“The only disability I have is other people” –

Navigating Stigma: The changing role of friendship in people with acquired physical disabilities.

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Abstract

Background

Stigma is considered to be the main barrier to friendships in people with acquired physical disabilities. Occupational Therapy as a dynamic, client-centred process is well positioned to address stigma. Whilst the process of stigmatisation in intellectual disability has been thoroughly examined in literature, there is a lack of research examining stigma associated with acquired physical disabilities, and the role it plays in the trajectory and function of friendship. The UN Convention on the Rights of Persons with Disabilities aims to minimise the attitudinal barriers to engagement and promote inclusion. However, this is yet to be ratified in Ireland.

Objectives

The purpose of this study is to explore the experiences of stigma in adults with acquired physical disabilities specifically investigating the impact of stigma on the role of friendship.

Methods

Semi-structured interviews were completed with three adults (25-45) with acquired physical disabilities, recruited through local disability organisations as part of a longitudinal navigating stigma study.

Results

Thematic analysis explored experiences of stigma participants encountered after acquiring their physical disability. It also yielded sub-categories describing the strategies participants employed to navigate stigma to create and sustain friendships: 1) Disrupting societal norms, 2) Ableism, 3) Invisibility versus hyper-visibility of stigma, 4) Segregation versus Inclusion.

Conclusion

These findings highlight the role occupational therapists can play facilitating people with acquired physical disabilities re-establish their occupational identity. Through establishing peer mentoring programmes, engagement in meaningful activities can be achieved allowing friendships to be created and sustained through meaningful occupations, minimising the lived experience of stigma.
Introduction

Friendships are an integral component of relationships to most people. Described as the most important of all human relationships, they provide a foundation of support and understanding for the person, thereby sustaining and enabling the development of both a persons’ self-esteem and self-identity (Newton et al. 1994; Cummins and Lau 2003; O’Connor 2005). Friendships serve multiple purposes; they indicate a persons’ quality of life, provide companionship, assistance, guidance and support, promoting health and well-being. As adults move from being able bodied into acquiring a disability, friendship roles change and they acquire greater importance. Even though people with disabilities do not see themselves as disabled or view their identity based on impairment (Warren 2002), research has shown that society recognises them as dissimilar (Ellerton et al. 1996; Lagerheim 1998). It is through identity that an understanding of complex relationships between individuals and society emerges. (Shakespeare 1996).

Differences in the quality of relationships between people with and without disabilities have been explored in multiple tenants of friendships across a wide range of social networks (Sands and Kozleski 1994). However, there is a distinct lack of research which examines the changing role and function of friendships post the onset of physical disability. Through acquisition of physical disability, the trajectory of friendships is altered and through a loss of friendships, people with physical disabilities feel marginalised and that society holds negative attributes and attitudes towards them. This results in avoidance and an expression of stigma towards disability (Kitchin et al. 1998).

Terminology

For the purpose of this study, it is imperative to have clear definitions of friendship and disability.

Friendship is defined as a reciprocal relationship between people who voluntarily spend time together which existed for at least 6 months prior to or post the acquisition of a physical disability.

Disability: “A substantial restriction of the person to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment” – Part Two, Disability Act 2005.
Literature review

In his seminal work, Erving Goffman defined stigma as “undesired differences”, a characteristic which is deeply discrediting and which can produce undesired attitudes towards a person (Goffman 1963, p.5). Stigma describes a relationship of devaluation (Marshall 1994). Goffman argues that in order to understand stigma, it is necessary for researchers to shift from a focus on attributes to a focus on relationships. Many researchers in sociology have used Goffman’s research as a guide to explore how various stigmatised groups have managed stigma and negotiated identity to create lasting relationships (Herman 1993; Cahill and Eggleston 1995).

Link and Phelan (2001) define stigma through merging the interwoven components which exist within the stigma concept. They found stigma to be present through five keys processes of labelling, stereotyping, separation, status loss, and discrimination working together in synthesis. For stigma to exist, power must be exerted by one force, society, over another, the individual with the illness or disability (Link and Phelan 2001). This definition has implications for understanding several core issues in stigma research. It recognises stigma as an evolving, ever present concept. Not only does the person have to deal with their own diagnosis and illness, they also have to navigate the stigma associated with it (Jones et al. 1984; Williams 2009).

The presence of stigma serves to lower self-esteem and self-efficacy (Link et al 2001; Corrigan and Watson 2002) and leads to the person with the acquired physical disability having a sub-standard quality of life (Graf et al. 2004). Studies by Graf et al 2004 and Gaebel et al 2006 re-affirmed this belief that stigmatisation and discrimination create a negative self-concept about perceived quality of life. These studies found that people with acquired physical disabilities perceived stigma as reflecting poor general health, physical condition and emotional well-being. It interferes with daily routines, activities, family, friendships, social and working lives, as well as the emotional well-being and quality of life of those impacted (Janssens et al. 2003).

