



# UNIVERSITY *of* LIMERICK

O L L S C O I L L U I M N I G H

**MSc Occupational Therapy (PQ)**

**Module Code and Title:** OT6054 Occupational Therapy Project 4

**Module Co-Ordinator:** Dr Katie Robinson

**Research Supervisor:** Dr Rosemary Gowran

**Student Number:** 09005366

**Year:** 2

**Word Count:** 4,498

**Submission Date:** 11/04/2016

# **Wheelchair and Seating Service Provision in the Republic of Ireland: Exploring Service Users' Perspectives**

## Table of Contents

Abstract.....	3
1. Introduction.....	4
2. Literature Review.....	4
3. Methodology.....	5
4. Findings.....	8
5. Discussion .....	13
6. Conclusion.....	17
References.....	18

# Wheelchair and Seating Service Provision in the Republic of Ireland: Exploring Service Users' Perspectives

## Abstract

**Purpose:** To explore the perspectives of service users availing of wheelchair and seating service provision in the Republic of Ireland, within the context of muscular dystrophy.

**Method:** Four participants availing of wheelchair and seating service provision were interviewed using a semi-structured, open-ended interview protocol. Three participants were adult wheelchair users with muscular dystrophy and one a wheelchair associate, the mother of an adolescent with muscular dystrophy. The research was informed by a qualitative research methodology and data analysed using thematic analysis.

**Results:** Three themes emerged following data analysis: 'becoming and being a wheelchair user: progression, participation and provision', 'influences on service user experience: resources and rapport' and 'navigating the system: support, self-advocacy and suggestions'. Participants gave their perspectives of the personal impact of muscular dystrophy and wheelchair use, provided examples of what influenced their experiences of service provision and described how they themselves navigated the services of which they availed.

**Conclusion:** Areas of consideration by occupational therapists practicing within the realms of wheelchair and seating service provision were highlighted, such as the importance of understanding the lived experience of service users and establishing sufficient therapeutic rapport. Funding, waiting times and client-therapist relationships were highlighted as areas that appeared to impact upon service user satisfaction. The consequence of inadequate service provision is discussed as is the importance of supporting the implementation of best practice guidelines and the creation of governmental policy regarding personal mobility in the Republic of Ireland.

**Key Words:** Muscular Dystrophy, Wheelchair and Seating Service Provision, Occupational Therapy.

## **1. Introduction**

The World Health Organization (WHO) highlights wheelchair provision as a human right for people with mobility issues and defines it as ‘*an overall term for wheelchair design, production, supply and service delivery*’ (WHO 2008, p. 11). The United Nations’ Convention on the Rights of Persons with Disabilities (UNCRPD) outlines the state’s obligation to ensure the rights of persons with disabilities are met during mobility service provision (United Nations 2006). The Republic of Ireland (ROI) has not ratified the UNCRPD and is thus not required to provide reports addressing the implementation of its rights (Inclusion Ireland 2016). Unlike countries such as Sweden and the United Kingdom, there exists no governmental policy for provision in the ROI (Lilja *et al* 2003; National Health Service 2010; Gowran *et al* 2012). People with progressive conditions such as muscular dystrophy (MD) have complex, ever-changing mobility needs and addressing these may prove challenging for services (Muscular Dystrophy Campaign 2011). The research aimed to explore the perspectives of service users in the context of their manual and/or powered wheelchair and seating service provision in the ROI (hereon referred to as ‘provision’) and is part of a broader enquiry being conducted at the University of Limerick. ‘Service user’ for the current study refers to wheelchair users with MD or associates of same who have engaged with provision services.

## **2. Literature Review**

### *Muscular Dystrophy and Provision*

The muscular dystrophies are a set of un-curable genetic neuromuscular conditions where muscle strength is progressively weakened (Muscular Dystrophy Ireland 2016). Wheelchairs are necessary in facilitating independent mobility for many people with MD (Muscular Dystrophy Campaign 2011), where timing, accuracy and continued evaluation of provision is paramount to meet their subjective needs (Love and Benson 2006; Stone *et al* 2012). There currently exists a gap in knowledge concerning the intricate aspects of provision for people with MD (Richardson and Frank 2009). Richardson and Frank (2009) conducted a retrospective review examining the complexities experienced by service providers during the provision of powered wheelchairs to people with MD. Wheelchair user requirements relating to functionality, pain and deformities emerged as areas of difficulty for service providers, and a lack of planning for disease progression was highlighted. The study did not discuss service

user perspectives, nor did it include manual wheelchair users. In contrast, Samuelsson and Wressle (2008) conducted a quantitative study on wheelchair user satisfaction concerning provision in Sweden. They found that wheelchair users were satisfied with the service received however acknowledged the need for additional studies of underlying factors impacting upon provision (Samuelsson and Wressle 2008). The study did not specify clients' diagnoses and omitted powered wheelchair users.

