How Friendship is understood in Adults with Intellectual Disabilities

Across three Life Stages.

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Background

Community participation is a major goal for all disabled people, but one which has proven difficult for adults with intellectual disabilities (HSE 2011). With a strong history of isolation and current change in policy towards community integration, research shows social networks for adults with intellectual disabilities has been restricted. The experience of friendship has long been recognised as an important element in a satisfying lifestyle for people with intellectual disabilities (Knox and Hickson 2001).

Objectives

The purpose of this study was to look at how adults with Intellectual disabilities create lasting friendships at home and in the community. It aimed to do this by investigating how friendship is understood in adults with intellectual disabilities across three life stages using Levinson’s developmental theory.

Methods

This is a qualitative study. Six participants with intellectual disabilities were interviewed using semi structured interviews. The interviews were transcribed and the data was analysed thematically.

Results

Two categories emerged from the data. (1) Elements that shape friendship. Participants discussed how family, services, community and housing impact on friendships. (2) The meaning of friendship. Participants’ defined friendship by the amount of time spent with people and by describing different relationships they had. The importance of community participation was identified by a number of participants in creating friendships.

Conclusion

The preliminary findings suggest where people live, services or communities they are involved in appear to have an impact on friendship. Occupational therapists have a role in facilitating projects to promote interaction with local communities for adults with intellectual disabilities.
Title: How friendship is understood in adults with intellectual disabilities across three life stages early adulthood, age thirty transition and midlife.

Introduction

Inclusive community living involves the creation of long lasting relationships between family, neighbours and social relationships (HSE 2011). Community participation is a major goal for all disabled people, but one which has proven difficult for adults with intellectual disabilities (Brady and Gates 2003). There is a significant social barrier held by other members of the community towards people with disabilities (Green et al 2005). Stigma is something disabled people have to deal with every day (Jahoda and Markova 2004). Stigma arises when a person is different from dominant social norms on a particular dimension which is negatively evaluated by others (Jahoda and Markova 2004). This study aims to look at the creation of lasting relationships of adults with intellectual disabilities and how discrimination might effectively be disrupted.

The search strategy used for this research included books, Google search, and data-bases such as Academic Search Complete, Medline, AMED, and CINAHL. Keywords were stigma, intellectual disabilities, mental retardation, integration, inclusion, deinstitutionalization, ageing and learning difficulties.

Literature Review

Goffman’s (1963) work on stigma remains influential. He defined stigma as an attribute that is shameful and reduces a person’s identity from that of a normal human being to a ‘not normal’ under privileged person. Extending Goffman’s work Link and Phelan (2001) argued that power must be exercised and is essential for stigma to occur. Link and Phelan (2001) highlight how people have a tendency to look down on attributes of a person with a disability like a mental illness, or physical dysfunction, with self-pity. This also highlights distinction between ‘them’ and ‘us’ (Green et al 2005, Link and Phelan 2001). Status loss and discrimination occur when stigma reduces an individual’s participation in the social or economic life of their community (Green et al 2005).

Community participation and community involvement in an essential part of establishing meaningful relationships (Cummins & Lau 2003). Without links to a community people live
in isolation. Notably, in disability research community is represented as the opposite of segregation or isolation in ‘special’ facilities or services which only include disabled people and those who are paid to support them (Brady and Gates 2003). Institutions are an extreme example of how power is exercised to separate the nondisabled ‘us’ from the disabled ‘them’. There is a strong history of isolation among people with disabilities, in particular adults with intellectual disabilities (Jahoda and Markova 2004). Until recently in Ireland, it was believed that the best place to provide care for people with intellectual disabilities was in residential institutions separated from their local communities (HSE 2011). By separating people with intellectual disabilities into institutions, it automatically stigmatized this population. However there was a shift in thinking, through the introduction of policies and structures (HSE 2011, HRB 2011, United Nations 2006) Strategies such as National Housing Strategy for people with disabilities to provide funding, Man Power Strategy to support programmes of transition to community settings and National Protocols to support community inclusion (HSE 2011). Ireland is committed to ensuring the move of adults with intellectual disabilities to community settings from institutional settings (HSE 2011).

