

# **The Visibility of Disability: Experiences of Stigma among Wheelchair Users**



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## **MSc in Occupational Therapy Research Project 4**

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# **The Visibility of Disability: Experiences of Stigma among Wheelchair Users**

## **Abstract**

Despite the substantial evidence base highlighting the benefits of engaging in leisure activities; participation in this domain of occupation is greatly reduced in people with physical impairments and is frequently limited to solitary leisure engagement. Physical and attitudinal barriers within the environment have been identified as potential explanations for this. The UN Convention on the Rights of Persons with Disabilities aims to minimise these barriers and promote full inclusion but it has yet to be ratified in Ireland. The purpose of this study was to explore the experiences of stigma among wheelchair users during social leisure engagement.

The aims of the study were met by carrying out semi-structured interviews with eight adults who became wheelchair users during adolescence or in adulthood. Thematic analysis was employed to analyse data. Results included themes related to the visibility of disability. Participants reported feeling invisible as people but felt that the wheelchair was hypervisible and resulted in stigmatising treatment from strangers. The accounts of these experiences occurred more frequently in the earlier years of being a wheelchair user and participants identified changes in their personal factors as one of the reasons for this shift. Occupational therapists are ideally placed to enable clients to assert their right to full and equal participation through meaningful occupational engagement.



## **Introduction**

Occupational therapy is guided by the premise that engagement in meaningful occupation is necessary to optimise health and wellbeing (Majnemer 2010; Townsend and Polatajko 2007; Wilcock 1998). Three main occupational performance areas have been identified as self-care, work, and leisure (Law *et al* 1998; Law 2002; Majnemer 2010). Choice, ability and opportunity to engage in and achieve a balance in all three areas is key to maximising a person's self-perception of health and well-being (Law *et al* 1998). The area of leisure has traditionally held a lower priority than other areas of occupation both clinically and within the literature (Primeau 1996). The benefits of leisure for maintaining health and wellbeing are extensive and far reaching and may be amplified for people with disabilities (Anderson *et al* 1997; Devine 2004; Freudenberg and Arlinghaus 2010; McAvoy *et al* 2006; Rolfe *et al* 2009). However, participation in leisure activities is generally reduced in people with physical impairments (Boucher *et al* 2010) and is often limited to solitary leisure activities that can be engaged in at home (Aitchison 2003). Environmental physical and attitudinal barriers have been identified as the primary reasons for this disparity (Bedini 2000; Cahill and Eggleston 1995).

In March 2007, Ireland signed the United Nations Convention on the Rights of Persons with Disabilities which aims to reduce barriers to inclusion of people with disabilities in the community (Inclusion Ireland 2011). The convention recognises the equal right of all people with disabilities to full enjoyment and participation in the community but despite being one of the first countries to sign the convention, it has yet to be ratified in Ireland (Quinn 1999). This study focuses on one of the barriers to full participation in leisure engagement. The aim is to explore the experiences of stigma among wheelchair users during social leisure engagement.

## **Terminology**

Participants used the term "wheelchair user" when referring to a person who uses a wheelchair and the term "disabled person" when referring to a person with a physical impairment. These terms will be employed for the purpose of this article to reflect the

language of the study group. The term “disabled person” is also used by disability theorists to refer to people who are disabled by environments and attitudes that exclude bodies of difference (Oliver 1990).

## **Literature Review**

Leisure can be defined as “activity to which the individual turns at will for relaxation, diversion or broadening his knowledge and his spontaneous social participation” (Hawke 1985 p.299). The benefits of leisure are extensive. It increases physical well-being (Aitchison 2003; Timmons and MacDonald 2008), increases self-esteem (Aitchison 2003; Timmons and MacDonald 2008), increases emotional well-being (Cassidy 1996), decreases stress levels (Trenberth 2005), generates feelings of enjoyment (Kleiber 1999; Tinsley *et al* 1993) and promotes a sense of accomplishment, satisfaction and competence (Hutchison *et al* 2008). Leisure participation also plays a role in the stress coping process and is a means to overcome negative life events (Trenberth 2005).

A recurring theme throughout the literature is the role that leisure plays in providing opportunities to build and enhance social relationships (Fenech 2008; Hutchison *et al* 2008; Timmons and MacDonald 2008; Trenberth 2005; Unruh *et al* 2000). Participation in social leisure helps to develop feelings of belonging, acceptance and support among peers (Hutchison *et al* 2008). Evidence suggests that the multiple benefits associated with social leisure engagement may be even more pronounced for people with physical disabilities compared to nondisabled people (Anderson *et al* 1997; Freudenberg and Arlinghaus 2010; McAvoy *et al* 2006). People with disabilities report that the independence they associate with leisure participation positively impacts on how they interact with the world around them and how in turn they are viewed by others (Rolfe *et al* 2009). The associated psychological benefits from feelings of achievement and personal growth while engaging in leisure occupations are also particularly evident (Anderson *et al* 1997; Freudenberg and Arlinghaus 2010; McAvoy *et al* 2006). Additionally; group membership associated with leisure contexts results in a strong social identity and status of belonging (Devine 2004; Rolfe *et al* 2009).

Despite the extensive benefits of leisure; participation in leisure activities is generally reduced in people with physical impairments and leisure activities tend to be limited to solitary rather than social leisure activities (Boucher *et al* 2010; Parker *et al* 1997). Environmental factors play a significant role in fulfilling occupational potential and an unsupportive environment can act as a barrier to facilitating occupational choice (Whiteford 2000). There are a greater number of constraints to accessing leisure participation for people with physical impairments and reduced physical accessibility is widely identified as a key barrier (Dijkers 1998; McKinley and Meade 2004; Rolfe *et al* 2009; Specht *et al* 2002). Link and Phelan (2001) describe this disabling environment as structural discrimination and Parker (2001) describes poor accessibility as a direct reflection of a society's acceptance and respect for people with disabilities.

