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

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Acknowledgements

Disclaimer

December 2018

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Glossary of Terms

DEASP   Department of Employment Affairs and Social Protection

HRB   Health Research Board

IDS-TILDA   Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

NDA   National Disability Authority

NDIS   National Disability Inclusion Strategy 2017-2021

NIDD   National Intellectual Disability Database

UNCRPD   United Nations Convention on the Rights of Persons with Disabilities

Executive summary

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

1. 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

2. 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

3. 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

1. Introduction

1.1 Background to research

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 communities.

Over the past decade, a number of strategies and policies have been developed to promote social inclusion, including the National Disability Inclusion Strategy 2017-2021(Department of Justice and Equality, 2017), and policies aimed at driving social inclusion through, for example, community living, education, and employment. Most recently, Ireland has at last ratified the UNCRPD, a key pillar of which is the right to live independently and be included in the community.

Despite this, people with intellectual disabilities are more likely to experience social exclusion than the general population. They are more likely to experience poverty and deprivation than non-disabled people, and to live lives in segregated places. They are less likely to have romantic relationships. People with intellectual disabilities are also at a disadvantage in relation to education and employment outcomes compared to both other people with disabilities and non-disabled people.

However, in spite of this, there are also people with intellectual disabilities taking part in their communities and living ordinary lives all over Ireland. This research aimed to give an opportunity for people to hear their stories and know that it is possible for people with disabilities to live ordinary lives in the community.

1.1.1 '19 Stories of social inclusion' Australia

'19 stories of social inclusion' is the result of a collaboration between the Disability Research Initiative at the University of Melbourne, and Belonging Matters, a community based organisation.[1]

The project tells the stories of 19 Australians who are living 'social inclusion'. The stories capture the diverse ways that people with disabilities belong and contribute to their communities.

19 stories were chosen to highlight Article 19 of the UNCRPD, the right to live independently and be included in the community - a key underpinning of social inclusion for people with disabilities.

The authors of the report note that there tends to be a focus on what disability services can do to drive social inclusion. The risk with this is that disability services can be presented as an end in and of themselves rather than one of the many possible pathways to achieve an ordinary life (19 Stories of Social Inclusion, 2017).

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[1] 19 Stories of Social Inclusion *https://www.19stories.org*

The approach taken in the Australian project involves starting with the 'success stories' and working backwards to find out what people have done to get where they are and what has helped along the way.

The path to an ordinary life may include disability services but may not, and may also include mainstream community services, through self-directed support, through family leadership, circles of support, accessibility measures in mainstream services and organisations and so on (Dickinson, 2015).

1.2 Situating the research: The Irish context

Historically, the model used to support people with intellectual disabilities was one of 'wrap around' care – a person would live and access all services from the same provider on a campus setting.

There has been a shift in thinking informed by international human rights treaties and international and national evidence of the negative impacts of institutional service provision on the inclusion of people with intellectual disabilities. People with disabilities have been key to this shift and have often led this change, for example, through the independent living movement.

Policy in Ireland, for the most part, aims to provide personalised services so that people with intellectual disabilities can live autonomous, socially included lives in their communities. However, a significant implementation gap exists between policy and practice and in reality, much service provision is characterised by segregation and a 'one size fits all' approach.

This section contextualises the research by outlining some recent developments in policy and practice.

1.2.1 Spring 2018: Ireland ratifies the UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is an international agreement on the rights of persons with disabilities. It does not create new rights but instead requires states to ensure, protect and promote the rights of persons with disabilities.

Ireland ratified the UNCRPD in 2018 and it is now obliged to take measures to create an enabling environment and remove the barriers that may exist within society that prevent people with disabilities accessing their rights.

Many of the articles contained in the Convention are relevant to social inclusion. However, Article 19, which recognises the equal right of all persons with disabilities to live independently and be included in the community, is crucial.

In its General Comment on Article 19, the CRPD Committee (2017, p5) stated

"The right to be included in the community relates to the principle of full and effective inclusion and participation in society… It includes living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities to enable them be fully included and participate in all spheres of social life. These services can, among others, relate to housing, transport, shopping, education, employment, recreational activities and all other facilities and services offered to the public, including social media. The right also includes having access to all measures and events of political and cultural life in the community, among others public meetings, sports events, cultural and religious festivals and any other activity in which the person with disability wishes to participate".

The general principles of the Convention (Art. 3), particularly respect for the individual's inherent dignity, autonomy and independence (Art. 3 (a)), and the full and effective participation and inclusion in society (Art. 3 (c)), are the foundation of the right to live independently and be included in the community.

It is worth noting that Ireland has not ratified the Optional Protocol (OP), the mechanism that would have allowed people with disabilities to take complaints to the UNCRPD Committee itself, once all national avenues of complaint or appeal have been exhausted. Use of the Optional Protocol in the UK resulted in an inquiry by the UN into the impact of the government's policies on the rights of disabled people (Committee on the Rights of Persons with Disabilities, 2016). It resulted in widespread media coverage, bringing public attention to the rights infringements people with disabilities in the UK were experiencing.

Ireland has committed to ratifying the OP following Ireland's first report to the Committee.

1.2.2 Social inclusion in Irish policy

A desire to promote social inclusion has been a feature of disability policy in Ireland for some time. Policies tend to focus on social inclusion in specific areas with separate policies on, for example, community living, day services, education and employment.

In 2004, the government launched the National Disability Strategy (Government of Ireland, 2004), aiming to provide the basis for participation of people with disabilities in society. The key elements of the plan were:

- The Disability Act 2005. This set out a limited right to an assessment of need and corresponding service statement as well the law on the accessibility of public services
- The Citizen's Information Act 2007, which aimed to establish a personal advocacy service for people with disabilities.
- The Education for Persons with Special Educational Needs Act 2004

- Sectoral plans for six key government departments, setting out how they would act to deliver services for people with disabilities.

An implementation group was established in 2011 to provide leadership and whole of government collaboration on the implementation of its various elements and an implementation plan was published.

During this period, there were other developments such as the publication of the Value for Money and Policy Review of Disability Services (Department of Health, 2012), the Comprehensive Employment Strategy for People with Disabilities (Government of Ireland, 2015) and the Progressing Disability Services for Children and Young People programme (HSE, 2009).

In 2011, a strategy designed to implement deinstitutionalisation in Ireland was published. 'Time to Move on from Congregated Settings – A Strategy for Community Inclusion' focused specifically on 4,000 people in 72 centres which it called 'congregated settings' (defined as ten or more people sharing a single living unit or where the living arrangements are campus-based) (HSE, 2011).

Publication of the strategy was considered a milestone and established a national policy for a new approach to community living for persons with disabilities. The strategy was clear in recommending that all congregated settings would be closed within 7 years (by 2018). It is now clear that there have been significant delays in achieving the targets within this strategy. In 2018 at least 2,580 people with disabilities are still living in large, segregated institutions in Ireland.[2]

Almost 70% of people with intellectual disabilities live in home settings with parents or relatives, about 27% live in residential settings, many of which have institutionalised policies and procedures and only 4% live independently (NIDD, 2016).

'New Directions' was published in 2012 following a review of HSE day services for people with disabilities. It proposed an approach to day services based on the principles of person-centredness, community inclusion, active citizenship and high quality service provision.

A key feature of New Directions is individualised, outcome-focussed supports to allow adults using services to live a life of their choosing in accordance with their own wishes, needs and aspirations. In the context of future service development, it calls for supports which focus on the wider needs of the person and the contributions they can make. These supports embed the person in their natural support system and wider community, drawing on formal mainstream and disability services and supports in response to people's needs.

Despite the establishment of implementation groups and plans for many of the above policies, many actions committed to by the NDS remained outstanding and were

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[2] As of February 2017 - PQ 5585/17, HSE, 2017.

reiterated in the National Disability Inclusion Strategy 2017-2021 (Department of Justice and Equality, 2017).

Social inclusion is also a goal of mainstream policy. Strategies such as the National Action Plan for Social Inclusion aim to address poverty and social exclusion among the population overall. The NAP Social Inclusion 2007 – 2016 recognises that poverty and social exclusion is higher among persons with disabilities (Dept. of Social and Family Affairs, 2007).

The focus to date has been on supporting people with disabilities of working age into employment (Department of Social Protection, 2016). While this is much needed, concern has been expressed that the new version of the strategy, currently under development, focuses on activation and employment to the detriment of other aspects of social inclusion, such as ensuring an adequate income or access to services (Social Justice Ireland, 2018).

Social inclusion is also a key element of the 'Sustainable Development Goals' developed by the United Nations and adopted by Ireland (United Nations Development Programme, 2012). The UN developed the 17 goals in what it calls "an inclusive agenda". Many of the goals e.g. education, work & economic growth, industry and infrastructure, sustainable cities and peace & justice have inclusion at the heart of the goals. The prioritisation of inclusion within the goals demonstrates the importance of social inclusion in building sustainable communities.

1.2.3 Emergence of personal models of support
The Value for Money and Policy Review of Disability Services (Department of Health, 2012) outlined the importance of personalised or individualised supports to achieving self-determination and a fully included life in the community.

In 2016, the Taskforce on Personalised Budgets was established with the aim of making recommendations on a model of personal budgets for Ireland. The Taskforce made its report to the Minister of State for Disability Issues in July 2018.

Alongside these policy developments, there has been an emergence of organisations aimed at supporting people with disabilities to live self-directed lives in their communities (for example, Leap) as well as agencies offering broker-type services aimed at supporting people to manage a personal budget (such as Possibilities Plus and AT Network). In addition, some innovative service providers are creating pockets of personalised practice around the country (Muriosa and WALK among others).

1.2.4 Evidence of social exclusion of people with disabilities in Ireland
The previous sections have demonstrated the range of policy commitments relevant to social inclusion. However, available data clearly shows that many of the goals set out in policies have still to be implemented and there are still many people who have not had the opportunity to live a socially included life.

As stated in section 1.2.2, the majority of those people with intellectual disabilities that are in receipt of disability services are living in family homes, often with ageing parents. Only 4% are living independently, while the remainder live in group homes or larger institutions (Health Research Board, 2017).

Poverty is a barrier to inclusion. While there is no data available specifically on poverty among people with intellectual disabilities in Ireland, evidence from the Survey on Income and Living Conditions indicates that people with disabilities are more likely to experience poverty and deprivation than others. While 8% of the population experienced consistent poverty in 2016, 26% of the disabled population did so (SILC, 2016).

According to Census 2016, people with a disability are less likely to marry or have a family. Among those in the 40-44 age group, only 14% are married compared to 67% of the general population (Census, 2016).

People with intellectual disabilities are at a disadvantage also in relation to education and employment outcomes compared to other people with disabilities and people without disabilities. Having a job helps to combat social exclusion but only 21% of people with intellectual disabilities were working in 2016 (CSO, 2017).

At the same time, people with intellectual disabilities are often excluded from the life of the community through a lack of accessible information, inaccessible spaces, poor provision of and inaccessible public transport in many areas of the country, and a general lack of supports to enable social inclusion.

While this research aims to demonstrate positive stories of social inclusion, it is worth bearing in mind that those people with intellectual disabilities who are living fully or partly socially included lives, are often doing so in spite of continued social exclusion and the prevalence of multiple barriers to inclusion in society.

1.3 Structure of this report

- Chapter 2 looks at the literature on social inclusion in Ireland. It outlines issues with defining social inclusion and identifies a number of key themes which include relationships, productive activities, accommodation/living arrangements, supports, making choices and the role of personalised supports. It also provides a brief outline of the findings from the Australian 19 Stories project.

- Chapter 3 presents the methodology, describing the participatory research approach. This chapter describes the sampling strategy, recruitment of participants and data analysis.

- Chapter 4 sets out the results from the 19 interviews which includes a profile of the participants and their experiences of social inclusion. Thematic analysis of the

data is reported under three headings – the value of a socially included life, enablers of social inclusion and supporter activities and attributes.

- Chapter 5 discusses the results in the context of the literature on social inclusion and reflects on what policy and practice messages can be derived from the findings. A number of recommendations are made.

- Appendices include: Participants' profiles (Appendix 1), Promotional flyer (Appendix 2), Information on ethical approval and consent and information forms (Appendix 3), Interview schedules (Appendix 4) the Research Advisory Committee membership (Appendix 5) and interview code book (Appendix 6).

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. Taken together, they demonstrate what successful implementation of Article 19 of the UNCRPD looks like.

2. Literature Review

2.1 Introduction

A review was undertaken of peer reviewed academic literature and of reports from relevant Irish governmental and non-governmental agencies. The principal question guiding the review was: "What is the evidence of social inclusion of persons with intellectual disability in Ireland?"

The literature review focuses on a number of themes in relation to social inclusion, drawing from the international literature and with a focus on Irish research.

2.2 What is social inclusion

Researchers agree that social inclusion can mean many different things to different people. Bigby (2012), in her review of the literature says it is a "poorly understood" concept. People's experience of social inclusion is complicated and involves the person and the environment around us.

Cobigo et al (2012) suggest defining social inclusion as a series of interactions between the person and the environment that:

- Allow people to use services and goods
- Allow people to experience valued roles of their choosing
- Recognise the person as an able and trusted member of the community
- Allow a person to belong to a group in which there is reciprocity and support.

It represents more than mere physical presence, but "participation and engagement in mainstream society" (Cobigo et al, p76). The authors talk about the importance of social inclusion being practical, respectful of the choices of the individual and measuring success, not just by how much somebody does, but also by how it "felt" to the individual.

Cobigo et al build on important work done by a number of other researchers such as Hall (2009) and Abbott and McConkey (2006), arguing the importance of ensuring that practices aimed at social inclusion are meaningful for people with intellectual disabilities.

2.3 Evidence of Social Inclusion

Martin and Cobigo (2011) propose that social inclusion can be usefully considered under five headings:

- Relationships
- Leisure
- Productive activities
- Accommodation/ living arrangements and

- Informal supports.

Evidence on each of these elements of social inclusion is briefly presented below.

2.3.1 Relationships

Significant reciprocal relationships are identified by persons with intellectual disabilities as very important (Garcia Iriarte et al., 2014). McVilly et al (2006) report that value was placed on connecting with others with similar life experiences or experience of disability. However, many people with intellectual disabilities don't have close friends and very few have romantic relationships (Burke, McCallion and McCarron, 2014; Emerson and McVilly 2004).

Irish research with older people with intellectual disabilities raises concerns about social isolation. Findings from the IDS TILDA project indicate that older people with intellectual disabilities tend to have diminishing contact with family members as they age (Burke, McCallion and McCarron, 2014). In addition, the study found that among people with an intellectual disability over 55, 99% were unmarried (McCarron et al., 2011).

Persons with intellectual disabilities identify that they would welcome guidance in developing relationships and practical support in sustaining them (McConkey et al., 2007) and Irish research has shown that personalised supports can help people to have more contact with friends and family (Garcia Iriarte et al., 2016).

2.3.2 Leisure

Being involved in leisure activities is identified as important by people with intellectual disabilities (Garcia Iriarte et al., 2014). However, few are involved in mainstream clubs or activities (Bigby, 2011).

Abbot and McConkey (2006, p280) undertook qualitative work with sixty-eight people with intellectual disabilities, exploring what they believed to be the barriers to social inclusion. This research records that "There aren't enough activities for us to get involved in". Furthermore, the IDS-TILDA study finds that among older people, 70% were dependent on paid staff for participation in social/leisure activities (Burke, McCallion & McCarron, 2014, p281).

Attending social or leisure activities isn't enough to ensure social inclusion. Dutch research tells us that even when people with intellectual disabilities attend mainstream leisure activities they may have very little interaction with others without a disability (Dusseljee et al., 2011). The literature indicates that people with disabilities need support to translate an engagement with mainstream leisure activities into an experience of social inclusion.

2.3.3 Accommodation/Living arrangements

Of the 27,863 people registered with the National Intellectual Disability Database (NIDD) in 2016, only 4% were living independent or semi-independent lives in the community. Most (69%) lived at home with family members or relatives. Others (27%) live in residential settings, with around 2,580 of these people still living in large institutions.[3]

Research findings agree that people living in community settings have larger and more active social networks and those living independent or semi-independent lives have the most active social networks (Duggan and Linehan, 2013).

However, much research points out that living in the community is not enough. People need to be supported to make connections and work needs to be done with communities and mainstream services to include people (McConkey et al., 2017).

Garcia Iriarte et al (2016) identify that there is a need for further training for staff in order that they may be able to facilitate community inclusion. The role of paid workers and parents needs to shift from "carer" to supporter, trainer or community worker in order to facilitate community inclusion, and this will require consideration of the competencies for staff in these roles.

2.3.4 Productive Activities – Work and Education

Access to paid employment is identified as a priority in studies with people with intellectual disabilities (Garcia Iriarte et al., 2014).[4] However, only 17% of persons with intellectual disabilities were working according to the most recent Census. This compares with 33% of all persons with disabilities and 66% of the general population (Census, 2016).

Among those registered with the National Intellectual Disability Database, rates of employment are even lower. NIDD data shows that only 158 of the 27,863 people registered in 2016 were in open employment with a further 662 in supported employment and 2,525 in sheltered workshops.[5] Finally, the majority of those who are in work are working part time, whether by choice or necessity.

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[3] The limitations of the NIDD should be noted in that it provides a picture of the living arrangements of those persons registered but is an under estimation of the numbers of people with an intellectual disability when compared to the Census.

[4] These are the findings of an Irish survey of people with intellectual disabilities conducted in 2009. In the study, a total of 168 people with intellectual disabilities from Northern Ireland and the Republic of Ireland participated in 23 focus groups

[5] The research team understand that the HSE is progressing an accurate count of persons in a variety of sheltered and supported employment situations, and these figures may therefore by subject to some revision in the future.

Studies describe the involvement of people with intellectual disabilities in unpaid work, such as volunteering roles and unpaid caring roles. An Australian study of encounters between persons with and without disabilities, records important volunteering roles for people with intellectual disabilities and suggests that volunteering allows people from many different parts of society to work together and increases the chances of social interaction (Wiesel and Bigby, 2016).

There is anecdotal evidence in Ireland that persons with intellectual disabilities volunteer in a great variety of enterprises but this remains broadly undocumented. In addition to volunteering there are indications that people are acting in unpaid caring roles. Census data tells us 1245 people with an intellectual disability were looking after home/family in 2016 (Census, 2016). A discussion paper by the Care Alliance suggests that there is a growing number of people with intellectual disabilities undertaking daily care tasks such as cooking, personal assistance and companionship for family members (Care Alliance, 2015).