Extension to wider networks has potential for enriching lives of people with intellectual disabilities, increasing social participation as well as enhancing the life to the wider community (Hogg et al 2008, Cummins and Lau 2003, Bigby et al 2008, Brady and Gates 2003). Community living offers the prospect of an improved lifestyle and quality of life over institutional care (HSE 2011, McCarron et al 2011). Successful community living requires close attention to the way services are set up and run, especially staff. Adults with intellectual disabilities are often dependent on others to bring about strategies that can make a change, which may be one of the reasons why their social exclusion continues even though there are major shifts in service delivery and policy to increase their community presence (Abbott and McConkey 2006). Research shows that social networks for adults with intellectual disabilities are typically restricted to family members, service providers, staff members and peers with intellectual disabilities (Hogg et al 2008, Cummins and Lau 2003).

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (2011) reports 50% of participant’s experiences loneliness, with some people expressing simple, but currently unachievable, wishes like drinking tea with a friend. This can be understood as a basic desire to have ‘normal’ relationships comparable to those of
nondisabled people. Nirje (1994) describes the normalization principle, one of the foundations of inclusion and embedded in philosophy of critical disability theory (Pothier and Devlin 2006). This principle shows that by making available patterns and conditions of everyday life which are as close as possible to ‘norms’ and patterns of mainstream society to adults with intellectual disabilities, society would be more inclusive. However this principle can be effective in adapting environment in a short time but patterns of people’s behaviours and attitudes is not as simple and takes a lot longer. Hence, there is a barrier in the creation of friendships for this ageing population of adults with intellectual disabilities. The IDA-TILDA (2011) reports that 37% of adults with intellectual disabilities reported never meeting friends. This adverse result was linked to residential accommodation. Despite the introduction of policies and procedures there still remains a social barrier for the adults with intellectual disabilities in community settings forming lasting friendships. Studies show a number of barriers such as residential settings, age and a strong history of discriminatory attitudes towards adults with intellectual disabilities (Jahoda & Markova 2004, Jahoda et al 2010). On the contrary 48% reported meeting friends often, hence despite these barriers there is a population who manage to create friendships (IDA-TILDA 2011).

The experience of friendship has long been recognised as an important element in a satisfying lifestyle for people with intellectual disabilities (Knox and Hickson 2001). Most individuals build their lives around friendship and family. A friendship consists mainly of being attracted to someone who is attracted in return, with parity governing the social exchange between the individuals involved (Hartup and Stevens 1997). Friendship is experienced differently across different age groups (Patterson 1993). Levinson’s developmental theory (1986) provides the framework for understanding changes over the life course. Levinson defines the life cycle of a person as a sequence of eras. Each era has its own bio-psychosocial character and each makes its distinctive contribution to the whole. There are major changes in our lives from one era to the next hence as one begins the previous one is approaching its end. A cross-era transition which generally last about 5 years terminates the out-going stage and initiates the next. This study looks at three cross-era transitions. The early adult transition from about 17 to 22 a developmental period in which pre-adulthood draws to a close and era of early adulthood gets underway. The age 30 transition is a stage where we begin to re-evaluate our path in life. Then the midlife transition roughly age 40 to 45 which brings about the termination of early adulthood and the start of middle adulthood.
This study aims to look at how adults with intellectual disabilities create lasting friendships at home and in the community. It aims to do this by investigating how friendship is understood in adults with intellectual disabilities across three life stages early adulthood, age thirty transition and midlife.

**Methodology**

A large qualitative research project titled Navigating Stigma to Build Real Communities aims to look at how people with disabilities navigate stigma to create real relationships in their communities. The study reported in this paper is part of this larger project.

**Research Design**

Critical disability theory is the overarching theory informing this qualitative study (Halloway 1997). It puts the power into the hands of those with a disability. It questions power relations and promotes self-advocacy (Dowse 2001). This study is guided by the work of Goodley (2001) he reports the critical approach is adapted in looking at material formations of what is considered normal and abnormal. He shows how disability research recognises the social and cultural formations of ability and inability of adults with intellectual disabilities and it works with them within this culture (Goodley 2001). The UN Convention on the Rights of Persons with Disabilities (2006) highlights the right of all people with disabilities to live in the community with choices equal to others. Those communities should take effective and appropriate measures to facilitate full enjoyment for their full inclusion and participation in the community.

