



# UNIVERSITY *of* LIMERICK

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

**MSc Occupational Therapy**

OT6054 Project 4

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**12005045**

Second Year

5000

23/04/14

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Appendix 1 - Information Letter

## **Acknowledgements**

First and foremost I would like to extend a sincere thank you to my supervisor and lecturer Dr. Nancy Salmon. Her consistent calmness and presence meant that I was reassured throughout the process of completing this research article. Secondly, I would like to acknowledge the staff and lecturers in the University of Limerick who continue to support and encourage my learning in many ways, including Emma Burns for her kindness and help throughout the project. I would also like to recognise the University itself which has facilitated this learning opportunity. Furthermore, I would like to thank my classmates with whom I shared this research project and to those with whom I shared the last eighteen months, various discussions and encouragements during the last eighteen months helped guide my learning and my thinking which has contributed to this study.

I would like to extend limitless gratitude to my family; Mom, Dad, Tim, Miriam, Joanne and all my aunts, uncles and cousins. Your continued expressions of curiosity and encouragement will not be forgotten. I will forever be grateful to Marcel and Rosalie for their reassurance, support and fun throughout my studies at the University of Limerick, your patience and love did not go unnoticed! I also offer huge appreciation to my friends that aided me in my undertakings throughout the last two years. Lastly, I would also like to show my gratitude to the four participants who gave their time and honesty to be part of this research.

**‘How do People with Disabilities Navigate Stigma to Create Lasting Relationships at Home, at Work/School, and in Their Communities?’**

## Abstract

**Background:** It is recognised that tertiary education can be a challenge for people with visual impairments. Current literature largely focuses on the experiences of older adults and children in relation to visual impairments. The research aim is to explore the subjective experiences of people with visual impairment in tertiary education in relation to services and stigma.

**Objectives:** This study aims to evaluate the encounters of people with visual impairment within tertiary education. This research also aims to identify the areas of improvement that may be required to ensure inclusion and an equal educational experience for people with visual impairment.

**Methods:** Qualitative research with the use of semi-structured interviews employing thematic analysis was executed. Recruitment was carried out via snowball sampling. Participants included four people, three female and one male, who have a visual impairment and attended tertiary education, ranging in age from 35 – 47. Analysis was carried out using the ATLAS.ti software.

**Results:** Participants expressed positive and adverse experiences within tertiary education. Two main themes emerged; supports and services and societal issues. Supports and services appeared to be varied and inconsistent. Third level policies for people with disabilities appear to focus on access over equity. Stigma was encountered as equal participation was limited. College was however a new opportunity for personal growth.

**Conclusions:** Participants discuss difficulties in accessing services in a timely and consistent manner but also encountered positive outcomes. As Occupational Therapy is an evolving profession within tertiary education, this research is valuable for informing the currently developing practice.

*(Word Count: 250)*

**Key words:** Disability, Stigma, Education and Visual Impairment.

## 1. Introduction

This research paper explores the experiences of people with visual impairment in tertiary education. Participation and development of relationships within the educational system can be a challenge for people with disabilities (Mohammad Salleh and Zainel 2010; Denhart 2008). The objective of this paper is to explore these relationships and investigate the navigation of stigma within this context. The information gathered intends to enhance existing research on visual impairment. This research also aims to identify the areas of improvement that may be required to ensure inclusion and an equitable educational experience for people with visual impairments. This paper is interested in various elements of the subject's experiences including services, supports, opportunities, relationships and societal influences.

Preliminary research of existing studies was carried out through database searches from the period of September 2013 - April 2014 including; Science Direct, JSTOR, AMED, ATLAS, CINAHL, Google Scholar, GreenFILE, Medline, PubMed and UK/EIRE Reference Centre. The first sections of this paper focus on broad issues relating to disabilities, stigma and education and the latter sections focus on visual impairment in relation to education and stigma.

## 2. Literature Review

### Disability

The World Health Organisation (WHO) describes disability as the experience of limited activities and participation through biological impairment, encompassing both person and environment (WHO 2013). The National Disability Authority (NDA) recognises that disability encompasses one whole group, yet there are a range of factors at play; gender, class, age, experience and sexuality. Disability can include sensory, physical, neurological, psychosocial, intellectual or medical impairments (NDA 2001). The International Classification of Functioning, Disability and Health focus on environmental barriers that create disability. On a whole, it appears that disability is the correlation between person, body and environment (WHO 2011).