### *Occupational Therapy and Provision in the Republic of Ireland*

Wheelchair provision plays a vital role in the lives of people with mobility issues and can support independence and engagement in occupations (Hardy 2004). Occupational therapists are responsible for provision in the ROI (Health Service Executive 2016) and have a duty to ensure a collaborative approach is adopted with their client in addressing their mobility needs (Murray 2012). Provision is offered primarily on a local level and is inconsistent across services with a lack of imposed standardization and official guidelines (Gowran *et al* 2012; Simms and McCaffrey 2012). A mixed methods study by Dillon *et al* (2012) examined wheelchair users' perspectives of provision in the ROI. The study found an overall sense of service user satisfaction, however participant recruitment was limited to those in receipt of one specific service. Therefore, results may not be truly indicative of satisfaction with provision in the ROI as a whole (Dillon *et al* 2012). The current study therefore aimed to explore the perspectives of service users availing of provision across the ROI in the context of MD.

## **3. Methodology**

### *Design*

A critical theory paradigm was chosen for the study as it supports occupational therapists in addressing client's needs within a broader social context and acknowledges the potential for socio-political factors to impact upon one's lived experience (Luborsky and Lysack 2006; Reeves *et al* 2008; Carpenter and Suto 2008). The research aimed to explore the perspectives of service users, thus a qualitative approach was employed as this facilitates the exploration of people's diverse viewpoints (Flick 2009). Semi-structured interviews were used as they can support participants in expressing their subjective experiences (Kvale 2007). The broader enquiry being conducted at the University of Limerick previously employed a postal survey

mixed methods approach, therefore an approach using qualitative in-depth semi-structured interviews was deemed appropriate in contributing to the over-arching research.

### *Method*

Recruitment for interviews was via purposive, criterion sampling assisted by a gatekeeper from an organization for people with MD (see Table 1). This form of sampling allows for the recruitment of information-rich participants with knowledge of the research topic (Palinkas *et al* 2015).

Table 1: Inclusion Criteria for Wheelchair Users and Wheelchair Associates

<b>Wheelchair User</b>	<b>Wheelchair Associate</b>
Diagnosis of MD	Associate of a person with a diagnosis of MD (e.g. parent/guardian)
Aged 13 years or over	Aged 18 years or over
Manual or powered wheelchair user	Associate of manual or powered wheelchair user
Previous engagement with provision services in the ROI	Previous engagement with provision services in the ROI
Fluent English	Fluent English

A recruitment e-mail was dispatched from the organisation inviting members to participate. Three wheelchair users and one wheelchair associate agreed to participate, details of which are outlined in Table 2 and Table 3 respectively.

Table 2: Wheelchair User Participant Information

<b>Name*</b>	<b>MD Diagnosis</b>	<b>Status</b>	<b>Wheelchair</b>	<b>Life-Stage</b>
Louise	Limb Girdle 1B	Wheelchair User	Manual	Early Adulthood
Alice	Facio-scapulo-humeral	Wheelchair User	Powered	Late Adulthood
Jacob	Becker's	Wheelchair User	Powered	Middle Adulthood

\*Pseudonym

Table 3: Wheelchair Associate Participant Information

<b>Name*</b>	<b>Association to Wheelchair User</b>	<b>Name* of Wheelchair User</b>	<b>MD Diagnosis</b>	<b>Wheelchair</b>	<b>Life-Stage</b>
Mary	Mother	Kevin (Son)	Duchenne	Powered	Adolescence

\*Pseudonym

In person or telephone interviews were scheduled with participants at their convenience and took place between September 2015 and January 2016, lasting between 45 minutes to 1 hour 30 minutes. In person interviews were conducted at participant’s homes, their preferred location. An interview guide was used to ensure compliance with the broader study being conducted at the University of Limerick. This was influenced by Kronenberg *et al*’s (2009) political reasoning tool which examines people’s perceptions in relation to their experiences and Capra’s (2003) work on reflective consciousness which explores the beliefs of the person. Interviews were audio-recorded, transcribed verbatim and analysed.

#### *Data Analysis*

Thematic analysis was employed as it can unearth both obvious and indirect concepts present within data (Guest *et al* 2012). Braun and Clarke’s (2006) six-phase thematic analysis guidelines were adopted, which includes familiarisation with the data set, generation of codes, search for and review of themes, definition of themes and final production of the report. Analysis was assisted by QSR NVivo 10 software.