**Participants**

Purposive sampling, which is selecting a sample in a deliberative and non-random fashion, (Knox et al 2000) was used for this study. The participants were recruited through poster’s put up in various centres round Limerick and by word of mouth to people around the Limerick area. Posters were clear and easy to understand through the use of imagery (see appendix A). Adults with intellectual disabilities who were interested in participating in study took the contact information from poster. If it was word of mouth they heard about the study the information was passed on to them from various sources like project workers or co-ordinators in different centres. Six self-selecting participants with intellectual disabilities
were recruited, four male and two female ranging from ages 19 to 45 years. Two participants lived with their parents, three lived independent and one lived in residential care. The researcher met with participants at a place the participant chose. Three participants completed interview in service centres, one in a residential centre and two participants completed interview in their own house. The interviewee went through an information sheet so they have the knowledge of what exactly the study was about before they give their consent. The information sheet and consent form had both images and text to help the participant comprehend (see appendix B & Appendix C).

**Data Collection**

In-depth semi-structured interviews were completed with all participants, following the interview guide created for the larger study (see appendix D). The interview consisted of open ended questions, visual aids such as headline from recent newspaper and visual diagram of circles to help participants who is close to them (see appendix E), and a diary sheet (see appendix F). Participants had the choice of completing the interview over two days. However, all participants completed the interview in the one day.

The interview was audio-recorded with the consent of the participant and was transcribed after each interview. The recording was deleted of the recording device after it had been transferred to a hard drive, an electronic storage system where all interview recordings are kept on file. This is kept locked in a drawer of the principal investigator’s office of the larger study. The transcripts were cleaned and names of people or places were removed to protect participants’ privacy. Participants were given an option of having a copy of their transcript after their interview.

**Data Analysis**

The interviews were analysed using thematic analysis. Braun and Clarke (2006) argue qualitative approaches are incredibly diverse and complex, and thematic analysis is seen as a foundational method for qualitative analysis. Thematic analysis is a method for identifying, analysing and reporting patterns or themes within data. This was applicable in this study, the study aimed to identify friendships in adults with intellectual disabilities, across six different interviews within three different lifespans. Braun and Clarke (2006) outline a process of six different phases of thematic analysis. First step was to familiarising yourself with the data, by
transcribing each interview and reading over the transcripts. After becoming familiar with the data one generated an initial list of what was interesting across data, and produced initial codes. Following this step, one grouped the codes into potential themes, stage three of thematic analysis. This was the final stage of analysis of this study. This involved coding each transcript by given each line a number in the transcript and grouping each potential category using Microsoft excel spread sheet. This was then finalised to two categories with a number of sub categories in each.

**Ethical Considerations**

There were many ethical considerations taken into account with this group of individuals. First the larger project was approved by Education and Health Sciences Research Ethics committee in University of Limerick and by Marie Curie Research Ethics Committee. The researcher received ethic’s training on the ethics review process at University of Limerick, balancing ethical tensions, recruitment, and interview process. The researcher had an ethic’s meeting with supervisor before data collection started to review the consent process. One was mindful throughout all stages of the research process of various issues that could have arisen in the context of this study with adults with intellectual disabilities (NDA 2009). In relation to attainment of consent, it was very important this group of individuals knew what the study was about, what was going to be asked in the interview, how it was going to be recorded and what was done with the recording after their interview. To make this clearer, the consent form had images as well to help the participant comprehend the text accompanied with it. It was made clear to participants that their names would not be used in study. There was the option to divide the interview in two parts. Participants were also reminded on a number of occasions throughout the interview they didn’t have to answer all questions. It was also important for this group of people that they understood their rights and that the interview could be stopped at any time.

**Findings**

Each participant gave a description of their weekly routine, discussed who they spent their time with and people they were close to and comfortable with. All six participants spoke differently about their relationships with people. Some reported having close friends they spend time with, others reports having many friends, others reported their family members or
people in the service they attend as friends throughout the interview. Two main categories emerged from the six participants interviews.

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-Category</th>
<th>No. of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elements that shape friendship</td>
<td>Housing</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Structure of day service</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Community Participation</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>6</td>
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<tr>
<td>How Friendship is understood</td>
<td>Meaning</td>
<td>3</td>
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<tr>
<td></td>
<td>Who friends are/ types of friends</td>
<td>6</td>
</tr>
</tbody>
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Table 1: Findings

1. **Elements that Shape Friendship**

There were a number of different components that influenced friendship formation.

