

We envision a world where care for individuals with intellectual disabilities and autism is rooted in human connection, interdependence, and kindness. This can be achieved through an intelligent combination of person-centred, locally designed services and the fostering of resilient, caring social networks.

The LivesthroughFriends Summer Institute

The Lives through Friends Summer Institute in September 2024 brought together experts from around the globe - experts by experience and experts in allyship - to discuss the shortcomings of current care systems and explore alternative approaches. The goal was to promote effective practices and inspire a new international narrative for change.

A Communique for Change

This Communique is a collective expression of our shared concerns and aspirations. As Michael J. Sandel has observed,

"The most fateful change that unfolded during the past three decades was not an increase in greed. It was the expansion of markets, and of market values, into spheres of life where they don't belong."

This shift has influenced social care professionals to focus excessively on methods and measures, often at the expense of the original purpose. Regulatory systems driven by fear, compliance, and control have created a climate where vulnerability may be exploited, and genuine understanding is sacrificed. Systems have been hardened and become distanced from people, communities and everyday life. As a result, the creativity and resourcefulness of frontline workers are being unnecessarily restricted, and processes and procedures have become too complex to be navigated by those they are meant to serve. We can do a lot better. There are some notable exceptions where agencies have reorganised and put people, gifts, relationships and place first. However, others continue to use the language of reform and say they support a move to collective acts of care and community capacity building, but do so without a realistic understanding of the fundamental changes in approach that are needed.

The Empowerment of Individuals and a Shift in Perspective

A major challenge is to help individuals with disabilities to empower themselves and actively participate in shaping the systems that impact their lives. We must shift from transactional interactions to deep, meaningful conversations that acknowledge the unique perspectives, connections, and strengths of each person.

Instead of assessing individuals, we should listen to them. By adopting a curious mindset, we can explore new possibilities, test innovative ideas, and move away from harmful practices like "digging in heels" to achieve desired outcomes.

Self-Advocacy and Community-Centred Care

Self-advocacy should be at the heart of new, localised preventative services. Many individuals with disabilities feel fearful, uncertain, and lost in jargon due to the current system. Their voices are often overlooked in decision-making processes, hindering their ability to live fulfilling lives. Effective services must be adaptable and supportive, complementing individuals' gifts, talents, skills, and networks. They should be driven by the unpaid caring economy of family, community, and friends, with attention always given to developing potential and participation.

A System of Possibility

It's important to remember that the system is not the people. Many individuals within the system are well-intentioned but constrained by broken processes. We must create a system that allows staff, users, and families to maintain their values and embrace change. Every family is unique, and everyone is fallible. By reducing fear, modelling calm, and building confidence, we can foster a culture of community and resilience. Resonance, our gut feeling, is a powerful tool for changing minds.

A Collective Effort

Achieving change requires the constant support and contributions of everyone. Many of us already prioritise relationships and community. By modelling positive behaviour, we can inspire others to follow suit.

Individuals with disabilities and their families should lead conversations about what truly matters to them. Professionals must step aside and allow their collective voice to emerge. We envision communities led by people who live and work there, built at the speed of trust, an interactive social network of 'homes' for all to enjoy.

The Role of Professionals

Professionals must adopt new roles as facilitators, reflective creators of opportunities and fun, resilient and patient collaborators, compassionate and purposeful innovators, and above all, social networkers.

By embracing these roles, we can transform our communities into places of possibility, not problems. As one of the delegates said,

"A small piece of a massive painting. A never-ending painting – adventure after adventure."

