family members, ensuring that the support provided aligns with their will and preferences is a challenge that many self-advocates report.

People with intellectual disabilities are most commonly supported by their parents, but as they become adults their expectations for independence do not always align with the expectations of the family members who are providing support.

Many self-advocates report that getting support to make decisions or participate in their community can be challenging when it is provided by a family member, because they might focus on protection and safety concerns over the right to choose.

"When my mother wants to control, I tell her I want to control myself, I want to make decisions myself."

A self-advocate from China

"It's almost the care and protection rather than the care and support. [...] Even though I live in Wellington, my family lives in Auckland, you can't do this, you can't do that. And if I was to tell them the same, excuse me, it's my life, I'll do what I want. I think sometimes... We've always got to, you know, we've got to be allowed to make mistakes and things."

A self-advocate from New Zealand

"There is a line that no one wants to cross with their parents because they can be very overprotective, but because they care and are worrying about their children. And that is a very divisive point. The truth is that it is a very tricky line to tread because, there is a line called overbearing behavior from the family members or parents. It's because they're very extremely worried about you. They don't want you to have a bad life."

A self-advocate from Colombia

For people with intellectual disabilities who feel that they aren't getting the support they want from their family members, it can be a stressful experience to speak up about this. Self-advocates reported that challenging your parent or your sibling who has played a key role in providing support over your lifetime is a more difficult and emotional experience than challenging poor support from a paid supporter.

Navigating these dynamics and trying to balance preserving family relationships with getting the support they feel is most appropriate is a source of stress for people with intellectual disabilities and can cause a rift in family dynamics with lasting impacts.

"And then if they're not helping you in the right way, to ask them not to support you anymore - that takes a lot of courage for people with disabilities to do. To say I don't want you to be my support anymore. And to be able to tell them why you don't want them to be your support anymore. Because there's a lot of things that people are afraid to say to support people."

A self-advocate from USA

Insufficient quality of care and support

Compensating for failures and gaps in formal and community services does not only impact the family carer as explored above, it also has a real effect on the person with an intellectual disability requiring that support.

Families are stepping in and filling these gaps, which means that despite the lack of functioning care and support systems, people with intellectual disabilities are still getting their basic needs met, their rights advocated for, and support to be included in the community. But the toll that shouldering the care burden alone takes on families impacts the quality of care and support they can provide, in turn impacting the people with intellectual disabilities they support.

Families want to provide their relative with an intellectual disability the best support they can, but face real barriers to delivering high quality care. The burnout, isolation, and loneliness explored in the section above create real mental health impacts for family members, which reduces their capacity to deliver care and support. The financial impact on families to compensate for added disability costs results in families balancing employment or livelihood activities which take away time from care and support responsibilities, or taking a cut in income to provide full time care and support which results in having to deliver that care and support while experiencing poverty.

Many families also report physical limitations to the care they can provide, particularly for people with high support needs who need mobility support like lifting or carrying - and the capacity of parents in particular to provide this kind of physical support decreases as they age.

The significant amount of care and support many people with intellectual disabilities need was never meant to be delivered by one person - it requires functioning formal services, community support, and informal support to work together in balance to ensure that people get the support they need. When the other pillars of support are not functioning and families take on the responsibility of care alone, the emotional, physical, and financial challenges they face prevent them from providing as robust a care and support mechanism as should be available to persons with disabilities.

With this pressure building on families, many family carers are unable to provide the volume of care needed. When families are taking on unsustainable care and support workloads without the support they need as care providers, there is a risk that the support they provide can become just about survival, not about participation and inclusion.

"I am the only caregiver 24/7 to ensure he survives. Not just live a healthy, happy, safe life, but actually survives."

A mother from Canada

Risk of institutionalisation

When these challenges are faced by families and they do not have access to any alternatives, families are often left in positions where they are forced to send their family member with an intellectual disability to segregated places like institutions to receive care and support. Institutional living excludes, isolates, and violates the rights of persons with intellectual disabilities, but families are forced to make these choices because formal services and community support are not available in any other format.

Until formal support services and community services are able to deliver enough care and support to lift the burden on families, this imbalance in provision across the different pillars of care creates real risks of people with intellectual disabilities not having their needs met or facing institutionalisation.