1(a) **Housing/ where people live**

The participants housing ranged from living with their parents, residential housing and independent living. All participants spoke positively about their housing arrangement and reported good relationships with the people they live with. One participant who recently moved from her family home to independent living spoke about spending a lot of time with the girl she now lives with.

"see when living independently myself and (person lives with) like to spend time doing things"

Two participants reported enjoying spending time at home which was their family home. They spoke about spending time on their own, how they liked spending time in their room or watching T.V with their family members.
“no mainly I'd stay at home”
“I just like doing my own thing”

The participant who lived in residential housing reported a lot about spending time with staff members and referred to her timetable when speaking about how she spends her time.

“Nowadays staff know that I do go out for a walk when I ask can I put it on the timetable”
“Eh no ya have to go by the timetable and that’s just it”

For four out of six participants, housing appeared to influence who they interacted with and when they did so.

1(b) Structure of service

All six participants spoke about attending a day service during their week day diary. Some reported spending five days a week, nine to five. Others reported attending one or two days a week. Some reported the day centre as work where they did jobs, others spoke about it as a place where they met friends and did fun activities. Five participants reported having friends in the service they attended. One participant just associated friends with the service they attended and only reported spending time with friends there. When speaking about friends in service:

“I: Would there be many people that you see as good friends?
P: Anyone at all.
I: Okay, and is there anyone you would see as your best friend?
P: No I just like having friends.”

Two participants expressed the service as part of their routine and only associated with it on certain days.

“P: I pop in there but that’s were I go only on a Monday and a Thursday
I: and who’s in there that you meet up with
P: I meet up with [name] On a Monday and then [name] would be there and sure all the staff would be there in the morning “

The structure of service for this group of people appeared to be associated with staff, other service users and specific days of the week.

1(c) Community Participation
Three participants spoke about being involved in their local communities. Whether it was volunteering for local tidy towns, playing darts in local club or been involved in local youth groups. Through this interaction participants spoke about meeting and forming friendships. One participant referred to a group of friends as “dart friends”. When asked about darts and who attends:

“it’s informal who turns up you could be lucky you could meet the same people or could be totally different people who turn up its open to everyone.”

Two participants spoke about the importance about community involvement for people with disabilities.

“yea I do well I think community is very very important for a person with a disability to be seen involved in the community because you have something to contribute to your community by been involved in it…….”

“everyone fits in...everyone fits into positive relationships”

The participants that spoke about community participation reported position relationships. Two participants reported they preferred to be at home than out in community. They reported they preferred spending time alone.

1(d) Family

All six participants reported family as people they are closest too. Three participants reported spending a lot of time with family. One participant spoke about going to local pub with their family.

“P: we would go to the local pub

I: so would you go there and just hang out for a little while?

P: yeah I go with my mum and dad there and I might meet cousins there as well”

Families were described as a strong influence in supporting friendship and community participation.
“I presume well it’s all down to the family I think when you’re young and you get a chance of going out and meeting people that your brothers or sisters know or your cousins or relations or things like that things that introduce you to the social environment that’s how I think you can build up a relationship or identify places where you can go and if your family isn’t there you know the law of the land like”

Interestingly this participant identified family as an important component in friendship formation.

2. How friendship is understood

The meaning of friendship and how it is understood was different across the six participants. All participants spoke about friends and reported meeting friends when talking about people they were close too and in their weekday diary. However there was a wide range in different types of friends or who friends were throughout the six participant’s interviews.

2(a) Meaning of friendship

Participants were asked to identify people they knew well, people they knew a little and people they didn’t feel comfortable around. Each participant identified a range of people in each category. Some participants identified people on the amount of time they spent with them, others spoke about people who were caring and good to them while others spoke about people they could talk to and relax with. What appeared to define friendship with this group of participants was the about of time spent with people. When participants were asked directly about friends they’re responses varied from having loads of friends, to having a particular friend. Some participants identified close friends. However no participant mentioned the term best friend and when asked they just identified friends.

“I: Is there anyone you would see as your best friend?