Disability may be considered to be created through the eyes of 'able-bodied' persons who deem people with disabilities to be ineffective in giving significant societal contributions. *"Thus, whatever disability is, it is something that people define, understand, and come to know and live with in particular ways"* (Titchkosky and Michalko 2009, p.2). People with disabilities need to break through barriers in order to fight stigma (Farenga and Ness 2005). In order to challenge the moulds and expectations of the majority, people with disabilities need make their experiences increasingly understood (Titchkosky and Michalko 2009).

### Stigma

Stigma is defined by its founding father, Goffman, as *"an attribute that links a person to an undesirable stereotype"* (1963, p.11). Stigma brings with it marginalisation, discrimination, powerlessness and stereotypical labelling. It stems from macro systems such as, policy, society, economy, and positions of power (Bruce and Phelan 2001). The three types of stigma involve that of body, character, nationality and race or religion (Goffman 1963). The effects of stigma, unfortunately, often tend to be unrecognised. Consequences on status, health, housing and quality of life can be blind to the eyes of society. Stigma causes people with disabilities to experience limitations to their quality of life (Farenga and Ness 2005).

### Tertiary Education and Disability in Ireland

The Irish education system has widened its student selection policies and has enhanced government programmes to increase participation of people with disabilities. However, the existing educational structure requires modifications to allow for true inclusion. The voice of

people with disabilities is growing stronger, but marginalization and deficiencies still exist within the education system (Oliver 2009). Physical barriers, education delivery and assessment methods are among the services that currently require improvement (Shevlin et al. 2010). Tinklin and Hall (1999) state that approximately half of Ireland's libraries have limited access for people with disabilities. Kenny et al. (2000) suggests that there are insufficient expectations of Irish people with disabilities within the educational system.

### **The Educational Experience**

Article 24 in the Convention of the Rights of Persons with Disabilities (UNCRPD), though not yet ratified in Ireland, states that all persons with a disability are entitled to have access to tertiary education "*without discrimination and on the basis of equal opportunity*" (UNCRPD 2006). Students with disabilities in third level can face multiple challenges; social, physical and attitudinal. Many people with disabilities report feeling underprepared for third level, possibly compounded by an unfinished secondary education (Kochlar-Bryant et al. 2008). Students identified attitudinal barriers as the major limitation in educational progress. However, experiences of stigma in tertiary education were experienced less than in previous educational settings and social opportunities increased. Students also reported isolation and struggles in accessing supports and services (Shevlin et al. 2010). This educational disempowerment can affect a student's quality of life (Leicester 1999). Developing educational competence is important in building self-esteem (Quinn 1998). According to Shevlin et al. the experiences of Irish students with disabilities is invisible in terms of choice and independence in Ireland (2010).

### **Visual Impairment**

Having a visual impairment is only one aspect of a person's life; it does not predict who a person is or their quality of life (Milian and Erin 2001). In 2011, there were 51,718 people with a visual impairment in Ireland. This equates to 1.1% of the population (CSO 2012). Associated dependency for people with a visual impairment can exist due to the overgeneralization of the features of blindness (Milian and Erin 2001).

### **Education and Visual Impairment**

In Ireland, accessible tertiary education for people with visual impairments is not always readily available. However, the number of students with visual impairments has risen by 45% in the last five years (NCBI 2012). People with visual impairments represent approximately 2% of the student population (NCBI 2012). A Disability Access Route to Education offers extra supports for applicants on a reduced points system. According to the Association for



Higher Education Access and Disability, third level students with visual impairments are under-represented and as Kenny et al. (2008) points out they feel as though lecturers do not genuinely listen to them. Despite these challenges, 95% of people with visual impairments complete their college courses (NCBI 2012). Although progression has taken place in Ireland, there is still a considerable journey ahead (Kennedy et al. 2008). Following consideration of this literature this research papers aim is to focus on visual impairments and to explore **‘How do People with Visual Impairments in Ireland Experience Equity in Tertiary Education?’**

### 3. Methods

The data in this research is part of a larger qualitative study on stigma navigation and lasting relationships. This research is being gathered under the supervision of Dr. Nancy Salmon of the Department of Clinical Therapies in the University of Limerick. A qualitative approach using semi-structured interviews to gather the data was chosen. Through the use of qualitative research, aspects of the contextual factors of a person's experience can be explored (Yin 2011). This method was chosen over quantitative research which is an analysis of specific numerical data, as the aim of this research paper is to describe the holistic experiences (Denscombe 2007). Critical disability theory is the framework that guides this paper as it conveys the voices of those with the lived experience of disability in relation to barriers enacted by the environment (Hosking 2008).

