

What a 95-Country Study Taught Us About the Illusion of Inclusion

1.0 Introduction: The Gap Between a Place and a Purpose

For decades, the goal for community living has seemed straightforward: move people with intellectual disabilities out of isolating institutions and into local neighborhoods. The common assumption has been that a change of address is a change of life—that placing someone in the community is the same as making them part of it. We have measured progress by counting the number of institutions closed and the number of group homes opened, believing that physical presence is the ultimate benchmark of inclusion.

But a landmark global report published over a decade ago, drawing from the experiences of thousands of people across 95 countries, revealed a much more complicated and sobering reality. In 2012, it challenged our comfortable assumptions by showing that a physical location does not automatically grant a person a sense of purpose or belonging. This raises a critical question for us today: Why do the hard truths uncovered in that report remain shockingly relevant? What have we failed to learn in the years since? The report makes it painfully clear that simply leaving an institution doesn't guarantee you've joined a community. True inclusion is not about real estate; it's about relationships, choice, and a fundamental shift in how we see and support one another.

This post will explore four surprising and essential truths from that massive study. These are not just data points; they are the lived experiences of self-advocates and their families, offering a powerful roadmap for what it truly means to belong—a roadmap we are still struggling to follow.

2.0 Four Surprising Truths About Life in the Community

The report's findings force us to look beyond simplistic solutions and confront the deep, systemic barriers that persist even when the intentions are good. Here are four of the most critical takeaways.

2.1 Takeaway 1: We're Chasing "Independence" When We Should Be Building "Interdependence"

For many, the term "independent living" conjures an image of a person living alone, self-sufficient and without need for support. But the report argues forcefully that this is a misnomer, a culturally specific ideal that often creates more barriers than it breaks down. For people with intellectual disabilities—and arguably for all human beings—the goal is not to be completely free from reliance on others. Life is not about isolation; it's about connection.

The true aim is interdependence: a life where individuals have meaningful relationships, genuine choices, and control over their own lives within a network of mutual support. This concept shifts the focus from a person's ability to perform tasks alone to their ability to govern their own life

with the support they need. It recognizes that relying on family, friends, and community is a natural and desirable part of the human experience, not a failure to be "independent." The heart of this paradigm shift is captured perfectly in the report:

"The goal of Article 19 and the CRPD is interdependence, self-governance and self-determination, not independence from other human beings. Article 19 is about people with intellectual disabilities being full citizens, people with meaningful and realistic choices and people with both rights and responsibilities in their community and in their nations."

2.2 Takeaway 2: Leaving the Institution Doesn't Guarantee You've Joined the Community

One of the report's most powerful warnings is against what it calls "Second Order Deinstitutionalization." This is the process where the community-based programs created to replace institutions become smaller, segregated facilities themselves. Because these programs often lack a core philosophy of person-centeredness, self-determination, and full participation, they become institutions in spirit, if not in scale.

We have learned that physical presence is not the same as social inclusion. For example, a person may spend their days in a "community" program that is, in reality, a sheltered workshop attended only by other people with disabilities, effectively replicating the segregation of an institution under a different roof. They can live on a residential street but have no relationships with their neighbors. This creates an illusion of inclusion while maintaining the core practice of segregation. As one Canadian father powerfully stated, the journey is far from over:

"While my daughter is living in the community, she is not yet a fully participating member of her community ... but we are making progress."

2.3 Takeaway 3: Institutions Are Still Being Built—They Just Have Better Names

Despite more than fifty years of research confirming their deeply harmful effects, institutions have not disappeared. One of the most insidious ways they persist is by hiding in plain sight, rebranded with euphemisms that sound modern, caring, and community-oriented. The report identifies a long list of these misleading labels used to mask the reality of congregate, segregated settings.

- Homes for Special Care
- Special Care Homes
- Personal Care Homes
- Farms/Ranches
- Gated Community
- Developmental Maximization Unit
- Community Living Centres
- State Schools
- Neuro-behavioural treatment Centres
- Long Term Care homes
- Centers of Excellence

- Cottages
- Living Centres

These friendlier names obscure the fundamental truth that residents are still isolated from the broader community and denied control over their own lives, continuing a legacy of segregation under a more palatable guise.

2.4 Takeaway 4: Families Are the Default Support System, and They're at a Breaking Point

Across the globe, one fact is overwhelmingly consistent: families are the primary, and often the only, source of lifelong support for people with intellectual disabilities. The report reveals the immense and often invisible burden this places on them. Data shows that 58% of family caregivers spend over 40 hours a week providing support—the equivalent of a full-time job for which they receive little to no assistance. The cumulative toll is staggering: nearly half (46%) report having more caregiving responsibilities than they can handle, while the vast majority suffer from physical fatigue (88%) and emotional stress (81%).

This relentless responsibility creates enormous strain, forcing parents and siblings to become lifelong caregivers, advocates, and case managers. They navigate this journey in isolation, their own lives and well-being frequently sacrificed. This unsustainable reality was captured in the heartbreaking words of a mother in Russia, who shared a sentiment felt by countless families worldwide:

"It's a shame that a mother's life stops after the birth of such child."

3.0 Conclusion: From Location to Belonging

The message from this global study is as urgent today as it was a decade ago: true inclusion is not an address on a map or a line item in a service budget. It is a fundamental shift in how we structure our societies to ensure every member has a valued place. Moving people out of institutions was a necessary first step, but it was never the final destination. The real work lies in dismantling the social and systemic walls that continue to isolate people even when they are living next door.

Achieving this requires more than just well-meaning programs. It demands a transformation of our core systems—inclusive education that fosters relationships from childhood, employment opportunities that offer purpose and economic freedom, and a societal attitude that moves from tolerance to genuine acceptance and interdependence. It means recognizing that communities are not just stronger when everyone is included; they are incomplete until they are.

Now that we know physical presence isn't enough, what is one tangible thing our own community could do to move someone from simply living here to truly belonging here?