#### *Validity, Reliability and Trustworthiness*

Validity and reliability of the research was supported through the use of Lincoln and Guba’s (1989) areas of consideration for trustworthiness: credibility, transferability, dependability and confirmability (Whittemore *et al* 2001). Member checking was offered to participants to support credibility (Yin 2011), however only one participant availed of this and did not provide a response following receipt of their interview summary. Transferability of qualitative data is a judgement made by the person who receives it however endeavours were made to accurately describe participant information and details of data collection to support this (Lincoln and Guba 1989; Graneheim and Lundman 2003). Dependability was sought through accounting for any changes that occurred during the research and confirmability of data interpretation was strengthened through the use of a reflexive journal (Lincoln and Guba

1989). Maso (2003) highlights the use of reflexivity as a tool that can enhance qualitative research, improving its trustworthiness. A reflexive journal was kept throughout the research in an effort to examine how aspects such as the researcher's background, experiences and suppositions may have impacted upon the research (Finlay and Gough 2003).

### *Ethical Considerations*

Sensitivity on behalf of the researcher was a priority throughout as the emotional and psychological responses to wheelchair provision may differ for people (Muscular Dystrophy Campaign 2011). Ethical approval was granted by the Education and Health Sciences Research Ethics Committee at the University of Limerick. Informed consent was obtained following participant's receipt of the study's information sheet (Stein *et al* 2013).

Pseudonyms were used in an effort to respect anonymity. As recruitment was through membership of an organisation, members were assured participation was voluntary and they could refuse to partake without consequence. All participants were over 18 years therefore ethical considerations regarding child involvement in the study were not required.

## **4. Findings**

Three themes were identified, each with subthemes used to structure their content as follows: 'becoming and being a wheelchair user: progression, participation and provision', 'influences on service user experience: resources and rapport' and 'navigating the system: support, self-advocacy and suggestions'.

### **Becoming and Being a Wheelchair User: Progression, Participation and Provision**

Exploring participant's perspectives of provision warranted a greater understanding of their personal accounts of muscular dystrophy and initial wheelchair use experience. Participants described their experiences of becoming and being a wheelchair user with MD, or in Mary's case, being a mother of a wheelchair user with MD. Topics discussed included the physical and occupational performance implications of being a wheelchair user with a progressive condition, the effects of such on social participation and the importance of receiving client-centred provision. Such factors were deemed to have a foundational element in understanding the perspectives of participants concerning their provision experiences.

### *Progression*

The advancing and progressive nature of MD was acknowledged by participants:

‘This...this....this condition is...eats you up you know’ (Mary).

Louise offered her perspective on the personal impact of having MD and the possibility of progressing from manual to powered mobility:

‘I don’t like it at all...I used to get very upset...it’s just like ‘yeah whatever’ but you see I have started now like...when you said to me what will you call me [discussing a pseudonym]...I said you can call me a cripple’ (Louise).

The progression of MD was also acknowledged in relation to its potential impact upon future occupational performance areas:

‘Hopefully in 2 years’ time I will [still] be able to drive, but things are progressively getting worse with this complaint I have’ (Jacob).

### *Participation*

The implications of becoming and being a wheelchair user in relation to social participation arose during interviews. Jacob described his initial feelings upon being provided with a wheelchair and recounted an experience in which a friend visited and reacted to seeing his wheelchair:

‘I said by Jesus then...I’m fecked, no one will talk to me’ (Jacob).

‘He said ‘oh Jesus what happened to you? I’ll come back again!’ I explained to him what I have...once people see a wheelchair beside you they say that man is dead...he’ll be dead in a week or whatever’ (Jacob).

Mary described a social experience which subsequently impacted upon her son’s desire to participate in the leisure-based activity of going to the cinema:

‘Three boys saw him coming out of the wheelchair bathroom with his mother...they were horrible. He hasn’t gone to the cinema since...they laughed and sniggered...he pretended he didn’t see it’ (Mary).

### *Provision*

The importance of receiving adequate provision as a wheelchair user was discussed in relation to facilitating independent mobility and supporting occupational engagement:

‘The chair is the biggest issue because at the end of the day the chair is your legs’ (Louise).

‘It’s important to have the positioning right and seating right...[the wheelchair] is his legs you know’ (Mary).

Jacob highlighted the advantage of being provided a standing wheelchair that enables him to rise up and walk, as well as participate in activities of daily living:

‘I’m able to get cups out of the high up press...it means that I can sort of manage on my own’ (Jacob).

### **Influences on Service User Experience:** Resources and Rapport

All participants offered their perspectives on aspects of provision that were somewhat dissatisfactory. Factors relating to resources such as funding and waiting times appeared as sources of contention that impacted upon service-user satisfaction with provision. Client-therapist interactions and the formation of sufficient rapport also emerged as contributing to that standard of provision received.