#### Participants

Three female participants and one male participant took part in this study. The participants in this study attend or have attended tertiary education and have experience of visual impairment. The recruitment of participants was carried out via snowball sampling as access to participants was limited due to third level ethics systems. This also followed unsuccessful attempts to reach outside agencies. Identification of one participant allowed other participants to be accessed. Snowball sampling assisted access to participants within a limited timeframe (Bailey 1994).

Participant	Age	Gender	Dwelling
Danielle	35	Female	Urban
Linda	46	Female	Urban
Emily	47	Female	Urban
Denis	35	Male	Urban

#### Method

Following email exchange between interviewer and interviewees, interviews were conducted at a location of the participant's choice between July and September 2013. Each interview lasted approximately one hour and 45 minutes. A semi-structured interview guide was used to ensure the data collection was guided to match the broader study. Semi-structured interviews also allow for flexibility within the study (Wilkinson and Birmingham 2003).

The interviews were audio taped, transcribed and entered into ATLAS.ti for coding. ATLAS.ti is a computerised analytical tool for qualitative research. ATLAS.ti increases the effectiveness of analysis by organising and tracking data and is an effective method of

mapping information. ATLAS.ti improves the confirmability of the data as it strengthens the codes and adds to the transparency of the research. Utilising the analytical memo option in ATLAS.ti benefits the auditability of the data as progress was monitored throughout the investigative process (Friese 2012). A pre-existing code list, created by students involved in the broader study, was used for the analysis of the data.

Thematic analysis was used to examination and highlight patterns in the raw data (King and Horrocks 2010). Stages one, two and three of Braun and Clarke's thematic analysis were executed (2006). Thematic analysis provides a flexible means within which patterns emerging from the data represent the experiences of the participants. Accomplishing familiarisation with the data via completion of transcriptions, reading and re-reading followed by coding and theme identification, allowed for patterns in the data to be formed (Braun and Clarke 2006).

Field notes were completed to ensure the reflexivity of the study as subjective reactions were recorded following each interview, allowing for some personal reflection and enhancing the trustworthiness of the results (Pinnegar and Hamilton 2009). Following analysis, summaries were completed and sent to all participants to ensure the credibility of the analysis (Parsons 2008).

### **Ethical Considerations**

The ethics proposal was completed by Dr. Nancy Salmon and approved by the University of Limerick ethics committee. The ethics approval number is EHSREC11-35. Confidentiality was ensured throughout the data collection process. Pseudonyms names were chosen to ensure the protection of the participants. All data relating to the study was stored in a secure location. No reward or payment was given to participants.

Some unforeseen ethical considerations included the need for access to audio or electronic formats of information. Preferred means of communication was identified from each participant. As a result the interviewer communicated with participants regarding recruitment via electronic format. Each participant received an electronic format information letter (**Appendix 1**) and a consent form prior to interviews. The interviewer also prepared and offered participants audio versions of the information letter and interview guide. Changes to the consent procedure meant that consent was audio recorded.

## 4. Findings

Following stages one, two and three of thematic analysis, the main themes that evolved from the research comprise of the supports and services and influences from society. The first theme, supports and services, incorporates access to materials, lack of reliability and various interactions with peers and professionals. The second theme involves the broader societal issues that impacted on the participants. These issues included policy translation, stereotypical attitudes and equity versus access. It appears that tertiary education offered opportunities of personal growth, confidence and relationship building through the shared experience of education. These positive attributes were shared with negative experiences of stigma in relation to inconsistent supports and services and broader influences from society.

### Supports and Services

As the broader research question suggests, this study investigated the navigation of stigma in relation to lasting relationships. Some participants did comment on the creation of lasting relationships from the tertiary education experience. Following analysis it was evident that navigation of stigma did not revolve entirely around lasting relationships as the broader question considered. The working relationships with professionals, however, were important due to the knock-on effects on supports. The challenging experiences that emerged focused on timely access to consistent information and support. For example this participant describes the strain on her lifestyle balance due to the time consuming manner in which she had to access lecture notes.