Stigma is associated with chronic diseases (Jacoby, 2003) mental health issues (Mc Sween 2002; Schulze 2003) and other disabilities (Tak-Yink SA et al. 2003). Whilst some physical disabilities are visibly identifiable, others are not immediately visibly detectable (Joachim and Acorn 2001). Having a physical disability and being different to the general population...
subjects an individual to possible stigmatisation by those around them who do not have a disability (Williams et al., 2009).

Green et al. 2005 note that society’s beliefs, stereotypes, perceptions of stigma act as a barrier to the sustenance and creation of relationships for people with disabilities. Located within a socio-political context, Link and Phelan (2001) found that stigma is associated with four major themes: labels and identity, negative social value, sub-human perception and poor social standing. Sekidides (2001) argues that people with disabilities ground themselves in a societal context to construct a meaning of self-identity. Relationships with friends play a vital role in the concept of self-identity. The label “disabled” is often associated with deviation (Adkins 2003) and according to the social model of disability to be labelled disabled effectively excludes an individual from mainstream society (NDA 2006). The NDA (2006) attitues the largest obstacles which people with physical disabilities strive to overcome, they remain viewed in a negative manner, different from societal norms. Physical presence in the community is not sufficient of itself to achieve integration and the physical disabled population remain marginalised (Barber and Hupp 1993).

Research has shown that people with physical disabilities are more susceptible to health difficulties when compared to the non-disabled population (Brody et al 2001) and are resultantly more vulnerable to stigma and discrimination (Gouvier and Coon 2002). People with physical disabilities are associated as having fewer socially desirable traits and non-disabled people consequently behave differently around them. Therefore, society hold negative attitudes and express discrimination, ignorance and fear towards people with physical disabilities, knowingly disregarding and shunning them, resulting in occupational alienation and isolation (Kitchin et al. 1998).

The aim of this paper is to investigate how people who acquire a physical disability in adulthood navigate stigma with regard to normative expectations and manage the disruptions which occur in relationships, to live meaningful lives in both a personal and societal context.

Methodology

This study is part of an overarching Navigating Stigma project taking place between 2012 and 2016. During this time over 160 qualitative interviews will be completed, describing how people with disabilities in Ireland navigate stigma to create a sense of belonging at home, work and in their communities. This research will examine to experience of people with
disabilities in Ireland, highlighting the centrality of the experience of stigma attached to
disability. Together these interviews will comprise an innovative database that will offer a
valuable cultural archive highlighting the experiences social inclusion in Ireland from 2012-
2016.

Critical Disability Theory is the paradigm which guides this study. The main focus of critical
disability theory is to force dominant “normal” members of society to remove themselves
from their perceived position of power and superiority to move towards a society whereby
disabilities no longer act as a means of separation (McKenna 1997; Eldridge 1997; Michalko
2002).

Qualitative research is defined as the study of people and events in their natural setting (Stein
et al 2012). Materials are collected and used to describe problematic issues which arise in an
individual’s life (Denzin and Lincoln 1994b). Qualitative methodology lends itself to
disability research as it enables participants to have their voices and unique experiences heard
through their own words (French 1994; Westby and Blackman 2010). It enables the
researcher to get involved with the participant in their natural setting, to understand the
meaning participants attribute to the phenomena under investigation (Stein et al. 2012).

Qualitative approaches are incredibly diverse, complex and nuanced (Holloway and Trodes
2003). Ethnography and Grounded Theory research was excluded as they focus on culture
and generating theory respectively (Holloway and Trodes 2003). A qualitative methodology
approach using thematic analysis was employed (Braun and Clarke 2006). Ample data was
generated through using qualitative methods, enabling researchers to narrow down the subject
area discussed; thereby avoiding analysis consisting merely of extensive lists of instances and
observations. A systematic, subjective approach was used to describe life experiences (Braun
and Clarke 2006).

Semi-structured interviews were employed in this study as they enabled participants to
describe their experiences in as much detail as they wished (Carpenter and Suto 2008; Flick
2011). Through employing this structure, the researcher maintained a degree of control
throughout the interview process, directing the flow of the interviews, whilst simultaneously
allowing the participant autonomy and freedom to describe experiences in as much detail and
depth as they desired (May 2001; Reynolds 2003; Willig 2006; Whitehead et al. 2006). In
research, the emphasis is placed on gathering personal experiences and attitudes associated
suggest that a small sample, composed of people who have personal experiences associated with the phenomena is able to provide meaningful data. As such three participants with various acquired physical disabilities were recruited from local disability organisations, associated with the over-arching Navigating Stigma project, and were interviewed.