### *Resources*

Alice spoke of how she felt her seating clinic, when compared to another branch she knew of, was not living up to its potential and how the issue of resource allocation was a potential contributory factor to this:

‘They’re not living up to their potential...maybe they are understaffed. There’s another wheelchair clinic and it’s state of the art, the apple of everyone’s eye...whereas my clinic is paint peeling...the impression I get is that most of their resources go into the other wheelchair clinic’ (Alice).

Mary emphasised the difficulty in getting funded for wheelchair and seating assistive technology and how the economic stance of the state appeared to impact upon this:

‘Funding is what is so hard, they recommend something and then it goes for approval, if you’re not on top of it every week it’s going to languish on top of a pile forever...Ireland was going through, you know, what it is going through, they tell you funding isn’t affected, yes it is’ (Mary).

Alice expressed her frustration at the backlog of appointments and lengthy waiting times she experienced with her seating clinic:

‘We are forever waiting for an appointment and then they cancel them at the last minute...it’s really been very frustrating’ (Alice).

### *Rapport*

The client-therapist relationship appeared to have an impact upon the levels of satisfaction participants experienced in relation to provision. Mary spoke of her anger towards an occupational therapist during a home assessment with her son:

‘Two of them [occupational therapists] came to the house and another man, and by the time they left the house, they had me so angry... it was an absolute disaster. I barred that OT from the house’ (Mary).

She described not being informed by her occupational therapist that the other man was a company representative. This lack of transparency led to feelings of offence:

‘I just find that it’s actually offensive to bring a rep to a house when you’re assessing a child’ (Mary).

Louise described her overall perspective of provision, and how negative interactions with her occupational therapist impacted upon the service received:

‘Personally, it’s shite for me. I know there’s no funding... I get that, but at the end of the day sometimes I feel especially with my occupational therapist, that fell on deaf ears’ (Louise).

When asked what frustrated her most about the provision she received, Louise responded:

‘The fact that I had to roar at her [occupational therapist]...we kind of came to the conclusion that she was more about the money...it’s like she didn’t care about anything else really’ (Louise).

Conversely, Alice spoke highly of her occupational therapist and how she saw her as both a practitioner and friend:

‘One [occupational therapist] has been with me ever since I had my first stumble...she has remained a friend...they [occupational therapists] go down every avenue to go down and find solutions which is wonderful’ (Alice).

### **Navigating the System:** Support, Self-advocacy and Suggestions

Participants described their role in navigating provision services. Aspects such as family involvement emerged as sources of support that people drew upon to assist in this. The importance of self-advocacy and having a voice when things are unsatisfactory arose. In closing, participants offered suggestions that may benefit future provision for service users.

#### *Support*

The concept of support emerged from all interviews. Jacob reflected on how his wife was a supportive figure in navigating the provision system and liaising with the occupational therapist:

‘My wife got onto the occupational therapist, she said ‘oh god he needs a chair, get a chair’, so they came out straight away’ (Jacob).

#### *Self-Advocacy*

Mary spoke of her role in advocating for her son when navigating the provision system:

‘Being quiet will get you nowhere...as I say, you have a special needs child, obviously this happened for a reason, you are needed for your advocacy and for your voice and for standing up for your child’ (Mary).

When dissatisfied with the level of input and contact from her occupational therapist, Louise also used her voice as a service user to address the issue:

‘I had enough... the last time I spoke to her [occupational therapist] before we had a row...she said she would talk to her manager...so weeks went by, I said to mam I’m going to make a complaint, I have to do something’ (Louise).

### *Suggestions*

Overall, participants portrayed how in order to feel supported during provision, a sense of being listened to and a deeper realisation of what it’s actually like to be a wheelchair user is required. Louise highlighted that the biggest challenge for her when navigating the system was for relevant professionals to fully understand what it’s like to be a wheelchair user. She portrayed how the lived experience of being a wheelchair user may be most powerful in generating a full understanding of what it’s like, and her perspective was that this could be reflected in occupational therapy practice:

‘I would like to see an occupational therapist in a wheelchair...I don’t mean you getting into a wheelchair. I actually mean a wheelchair user as an occupational therapist’ (Louise).

Mary suggested how based on her experiences, increased therapist training in interpersonal skills would benefit service provision:

‘I think a little bit of training in how to deal with people would be no harm in any of the services...and that involves research and it involves coming from the top down, the management is so important’ (Mary).