It is clear that people with intellectual disabilities and their families are both facing negative impacts associated with their place in the care and support system, and urgent action must be taken by governments to provide desperately needed support.

Reform to formal sector services and social protection mechanisms is an important first step to reduce the burden of informal care on families. Any care system reform must additionally take action to address the physical and mental health impacts of caring.

Specific strategies to deliver on these system reforms are explored in the next section.

Key Takeaways:

- Being forced by inadequate systems to deliver the vast majority of care and support has left families facing isolation, loneliness, burnout, and financial impacts.
- Delivering care impacts family members differently, with female family members more likely to experience the negative consequences of their care and support roles.
- Families filling the gap in care systems does not only impact the primary family care provider, it impacts the whole family - including siblings.
- These constraints on families puts people with intellectual disabilities at risk of institutionalisation or not having their needs met.
- People with intellectual disabilities who are themselves carers face the same mental, physical, and economic impacts of being a care provider, while also facing additional challenges navigating inaccessible systems.

What would an inclusive care and support system look like?

> ***"It would be ideal if our daughter had an inclusive programme to attend rather than a segregated one."***
>
> A mother from Canada

The experiences of people with intellectual disabilities and their families have made clear that current care and support systems are not working. Care and support needs are not being met, rights are being violated, and families are paying the price for failing systems.

As governments look towards care reforms, what would a care and support system fully inclusive of people with intellectual disabilities and their families look like?

> ***"We need better policies that support inclusion"***
>
> A sibling from Pakistan

People with intellectual disabilities and their families are clear in their call for a care and support system rooted in full inclusion in the community. Inclusion is a central demand from both people with intellectual disabilities and their families, who stress that when people with an intellectual disability can access education, healthcare, employment and transportation on an equal basis with others, the level of care and support needed is significantly reduced.

An inclusive care and support system should align with the United Nations Convention on the Rights of Persons with Disabilities (CRPD). It should ensure that people with intellectual disabilities can access the support they need to live independently, participate in their communities, and exercise choice and control over their lives, especially under Article 19 on living independently and being included in the community.

While the right to care is not yet universally recognised (the right to care was recognised by the Inter-American Court of Human Rights as an autonomous human right in August 2025), the right to receive support is clearly reflected in the CRPD through several provisions, particularly Article 19.

By combining the support needs identified by families with the rights and principles set out in the CRPD, we can define the key elements of an inclusive care and support system.

Based on the feedback from people with intellectual disabilities and their families about what they need, an inclusive care and support system is rooted in 5 key elements:

1. Choice and autonomy
2. High quality, community-based options
3. Whole family approach
4. Affordable and appropriately resourced
5. Rooted in self-advocate and family leadership

These 5 elements are interdependent and must exist together in an integrated system. Care reform must embed all 5 key ingredients to ensure that care systems uphold human rights, fully meet needs, protect families providing care, and address negative impacts of current care and support failings.

When these 5 elements are aligned, people with intellectual disabilities will have access to effective, well-resourced, self-directed care support and the care burden on families will be reduced, while protecting the essential role that families want to continue to play.

"Care reform should be built on dignity, inclusion, shared responsibility, and meaningful participation."

A sibling from Ethiopia

Choice and autonomy

The type of care and support services that the person receives should be their choice, and they must have the autonomy to make their own decisions about services.

People with intellectual disabilities should be empowered to make their own informed choices about care and support, which means that supported decision-making is available for all persons with intellectual disabilities, including persons with high support needs with little or no speech.

> ***"It's actually having the care and support of what I want, not what the provider thinks I want. So I'm in control. I know we all need care and support, but, you know, there's a difference between support and control. And some carers and providers actually like to take control of it."***
>
> Self-advocate from New Zealand

Families also want to have a choice about the services available and choice in the way they are spending funding allocations.

Importantly, choice needs to be genuine - families only having the option to secure care and support delivered in a segregated setting is not a free choice.

Similarly, families being forced to decide between staying in the workforce or their family member getting the care and support they need is not a free choice. For people with intellectual disabilities and families to have genuine choices about the care and support they receive, governments must put in place other policies that support choice - like policies to close segregated settings that force people to access services away from the community, and flexible working policies that ensure families have the choice to stay in the workforce while providing care and support.