The interviews lasted between 50-90 minutes in length and were conducted in an environment which was both convenient and comfortable for the participants. The interviews were audiotaped. Field notes were recorded immediately post interviews (Shaw and Gould 2001; Smith 2003). Participants were asked to discuss their experiences living with an acquired physical disability; how they were affected by stigma and their experiences of friendships which emerged after they acquired their disability.

Thematic analysis is a form of analysis used to identify the main categories in small qualitative data research projects (Boyatzis 1998; Roulston 2001; Braun and Clarke 2006). This approach allows the data to be analysed in a comparative form with the emergence of certain topics after the interview process has been completed (Flick 2011). The three semi-structured interviews were transcribed verbatim. Thematic analysis proved to be a flexible and resourceful research tool, which allowed for the emergence of multiple detailed, complex categories from the interviews (Braun and Clarke 2006).

Transcripts were uploaded into the software programme Nvivo9, a specific programme for coding qualitative data. A set code list was developed collaboratively with the research students involved in this overarching Navigating Stigma project, and the same coding scheme was applied across all transcripts. This allowed for emergent categories to be linked together, compared and contrasted, thus enhancing the validity of the research findings. In order to correlate multiple findings, each transcript was read numerous times until similarities and contrasts emerged. At this juncture, the coding process began (Braun and Clarke 2006). These codes were arranged into categories and more in-depth analysis produced sub-categories (Coffey and Atkinson 1996).

**Reflexivity**

Reflexivity was a key component employed throughout the research as a form of self-analysis and appraisal tool. This ensured that the researcher’s personal experience of living with a physical disability did not influence any of the participants during the interviews (Dowling 2006). Field notes were recorded immediately post interview (Carpenter 2000). Perceptions,
non-verbal behaviour and body language were all noted, documented and incorporated into
the data and analysis, significantly reducing the influence of personal bias on later
interpretation of the interview (French et al. 2001; Mason 1996). The researcher’s role was
monitored and discussed during research supervision to ensure that data analysis was
thoroughly grounded in the data, thus ensuring that the participants experiences were
accurately portrayed (Carpenter 2002).

**Ethical considerations**

This project sought and obtained ethical approval from two separate ethical committees –
Education and Health Sciences Research Ethics Committee at UL and the Marie Curie
Research Ethics Committee. Ethical issues are of extreme importance in conducting research
which contains personal meanings and feelings of a participant (Flick 2011). It is concerned
with the steps taken to ensure the protection of the participants in the research being
conducted (Schnell & Heinritz 2006). Ethical issues were researched by examining the
ethical models of Schnell & Heinritz (2006) and Murphy & Dingwall (2001). As with all
research there are many ethical issues to consider but for the purpose of this paper the
researcher chose to explain two areas in particular.

Participation in the research was voluntary and participants received an information leaflet
about what was entailed in each interview before the interviews took place (Allmark 2002).
Informed and written consent was obtained before the interview process began and the
participant acknowledged that they were free to leave the interview at any juncture without
consequence (Wolff 2004). Whilst interviewing the participant about the severity of their
illness during the interview, the researcher needed to be very accommodating for the
emotions and data variances which result. The questions were approached in a graded
manner; beginning with trivial, factual questions before introducing the emotional charged
questions of stigma associated with acquired physical disability and the role it played in
friendships (Thomson et al. 2004).

Confidentiality and anonymity are crucial components of research. All personally identifiable
information was removed and only the age and the sex of the participants were recorded
(Beauchamp and Childress 2001). It is imperative that readers are unable to identify any of
the participants (Luders 2004b). The interview is transcribed verbatim instantaneously post
interview. Research students involved in the overarching Navigating Stigma project had
access only to the data they gathered or from participants who met the criterion for their
particular research study. The principal researcher has access to all of the interviews accumulating in the database. Once transcribed, the recorded tape is destroyed. The anonymised transcripts were sent to the principal researcher for electronic storage on an external hard drive stored in office as a cultural archive for at least 10 years, as per university protocol.

Findings

By placing people into categories, streamline thinking was enabled, which in turn allowed for the emergence of stigma as one category which was distinctly favoured over another; non-disabled versus disabled (Link and Phelan 2001). Each participant recalled stigmatising scenarios they experienced with their friends after the onset of their physical disability. To examine the stigma experience fully, it was necessary to view the experience through Link and Phelans five intersecting elements of stigma (2001). These headings were used to fully examine the role stigma played in the friendships of the three participants, and how they navigated this stigma to sustain, and create friendships.
The trajectory and function of friendship

For all three participants, the main consequence of acquiring a physical disability was a change in the trajectory and function of friendship. All participants described acquiring a physical disability as signifying a loss in personal control. The diminished sense of control spurred the participants towards actively seeking ways to regain autonomy and belonging. For each participant, friendship played a vital role in restoring independence and self-efficacy in their lives through sustaining and enhancing self-esteem and their management of their acquired physical disability.