*“I used to tape my lectures, because I can’t type fast enough, I only use one hand...and so, I’d come home in the evening and I would type up all my lecture notes, so that was a huge chunk of the evening gone” (Linda).*

Difficulties in accessing overheads, lecture notes, library materials, books and assignment corrections meant that students found themselves having to challenge the system and individually pursue equity.

*“A couple of days before my Christmas Exams I was getting reading materials for the whole semester” (Danielle).*

It appears from the data that the difficulties lie, not in access to tertiary education but instead equity within the educational system. While some participants commented on the physical barriers that exist, access to information and discrepancies for equal participation as a result, was the biggest barrier. Relational working alliances with peers and professionals were an

important factor as the services appeared to lack in consistency. The degrees of support received were largely dependent on the individual encounters and relationships with lecturers.

*"The first day I started the librarian brought me around and it wasn't even his job" (Denis).*

This participant describes the experience of accessing necessary materials.

*"And their [people with visual impairments] constantly having to fight that battle to get their written material, in a timely fashion, in a manner that they can utilise... you're always having to challenge the system... it's quite easy to slip behind" (Emily)*

The services on a whole appeared to relate to the individuals with which the participants were encountering. No automatic system of services seemed to be in place as some facilities were inconsistent.

*"I'll always have to approach the lecturers afterwards and say 'listen I have a visual impairment so if you're doing up notes could you please give them to me'" (Linda).*

Some participants spoke of being made feel like an annoyance when seeking supports.

*"I went up to him, and I said, 'I need to...record the lecture...and he just looked at me and he said 'Well! If you must, you must'" (Emily).*

One participant experienced deterioration in services when returning to the same college a year later.

*"I think they, [the lecturers] couldn't have done enough for me to be honest, it was when I went and did my post grad I had major problems" (Denis).*

Another participant was unable to access the disability office due to attendance of an evening course.

*"They [supports] were limited because their offices would be closed" (Linda).*

On a whole, participants felt that they did not experience equal opportunities to their peers, as services were not readily available.

Due to advancements in technology however, supports are improving. Furthermore, education was felt to be more accessible than employment. Some participants spoke of meeting various helpful individuals, for example; lecturers, librarians and peers with which the participants engaged in mutually supportive relationships.

*"They would help me out a lot and I would help them in turn, I made great friendships with people...it was positive" (Denis).*

Participants experienced varying degrees of support in relation to access to information. At times, the amount of support and ease of access to materials appeared to depend on the individual lecturer. Seeking supports depended on the formation of a professional alliance.

*"I approached the lecturers directly...Some were a bit weird, the majority of them were helpful" (Denis).*

Despite the varying services participants spoke highly of their college experiences in relation to creating friendships, building confidence and encountering new opportunities.

*"I would still say one of the best experiences in my life...I absolutely loved it" (Linda).*

*"I flourished in third-level" (Danielle).*

### **Broader Barriers**

Some broader concerns were raised by participants regarding policies within education. There appeared to be insufficient policy implementation and translation into practice. In some circumstances if policies were in place, they were not experienced on the ground.

*"Introducing policies isn't sufficient, within institutions there has to be an all-round attitude...from the top down and from the bottom up" (Emily)*

Stereotyping and prejudice was encountered by some participants from professionals and colleagues.

*"I ended up with a different supervisor; [she] turned out to be a bit of a bully" (Danielle).*

One participant described experiences of hostility from peers due to utilising classroom assistive equipment.

*"This [recording lectures] kind of became a bone of contention between myself and some of the other students" (Linda).*

Participants discussed experiencing insufficient opportunities for employment despite high levels of education. Appreciation of education was noticeable by the fact that opportunities for employment generally and relative with their credentials was not always available.

*"I have always found it really difficult...to get paid employment" (Danielle).*

This is testament to their appreciation of education and the educational process in spite of the reduced opportunities for appropriate transfer of learning to paid employment. Some of

the required improvements however were societal issues which require change on a macro level.

*“It’s a matter of trying to change society’s assumptions” (Emily).*

## 5. Discussion

This section will discuss the research findings in relation to tertiary services, working alliances and stigma in education. The discussion will include implications for Occupational Therapy practice, discuss the study limitations and make recommendations for future research.