Choice and control in practice: Self-Directed Support in Scotland

Scotland's system of Self-Directed Support (SDS) represents one of the most significant efforts internationally to transform social care from a service-led model to one based on individual choice and control. In this model, people with disabilities can receive cash payments that allow them to purchase their own services and support, as opposed to systems where governments pay service providers directly.

Scotland's Social Care (Self-Directed Support) Act mandated local authorities to offer people requiring social care a range of options for directing and arranging their own services. It established four SDS options:

1. **Option 1 – Direct Payment:** The individual receives a cash payment and arranges their own support.
2. **Option 2 – Individual Service Fund:** The individual directs how their budget is used, while a provider or local authority manages the funds for them.
3. **Option 3 – Arranged Services:** The local authority selects and arranges support on the person's behalf.
4. **Option 4 – Mix of Options:** A combination of the above approaches.

The Scottish model was designed to ensure that self-direction was not limited to people able or willing to manage a direct payment. Instead, it sought to create a continuum of choice and control applicable to a wide range of people, including persons with intellectual disabilities, physical disabilities, mental health conditions, older people, and unpaid carers.

With SDS, choice and control are firmly embedded within Scotland's social care policy framework. Many individuals have gained greater flexibility over how support is organised. SDS has encouraged more personalised approaches, strengthened recognition of people's rights and aspirations, and supported innovation among providers. The approach aligns closely with the principles of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 19 on the right to live independently and be included in the community.

Scotland's SDS model has some limitations, notably the variation in how SDS is delivered across local authorities - with some people with disabilities reporting that they are not always being informed of their 4 options. Some organisations of persons with disabilities have argued that SDS in some local authorities can become an administrative process focused on budgets rather than a genuine mechanism for achieving greater autonomy and inclusion.

Even with its limitations, Scotland's experience with SDS gives policymakers a model that can help embed choice in care and support systems. It has potential to be strengthened through mechanisms that ensure consistency in application across local authorities and capacity building for local governments, service providers, and communities to ensure the support is in place for people to live the lives they choose.

High quality, community-based options

> ***"Training for care and support workers must be strictly in the framework of the social model, and the CRPD."***
>
> A mother from Argentina

Services provided in an inclusive care and support system are high quality, with monitoring to ensure quality levels are maintained, and are based in communities.

Where services are available, families tell us that they often do not meet their needs or expectations. Professionals are poorly trained and low paid, resulting in high staff turnover and a lack of the continuity in the support provided. Families further highlighted that many care workers continue to operate from a predominantly medical perspective and lack training in a human rights–based approach, which undermines quality of existing services.

An inclusive care and support system has high quality standards rooted in the Convention on the Rights of Persons with Disabilities (CRPD), and is consistently monitored by governments to ensure that needs are being met and rights are being fulfilled.

For support services to comply with the CRPD, they must be based in communities. They must be available in places that all community members access and use, close to where people live, and not concentrated only in urban areas or capitals. Inclusive support services are never delivered in segregated settings.

"Care reform should move toward community-based and rights-based models, not back toward segregation."

A sibling from Ethiopia

Community-based options in practice: circles of support in Kenya

KAIH, a national OPD representing people with intellectual disabilities and their families in Kenya, has developed a model that responds to the need for locally-based support in communities across the country that may not have access to formal services.

A circle of support consists of between fifteen and thirty people who live locally to each other. All members of the circle are either a family member of a person with a disability, or a person with a disability themselves. The circle meets regularly, and agrees on the activities that they will do to respond to the needs and interests of its members as a collective. A primary priority for circles of support is the redistribution of care and support work amongst members - a collective responsibility. Members of circles work together to coordinate provision of rotational child care, respite care, buddy systems and support persons. These activities concurrently provide relief to family members who would often otherwise provide all of this care and support alone, and affirms the right of people with disabilities to receive good support to be included in the community.

KAIH supports the establishment of circles of support by providing training on good governance as well as training about their rights as people with disabilities and family members.

KAIH also supports circles to formally register as community groups, which enables them to access devolved government funds, and permits them to engage in advocacy efforts within their local communities.

Though originally designed and delivered by KAIH and members of circles themselves, the Kenyan government has launched a pilot project seeking to duplicate this model across the country, aligning with the ten year national care reform strategy established in 2022 aiming to shift care and support from institutions back into communities.