Jack described the importance of friendships, and the impact which being surrounded by wrong forms of friendships can have on a person. Jack described forming friendships with people in his local pub after acquiring his disability:

“They become your best friends and family...I drank from 12 in the day, till I could stand up no more...suddenly people aren’t looking at you ‘is he alright? He’s lost his leg’... you become a nuisance. You’re loud and messy. You do silly things, take off your prosthesis and drink out of it, throw it across the room”.

Here Jack discusses how he forged destructive friendships with people who promoted drunken, socially unacceptable behaviour allowing Jack to spiral uncontrollably into a “drunken nuisance”. Not all friendships positively enhance self-esteem or affirm re-instil values in a person, as happened with Jack. He also states the importance of talking to the right person about your concerns and how their involved and redirect your life back on a positive trajectory:

“People say, talk to someone, well you got to find the right person to talk to... So it’s about picking the right person”

He highlights the importance of having the right form of friends around in a time of crisis can create a positive impact on how he dealt with issues which were having negative consequences on his life adaptation post acquiring a physical disability.

Lily described how initially the onset of disability had a tremendous negative impact on her friendships, stating that “when I went to hospital, I lost a lot of friends”. However, the onset of disability also had a positive effect on her friendships as it served to sustain and enhance authentic friendships: “I became a lot stronger with the people who stuck around”.
Through the onset of her acquired physical disability, Lily lost a lot of friends. However the friendships that remained grew stronger and now she has a solid network of friends who serve to support and enhance her well-being.

Conversely, Fiona adopted an ableist approach of self-imposed isolation to protect her from potential stigma she would suffer if people found out about her newly acquired disability. Immersing herself in her home environment, Fiona redefined the role of friendship in her life and has only told one friend about her disability stating:

“I don’t know where I would be without her...I would confide in her”.

Explaining how she redefined the role of friendship Fiona states that she re-categorised her friendships in terms of trust believing that the divulgence of her physical disability would not impact these friendship in a negative manner:

“I’m looking at this as a way of who would be the people I’d trust with telling now”.

Through re-defining friendships and the role they play in her life, Fiona was able to control knowledge about her disability. As a result she was more comfortable engaging with her friends.

**Ableism, disrupting societal norms to create sustainable friendships**

Ableism, a form of discrimination is rooted in the belief that non-disabled adults are superior to disabled adults was employed by Fiona as a means of conforming to societal expectation of people with acquired physical disabilities. Self-exclusion – the participation in activities with similarly disabled others – is a self-affirming strategy employed by both Jack and Lily which enabled them to reject ableism and ultimately provided freedom from societal judgements.

Society’s pervasive negative attitudes about disability are challenged by Jack through his established of the “Village of the Dammed” Football team. People with physical disabilities came together through their passion for sport, disrupting the norms of Ableism through participating in social activity, challenging the stigmatising and isolating physically disability stereotype. This enabled friendships to foster and develop. Jack recalls one incident which forged their friendships:
“We were coming through customs and we were all like village of the damned, kept taking off all these bits and pieces beep, beep, beep, beep… village of the damned like broken people coming…[we] learned to laugh and see the funny side, because [we] did as a group”.

This self-affirming moment enabled Jack and his physically disabled friends, to be proud of their disability, not embarrassed or try to hide it from non-disabled population.

Invisibility of the person and hyper visibility of the disability

A common theme which emerged from the interviews was the participants perceptions of their invisibility in social settings with friends. Jack described a situation shortly after acquiring his disability, meeting friends who did not know how to act so they made him invisible and actively avoided him.

“These people had known for a while and didn’t know how to approach [me], people didn’t know what to say to, so people would avoid [me]”.

In his interview, Jack also describes multiple scenarios of applying for jobs. However, as soon as perspective employers learned of Jacks disability, they are no longer interested in Jacks positive traits but could merely see his disability, something which Jack found ‘really really distressing’ and left him feeling stigmatised by the word disabled. As soon as people hear the word disabled they immediately think ‘broken!…that’s the image people have’.

Lily observed that if there was someone present with her when she was engaging with a stranger, that they generally bypassed her and spoke to the friend or family member who was present. She continued to describe numerous scenarios whereby people assumed the people she was with were her primary carer rather than a friend or family member:

“They look past me and address my friends and family…I’m a person too, so why pass me over?”

