MSc Occupational Therapy (PQ)

OT6054 – Occupational Therapy Project 4

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Perspectives and Power Dynamics in Inclusive Research: Experiences from an Irish Context

Abstract

Introduction: The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006) outlines the accountability that state parties have to involve people with disabilities in research that affects their lives. Inclusive research has developed to move people with intellectual disabilities away from the traditional role of a research subject, towards a more power-balanced research collaboration that can create individual and societal change.

Method: This study adopted a qualitative methodology guided by critical disability theory. Semi-structured interviews and one focus group were carried out with seven individuals with intellectual disabilities, two supporters, and five academics, to explore their experiences of engaging in inclusive research in Ireland. Thematic analysis using Atlas.ti software was used to interpret the data.

Findings: Three key themes emerged: ‘Meanings of inclusive research’, ‘Importance of inclusive research’ and ‘Power relations within inclusive research’. The findings revealed a range of definitions of inclusive research. Advocating for change at policy level was a common motivator for participants to engage in the process. Experiences of power imbalances were highlighted, in particular barriers created by academic standards.

Conclusion: Definitions of inclusive research in Ireland can be seen to occur along a continuum. An inherent power imbalance exists between expectations of inclusive projects, and academic research standards across all disciplines, that can prevent the participation of people with intellectual disabilities in research. Occupational therapists are well-positioned to address the recommendations of the CRPD by supporting self-advocates to engage in inclusive research, which can enable them to create change in their lives.
Introduction

Research is carried out to better understand our own lives and the lives of others, to extend knowledge, or to bring about political or social change (Brechin and Sidell 2000). Disability research has traditionally been reserved for people who do not have a disability, which can lead to deficient understanding (Goodley 2011). In recent years however there has been a move towards more inclusive research practices (Puyalto et al 2016); many of which are based on guidelines from the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 31 of the CRPD specifically outlines the responsibility of State Parties to ensure accessibility of research to people with disabilities, while Article 33 denotes that they should be involved in the monitoring of its implementation (United Nations 2006). Disability researchers need to move beyond the tendency to ‘give’ participants a voice, towards engaging in a more power-balanced collaboration (Roberts et al 2011), where a shared voice between researcher and researched can create individual and societal change (Nind 2008). One way to achieve this is through the practice of inclusive research (García Iriarte et al 2014; Johnson et al 2014; Williams et al 2015).

Literature Review

What is Inclusive Research?

Inclusive research was first defined by Walmsley (2001) as the involvement of people with intellectual disabilities as more than just subjects. They are collaborated with, rather than viewed as a source of information or data (Frankena et al 2015). The approach has developed elements of control, access and ownership that enable people with intellectual disabilities to generate research questions, engage in data collection, data analysis, and dissemination of results (Walsmley and Johnson 2003). More recently, it has been suggested that inclusive research ranges from a participatory methodology, where the emphasis is on partnership, to an emancipatory approach, which aims to have people with intellectual disabilities leading and controlling the research (Strnadová et al 2014). While generally regarded as a positive move for disability research, lack of conceptual clarity (Bigby et al 2014), and concerns regarding tokenistic involvement and authentic engagement (Walsmley 2005; Roberts et al 2011; Bigby et al 2014) highlight the fact that inclusive research remains poorly defined and understood in the literature.
Why Engage in Inclusive Research?

Substantial academic opinion exists regarding the rationale for employing an inclusive approach to research. Some believe that collaboration brings a range of skills and experience (Koenig 2011; Stevenson 2014; Strnadová et al 2014), while others identify that it provides a means for individuals with intellectual disabilities to advocate for policy and service change in their lives (Tierney 2009; Kramer et al 2011; Johnson et al 2014). Their unique perspectives can offer new insights for formulating questions (García Iriarte et al 2014), and interpretations of data are grounded in real experience, which helps to broaden theoretical sensitivity and analytical focus (Koenig 2011, p.220).

Notably, first-hand opinions of researchers with disabilities are harder to locate. There are reports made regarding feelings of pride, accomplishment, a sense of purpose and belonging (Abell et al 2007), increased confidence, independence and freedom (Flood et al 2012). However, these are commonly reported by a non-disabled researcher, making it more difficult to discern the voice that you are actually hearing.