P: No I just like having friends”

A few participants spoke about having close friends and reported how they enjoyed spending time with them each week.

“P: Oh I have a particular friend”
I: What would you do with that friend every week?

P: yea we might go to the pictures, we go different places [pause] coffee [pause] meal..”

Friendships were identified a lot in shared interests.

“I: who do you play darts with?

P: Friends that meet up”

The importance of friendship was identified by three of the participants. When discussing people they were close too three participants stated briefly a description of their relationship with the person identifying between a friend and acquaintances. While others stated everyone as friends which left the meaning unclear at times.

2(b) Who friends are/ types of friends

The participants identified a wide range of friends from people they work with, to people they live with, family members, staff members, neighbours, people in their community and people in services they attend. An example of this is a participant speaking about her fitness instructor.

“She’s a good instructor and a very good close friend of mine like staff here.”

The participant here identifies staff members as friends. While another participant spoke about staff members as work related friends.

“she would be work related yeah but I would salute her if I seen her”

Family members were also recognised as friends. The interviewee asked one of the participants’ what they do when meeting friends. Participant responded:

“P: we would go to the local pub

I: so would you go there and just hang out for a little while?

P: yeah I go with my mum and dad there and I might meet cousins there as well”

Some participants spoke about friends who share the experience of a disability.
“well there’s a few that I meet up with, there’s a friend in a wheelchair that I met up with every Saturday and we get a coffee in [name of cafe]”

The participants also mentioned specific types of friends such as virtual friends for example “Facebook friends”. Some participants referred to friends as days they met them during the week for example “Saturday friend”.

**Discussion**

Preliminary findings suggest there are a number of elements that effect the formation of lasting friendships for adults with intellectual disabilities.

**Life stages**

Exploring the three different life stages across the six participants there appear to be a number of factors that influenced friendship. There were a lot of similarities around friendships and relationships between the two participants in the early adulthood transition life stage, and between the two participants in the midlife transition in that two participants in early adulthood were living at home with their parents and the two participants in midlife transition were living in independent living arrangements. The housing arrangements of all participants appeared to have an influence on their social interactions. For example the two participants in the early adulthood stage reported a lot about spending time with their parents and did a lot of activities with their family. Levinson (1986) describes the early adult stage as where one modifies his or hers relationship with the pre adult world and begins to form a place as an adult. Friendships are formed on shared experience and similarities (Hartup and Stevens 1997). Participants in early adult stage reported spending a lot of time alone or with their family.

While the two participants in midlife reported spending their time with a mix of people ranging from family members to people in community. Levinson (1986) describes the midlife transition as a time of question of meaning, direction and value in a person’s life. Friends are fewer than early adulthood but more selective and deeply valued (Hartup and Stevens 1997). Two participants in the midlife transition appeared to have a wider social network than the two participants in early adulthood. Carstensen (1992) show how as people age the rate of social interaction decline. Interestingly for this group of participants it was the opposite. The
two participants in early adulthood reported spending a lot of time at home and a lot of time alone playing computer games. While the two participants in midlife transition appeared to be very active in their local community where they were involved in youth clubs, tidy towns and went to local football games.

Two participants which were in early adulthood transition only identified people who they were in services with and their family as friends, while the two participants in the midlife transition gave clear descriptions of their relationship with various different people from family to service to community and identified friends from these. The participants in the mid thirty transition identified people they spent most of their time with such people they lived with or staff.

**Elements that shape friendship**

There were a number of influences on friendship formation for the six participants. The importance of services in the participants’ lives was evident through the six interviews where all participants reported attending services at some stage in their week. How services were set up appeared to influence friendship for the six participants. One of the participants spoke of a desire to get out in the community more however this was restricted when referring to the ‘timetable’ a number of times during the interview. They spoke getting out for walks around their local town but it would depend on what staff members were on. This is an example of how power can influence people’s interactions with extended community. Brady and Gates (2003) research show the use of ‘special services’ which only people with disabilities use or can influence unintended isolation for people with disabilities from wider communities. Hartnett et al (2008) demonstrated community based services for adults with intellectual disabilities in Ireland had a positive effect on their quality of life by providing new found social roles, new hobbies and work opportunities. Three participants highlight the importance of community participation for people with disabilities. They spoke about their enjoyment of being involved with local tidy towns or local youth club meeting new people forming new friendships.