Inclusion in education remains a challenge in Ireland. Levels of education among persons with intellectual disability remain low, although are improving slowly: 63% of persons with an intellectual disability in Ireland have not gone on to second level education (Watson and Nolan, 2011). However, access to education has been changing. Over the last 20 years the numbers of pupils with intellectual disabilities attending mainstream schools has been steadily growing (McConkey et al., 2015).

Inclusion at secondary school level has been slower than at primary level and has recently slowed down (ibid). Further contemporary reviews reveal that barriers remain to mainstream schooling but that quality teaching and supportive attitudes alongside genuine partnership with parents are key to good inclusive education (Day and Prunty, 2015).

It is difficult to get information on the numbers of persons with intellectual disability in higher education or further education (Duggan and Byrne, 2013; WALK 2015.)

The reports recognise that there are significant barriers accessing mainstream training and education. The NIDD reports reveal that 4% of those over 18 (841 people) were in education in 2016 (71 in third level education and 278 attend vocational training). With most young Irish people progressing to further education of some sort this acts as a major point of exclusion and segregation for persons with intellectual disability.[6]

Duggan and Byrne (2013) review provision of post school education and training for persons with disabilities. Their findings conclude that education outside the HEAs have fewer structured programmes to provide for persons with disabilities. They recognise that like all organisations, educational providers, are subject to broader

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[6] While the NIDD provides information on the number of people over 18, it does not provide data on the number of people between, for example, 18-25 which might provide a more accurate picture of involvement of young people with intellectual disabilities in further education.

legislative instruments, such as those that prohibit discrimination or mandate equal treatment. However, the further education sector "does not have the benefits of measures such as the HEA disability access programme and does not quantify the proportion of students with special educational needs" (p161). It is noted that they do often provide extensive programmes of support but not on a national basis and structured manner. Indeed, Duggan and Byrne go on to say "that even in situations where enabling legislation, regulations and policies do exist, actual practice can fall far short of the legislative prescription" (p161).

Adult education and continuing education programmes often play an important role in overcoming exclusion for groups outside of mainstream education. However, here again, Duggan and Byrne find a dearth of policies and practice to include persons with disabilities.[7] WALK, a Dublin based service, adds weight to these findings in their report (WALK, 2015).

2.3.5 Informal Supports

Informal support is that provided by family, friends and other people in a person's social network. Informal supports provide the network to enable inclusion in community life. Though many people with intellectual disabilities are living with family members, outside of parents and siblings, persons with intellectual disabilities have a smaller number of informal supports such as partners, children, friends, acquaintances, and local community connections.

Duggan and Linehan (2013) note in their review of the literature that the further persons with disabilities are from community settings, the less likely they are to have informal networks of support such as neighbours, local shop workers, church groupings and so on.

In addition, the IDS-TILDA study reminds us that older people with intellectual disabilities lack key providers of informal support in later life, namely a spouse or children (Bigby, 2010).

2.4 Additional Themes from the Literature

Three additional themes identified in the literature are outlined here.

2.4.1 Making Choices – Self determination

Literature on living arrangements and access to education identifies the importance of self-determination in the achievement of a socially included life (Duggan and Byrne, 2013). Research reports point to the need for supporters to assist persons with intellectual disabilities to acquire the skills and practice at making choices and thereby gaining control (McConkey et al 2013; Garcia Iriarte et al 2016).

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[7] It should be noted that both the Education Training Boards and Solas have been established since this report was published.

Quinn (2009) draws attention to the importance of legislative change in Ireland to support this. The Assisted Decision Making (Capacity) Act 2015 is vital in supporting a self-determined life. A principle underpinning the Act is that decisions should no longer be made in the perceived best interests of a person but rather, the person should be supported to make decisions that reflect their own needs and wishes.

2.4.2 The role of personalised support in social inclusion

The role of personal supports in achieving social inclusion was examined in Irish studies. McConkey et al (2013) propose an understanding of personal or individual supports as those which:

- Address the unique needs of the person, focusing on their strengths and abilities
- Are chosen by the person
- Are delivered in the community, fostering inclusion and participation

This research with over 100 persons with intellectual disabilities, found that personalised supports enabled "self-determination" and the emergence of a sense of "identity" (Ibid p120).

Wynne and McAnaney (2014) report on a study with young people accessing mainstream work, education and training. The young people with intellectual disabilities found the personalised service supported "citizenship, employability, social inclusion and overall quality of life".

Reports by government, such as the Value for Money and Policy review of Disability Services (Department of Health, 2012) recommend goals of inclusion and choice be made happen through use of individualised or personalised supports. The use of individualised funding to support this is being expanded and explored in many different countries, including Ireland, with the Task Force on Personalised Budgets recently submitting their report and recommendations to government (Department of Health, 2018).

Some argue that it is important to consider personal budgets or individualised funding in order to move away from "services" and place people with disabilities in mainstream communities (Power, 2013).

2.4.3 Exclusion

The literature reminds us that there are many groups who are excluded in society. Persons with intellectual disability are more likely to be members of some of these group such as those living in poverty (SILC, 2016).

In addition, like every other citizen of the state, persons with intellectual disabilities, are also members of other groups that experience exclusion such as the elderly,

those experiencing mental health issues, the LGBTQI+ community, women, migrants or ethnic minorities.

The interconnected nature of various aspects of a person's identity impacts on their experience of social inclusion and people can experience multiple exclusions.

2.5 Social Inclusion and the '19 Stories' project, Australia

The '19 Stories of Social Inclusion' project carried out in Australia provided the inspiration for this project as well as a source of comparative data. The project used an appreciative enquiry approach in that it focused on capturing stories of people's lives, focusing on their successes. 19 stories were chosen as a way of highlighting what Article 19 of the UNCRPD, living in the community, means in practice.

Common themes were identified throughout people's stories, including: valuing and having a vision for a good life, focusing on unique identity rather than disability, being present in ordinary places rather than segregated or 'special' ones, having a range of reciprocal relationships, having opportunities to contribute and the supports to do so and having a sense of belonging (19 Stories of Social Inclusion, 2017).

In a review of the literature carried out as part of the 19 Stories project, Gooding, Anderson and McVilly (2017) argue that, for the most part, social inclusion remains a policy aspiration rather than a reality. The authors note an emphasis on deinstitutionalisation in the literature along with general agreement that this has not led to more accessible societies for people with intellectual disabilities. They caution against the creation of specialist spaces in community settings or 'care in the community' that can give rise to the 'illusion of inclusion' when large institutions are closed (Welsby and Horsfall, 2011 in Gooding, Anderson and McVilly, 2017).

2.6 Critique of literature

While there has been some research carried out in Ireland on social inclusion among people with intellectual disabilities, there are gaps in the evidence base on certain issues, including the involvement of people with disabilities in unpaid work and the numbers of people with an intellectual disability in higher or further education as well as their experience of such.

The literature also points to the absence of positive stories of social inclusion in the public domain in Ireland.

2.7 Summary

The principal question posed in this review was "What is the evidence of social inclusion of persons with intellectual disability in Ireland?". The discussion explored

evidence under five themes – relationships, leisure, productive activities, accommodation/living arrangements, and informal supports.

The following points emerged from this review:

- Few people have close friends and very few have romantic relationships Personalised supports can help people develop and sustain relationships
- While people are involved in leisure activities these are often not mainstream and even if they were people need more support to experience social inclusion
- Only 17% of people are working, the majority part time. Anecdotal evidence of volunteerism is undocumented
- Levels of education are low but access to mainstream schools is growing Significant barriers remain in accessing mainstream training and education
- The more distant people are from community settings the fewer informal supports they will have
- People need to acquire skills in making choices and gaining control
- Personalised supports enable self-determination, citizenship and employability.

3. Methodology

3.1 Introduction

This chapter presents the methodology, describing the participatory research approach. The governance of the research is outlined as well as the sampling strategy and the recruitment of participants. Data collection methods are presented, namely semi-structured interviews conducted with 19 participants by one consistent researcher along with two co-researchers with lived experience of intellectual disability who each did half of the interviews.

3.2 Research aims and objectives

Taking the '19 Stories of Social Inclusion' project carried out in Australia as its inspiration, this research adapts the 19 stories project to Ireland.

The research question for the project is: What experiences of social inclusion do people with intellectual disabilities have in Ireland?

The aims of the study are:

- To identity positive examples of people being included in the community through their relationships, work or living situation or other type of social participation
- To uncover the steps taken to achieve or contribute to social inclusion and identify the supporting and enabling factors
- To develop key policy messages that can inform the implementation of policy and practice on the social inclusion of people with intellectual disabilities
- To co-produce a piece of work with researchers with intellectual disabilities
- To present the information in accessible formats, in line with Articles 9 (Accessibility) and 31 (Statistics and data collection) of the UNCRPD.

3.3 Inclusive research

This project was conducted through a participatory research approach, also known as inclusive research, in which people with intellectual disabilities, who are experts by experience, were involved in all stages of the research process (Walmsley and Johnson, 2003).

Since the 1990's there has been a movement to challenge the power relationships within disability research. Oliver (1992) and Zarb (1992) proposed models of "emancipatory" research in which persons with disabilities are in control of all aspects of the research. Since this time, approaches to disability research that include persons with disabilities as part of the research team have become more prevalent (Priestley et al 2010). Garcia Iriarte et al (2014, p149) set out three sets of reasons for this. They propose:

- Epistemological reasons – that is in order to provide an insider perspective on the issue under research
- Political reasons– to ensure that people with disabilities are in control of that which is about them
- And action-orientated reasons – to effect social and political change.

This research has been undertaken not as emancipatory research as the research proposal was developed and agreed prior to the engagement of the co-researchers with intellectual disabilities. However, it is considered inclusive research in that the two co-researchers with intellectual disabilities were members of the research team.

All three researchers worked together in developing and piloting the interview schedules; co-interviewed the participants; reviewed and revised the process; identified emerging themes and finally reviewed the analysis prior to report writing.

Finally, a recent review of inclusive research reports that although experts by experience find working as researchers valuable, they are frustrated by the lack of change resulting from research findings (Garcia Iriarte et al. 2014). The importance of dissemination of the participants' stories by means of easily accessible videos was identified and articulated with strength by the experts by experience in the research team. The findings from research carried out with participants with disabilities is often not accessible to them. This makes it more difficult for them to use the evidence, for example, to campaign for change. By making the stories available in accessible formats (videos, short narratives and photos), the project promotes the use of evidence on social inclusion by people with intellectual disabilities and families. In this way, people with intellectual disabilities and families may be enabled to contribute to bringing about greater levels of social inclusion.

In addition to the co-researcher role of two people with intellectual disabilities in the project, further input from two other people with intellectual disabilities was provided at the Research Advisory Committee, as described in the next section.

3.4 Research governance

A Research Advisory Committee (RAC) was formed to provide advice on what social inclusion means for people with intellectual disabilities in an Irish context, to support sample recruitment and to help with the identification of policy messages emerging from the analysis of the stories.

The RAC included a range of people from the different geographical regions in Ireland, professionals, family members and people with intellectual disabilities. In addition, the project also benefitted from the support of an international expert on disability and social inclusion, Emeritus Professor Roy McConkey, who acted as an advisor to the project team.

An easy to read project brief was created to recruit people to the RAC and an important aspect of meetings was ensuring an accessible and inclusive process. Agendas and other information was produced in easy to read format and group discussions and preparation before the meetings allowed people with intellectual disabilities to participate in all aspects of the meetings.

Two meetings of the RAC were held. The first focused on a presentation of the literature review, defining social inclusion and clarifying the criteria for the selection of study participants. The second focused on the findings from the research and the messages for policy arising from the findings.

3.4.1 Ethics
The project received ethical approval from the ethics board of the School of Social Work and Social Policy at Trinity College Dublin. More details, including copies of information and consent forms can be found in Appendix 3.

3.5 Sampling
In qualitative studies of this nature the numbers do not need to be large to collect adequate data as it is anticipated that they will provide "information rich" data to analyse (Patton, 2002, Braun and Clarke, 2013). Hence, a purposive sampling strategy was employed to identify nineteen participants. In purposive sampling, each participant is chosen for their ability to provide the most "relevant, comprehensive and rich information" about the research question (Marshall and Rossman, 2011).

3.5.1 Criteria for selecting participants
Inclusion criteria were adapted from the Australian '19 Stories' project and refined following the first meeting with the Research Advisory Committee.

Criteria for inclusion in the study were advertised on the promotional flyer used to inform and recruit participants (See Appendix 2) and included that participants were taking part in mainstream work, education or community life, over 16 and living in Ireland for more than 2 years. Mainstream was defined by the project team as meaning that something is open to all persons, not just people with a disability.

Male and female participants from diverse locations, a range of ages, varied experiences of social inclusion and finally varied support needs were sought. As a qualitative study the research did not seek this range of participants to generalise from their experiences but rather, as they would be considered good sources of information and thereby bring a breadth of perspectives and experience to the study (Braun and Clarke 2013). A sampling frame was developed to assist with ensuring a varied sample.

During sampling, particular attention was paid to ensuring that participants were diverse in terms of the kinds of supports accessed and required.

The study sought to avoid categorising people according to perceived levels of intellectual disability (i.e. mild, moderate, severe, profound). This was done for a variety of reasons:

- Firstly, out of respect for the dignity of participants

- Secondly, in recognition that needs change over time and people's needs can be higher in some situations or periods of the lifecycle than others. For example, in one study carried out in Australia, some participants had been labelled as 'high support' prior to the implementation of individualised supported living arrangements but due to the supportive nature of the arrangement, they developed additional skills (Cocks & Boaden, 2009)

- Lastly, as this research focused on what people had achieved, their strengths and their individuality, it was not appropriate to investigate thoroughly what were their support needs. Some information on support needs was gathered through self-report by participants.

In addition, the research sought to include people with complex support needs in the sample. People with complex support needs are generally seen to require intensive and/or ongoing support. Rankin & Regan (2004, cited in Collings, Dew and Dowse, 2017, p142) refer to complex needs as having both "breadth and depth in the sense that they span multiple domains and/or involve high levels of need in one or more areas".

3.6 Recruitment

A recruitment strategy was agreed by the research team:

- A promotional flyer was produced and a webpage for the project was posted on Inclusion Ireland's website (see Appendix 2)

- Easy to read consent forms and information forms for participants, participants' parents/legal guardian (for participants under 18), supporters and gatekeepers were produced (see Appendix 3 for sample consent form).

These tools were used when spreading the word about the project and for recruiting participants.

Recruitment was initially through the contacts at the RAC and through the networks of TCD and Inclusion Ireland and of the Research Assistants. Subsequently a wide range of voluntary, statutory and community organisations were contacted by email. Mainstream community websites such as Activelink were also employed to disseminate information on the project and information on the project was promoted through the Inclusion Ireland newsletter.

Potential participants were advised to contact Inclusion Ireland initially and that the Research Assistant would return their call as soon as possible. The Research Assistant using a template, had a first introductory phone call with potential participants, assessing if they met the criteria for the project and, if so, discussing possible date/time/location for an interview. Furthermore, potential support needs of participants in order to participate in the interviews were discussed.

Final selection of participants was done in consultation with the research team and with reference to the sampling framework. Once selected, participants were contacted once again, reminded of what the process entailed and of their right to reconsider their involvement at any time. A period of seven days was provided for participants to review their involvement with the project. If appropriate, easy to read consent forms were sent to participants in advance of interviews. Those people who were not selected were contacted by the Research Assistant to thank them for their application and to explain that although their story was important, we were not able to include them as we were seeking a diversity of experiences.

3.7 Data collection

Data was collected by means of semi-structured interviews. An interview schedule guided the conversation and enabled the interviewers to maintain flexibility while also covering the agreed topic areas.

Participants most often had an experience of one or two discrete areas of social inclusion such as working or education. This was established by means of an initial telephone call to the participant or the participant and supporter. Hence, a range of different interview schedules were prepared each of which focused on one such area of social inclusion. Each schedule followed the same format and had three sections which were common to all (See Appendix 4 for interview schedules).

The schedule was developed with "main questions" to introduce the topics, "follow up questions" to seek details and "probes" to encourage participants to provide depth and detail (Rubin and Rubin, 2012, p132). The interview was piloted with co-researchers and some small changes were made. The pilot identified that it could be challenging for some participants to answer the questions without time to prepare. To meet this challenge, an easy to read version of the schedule was developed and sent to those who requested it.

Nineteen participants were each interviewed by two of the three researchers. One researcher remained consistent through all the interviews and two co-researchers with lived experience of intellectual disability did half of the interviews each. All interviews were recorded. Interviews took place in locations chosen by participants; 12 in their own homes., 2 in cafes and the remaining 5 in meeting rooms.

Two participants, a married couple, were interviewed together. Two participants required two visits. This facilitated the participant to familiarise themselves with the

researchers and to conduct the interview at a pace that suited them. The interviews ranged from 45 minutes to just under 2 hours.

3.7.1 Support for interviewees

Twelve interviews were conducted with supporters present. This choice was left to participants. In 9 of these, interview support was minimal. Supporters' roles ranged from a very occasional prompt (n=5) when the participant had forgotten information and requested assistance to a more active role in facilitating a participant to understand a question (n=4) or to prepare their answer. Sometimes supporters, with the consent of the participant, provided additional information. In a further interview, supporters facilitated communication between researchers and participant. In two interviews, where participants did not communicate verbally, supporters spoke for participants. Interviewers addressed their questions to participants in all interviews apart from these last two. After establishing a connection with both participants, it became clear that although they remained present for the interviews, they preferred questions to be directed to supporters.

3.7.2 Reflections on the interview process

Face to face interviews were undertaken for this research as they are typically viewed as the ideal way to collect interview data (Braun and Clarke, 2013). Qualitative interviews are individualistic, and every interviewer or interviewing team has their own style (Rubin and Rubin, 2012). While this is not regarded as a flaw, its value is enhanced by adopting a self-reflective approach.