An additional environmental challenge to wheelchair users accessing public spaces is the psychosocial environment (Cahill and Eggleston 1994, 1995) and stigma has been identified as a significant barrier to leisure engagement (Bedini 2000; Specht *et al* 2002; Wickham *et al* 2000). Goffman (1963) suggests that individuals with physical disabilities possess a stigma as they are viewed as deviating from bodily expectations. The experiences of stigma are more prevalent among people with visible disabilities than among people who have a disability that is not immediately obvious (Goffman 1963). This is evident in the experiences of stigma among wheelchair users in public places. The icon of a person in a wheelchair is the universal symbol for disability, thus the wheelchair alone elicits negative assumptions of inability and incompetence (Papdimitriou 2008; Cahill and Eggleston 1995). Common responses faced by wheelchair users in public places include non-person treatment (Cahill & Eggleston 1995), treatment as an open person with no need for privacy or treatment as a child by strangers (Cahill and Eggleston 1995; Green *et al* 2005). Such encounters deny or diminish the personhood of wheelchair users; resulting in status loss, discrimination and a profound sense of being devalued that can result in social isolation within the community (Green *et al* 2005). The experience of stigma while engaging in community based activities adds an emotional overlay to a physically challenging situation for wheelchair users (Bedini 2000; Cahill and Eggleston 1995). The aim of this study is to explore these experiences of

stigma among wheelchair users and specifically focuses on the experiences while engaging in community based social leisure activities.

## **Methods**

### **Approach**

Qualitative methodology was employed as this method is particularly suited for research questions related to understanding and exploring the lived experience of disability (Maxwell 1996). Ethnographic interviewing was the qualitative approach used to provide insight into participants' views (Carpenter 2002). McCracken (1988) suggests that this is one of the most powerful qualitative methods to gain insight into the daily life experiences of the participant. As a researcher who does not identify as disabled, strategies were put in place to incorporate a critical stance towards conventional assumptions about disability (Hammell 2007). To that end a critical disability theory guided all aspects of this study. The focus of the research was not on the ability of the wheelchair user but rather attended to the experiences of stigma related to social leisure engagement (Stone & Priestley 1996). Reflexivity was a key strategy used throughout the research process in order to engage in self-critique and self-appraisal and ensure that personal experiences did not influence the research process (Dowling 2006).

### **Participant recruitment**

Participants were recruited through two organisations working with people with physical disabilities. An information leaflet providing an overview and objectives of the study was sent to both gatekeepers (Appendix A). Participants were recruited from within the organisations and participation was voluntarily. Inclusion criteria was that participants were over 18 years old, were English speaking and used a wheelchair as a means of mobility.

### **Data Collection**

The aims of this study were met by completing semi-structured interviews with participants. In-depth semi-structured interviews with open ended questions form the basis of ethnographic interviewing and encourage the participant's narrative to unfold (Carpenter 2002). The interview covered how participants spent their leisure time, their level of involvement in social leisure activities and experiences of stigma within the context of social



leisure participation. An interview guide (Appendix B) focused the interviews and ensured similar questions were asked across all interviews. Interviews took place in the gatekeepers' offices and lasted up to 90 minutes. Audio recording was used and interviews were transcribed verbatim prior to analysis. Field notes provided a mechanism to record researcher perceptions and impressions and dynamics of the interaction immediately following each interview (Carpenter and Hammell 2002; Emerson *et al* 1995).

### **Data Analysis**

Thematic analysis was employed as a method for identifying, analysing, and reporting patterns within the data (Braun and Clarke 2006). Nvivo software was used to facilitate this process. Inductive analysis was carried out using Braun and Clarke's (2006) six phases of analysis. The researcher became familiar with the data by reading through interviews and field notes. Initial codes were generated and themes were then allocated, reviewed and finalised before producing a report of the findings (Braun and Clarke 2006).

### **Trustworthiness**

Carpenter (2002) identifies the researcher as a key research instrument who's knowledge and insights influence data analysis. Reflexivity was used as a strategy throughout the research process to examine the researcher's underlying assumptions and promote a transparent analysis. The researcher's role was monitored and discussed during research supervision to ensure that data analysis was thoroughly grounded in the data so that participants' experiences would be accurately portrayed (Carpenter 2002).

### **Ethical considerations**

Ethical approval was received from the Health Sciences Ethics Review Committee at the University of Limerick. Participation was voluntary with no incentives offered. An overview of the study and interview process was outlined before each interview and the participant was advised that they could withdraw at any time without consequence. A consent form (Appendix C) was reviewed and signed before the interview. The researcher offered to read the consent form so that any participant with literacy difficulties or visual impairments did not have to volunteer this information if they did not wish to do so. A list of counselling

services (Appendix D) was compiled in the event that reflection on life events during the interview caused discomfort or emotional stress for participants.

Participants were given the option of being sent a brief summary of the key points of the interview within one week so they could determine whether it was a reasonable reflection of their experiences (Hammell 2006). This also provided the opportunity to withdraw any information they did not wish to include. Anonymity in terms of being part of the study was difficult to guarantee as recruitment and interviewing occurred within an organisation. However confidentiality was assured. All transcripts were anonymised and demographics are not presented in a table format to further protect participants' identity. Digital recordings of each interview along with anonymised transcripts are in electronic storage on a password protected computer in the research supervisor's office per university policy.