## **5. Discussion**

Participant’s perspectives unearthed the complex interactions between MD, wheelchair use and service provision. Three themes were identified: ‘becoming and being a wheelchair user:

progression, participation and provision’, ‘influences on service user experience: resources and rapport’ and ‘navigating the system: support, self-advocacy and suggestions’. These will be synthesised and discussed in relation to the current literature, including their implications for occupational therapy and future research. The limitations of the study will also be considered. Participants highlighted the multi-faceted impact that becoming and being a wheelchair user with MD can have on identity, social interactions and the need for correct provision. The research aimed to explore the perspectives of service users availing of provision and in order to do so effectively, gaining an understanding of the intricacies of life as a wheelchair user with MD was deemed beneficial. Ahlström and Sjöden (1996) highlight the psycho-social illness related complexities experienced by people with MD such as isolation and a fear of being viewed differently which were reflected in the current research. Participants of the current study gave accounts of stigmatised interactions with others as wheelchair users. The experience of stigma has been reported in studies on wheelchair use, where despite wheelchairs supporting independence in mobility for people, the visibility of physical dysfunction that they represent remains (Papadimitriou 2008). The wheelchair is the universal symbol of disability (Papadimitriou 2008) and this warrants the questioning of how we view wheelchair users within society, particularly when there is no governmental policy for provision.

We must examine the political forces at play that cause us to question why in the year 2016, there remains a need to advocate for the introduction of governmental policy regarding personal mobility in the ROI, when it is defined as a human right that facilitates occupational engagement (United Nations 2006; Hardy 2004)? Occupational apartheid concerns the political separation of minority groups through factors inhibiting their access to dignified, meaningful occupational engagement (Kronenberg *et al* 2005). It may be argued that the lack of policy governing provision and subsequent inequalities in the standard of service delivery (Gowran *et al* 2014) could potentially be construed as occupational apartheid. Participants highlighted the distribution of resources, funding, waiting times and negative encounters with relevant professionals as factors that impacted upon their provision experiences. Funding, presence of company representatives during assessments and waiting times have previously been highlighted as sources of contention for people availing of provision (Suzuki *et al* 2000; Gowran *et al* 2012; Bray *et al* 2014). Extensive waiting times are indicative of inadequate provision and the consequences of such for people with rapidly changing conditions such as MD must be addressed (Hill and Phillips 2006). The International Classification of

Functioning, Disability and Health (ICF) highlights the role of mobility devices in influencing one's experience of health, disability and/or functioning (WHO 2001) and the purpose of wheelchair provision is to enable mobility and support people in occupational engagement (Curtin *et al* 2010). Inadequate provision may however lead to occupational deprivation, as a wheelchair that doesn't meet the user's needs may impede rather than support function, thus impacting upon one's ability to engage in occupations (Di Marco *et al* 2003; Whiteford 2010).

The ROI experienced a 9% reduction in public health expenditure since 2008 (WHO 2014) and the potential effects of this on service user satisfaction should be addressed on a political level. Participants highlighted the need for advocacy within service provision, particularly when dissatisfied with the service received. Acknowledging the voice of the service user is important in building upon service quality. There has been a challenge from the disability movement for professionals to acknowledge service users as the experts concerning their provision (Sapey *et al* 2005). This may be supported through the adoption of the social model of disability throughout healthcare provision, where the perspective of the service user is sought and respected, as opposed to the medical model that may focus primarily on the impairment not the person (Hughes 2010). The use of service user outcome measures by provision services is recommended for recognising the voice and overall experience of service users post provision (Gowran *et al* 2012).

#### *Implications for Occupational Therapy Practice and Future Research*

Occupational therapists must focus holistically on the overall health and well-being of the person with whom they engage with, not solely on the distribution of equipment (Wilcock 1999). Participants of the study expressed a desire for occupational therapists to make an increased effort to understand what it feels like to be a wheelchair user, and many of the frustrations experienced by participants appeared to stem from the client-therapist relationship. Incorporating successful client-centred interactions within occupational therapy requires the development of a partnership between both client and practitioner (Duncan 2012). Such partnerships can be supported through seeking client feedback following engagement with services (Duncan 2012). Occupational therapists have a duty to support client-centred relationships throughout the provision process through listening, showing respect, being empathetic and fully disclosing relevant information in order to support clients

in decision making regarding their care (Duncan 2012). Respect and collaboration within a therapeutic relationship has been shown to impact positively upon rehabilitation outcomes (Law 1998). Training in interpersonal skills for occupational therapists was highlighted as a suggestion for improving provision, particularly in relation to client interactions and disclosing relevant information. The Association of Occupational Therapists of Ireland's (AOTI) 'Code of Ethics and Professional Conduct for Occupational Therapists' addresses the concept of 'Respect for the Rights and Dignity of the Client' (AOTI 2013). This can be achieved through courteous, respectful and dignified client interactions in which the client is fully informed about the occupational therapy intervention received. Practicing members in the ROI must be aware of their responsibility to abide by the Code which reflects the core principles of the profession (AOTI 2013).