A Note on Language

Self-advocacy affords people with intellectual disabilities the opportunity to speak for themselves (Caldwell et al 2012) and challenge oppressive phenomena (Roets and Goodley 2008). People with intellectual disabilities who have engaged in inclusive research are respectfully referred to as self-advocates throughout this paper in line with this view.

Occupational Therapy and Inclusive Research

Article 3 of the CRPD (United Nations 2006) cites that all people with disabilities should be able to participate fully and effectively in an inclusive society. The Association of Occupational Therapists of Ireland (AOTI) states the primary goal of occupational therapy is in enabling people to participate in activities of daily life (AOTI 2016). People with intellectual disabilities in Ireland have reported a lack of choice and autonomy in making decisions about their lives (García Iriarte et al 2014), which can lead to experiences of meaninglessness and purposelessness that result in the injustice of occupational alienation (Townsend and Wilcock 2004). Given that barriers to occupational participation by people with intellectual disabilities are often contextually based (Channon 2014), understanding disability from their perspective is fundamental to enabling occupational participation in a client-centred way (McCormack and Collins 2010). Sumison and Law (2006) outlined five
core elements of client-centred practice; power-balanced collaboration, listening and communication, partnership, choice and hope; all of which draw parallels with the core principles of inclusive research (Johnson 2009).

Summary

While the CRPD was instrumental in the move towards inclusive research, it does not provide strategies as to how its principles might be implemented (Johnson 2009). Specific inclusive research methodologies are vague and definitions of what denotes inclusivity, from tokenistic involvement to complete control, are blurred (Nind and Vinha 2012). Bigby et al (2014) suggest that understanding a range of different perspectives, and publishing guidelines to that effect, will be a vital step in taking inclusive research into the future. This paper thus aims to explore definitions and experiences of inclusive research by self-advocates, their supporters, and academic research counterparts to inform client-centred occupational therapy practice in the Republic of Ireland.

Method

Research Design

Individual interpretation and the impact of context on lived experience are core features of a qualitative approach (Butler-Kisber 2010). As this study sought to gain a greater understanding of participant experiences of inclusive research, a qualitative methodology was chosen (Creswell 2014). The research was guided by critical disability theory, where social expectations of normalcy, and the shortcomings of society in accommodating difference, can oppress the rights of people with disabilities (Hosking 2008). This study forms part of a wider investigation of inclusive research currently underway at the University of Limerick.

Ethical Considerations

Ethical approval was obtained from the Faculty of Education and Health Sciences Research Ethics Committee at the University of Limerick; approval number EHS29021283. This study formed part of the requirements towards an MSc Occupational Therapy qualification, during which the researcher had to adhere to strict deadlines. Considering the conclusion by Bigby et al (2010) that inclusive research is unlikely to be suited to projects with tight timelines, it was not possible to use an inclusive approach. It was therefore paramount to remain as inclusive as possible within the parameters of the study. The Tri-Council Policy Statement: Ethical
Conduct for Research Involving Humans (TCPS-2) (Canadian Institutes of Health Research 3014) was used to guide design of accessible, easy-to-understand information sheets, consent forms and interview guides. Participants were informed of the voluntary nature of participation and their right to withdraw their data from the study. To protect the anonymity of all participants, participant numbers were used during data analysis and to present the findings. As there was one focus group in the dataset, there was an added risk around confidentiality and disclosure (Liamputtong 2011) that was outlined in the consent form and again by the interviewer before the group began (Smith 1995).

**Participants**

Email invitations with an information letter explaining the project were distributed to academics, supporters and self-advocates across Ireland. Participants were seven self-advocates, two supporters, and five academics (Table 1). The inclusion criteria were adults who could understand English, an ability to communicate verbally via an interpreter or supporter, and an involvement in inclusive research.