Despite an improvement in tertiary education disability services, structural barriers remain. These obstacles prevent students having equitable opportunities to their peers (OECD 2006). The structural barriers mean that the participants experienced a system where norms, behaviours and routines disadvantaged them over the dominant population (Brander et al. 2012).

The findings suggest that the participants experienced stigma on a number of levels. Firstly, in a direct sense; the data shows how individual attitudes influenced the educational experience. The working alliance appeared to influence the equity of supports. This is evident from the various encounters with lecturers in relation to the ad hoc supports participants received. The practicalities of service provision affected the equality of participation. This points to the varied experience of professional alliance. Practical needs appeared to arise from relationships with professionals who are possibly equitably well disposed of the needs of people with disabilities, resulting in an ad hoc service delivery. This lends the notion that supports and professional relationships are identifiable factors yet not inseparable influences. Relationships and services appear to be inextricably linked as supports seemed to depend on individual professional encounters. This correlates with the work of Shevlin et al. where they reported attitudinal barriers as the most significant for persons with experience of disability in Irish third level, stating *that "Positive staff attitudes were informed by personal interest in disability issues rather than institutional support for students with disabilities"* (2010, p.18).

Moving to more indirect influences; the services which attend to the majority population influence how those in the minority function within education (Bronfenbrenner 1979). Systems that serve the majority, such as receiving lecture notes after class can limit and create barriers for those who require electronic format or the use of computerized software. As the results suggest, in correlation with Evans Getzel and Thoma (2008), the student requires significant levels of self-determination in order to receive the services due to the demands of seeking the required supports. Evans Getzel and Thoma, in their study of people with disabilities in tertiary education, point out that self-determination and skills are a requirement



to stay in college and in seeking supports. Systems that are not made aware of the requirements of its recipients operate in such a manner that the needs of the majority are catered for at the expense of those who may not have immediate prior contact with service providers.

The influences of organisational systems, policies and culture also have impacted on the student experience (Bronfenbrenner 1979). As the service users in education change, so too should the supports and services. It appears from the participant's experience that supports have updated but not in a manner that allows for complete equitable opportunities. The evolving society has increased access to education for people with disabilities but a question remains as to the extent of equitable opportunities within the tertiary education system (Hook et al. 2004). Focusing mainly on access means emphasis may be more concentrated on the presence of students with visual impairments as opposed to experiences of equity. Genuine participation in a reflective educational experience is required for true equity (Heron 2005). Policies and practice that facilitate genuine participation, as Heron (2005) describes, would not only benefit the minority but would also be beneficial to all students. Heron advocates for a more facilitative process rather than an authoritarian education (2005).

In 2000, a white paper on adult education prioritised equality as one of its core principles (Learning for Life 2000). In this document the Irish government acknowledges the barriers to equity for people with disabilities in education. It states that the provision of services for people with disabilities should be catered for by the individual institutions. This article proposes that staff in educational services should be educated as to the needs of students with disabilities, emphasising that progress should aim to complement the students as opposed to providing a uniform service (Learning for Life 2000). Fourteen years on and the experiences of participants in this study suggest that supports are, for the most part, not automatically available.

The United Nations Convention on the Rights of Persons with Disabilities recognizes that in the past, rights of people with disabilities were neglected at policy level. Focus appears to be on equal access to education. Equal participation is mentioned within the article but it does not outline how this might be achieved (UNCRPD 2006).

According to the Disability Federation of Ireland, 50% of students with a visual impairment do not attend tertiary education (2009). Experiencing limited access to substantial aspects of life and being excluded from full participation based on disability are examples of stigma. These experiences can impinge on one's self-esteem. These factors can lead to difficulties in academic achievement (Major and O'Brien 2005). These encounters with stigma demonstrate that the education system in Ireland may need to develop their approaches to

service provision to ensure that people with visual impairments are encouraged to enter third level and to also have the opportunity to engage equally within the system.