On a macro level, occupational therapy has a role in addressing the political elements of society that impact upon people's engagement with occupations (Kronenberg *et al* 2005). Creating a society which supports the rights of people to engage with meaningful occupations includes the correct provision of mobility devices and occupational therapists have a responsibility for the assurance of such rights within the services they provide (Kronenberg *et al* 2005). This can be done through thinking globally and acting locally. For example, considering the UNCRPD's (2006) right to personal mobility, occupational therapists may critique the service they are providing on a local level, and question whether the service is one in which they would be happy for a family member to avail of (known as the 'relative test') (Kronenberg *et al* 2005). There are currently no national policies or guidelines in existence for the provision of wheelchair and seating services (Gowran *et al* 2014) and such lack of policy is seen as a barrier to accessing mobility devices (WHO 2011). Occupational therapists have a part to play in supporting the development of governmental policy that may ensure the rights of those availing of provision services are met and that services are provided on an equal level across the ROI (Gowran *et al* 2012). Future research may explore the experiences of services users with differing complex conditions as well as the perspectives of relevant professionals in order to generate a greater understanding of the forces at play within provision. Further examination of the causality of extended waiting times within services and its impact on the occupational engagement of service users is recommended (Gowran *et al* 2012).

## *Limitations*

The study was not without limitations. The sample size of four participants was small and thus the study's success at reaching data saturation is questionable (Guest *et al* 2006). In addition, the lack of a clear database representative of people with MD in the ROI affects the generalizability of the findings, which should be approached tentatively. Efforts were made to increase participant numbers and ethical approval was received during research conduction to recruit via the gate-keeping organisation's social media, however this was limited by time constraints. Potential participants who may have communication difficulties were inadvertently overlooked as participants were only recruited via standard e-mail or social media. Future research of the topic would benefit from further recruitment of service users. Participants who took part in the study were from different geographical areas in Ireland, availed of different provision services and were a mixture of manual and powered wheelchair users/associates. This amount of participant variation when coupled with a small sample size may have impeded the generation of common themes during analysis. Participants availed of different services which may adopt different models of provision, thus it is difficult to decipher what does and doesn't work for each provision service. The motivation for people to agree to participate must also be noted, with those with a specific type of experience with provision services potentially being more inclined to offer their perspectives. The researcher who conducted the study was also new to performing qualitative research with novice interview skills.

## **6. Conclusion**

The research aimed to explore the perspectives of service users availing of wheelchair and seating service provision in the ROI. The complexities of becoming and being a wheelchair user emerged from the interviews and this was considered an important aspect to acknowledge. Such findings are important as they highlight the need for relevant professionals interacting with service users to recognize the impact of providing a wheelchair on one's lived experience. The study highlighted the discrepancies in existence concerning service user experience of provision. The introduction of governmental policy, guidelines and outcome measures regarding provision in the ROI are proposed as steps in counteracting such incongruities, which may assist in alleviating the occurrence of occupational apartheid and occupational deprivation for service users. The advocacy of service users for correct and

appropriate provision cannot be overlooked and it is proposed that the development of policy and guidelines include the perspectives of service users. The introduction of policy and guidelines alone may not be sufficient in ensuring satisfactory provision (Bray *et al* 2014). There lies an additional responsibility amongst occupational therapists to actively engage with such publications in order to provide a high quality service (Bray *et al* 2014) and to endeavour to understand the lived experiences of those with whom they engage.

*‘You never really understand a person until you consider things from his point of view, until you climb into his skin and walk around in it’* (Harper Lee 1960, p. 36).

## References

- Ahlström, G. and Sjöden, P. (1996) 'Coping with illness-related problems and quality of life of adult individuals with muscular dystrophy', *Journal of Psychosomatic Research*, 41(4), 365-376.
- Association of Occupational Therapists of Ireland (2013) *Code of Ethics and Professional Conduct* [online], available: <https://www.aoti.ie/attachments/a4e97af7-3a2a-48dd-b3df-c63e1bcaf6e9.PDF> [accessed 13 Jan 2016].
- Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), 77-101.
- Bray, N., Noyes, J., Edwards, R.T. and Harris, N. (2014) 'Wheelchair interventions, services and provision for disabled children: a mixed method systematic review and conceptual framework', *BMC Health Services Research*, 14, 1-18.
- Capra, F. (2003) *The Hidden Connection: A Science for Sustainable Living*, London: Harper Collins Publishers Ltd.
- Carpenter, C. and Suto, M. (2008) *Qualitative Research for Occupational and Physical Therapists: A Practical Guide*, Oxford: Blackwell Publishing.
- Curtin, M., Molineaux, M. and Supyk-Mellson, J. (2010) *Occupational Therapy and Physical Dysfunction*, London: Churchill Livingstone Elsevier.
- Di Marco, A., Russell, M. and Masters, M. (2003) 'Standards for wheelchair prescription', *Australian Occupational Therapy Journal*, 50, 30-39.
- Dillon, A., Campbell, N. and Ryan, C. (2012) "'Your seating, your say": using a standardised approach to evaluate user's perspectives of seating equipment and service deliver in a community setting', *The Irish Journal of Occupational Therapy*, 39(2), 33-40.
- Duncan, E.A.S. (2012) *Foundations for Practice in Occupational Therapy*, London: Churchill Livingstone Elsevier.