Lily experienced going from invisible as a person to being hyper visible in her wheelchair when out shopping with friends in shopping centres and in town.

“Strangers wouldn’t know my situation and they can stop and stare. I find that very uncomfortable”.

She recalls people not seeing her as a person but being pre-occupied by viewing the wheelchair and equipment she has present with her.
Discussion

Each participant was engaged in multifaceted friendships. All of the participants involved in this study went through a period of segregation, either imposed by non-disabled peers or by themselves. As a result, the trajectories of the friendships were effected (Bunch & Valeo 2004). McKay (2006) states that disabled adults should co-exist with non-disabled adults in an egalitarian society. This policy of inclusion failed to account for the stigmatisation of disability. In reality, people with physical disabilities merely share space with nondisabled people instead of actively partaking in collective experiences that facilitate belonging (Doubt & McColl 2003). Unless policies explicitly tackle to issue of stigma in society, it will continue to be interpreted as merely sharing space, where shared interaction is ignored, therefore promoting segregation and isolation of non-disabled adults from those who acquire a physical disability.

Another form of discrimination, Ableism believes that non-disabled beings are superior to disabled beings (Linton 1998). By accepting ableism, disabled peoples life chances are negatively impacted upon whereby they are expected to sit on the side-lines of life (Goffman 1963; Shakespeare 2006). This was actively resisted by two participants in the study. Research by Davis and Watson (2002) demonstrated that disabled beings are neither defenceless nor unapt. Through employing disruptive strategies, they actively sought to alleviate exclusion, thereby allowing the creation and sustenance of friendships. This echoes findings by Kennedy (2009) and Low (1996), who found participants were unhappy to remain isolated, disrupted the norms of ableism through connecting with similarly disabled beings, brought together through a shared experience of stigma. According to Marcus (2005), a greater sense of acceptance and belonging is achieved through being surrounded by peers who share a disability experience. Self-exclusion is a viable strategy to employ as a means of creating and sustaining friendships in the context of stigma.

The findings also revealed an interesting juxtaposition. Participants reported feeling hyper-visible due to physical disability. However, they also felt invisible during social interaction. A study by Scrambler (2006) echoed these results and found that disabled people are represented through negative social stereotypes whereby they are perceived as being socially incompetent. These results are consistent with other studies. Most notably the study by Dovidio et al (2001) which found that people with a visible disability are perceived as being helpless or as having a cognitive impairment.
Toriello et al (2007) proposed that non-disabled beings prefer to socially distance themselves from people with a visible physical disability to avoid stigma by association, identified by Goffman (1963) as courtesy stigma. In their interviews, two participants admitted to participating in courtesy stigma before they acquired their physical disability. Goffman's concept of courtesy stigma explains which people familiar to the participants actively avoided them when they saw them socially for the first time post onset of their acquired physical disability. According to a study by Dovidio et al (2011) people associate the presence of disability with their own vulnerability, and alerts them to the fact that they too could potentially acquire a physical disability. This leads to the avoidance, segregation and stigmatisation of people with disabilities. This theory concurs with Scramblers (2006) research which states that the exclusion and rejection of disabled people is a primary component of stigma, and shows a disregard for physical and mental wellbeing of people with disabilities.

Stereotypes are extremely prevalent in sport where a physically disabled body does not bear a resemblance to the image of what a sporting body should represent (Anderson, 2009). Jack spoke about a situation when he was applying for a job and how the interviewer engaged with him differently when he realised he had prosthesis. Perhaps the interviewer struggled with these two identities co-existing: Jack the potentially skilled employee and physically disabled Jack with prosthesis were incompatible. This disrupted his normative expectation of what each should look like. Similar to findings by Zitezelberger (2005), the findings in this study signify the presences of a dual process at work: participants felt hyper-visible due to their physical disability yet invisible and being shunned in social situations. Martens et al (2004) associates the presence of both invisibility in social setting and hyper-visibility of disability as contributing factors to the presence of stigma suffered by disabled adults who differ from normative standards. Townsend and Wilcock (2003, 2004) concur with these findings and believe that the participation of people with physical disabilities in social activities results in occupational alienation, injustice and marginalisation. Such experiences deviate from the UN Convention on Rights of People with Disabilities and do not allow for people with disabilities to participate fully with non-disabled citizens.

Wilcock (1998) linked occupation to the process of becoming, through which humans achieve identity and authenticity. Schultz and Schkade (1992) argue that occupational adaptation is an intrinsic process adaptive process employed to negate external stressors in a bid enhance occupational participation. Therefore, it can be assumed that developing
friendships with similarly physically disabled people is an adaptive strategy enacted to facilitate change in how people manage their condition and attain a more meaningful participation in life. Forging alliances and creating new friendships allowed participants to assume greater control over their health, well-being and social identities. This is consist with Ungar’s (2001) exploration on marginalised youths, in which the youths described strategically forged friendships to create supportive coping networks when confronted with new and challenging life events.