## **Findings**

### **Participants**

Eight participants volunteered to participate in the study; six participants became wheelchair users as adults and two became wheelchair users during adolescence. The length of time participants had been wheelchair users was between four and thirty years. Four participants had a spouse or partner and four were single. Participants identified their chosen social leisure activities as going to bars and restaurants; kayaking; playing darts; shopping and going to concerts. Three main themes emerged from the interviews: the invisibility of the person, the hypervisibility of the wheelchair and the changing experiences of stigma.

### **Invisibility**

A recurrent theme was the treatment of participants as if they were not present or visible in social situations. All participants described situations in which someone addressed their walking companion rather than addressing them or spoke about them as if they were not present. Participants explained that people often assumed that their walking companion was primarily their carer rather than a friend, partner or family member. Chloe described a situation in which someone looked past her and asked her fiancé if he had her ticket.

Maggie observed that if there is someone else with her people generally spoke to them rather than her:

*The person behind the desk was talking to my son and saying “does she need assistance?” ....so I looked at him and I said “you can tell her I don’t need assistance”.*

Eileen spoke about being out with a friend when a stranger told her friend she “*was great to bring her out*”. Sean recalled paying for dinner with his credit card and the waitress handed his credit card back to his wife instead of him afterwards. Three participants recalled that local people who they had known for years actively avoided engaging with them when they returned to their local pub as wheelchair users. The sense of being invisible extended beyond not being treated as present. Sean described feeling invisible as a sexual being when he first began socialising as a wheelchair user:

*When you’re 21 and you’re going in somewhere where the girl serving you is the same age as yourself and you expect her to interact differently....you kind of feel that you’re asexual....that was difficult.*

Two other participants also spoke about the difficulties meeting a partner and perceived this as being directly associated with being a wheelchair user. Maggie recollects a previous boyfriend suggesting that she was lucky that somebody agreed to go out with her.

### **Hypervisibility**

Participants also described circumstances when they felt their wheelchair was hypervisible and attracted unwanted attention in public. All participants identified situations when strangers made congratulatory remarks to them such as “*aren’t you great*” for no apparent reason other than that they were using a wheelchair in a public place. Strangers sometimes spoke to participants in a childlike manner and several participants recalled being patted on the head in public. Sean recollected a stranger buying him an ice-cream; an action he associated with how someone might treat a child. Jim noted that it used to be great to get free chocolate when he was younger but not when he was thirty-seven. This behaviour was interpreted by participants as being directly associated with the hypervisibility of the

wheelchair. One participant recalled an elderly lady being intimidated by him before his accident and speaking to him differently later when she saw him using a wheelchair:

*I would have known her to see...I approached her....she jumped, she saw this guy in motorbike leather gear and thought this fella is going to mug me....after I had my accident I was pushing down the road and I had the same motorbike jacket on....She said "aren't you great" and I thought well maybe I will mug her now.*

Three participants noted that people engaging with them as normal when they could not see the wheelchair and engaged with them differently when it became apparent that they were a wheelchair user. Sean described how someone interacted with him differently when it became apparent he was a wheelchair user as well as a kayaker:

*I was in the water one day and there was a guy out fishing in a boat on the lake and I kayaked by and we got chatting. Then later I was out of my kayak and he came in off his boat....I got talking to him and he spoke to me differently; definitely; and I then realised that he saw the wheelchair and did a double take.*

This response to the wheelchair was more prevalent when participants were socialising with friends who were also wheelchair users. Strangers often made assumptions that they were from an institution. One participant recollected a stranger commenting *"isn't it lovely to see them out for the day"*. A number of participants recalled such experiences and said they used to avoid social situations with other wheelchair users. Maggie remembered in the early days as a wheelchair user, she actively avoided another wheelchair user she knew to avoid being further discredited.

### **The changing experiences of stigma**

Interestingly, while participants recollected occasions when they felt stigmatised; most of the examples they gave occurred several years ago. When questioned further, participants said that they did not really experience stigma anymore and it was more common during the earlier years of being a wheelchair user. Four participants questioned if this was related

to their own evolving confidence that prevented others from engaging in stigmatising behaviours towards them:

*Its years since I've got the sort of attitude around people.....In the earlier days maybe but I think that was more down to me. I probably shied away into myself, I didn't engage. I let whoever was with me, so automatically people spoke to them rather than me.*

Noel also acknowledged that he had not experienced stigma in a long time and suggested that this may be because he “*is more comfortable in his own skin*”. Sean queried whether people engaged with him differently in the early days because he appeared more vulnerable and Eileen wondered if her own approach was reflected back to her by others:

*I think it doesn't matter who you are or what you're going through. I think it's what you give off is what you receive back. And if you're not comfortable in your own skin nobody else is going to be comfortable around you.*

Another participant questioned his interpretations of others' actions:

*People turn to see who's coming into the pub. But back then I thought they were looking at me because I was in the chair and it was dreadful, very difficult.... but I don't notice I'm in a wheelchair anymore because at this stage its part of me.*

While participants considered their own role in the stigma process, many also deemed that a changing society was the reason for the shift in their experiences of stigma. One participant believed that attitudes had changed and that people are familiar with seeing wheelchair users in public places. Another participant suggested that the media played a powerful role in de-stigmatising wheelchair users and identified the increased prevalence of disabled people playing soap characters as a positive change.