This is a particularly valuable replicable model for governments in low- and middle- income countries. By embedding resources for national OPDs to coordinate and train circles of support in national or local budgets, impact can be amplified across communities around the country.

Whole family approach

Inclusive care and support systems recognise the role that family members play in the life of their relatives with intellectual disability. These systems must consider the needs of persons with intellectual disabilities AND the needs of their families, including siblings.

Families are filling governments' gaps in providing support to persons with intellectual disabilities, but do not feel recognised or supported. While care and support is something that every person takes part in at different times of their life, the care and support that families of persons with intellectual disabilities provide is exceptional and goes beyond what regular support and care for family members should look like. The role they play needs to be recognised by governments, and their support needs must be considered in the design of care and support services.

Currently, care and support systems are designed primarily based on the needs of people with disabilities. While this is essential, additional mechanisms that ensure families are also getting the support they need goes hand in hand with disability-specific supports and services.

Support for people with disabilities and support for families cannot come at the expense of each other - both need specific support based on their needs.

Inclusive care and support systems that also consider the needs of families in addition to persons with intellectual disabilities would embed free access to support like:

- <u>Respite services</u>

  Respite services are a crucial way to address the mental health and psychological impacts of care provision for families. An inclusive care and support system would provide respite services to families - whether in the form of in-home support or in inclusive community settings. This support for families is essential.

> ***"[If I could change the support I have now] I would increase how often respite support is available"***
>
> A mother from Spain

> ***"We need daily help which would contribute to relieving the pressure on me due to the many household and children responsibilities"***
>
> A mother from the UAE

- <u>Mental health support, including peer support</u>

  An inclusive care and support system taking a whole family approach considers the mental health needs of family carers. Having psychological support available for families is essential to help them face and reduce the psychological impact and reduce burnout. This support could be in the form of professional psychological support, or through peer support groups. Families highlighted how important it is for them to hear other experiences, in particular positive experiences that help them in their journey.

"I would like to have a connection to people who know about people with intellectual disabilities, someone positive, someone with experience that could be a guide, offer direction, give us a boost, take some of the emotional labour"

A mother from Canada

"I want more support for everyone in the family. [...] How can just one person bear all the responsibility?"

A sibling from Pakistan

- Information and training

An inclusive care and support system ensures that families have the resources they need to play their care roles. Whether they are young parents newly confronting a diagnosis or older parents supporting an adult child, having help to understand the disability, learn about their child's rights, identify available services, navigate complex administrative procedures, and access information on existing support and how to obtain it is so important for families.

"What we need right now is information, and support to understand laws and policies."

Self-advocate from Colombia

"I would like to have access to a social worker to help me with the paperwork and the possibilities I have. Also to a psychologist, because it is exhausting to be a single parent caregiver. "

A mother from Spain

Whole family approach in practice: Family support groups in Egypt

Family peer support groups are spaces in which family members of people with intellectual disabilities come together. In Egypt, family peer support groups are set up and supported by SETI Caritas, a service provider, and led and operated by families.

Within these groups, experienced family members of children with disabilities volunteer to share their experiences and support young families to navigate information and services, provide training, emotional support, respite and advocacy through informing and training other parents on the rights of their children with disabilities. Families are not paid for their role in these support groups. Each group elects their own coordinator and assistant coordinator among the family members. SETI Caritas supports the groups by providing the meeting venue and some refreshments. A rotating facilitator role is designated to be the link between the organisation and the group.

While other family groups may exist, most of them focus on the direct support needs of their relatives with an intellectual disability. These family peer support groups are unique in that they provide families with a space to talk about their own role as care and support providers and devote time and consideration to their own health and well-being.

Family members from many support groups across Egypt became agents of change in their communities, raising awareness amongst medical staff, officials, service providers and other stakeholders. They also became recognised as official representatives of families by their governments from the local to national level, and they are often invited to participate in consultations, meetings or events, such as the revision of the 2018 law of Rights of Persons with Disabilities.

SETI has issued a Guide for Formation of Family Support Groups that describes and documents the way Family Support Groups work, allowing for replication. Policymakers can learn from this good example, embedding funding for local family groups to come together in their care and support budgets.