- Finlay, L. and Gough, B. (2003) *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*, Malden, MA: Blackwell Science Ltd.
- Flick, U. (2009) *An Introduction to Qualitative Research*, 4<sup>th</sup> ed., London: SAGE Publications Ltd.
- Gowran, R.J., McCabe, M., Murphy, N., Murray, E. and McGarry, A. (2012) 'Research article: wheelchair and seating service provision: exploring users' perspectives', *The Irish Journal of Occupational Therapy*, 39(2), 3-14.
- Gowran, R.J., McKay, E.A. and O'Regan, B. (2014) 'Sustainable solutions for wheelchair and seating assistive technology provision: presenting a cosmopolitan narrative with rich pictures', *Technology and Disability*, 26, 137-152.
- Graneheim, U.H. and Lundman, B. (2003) 'Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness', *Nurse Education Today*, 24(2), 105-112.
- Guest, G., Bunce, A. and Johnson, L. (2006) 'How many interviews are enough? An experiment with data saturation and variability', *Field Methods*, 18(1), 59-82.
- Guest, G., MacQueen, K.M. and Namey, E.E. (2012) *Applied Thematic Analysis*, London: SAGE Publications.
- Hardy, P. (2004) 'Powered wheelchair mobility: an occupational performance evaluation perspective', *Australian Occupational Therapy Journal*, 51, 34-42.
- Health Service Executive (2016) *Occupational Therapy* [online], available: <http://www.hse.ie/eng/services/list/2/PrimaryCare/pcteams/dublinsouthpcts/dunlaoghaireglasthulepct/ot.html> [accessed 12 Mar 2016].
- Hill, M.E. and Phillips, M.F. (2006) 'Service provision for adults with long-term disability: a review of services for adults with chronic neuromuscular conditions in the United Kingdom', *Neuromuscular Disorders*, 16, 107-112.
- Hughes, R. (2010) 'The social model of disability', *British Journal of Healthcare Assistants*, 4(10), 508-511.

- Inclusion Ireland (2016) *The United Nations and Disability: Convention on the Rights of Persons with Disabilities (UNCRPD)* [online], available: <http://www.inclusionireland.ie/content/page/united-nations-and-disability> [accessed 10 Mar 2016].
- Kronenberg, F., Algado, S.S. and Pollard, N. (2005) *Occupational Therapy without Borders: Learning from the Spirit of Survivors*, London: Churchill Livingstone Elsevier.
- Kronenberg, F., Pollard, N. and Sakellariou, D. (2009) 'A political practice of occupational therapy' in Kronenberg, F., Pollard, N. and Sakellariou, D. *A Political Practice of Occupational Therapy* (eds.), London: Churchill Livingstone Elsevier.
- Kvale, S. (2007) *Doing Interviews*, London: SAGE Publications Ltd.
- Law, M. (1998) 'Does client-centred practice make a difference?' in Law, M. (ed.) *Client-Centred Occupational Therapy*, Thorofare, NJ: Slack Incorporated.
- Lee, H. (1960) *To Kill a Mockingbird*, Philadelphia: J.B. Lipincott Company.
- Leech, N.L. and Onwuegbuzie, A.J. (2011) 'Beyond constant comparison qualitative data analysis: using NVivo', *School Psychology Quarterly*, 26(1), 70-84.
- Lilja, M., Månsson, I., Jahlenius, L. and Sacco-Peterson, M. (2003) 'Disability policy in Sweden', *Journal of Disability Policy Studies*, 14(3), 130-135.
- Lincoln, Y.S. and Guba, E.G. (1989) *Fourth Generation Evaluation*, London: Sage Publications.
- Love, J.A. and Benson, J. (2006) 'Community use of a pushrim activated power-assisted wheelchair by an individual with facioscapulohumeral muscular dystrophy', *Physiotherapy Theory and Practice*, 22(4), 207-218.
- Luborsky, M.R. and Lysack, C. (2006) 'Overview of qualitative research', in Kielhofner, G. (ed.) *Research in Occupational Therapy*, Philadelphia: F.A. Davis Company.