Each interview in this research was unique, none following questions in the same order and each bringing a varying level of depth to different aspects of their experiences of social inclusion. The semi-structured interview format, informal as it was, did not yield good data from some of participants. In these interviews the researchers moved to a less structured format. The researchers sought to chat about whatever interested the participant and shared personal anecdotes to create the conditions of an ordinary conversation. This often 'unlocked' participants, perhaps deconstructing the perceived power of the researchers and reducing concerns about getting answers "right". Indeed, frequently the researchers were asked by participants whether they were "doing all right". This flexibility was important in order to generate the data sought (Rubin and Rubin, 2012). To assure rigour in the data collection the research team reflected on the process of interviews after each one.

Working effectively as a pair of researchers also required reflection and refinement. The researchers had never worked together before. Therefore, in early interviews clearly designated roles were agreed and allocated to each. The researcher with the most research and interview experience took a lead role but as skills and confidence developed greater flexibility emerged in the process. Consistent reflection on the process enabled learning about interviewing but also more intuitive practices developed between researchers.

3.8 Data Analysis

Data analysis started from the early stages of data collection. All interviews were transcribed. Memos and post interview notes were also made and stored along with the transcribed data.

To analyse the data in this study a thematic analysis was undertaken. The process of data analysis was broadly guided by the 6-phase process developed by Braun and Clarke (2013). Following the first stage, transcription, the lead researcher familiarised herself with the transcripts by reading and re-reading them and taking note of items of potential interest. At this point the interviewer proceeded to code the first five interviews. Code books were made for these interviews and then after the fifth interview were amalgamated into one. This code book was used when coding the subsequent 14 interviews and added to as the analysis progressed.

Three overarching themes were identified and sub-themes emerged. The researcher also made use of post-interview notes in the generation of themes from the code book. A final re-reading of the data with the revised codebook of themes and subthemes was undertaken.

Although analysis of the transcripts was the work of the researcher with most research experience, the two researchers who were experts by experience contributed to the data analysis in two significant ways. As Richards (2015) suggests, qualitative data analysis and collection is not linear but "looping" in nature. So, the analysis started immediately with post interviews notes and discussions. In addition, when the code book was developed it was presented to the experts by experience to review. In this way each theme was discussed and considered, and refinements suggested. Finally, themes were checked with members of the team from academic and policy backgrounds.

3.8.1 Developing messages for policy and practice

A key aim of the project was to determine what participants' stories could tell us about policy and practice.

A multi-layered approach was taken to the development of messages for policy and practice. This involved reflection by the Research Advisory Committee (RAC) on the key findings emerging from the research and development of key messages by the research team. Advisor to the project, Emeritus Professor Roy McConkey also reviewed the findings and development of key messages as well as Inclusion Ireland staff working in the areas of policy, information, communications and community engagement.

3.9 Limitations of methodology

In this study, data was collected from a small, purposively selected sample of people with intellectual disability who had achieved some measure of social inclusion in their lives. The study cannot be said to be representative of persons with intellectual disabilities and their experiences of social inclusion. The small sample and the bias towards persons who had positive experiences of social inclusion reinforce the inherent unrepresentative nature of small scale qualitative research.

However, in qualitative research one is searching for insight and meaning (Braun and Clarke, 2013). By asking people with intellectual disabilities themselves, rather than supporters, about this experience of social inclusion one gained insight into the meaning of the experience and what was valuable to them in enabling it to happen. It is possible to argue that this approach lost out on some of the details about practical steps taken to achieve same.

In two interviews, data was collected directly from supporters as the person with an intellectual disability did not use words to communicate. Although this enabled the study to include persons who communicate by nonverbal means, it inevitably led to a different quality of insight on the experience of social inclusion during these interviews. A longer period of engagement with some participants may have addressed some of the communication issues.

In addition, it was not possible within the scope of this project to carry out repeat interviews with all participants. For some participants, repeat interviews or perhaps focus groups could have explored identified themes more fully and what participants thought would overcome some of the barriers.

3.10 Summary
- The aim of the research was to identify people with intellectual disabilities living socially included lives in their communities and to find out what has helped them along the way
- The study used an inclusive research design in that people with intellectual disabilities were co-researchers and people with intellectual disabilities were part of the Research Advisory Committee
- Interviews were conducted with 19 participants and data was analysed using thematic analysis.

4. Results

"Go do it because it is good out there". Tom

4.1 Introduction

In this chapter the results of the research will be reported. Section 4.2 will provide a profile of the participants and section 4.3 provides a profile of the experiences of social inclusion they reported. Together, these two sections provide the context for the reporting of the thematic analysis in the following sections.

The later sections present the results of the thematic analysis of the data collected. This is reported under three broad headings:

- The value of a socially included life
- Enablers of social inclusion
- Supporter activities and attributes

As this research aimed to capture positive stories of social inclusion and to uncover the steps taken to arrive here, those activities and qualities which enabled social inclusion are reported on in this main body of the results and not the barriers or challenges. However, as it may provide a useful context to the results, a short summary of the challenges which people experienced is provided at the end of the chapter (Section 4. 7 - Social inclusion as an ongoing journey).

4.2 Participant profile

4.2.1 Age, gender and geographical spread

Nineteen participants were interviewed with a spread of ages, although mainly clustered in the 25-55 age groupings (See Chart 4.1)

Chart 4.1 Ages of Participants

16-24: 2
25-39: 8
40-54: 6
55 +: 3
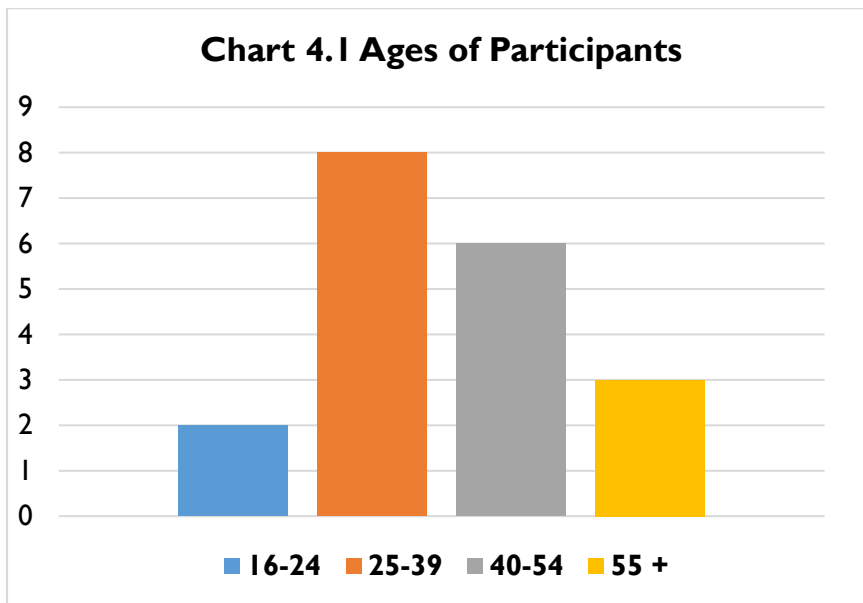
Nine men and 10 women took part in the research from a wide geographical spread throughout Ireland.

Chart 4.2 Gender of participants

Male
Female
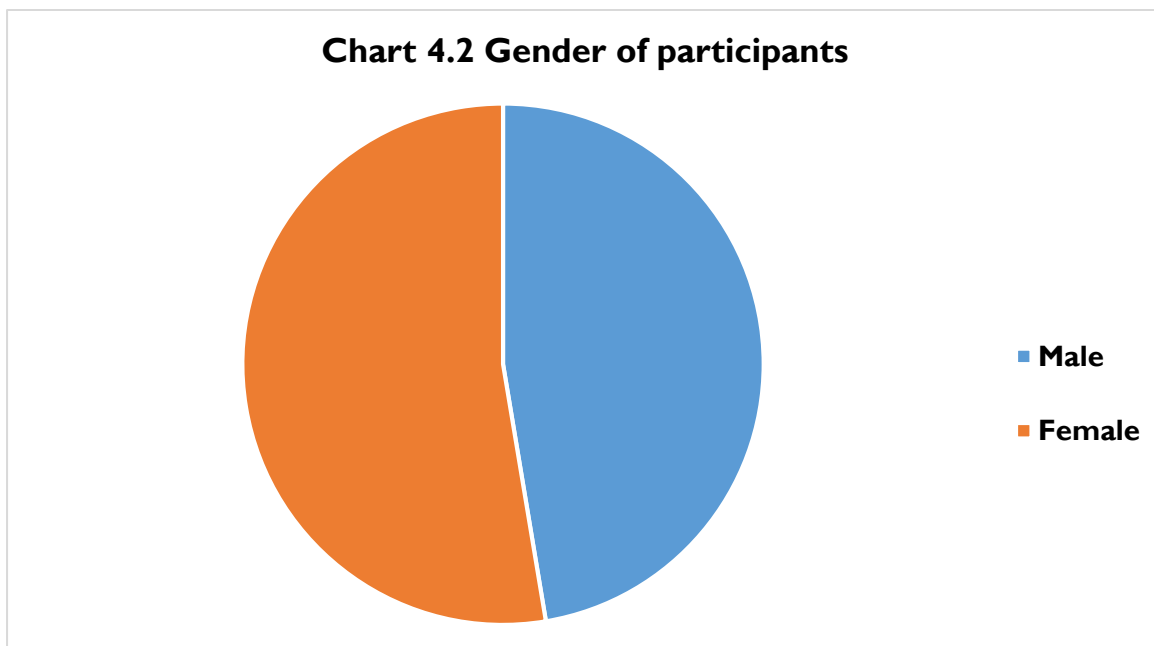
A diverse sample was achieved with 6 living in villages or rural areas, 5 in towns and the remaining 8 in cities and their suburbs.

Chart 4.3 Where participants lived

- Villages/Rural
- Towns
- Cities/Suburbs
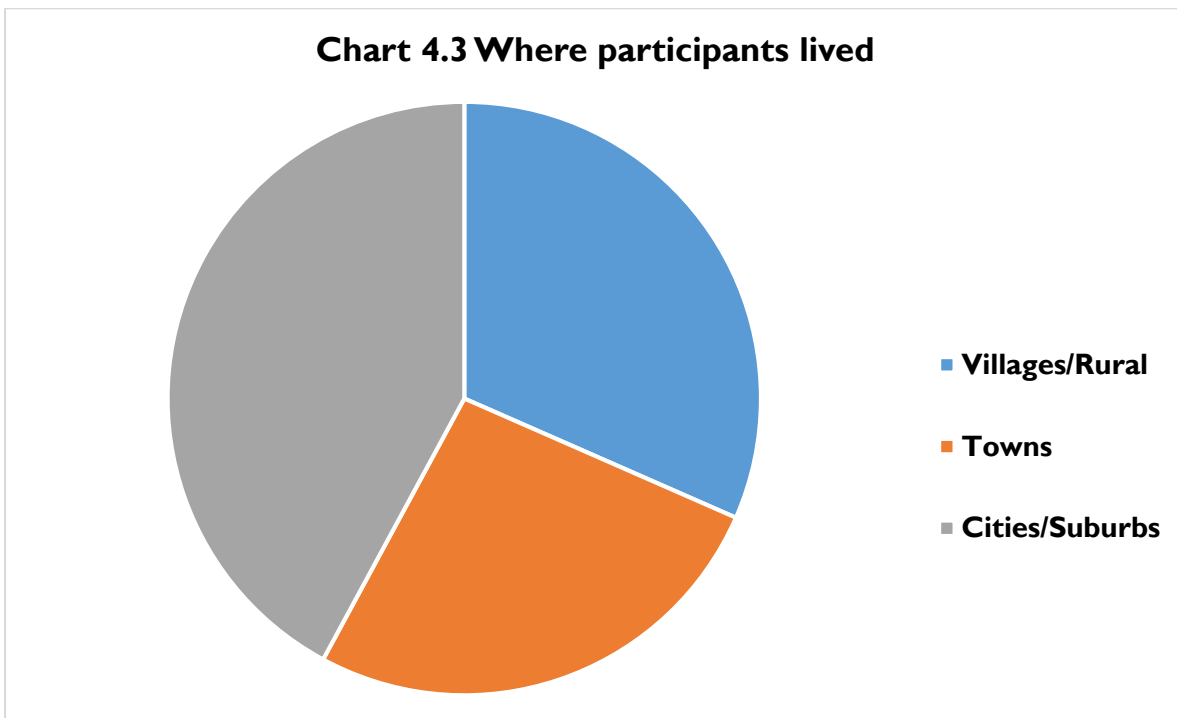
4.2.2 Disabilities and support needs

Participants were a diverse group and accessed a range of supports across various aspects of their lives and to varying intensities.

As stated in the previous chapter, participants were not grouped according to levels of intellectual disability. Most people identified as experiencing multiple disabilities:

- All participants identified as having an intellectual disability
- Ten identified that they had additional health conditions or physical disabilities
- Three disclosed that they had mental health challenges
- One person advised us that he had autism
- Three people used motorised wheelchairs.

Support needs were self-reported by the participant:

- Seventeen participants were receiving some support from disability services. This ranged from intermittent contact to 24-hour support
- Four people identified that they needed a supporter with them 24 hours a day
- One of those not in receipt of support from a disability service had a personal budget
- One participant received support solely through mainstream services.[8]

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[8] Mainstream is defined for the purposes of this project as something that is open to all persons, not just people with a disability.

Participants reported accessing supports around practicalities. This ranged from daily support for home living or self-care to intermittent support for form filling, financial matters and decision making. Participants also reported accessing support on emotional and psychological matters. A number of participants required support to take part in work, education and community activities.

Participants varied in what supports they needed and in their intensity. As outlined in Section 3.5.2, complex needs can be understood as involving breadth and depth, in that a person has support needs across multiple areas and/or high levels of need in one or more areas (Rankin and Regan 2004).

While it is recognised that support needs change across the lifecycle and can be higher in some situations than others, four participants could be considered to have complex needs at the time of the study, using this definition. All four receive 24-hour support.

4.3 Profile of Experiences of Social Inclusion

To report on social inclusion is to report on something complex and interwoven. It is not simply about presence at community activities but about belonging and contributing. However, this section attempts to outline the different aspects of participants' lives that, taken together, have helped or contributed to a socially included life and provides a context for the subjective experiences of social inclusion described by participants in the following sections.

4.3.1 Involvement in work

Twelve of the nineteen participants were working. One participant had retired. People with a range of support needs were at work. Three participants had specialist support workers attend work alongside them. Two of these were provided through services and one was a personal assistant paid for through a personal budget.

Of the 12 participants at work, ten were employees. Two worked in shops, four in the hotel/catering trade, and the others in banking, a local authority, an agricultural firm and childcare. All were paid and most (n=7) identified that they had become permanent after a period of work experience in that company. Some (n=5) had been working in the same company for over 10 years. The hours people worked varied from two sessions of 1 hour (n=1) to 20 hours a week (n=5). None of the participants worked more than 20 hours a week.

One participant was self-employed. He and his support workers identified work they could do together to generate an income and contribute. These included some recycling work and woodwork.

The final working participant worked 20 hours a week in an unpaid capacity in an independent disability service. Although unpaid, there were aspects of internship to

this situation in that the participant received training and support in developing skills in her chosen career.

4.3.2 Where participants lived

Participants lived in a variety of settings. Ten of the nineteen participants identified that they were living in independent settings, either with or without formal support.

Four of the ten were renting from the local authority with a fifth about to sign with their local authority. One was a home owner. Three more rented from specialist services, one in sheltered housing for the elderly and the others in disability services. The ownership of the final property is not known to the researchers.

Participants living in their own homes received varying amounts of support to do so. Two participants received 24-hour support. The remaining eight participants varied greatly in their support needs from broadly physical and practical to emotional support and from intermittent to regular. Support was provided by a mix of formal and informal supporters.

The remainder of participants lived with family (n=7) or in community or group homes (n=2). Those who lived with family were the younger participants in the study.

4.3.3 Involvement in education

Three participants were engaged in mainstream accredited education. Two were in fulltime programmes in third level institutes with one having received level 6 accreditation in her chosen area of study. The third person was studying in the evening at a local college. Three additional participants were being supported to apply to mainstream courses but had not completed this process.

In addition to the above, several participants (n=10) were involved in adult education and skills enhancement. Half of the participants were taking part in specialist disability specific courses often located in mainstream colleges. For example, participants had completed courses such as relationship skills, IT, gardening, cookery, interviewing skills and literacy. Often, these took place in a local Institute of Technology or at an Education and Training Board centre. While these courses were for disabled people only, participants reported that such programmes provided them with skills and knowledge for participation in socially inclusive activities. These participants were involved in other mainstream aspects of social inclusion, such as living in the community and working in mainstream jobs.

4.3.4 Inclusion in mainstream community activities

Nine participants identified that they participated in mainstream community activities:

Two participants were active members of local knitting groups

- One attended a weight management club
- Two were members of bands or attended regular music sessions and two were member of choirs
- Two took part in the local tidy towns activities
- One participant attended Toastmasters, a group that supports people engage in public speaking

In addition, several participants volunteered with local groups where volunteering is part of the ethos. Some on a regular basis such as with the GAA club (n=1), a local social club (n=1) and graveyard maintenance (n=1). Others with time limited projects such as summer projects for local children (n=1) or an annual arts festival (n=1). One participant has given regular time in the past to youth groups.

4.3.5 Relationships

The above sections describe the discrete "experiences" that people were involved in. More nuanced understandings of social inclusion were also apparent, one of which was the experience of maintenance and creation of relationships.

Some (n=5) participants reported being in intimate or romantic relationships. Two participants in the study were married to each other. The married couple lived together and had been married 3 years. Three other participants identified that they were in long term relationships.

Participants also reported on their experiences of friendships. Ten of the participants identified that they were 'self-directed' in maintaining friendships and organising their social lives. Living independently and/or transport or accessibility were positively associated with this important capacity. People spoke about going to the cinema, meeting for coffee or meals or going to the pub with their friends.

4.3.6 Being a consumer in one's community

Participants who were living independently or in employment reported opportunities to participate in society as consumers. Informal relationships were reported to be made in banks, Post Offices (n=2) local shops and shopping centres. Some of these contacts led to friendships. Others just to being able to greet people in one's neighbourhood.

4.4 Theme One: The value of social inclusion

This section reports what participants told us about the value and meaning of social inclusion and of participation in community life. It is organised into three sub-themes:

- How inclusion made participants feel
- How social inclusion creates opportunities for further social inclusion
- Participants as agents of change

4.4.1 How Inclusion made participants feel

Being involved in mainstream activities gave participants a sense of belonging and contributing. Working participants expressed similar sentiments to those expressed by the general working population i.e. a sense of being valued and participating.