That may look like funding local OPDs to deliver peer support for families, or resourcing family peer support in local authority budgets and mandating partnership with OPDs to deliver this work.

Affordable and appropriately resourced

In an inclusive care and support system, full coverage of disability extra costs should be universal.

Families consistently describe the significant economic impact of providing care and support to a family member with an intellectual disability. Although some cash benefits exist, they are often hard to access due to complex and bureaucratic procedures, they might have difficult eligibility criteria such as being conditioned with the employment status, and many families call for stronger and more reliable financial support that reflects the high direct and indirect costs associated with meaningful care and support.

> ***"Additional services shouldn't be forgotten in health. Families suffer in poverty due to healthcare bills. We need financial support. Care is expensive!"***
>
> A mother from Rwanda

Financial support is essential to secure good quality support services where these exist, or to access services that are genuinely tailored to needs rather than based on professional assessments that overlook their lived realities. Families also highlight the high out-of-pocket health expenses, especially for therapies, which are often expensive and not reimbursed. Many families describe losing a source of household income because one member must reduce or leave paid work to take on care provision responsibilities.

> ***"Every family has the right to receive services regardless of their income. You pay taxes every year. The complete amount of money spent on private therapies is not refundable. You don't even get half of the amount."***
>
> A mother from Canada

More financial support with better flexibility is an essential part of an inclusive care and support system.

Self-directed budgets managed by people with intellectual disabilities and families are an important way that inclusive systems ensure people have access to the support they need without being pushed into poverty. They are also a key mechanism for embedding choice as another key ingredient in an inclusive system.

"I'd love to have them [services] offered and paid by the government. At least part of that"
A mother from Canada

"We need support in the cost to make it less of a burden on the family budget."
A mother from Egypt

Affordable and appropriately resourced in practice: Coaching in Finland

Coaching is a service in Finland that provides people with disabilities support to live independently, and is made up of the support they choose based on what is most important to them at that point in their life.

The service is delivered individually or in groups, online or in person, and is always tailored, with goals and priorities planned together by the person receiving support, their families and other supporters, with help from their coach.

Coaching is used by people with disabilities who need support in everyday life skills, participation, and managing life changes. It can be provided to young people, adults, and older people, depending on individual needs and life situations. It is mainly designed for life transition situations, such as moving out of the family home and changes in education or work, making sure the support is not interrupted or stopped because of life change situations.

Coaching can include support to develop and improve skills such as communication, using technology and navigating online services, managing time and finances, and carrying out everyday household tasks like cooking and cleaning. It can align with whatever support the individual wants and needs. It helps the person with an intellectual disability and their family navigate through complex systems by providing information on housing options, employment and education pathways, and their legal rights and available services.

The model originated in civil society - Tukena, a service provider and Inclusion International member in Finland, co-created the concept of transition coaching together with people with intellectual disabilities and families in the 1990s, and has been providing the service ever since.

Importantly, in 2025, coaching was enshrined in national legislation as a statutory public service, and is now implemented and coordinated by local authorities across Finland. Through becoming a statutory service anchored in national legislation, this provides a more sustainable stream of resources to the programme and enabled more users to access it for free.

The model was developed in a participatory way involving people with intellectual disabilities and their families meaningfully, supported by Tukena. It is deeply grounded in their lived experience, real-life questions and everyday needs.

Coaching is a good practice chiefly because it takes a holistic approach, viewing a person's life as a whole - their personal identity and interests, living situation, employment and more - as well as drawing in existing support networks including families, friends and professional support persons. This broad perspective and genuine collaboration ensures that support is not fragmented, but coordinated, person-centred, and empowering - all while being in line with the individual’s choice about the kind of support they want for the inclusive life they envision.

In the Finnish context, coaching responds to clear structural, cultural, and informational gaps within an otherwise largely comprehensive welfare system.

Finland generally has strong and reliable public services, but these services can be fragmented and siloed in practice - families are often surrounded by many professionals from different sectors, like education, social services, employment and housing, yet cooperation between these actors is not always close or well coordinated. Coaching addresses this gap by providing clear, understandable information, enabling people to make informed and supported choices based on their personal goals, unconstrained by difficulty in navigating available services, in this way coaching forms the final puzzle piece for a robust safety net that holds firm even during times of transition.