## Discussion

The findings in this study revealed a paradox between participants feeling hypervisible as wheelchair users yet invisible as people during social leisure engagement. Scrambler (2006) identifies exclusion and rejection as components of the social process of stigma. This was demonstrated in this study when participants were treated as though they were invisible in social situations and played out in a number of ways. The experience of strangers addressing participants' walking companions instead of them represented a negative societal stereotype that the wheelchair user is somehow incompetent. This is consistent with the findings from previous studies which showed that wheelchair users were presumed to be either helpless or to have cognitive impairments (Cahill and Eggleston 1994, Dovidio *et al* 2011). Ironically, the very device that supports social participation appears to symbolise helplessness to nondisabled strangers. Toriello *et al* (2007) suggested that some people prefer to maintain a greater social distance from a person with a visible disability; perhaps avoiding courtesy stigma that was identified by Goffman (1963) as stigma by association. Courtesy stigma could serve to explain why familiar people actively avoided interacting with participants when they saw them socialising as a wheelchair user for the first time. Participants assumed that people simply did not know what to say to them. Dovidio *et al* (2011) proposed that visible presence of disability alerts people to the possibility that they too are vulnerable and have the potential to acquire a disability. These fears can be expressed through avoidance, marginalisation and stigmatisation of people with disabilities. The treatment of participants as though they are not present epitomises the exclusion and rejection Scrambler (2006) identifies as components of stigma and represents a disregard for someone's personhood.

Mirroring the findings of Esmail *et al* (2010), two participants identified the feeling of being asexual when they became wheelchair users. Sakellariou and Algado (2006) suggested that the desire to flirt and be recognised as a sexual being is typical within Western societies. One participant identified the prospect of meeting a partner as one of his primary reasons for socialising in bars. However when he became a wheelchair user, he no longer fit into the elite group of people considered to be sexual beings. Two other participants in this study described difficulties in meeting a partner and attributed this to being wheelchair users.

While one participant was engaged, she talked about strangers assuming that her fiancé was her carer rather than her partner. This suggests that she was primarily considered to be someone requiring help before being considered to be a sexual being with a partner. These findings could be explained by Shakespeare's (1999) theory that people with disabilities are often thought of as belonging to a third, asexual gender. Esmail *et al* (2010) proposes that being labelled as asexual is a social stigma that has been created and continually supported within society.

The paradox of being hypervisible as a wheelchair user instead of visible as a person was evident within the findings. Every participant recollected numerous occasions when they were infantilised by strangers. Some participants imitated a stranger's higher pitched voice when they were relaying comments that had been made to them in public. This echoes results from Liesener and Mills (1999) who ascertained that nondisabled individuals used more words and spoke louder than usual when speaking to adult wheelchair users; comparable to how they spoke to a 12 year old. Participants in this study also spoke about being patted on the head by strangers, with two participants being given sweets by strangers. This reflects findings from Robey *et al* (2006) where nondisabled individuals implicitly associated disability with childlike characteristics and displayed this through infantilising behaviours.

All participants recollected strangers remarking "*aren't you great*" or making congratulatory comments to them for simply being out socialising as a wheelchair user. This concurs with Cahill and Eggleston (1995) who observed that strangers frequently acknowledged wheelchair users' very presence in a public place as being noteworthy. The hypervisibility of the wheelchair was particularly pertinent for one participant on one of his first social outings as a wheelchair user. An elderly lady who had previously perceived him to be a threat made a congratulatory comment in an infantilising manner when she first saw him wheeling down the street. This is a powerful example of the stereotypical view of the wheelchair user as a helpless person.

Another robust example of a stereotypical ideation associated with the visual of the wheelchair was the reaction of a fisherman who realised the kayaker he had been speaking

to on the water was in fact also a wheelchair user. The participant spoke about how the fisherman engaged with him differently when he realised he was a wheelchair user. Perhaps the fisherman struggled with these two identities co-existing; the body of a kayaker and of a wheelchair user were incompatible. This disrupted his normative expectation of what each should look like. This finding is consistent with that of Zitzelsberger (2005) who noted that women with disabilities perceived that their identity was disrupted when they deviated from the normative standards of having an “acceptable” body. Similarly Cahill and Eggleston (1994) remarked on an occasion when a wheelchair user was told she was “*too pretty to be in a wheelchair*”. While this may have been meant as a compliment, the suggestion was that an attractive person deviates from the norm by not fitting firmly into someone’s image of a person with a physical disability. Similar stereotypes are particularly prevalent in sport where a disabled body often does not meet the guidelines of the “ideal sporting body” (Anderson 2009).

The findings in this study represent a dual process of being visible as a person but hypervisible as a wheelchair user. This is consistent with findings by Zitezelsberger (2005) that the hypervisibility of disability is often accompanied by being shunned. Martens *et al* (2004) identify both of these forces as direct contributors to the stigma of people who deviate from cultural standards of normality. This reflects occupational alienation and marginalisation of wheelchair users while engaging in social leisure activities (Townsend and Wilcock 2003, 2004). These experiences demonstrate occupational injustice and do not correspond with the UN convention on rights for persons with disabilities which aims to ensure that people with disabilities can enjoy their right to full participation on an equal basis with all other citizens (Quinn 2009).