### **Occupational Therapy**

As Occupational Therapy has established an evolving role in working with college students, it is essential that as Occupational Therapists we familiarise ourselves with the lived experiences of college students (McCarthy and O'Sullivan 2011). This research is an asset to the field of Occupational Therapy because it is crucial that we develop an understanding of the subjective experiences of our clients. It is important that Occupational Therapists are aware of the lived experience of people with visual impairments due to the potential impact on performance in daily activities. Trinity College Dublin (TCD) outlines the person, environment and occupation model within their Disability Service Plan for 2011-2014. This highlights the significant correlation between Occupational Therapy and tertiary education. Trinity College Dublin also offers a support service for people with disabilities transitioning into employment following education; this would be a suitable pathway for Occupational Therapists working in tertiary education (TCD 2013). Occupational Therapy interventions may also involve working with people with visual impairments in the home or in the community (Stanley and Orchanian 2003).

Another aspect of this research that offers value to the field of Occupational Therapy is the correlation between therapeutic relationships and service delivery. The therapeutic relationship is vital in achieving positive therapeutic outcomes (Ikigug 2007). This paper demonstrates how the varying degrees of a professional relationship can influence the recipient experience. It is essential as Occupational Therapists that we treat each client with equal respect and dignity. These guidelines are within the core values of Occupational Therapy and hence are delivered in a flexible and appropriate manner in which the client is centrally involved in decision making (Chisholm et al. 2004).

### **Limitations and Recommendations**

Due to time constraints of this research, steps one, two and three of Braun and Clarke's thematic analysis have been executed (2006). Thus, this research is considered a preliminary study. However, a more in depth analysis of the research will be completed prior to potential publication of the study. Nevertheless, this study in combination to the Navigating Stigma project will allow for some transferability of the data.

The sample size of this research limits the extent of result generalization (Institute of Medicine 2001). Snowball sampling also decreases the strength of the findings. Snowball

sampling does not allow for complete random selection of participants and also lends to the recruitment of participants who are willing to disclose their experience (Sinclair et al. 2013). It should also be noted that these results have been gathered from participants who attended three different colleges, so the results cannot be reflective of all third level institutions in Ireland. Any further research should include participants from a wider variety of third level institutions across Ireland. It is recommended that future studies include participants of varying disability experiences, with a larger cohort for a more general insight to the lives of people with disabilities in tertiary education. This would also allow for clearer recommendations to be made to the institutions themselves in terms of suggested service improvements and allow for inter-rater reliability testing (Kember and Ginn 2012). However, from the data collected in this study, this article suggests a need for a consistent automatic system in relation to access to materials and supports be provided for students with visual impairments at third level.

A possible consultative system including a preliminary, intermediary and conclusive audit of services and experiences of students, with and without experiences of disability, is suggested. This system could gather the information needed to orientate the facility towards equity consciousness. Guidelines and provisions for these options should be designed by students themselves. In order for these services to be truly resourceful they would be best offered prior to entrance into the classroom setting, for example; orientation to library prior to course commencement (Trief and Feeney 2005). The results from such audits could be generalised to the whole of tertiary education and not based on random exchanges between individuals. This auditing system should be extended to influence the policy of institutions and passed down to the professionals that comprise the system. Following this, an unequal system of supports where people with visual impairments and or people with the experience of disability receive extra provisions may facilitate equity (Vallentyne 2003). Policy driven formalizations designed by the students themselves may offer a less attitudinal approach to service delivery (Ringold et al. 2012).

In planning for the future, this research would like to suggest that services for people with experience of disability would be designed by its recipients and stem from policy level. Having an equality proved measure would, in the future, decrease feelings of having to challenge the system. This structure would allow for subjective experiences to influence decision making and thus service delivery on the ground. The intention is to increase the consciousness of stakeholders, mitigate inconsistencies and begin to build these ideas into the culture of education.

Addressing the institutional guidelines in relation to disability provision and imposing structured procedures may offer professional's opportunities to propose a more streamlined service delivery (OECD 2008). It is important to mention that while the needs of people with visual impairments may vary greatly, the educational experience would be significantly enhanced if students were presented with options as to how they would prefer to receive resources.

## 6. Conclusion

This study has discussed the subjective experiences of stigma for people with visual impairments in tertiary education. The first theme revolved around inconsistent supports and services. The second theme relates to the broader societal issues which impacted on participants. The college experience also offered opportunities of confidence building, creation of relationships and personal growth. These positive experiences were however accompanied by encounters of stigma within tertiary education.

This paper has outlined the value of this research in relation to the profession of Occupational Therapy. As Occupational Therapy within tertiary education is an evolving field, this preliminary account of the subjective experiences of people with visual impairment is valuable to our learning. The realisation of the link between relationships and perceived service delivery is also relevant to Occupational Therapists as client-centeredness and the therapeutic relationship are fundamental components to our profession.