**Meaning of friendship**

There was a diverse meaning on friendship among the six participants. Influences on friendship appeared to vary between occurrence, difference between friends versus mere
acquaintances and quality of friendship. Participants reported friends when discussing an activity or place they did in their weekly routine. McVilly et al (2006) completed a qualitative study on friendship with intellectual disabilities and friendship was identified as shared leisure activities, together with provision of practical assistance or emotional support. Similarly for this study friendship was identified a lot with shared meaning or experiences. The meaning of friendship is a diverse term and is different to everyone. Hartup and Stevens (1997) state friendship consists mainly of being attracted to someone who is attracted in return with similarities leading the social exchange between the individuals involved. This is an interesting concept when considering the types of friend’s participants identified. There were various different types of friends such as staff, family, other people with disabilities, people in the community and virtual friends. All the types of friends identified, the participants had something in common with each other. This demonstrated the meaning of friendship was different to each participant in this study.

**Limitations of the study**

Recruitment of participants for the study was slow and limited which increased time constraints for analysing the results of the participants. A small sample size is one of the major limitations of this study. Participants were recruited in a deliberate and non-randomised way, so people that participated in the study wanted to.

The participant’s interview was self-reported so only the information they wish to disclose was available. This was limiting in that some participants mentioned about instances that happened in their life that they didn’t wish to talk about. However, Knox and Hickson (2001) completed a qualitative study in Australia on friendship in adults in intellectual disabilities which effectively highlighted the impact of the environment on friendship enactment by just interviewing four participants.

**Implications of the study**

This study highlights important considerations for occupational therapists working with adults with intellectual disabilities. The participants in this study highlighted the importance of the community for meeting new people and exposure to new relationships. The effectiveness of community based programmes described Hartnett et al (2008) increased integration and allowed opportunity for people with intellectual disabilities to meet new
people. Occupational therapists have the potential to enrich adults with intellectual disabilities lives by encouraging community based programmes. It also increases the awareness of the importance of the environment for adults with intellectual disabilities.

**Future Research**

This study demonstrates the value of qualitative research with adults with intellectual disabilities. Friendship has been long recognised as an important element in satisfying lifestyle for people with intellectual disabilities (Knox and Hickson 2001). Further research in the identification of friendships of adults with intellectual disabilities and their connectedness with community will further investigate the concept of inclusive living (HSE 2011). With the current economic issues in Ireland it is important to highlight the needs and advantages of adults with intellectual disabilities in communities. It also suggests the important and influential contribution adults with intellectual disabilities themselves can make themselves and promote self-advocacy among this group by adopting participatory approaches to research in particular when investigating friendships (Knox and Hickson 2001).

**Conclusion**

This research aimed to look at how friendship is understood with adults with intellectual disabilities across three life stages. Data was limited to six participants in total, two participants in each life stage. Findings suggest there are a number of elements that influence friendship such as housing, day service, community and family. It also suggested that the meaning of friendship and who friends are was identified differently across the six participants. This study highlights the need for further research on friendships in adults with intellectual disabilities. It also highlights the importance of community based programmes for occupational therapists working with adults with intellectual disabilities.
References


Self-advocates have the last say on friendship†. *Disability & Society*,21(7), 693-708.


If you have been diagnosed with an intellectual disability and are aged 18+ years, we want to hear about how you build relationships at home, school or work and in your community.
### Building Real Communities Information Sheet

<table>
<thead>
<tr>
<th>We want to learn about people with disabilities in Ireland, creating lasting relationships at home, at school or work and in our communities.</th>
<th>URL: <a href="http://www.botanus.com/blog/1">www.botanus.com/blog/1</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>If you agree, you can tell your story about making and keeping strong friendships with family, friends and people at school or work.</td>
<td>URL: <a href="http://www.onwisconsin.uwalumni.com">www.onwisconsin.uwalumni.com</a></td>
</tr>
<tr>
<td>If you are over 18 years old and have an intellectual disability you can be part of our study.</td>
<td>URL: <a href="http://www.koolartwales.com/celebs/">www.koolartwales.com/celebs/</a></td>
</tr>
<tr>
<td>We would like to interview you for 2 hours, we can do the interview in 2 parts at a place and time you choose. If you agree, then our talk will be recorded.</td>
<td>URL: <a href="http://www.digitaldictaphone.org.uk/">www.digitaldictaphone.org.uk/</a></td>
</tr>
</tbody>
</table>
Paula will be doing the study with the help of Nancy and Fiona.