> ".. to be valued" (Tom).

> "...to be appreciated" (Ellen).

Some participants spoke about the importance to them of helping others (n=4).

> "For me it makes me feel good just helping others" (John).

In addition to those sentiments, this group of participants expressed how working countered some of the marginalising aspects of living with a disability.

> "Working makes you feel more part of normal" (Tom).

Jill echoed this feeling, articulating the value of "being involved with everyone else", adding that it can serve to counter prejudices about capacity.

> "Working …shows I am able" (Jill).

Working simply enabled some participants to redress the invisibility of persons with disabilities in Irish society.

"I want to be seen" (Niall).

"People would see you ...I'm not a person that's hidden away ... contributing to society" (Rory).

Others echoed this in a more general way:

"Well I like to be well known …. If you are inside, you won't be seen. Just go out and mingle with people" (Alan).

"Bill is well known in the village… if he is walking down the street ... there will be a wave out the window or somebody saying, "How are you Bill?" as they come out of

the shop… that would be through socialising in the town and little jobs around the area" (Supporter commenting on the change since Bill arrived when people were apprehensive to talk to him).

A simple and commonly expressed sentiment when asked about living independently or working or taking part in education was that of happiness:

"My heart is smiling when I walk in the door of my job" (Denis).

"It (work) feels great" (John).

"I couldn't be happier because I am independent" (Molly).

"I love this home and I wouldn't give it up for anything" (Mary).

"It's (education) a little bit difficult but it's great, its brilliant" (Alan).

Many participants (n=10) expressed pride in what they had achieved and the road they had travelled:

"See what I have achieved".

"I hope when people hear my story that they think well that's a great thing that Molly did. She made so much progress in her life" (Molly).

The value placed on "autonomy" or choice and control in people's lives came across strongly in the research.

> "For us we can do our own thing" (Jack).

> "I'm my own boss, so I make the decisions" (Alan).

This was expressed most strongly by participants who were living independently and by those at work. The value placed on **choice** about when, where and what participants did things such as go to bed, eat, or watch TV were expressed by almost all those living independently (n=9).

"I come and go when I like, I can invite who and when I like …very peaceful here" (Rory).

"Nobody there to prompt me every five minutes and telling me what to do…. at night I have the whole place to myself…" (Molly).

"It makes me happy I can do my own things like I go shopping on my own. I went to the pictures on Sunday" (Kathleen).

Value was placed by Karen on having some choice in who supported her and who she lived with as now that she had a home of her own she was involved in the recruitment of her supporters and her housemate.

"It was good to choose myself" (Karen).

All of those who had lived in congregated settings (n=5) spoke about how they valued **control** over the noise in their homes.

The good thing about living here is "It's quiet" (Karen).

Indeed, for two participants that access to peace and quiet was key to managing mental health.

4.4.2 Social inclusion creates opportunities for further social inclusion

Participants told us how being involved in one activity in their community led directly to involvement in another:

Once Rory was working for a couple of years he felt able to consider moving into independent accommodation because he had enough regular income

"Having my work and paid employment made it very possible for me to achieve what I have today which is my own place..." (Rory).

Jack could join the Tidy towns committee as he is now a permanent resident

Alan got valuable work experience from the connections he made at his mainstream college

Moving to her own home gave Karen access to personal supporters rather than shared staff. This control has given her the ability to plan daytime activities and consider college applications

A number of participants indicated that a move to a home of their own led to their further participation in community groups and education.

Participants told us about how their informal networks grew due to their participation in mainstream activities. The most often cited benefit of participation in mainstream activities was named as meeting people and connecting with others.

At least four participants could point to substantial friendships which have grown out of work. All of these participants are working approximately half time.

"It feels great to see my friends every day and socialise" (John).

A further five who work fewer hours reported sociability at work and at work events. Friendships at work were important to everyone even if they didn't spill over into life outside work.

"Co-workers are so supportive (Jack).

"Best bit of work is talking to other people at breaks" (Ellen).

"It's absolutely brilliant because staff are so friendly, and I get a lot of feedback there" (Niall).

In addition, being at work provided opportunities to make more friends and acquaintances in other ordinary places such as regular lunch time venues and shops.

"I go for lunch in Doyle's two days a week. I've made a good few friends there too" (Tom).

Mainstream education provided similar opportunities for Alan:

"I'm getting there to make friends with them" (Alan).

Living independently facilitated people to include themselves through the role of consumer. For participants, shopping has been a way into informal relationships in the community. In addition to friendships, networks of acquaintances were established. These are the sorts of connections that people rely on for day to day companionships and ease.

Others (n=5) acquired these types of connections through involvement in voluntary work:

"I meet lots of different people volunteering" (Jill).

"Everybody waves and greets Bill now as they see him involved in the voluntary work and using the local post office and shops" (Supporter).

Furthermore, mainstream community activities such as knitting clubs, music and sports provided a source of informal supports.

"The knitting club organised an outing for me when my mother died" (Mary).

"I have built up a lot of friendship through music" (Rory).

The data indicates that social inclusion seemed to enhance the capacities of families to engage with their family members with intellectual disabilities. Moves to independent accommodation from institutions facilitated families to support their family members with practicalities such as decorating rooms, work on the garden and so on. Having a space to entertain visitors facilitated further interaction through meals shared and cups of tea for all five participants who had moved from institutions:

"The kitchen table had take-out the night you moved in because with all the work done we were too tired to cook. All the family were there" (Karen's supporter).

Finally, just belonging in these ordinary environments appeared to release dormant capacities in some participants. For example, a job has released confidence in one

participant. He reported that he would not leave the house prior to starting work and now 6 months later he is confident and is out independently socialising in his community, has taken up golf and is applying for a part time course.

For another participant, independent living, with no staff presence, appeared to create space for her to start making plans for herself. In a short space of time she has organised her own holiday and the support to make it happen and made a new network of informal supporters in her local shopping centre:

"I couldn't do that …if I was in the hostel, I had to have staff everywhere I go, you see…" (Kathleen).

Sometimes supporters and participants alike reported that this move also helps supporters to realise the hidden capacities of those they support.

4.4.3 Agents of Change

As social inclusion led to further social inclusion it also led participants to take up roles as change agents in the society. Participants in the research told us consistently about how they engaged with Irish society to try and bring about change for people with disabilities:

"If I have made… If I have changed them to new societies then hopefully I will have encouraged other people to do similar" (Rory).

"I think that it is very important that people with intellectual disability or disability in general encourage each other to make the move" (Rory).

As participants became involved in mainstream activities they became more involved in bringing about change for others in society. One group saw themselves as "trailblazers". By that it is meant that they, by their innovations and breaking into a mainstream activity, make it easier for others who wish to come behind them.

"Every disability will be following me; every disability will be following me to that route … because I'm like a pioneer" (Alan).

Some have, by their presence changed work environments so that they are more accessible for others.

A majority (n=13) acted as advocates for change by, for example:

Educating students of social care, speech therapy and nursing. Some of this work was paid but much of it wasn't

"And they are learning from me" (Alan).

In leadership roles in self-advocacy groups or through involvement in activism:

Six participants had roles in disabled persons' groups where they advocated for change in services and policy. In some instances, groups and individuals were involved in national campaigns for legislative change such as that of the Assisted Decision Making (Capacity) Act and Ireland's recent referendum on access to abortion

Or in one case through creating a blog on accessibility in her town

Finally, one person was involved in service delivery and fundraising in an organisation which provided services to children with disabilities to improve their capacities to participate.

4.5 Theme 2: Enablers of Social Inclusion

This section reports on what helped participants to achieve socially included lives. The findings are organised into four sub-sections:

The focus on the unique individual rather than the disability

Leadership qualities of participants which enabled social inclusion

Inclusive environments

The involvement of supporters

4.5.1 Focus on the unique individual and not the disability

"Just follow where your heart goes" (John).

During the interviews there was little talk of disability. The starting point for planning a socially included life was identifying individual interests, strengths and resources.

"Really use their interests to make their life better" (Mary).

A number of participants reported a complex and multi-layered life that reflected their multi-faceted individual personalities.

Participants reported that in planning for work, job coaches and other supporters worked with them to identify personal interests and experiences which may lead to a good match in work. Examples included matching the experience of a farm-based childhood with an outdoor job in landscape work and in another, a gregarious nature and a real love of "the banter" led to a receptionist job. Both identified the importance of this process.

"I always like that kind of thing of meeting people and that kind I had. I would have been. I think my job was a couple like that" (Tom).

".... came and talked to us individually and asked us what we were interested in" (Rory).

The key to unlocking possible routes for engaging with the community for some people who had communication challenges was to seek information from family members about unique childhood experiences and current interests. This along with spending time with the participant themselves provided clues to the unique individual and how they may participate in their community. For example, a passion for looking at photos led a supporter to consider a trip to the photographic gallery. This has unlocked a passion for galleries. This allows this participant to meet and greet many people in his travels and this, his supporter reports, satisfies a need to connect and belong.

Following individual interests led to participation in a variety of inclusive activities such as volunteering at GAA or playing traditional music or taking part in clubs such as Toastmasters, knitting clubs and so on. One participant developed an interest in drama in childhood which led to a coveted volunteer role in the arts as an adult.

By connecting directly with one man's passion for film a relationship was established through photography and film. This assisted him to build confidence to be supported to apply and take part in a third level course in the same area.

Personalising supports to the individual unlocked possibilities for further social inclusion. In a number of interviews, people told us how the hours that staff worked were being tailored to meet their needs. In one house, staff changed to work shifts of 24 hours as changeovers were causing stress and undermining the experience of self-direction in this man's own home. This flexibility of service provision enabled workers to plan a full day with the participant with greater opportunities to respond to what the participant wanted to do that day.

In another case, a participant reported individually tailored support provided greater opportunity to control and plan contact with family and friends and other activities.

Some reported that they had different sorts of supporters to assist in different activities. For example, a farmer supported one participant to volunteer once a week on a neighbouring farm and a student supported another to socialise at the weekend.

Finally, the flexible use of funds from a disability service to pay casual workers to support a participant to attend a social function or a particular course was deemed facilitative.

4.5.2 Leadership qualities of participants which enabled social inclusion

Social inclusion is about ordinary lives in ordinary places. The research did not set out to find remarkable people with remarkable stories. However, as the evidence on the widespread social exclusion of people with intellectual disabilities in Ireland

indicates, stories of social inclusion are rarer than those of social exclusion. Therefore, it may be unsurprising that evidence was gathered of pioneering type skills and qualities in participants, who are pushing boundaries and overcoming barriers to social inclusion.

Participants evidenced a high degree of agency, self-advocacy skills and leadership. They identified qualities in themselves which have helped them to achieve this level of social inclusion. These include determination, positivity and a desire to progress and change.

Determination was mentioned by a majority of participants:

"You have to be determined, it's hard at the beginning" (Kate).

"You can if you put your mind to it" (Susie).

"I knew I could do better than that" (John).

Determination was allied with hard work and persistence. Karen lobbied everyone she met, including HIQA, and wrote to everyone telling them that she wanted a home.

"… it's hard work and yet you want to do it. It's hard to do" (Karen).

Bravery to take a risk was recognised by a number and the importance of risk taking articulated.

"Take a risk" (Rory) and a "give it a go" (Kate) attitude were advised.

Connected to the idea of risk-taking was the idea that change was good and participants almost all expressed an interest in trying new things and "being adventurous" (Denis).

"Different things, just different things" (Niall).

"Doing new stuff and new skills" (Jill).

Positivity was reported by several participants as key to their success:

"I always try and come in and brighten up people's day …I always see the positive side of things" (Susie).

"Really count my blessings for the good life I have" (Christine).

Keeping positive in the face of adversity was named by many:

"Don't listen to others. Like just believe in yourself" (John).

There was an additional cluster of qualities apparent in this group of leaders. They may be related to the requirement for persons with disabilities to sometimes have to

work with supporters to achieve their goals. The capacity to work in partnership with others was evidenced in the research as was the capacity to ask for and receive help.

Throughout the telling of their stories there was much evidence of how many times participants felt they had been let down by services, families and Irish society. However, a capacity to move on and trust again was frequently observed. For example, when Bill's supporter was asked to identify the qualities which had enabled his successful inclusion, he said:

"Well he's a very patient man…. he is a trusting man... Bill is one of the most forgiving people that I have ever come across".

The building of relationships with supporters was evidenced throughout the interviews and there appeared to be genuine warmth between supporters and participants. Every participant who could use words to communicate (n=17) spoke about the value of connecting with other people. Paid supporters of the other two participants spoke powerfully about how much their relationships meant to them.

"I love hanging around with Mark, we are friends" (Supporter).

Participants demonstrated good use of help and support. For a start they recognised the value of getting help:

"...Never be afraid to ask for help" advice from Molly.

"When you make a decision to go work or move into your own home think ... and look for support from someone" (Rory).

"Invite people to help" (Jill).

In addition, they told us they were discerning about where to go for help with different problems. For example, participants told us they would go to the social workers for "deep problems" (Catherine) or for support with "relationships" (Ellen).

4.5.3 Inclusive Environments

The environments people inhabited impacted on participants' capacities to experience social inclusion. Participants reported that accessible public transport or physical accessibility to ordinary community services enables social inclusion and autonomy. Moving to be in walking distance of work enabled one person to benefit from the social aspects of work and the community.

"I can walk to work, and I can walk home …. I'm within walking distance of almost everything" (Rory).

Another moved to access a greater number of transport options.

Town/urban dwellers reported independence around access to friends and casual socialising such as the pub or cinema, without the need for support.

"I take a walk into town on a Saturday to get my hair done" (Molly).

Many in supported, independent living arrangements made casual reference to making their way to the shops:

"I love living here …. because I'm near all the services and I'll get the bus to [xxx]" (Christine).

In addition, the openness of communities and organisations and the individuals within them to including persons with intellectual disabilities positively influenced participants' experiences of social inclusion.

Participants identified educational establishments which valued diversity and identified this as an enabling quality of this establishment. In another college, a participant was invited to meet and consult on how the college might facilitate their participation in a course of their choice, indicating a desire to recruit them. These kinds of actions helped facilitate inclusion rather than creating barriers.

A number of workplaces demonstrated consideration for the progression of their workers with intellectual disabilities, thereby conveying the value of their participation and the commonality of their needs with other employees.

Ordinary places such as post offices, pubs and shops in the community welcoming and engaging with participants was reported by participants. These actions to include participants were noted as important in contributing to a sense of belonging in new communities.

Work on supporting aspects of the environment to overcome their concerns and to develop inclusive environments was recorded and involved the skilled work of supporters alongside the participants.

4.5.4 The involvement of supporters

"They can help you make your dreams come true" (Alan).

The universal advice from participants in this study when asked how people should go about making social inclusion happen for themselves was to "ask for help". This indicates, as noted above, a valuable capacity to use and value appropriate support.

This also indicated the sense of control and choice most, not all, participants felt over the nature of the support they were receiving. They tended to use a range of different supports for different needs. Sometimes they were choosing when and from whom they would request assistance.

The interviews most often revealed a flexible mix of paid and unpaid (formal and informal) support in participants' lives to enable them to achieve their goals. This was broadly co-ordinated and created by the person themselves (n=2) or with assistance from a key family member (n=2) or by a key person in disability services (n=7).

The importance of family support was identified by 15 of the 19 participants. Catherine expressed the sentiments of quite a number of participants (n=5).

"But for my mom we wouldn't be where we are now" (Catherine).

Only one participant had a personal budget. However, three others appeared to have flexibility and control over how their allocation of personal assistant hours or care budget was spent.

Having established the involvement of supporters as a key enabler of social inclusion the following section reports what participants have to say about the sort of interventions that made a difference and what good support looks like.

4.6 Theme 3: Supporter activities and qualities

This final section considers in greater detail the nature of supporter involvement in enabling participants to live included lives. This theme is further divided into four different sub-themes:

- Qualities of supporters and supporting activities that facilitate inclusion
- Supporting actions which work on the environment
- Supporting actions which work directly with participants
- Accessing mainstream supports

4.6.1 Qualities of supporters and supporting activities that facilitate inclusion

The research participants provided insight into what they valued and found helpful in the qualities of the supporter, the relationships and their activities. These insights are reported on below.

Participants consistently advised that support should be very plentiful at the start of anything new while participants are learning new skills and familiarising themselves with new places. Subsequently good support did not disappear but remained available.

"I'll pop in every two or three weeks to see" (Ellen's Job support worker).

"She always rings me and see how I'm getting on, see if I am enjoying (my job)" (John).

Some participants articulated the value of support which was a "light touch" and was just there when needed and no more.

"I think I needed it at the start but now I'm okay" (Ellen).

"I try working out on my own, I try and figure out myself …. if I need a bit of help, I just ring my support worker and the chat helps" (Mary).

"My supporter is there only if I really need her…even here when I go here I manage on my own" (Susie).

This is linked with an appreciation of choice in the use of support by participants

"I can get (service) to help me negotiate the changed role …. Helped me just when I needed it" (Tom).

"You can just flow in whenever we want. It was grand…" (Christine on a support service).

Furthermore, at least seven participants identified a particular set of qualities in a supporter relationship that they valued greatly and reported that supporters who demonstrated these qualities were attributed with a significant role in enabling participants achieving what they have. The following qualities of positive relationships were reported by participants:

Relationships based on a conveyed common sense of humanity.

"I had one person in the service that was a key worker and he was the best key worker we ever had. He was more like a person …. He sat down and played PlayStation and …we'll talk. Because he brings them down to the level that I know, that makes me feel better" (Jack).

Supporters that sat alongside participants and built their relationship up from establishing a shared a common interest or experience.

"I was a smoker and Bill was a smoker at the time and that was what we had in common and that's what we done. As simple as that we sat in that front garden for two or three hours every day for a few weeks until he moved". (Supporter).

"We have a lot in common" (Mary).

A sense of equality demonstrated by an expression of reciprocity in the relationship.

"And then we became friends over the years, I really value my trips with him" (Mark's supporter).

"He was happy to work with me and he heard about me doing filming. I showed him one of my films and he watched, and he thought it was amazing. We had that kind of relationship, like friends" (Alan).

A sense of give and take in the relationship.

"I was lucky … we became more friends and that. As much as I taught her she taught me" (Christine).

This wasn't just confined to paid supporters but also to informal supporters like cousins, parents and sisters, where participants reported supporting them in return for the support they had given them.