Participants in this study added an interesting dimension to these experiences. When relating their experiences of being stigmatised, participants predominantly relayed experiences from the initial years of being a wheelchair user. Three participants surmised that this was linked to environmental reasons. One participant reasoned that there were only two wheelchair users in his community nearly twenty years ago but that people have become more familiar with seeing wheelchair users in current times. This concurs with Griffiths and Lunsky (2000) who ascertained that while negative stereotypes of people with



disabilities still exist, attitudes are slowly becoming more positive and inclusive. An alternative explanation was given by three participants who suggested that they presented themselves with greater confidence and felt that this helped to fashion a more positive attitude from people they were engaging with. This concurs with Elliot *et al's* (1991) theory that the response of people with disabilities to nondisabled people can shape social engagement and counteract stigma. Pinel (1999) identified that people have different levels of perception of stigma or stigma-consciousness. One determinant of these perceptions is the extent to which someone expects to be stereotyped and Ruggiero and Taylor (1997) found that perceptions of discrimination are related to poor self esteem. One participant related his confidence to the integration of the wheelchair to his identity and said that while he knew he had a disability, he considered himself to be an able bodied person who required a wheelchair to get around. Papadimitriou (2008) describes this process as becoming en-wheeled.

### **Implications for Occupational Therapy practice**

Hammell (2008) suggests that occupational therapists should assert the right of all people to engage in meaningful occupations that contribute positively to their wellbeing. This study highlights the occupational alienation and marginalisation that wheelchair users can encounter as a result of stigmatising experiences during social leisure engagement. Stigmatising experiences can therefore deny wheelchair users full participation in a domain of occupation that provides multiple benefits to their wellbeing (Devine 2004). However, occupational therapists are ideally positioned to enable clients to experience full enjoyment and participation as recommended by the UN Convention. In order to maintain the ethos of holism and client-centredness in occupational therapy (Finlay 2000), occupational therapists must look beyond simply providing wheelchairs to clients. An emerging embodied identity as a wheelchair user was one of factors identified by participants as a dependent on the level of stigma they experience during social leisure engagement. Bates *et al* (1993) suggest that clients require support to incorporate the wheelchair into their daily life to maximise their occupational engagement. This also had a positive impact on participants' confidence which was identified as another variable of the level of stigma they experienced. These findings help to deepen occupational therapists' understanding of wheelchair users'

perspectives of stigma during social leisure engagement. Hammell and Carpenter (2002) highlight that understanding clients' perspectives is an important factor to inform occupational therapy practice.

### **Limitations**

One of the limitations of this study is that all the participants had acquired their disabilities and no participant was a lifelong wheelchair user. A greater mix of demographics could provide experiences of stigma that might deepen the analysis. A larger number of participants would also enable a fuller theory to be developed about the changing experiences of stigma over time. 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. Another area for research would be to compare wheelchair users' experiences of stigma with how much they feel the wheelchair has become part of their body. It would also be important to explore how occupational therapists could empower clients to manage experiences of stigma so that they can engage fully in meaningful occupations.

### **Conclusion**

One of the core concepts in occupational therapy and occupational science 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 leisure engagement, people with disabilities do not engage in this domain of occupation as much as nondisabled people. The aim of this study was explore the experiences of stigma among wheelchair users during social leisure engagement. The findings revealed the complexities of stigmatising experiences and contribute to a more in-depth understanding of how wheelchair users experience stigma during social leisure activities. It highlights the dual process participants encountered of feeling invisible as a person while feeling that their wheelchair was hypervisible and attracted associated stigmatising behaviours from strangers. 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. This study provided an interesting perspective on the evolving experiences of stigma among wheelchair users and how these experiences appear to become less prevalent with time. It identified changing attitudinal factors within the social environment as a potential reason for this shift but also pointed to clients' personal factors as another potential reason for this trajectory. The personal factors identified were increased confidence and the integration of the wheelchair as part of their body. Occupational therapists' remit ideally positions them to help clients address both of these factors through engagement in occupation. It is crucial that occupational therapists realise their potential to enable clients to assert their right to full and equal participation in meaningful occupations as failure to do so would constitute an additional injustice to this client group.

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## Reference List

Aitchison, C. (2003) 'From Leisure and Disability to Disability Leisure: developing data, definitions and discourses', *Disability & Leisure*, 18(7), 955-969.

Anderson, L., Schleien, S.J., McAvoy, L., Lais, G. and Seligmann, D. (1997) 'Creating positive change through an integrated outdoor adventure programme', *Therapeutic Recreation Journal*, 31(4), 214-229.

Anderson, D. (2009) 'Adolescent Girls' Involvement in Disability Sport: Implications for Identity', *Journal of Sport and Social Issues*, 33(4), 427-449.

Bates, P. S., Spencer, J.C., Young, M.E., Hopkins, D. (1993) 'Assistive technology and the newly disabled adult: Adaptation to wheelchair use', *American Journal of Occupational Therapy*, 47(11), 1014-1021.

Bedini, L. (2000) "'Just sit down so we can talk:": Perceived stigma and community recreation pursuits of people with disabilities', *Therapeutic Recreation Journal*, 34(1), 55-68.

Boucher, N., Dumas, F., Maltais, D.B. and Richards, C.L. (2010) 'The influence of selected personal and environmental factors on leisure activities in adults with cerebral palsy', *Disability & Rehabilitation*, 32(16), 1328-1338.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology' *Qualitative Research in Psychology*, 3(2), 77-101.

Cahill, S.E. and Eggleston, R. (1994) 'Managing Emotions in Public: The Case of Wheelchair Users', *Social Psychology Quarterly*, 57(4), 300-312.

Cahill, S.E. and Eggleston, R. (1995) 'Reconsidering the stigma of physical disability: Wheelchair Use and Public Kindness', *The Sociology Quarterly*, 36(4), 681-698.