**Implications of OT practice**

Hammell (2008) argues that occupational therapists should assert the right for all people to engage in meaningful occupations which positively affects wellbeing. This study highlights the occupational alienation and marginalisation that people with physical disabilities can encounter as a result of stigma, particularly in relation to friendships. Hammell and Carpenter (2002) highlight understanding clients’ perspective is an integral component of occupational therapy. Stigmatising experiences deny people with acquired physical disabilities full participation in occupations which provide multiple benefits to their wellbeing (Devine 2004). Krupa (2008) asserts that occupational therapists are ideally positioned to take a leading role in eradicating stigma and should politicise the power of occupations for achieving anti-stigma goals, thereby enabling clients to experience full enjoyment and participation as recommended by the UN Convention.

In order to maintain the ethos of holism and client-centeredness in occupational therapy, occupational therapists must look beyond simply equipment provision to these clients (Finlay 2000). In future, occupational therapists could tackle the social stigma of people with physical disabilities through working with wider disability groups to develop a more positive self-image. Therefore, in future people who acquire physical disabilities will have access to a more positive collective identity on which to construct a positive self-image, reducing the potential for stigmatisation (Kielhofner 2005). One practical way occupational therapists can facilitate this proposed change is by creating peer mentoring programs within their existing support organisations (Kielhofner 2005).

Kronenberg and Pollard (2005) suggest community based interventions have the potential to eliminate stigma, health inequalities and occupational deprivation as they promote inclusion and de-stigmatisation. These interventions give disabled and non-disabled members of the
community a chance to collaboratively interact through sharing a common interest (Fieldhouse 2003).

**Limitations**

This study takes an important step towards understanding the role of stigma on people with acquired physical disabilities, particularly in relation to the role and function of friendship. However, it is acknowledged that several limitations exist which restrict conclusions that may be drawn. A small sample size was chosen given the timeframe and resources available. A larger sample size is recommended. This will allow an in-depth analysis of how stigma effects friendships post the onset of physical disability and would provide further information into the factors influence the function and trajectory friendships. The researcher’s relative inexperience in conducting this type of study must also be considered. The inclusion of a second person to review the data to ensure the categories selected were accurate would have enhanced the reliability of the study. However, the study has numerous strengths which include the nature of the inquiry and the research method employed. Using a qualitative mode of inquiry, this study explored the process of stigma in friendship from the perspective of the individual. Another noted strength of the study is evident through the researcher’s efforts to establish criterion of trustworthiness in the research process. Potential for future research would be to add depth to this study by using participant observation as an additional research method so that any nuances in these experiences could be captured.

**Conclusion**

One of the core concepts in occupational therapy is the importance of having an occupational balance of self-care, work and leisure to maximise health and wellbeing. Despite an exhaustive list of benefits of social engagement, people with acquired physical disabilities do not engage in this domain of occupation to the same extent as nondisabled people. The aim of this study was to explore how people with acquired physical disabilities navigate stigma, particularly in relation to the function and trajectory of friendships. The findings revealed the complexities of stigmatising experiences and how these experiences of stigmatisation affect the role of friendship in multiple forms. It highlights the dual process participants encountered of feeling invisible as a person engaging with non-disabled friends yet hyper-visible and stigmatised by their visible disability. The inequality that participants experienced as a consequence of this process represents a violation of the inherent dignity and worth of the person and does not concur with the objectives of the UN convention. It is crucial that
occupational therapists realise their potential to enable clients to assert their right to full and equal participation in society as failure to do is a breach of the UN Constitution on the rights of people with disabilities. It is important that occupational therapists define their role and as a result seize opportunities to expand the profession in relation to eliminating the stigmatisation suffered by people with acquired physical disabilities.
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References


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Appendix A: Initial Email Contact

This is the email script (and phone script) for point of first contact between Nancy Salmon, or a research student involved in this project, and potential participants.

Dear [insert name of participant],

Thank you for contacting me about the Building Real Communities project. The interviews will happen in summer 2012. We can have the interview in a place that you choose and feel comfortable in. We can make sure that the time we pick for the interview that suits you. The Interview will take about one hour.

This study will look at how people with disabilities in Ireland create lasting relationships in real communities. Nancy Salmon, a lecturer at the University of Limerick, is doing this study along with a group of research students. Over the next four years we will do interviews with many people in Ireland, creating a large collection of personal stories describing living with a disability, health condition or mental illness. Each student researcher will do up to 10 interviews. All together we will bring together the stories of over 150 Irish people with disabilities.