Participants and supporters spoke about the importance of matching them to each other based on temperament and interest. This seems particularly important for those who need a supporter with them all the time to facilitate inclusion.

Three participants were involved in drawing up job descriptions and interviewing for personal assistants or supporters. For another participant, matching supporters, with the participant was of highest priority.

"It's all about the match…. It's Bill's house" (Supporter).

Good support evidenced an awareness of the perceptions of others in the environment into which participants were endeavouring to be included. To this end, plans were made to ensure that support was given in an unobtrusive way that didn't label participants when they joined a group or were supported at work. One participant told us that her supporters were chosen to be of similar age to her so that when she went to join a club they presented themselves to the group as friends.

"…just turned up as friends" (Mary).

In another, both the participant and the Personal Assistant joined the class as students in their own rights and sat separately. In this way support was present but not diminishing of the participant.

Furthermore, evidence was presented of how participants were supported to engage in activities which strategically challenged perceptions of persons with disabilities as non-contributors. To this end, supporters helped to identify opportunities for lecturing and advocacy. In addition, work which maximised participants' opportunities to meet community members in ordinary roles were strategically planned. For example, one participant was supported to make benches. These were then rented to county councils, garages and so on. Renting them, rather than selling them, ensured that the participant had to call regularly to people and make connections. This and a number of other activities were seen to nudge the community to change their views about intellectual disability and approach the participant as part of their community.

It was observed that creativity and entrepreneurship were supporter qualities which facilitated the creation of a varied and included life. Supporters worked with participants to imagine big lives based on their interests and dreams and not on their ability to take part or to do the task in the traditional way.

They started with a vision and set about working out a way of making it happen. For example, they found ways of creating a life with aspects of work, a social life and a volunteering role in his local community for one participant who received support 24 hours a day.

In another participant's life, supporters negotiated that he would provide lectures to social care students and they would provide in class support for him on his course. Indeed, in most stories there was evidence of creativity in finding appropriate supports and opportunities for participants.

Supporters appeared to approach a challenge with a problem-solving attitude and to draw on networking and negotiation skills to make things happen.

Alongside these qualities, the ability to be flexible and not to be contained by a narrow job description was reported. Supporters were flexible with work timetables and work tasks in line with the requirements of participants.

"We just work it around whatever's happening in Mary's life and whenever she needs the support and that's working, that model is working really well" (Mary's supporter).

Good support recognised the constantly changing nature of participants, their needs and their interests. Hence plans were not static but under continuous review.

4.6.2 Supporting actions which work on the environment

The participants identified a range of actions by supporters which facilitated them to achieve a socially included life. In this section we record the sorts of activities that sought to influence workplaces, colleges, services and so on in order to facilitate the participant's successful inclusion.

Supporters, along with participants, were frequently involved in advocacy work with county councils, education boards, and services in order to access mainstream services and supports for the participant they supported.

In addition, some paid and unpaid supporters worked with mainstream establishments to develop new ways in which they could deliver their services in an accessible way or accommodate difference. For example, supporters helped to adapt an educational programme to suit one of the participants. In workplaces, supporters developed systems to assist participants to work to their maximum capacity. For example, for Ellen, a workable system was devised to discern different batches of cutlery in a busy restaurant.

Successful models of included lives for participants often came about due to the capacity of supporters to identify opportunities and resources in the community which could be engaged to assist with inclusion. For example, one worker identified an opportunity for a participant to contribute in a meaningful way both for himself and his new community by supporting the participant to provide regular maintenance of untended graves.

Furthermore, participants often reported that supporters sought out groups and classes for them in their local areas that they may wish to join. A number of these became effective ways of making connections in a new local community after a house move.

4.6.3 Supporting actions which work directly with the participants

The research participants identified many ways in which supporters had worked directly with them to enhance their capacity to participate fully in mainstream activities.

According to participants, an important starting point was working with a supporter to identify what it is you want in life and to identify one's strengths and passions. In this way participants created a profile of oneself based on their own individuality.

Furthermore, participants found value in planning and preparing for upcoming events, challenges or changes with supporters with expertise:

"Make sure to have a person that knows about moving out" (Mary).

Supporters provided a range of psychological supports to enable participants to manage anxiety and to address a range of personal matters. These would have had the potential to undermine their participation in a socially included life if not addressed.

Three participants spoke specifically of talking with social workers to resolve relationship difficulties and manage frustrations. Others spoke about how supporters had assisted them to develop coping skills. And others spoke about the value of having someone to phone:

"…If I have worries about things I might give her a tinkle on the phone and she chat to me and that helps" (Mary).

Participants reported assistance in acquiring skills and building capacities. Supporters taught or arranged for teaching on cookery, money management and so on. Participants noted that these assisted them to live more independently or to access work. For example, attendance at an interview training course has provided one participant with confidence to interview for her supporters.

In very many instances, supporters simply provided essential practical support such as cooking a meal, budgeting or filling in forms where participants required it.

"Like if I have a problem she'll simply tell us to write down what we want to say to the council and she will send it after the council, but she'll put in her words" (Catherine).

Finally, some participants received help from supporters to attend and undertake tasks at work, in education or as they volunteered. These sort of supporter tasks ranged from simple prompts to joint working. For example, one man puts boxes together and he requires some assistance to complete the corners.

4.6.4 Accessing Mainstream supports

In several interviews, examples were given of participants relying on mainstream rather than disability specific supports.

In the majority of workplaces participants reported that they resolved difficulties with the workplace management structures.

"You know x would be in charge so if I have any problems I can go up to them and say to them…. you know that there is support there, if needed" (Tom).

"I'll go out and ask one of the older members of the staff and they show me where it is and once they show me I can remember where it is" (John).

Two of the three engaged in mainstream education told us that they accessed the college supports rather than any specialist supports from a disability service.

One participant was living in supported housing for the elderly and accessing all the mainstream services provided for the elderly. She was included in many groups and activities because of this.

4.6.5 Social inclusion as an ongoing journey

While this study focuses on where participants have got to in their journey towards a socially included life, some participants also shared where they would like to get to.

Broadly, participants were striving for greater levels of inclusion and looking for support to do so. Three participants spoke about how they would like more work and would like to be considered for progression within the workplace. It seemed some had secured a part time job and then either their supporters or their employers considered that was the "job done". Others were looking for additional ways of engaging with their community through classes or groups.

In telling their story participants told us of the challenging context they had to overcome, including institutionalisation, separation from family and informal support networks, exclusion from education, workplaces or social groupings.

Furthermore, participants referred to having to deal with an imbalance in power when dealing with authority. This could be the disability organisation they received support from or a government agency they were dealing with.

These challenges, though not insurmountable by participants, presented an ongoing challenge when building a socially included life.

4. 7 Summary

19 participants of different ages, genders and geographical locations were interviewed. Participants were a diverse group, accessing a range of supports across various aspects of their lives and many with multiple disabilities. Four participants could be said to have complex support needs at the current time

Different participants were engaged in different aspects of living a socially included life, such as, living in their own homes, working, volunteering, in mainstream education, attending mainstream clubs and social activities and forming friendships and relationships

Participants reported on the value of social inclusion, including how it made them feel, how social inclusion creates opportunities for further social inclusion as well as their roles in creating positive change in society so that other people with intellectual disabilities can live socially included lives

Seeing people with intellectual disabilities as unique individuals, the leadership qualities of participants, inclusive environments and the involvement of supports enabled socially included lives

Participants reported on the nature of the support in their lives and set out the qualities of good support.

5. Discussion

5.1 Introduction

In this chapter the results of this study will be discussed in the context of the relevant literature and where possible, with reference to the project which inspired this work, the 19 Stories of Social Inclusion project carried out in Australia. Consideration is given to the implications for policy, practice and future research as well as for people with intellectual disabilities and families arising from the findings of the study. Lastly, recommendations for policy and practice are made.

The discussion is organised around three themes:

- How the results of the research contribute to our understanding of social inclusion
- The changing nature of support in the context of recent relevant research
- The environmental context of social inclusion in Ireland.

5.2 Understanding Social Inclusion

Although social inclusion is widely recognised as a "good thing" in Irish and international policy, there is a lack of consensus as to what constitutes social inclusion (Cobigo and Stuart 2010, Gooding et al 2017, Simplican et al 2015).

This chapter discusses the results of the research in light of the understanding of social inclusion proposed by Cobigo et al (2012), as set out in Chapter 2 of this report.

Cobigo et al (2012) reviewed the literature on social inclusion in search of "key components, definitions and conceptual approaches to social inclusion" and suggested it was important that there was a "shift" in our understanding of same. They argued that social inclusion often imposed a definition of what was successful social inclusion on persons with disabilities which was based not on their choosing but upon "dominant societal values and lifestyles". In addition, this was measured by "productivity and participation in community-based activities" (p75). These understandings they argued, potentially excluded people with more complex needs and reduced a sense of choice for persons with intellectual disability to follow what was meaningful for them (Cobigo et al 2012).

This study was undertaken with an understanding of social inclusion as not merely placement, but "participation and engagement", in mainstream society (Ibid, p76). It recognises that social inclusion is a "dynamic process" and that it involves "complex interactions" between the person and the environment (Ibid, p79). It places central importance on elements of choice, self-direction and the "felt" sense for the subject. The focus of this qualitative study on participant's experience, rather than quantification of socially inclusive activities, crucially enabled the gathering of insights into the "felt" sense of, or the personal value placed on, inclusive experiences by participants.

Reflecting on these insights, we note that the participants in this study appeared to prize certain qualities above others:

* Choice and control over their environment
* Belonging and connection
* The dynamic process

These were strongly reported by participants as a valued outcome of social inclusion and echoed the key components of Cobigo et al's (2012) definition. Each will be reviewed in turn.

5.2.1 Choice and control

The centrality of choice is articulated in Article 19 of the UNCRPD which sets out the equal right of persons with disabilities to live in the community "with choices equal to others."

Study participants described a process that started with choice, was broadly participant led and in turn facilitated a greater sense of choice and control in their lives.

As people spent more time in the community there was evidence that participants were engaged with greater autonomy in building self-directed lives. For example, acquiring a home enabled supports to be more personalised and uncoupled from group provision of supports. The canvas became bigger and people began to be able to dream. Indeed, the incremental nature of social inclusion; that is that social inclusion leads to further experiences of social inclusion, was echoed in earlier studies. For example, McConkey et al (2013), in an extensive evaluation of personalised supports to persons with disabilities, reported:

> "But a striking finding from many studies and one echoed here too, is the freedom that people experience when they are no longer part of a service system and they take or regain control of their own lives and are able to develop their own individuality and identity" (p120).

However simple 'placement' in the community or access to work did not lead to the development of autonomous lives. Only in those examples where participants had access to supports did the study evidence this positive development. The role of support in enabling choice and control is echoed in a number of Irish reports (Duggan and Byrne 2013, McConkey et al 2013, Garcia Iriarte et al 2016). Supporter roles will be discussed in the following section (5.3).

5.2.2 Belonging and Connection

Cobigo et al (2012) articulate the importance of belonging and connecting to understanding of social inclusion.

> "The focus on social inclusion should be to develop a sense of belonging and a social network that provides natural and informal supports" (p79).

The opportunity to meet and connect with a range of people was named as an important and satisfying outcome of socially inclusive experiences for almost all the participants. Furthermore, this was equally valued by those who didn't communicate with words.

Participants and their supporters reported a sense of importance to being seen and recognised by, at a minimum, a wave or a handshake. This and more complex social interactions were given high value. Meeting and greeting was reported to provide a sense of belonging.

Participants identified varied networks of informal support arising out of what are identified as mainstream activities such as community groups and work places. Furthermore, a small number (n=5) reported acquiring friendships from these experiences which were sustained outside of those settings.

Similar findings were reported by the '19 Stories' project where participant's reported a sense of belonging, a feeling of acceptance, feeling welcome and feeling a part of things as key to living a meaningful and inclusive life (19 Stories of Social Inclusion, 2017). Being socially included was about being immersed in ordinary and typical places in the community and using community resources where possible.

Participants also reported that they acquired friendships and networks of support from disabled spaces[9] and activities such as social clubs or Special Olympic sporting clubs. Several (n=9) spoke about friendships, which were sustained independently, which resulted from these activities. Participants in this research challenged the team to consider who defines social inclusion. Cobigo et al (2012) argue that social inclusion must be:

> "Understood as relative to an individual within the group to which he or she wants to belong" (p81).

Indeed, one participant in choosing his activity with his designated "social inclusion worker" chose to bring him to his "special" dance class and wanted him to join his world and his friends with intellectual disabilities. Cobigo et al argue that choices are key and not based on "dominant societal values and lifestyles" (Cobigo et al). Other commentators considering the matter of inclusion suggest that these spaces may provide "shelter" and mutual support in a challenging life (Hall 2010, Power 2013).

This is not meant to imply that one can be socially included while only in separate spaces, but more an insight to the value of choice and self-determination, particularly while many mainstream social spaces may be experienced as isolating for persons with intellectual disabilities.

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[9] This term is borrowed from Hall (2012). In his work on intellectual disability theatre he talks about the value of having some places which are regarded as "disabled" spaces.

5.2.3 The dynamic process of social inclusion

Lastly, participants provided evidence of the incremental nature of building a socially included life, contributing to an understanding of social inclusion as a dynamic and evolving concept.

Participants provided evidence of the process of building a socially included life. This often had, as its starting point, a relationship with a supporter which was experienced as inclusive. In this relationship, the supporter demonstrated how they valued and saw the unique person and did not define the person by their disability. The relationships recognised the reciprocity within them and were based on a choice by the participant to engage.

Thus, one can suggest social inclusion starts with a socially inclusive environment, culture or process and furthermore the trust and security it provides enables further inroads into further socially inclusive experiences.

The following section considers the way supporters are required to shift their practices in order to meet this shifting understanding of social inclusion.

5.3 The changing nature of support

The discussion in this section is further divided into three sub-sections:

- The first will identify the alignment between recent literature and this study on the importance of supporters moving away from traditional roles based on care and protection in order to facilitate social inclusion
- The second deliberates on the necessity of shifting away from group practices to personalised supports
- Finally, there is reflection on the organisational challenges of this shift.

5.3.1 From care to support

Research reports and policy documents posit that traditional contexts of "caring" for persons with intellectual disabilities do not support social inclusion (Garcia Iriarte et al 2016, McConkey et al 2013, Department of Justice and Equality 2017). Data collected for this study confirm the changing role of both formal and informal supporters of persons with intellectual disability who seek to live included lives in their communities. One change would appear to be from role of carer to one of supporter.

Participants identified supporter actions which had assisted them in achieving a level of social inclusion. None of them described a caring type of role. Reports of the sort of support which enabled participants to have socially inclusive experiences confirm the requirement for support to change from its traditional manifestation.

Garcia Iriarte et al (2016), reporting on the role of support staff as people moved out of congregated settings, identified that worker's roles were changing "from clinical to community support roles" (p162). The sorts of task identified in these new roles were ones of advocacy, building social skills and community connecting. In

addition, the importance of both supporting people to make their own decisions and respecting these decisions, is documented in the literature. These range of tasks closely echo those identified by the participants of this study.

Although the value of these changes is recorded in this and other studies, previous research has identified that these sorts of tasks are often seen as low priority (McConkey et al 2013). Many support staff continue to take on more caring roles and limit their support for inclusion because of concerns about the risks for people of taking part in community activities (Duggan and Linehan (2013).

Matters of risk also relate to supporting people to make their own choices and Marshall argues that supporters must "accept a degree of risk in favour of the individual's perspective" (Marshall, M. 2015 in Fleming et al 2016, p11). Indeed, literature reviews on the subject identify that supporters feel they are ill prepared and untrained for these new roles (Fleming et al 2016, Gooding et al 2017). It is argued that there is a need for training for both paid and unpaid supporters "in order to facilitate a culture of equality where everyone is a valued citizen and where disabled people are not expected to compromise" (Fleming et al 2016 p12).

The literature also urges consideration of the qualities of support workers and suggests that in order to support persons to be included in their communities, certain qualities rather than qualifications should be sought. For example, Garcia Iriarte et al suggest that:

> "People who already are involved in local communities and who have a commitment to their locality may be more important qualities in selecting new staff than their…qualifications" (2016, p162).

This too resonates with the findings of this study where sessional supporters were recruited because of their particular position in the community or common interest with the participant, rather than a particular qualification. These local links or interests supported the participant to engage in the community.

Perhaps allied to this unpacking of the supporter role and position is a shift in the quality of the relationship. Garcia Iriarte et al (2016) report briefly on this. They noted that as staff moved closer to the kinds of roles outlined above, they:

> "Changed …. how they viewed persons with disability as expressed in the development of trust with the people they supported" (p162).

They suggest that the centrality of positive regard and shared enjoyment to positive working culture was also recorded in earlier research with persons with high support needs (Bigby et al 2015).

Participants in this study spoke about the qualities of connection and friendship which they valued greatly in supporters. The level of trust arising out of these qualities appeared to assist them to take risks and engage in mainstream activities and roles.

Participants and supporters in this study both spoke of relationships that had the quality of friendships, including where these relationships were with paid supporters. This increased fluidity within relationships is potentially a challenge to the historically professional and bounded relationships of disability services and may pose ethical questions. Indeed, two participants referred to a perceived unwillingness of their services to tolerate such personal relationships although they were really valued by them.

At the same time, participants were discerning in what kinds of support they requested from different supporters, reporting that they consulted with social workers in relation to 'deeper' or more emotional problems.

While the role of supporter shifts there also appeared to be an inevitable shift towards a more personalised delivery and conceptualising of support.

5.3.2 Personal supports

In this study participants found particular value when supports to them were personalised and across the literature, support for social inclusion leads to the provision of supports in a more personalised way. Gooding et al (2017) report that the push for social inclusion leads to a:

"Reconceptualising of traditional disability services…. Towards more personalised forms of support that facilitate connections to local communities (p16).

McConkey et al (2013) provide a relevant definition:

"Personal or individual supports are those which address the unique needs of the individual, focusing on their strengths and abilities, are chosen by the person and are delivered in the community, fostering inclusion and participation" (p1).

The Australian 19 Stories of Social Inclusion project found that support which began with a recognition of the uniqueness of the individual was a key learning. They report that it is vital that the starting point be:

"Understanding their interests, desires and drives and finding ways that we can use these to connect individuals to their communities" (Dickinson 2017, p3).