- Carpenter, C. (2002) 'Exploring the lived experience of disability' in Hammell, K.W., Carpenter, C. and Dyck, I., eds., *Using Qualitative Research: A Practical Introduction to Occupational and Physical Therapists*. London: Churchill Livingstone.
- Carpenter, C. and Hammell, K. (2002) 'Evaluating qualitative research' in Hammell, K.W., Carpenter, C. and Dyck, I., eds., *Using Qualitative Research: A Practical Introduction to Occupational and Physical Therapists*. London: Churchill Livingstone.
- Cassidy, T. (1996) 'All work and no play: A focus on leisure time as a means for promoting health', *Counselling Psychology Quarterly*, 9(1), 77-90.
- Devine, M.A. (2004) "'Being a 'Doer' Instead of a 'Viewer': The Role of Inclusive Leisure Contexts in Determining Social Acceptance for People with Disabilities", *Journal of Leisure Research*, 36(2), 137-159.
- Dijkers, M. (1998) 'Community Integration: Conceptual Issues and Measurement Approaches in Rehabilitation Research', *Topics in Spinal Cord Injury Rehabilitation*, 4(1), 1-15.
- Dovidio, J.F., Pagotto, L. and Hebl, M.R. (2011) 'Implicit attitudes and discrimination against people with physical disabilities' in Wiener, R.L. and Wilborn, S.L., eds., *Disability and age discrimination: Perspectives in law and psychology*. New York, NY: Springer.
- Dowling, M. (2006) 'Approaches to reflexivity in qualitative', *Nurse Researcher*, 13(3), 7-21.
- Elliott, T. R., MacNair, R.R., Yoder, B. and Byrne, C.A. (1991) 'Interpersonal behavior moderates "kindness norm": Effects on cognitive and affective reactions to physical disability', *Rehabilitation Psychology*, 36(1), 57-66.
- Emerson, R.M., Fretz, R.I. and Shaw, L.L. (1995) *Writing Ethnographic Fieldnotes*, Chicago: The University of Chicago Press.
- Esmail, S., Darry, K., Walter, A. and Knupp, H. (2010) 'Attitudes and perceptions towards disability and sexuality', *Disability and Rehabilitation*, 32(14), 1148-1155.

- Fenech, A. (2008) 'The Benefits and Barriers to Leisure Occupations', *NeuroRehabilitation*, 23(4), 295-297.
- Finlay, L. (2000) 'Holism in occupational therapy: elusive fiction and ambivalent struggle', *American Journal of Occupational Therapy*, 55(3), 268-276.
- Freudenberg, P. and Arlinghaus, R. (2010) 'Benefits and constraints of outdoor recreation for people with physical disabilities: Inferences from recreational fishing', *Leisure Sciences*, 32(1), 55-71.
- Goffman, E. (1963) *Stigma: Notes on the management of a spoiled identity*, New Jersey: Prentice Hall.
- Green, S., Davis, C., Karshmer, E., Marsh, P. and Straight, B. (2005) 'Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families', *Sociological Inquiry*, 75(2), 197–215.
- Griffiths, D.M. and Lunsky, Y. (2000) 'Changing attitudes towards the nature of socio-sexual assessment and education for persons with developmental disabilities: A twenty year comparison' *Journal of Developmental Disabilities*, 7, 16–33.
- Hammell, K.W. (2008) 'Reflections on ... well-being and occupational rights', *Canadian Journal of Occupational Therapy*, 75(1), 61-64.
- Hawke, J.T. (1985) 'Occupational therapy and the role of leisure', *The British Journal of Occupational Therapy*, 48(10), 299-301
- Hammell, K.W. (2006) *Perspectives on disability and rehabilitation: Contesting assumptions; challenging practice*, Edinburgh: Churchill Livingstone Elsevier.
- Hutchinson, S.L., Yarnal, C.M., Staffordson, J. and Kerstetter, D.L. (2008) 'Beyond fun and friendship: The Red Hat Society as a coping resource for older women', *Ageing & Society*, 28(7), 979-999.
- Inclusion Ireland (2011) *Inclusion Ireland Annual Report*, Dublin: Inclusion Ireland.

- Kleiber, D.A. (1999) *Leisure Experience and Human Development: A Dialectical Interpretation*, New York: Basic Books.
- Law, M. (2002) 'Participation in the Occupations of Everyday Life', *The American Journal of Occupational Therapy*, 56(6), 640-649.
- Law, M., Steinwender, S. and Leclair, L. (1998) 'Occupation, health and well-being', *Canadian Journal of Occupational Therapy*, 65(2), 81-91.
- Link, B. and Phelan, J (2001) 'Conceptualising Stigma', *Annual Review of Sociology*, 27, 363-385.
- Liesener, J. J. and Mills, J. (1999) 'An experimental study of disability spread: Talking to an adult in a wheelchair like a child', *Journal of Applied Social Psychology*, 29(10), 2083–2092.
- Majnermer, A. (2010) 'Balancing the boat: Enabling an ocean of possibilities', *Canadian Journal of Occupational Therapy*, 77(4), 198-208.
- Martens, A., Greenberg, J., Schimmel, J. and Landau, M. J. (2004) 'Ageism and death: Effects of mortality salience and similarity to elders on distancing from and derogation of elderly people', *Personality and Social Psychology Bulletin*, 30(12), 1524–1536.
- Maxwell, J. (1996) *Qualitative research design: An interactive approach*, CA: Sage.
- McAvoy, L., Holman, T., Goldenberg, M. and Klenosky, D. (2006) 'Wilderness and Persons with Disabilities', *International Journal of Wilderness*, 12(2), 23-31.
- McCracken, G. (1988) *The Long Interview*, Newbury Park: Sage.
- McKinley, W.O. and Meade, M.A. (2004) 'Community Integration Following SCI', *NeuroRehabilitation*, 19(2), 79-80.
- Oliver, M. (1990) *The politics of disablement: A sociological approach*. New York: St. Martin's.