Appropriate resourcing of care and support systems does not only consider how to help families manage the extra costs associated with disability - it also ensures that formal sector services have sufficient resources - as in the case of how coaching was enshrined in legislation to ensure consistent funding.

Another key factor for resourcing service providers is the care provider workforce. Families report that formal service providers face chronic understaffing, which translates to reduced support for the people with disabilities who need human support services. In regions across the world, care work is undervalued labour, with low wages for formal sector care workers having a significant impact on the ability of service providers to attract and retain care workers. An adequately resourced inclusive care system values care work, and pays formal providers of care and support wages that are in line with the essential role they play.

Should families be compensated as informal providers of care?

Care work is work, and care reform advocates call for formal sector care providers to be appropriately compensated for their work. Where does this leave family members of people with intellectual disabilities, who themselves are providing informal care on a full-time and often 24-hour basis - far beyond the care role that family members of persons with disabilities are expected to play.

In some countries, family carers do receive direct financial recognition for their role, often through a carer allowance. In Kenya, for example, recent care and support reforms recognise the “time for care” that family members provide by offering a cash transfer as compensation for their time. In Colombia, care allowances are provided to family members who deliver care and support, but only for those who are living in extreme poverty. In Australia, families may receive a household cash transfer, separate from their disability allowance, which is often used to cover disability-related costs associated with care. In other contexts, families may receive a budget or funding package and are responsible for managing and organising their own support - usually a combination of formal services and informal care.

While these support mechanisms and other financial support are intended to support families in their caring role, family members around the world have differing opinions on if families should be compensated for their caring role as a full-time job. Across Inclusion International's research, families universally emphasised that they want their unique role to be recognised as having different responsibilities from that of families of people without disabilities, but the idea of being “compensated” provoked strong and sometimes conflicting reactions.

Many families living in contexts where services are limited, absent, or inadequate, particularly in low- and middle-income countries, view their role as equivalent to that of a paid professional. They act as the sole provider of care and support, often are not able to earn other income due to caring duties, and also face significant emotional and physical impacts of this work. In contexts where there are no viable options for formal care and support services, or in contexts where only segregated service provision is available, families call for financial recognition of the work they do.

In contrast, other families, particularly families in countries that have more robust formal services, express concerns that paying family members could entrench expectations that families must provide care and support as an obligation. They worry that this would allow governments to shift or drop their responsibility to provide adequate care and support systems.

"Family caregivers should be compensated for their work and their lost earning/saving potential and the financial burden of extraordinary expenses. This should not be done on a reimbursement basis that increases the already onerous administrative burden on caregivers. It should be a stipend."

A mother from Canada

"I worry about advocating for compensation for families because I worry that means that it ends up, 'Oh well, families will just take care of it all'. And in some ways, that just promotes the concept of isolation of families [and] of people with disabilities. 'Don't worry. The families are going to take care of it."

A mother from Canada

Families told us that decisions about how families are financially supported as an element of inclusive care and support systems must be tailored to each country, taking into account available formal services, the level of inclusion, the economic situation, and the cultural context. Mechanisms for financially supporting families that are appropriate in different contexts is an area for further research.

A final factor of appropriately resourced care and support is ensuring appropriate resourcing is sustainable, with commitments to maintain funding levels and increase them with inflation to ensure that people with intellectual disabilities and their families do not lose essential support.

Families express concern about the impact of funding cuts and shifting policies on their already fragile situation, especially at key transition points such as the move from childhood to adulthood and into older age where people often lose benefits or lose access to services.

"Most families have low financial capacity because they stay with their child for support. The government should enable direct support. Our families should be considered specifically."

A mother from Rwanda

"The supports we access are constantly under threat in that there is always the threat of cuts."

A mother from Canada

"During the pandemic we tried to get disability cards, but we didn't make it in time before the coup."

A sibling from Myanmar

Governments must invest in social protection systems so that the support services needed by persons with intellectual disabilities and their families are available and affordable, whether they are provided and funded directly through Government led services or through personal funding that is flexible and sufficient.

Rooted in self-advocate and family leadership

Inclusive care and support systems cannot work without meaningful involvement of the people they support.

Persons with intellectual disabilities and families should be consulted when developing programmes and services. They should also be involved in the monitoring and evaluation mechanisms.