Isolation is a recorded concern for people with intellectual disabilities moving from congregated settings or day services into more mainstream provision (Duggan and Linehan 2013). Developing community connections and networks of support for each individual is an essential response to this which can only be delivered by personalising supports (Power 2013, McConkey et al 2013). Participants in this study reported examples of supporters mapping opportunities for them to take part in community activities and in the provision of tailor made supports to make connections within them.

According to the literature, this work is slow and incremental, (McConkey et al 2013, Power 2013). Indeed, McConkey et al (2013) note:

> "That people who had experienced personalised supports for longer seemed to have fuller lives than those who had recently moved to these type of arrangements" (p177).

Supporters and participants in this study spoke about the importance of giving time to planning and slowly working towards goals. The incremental nature of the work also speaks to the importance of trying and failing and discovery of new skills and interests. Power (2013) reflects this in his study of personalised care that 'success stories' often involve getting it wrong in the first instance. The personalised nature of the support allows for and encourages trying new things and accepting that some things don't work out.

> " …. Personalisation is about supporting people to create and recreate their own individuality and identity" (McConkey et al 2013, p121).

With the personalising of supports in this study, what emerged were lives which meandered and changed as interests, capacities and circumstances shifted. Indeed, change and "trying new things" was something participants in this study valued. Participants tried different kinds of community groups before settling on one that worked for them, in the same way that others living in the community change their outside work activities. One participant tried different kinds of work before settling on a job that suited him. Individualising or personalising support enabled this recognition of the evolving nature of a human being. It was in direct contrast to the inflexibility of group practices that are typical of many services.

Although only one person in this study was in receipt of a personal budget[10] others (N=4) reported flexible management of a pot of money or resources to recruit a range of different staff and to manage support hours in a flexible way. Three of these were attached to innovative 'units' within their service and the remaining participant negotiated a particular arrangement. Furthermore, these research findings suggest that this flexibility enables the recruitment of a variety of supporters with and without qualifications, and that the budget could be used to target barriers to social inclusion which have arisen in this research, such a transport, in a creative way.

McConkey et al (2013) propose two mainstreaming perspectives on personalisation. Personalisation often responds to "the similarity of the needs of all people rather than to their difference" (p 120). In this research, participants articulated the value they placed on expressions of common humanity by supporters. These relationships have been the starting point of personalising supports for many of the study participants. McConkey et al (2013) also challenge society to consider a complementary strategy for the provision of personalised services. They suggest that:

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[10] This may reflect the fact that access to personal budgets in Ireland at present is in a state of flux

> "Mainstream or community services be funded to develop personalised services for persons with particular needs in their communities – co-worker supports in work or buddies in the gym" (p120).

5.3.3 Organisational challenges

The changing nature of support needs created challenges for management of services. Indeed, the literature identifies that this can hinder the progress of social inclusion (European Union Agency for Fundamental Rights, 2012).

Garcia Iriarte et al (2016) report that supporting roles that focused on developing community links conflicted with organisational priorities of some services which limited support once people had moved to the community (p162). Furthermore, services managers reported that there was a need for a changed organisational 'mind-set' at all levels in order for these new models of services to be implemented.

The context of risk and its challenge to traditionally protective services and to the current concerns with health and safety monitoring must be considered. However, the rights based approach articulated in the UNCRPD and the Assisted Decision Making (Capacity) Act could provide a context for organisations to support self-determination and the associated perceived risks.

5.4 Changing the External Environment

These stories, as told by participants, take place against a backdrop of widespread social exclusion of people with intellectual disabilities, as outlined in the earlier chapters.

There was awareness amongst participants and their supporters of the importance of changing attitudes in the outside environment to facilitate the full inclusion of people with intellectual disabilities. This too was a recommendation of the Australian 19 stories project. Dickinson (2017) highlights the importance of:

> "…Work to educate the broader community about disability and to break down the stigma attached to disability" (p3).

A forthcoming study by the EU Agency for Fundamental Rights reports that participants feel positive stories of people with disabilities living in the community are much needed in Ireland and would go some way towards changing attitudes (EU FRA, 2018, forthcoming). The Australian 19 Stories of Social Inclusion project also articulated the value of role models calling for "more role modelling of inclusion within the mainstream media and Australian public life" (Dickinson, 2017).

Indeed, participants in this project spoke about the importance of storytelling and work such as this project which provides an opportunity to show Irish society the potential of persons with intellectual disability to live socially included lives.

Furthermore, most participants were involved in some way in advocacy and education work. The focus of this work was both to support others with intellectual

disability to live a fuller life and to lobby and advocate for changes in policy and practice at both a local and national level. Abbott and McConkey (2006 remark that self-advocacy has been key to other movements which have overcome stigma and discrimination.

Informal and formal supporters in this study were also involved in educating community members and organisations at a local level to facilitate inclusion. In addition, supporters created opportunities for participants to take part in activities which would challenge perceptions and thereby create greater opportunities for those they supported. This is supported in the literature which tells us that societal exposure to persons with intellectual disabilities breaks down barriers (Hernandez et al, 2008, Luecking, 2008).

Commentators (McConkey et al 2013, Dickinson 2017) challenge us to recognise that social inclusion is not just for persons with disabilities but is an issue for everyone. Gooding et al (2017) propose that policy makers could consider ways "to provide incentives and resources for developing accessible communities" (p27). The creation of an inclusive society is a mainstream issue that all citizens need to attend to. The ratification of the UNCRPD by Ireland this year brings the realisation of all human rights for persons with disabilities more urgently to the fore and provides a framework for advocacy.

5.4.1 Role of internal factors?

The study provides evidence on the role of an inclusive external environment and good support in providing opportunities for persons with intellectual disabilities to take control and lead in the creation of their own lives.

Participants themselves also identified certain intrinsic factors such as determination, positivity and a desire for change that helped them to create a socially included life for themselves. This raises the question of whether intrinsic qualities or personal traits also play a role in social inclusion.

In reporting the findings of this study, it has been important to recognise the agency of persons with intellectual disabilities in the creation of socially included lives. This evidences a divergence from earlier approaches where interventions were led by and delivered by others. Study participants reported that they had advocated for opportunities for social inclusion, had had a part in developing those experiences and in turn had sought to support the right of others to do the same. While the study records the role of persons with intellectual disabilities in crafting their own inclusion and the qualities and skills they drew on to realise their ambition, it does not identify the type of person who is more likely to be included or identify certain personality traits which go hand in hand with inclusion.

The study was not psychological in nature and it was not possible from a relatively short interview to confirm the presence or absence of personality traits. In addition, personal qualities and characteristics might change over time and in different circumstances.

There is also a danger in associating intrinsic qualities with successful social inclusion. It risks associating the experience of social exclusion among people with intellectual disabilities with a lack of some positive quality and thus, blaming a person for their own social exclusion while powerful structural factors, such as institutionalisation and poverty, have yet to be successfully addressed.

While the study indicates that participants played a lead role in being drivers of their own lives, it is not possible from this study to establish the relative contribution to social inclusion of determination of the person, personality of the person, inclusive environments, good support or family support. It is likely that all play a role.

5.5 Messages for policy and practice

The 19 stories collected as part of this project, though small in number, throw up a number of policy and practice issues. While commitments are made on social inclusion in a range of policies, both disability specific and mainstream, in some ways, policy and practice also act to hinder social inclusion. For example, while the Time to Move On from Congregated Settings policy aims to ensure people with disabilities can live in the community – a key element of a socially included life - the HSE do not in fact have a policy against new admissions to congregated settings and in practice, people a number of people continue to be admitted to institutions of one kind or another each year.

It is clear that co-operation across all government departments and sectors of society is vital when considering successful social inclusion of the diverse range of people who have an intellectual disability.

The following section considers what the findings tell us with regard to policy and practice.

5.5.1 Understanding social inclusion

Participants' understandings of social inclusion were broad and incorporated the various elements associated with inclusion in the community, such as inclusive work, education, community social activity, and living in a home of your own. But they also included more difficult to quantify elements such as relationships with others, a sense of belonging and being valued, of contributing and exercising autonomy. Similar themes were reported in a recently published study on loneliness where people identified self-representation, connection, and meaningful relationships with others as key elements of an included life (Loneliness Taskforce, 2018).

How social inclusion is understood determines how it is supported in both policy and practice. For example, New Directions, which aims to shift day services to a more person-centred, community based model, acknowledges the need to accommodate a wide diversity of need:

> "…from those with severe and profound disabilities, challenging behaviours and high support needs who are likely to need long-term, specialist service provision to people with lower support needs and greater potential for community participation and inclusion" (HSE, 2012, p21).

The implication here is that people with more complex support needs have less potential or even no potential for social inclusion. The study clearly shows that people with intellectual disabilities, in all of their diversity, can live a socially included life that they value, with the right supports. The notion that social inclusion is dependent on a perceived capacity to benefit from it is deeply against the principles and articles of the UNCRPD.

As stated previously in this report, social inclusion is a key feature of policy in Ireland, both disability specific and mainstream. However, social inclusion is not defined in policies such as the National Disability Inclusion Strategy (Department of Justice and Equality, 2017) or the National Action Plan on Social Inclusion (Department of Social Protection, 2016). This raises the question of whether these policies are sufficiently broad to take account of people with intellectual disabilities experiences of social inclusion.

Only a small number of participants reported that they were in intimate relationships but we know that partners and children are key supports as people age. Until recently, Ireland's Criminal Law (Sexual Offences) Act 1993 created barriers to the enjoyment of sexual relationships by persons with intellectual disabilities and barriers to the provision of sexual education by its categorisation of people with 'mental impairment' as incapable of consenting to sex. While key elements of this law were repealed in 2017, the revised law still contains a category of 'protected person', which continues a status approach and means that persons with intellectual disabilities are still regarded in a paternalistic way.

While the National Disability Inclusion Strategy 2017-2021 (Department of Justice, 2017) brings together policy commitments on education, housing, employment and so on, there is nothing within it that seeks to address the specific area of personal or intimate relationships for persons with disabilities.

The current review of Religious and Sexual Education in Irish schools might provide a space in which to review and address some of the gaps in this regard.

5.5.2 Choice and control

The emphasis placed on exercising choice and control by participants underlines the importance of providing structures and supports for people with intellectual disabilities to make their own decisions. Currently, many people with intellectual disabilities don't have the opportunity to make choices for themselves and have no legal entitlement to support to make decisions.

Although signed into law in 2015, not all parts of the Assisted Decision Making (Capacity) Act have been commenced and the Lunacy Act remains in law. The establishment of key structures, such as the Decision Support Service, will put in place structures for formal supports of a person's choosing. However, implementation has been slow and indications are that this service will not be operational until 2020 at the earliest.[11]

5.5.3 Self-advocacy and Advocacy

The findings confirm the importance of advocacy to the enjoyment of rights by people with intellectual disabilities. Indeed, it appears that the strong leadership and self-advocacy role played by participants was crucial to them attaining such socially included lives.

Although there are reported high levels of participation in self-advocacy in this project, self-advocacy is poorly funded in Ireland and people with intellectual disabilities rarely have an opportunity to have a say in decisions that affect their lives. The findings suggest a need to build capacity for leadership in the population with intellectual disabilities so that people with intellectual disabilities can play a role in decision-making. In this context, the implementation of Transforming Lives, Working Group Three report 'Ordinary Lives in Ordinary Places – The Plan for Effective Participation in Decision-Making' is particularly important.

While participants' supporters advocated on their behalf, this remains an ad-hoc system. The National Advocacy Service falls short of the independent, statutory Personal Advocacy Service committed to in the Citizens Information Act 2007 as advocates have no statutory powers, there are long waiting lists reported and the exclusion of children with disabilities from the remit of NAS means there is no national, statutory service providing advocacy for children. There is also a notable absence of any commitment on advocacy in the National Disability Inclusion Strategy.

5.5.4 Personalisation

That people spoke little of disability throughout the research is an important finding. Instead, participants noted the importance of looking at the interests, strengths and resources of unique individuals. Yet, people continue to be labelled according to categories of mild, moderate, severe and profound intellectual disability, e.g. by the Health Research Board, which frequently serve to define and limit the kinds of supports and services they can access. The research would suggest the need to look beyond the categorisation of persons with intellectual disabilities in policy and practice and instead focus on the person as an individual. This will be challenging but is necessary. In this way, supports can be built up around a person, focusing on their personal wishes, needs and abilities.

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[11] As stated by Minister Charles Flanagan on 13th November 2018, PQ 46563/18 and 46564/18

The importance of personal supports to the achievement of an ordinary life by persons with intellectual disabilities has been well established in the literature and the findings of this study add to the evidence base. Yet there is little evidence in the public domain to say whether increased personalisation of services is actually happening.

Despite the emphasis on personal supports in the Value for Money and Policy Review of Disability Services and other policies, around three quarters of the €1.7bn allocated by the HSE to disability services every year is spent on residential and day services, many of which are segregated, 'one size fits all' services.

It is not clear how much funding is allocated to personalised models of support or how much funding will be allocated to allow persons with disabilities to access personal budgets. It is evident that the HSE will need to be more pro-active in developing new service models as the majority of service providers are clearly failing to do so.

5.5.5 Changing nature of support

The study provides strong evidence on the need to shift away from traditional, paternalistic notions of 'care' and towards support if people with intellectual disabilities are to have their right to socially included lives recognised and supported.

This need has been recognised recently in the National Disability Inclusion Strategy which makes a commitment to changing the model from one of 'care' to one of 'support' to achieve maximum independence. However, responsibility for implementing this massive shift is assigned to the HSE and disability service providers. To really change this culture, a broad range of stakeholders need to be involved including non-disability related service providers, training colleges and professional and regulatory bodies.

Recent recommendations contained within the report of the Task Force on Personalised Budgets indicate the challenges of changing traditional practices that can be restrictive in nature. The Task Force recommends that the HSE will maintain a list of approved service providers with people with a personal budget having to recruit from this list. It also proposes that mandatory training for personal budget holders be completed. While well intended, these restrictions can be limiting for people with disabilities. There is evidence in both this and previous research that for social inclusion purposes, sometimes qualities and local connections are more important than qualifications. It is essential that the proposed demonstration projects are evaluated in order to determine the impact of such requirements on personal budget holders.

The changing nature of support has implications for the training of those paid to support people with intellectual disabilities.

On the one hand, training courses for nurses, social workers and allied health and social care staff should include training on personalisation and supporting social inclusion and those working with people with intellectual disabilities should receive ongoing training in these areas.

However, a more fundamental shift is required. The Sláintecare report recommends that 'care' is provided at the lowest level of complexity. In the context of social care supports, this raises questions about the continuing development of intellectual disability nurses, whose training is about developing sound clinical nursing skills, when the need to move toward community inclusion has been clearly established in research and policy.

The findings of this study as well as other research carried out in Ireland would seem to indicate that support for social inclusion should be more focused on community connections, advocacy, building social skills and supporting people to make their own decisions.

5.5.6 Positive risk taking

Linked to the need for culture change in service provision is the need for positive risk-taking. Risk and safety are often seen as two sides of the same coin. It is assumed that services that are risk-averse are somehow safe. However, it could be suggested that being risk-averse in relation to social inclusion is a symptom of poor management and leadership rather than providing a safe service. HIQA reports frequently indicate that risk averse services in the social inclusion context often are found to have poor fire safety, under report or fail to report abuse and other adverse events, poor medicines oversight and other poor standards of care.

While the focus on health and safety in inspections by HIQA to date has been understandable – health, safety and security is a basic right - so too is social inclusion. In this context, the commitment in the NDIS that HIQA will focus on inspections against key quality of life outcomes in the next round of inspections is an important one. Reporting must demonstrate the performance of the service against the nine outcomes identified by the National Disability Authority as being central to living in the community (NDA, 2016).

To support positive risk-taking, support staff need permission and clear policies around letting the people they support take risks. If supporters are unsure of their role and suspect they will be held accountable if something goes wrong they are likely to act defensively, limiting opportunities for social inclusion.

The Assisted Decision Making (Capacity) Act 2015 clarifies that a person should be supported to make decisions that reflect their own needs and choices regardless of whether they are in the person's best interest. It allows for decisions that may seem unwise to some to be respected if the person has the capacity to make that decision. This will be a big challenge for staff who are currently working in a 'safety-first'

environment and the codes of practice being developed will be crucial in providing guidance in this regard.

5.5.7 Inclusive environments
Participants provided evidence on the important role that inclusive environments played in supporting them to live socially included lives. They reported that valuing diversity, a willingness to listen to participants and the provision of reasonable accommodations by educational institutes and employers supported them to be included.

This reinforces the importance of policies which seek to make mainstream spaces, services and supports accessible to people with intellectual disabilities. This would suggest a key role for the Public Sector Duty, as set out in the Irish Human Rights and Equality Act 2015 which places a positive duty on public bodies to promote equality, ensure human rights are realised and eliminate discrimination.

Access to transport was a key enabler and would suggest that accessible transport (across urban and rural areas) and transport supports should be key objectives of social inclusion policy. Since the closure of the Mobility Allowance and the Motorised Transport Grant scheme to new applicants in 2013, a replacement scheme, proposed under the Health (Transport Support) Bill has not been progressed. The absence of such transport supports acts as a barrier to social inclusion and means that some people with intellectual disabilities have to rely on others to access the community.

Though the proposed model of personal budgets applies only to services funded by health and social care services, this study provides an impetus for a whole of government approach to personal budgets. This would, for example, allow people to use a personal budget for transport costs to enable social inclusion.

5.5.8 The importance of work
Though only one element of living a socially included life, the importance of work to social inclusion comes across clearly in participant's stories. Work was seen as important in providing the income to enjoy other aspects of social inclusion (such as one's own home) as well as providing sources of social engagement, friendship, and a sense of contribution and being valued.

In this context, it is worrying that in spite of commitments in the Comprehensive Employment Strategy, recent research suggests that little progress has been made with regard to employment among people with intellectual disabilities. An analysis of NIDD data over a five-year period indicates that the proportion of people attending day services increased while the proportion of those receiving employment supports fell (McConkey et al, 2018). Among people with intellectual disabilities, there was no significant improvement in employment rates between 2011 and 2016 (CSO, 2012; CSO, 2017).