Being part of this study is voluntary and you can stop being part of the study at any time. If you choose not to stay in the study, it will not affect your access to services.

If you are interested in finding out more details about this study I can send you the research information letter by post or email. This letter explains in detail what the study is about and how you can take part. If you are interested in finding out more about the study, please let me know and I’ll email it to you. Or you can let me know your postal address and I can send out the information sheet.

If you have any questions about the study please contact me.

Thank you for your interest in the study and I look forward to hearing from you,

Paul Fitzgerald 0428493@studentmail.ul.ie
Appendix B: Recruitment Poster

Building Real Communities

If you have [insert name of disability or diagnosis here] and are over 18 years of age....

We want to hear about how you build relationships at home, at [school or work] and in your community.

In Partnership with [insert name of organization here]

For information please contact [insert name of research student here] or Nancy Salmon
Department of Occupational Therapy
University of Limerick
(61) 234275
nancy.salmon@ul.ie
Many people with disabilities talk about being treated differently. You are asked to take part in a project which aims to look at how people who acquire a physical disability in adulthood (aged 25-45) experience stigma after acquiring a physical disability. This project will be done by a student researcher, Paul Fitzgerald, as part of his study in Occupational Therapy at the University of Limerick.

Areas we would like to know more about include

1) **Your time**: How you spend time during the day at home, at school/work, and in the community.

2) **Your friends and family**: Who you enjoy spending your time with and what makes those relationships last.

3) **When things go badly**: Times when you were treated unfairly because of having a disability or medical diagnosis.

4) **When you are treated well**: What makes life go well at home, at school or work, and in your community.

You will be asked to talk to Paul Fitzgerald for about one hour in a place where you feel at ease. For example, this could be a social club, a sports event, a library, your home or a quiet park. Paul is a student occupational therapist. Your story will be recorded and you can have a copy of the interview if you like. You will be sent a short summary of the interview. All of the things you tell us will be kept private. Your name and details will not be in anything that is written about this research. There is no reward for taking part in the study.
If you would like to be part of this research, you must be over eighteen years of age. You must be willing to talk about times when you feel that you were treated differently because of having a physical disability. Taking part in this project is completely up to you.

Please contact Paul Fitzgerald by email if you have any questions about this project at 0428493@studentmail.ul.ie

You can also contact Dr. Nancy Salmon, Paul’s research supervisor by email at nancy.salmon@ul.ie or by phone at (061) 234275.

If you have any concerns about this study please contact: Chairman Education and Health Sciences Research Ethics Committee
University of Limerick
Appendix D: 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: Consent Form

Agreement Form

Project Title: Building Real Communities

Introduction

You are invited to be part of a research project about how people with disabilities in Ireland create lasting relationships in real communities. Nancy Salmon, a lecturer at the University of Limerick, is doing this study along with a group of research students. Over the next four years we will do interviews with many people in Ireland, creating a large pool of personal stories describing living with a disability, health condition or mental illness. Each student researcher will do up to 10 interviews. All together we will bring together the stories of over 150 Irish people with disabilities.

The study is described below. Being in the study might not help you, but we might learn things that will help others. Being part of this study is voluntary and you may stop being part of the study at any time. If you choose not to stay in the study, it will not affect your access to services. You will be asked to spend about 1.5 hours in the study. This includes the time it takes to get ready to meet Paul Fitzgerald and the time you spend together. If you have any queries about the study you can ask Nicola or Nancy Salmon.

Contact Information:

Address: Paul Fitzgerald
0428493@studentmail.ul.ie

Supervisor: Dr. Nancy Salmon
Phone: (061) 234275
Email: nancy.salmon@ul.ie
Purpose of the Study

The purpose of this study is to learn how people with disabilities in Ireland create lasting relationships at home, at school or work, and in our communities. Detailed stories about these relationships will be created.

What will you be asked to do?

Ten people with disabilities will be part of this study. If you agree, you can tell your story about making and keeping strong relationships with family, friends, and people at school or work. If you agree then your talk with Paul will be recorded and later typed out. You can decide if things you say can be used when Paul, Nancy or Fiona tell other people about this study. No one will be told the words are from you.

Who can be in the study?

Adults who acquired a physical disability between the ages of 25-45, who use English or Irish are invited to be part of this study.

Who will be doing the research?

Paul will be doing this study with the help of his supervisor, Dr. Nancy Salmon and Dr Fiona Kumari Campbell. These people are able to read a typed up copy of what you tell Paul. Dr. Campbell lives and works in Australia at Griffith University. She will only see your story Nicola takes out your name and any details that would give away who you are.

