

19 Stories of Social Inclusion – Ireland: Stories of Belonging, Contributing and Connecting

Executive Summary

**Christine Magee, Tomás Murphy, Margaret Turley, Michael Feely,
Edurne García Iriarte, Roy McConkey and Inclusion Ireland.**



Údarás Náisiúnta Míchumais
National Disability Authority

Introduction

Irish disability policy, in line with international treaties such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), aims to support people with intellectual disabilities to live included lives in their community. Despite this, people with intellectual disabilities are far more likely to experience social exclusion than non-disabled people. However, there are also people with intellectual disabilities taking part in their communities and living ordinary lives all over Ireland. The aim of this research is to let people hear their stories and to show that it is possible for people with intellectual disabilities to live socially included lives in communities.

This research is inspired by the '19 Stories of Social Inclusion' project carried out in Australia. Its approach was to start with the 'success stories' and work backwards to find out how people have created socially included lives for themselves.

This report is accompanied by an easy to read report of the research as well as a series of stories, some told through video, some through images and text, hosted on the Inclusion Ireland [website](#). The dissemination of the participants' stories by accessible means aims to support people with intellectual disabilities and families to contribute to bringing about greater levels of social inclusion. Taken together, the report and stories demonstrate what successful implementation of Article 19 of the UNCRPD looks like.

What is social inclusion - key findings from the literature

Social inclusion is a poorly understood concept and can mean different things to different people. It is about more than mere physical presence and requires participation and engagement in mainstream society (Cobigo et al, 2012). Self-determination is important in achieving a socially included life (Duggan and Byrne, 2013). People with intellectual disabilities may require support to acquire the skills and practice at making choices and thereby gaining control (McConkey et al, 2013; Garcia Iriarte et al 2016). The literature shows that personalised supports play a key role in enabling self-determination, citizenship, social inclusion and quality of life.

About this research

This project used an inclusive research method in that people with intellectual disabilities were involved in all stages of carrying out the

research. Interviews were carried out by three researchers, two of whom were experts by experience. People with intellectual disabilities were also members of a Research Advisory Committee for the project.

Criteria for inclusion in the study were widely advertised and 19 participants were identified and interviewed. Interviews were analysed using thematic analysis.

About the participants

Participants were men and women of different ages, living in cities, towns and villages all over Ireland. All participants identified as having an intellectual disability with most participants having multiple disabilities, including health conditions, physical disabilities, mental health challenges and autism. Participants varied in what supports they needed and in their intensity. This ranged from intermittent contact to 24-hour support.

Participants were living socially included lives in a number of different ways: through involvement in mainstream work or education; living in their own homes in the community; involvement in mainstream community activities and through relationships, friendships and connections.

What we found

The value of social inclusion

- Participants told us that social inclusion gave them a sense of belonging and contributing and placed great value on having choice and control in their lives
- Being socially included created opportunities for further social inclusion. For example, a move to their own home enabled participants to get involved in mainstream community groups
- Being socially included led participants to make positive change for other people with intellectual disabilities

Enablers of social inclusion

- Focusing on the unique individual and not the disability enabled social inclusion
- Participants' self-advocacy skills and leadership qualities helped them to achieve this level of social inclusion

- Inclusive environments that were physically accessible, welcoming, open to change, and which valued diversity contributed to participants' sense of belonging and participation and in their community
- Good support was a key enabler of social inclusion

Supporter activities and qualities

- Good support was based on a common sense of humanity, reciprocal relationships and shared interests
- Inclusion was enhanced by supporters who helped to adapt external environments, advocated for support, identified community resources and opportunities
- Working with a supporter to identify goals, strengths and interests was identified as a good starting point

What does this mean for policy and practice?

Social inclusion is a key feature of mainstream and disability policy in Ireland. However, it is not defined in Irish policy. This raises questions as to whether the definition is sufficiently broad to take account of people with intellectual disabilities' experiences of social inclusion or to support its achievement.

The emphasis placed on choice and control by participants underlines the importance of providing structures and supports for legal capacity. However, one of the primary legislative supports for legal capacity - implementation of the Assisted Decision Making (Capacity) Act 2015 - has been slow and key structures have yet to be established.

The strong leadership and self-advocacy role played by participants was crucial to them attaining such socially included lives and suggests a need to build capacity for leadership among people with intellectual disabilities overall. Implementation of the Transforming Lives, Working Group 3 report on participation in decision making would seem particularly important to achieve this.

This research adds to the evidence base on the importance of personal supports to the achievement of socially included lives. However, while work is ongoing to move towards more person-centred services and some service providers are demonstrating good practice, many disability services remain 'one size fits all' services. It is evident that the HSE needs to be more pro-active in developing person-centred, community-based

models of support as it is clear there are challenges in delivering this change in a timely manner in some instances.

The study provides strong evidence on the need to change from paternalistic notions of 'care' to that of support if people with intellectual disabilities are to have their right to socially included lives recognised and supported. Supporters require skills in developing community connections, advocacy, building social skills and supporting people to make their own decisions. Service providers need to re-evaluate their approach to risk in favour of a more balanced approach that supports social inclusion.

The study reinforces the importance of policies which seek to make mainstream spaces, services and supports accessible to people with intellectual disabilities and suggests a key role for the Public Sector Duty.

Recommendations for policy and practice

- The National Disability Inclusion Strategy 2017-2021 could foster a broader understanding of social inclusion by addressing key omissions, such as support for relationships, advocacy and self-advocacy
- Full implementation and adequate resourcing of decision-making structures and supports such as the Decision Support Service and Plan for the Effective Participation in Decision Making as well as ratification of the Optional Protocol to the UNCRPD will support people with intellectual disabilities to exercise choice and control
- Person-centred practice would be expedited if the HSE required services to unbundle funding and allocate a budget for each person, as a condition of their Service Level Arrangements. Targets could be set for the proportion of persons receiving personal supports
- Disability services could also take steps to unbundle funding, facilitate the person to choose their own supports, take a positive approach to risk and ensure staff have the skills and knowledge to work in a community-focused, person-centred way, in line with New Directions
- A whole of government approach involving the Department of Health, Department of Housing, the HSE and local authorities is required so that people with disabilities can access housing and the supports required to live independently. Personal budgets can play a key role in this
- Use of a commissioning approach to the funding and provision of services would increase the diversity among service providers and promote innovative, person-centred providers
- Peer and self-advocacy should be promoted within annual reviews of person-centred plans and training resources made available. These

could be supported through the development of Equality and Rights Committees in disability services

- Public bodies should carry out an audit of their organisation and identify and address barriers to accessing their services, in line with the Public Sector Duty