- Pal, G.C. (2011) 'Disability, Intersectionality and Deprivation : An Excluded Agenda', *Psychology and Developing Societies*, 23(2), 159–176.
- Papdimitriou, C. (2008) 'Becoming en-wheeled: the situated accomplishment of re embodiment as a wheelchair user after spinal cord injury', *Disability & Society*, 23(7), 691–704.
- Parker, K.J. (2001) 'Changing Attitudes Towards Persons with Disabilities in Asia', *Disability Studies Quarterly*, 21(4), 105-113.
- Pinel, E.C. (1999) 'Stigma Consciousness: The Psychological Legacy of Social Stereotypes', *Journal of Personality and Social Psychology*, 76(1), 114-128.
- Primeau, L.A. (1996) 'Work and leisure: transcending the dichotomy', *The American Journal of Occupational Therapy*, 50(7), 569-577.
- Quinn, G. (2009) 'Bringing the UN Convention on rights for persons with disabilities to life in Ireland', *British Journal of Learning Disabilities*, 37(4), 245–249.
- Robey, K. L., Beckley, L. and Kirschner, M. (2006) 'Implicit infantilizing attitudes about disability', *Journal of Developmental & Physical Disabilities*, 18(4), 441–453.
- Rolfe, D.E., Yoshida, K., Renwick, R. and Bailey, C. (2009) 'Negotiating participation: how women living with disabilities address barriers to exercise', *Health Care for Women International*, 30(8), 743-766.
- Ruggiero, K.M. and Taylor, D.M. (1997) 'Why Minority Group Members Perceive or Do Not Perceive the Discrimination That Confronts Them: The Role of Self-Esteem and Perceived Control', *Journal of Personality and Social Psychology*, 72(2), 373-389.
- Sakellariou, D. and Algado, S.S. (2006) 'Sexuality and Disability: a Case of Occupational Injustice', *British Journal of Occupational Therapy*, 69(2), 69-76.
- Scrambler, G. (2006) 'Sociology, social structure and health-related stigma', *Psychology, Health & Medicine*, 11(3), 288-295.

- Shakespeare, T. (1999) 'The sexual politics of disabled masculinity', *Sexuality and Disability*, 17(1), 53-64.
- Specht, J., King, G., Brown, E. and Foris, C. (2002) 'The importance of leisure in the lives of persons with congenital physical disabilities', *American Journal of Occupational Therapy*, 56(4), 436-445.
- Stone, E. and Priestley, M. (1996) 'Parasites, pawns and partners: disability research and the role of non-disabled researchers', *The British Journal of Sociology*, 47(4), 699-716.
- Timmons, A. and MacDonald, E. (2008) 'Alchemy and magic': the experience of using clay for people with chronic illness and disability', *British Journal of Occupational Therapy*, 71(3), 86-94.
- Tinsley, H.E.A., Hinson, J.A., Tinsley, D.J. and Holt, M.S. (1993) 'Attributes of leisure and work experiences', *Journal of Counselling Psychology*, 40(4), 447-455.
- Toriello, P.J., Leierer, S.T., Sheaffer, B.L. and Cubero, C.G. (2007) 'Threat and Visibility Impact of Disabilities and Other Conditions on Social Distance Preferences', *Rehabilitation Education*, 21(3), 159-170.
- Townsend, E.A. and Polatajko, H. J. (2007) *Enabling Occupation II: Advancing an Occupational Therapy Vision for Health, Well-being & Justice through Occupation*, Ottawa: CAOT Publications.
- Townsend, E. and Wilcock, A. A. (2003) 'Occupational justice' in Christiansen, C. and Townsend, E., eds., *Introduction to occupation: The art and science of living*, New Jersey: Prentice Hall.
- Townsend, E. and Wilcock, A. A. (2004) 'Occupational justice and client-centred practice: A dialogue in progress', *Canadian Journal of Occupational Therapy*, 71(2), 75-87.
- Trenberth, L. (2005) 'The role, nature and purpose of leisure and its contribution to individual development and well-being', *British Journal of Guidance & Counselling*, 33(1), 1-6.

- Unruh, A.M., Smith, N. and Scammell, C. (2000) 'The occupation of gardening in life-threatening illness: A qualitative pilot project', *Canadian Journal of Occupational Therapy*, 67(1), 70-77.
- Whiteford, G. (2000) 'Occupational Deprivation: Global Challenge in the New Millenium', *The British Journal of Occupational Therapy*, 63(5), 200-204.
- Whiteford, G. (2004) 'When people cannot participate: occupational deprivation' in Christiansen C. and Townsend, E., eds., *Introduction to occupation*, New Jersey: Prentice Hall.
- Wickham, S.E. and Hanson, C.S. (2000) 'A pilot study: attitudes toward leisure and leisure motivation in adults with spinal cord injury', *Occupational Therapy in Health Care*, 12(4), 33-50.
- Wilcock, A. (1998) 'Reflections on doing, being and becoming', *Canadian Journal of Occupational Therapy*, 65(5), 248-257.
- Zitzelsberger, H. (2005) '(In)visibility: accounts of embodiment of women with physical disabilities and differences', *Disability & Society*, 20(4), 389-403.

## Appendices

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## Appendix A



### Information Sheet

You are invited to take part in a research project to explore of the experiences of stigma of people who are wheelchair users while socialising. This project will be carried out by a student researcher as a requirement for a Masters in Occupational Therapy in the University of Limerick.