Rooting support systems in self-advocacy and family leadership in practice: Layered Support in Argentina

In Buenos Aires, Argentina, people with disabilities and their families have played a key role in designing the "layered support" model, which links government-funded support with the expertise and leadership of organisations of persons with disabilities (OPDs). This layered model was designed by the core membership of Asociación Azul - people with disabilities - with the support of coordinators and facilitators to bring their vision of a support system based in independence, flexibility and choice to life.

The layered support model involves access to personal assistance for people with disabilities funded by the provincial government, with personal assistants being trained by OPD Asociación Azul to ensure that they are delivering support in a way that is consistent with the Convention on the Rights of Persons with Disabilities (CRPD), the social model of disability, and the vision that people with disabilities and their families have for inclusive services. As part of the model, families of people with disabilities also access funded peer support through OPDs.

The layered support system in Buenos Aires is a promising practice as it challenges the dominance of segregated services and institutions in Argentina, which are the only ways that most people can receive support from outside of their families. Successes associated with the model are striking against this backdrop - people with disabilities have been able to achieve goals such as finishing secondary school, enrolling in university and finding employment through the support they have accessed through this mechanism. The social benefits of the layered support model are equally valuable - people are enabled to build and maintain strong social relationships, travel and live independently and be a part of community organisations. Where segregated services often stand in the way of these goals, this rights-based layered support system centres and prioritises them. The successes of this model also demonstrate how care and support mechanisms that are rooted in the vision for support and inclusion of people with disabilities themselves and their families are the most effective at responding to their needs and ensuring meaningful inclusion in the community.

Key Takeaways:

- Care and support should be high quality and community-based - inclusive care and support is never delivered in segregated settings.
- Care and support mechanisms should be rooted in choice and autonomy, with genuine options for people with intellectual disabilities and their families available through mechanisms like supported decision-making.
- Care and support must take a whole-family approach, meeting the needs of people with intellectual disabilities but also considering needs of families like respite support, information and training, and mental health support.
- Care and support systems need to be affordable and appropriately resourced - including compensating care workers fairly and ensuring families are not out of pocket for disability-related costs.
- Care and support systems should be rooted in self-advocacy and family leadership, giving the people who use the services the opportunity to co-design and monitor care and support mechanisms.
- Good examples of how these key ingredients can be operationalised exist in Kenya, Argentina, Scotland, Egypt, and Finland.

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.

Conclusion

Around the world, people with intellectual disabilities and their families are sharing the same message: current care and support systems are not meeting their needs. Despite differences in national contexts, levels of income, and existing service structures, the experiences documented in this report reveal strikingly consistent patterns. Formal supports are too often unavailable, inaccessible, fragmented, or delivered through segregated models that limit choice and inclusion. As a result, families continue to shoulder the overwhelming responsibility for providing care and support, frequently without recognition, adequate assistance, or opportunities for respite.

Care and support reform represents a critical opportunity to move beyond outdated approaches that view people with intellectual disabilities primarily as recipients of care. Instead, reform must recognise them as rights holders, active members of their communities, and, increasingly, as care providers themselves. Building inclusive care and support systems requires governments to take responsibility for ensuring that support is available, accessible, adequately funded, and rooted in the principles of the Convention on the Rights of Persons with Disabilities.

This report also demonstrates that a different future is possible. Across countries, people with intellectual disabilities, families, and their representative organisations have identified what effective care and support systems should look like. They have called for systems that uphold choice and autonomy, provide high-quality community-based supports, strengthen inclusive mainstream services, recognise and support the essential role of families, and are designed and governed with the leadership of people with intellectual disabilities themselves.

The evidence presented in this report leaves little doubt about the urgency of action. Continuing to rely on families to compensate for inadequate systems is neither sustainable nor equitable. Investing in inclusive, community-based care and support is not only a human rights obligation—it is essential for building stronger communities where people with intellectual disabilities and their families can live with dignity, participate fully, and thrive.

As governments shape the future of care, people with intellectual disabilities and their families must not simply be consulted — they must help lead the way.

Lasting reform will only succeed if it is informed by the lived experiences of those who navigate care and support systems every day. The vision of people with intellectual disabilities, their families, and their representative organisations provides both the roadmap and the foundation for care and support systems that truly leave no one behind.

A parent in Argentina provides communication support.