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Involvement in Inclusive Research</th>
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<tbody>
<tr>
<td>P1</td>
<td>Female</td>
<td>Academic</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>Academic</td>
</tr>
<tr>
<td>P3</td>
<td>Male</td>
<td>Self-advocate</td>
</tr>
<tr>
<td>P4</td>
<td>Male</td>
<td>Academic</td>
</tr>
<tr>
<td>P5</td>
<td>Female</td>
<td>Self-advocate</td>
</tr>
<tr>
<td>P6</td>
<td>Male</td>
<td>Academic</td>
</tr>
<tr>
<td>P7</td>
<td>Female</td>
<td>Self-advocate</td>
</tr>
<tr>
<td>P13</td>
<td>Female</td>
<td>Supporter</td>
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<td>P14</td>
<td>Male</td>
<td>Self-advocate</td>
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<td>P8</td>
<td>Female</td>
<td>Supporter</td>
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<td>P9</td>
<td>Male</td>
<td>Self-advocate</td>
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<td>P10</td>
<td>Female</td>
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<td>P11</td>
<td>Female</td>
<td>Self-advocate</td>
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<tr>
<td>P12</td>
<td>Male</td>
<td>Self-advocate</td>
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**Focus Group**

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<tr>
<th>Name</th>
<th>Gender</th>
<th>Involvement in Inclusive Research</th>
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<tbody>
<tr>
<td>P13</td>
<td>Female</td>
<td>Supporter</td>
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**Data Collection**

A pre-existing data set of twelve interviews, carried out by the research supervisor from 2012 to 2014, was accessed. Two more interviews were completed by a research assistant in 2015.
and added to the data for this study. Data was collected through semi-structured interviews comprising of individual interviews, interviews where a supporter was present, and one focus group that was convened based on the preference of participants. Interviews can explore understanding and perception (Peters and Halcomb 2015), which accommodates the subjective nature of the research question. Data from the interviews was transcribed verbatim.

**Data Analysis**

Thematic analysis (Braun and Clarke 2006) using Atlas.ti software was used to identify, analyse and report patterns across the data (Table 2).

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Familiarising yourself with the data</td>
<td>Read existing interviews and field-notes for P1-P12. Transcribed interviews for P13 and P14. Completed interview summaries for all interviews to document initial reactions and ideas.</td>
</tr>
<tr>
<td>2. Generating initial codes</td>
<td>Reviewed initial code list and chunks of text represented by each code. Added additional codes. Coded two new interviews.</td>
</tr>
<tr>
<td>3. Searching for themes</td>
<td>Collated codes into potential themes. Ran queries to gather all data relevant to each potential theme.</td>
</tr>
<tr>
<td>4. Reviewing themes</td>
<td>Checked if themes aligned with coded extracts and entire data set. Refined themes by merging those that represented similar ideas. Created a thematic map that demonstrated the relationship between codes and themes.</td>
</tr>
<tr>
<td>5. Defining and naming themes</td>
<td>Named and clearly defined the idea represented by each theme</td>
</tr>
<tr>
<td>6. Producing the report</td>
<td>Analysed chunks of text to choose quotes that best represented each thematic idea. Compared the themes that emerged with the research question and existing literature on inclusive research.</td>
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**Rigour**

Trustworthiness (Lincoln and Guba 1985) is vital to manage any influence that the researcher may have in qualitative research (White et al 2012). Trustworthiness can be enhanced through researcher reflexivity, which involves self-awareness and critical reflection on the influence that personal values and previous experience of the researcher may have on the research (Finlay 2006). Interviews were carried out by an experienced researcher who
completed detailed field notes. First impressions, emotions or contextual details that could influence the data (Tessier 2012) were documented using analytical memos contained in the Atlas.ti software. These memos were also used to record key decisions and insights during each stage of thematic analysis, which created an audit trail to promote transparency (Bowen 2009) and dependability (Cope 2014) of the research. External checks on reflexivity were made through research supervision, peer-group discussion, and peer-review (Pitney 2004). Using multiple sources to draw conclusions enhances credibility and trustworthiness of findings (Bryman 2012).