The segregation that occurs at school leaving stage may be, in part, due to poor policy and practice in the management of transitions from school into further education, training and employment. There is concern that, in some cases, occupational guidance for many young adults with intellectual disabilities being provided by the HSE can serve as a gateway to HSE funded day services rather than mainstream options. In addition, the option of deferring a place in a day service to try out mainstream options and then taking up a day service place if this does not work out has not been available in the past to young people with intellectual disabilities.[12] The school guidance services could easily be trained to include disability service options for people with intellectual disabilities without limiting the individual to just those options.

None of the participants in the study were working more than 20 hours a week. This raises a number of issues with regard to policy and practice.

Firstly, many mainstream work activation programmes are only open to those who are working a minimum of 30 hours. Activation programmes and supports need to be available for people with intellectual disabilities for part-time work, including where this is below 20 hours per week.

Secondly, where participants can and want to work more hours, barriers or perceived barriers to working more hours need to be addressed. This implies a need for greater public awareness of recent changes made through the Make Work Pay initiative.

5.6 Messages for people with intellectual disabilities and families

The study shows that there are people with intellectual disabilities living socially included lives all across Ireland. It demonstrates the importance of people with intellectual disabilities telling their stories, showing society the potential people with intellectual disabilities have and challenging attitudes and perceptions.

The stories of participants in this study provide useful messages for other people with intellectual disabilities living in Ireland. Indeed, one participant stated that it was important for people with intellectual disabilities to encourage other people with intellectual disabilities to 'make the move'.

In this spirit, this section uses participants own words to highlight some key messages for people with intellectual disabilities.

5.6.1 'I couldn't be happier because I am independent'

A key message from participants is the impact social inclusion has on their emotional health and happiness which comes from having choice and control in their lives. This

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[12] It is the authors' understanding that this situation has now changed on foot of the implementation of action 5.1 of the Comprehensive Employment Strategy for People with Disabilities. It is expected that around 30 young people will avail of deferred places in 2018.

can include small choices from the time they go to bed to choosing their support person.

Access to peace and quiet in their own homes was key for some participants in managing their mental health. This was in comparison to the noise they had no control over in congregated settings.

5.6.2 'It's all about the match'

A key lesson from the research is the importance of people choosing their supports. This includes:

- Recruiting supporters and having a choice over the nature of supports

- Having supporters who are not 'carers' focusing on disability but supporters who value the person as a unique human being, focusing on strengths and interests

- Having different supporters, some who will share interests, others who will support the person to connect with the community, access work or training

- Working in partnership with supporters on planning and working slowly towards goals which takes time

- Having a personal budget or a flexible pot of money means a person can recruit their own staff and manage their support hours in a flexible way, for those who wish to take this option.

People spoke about how important it is to have plenty of support at the start of anything new and how this can change to less support if needed.

5.6.3 'The knitting club organised an outing for me when my mother died'

The research shows that the more time people spend in the community, accessing mainstream activities, the more likely they are to feel more included. Joining groups and making connections can provide important supports to people at challenging times in their lives.

5.6.4 'The kitchen table had take-out the night you moved …with all the work done we were too tired to cook … all the family were there'

The process of people starting to live independently provided opportunities for greater connections with family members who helped with the move. Having their own space also meant people could entertain guests.

Families can play a key role in promoting the benefits of personalised supports and the difference it has made to their relative's life.

5.6.5 'I couldn't do that … if I was in the hostel, I had to have staff everywhere I go'

People's hidden capacities were revealed by living independently and it was important that this capacity was recognised by supporters. A capacity to 'ask for help' was emphasised by many participants since living independently can be very challenging.

5.6.6 'I think it's very important that people with intellectual disability or disability in general encourage each other to make the move"

The majority of participants acted as advocates and were involved in campaigns at local and national levels. This presented opportunities for taking up leadership roles, becoming politically active and inspiring others to become activists.

5.6.7 'I can walk to work and I can walk home'

People said that the practicalities of living close to community services, work, and social activities supports people to be more included in their community.

5.7 Messages for future research

While there is a rich amount of data captured through the stories of the participants in this study, it is clear that 19 stories do not capture the diversity of experience of people with intellectual disabilities in Ireland. There is a need to know more about the extent of inclusion amongst people with intellectual disabilities in Ireland.

This study intentionally focused on just a small number of success stories but further research should include larger scale studies.

Further research could also examine the social inclusion experiences of people with intellectual disabilities from ethnic minority backgrounds, those who identify as LGBTQI+, and those from different economic backgrounds to determine what role different parts of their identity plays in their experience of social inclusion.

Lastly, future research might have a longitudinal focus, to monitor the impact on people's lives as they move from segregated settings to more personalised options, especially in living arrangements.

5.8 Recommendations

5.8.1 Recommendations for policy

- As a key strategy aimed at driving inclusion among persons with disabilities, the NDIS and associated implementation groups could promote greater social inclusion by:

- Making a plan to include important aspects of social inclusion that have been omitted, such as support for relationships and supports for advocacy and self-advocacy

- Producing annual reports evidencing progress and outcomes on all aspects of social inclusion relevant to people with intellectual disabilities

- Bringing forward a replacement scheme for the motorised transport grant and mobility allowance, committed to in the Strategy, as a matter of urgency

- Leading an awareness campaign or work with employers and services on how they can play a role in including people with intellectual disabilities in the work place

- Choice, control and decision-making are critical to living a socially included life. Policy can provide the infrastructure to support this by:

    - Fully implementing and resourcing the structures recommended in the Plan for Effective Participation in Decision Making to support people with intellectual disabilities to be involved in decisions that affect their lives

    - Adequately resourcing the Decision Support Service, as established by the Assisted Decision-Making (Capacity) Act 2015 to provide a robust service to the population with intellectual disabilities

    - Ratifying the Optional Protocol to the UNCRPD to allow persons with intellectual disabilities to take complaints directly to the UNCRPD Committee, once national routes of complaint have been exhausted.

    - Providing accessible information on policies and policy changes to support people with intellectual disabilities to take part

- The availability of personal, self-directed supports and payments would create greater opportunities for social inclusion. Unbundling funding from traditional services would foster greater autonomy and control over the supports availed of. Conditions in Service Level Arrangements could be used to support service providers to unbundle funding and facilitate persons to choose their own supports.

- Social inclusion of persons with intellectual disabilities requires whole of government working between multiple government departments depending on the aspect of social inclusion the person wishes to pursue.

    - A whole of government approach involving the Department of Health, Department of Housing, the HSE and local authorities would support

people with disabilities to access housing and the supports required to live independently.

- A whole of government approach to personal budgets would ensure that people could use a personal budget to meet needs that are not covered by HSE-funded health and social care services, for example, transport.

• Transitions from school should support people with intellectual disabilities into mainstream further education, training and employment.

- Career guidance for young school leavers should set out options for mainstream occupations

- The option of deferring a place in a HSE funded day service should be available for young people with intellectual disabilities should they wish to try out mainstream options service

• The Department of Housing should increase the availability of suitable rental accommodation (in social housing especially) to enable people with intellectual disability to move from congregated settings or family carers

• Increase the diversity among service providers and promote innovative, personalised providers through a commissioning process.

5.8.2 Recommendations for practice and service provision

• Disability services should take steps to deliver personal supports to the people using their services, as committed to in disability policy. This could include:

- Unbundling funding and allocating a portion to each person using the service

- Giving the person the choice over how their budget is spent

- Facilitating people to pick their own support workers and direct how this support will work for them

- Supporting people accessing their service to engage in a full discovery process with the person on hopes, dreams, goals, etc.

- Ensuring staff have the appropriate skills and knowledge to work in a community focused, person-centred way

- Providing people with intellectual disabilities and family members with Information on personalised accommodation and support options; their availability locally, outcomes and how to access them

- Efforts from mainstream service providers to include people with disabilities, in line with equality legislation and the Public Sector Duty, would support social inclusion. This might include:

    - Carrying out an audit of their organisation and identifying barriers that exist for people with intellectual disabilities to access the service

    - Providing information on the service and relevant forms in accessible formats

- The promotion of self-advocacy and peer advocacy within annual reviews of person-centred plans and availability of training resources on this topic would help to build capacity for decision-making

- Routes to ensure participation in design and delivery of services could be further explored. This might include the development of Equality and Rights Committees in disability services

- There is a need to re-evaluate approaches to risk in favour of a more positive approach that supports social inclusion. Implementation of the commitment in the NDIS to evaluate services in the next round of inspections against quality of life measures as well as health and safety, would support this shift. So too would the delivery of clear policies and training on positive risk-taking for staff in disability services.

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Appendix 1 - Participant Profiles

Participant 1
A woman in her forties. Lives in a town. Works 2 mornings a week for 2 hours in the same place for 11 years. Member of a local knitting group. Runs a blog on accessibility in the town. Independent social life

Participant 2
A man in his forties who lives in a town with his mother. Works 2 full days a week. Independent and full social life. Keen interest in sports both as a participant and follower.

Participant 3
A man in this twenties. Lives in a city. Studies full time. Has a girlfriend and independent social life. A passion for film and photography.

Participant 4
A man in his late teens. Works 20 hours a week. Independent social life. He is planning to return to part time education to further his digital skills. Plays golf.

Participant 5
A man in his thirties living independently in the city suburbs. Married. Works part time. Independent social life. Very keen sportsman.

Participant 6
A woman in her early forties. Lives independently in city suburb. Married. Independent social life.

Participant 7
A man in his fifties. Supported to live in his own home in a rural setting. Self-employed part-time. Spent the majority of his adult life in an institutional setting.

Participant 8
A woman in her early thirties living with family in rural setting. Works part time. Volunteers in the arts. Has a personal budget. Sings in the local choir and a variety of personal interests that she engages in.

Participant 9
A man in his early thirties living with family in rural setting. Works one morning a week. Plays music locally. Volunteers with local CASA group.

Participant 10
A woman in her thirties living independently in a rural setting. Works two shifts a week. Plays and follows a number of different sports. Participates in adult education.

Participant 11
A woman in her late sixties. Living independently a town in supported housing for the elderly. Spent her life in congregated or community home settings until 2 years ago. Participant in a variety of community activities. Independent social life.

Participant 12
A man in his thirties living in a rural setting with his family. Works two mornings a week for the last 13 years. Volunteers at local GAA club. Supports family business at weekends and follow local GAA.

Participant 13
A woman in her late thirties, supported to live in her own home in city suburb. Very close family ties. Working with local 3rd level institutions to plan a return to education.

Participant 14
A woman in her early twenties, living on outskirts of town with her family. Provides 20 hours of voluntary work to local service. Participates in part time mainstream education. Advocacy work.

Participant 15
A man in his late forties who lives in a local authority house in a village. Works 20 hours a week. Active participant in the community. Independent social life. Great interest in music and plays with local music sessions.

Participant 16
A woman in her thirties who is a home owner in the city. Works part time. Participates in mainstream education. Level 6 qualification. Will return to college this year to complete a degree.

Participant 17
A woman in her forties living independently in the city suburbs. Sessional worker. Applying for mainstream education course. Participant in mainstream clubs.

Participant 18
A woman in her early sixties, living in her own home in city after a long period of living in congregated or group home settings. Independent social life. Loves to shop and go to the movies independently.

Participant 19
A man in his forties living in community home in city suburbs. Very close ties with family. Works two mornings a week. Passion for photographs and art galleries. Loves to dance.

Appendix 2 – Flyer

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

INCLUSION IRELAND

Stories of Social Inclusion Research

Inclusion Ireland and researchers from Trinity College Dublin are running a new research project, supported by the National Disability Authority.

The project is about social inclusion.

- We are going to collect **positive stories** so that others can hear about them and learn from them.

- We plan to **make videos** of some of these stories and put them on the inclusion Ireland Website.

Many people with intellectual disabilities are included in the communities where they live, leading ordinary, everyday lives.

We want to hear from people who have stories to tell about being included in their community and having a sense of 'belonging' in many areas of their life.

We want to hear from people who are actively participating in the communities where they live.

Who can take part in this research?

We are looking for people who:

- Are taking part in mainstream work, education or community life. **Mainstream** means that something is open to all persons, not just people with a disability.

- Are 16 years old or older

- Are living in Ireland for more than 2 years

- Working in a mainstream, paid job or have your own business

- Taking part in mainstream secondary school or college

- In a relationship with a partner. Do you have   children? Do you have good friendships with people you work with or other members of your community?

For this project, we are not looking for stories where:

- People had no choice about where they are living or who they are living with

- The majority of people's relationships are with paid staff

- People spend most of their day in disability services or are taking part in work or education that is just for disabled people

- People are volunteering somewhere where people are usually paid

As there may be many people who want to take part in the study, we may have to say no to some people.

This does not mean that your story is not important to us, but we can only talk to about 19 people.

Contact Inclusion Ireland   **info@inclusionireland.ie**

01-8559891   **www.inclusionireland.ie**

*This project is inspired by '19 Stories of Social Inclusion' carried out by the Disability Research Institute at the University of Melbourne and community partners.

https://www.19stories.org/

Appendix 3 – Ethics

The project received ethical approval from the ethics board of the School of Social Work and Social Policy at Trinity College Dublin.

Storage of data and confidentiality

Consent forms are safely stored in a locked cabinet at Inclusion Ireland premises. Consent forms will be shredded after 5 years. Under the Freedom of Information Act, participants will be able to access their personal information during the 5 years it is stored.

All interviews were anonymised with fictional names to avoid to the greatest extent possible any identification of the participant.

Original audio-recordings were sent securely for transcription to a professional service. Original audio-recordings were deleted from the devices used to record them. The original audio files will be stored for 5 years in a password-protected computer at Inclusion Ireland's premises. Under the Freedom of Information Act, participants will be able to access their personal information during the 5 years it is stored.

Time to consider participation

Participants had at least 1 week to consider participation in the study. Information forms were distributed to potential participants with the contact information of the research assistants should they wish to learn more about the project/participate in the project.

Accessible information and communication

The target population of this study was people with intellectual difficulties, some of whom may have communication difficulties. The information about the study was provided in easy to read format which includes plain English text with pictures. As potential participants may not have been able to read English, a note was included at the top of the information and consent forms to please have the forms read out loud to potential participants. All research assistant had research experience and experience of supporting others with communication difficulties to speak. Participants were also given the option to have a supporter with them with communication. The supporter identified by the person signed a consent form indicating agreement to support the person speak and not to speak on their behalf.

Participants for whom English is not their first language were also invited to take part in the study. A translator/interpreter (e.g., Irish Sign Language interpreter) was available if required.

The following forms are included in this Appendix:

- Accessible information sheet – study participants

- Consent form – study participants

Slightly amended versions of these forms were used for parents/legal guardians for participants under 18, for study participants under 18, supporters, and video participants.

- Consent form – study participants

19 Stories of Social Inclusion

Information Form: Study Participants

Please read this form out loud, if asked, to facilitate access

Inclusion Ireland and researchers from Trinity College Dublin are running a new research project supported by the National Disability Authority.

The project is about **social inclusion.**

We would like to **invite you to take part** in this study. Before you make a decision to take part, we want to explain:

• Why are we doing this research and

• What will you do if you take part.

Please take time to read this form and ask questions if anything is not clear or you want to know more about the study.

Take time to make a decision to take part.

This study has been approved by the Research Ethics Committee at the School of Social Work and Social Policy, Trinity College Dublin.

Who are we?

Inclusion Ireland is the national association for people with an intellectual disability.

With this study, we want to find people with intellectual disabilities who are living and participating in the community.

- We want to know what they have done to get where they are
- What has helped along the way
- We want to help them to tell their story.

Who can take part in this study?

We are looking for people who:

• Are 16 years old or older

• Have lived in Ireland for at least 2 years

• Have a positive experience of social inclusion.

As there may be many people who want to take part in the study, we may have to say no to some people.

This does not mean that your story is not important to us, but we can only talk to about 19 people.

What will you do if you take part?

If you take part in this study, you will be asked to do an interview for about one hour. In this interview, we will ask you to tell:

• Your story about social inclusion

• What did you do to have this experience

If you don't want to answer any of the questions, that's Ok.

You can tell that to the researcher and we will ask you another question.

You can make a decision to stop taking part in this study at any time. That will be Ok and nobody will be upset.

You will still be able to take part in other studies with Inclusion Ireland and Trinity College Dublin.

To keep things you say and to use your own words, we would like to audio-record your interview.

Some people do not like being recorded. If you don't like being recorded, that's Ok, we will take notes instead.

www.inclusionireland.ie

We want other people to know about positive stories of social inclusion. We will put these stories in the Inclusion Ireland website.

We will also ask you if you want to have a short video of your story.

You don't have to do this to take part in the study. You can still tell your story even if you don't want to have a video.

www.inclusionireland.ie

If we record a video with your story, the video will be at Inclusion Ireland's website for anyone to see.

You will make decisions about what is in the video and only when you are happy with the video, it will be shown to other people.

If you choose to have your video on Inclusion Ireland's website, you can still make a decision to take out your video later.

This is an example of a video about social inclusion https://www.19stories.org/story-7.

Are there any risks if you take part?

We don't know of any risks if you take part in the study.

If you feel upset during the interview, we will stop the interview and ask you if you want to continue later or another day.

We will also ask you if you want to talk to someone about you feeling upset. We will discuss this with you before the interview.

If you have your story with your name at the Inclusion Ireland's website, some people may be able to know who you are and to contact you.

You can make a decision about this when we do the interview and also later on.

Are there any benefits of taking part?

You will not get paid for taking part in this research.

However, we hope that the study allows us to find out:

• What are the experiences of social inclusion for people with intellectual disabilities in Ireland and

• What helped people have these experiences.

We hope this research can help other people who would like to enjoy social inclusion.

Will taking part be confidential?

We will keep recordings and written versions of what you say for five years.

Only the researchers from Trinity and Inclusion Ireland will be able to listen to the recordings. You can also ask for your recordings or personal files anytime during those 5 years.

www.inclusionireland.ie

We will not include your name when we type out what you said in the report.

We will give you the opportunity to have:

• Your story at Inclusion Ireland's website. You can choose to have your name with your story or not. If you choose to have your name with your story, anyone can identify you.

• A short video of your story at Inclusion Ireland's website. If you choose to have a video of your story, anyone can identify you.

When you tell us your story, if we think you or someone else has been harmed or is in danger, or if a crime has been committed, we will have to let the relevant authorities know about it.

We will tell you first, who are we going to talk to.

How will your information be kept?

The information you give us will be stored as follows:

• The consent form you sign will be stored in a locked file cabinet at Inclusion Ireland.