Keeping your story private

You will be asked to pick a fake name that will be used instead of your real name in the study. A paper that has both your real name and your fake name will be kept in a locked drawer in Nancy’s office at the university. Your real name will not be used in anything that is told to others about this research.

The recording of your talk with [Paul] will be stored on Nancy’s computer. They will be in a hidden file in the computer and will be password protected. All information from the study will be stored in a locked office at the University of Limerick for 7 years after the study ends. Paul will keep everything you say private unless you talk about abuse by a partner. Nancy has to report this to the local Gardai.

Your Rights
You can say that you don’t want to answer any question that is asked. You can stop talking with Paul at any time. He will not be upset and will stop right away. You can listen to the tape of your interview or read the typed copy. Paul can give you a copy of the summary she writes about your meetings. It will not affect Paul’s schoolwork if you decide you want to stop being in this study. You can ask her any questions you want to about the study or you can talk to Nancy.

Can anything bad happen if you are in the study?

Sometimes things come up when people talk that can make you feel upset. Talking about your relationships might feel uncomfortable. You don’t have to talk about anything you don’t want to. You can tell Paul you want to stop at any time. If you stay upset after the interview, Paul can help you find someone to talk with to help sort out your feelings.

Will you get anything good out of being in the study?

There is no pay for being in this study. The study will not help you, but it could give us ideas that will help other people with disabilities make and keep good relationships. This study gives you the chance to think about what makes your relationships work for you. This may help you feel good about the people in your life.

If you have any concerns about this study please contact: Chairman
Education and Health Sciences Research Ethics Committee
University of Limerick
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.

______ I know what this study is about

______ I know that I will not be named in any reports or talks about this study.

______ I agree that my interview with [insert name of student researcher] can be recorded.

______ I agree that [insert name of student researcher], Nancy and Fiona can include things I say in my interview when they tells other people about this study. I know that I can change my mind about this until [insert name of student researcher] has written up the first full draft of her final report about this study in November 2012.

______ I agree that Fiona Kumari Campbell from Griffith University in Australia can read my interview.

______ 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.

______ I was given a copy of the letter and this signed consent form.
### Appendix F: Diary

#### Weekday Diary

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Appendix G: People in My Life

- People I'm close to
- People I know well
- People I know a little
- People I don’t feel comfortable around
Appendix H: Resources for Mental Health

**First point of contact:**

It is recommended that anyone experiencing distress related to mental health contact their GP to discuss the situation and for advice about what services and supports might be available.

**Other services and supports include:**

1. **Aware:** This is a voluntary organization whose mission is “to create a society where people with depression and their families are understood and supported, are free from stigma and have access to a broad range of appropriate therapies to enable them to reach their full potential.”

   **Contact Information**
   
   Website: [http://www.aware.ie/](http://www.aware.ie/)
   
   Helpline: **1890 303 302**
   
   Email: wecanhelp@aware.ie

2. **Grow** is a voluntary mental health organization that helps people who are experiencing mental health problems.

   **Contact Information**
   
   Website: [http://www.grow.ie/](http://www.grow.ie/)
   
   Phone: 1890 474 474
   
   Email: info@grow.ie

3. **Limerick Mental Health Association:** This organization is connected to the national voluntary organization Mental Health Ireland. “The aims are to promote positive mental health and support people who experience mental health difficulties”

   **Contact Information**
   
   Website: [http://www.lkmentalhealth.ie/index.htm](http://www.lkmentalhealth.ie/index.htm)
   
   Phone: 061-446786
   
   Email: info@LKmentalhealth.ie
4. **Pieta House** offers counseling and support services to people experiencing a mental health crisis.

   **Contact Information**

   Website: [http://www.pieta.ie/Index.html](http://www.pieta.ie/Index.html)

   Phone: 353 (01) 601 0000

   Email: mary@pieta.ie

5. **The Samaritans** “provides **confidential** non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair”

   **Contact Information**

   Website: [http://www.samaritans.org/talk_to_someone/find_my_local_branch/ireland.aspx](http://www.samaritans.org/talk_to_someone/find_my_local_branch/ireland.aspx)

   Phone: 1850 60 90 90

   Email: jo@samaritans.org
Appendix I: Confidentiality Agreement

Before I access any information related to the Navigating Stigma to Build Real Communities Project, I understand that I am to keep anything I read or discuss with the principal investigator, co-investigator, or student researchers completely private. I will not discuss this information with anyone outside the project. I understand that I will not have access to the identities of any current or previous research participants. I will not make copies of any information in the qualitative database, nor will I take any information from the project away from UL campus without the explicit permission of the principal investigator. If I do not adhere to this agreement, I understand that my work on this project may be terminated immediately.

________________________________________
Research Assistant

________________________________________
Principal Investigator