Findings


**Theme 1: Perspectives on the Meaning of Inclusive Research**

This theme refers to the range of different perspectives offered by participants on the meaning of inclusive research. What emerged from the data was the concept of a continuum, ranging from a participatory approach at one end, to an emancipatory approach at the other. Some participants believed that in order to truly claim inclusivity in research, self-advocates needed to be involved at every stage of the process:

> You have to look at inclusion as broader than just listening to their stories...inclusive has to be from the start to the finish (P6)

This view sits firmly at the emancipatory end of the continuum and posits that self-advocates should be responsible for all stages of the research process. Others were of the view that inclusive research involved collaboration with people with disabilities to ensure that their perspectives were brought across in the research report:

> What’s really important to me is I want to ask their own opinions and their own experiences about how they make choices...they are the experts...and I'm going with what they say to me (P1)

According to this view, there is a need to involve self-advocates in research as they possess expert opinion. However, there is still the implicit notion that the research will be carried out by a third party, which places this perspective towards the participatory end of the continuum.
Some participants argued that it is easier to be inclusive at certain stages of the research process than others:

...how would you do qualitative analysis in an inclusive way...it does tend to be something that’s very theoretical and quite difficult conceptually to understand (P2)

This statement draws attention to traditional research practices and their suitability when attempting to use an inclusive approach.

There were also definitions of inclusive research that did not pertain solely to inclusion of people with intellectual disabilities on a research team, but all relevant people involved; such as policy makers, service providers and service users:

...So that everybody has an idea of what needs to be done and that they can actually give some input to that... that was really important to bring a group together in a shared understanding of common goal (P5)

From this perspective, all members of a research team are of equal value and should have equal opportunities to contribute. It challenges the belief that self-advocates must have complete ownership and control over research for it to be defined as inclusive. Instead, the perspective is that academic researchers and self-advocates have different areas of expertise to bring to the research team:

I think that kind of shared perspective that happens...if you’re on a research team, does everybody need to be part of every piece of the work? (P2)

This interesting viewpoint can be imagined to balance in the middle of the emergent inclusive research continuum.

**Theme 2: Why is Inclusive Research Important?**

This theme reflects why participants were motivated to engage in inclusive research. Many were influenced by the capacity of inclusive research to provide self-advocates with the opportunity to create their own change with regards to policy development and service provision that can have a profound impact on their daily lives.

The importance of getting a first-person account of the experiences of people with intellectual disabilities was paramount:
It means an awful lot...you’re getting people’s perspective on their lives, their feelings, their thoughts, whatever ideas they have and whatever experiences they’ve had (P13)

The importance of people with disabilities having a platform to be heard is invaluable. Disability research has traditionally been carried out by person who does not have a disability; inclusive research is changing the status quo:

It’s just a wonderful concept...it’s giving people with an intellectual disability an opportunity to decide on what research they want done and it’s usually on matters very close to them, rather than somebody else deciding what they think they should research (P14)

Self-advocates have control over what the research is about; they do not have to wait for someone to report a third-party opinion on what is needed. P9 stated “It’s given me a lot of things...it’s helped me a lot”. In addition to being able to fight for increased control over disability policy, self-advocates recognised personal benefits to engaging in inclusive that include increased motivation and confidence in their capacity to create change in their lives.

The final motivating factor for participants to engage in inclusive research was in addressing the rights of people with disabilities; in particular, their right to be included and consulted in research on service provision that is relevant to them in line with the CRPD:

I want to have a commitment in my work to respecting the rights of people with disabilities...certainly since 2006 really looking at the UN Convention on the Rights of Persons with Disabilities (P2)

What emerged from the data was that disability rights runs as an undercurrent to many of the participant’s accounts of their motivation to engage in inclusive research and why it was important.

**Theme 3: Power Relations in Inclusive Research**

This theme highlights the power disparity between people in government who make decisions on disability policy and people with intellectual disabilities whose lives are directly affected by these decisions. It also underlines how academic research standards can perpetuate power imbalances in research.
A strong message that emerged from the data was that inclusive research can help to tackle this power imbalance:

As academics, as politicians and policymakers you can’t keep making these big decisions that affect people's lives without including them in some way in the process (P2)

P7 agreed, noting, “We want to voice our opinions...with the government”. Inclusive research was a means to get the government to notice, to listen to first-person accounts of living with an intellectual disability in Ireland, so that existing policy and service provision might be considered, and finally changed. However, participants expressed frustration at how their efforts were not always successful:

In a lot of cases, we got no response or no acknowledgement, but I mean you keep plugging away at these things (P14)

This statement offers an important insight into the impact of hierarchical power dynamics on the lives of people with disabilities in Ireland and how some participants feel like they are constantly fighting an uphill battle against those who are making decisions around policy and service provision.