• The recordings of the interview will be stored first in an audio recorder device and then in the computer of the researchers.

• This computer is password protected and only the researchers will have access to it.

• When we type out what you said, we will delete your name and any other personal information that can identify you.

• These transcripts will be kept in the computers of the researchers and only they will have access to them.

• Under freedom of information legislation, you are entitled to access the information you have provided at any time.

What will happen to the results of the study?

We plan to use what you and other people tell us:

• In a report to the National Disability Authority. Your name will not be used.

• At Inclusion Ireland's website. Only if you want your story and your name to appear, we will include them.

• If you agree to have a short video of your story, we will put that up at the Inclusion Ireland's website.

• In research papers and conferences. Your name will not be used.

www.inclusionireland.ie

Do you have any questions?

• If you want to take part, we will ask you to sign the consent form.

• You can tell us if you want to take part 10 days from now.

• You can stop taking part in this study at any time and that is ok.

• Can you tell me what will you be doing if you take part in the study? I can ask you some questions.

Who should you contact for further information?

You can contact:

Inclusion Ireland info@inclusionireland.ie or 01-8559891.

Thank you!

_____I have read or someone has read the information form about this study.

_____I know that taking part in this study means that I will do an interview of about one hour, and that I can choose to have my story (in writing or in video) at the Inclusion Ireland's website.

_____All my questions have been answered.

_____ I know that I can stop taking part in this study at any time.

_____I understand that I will not get paid for this research but by taking part, I will help others understand what social inclusion is.

_____I agree to have my interview audio-recorded.

www.inclusionireland.ie

_____I agree to have my story at Inclusion Ireland's website.

Consent Form: Study participants

_____I agree to have my name with my story at Inclusion Ireland's website.

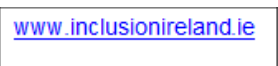_____I agree to have a short video of my story at Inclusion Ireland's website.

_____I know I can change my mind about having my story (with or without my name) and short video of my story at Inclusion Ireland's website.

_____I agree to have pictures of me taken.

_____I agree to have pictures of me in the written report, at conferences and other publications.

_____I agree to have pictures of me at Inclusion Ireland's website.

_____ I know that I can say that my interview cannot be used up until 2 weeks after doing it. If I do that, my interview will be deleted.

_____ I know that what I say will be treated confidentially.

_____ I know that in any report of this research my name will not appear and that other details about me will be hidden.

_____ I know that parts of what I say (without my name and other details about me) can appear in the report, publications and conference presentations.

_____ I know that if I am or someone else is at risk of harm, the researcher will talk to the relevant authorities. They will let me know this first.

_____ I know that my consent form and audio-recordings and transcripts (without my name) will be kept for 5 years at Inclusion Ireland's locked cabinets and in the researchers' computers.

_____ I know that under Irish legislation (Freedom of Information) I can check my interview or audio-recordings during the 5 years they are stored.

_____ I know that I can contact any of the people involved in the research to learn more about the study.

_____I agree to be part of this study.

_____   _____

Participant's Signature   Date

_____   _____

Appendix 4 – Interview schedules

Instructions

- We will have some general chat and endeavour to put the interviewee at ease before we start into the interview.
- We will have spent some time ensuring that we have got consent to taking part in the research.
- We have the interview organised into three parts and we plan to take short breaks at the end of each of these. But we will reassure the participant that they should also feel free to ask to pause or finish the interview at any time.
- We will explain that we will take turns to ask the questions. Saying X will do the first part and Y will do the second. The other person will listen and at the end might ask a few further questions.
- Finally, we will turn on the tape recorder, once the interviewee is agreeable to this form of recording.

VERSION 1   Interview Schedule - workplace

Thank you so much for giving your time today to tell us about your experience of social inclusion.

So, let's get started

Part 1   You are here to tell us your experience or story of social inclusion. You told us on the phone that you were working in …. Would you like to tell us about that?

Let the interviewee tell their story in their own words as much as they feel comfortable doing.

Prompt Questions - If they need help to get started

1. What sort of workplace is it?   *Shop, office etc.*

2. What sort of work do you do there? *Look for examples and some detail. Is that the same every day?*

3. What is a typical day at work like?

4. Has this changed overtime?

5. How many days do you work there every week?

6. About how many people work there?

7. Can you tell me about who you work with or spend time with in work?

   Do you have a special group of people you work with? Or maybe a manager that you have to report to? Does everyone have breaks together or how does that work? Do you spend time with people from work outside of work? Can you tell me about that?

8. Do you have any support to do your job? If you do can you tell me about it?

9. Can you describe what it feels like to be in this workplace?

10. What do you think are the good bits of working there? What are the benefits for you? Are there benefits for other people?

11. Are there difficult or hard bits? Can you tell us about them?

12. Are there things you would like to change about this experience?

We Would Suggest we take a break now.

Next, we will be talking about how this all came about.

Part 2 How did this all come about?

We are really interested to hear about how you came to be working in this workplace.

Prompt questions:

1. How did it come about?

2. Whose idea was it?

3. If it wasn't your idea did you feel you had a choice or a say in it?

(*can you tell me a little about how that happened?*)

4. Did you have any support from others to make it happen?

5. If you did could you tell me about that?

6. What sorts of jobs did you do to get this job?

7. What skills or talents did you need to have to make this happen?

8. Did you learn any new skills from the experience?

9. Do you have any advice to give someone else with an intellectual disability who is trying to get a job?

Part 3   The Importance of your story

1. Why did you want to tell your story? Why did you want to be part of this project?

2. Why is it important to you to be socially included?

3. Do you have any personal goals for this experience? Can you tell me

> # We suggest another short break before we do the final section.

about them?

Part 4   Current situation

We would like to ask you a few questions about your life generally if that is okay with you.

1. Where do you live?

2. Who do you live with?

3. Are you attending school or college or involved in any learning or studying? If you are can you tell me about it?

4. What sort of activities are you involved in? Clubs or church or sports and so on?

5. You seem to be living a very independent life. Do you have any supports that help you to do that?

6. What sort of supports, if any, do you need to live your life? And who might give that to you?

Part 5.   Telling your personal story in video.

As you know we hope to make videos of these personal stories of social inclusion so that others can learn from them. We would like to talk a little about that now. You know you are free to choose later whether you will have a video made of your story.

If you do have a video made of your story:

1. What do you think are the important things that a video of your story should show?

2. Where should we record it?

3. What people should be in the video?

4. Who do you think should see the videos or watch them?

5. What would you like people to think when they see the videos?

Thank you. We have reached the end of our interview. Is there anything else you would like to tell us?

Thanks again. Please feel free to contact us if there is anything you would like to ask.

Would it be okay for us to contact you if we have forgotten anything?

Thanks

VERSION 2 - Interview Schedule - Independent living

Thank you so much for giving your time today to tell us about your experience of social inclusion.

So, let's get started

Part 1   You are here to tell us your experience or story of social inclusion. You told us on the phone that you were Living…. *(We will remind them what they mentioned on the phone).* Would you like to tell us about that?

Let the interviewee tell their story in their own words as much as they feel comfortable doing.

Prompt Questions - If they need help to get started

1. What sort of accommodation is it? – flat, house etc.
    How many rooms? A little description of it?

2. Can you tell us a little about who you live with?

3. How long have you been living here?

4. Do you rent it / own it / etc?

5. We are interested to know if you have neighbours and if you do, how do you get on with them?

6. How about the community generally that you live in – do you know people? Are you involved in your community? If you are, tell us about it.

7. Do you have any supports to live here? Can you tell us about them? – how often? what they do to support you? Any other supports?

8. Can you describe what it feels like to live here?

9. What do you think are the good bits of living where you are? What are the benefits for you? Are there benefits for other people

10. Are there difficult or hard bits? Can you tell us about them?

11. Are there things you would like to change about this experience?

Part 2 How did this all come about?

We are really interested to hear about how you came to be living where you are?

Prompt questions

1. How did it come about?

2. Whose idea was it?

3. If it wasn't your idea did you feel you had a choice or a say in it? (*can you tell me a little about how that happened?*)

4. If you are living with other people did you get to choose who you lived with and where you lived?

5. Did you have any support from others to make it happen?

6. If you did could you tell me about that?

7. What sorts of jobs did you do organise this living arrangement?

8. What skills or talents did you need to have to make this happen?

9. Did you learn any new skills from the experience?

10. What advice would you give to other people who are trying to live in their own home?

Part 3 The Importance of your story

1. Why did you want to tell your story? Why did you want to be part of this project?
2. Why is it important to you to be socially included?

3. Do you have any personal goals for this experience? Can you tell me about them?

> **We suggest another short break before we do the final section.**

Part 4 Current situation

We would like to ask you a few questions about your life generally if that is okay with you.

1. Do you work? if you do can you tell me where you work?

2. Are you attending school or college or involved in any learning or studying? If you are can you tell me about it?

3. What sort of activities are you involved in? Clubs or church or sports and so on?

4. You seem to be living an independent life. Do you have any supports that help you to do that?

What sort of supports, if any, do you need to live your life? And who might give that to you?

Part 5 Telling your personal story in video.

As you know we hope to make videos of these personal stories of social inclusion so that others can learn from them. We would like to talk a little about that now. You know you are free to choose later whether you will have a video made of your story.

If you do have a video made of your story:

1.What do you think are the important things that a video of your story should show?

2. Where should we record it?

3. What people should be in the video?

4. Who do you think should see the videos or watch them?

5. What would you like people to think when they see the videos?

Thank you. We have reached the end of our interview. Is there anything else you would like to tell us?

Thanks again. Please feel free to contact us if there is anything you would like to ask.

Thanks

VERSION 3 Interview Schedule - community activity

Thank you so much for giving your time today to tell us about your experience of social inclusion.

So, let's get started

Part 1   You are here to tell us your experience or story of social inclusion. You told us on the phone that you were involved in …. *(We will remind them what they mentioned on the phone).* Would you like to tell us about that?

Let the interviewee tell their story in their own words as much as they feel comfortable doing.

Prompt Questions - If they need help to get started

1. What sort of a club is it? *Sports, drama, community group etc*

2. What do you do there? *Look for examples and some detail. Is that the same everyday time you go?*

3. How often do you go to the…?

4. Has this changed overtime?

5. About how many people are involved in the…...?

6. Can you tell me about who you spend time with in ….? *Do you have a group of people you are involved with Do you spend time with people from the club outside of the club? Can you tell me about that?*

7. Do you have any support to take part in the club? If you do can you tell me about it?

8. Can you describe what it feels like to be in this club?

9. What do you think are the good bits of being there? What are the benefits for you? Are there benefits for other people?

10. Are there difficult or hard bits? Can you tell us about them?

11. Are there things you would like to change about this experience?

Thanks

We Would Suggest we take a break now.

Next, we will be talking about how this all came

Part 2 How did this all come about?

We are really interested to hear about how you came to be taking part in this club or community group.

Prompt questions

1. How did it come about?

2. Whose idea was it?

3. *If it wasn't your idea did you feel you had a choice or a say in it? (can you tell me a little about how that happened?)*

4. Did you have any support from others to make it happen?

5. If you did could you tell me about that?

6. What sorts of jobs did you do to get involved in this activity/club?

7. What skills or talents did you need to have to make this happen?

8. Did you learn any new skills from the experience?

Part 3   The Importance of your story

1. Why did you want to tell your story? Why did you want to be part of this project?

2. Why is it important to you to be socially included?

3. Do you have any personal goals for this experience? Can you tell me about them?

> **We suggest another short break before we do the final section.**

Part 4 Current situation

We would like to ask you a few questions about your life generally if that is okay with you.

1. Where do you live?

2. Who do you live with?

3. Do you work? if you do can you tell me where you work?

4. Are you attending school or college or involved in any learning or studying? If you are can you tell me about it?

5. You seem to be living an independent life. Do you have any supports that help you to do that?

What sort of supports, if any, do you need to live your life? And who might give that to you?

Part 5   Telling your personal story in video.

As you know we hope to make videos of these personal stories of social inclusion so that others can learn from them. We would like to talk a little about that now. You know you are free to choose later whether you will have a video made of your story.

If you do have a video made of your story, there are somethings you might like to think about.

1. What do you think are the important things that a video of your story should show?

2. Where should we record it?

3. What people should be in the video?

4. Who do you think should see the videos or watch them?

5. What would you like people to think when they see the videos?

Thank you. We have reached the end of our interview. Is there anything else you would like to tell us?

Thanks again. Please feel free to contact us if there is anything you would like to ask.

Thanks

VERSION 4   Interview Schedule - Education

Thank you so much for giving your time today to tell us about your experience of social inclusion.

So, let's get started

Part 1   You told us on the phone that you were studying at …. Would you like to tell us about that?

Let the interviewee tell their story in their own words as much as they feel comfortable doing.

Prompt Questions - If they need help to get started

1. Can you tell us about the course you are studying?

2. How long is the course?

3. How many days a week do you attend college?

4. What is a typical college day like?

5. How many are on the course? Can you tell us a little bit about the other people on the course?

   Men/ women

   Ages

   Travel from far

6. How do you all get along?

7. Was it hard to get to know people?

8. Do you see people from the course outside of college?

9. What about your college

   How big is it? How many people attend ...?

   Do people from different courses meet up?

10. Do you have any **support** to do your college course?

    In college
    At home

    If you do can you tell me about it?

11. Can you describe what it feels like to be in this College?

12. What do you think are the good bits of doing this course? What are the benefits for you?

13. Are there benefits for other people?

14. Are there difficult or hard bits? Can you tell us about them?

15. Are there things you would like to change about this experience?

We Would Suggest we take a break now.

Next, we will be talking about how this all came about.

Part 2 How did this all come about?

We are really interested to hear about how you came to be studying this course.

Prompt questions:

1. How did it come about?

2. Whose idea was it?

3. If it wasn't your idea did you feel you had a choice or a say in it?

   (*can you tell me a little about how that happened?)*

4. Did you have any support from others to make it happen?

   If you did could you tell me about that?

5. What sorts of jobs did you do to get on this course?

6. What skills or talents did you need to have to make this happen?

7. Did you learn any new skills from the experience?

8. If you met someone with an intellectual disability who was thinking of studying here – what advice would you give them?

Part 3 The Importance of your story

1. Why did you want to tell your story? Why did you want to be part of this project?

2. Why is it important to you to be socially included?

3. Do you have any personal goals for this experience? Can you tell me about them?

> **We suggest another short break before we do the final section.**

Part 4   Current situation

We would like to ask you a few questions about your life generally if that is okay with you.

1.Where do you live?

2.Who do you live with?

3.Do you work? if you do can you tell me where you work?

4. Are you involved in any clubs or activities? If you are can you tell me about it?

5. You seem to be living an independent life. Do you have any supports that help you to do that?

6. What sort of supports, if any, do you need to live your life? And who might give that to you?

Part 5   Telling your personal story in video.

As you know we hope to make videos of these personal stories of social inclusion so that others can learn from them. We would like to talk a little about that now. You know you are free to choose later whether you will have a video made of your story.

If you do have a video made of your story, there are somethings you might like to think about.

1. What do you think are the important things that a video of your story should show?

2. Where should we record it?

3. What people should be in the video?

4. Who do you think should see the videos or watch them?

5. What would you like people to think when they see the videos?

Thank you. We have reached the end of our interview. Is there anything else you would like to tell us?

Thanks again. Please feel free to contact us if there is anything you would like to ask.

Thanks

Version 5 Interview schedule – Relationships

Thank you so much for giving your time today to tell us about your experience of social inclusion.

So, let's get started

Part 1.

You told us on the phone that you were in a relationship.

Can you tell us a little about your relationship?

Let the participants start where they wish and then prompt if they need it.

Prompts

1. How long are you together?

2. Can you tell us a little bit about how you met?

3. If living together or married – Ask a little about when they moved in together and when got married.

4. I suspect your life is like any other married couple. Can you tell us a little about your typical week? What ye like to do together?

5. Can you tell us about any supports, if any, you might have for your relationship?

6. Any other supports? How do they help?

7. It can be difficult for people with intellectual disabilities to have relationships. Can you tell me about any difficulties you had?

8. Were there any barriers to you getting together?

9. Any barriers to you moving in together or getting married? If so how did you overcome these?

10. Did you have people who supported you?

11. Can you tell us about what sort of support was helpful and what was not?

12. How does it feel for you to be in this relationship?

13. What skills and talents do you think you needed to have to make this relationship work?

14. Do you have any advice for people who want to find partner or have a relationship?

Part 2 The Importance of your story

1. Why did you want to tell your story? Why did you want to be part of this project?

2. Why is it important to you to be socially included?

3. Do you have any personal goals for this experience? Can you tell me about them?

Part 3   Current situation

We would like to ask you a few questions about your life generally if that is okay with you.

1. Where do you live?

2. Who do you live with?

3. Do you work? If you do can you tell me where you work?

4. Are you involved in any clubs or activities? If you are can you tell me about it?

5. Are you attending any education or training courses? If so can you tell me about them?

6. You seem to live an independent life. Do you have any supports that help you to do that?

7. What sort of supports, if any, do you need to live your life?   And who might give that to you?

Part 4   Telling your personal story in video.

As you know we hope to make videos of these personal stories of social inclusion so that others can learn from them. We would like to talk a little about that now. You know you are free to choose later whether you will have a video made of your story.

If you do have a video made of your story, there are somethings you might like to think about.

1. What do you think are the important things that a video of your story should show?

2. Where should we record it?

3. What people should be in the video?

4. Who do you think should see the videos or watch them?

5. What would you like people to think when they see the videos?

Thank you. We have reached the end of our interview. Is there anything else you would like to tell us?

Thanks again. Please feel free to contact us if there is anything you would like to ask.

Thanks

Appendix 5 – Research Advisory Committee (RAC) membership

Gerard Byrne	Disability expert by experience
Una Coates	Disability expert by experience
Nóirín Clancy*	Inclusion Ireland
Michael Feely*	Trinity College Dublin
Edurne Garcia Iriarte*	Trinity College Dublin
Padraic Fleming	HSE
Christine Magee*	Research Assistant, Project Team
Sandra McCullagh*	Inclusion Ireland
Tomas Murphy*	Research Assistant, Project Team
Molly O'Keeffe	Possibilities Plus
Heather Taylor	Parents and Guardians of Cregg Services
Margaret Turley*	Research Assistant, Project Team

*Project Team members