The various experiences of the students consisted of positive and challenging situations. From physical barriers to the creation of lasting relationships, on a whole the writer would conclude that the experiences, although challenging were advantageous to the participants. Yet it is important to note that equal participation in the eyes of the student is significant and that emphasis going forward ought to be on access to education accompanied by an equitable experience within it.

There seemed to be a link between supports and professional alliances as services appeared to be dependent on relational encounters resulting in an ad hoc service delivery. This dependency relationship causes the supports to be varied and reliant on individual encounters be they with lecturers, peers or support staff. This causes the writer to believe that relationships and services are inextricably linked and recommends that services are more streamlined through frequent auditing and institutional improvements designed with reference to the students themselves.

It is important to mention that as technology has significantly improved so too have services. The concerns in this paper relate to the delivery of those services where there appears to be a need for more streamlined provision of supports. It was evident from the research that the participants encountered individuals who were supportive and accommodating but they also encountered persons for whom it proved more challenging to offer necessary supports. An increase in the consistency and time efficiency of services would increase the inclusiveness of education. It is reasonable to suggest that services for people with visual impairments in

this instance need to be more automatic and tailored to the individual needs on the basis of chosen requirements.

Future studies of a similar nature would need to be executed in order to generalise the results. This paper suggests that policies and developments need to expand their focus from access to equality. It is hoped that from the data gathered in this research, combined with the broader study, that the current subjective experiences of people with disabilities in Ireland will be portrayed. This research hopes to inform others in order to help to break down the barriers of stigma and work towards an inclusive society (Heatherton et al. 2003). Through education and consciousness one can battle limitations in order to create change.

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## **Appendix 1**

### **Information letter**

## Information Letter

### Project Title: Building Real Communities

#### Introduction

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

The study is described below. Being in the study might not help you, but we might learn things that will help others. Being part of this study is voluntary and you may stop being part of the study at any time. If you choose not to stay in the study, it will not affect your access to services. You will be asked to spend about 1 and a half hours in the study. This includes the time it takes to get ready to meet your student researcher and the time you spend together. If you have any queries about the study you can ask Emma Burns, the research assistant who will be organizing the interviews, or Nancy Salmon.

Contact information:

Research Assistant: Emma Burns

Email: [emma.burns@ul.ie](mailto:emma.burns@ul.ie)



Supervisor: Dr. Nancy Salmon

Phone: 061 234275

Email: nancy.salmon@ul.ie

### **Purpose of the study**

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

### **What will you be asked to do?**

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

### **Who can be in the study?**

People with disabilities who are 18 years or older, who use English and who identify as having a medical diagnosis or disability are invited to be part of this study.

### **Who will be doing the research?**

Seven research students will be doing this study with the help of their supervisor, Dr. Nancy Salmon and Dr. Fiona Kumari Campbell, assisted by Emma Burns. These people are able to read a typed up copy of what you say in the interview. Dr. Campbell lives and works in Australia at

Griffith University. She will only see your story once your name and any details that would give away who you are have been taken out.

### **Keeping your story private**

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

The recording of your talk with your research student will be stored on Nancy's computer. They will be in a hidden file in the computer and will be password protected. All information from the study will be stored in a locked office at the University of Limerick for 7 years after the study ends. Everything you say will be kept private unless you talk about abuse by a partner that is happening now. This has to be reported to the local Gardaí.

### **Your rights**

You can say that you don't want to answer any question that is asked. You can stop talking at any time. Your research student will not be upset and will stop right away. You can listen to the tape of your interview or read the typed copy. Your research student will give you a copy of the summary she writes about your meetings. It will not affect their college work if you decide you want to stop being in this study. You can ask your research student any questions you want to about the study or you can talk to Nancy or Emma.

**Can anything bad happen if you are in the study?**

Sometimes things come up when people talk that can make you feel upset. Talking about your relationships might feel uncomfortable. You don't have to talk about anything you don't want to. You can say you want to stop at any time. If you stay upset after the interview, our research student can help you find someone to talk about your feelings and offer you support.

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

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

**If you have any concerns about this study please contact:  
Chairman Education and Health Sciences Research Ethics  
Committee University of Limerick Tel: 061 234101.**

**Ethics Approval Number: EHSREC11-35**