Self-advocates also felt that by engaging in inclusive research, they were achieving what they had previously seen as unattainable:

It was slightly unreal in a way that I was actually doing what academics do really...you find yourself in this situation of doing something that you never thought you would do (P13)

This statement represents the prestige that academia is perceived to have by self-advocates. However, in response to questions regarding power imbalances that exist between researcher and researched, the difficulty surrounding being inclusive in an academic environment was also noted:

...it is really difficult I think to manage the competing demands of an academic career and a commitment to being more inclusive in research practice...that’s a tough one always to balance (P2)
Academic institutions often place time and output demands on academic researchers that are unrealistic when engaging in inclusive research:

I was fortunate that I got fully funded to do this research...I couldn't have done it if I was still in my role as a lecturer because it was a huge amount of work (P5)

P10 points out that being required to meet academic standards can render inclusive projects unachievable; “...because of the [academic] time lines we will never be able to do both”. Academic environments then can be seen to form part of the problem when it comes to engaging in inclusive research. There is a sense that while the demands placed on academic researchers remain, inclusive research will never be ideally fostered in an academic environment. Other participants reflect this view when discussing academic research requirements:

...that’s part of the problem, that it’s probably that [ethics] form is probably not inclusive by its nature so I suppose it’s something that, I don’t know if it’s even possible to change these things but it might be worth asking the question (P14)

Some existing standards of research actually create barriers to engagement in inclusive research. It is therefore fundamental for academics to realise the responsibility they have when engaging in disability research:

Everyone is under a lot of pressure within university systems...that makes it easy to forget the level of responsibility or accountability that you have back to the people who shared their stories with you...it's easy to forget that what you're writing can affect people’s lives directly (P2)

Academic researchers often come under pressure to meet targets and numerical scores for research publication that may override beneficence of the research to the participants themselves.

**Discussion**

This study aimed to explore different perspectives and experiences of inclusive research in Ireland. The results indicate that while there are many parallels between participant’s accounts of inclusive research, there are also interesting differences. The findings revealed
that addressing the power imbalance between those who make decisions on disability policy and service provision in Ireland, and the people whose lives are directly affected by these decisions, was a common motivator for engagement in inclusive research. The final finding was also related to a power imbalance in terms of traditional academic standards for research and how they can negatively impact the participation of people with intellectual disabilities in research practices.

In an Irish context, inclusive research might be better understood along a continuum from participatory or partnership approaches to an emancipatory approach that favours total ownership and control. This is supported by recent literature that outlines the “different faces” of inclusive research that include diverse methodologies and varying levels of engagement on the part of researchers with an intellectual disability (Strnadová et al 2016, p.58). Questions were raised regarding different levels of involvement. The findings indicated that both academic researchers and self-advocates have different skills to bring to the table in inclusive research that should be embraced and not challenged. In reality, not all members of a research team in traditional practices are involved in all stages of the process; instead the collective skills of each member are valued (Stanley and Anderson 2015). There appears then, to be little reason behind an idealistic notion of normalising inclusive research practice with traditional research practices that are not conducive to an inclusive approach (Woelders et al 2015). Rather than trying to fit inclusive research into a stringent definition, we should maintain a flexible vision of what it means to be inclusive in research (Nind and Vinha 2012), while remaining mindful of the temptation to engage in tokenistic research in the name of ‘political correctness’ (Strnadová et al 2016).