Your story will be private and you can use a different name. Nancy and Fiona will read your story and with your permission may use parts for a larger study. Your story will be kept locked in Nancy’s office for 7 years.

You do not have to answer all the questions.
You can stop talking at any time.
You can listen to your interview.

If you feel upset we can stop or talk about something else.

There is no money for taking part in the study. Your story may help other people with a disability.

If you have any questions about this project please contact Nancy Salmon email at nancy.salmon@ul.ie - phone (061) 234275
### Appendix C: Consent Form

#### Agreement Form

I have read/heard the letter about this study. I have read/heard the consent form. All my questions were answered and I agree to be part of this study. I know that I am free to stop being part of this study at any time. I can ask for copies of my interviews.

<table>
<thead>
<tr>
<th>I agree that Fiona Kumari Campbell from Griffith University in Australia can read my interview.</th>
<th><img src="" alt="Image" /></th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree that my interview can be part of the big pool of life stories of people with disabilities in Ireland once my name and details are taken out.</td>
<td><img src="" alt="Image" /></td>
</tr>
<tr>
<td>I was given a copy of the letter and this signed consent form.</td>
<td><img src="" alt="Image" /></td>
</tr>
</tbody>
</table>
URL: www.istockphoto.com

___________________________________  _______________________
Your Signature (or Parent or Legal Guardian)  Date

___________________________________  _______________________
Researcher’s Signature  Date
Appendix D: Interview Guide

Navigating Stigma Interview Guide

Part 1: Consent Interview

Review information letter and consent form with potential participant. If person agrees to be interviewed, then complete the following questions at the end of the consent interview.

Introduction

Thanks for agreeing to talk to me today about how you have made strong relationships at home, at school/work, and in the community. We will talk about how you spend your time and who you like to spend time with. Remember that you don’t have to answer any questions you don’t want to and that we can stop talking whenever you like. Are you ready to get started?

Day profile

1) I’d like to see how you spend your time during the day and on the weekends. So let’s start with what a week day looks like for you [Fill out daily planner].

2) Does the weekend look different? [If yes, then fill out those parts of the daily planner]

People you like to spend time with

We all have many different kinds of people in our lives. Some people we share everything with, others are people we do things with. I’d like you to fill out this picture by putting the names of people you are closest to in the middle circle, people who you know and like in the middle circle, and people you only know a little bit in the biggest dark blue circle. The names
of people you don’t like but spend time with can be put outside the circles. [return to this diagram as a touchstone for rest of interview]

Tell me about who you’ve included in this diagram. [probe for the degree of intimacy in the relationships]

Now I’d like to talk to you about things you like to do.

**Things you like to do**

1) What do you like to do in your free time? [Use daily planner as a reference for this question]

2) Who do you enjoy spending time with? [Jot down names down as a reference point]

3) What do you like to do with these people? How much time do you spend with this person? [Refer to names mentioned by participant, establish if any of the friends who have been mentioned share same disability experience or diagnosis]

4) Are you able to do all the things you enjoy with your friends and family? [If no: what gets in the way?] [If yes: is there anyone else you know who don’t seem to get out and do as much as much as they would like, what stops that person from being able to spend time with family and friends?]

5) Would you like to do any of these activities more often? [If yes: what would those activities be, where, with whom, how often?]  

6) Would you like to do any of these activities less often?
Part 2: Full interview

Introduction

Thanks for agreeing to meet with me today. As you know this study is about how people with disabilities made strong relationships at home, at school/work, and in the community. Last time we talked about how you spend your time and who you like to spend time with. Today I’m going to ask your about times and places where you feel more or less comfortable. I will also ask you about anything that makes it harder or easier to do what you want to do in the day. Remember that you don’t have to answer any questions you don’t want to and that we can stop talking whenever you like. Are you ready to get started?

Being out in the Community

Some places are great to spend time at, while other places can be less comfortable. Let’s look back over your weekly diary to see where you spend your time.