- Maso, I. (2003) 'Necessary subjectivity: exploiting researchers' motives, passions and prejudices in pursuit of answering 'true' questions', in Finlay, L. and Gough, B. (eds.) *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*, Malden, MA: Blackwell Science Ltd.
- Murray, E. (2012) 'Rolling back the years: seating, a journey of transition and discovery', *The Irish Journal of Occupational Therapy*, 39(2), 27-32.
- Muscular Dystrophy Campaign (2011) *Wheelchair Provision for Children and Adults with Muscular Dystrophy and other Neuromuscular Conditions* [online], available: <http://www.muscular dystrophyuk.org/app/uploads/2015/02/wheelchair-guidelines.pdf> [accessed 12 Mar 2015].
- Muscular Dystrophy Ireland (2016) *What is Muscular Dystrophy?* [online], available: <http://www.mdi.ie/what-is-muscular-dystrophy.html> [accessed 16 Mar 2015].
- National Health Service (2010) *Healthcare Standards for NHS-commissioned Wheelchair Services* [online], available: <http://www.wheelchairmanagers.nhs.uk/270410-hswc.pdf> [accessed 19 Dec 2015].
- Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N. and Hoagwood, K. (2015) 'Purposeful sampling for qualitative data collection and analysis in mixed method implementation research', *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 533-544.
- Papadimitriou, C. (2008) 'Becoming en-wheeled: the situated accomplishment of re-embodiment as a wheelchair user after spinal cord injury', *Disability and Society*, 23(7), 691-704.
- Reeves, S., Albert, M., Kuper, A. and Hodges, D. (2008) 'Qualitative research: why use theories in qualitative research?', *British Medical Journal*, 337(7670), 631-634.
- Richardson, M. and Frank, A.O. (2009) 'Electric powered wheelchairs for those with muscular dystrophy: problems of posture, pain and deformity', *Disability and Rehabilitation: Assistive Technology*, 4(3), 181-188.

- Samuelsson, K. and Wressle, E. (2008) 'User satisfaction with mobility assistive devices: an important element in the rehabilitation process', *Disability and Rehabilitation*, 30(7), 551-558.
- Sapey, B., Stewart, J. and Donaldson, G. (2005) 'Increases in wheelchair use and perceptions of disablement', *Disability and Society*, 20(5), 489-505.
- Simms, L. and McCaffrey, A. (2012) 'Seating – what we've learned from experience', *The Irish Journal of Occupational Therapy*, 39(2), 22-26.
- Stein, F., Rice, M.S. and Cutler, S.K. (2013) *Clinical Research in Occupational Therapy*, 5<sup>th</sup> ed., New York: Delmar Cengage Learning.
- Stone, K., Tester, C., Howarth, A., Johnston, R., Traynor, N., McAndrew, H., Blakeney, J. and McCutcheon, M. (2012) *Occupational Therapy and Duchenne Muscular Dystrophy*, West Sussex: John Wiley & Sons Ltd.
- Suzuki, K.M., Lockerte, G. and Braun, K.L. (2000) 'Client satisfaction survey of a wheelchair and seating clinic', *Physical and Occupational Therapy in Geriatrics*, 17(2), 55-65.
- United Nations (2006) *Convention on the Rights of Persons with Disabilities* [online], available: <http://www.un.org/disabilities/convention/conventionfull.shtml> [accessed 10 Mar 2015].
- Whiteford, G. (2010) 'Occupational deprivation: understanding limited participation', in Christiansen, C.H. and Townsend, E.A. (eds.) *Introduction to Occupation: The Art and Science of Living*, New Jersey: Pearson Education Inc.
- Whittemore, R., Chase, S.K. and Mandle, C.L. (2001) 'Validity in qualitative research', *Qualitative Health Research*, 11(4), 522-537.
- Wilcock, A.A. (1999) 'Reflections on doing, being and becoming', *Australian Occupational Therapy Journal*, 46, 1-11.

World Health Organization (2001) *International Classification of Functioning, Disability and Health (ICF)* [online], available: <http://www.who.int/classifications/icf/en/> [accessed 22 Mar 2015].

World Health Organization (2008) *Guidelines on the Provision of Manual Wheelchairs in Less resourced Settings* [online], available: [http://www.who.int/disabilities/publications/technology/English%20Wheelchair%20Guidelines%20\(EN%20for%20the%20web\).pdf?ua=1](http://www.who.int/disabilities/publications/technology/English%20Wheelchair%20Guidelines%20(EN%20for%20the%20web).pdf?ua=1) [accessed 17 Jul 2015].

World Health Organization (2011) *Joint position paper on the provision of mobility devices in less resourced settings: a step towards implementation of the Convention on the Rights of Persons with Disabilities (CRPD) related to personal mobility*, [online], available: [http://apps.who.int/iris/bitstream/10665/44780/1/9789241502887\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/44780/1/9789241502887_eng.pdf) [accessed 15 Feb 2016].

World Health Organization (2014) *The impact of the financial crisis on the health system and health in Ireland*, Copenhagen: European Observatory on Health Systems and Policies.

Yin, R.K. (2011) *Qualitative Research from Start to Finish*, London: The Guilford Press.