Areas covered in this research will include

- 1) How you spend their leisure time
- 2) Barriers you have encountered that interfere with your recreational goals (e.g. physical barriers, transportation, discrimination) and
- 3) The strategies you have developed to get around these barriers.

This research has two parts - you may agree to participate in one or both. First, there is an interview and the second part involves the researcher joining you for up to 1½ hours in a public place where you often go with friends. For example, this could be a social club or sporting event. You also have the option of inviting a friend to join you for the interview or participant observation.

This interview will last up to 1 hours and the interviewer will be a student occupational therapist. It can take place in an office of The Irish Wheelchair Association or a quiet public place like the library or a park. It will be audio recorded and you will have the option to receive a short summary of the interview. All of the information you provide as part of the research study will be kept private. However, if you choose to participate in this research with a friend, that person will know about everything you say in the interview. Your name and any personal information will not be reported in any publications based on this research. There is no compensation or payment for taking part in the study.

If you wish to participate in this research, you must be a wheelchair user, be over eighteen years of age and be able to understand English. Taking part in this study is completely voluntary and there are no consequences if you choose not to participate.

Please contact the student investigator Carmel Egan by email if you have any queries in relation to this research project. Email address: [0806889@studentmail.ul.ie](mailto:0806889@studentmail.ul.ie)  
You can also contact Dr. Nancy Salmon, Carmel's research supervisor by email at [Nancy.salmon@ul.ie](mailto: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

Tel (061) 234101

## Appendix B

### Interview Guide

#### Demographics

- 1) Female/Male
- 2) Age
- 3) Marital Status
- 4) Housing
- 5) Do you live with others? If so, are they friends or relatives?
- 6) How long have you been a wheelchair user?

#### Day profile

- 1) Introduce a daily planner and talk through how a usual weekday and a weekend day would be spent

#### Leisure Occupational Choices

- 1) What do you like to do in your free time? Use daily planner as a reference for this question.
- 2) Do you like to incorporate social activities into your free time?
- 3) Do you feel you are currently able to engage in the social activities you would like to do?

#### Leisure Occupational Settings

- 1) Where do you feel most comfortable while socialising?
- 2) Why do you think you feel comfortable in that particular place?
- 3) Is there anywhere you ever feel uncomfortable while socialising?
- 4) Why do you think you feel less comfortable in that particular place? / What makes that place different to the place do feel comfortable?
- 5) Do you prefer to socialise at home or out in the community?
- 6) Who do you prefer to socialise with?

#### Barriers to participation

- 1) Is there anything that stops you from doing the things you enjoy with your friends and if so what?
- 2) If the person does not bring up stigma:  
Sometimes people describe feeling stigmatised, is that something that relates to your

experiences?

**(Interview Guide – page 2 of 2)**

**Experience of stigma:**

**If the person has not used the word stigma, use whatever word they did use e.g. discrimination or feeling uncomfortable**

- 1) What are your experiences of stigma while socialising?
- 2) Where do you experience stigma most often?
- 3) Do you feel you experience stigma the same amount as other people who are wheelchair users? Can you give me some examples others have told you about regarding their experiences of stigma?
- 4) What strategies do you use to manage these experiences? How effective are the strategies you use?
- 5) Are these strategies similar to those used by others you know who also use wheelchairs?
- 6) Do you feel that experiences of stigma affect your choice in social activities?
- 7) Do you feel you would like to engage in social activities more frequently?
- 8) Is there anything we haven't talked about related to stigma that you would like to add?



## Appendix C



### Volunteer Consent Form for Interview

I \_\_\_\_\_ am aware that I am invited to participate voluntarily in a research study to investigate the experiences of stigma of people who are wheelchair users while socialising.

- I have read and understand the volunteer information sheet.
- I am aware that the researcher is a student investigator who is completing this research as a requirement for the Masters in Occupational Therapy programme in the University of Limerick.
- I am aware that this research is being supervised by Dr. Nancy Salmon from the Occupational Therapy Department in the University of Limerick.

I have been informed by the student investigator Carmel Egan that:

- This research is to investigate the experiences of stigma of people who are wheelchair users while socialising.
- My participation will involve taking part in an interview lasting up to 1½ hours long.
- I understand that I will be asked about my personal experiences of stigma while socialising but I do not have to answer any questions I do not want to talk about.
- My participation and responses will be kept confidential at all times.
- The results of this research may be reported in a publication or presentation. However, I will not be identified in any way.
- My interview will be recorded and typed up and I will be given the opportunity to read a summary of my interview if I wish.
- I may withdraw from this research study if I wish without consequence up until the first draft of the analysis is written in December 2011.

**Having read the information leaflet and the information included in this document I agree that I would like to participate in this research study. I understand that by signing this form I am giving my consent to participate in the interview part of this study as described above.**

I have received and signed two copies of this form, one for me to keep and one to return to the student investigator Carmel Egan.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_

\_\_\_\_\_

Signature of Student Investigator

Date

## Appendix D

### Mental Health Support Groups

#### 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/>

Helpline: 1890 303 302

Email: [wecanhelp@aware.ie](mailto: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/>

Phone: 1890 474 474

Email: [info@grow.ie](mailto: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>

Phone: 061-446786 Email: [info@LKmentalhealth.ie](mailto: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>

Phone: 353 (01) 601 0000

Email: [mary@pieta.ie](mailto:mary@pieta.ie)

- 5) **The Samaritans** “provides confidential non-judgmental 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](mailto:jo@samaritans.org)