1) How many of the things you like to do happen out in the community? [refer to the weekday diary for prompts]

2) Where do you feel most comfortable when you are out with friends or family?

3) What is about that place puts you at ease?

4) Is there anywhere you ever awkward when you are out?

5) What makes that place different to the places that do feel comfortable?
[Probe for more detail: people, environment, interactions, activity, location, accessibility etc]

6) Do you prefer to socialise at home or out in the community? Why?
**Workplace or School** [only complete this section if person is working, has worked in the past or is attending school]

1. Now I’d like to hear more about the time you spend at work [or in school if participant is a student]. Can you take me through a regular work day? [might be reflected in diary].

2. What are the main things you do at work?

3. Who are the people you enjoy working with?

4. Are there people you prefer not to work with?

5. Tell me a recent experience you had working with people you feel comfortable with at work.

6. Tell me about a recent experience where you felt awkward or uncomfortable at work. What did you do to deal with this situation?

7. Does having a disability [or diagnosis] make any parts of your job difficult? If so, please describe.

8. Do people in your workplace know you have a disability?
   a. If so, how did you share this information with them? Why did you decide to tell them? Did you tell co-workers and/or supervisors? Did disclosing to them changed your working relationship in any way?
   b. If not, why have you chosen not to tell people about your disability?

9. Do you think you get treated differently than your nondisabled peers at work?
   a. If so, in what way(s)?
   b. [Here could give examples of subtle and obvious forms of discrimination in the workplace/school from recent newspapers or legal cases in Ireland].

10. Do you get treated differently by those who know about your diagnosis
11. What are some of the good things about people at work knowing about your diagnosis? What things are not good about people at working knowing?

12. Would you disclose your diagnosis again in the future to co-workers or supervisors? Why or why not?

**Being treated differently**

[Note: If the person has not used the word stigma, use whatever word they did use e.g. discrimination or feeling uncomfortable or treated differently because of disability or diagnosis].

1) [Present some key findings from stigma survey in Ireland 2007]

2) I have an interesting newspaper clipping here in which a person with a disability talks about her experiences of stigma while socializing and how she feels that this restricts how much she socialises. Is that something that you relate to?

3) Do you get treated differently about as often as other people with disabilities?
   a. Can you tell me stories from other people you know who are treated differently because of their disabilities? Why?

4) Have you ever been in a situation when you are out with family or friends where you were treated differently than people who don’t have [insert medical diagnosis or disability]?
   a. If yes, tell me about that.
   b. If no, do you know any stories from others who have had this experience?

5) Where do you get treated differently most often?

6) What do you do when you are in situations where don’t feel comfortable or safe? What works best for you?

7) Are these strategies similar to those used by others you know who also have [insert name of medical diagnosis or disability here]? [e.g. ask specifically about friends who have disabilities if participant mentioned them earlier in the interview]
8) Do you feel that these experiences affect your ability to participate in social activities?

Wrap Up

I would like to take a few minutes to be sure I have some of your personal details recorded correctly. Remember, this information will stay private and nothing you have said will be linked back to you in anything that is written or talked about from this study.

Participant Demographics (to be completed at the end of the interview)

1) Female/Male
2) Age
3) City or rural dwelling
4) Marital Status
5) Nationality
6) Housing: House, apartment, institution
   a. How long in current residence?
   b. Part of a housing scheme? Supported by a voluntary body?
7) Do you live with others? If so, are they friends or relatives?
   a. Were able to choose who you wanted to live with?
   b. Do you have any paid or voluntary support provided by others to enable you to live in your current residence?
8) How long have you lived with your [disability, medical diagnosis, mental health condition]?
9) How far did you go in your education?

10) Current employment status; work history
   a. Training
   b. If on work placement, who is support provided by
   c. Doing job of own choosing?

It’s been great talking with you today. You have given me a great deal to think about.

Is there anything we haven’t talked about that you would like to add?

I will send you a short summary of our talk today. Do you want me to send that by email or post? I am also happy to call you to talk through what is in that summary. Would you like me to do that? If so, please give me the phone number you would like me to call.
Appendix E: People in My Life

People I don’t feel comfortable around

People I know well

People I’m close to

People I know a little
### Weekday Diary

**Appendix F:**

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