The findings were similar to existing literature in terms of the motivation people have to engage in inclusive research. It was indicated that inclusive research provides a platform for self-advocates to voice their opinions, and to highlight and examine relevant issues themselves (Johnson et al 2014). It allows them to be heard as experts in their own lives (Grant and Ramcharan 2007). This finding supports the belief that equality and inclusion in research can support self-advocates to create the change needed to monitor the implementation of the CRPD and to hold those in power at governmental level accountable for it (García Iriarte et al 2014). Policymakers in charge of making decisions on service provision for disability often make ill-informed decisions based on budgets and resources; inclusive research provides an opportunity for the right people to ask the relevant questions in a meaningful way (Layton 2014).
The CRPD has yet to be ratified in Ireland, despite being one of the first signatories almost ten years ago (Doyle and Flynn 2013). An increase in fruitful inclusive research projects that do not simply investigate the experiences of people with intellectual disabilities but also seek recognition of the challenges they face (Tilly 2015) may well provide a catalyst for major and lasting change for people living with intellectual disabilities in Ireland.

The findings of this research highlight power dynamics inherent to the research process. One key point made by the entire range of participants in this study was the difficult nature of navigating existing academic standards of research. This adds support to literature that suggests that inclusive research can be compromised by endeavours towards academic rigour (Tuffrey-Wijne and Butler 2009). Difficult timelines, funding requirements, ethics applications and publication requirements (Strnadová et al 2016) are all issues raised by participants in this study that contribute to the growing evidence of academic barriers to inclusive research in the literature. As inclusive research is an attempt to redress the power imbalance between researcher and researched (Salway et al 2015), it is ironic that the very process that seeks to include people with intellectual disabilities is rife with power disparities that inadvertently lead to exclusion. The same expectation is currently placed on self-advocates as on academic researchers; however, striving for normalisation and sameness in research can actually dilute the unique perspectives that a researcher with an intellectual disability brings to the research team (Woelders et al 2015). Some participants in this study wondered if power could be redistributed to make academic research more inclusive of self-advocates. An interesting conclusion by Bigby et al (2014) however, raised concerns that by changing academic research to fit inclusive practice, we are in danger of inclusive research simply mimicking old practices rather than utilising the unique skills, strengths and knowledge that self-advocates can bring to research (Bigby and Frawley 2010).

The findings lend support to the belief that academic researchers may need to loosen their grip on standards of academic rigour in order to embrace the value of a new approach to research (Strnadová et al 2016). Echoed by the perspectives of participants in this study, the idea that welcoming a new framework can itself help to redistribute the power that is inherent to traditional research practices (Woelders et al 2015) is upheld. While inclusive research leans heavily towards the values of the CRPD, where concepts of equality and inclusion are at the forefront; normalisation has been discussed to be a rigid concept (Woelders et al 2013). Recognising that traditional academic research practices are not conducive to
recommendations made in the CRPD will be an important step in taking inclusive research into the future.

**Implications for Occupational Therapy**

The World Federation of Occupational Therapists (WFOT) recognise that the right to meaningful occupation should be ensured through equitable access to participation, regardless of difference (WFOT 2006). Their view aligns with the standpoint of the CRPD (Whalley Hammell 2015a), which seeks to ensure that all people with disabilities can participate fully in an inclusive society. In Ireland, there are 600,000 people living with a disability, who represent 13% of the population (Central Statistics Office 2012). The CRPD is likely to be pivotal in the review and development of disability policy in Ireland, and other signatory countries, in the coming years (Clifford 2011); a concept that clearly situates the work of occupational therapists within a rights-based context (Whalley Hammell 2015b, p.4).

The occupational therapy profession supports non-discrimination, inclusion, and the right of every individual to exert decision-making capacity in their lives (Hansen and Hinojosa 2004). Supporting clients to do the things they wish to do, in the ways, time frames, and places, that they wish to do them (Townsend and Polatajko 2007) is a key part of engaging with people with intellectual disabilities who are at risk of occupational injustice and alienation (Channon 2014) in Irish society. Inclusiveness in occupational therapy research, policy actions and practice will support practitioners to remain client-centred, tackle power imbalances, and embed the experiences of clients in practice epistemology (Layton 2014). As Hammell (2006, p.157) points out; through supporting the knowledge and lived experience of people with disabilities, occupational therapists can truly “translate client-centred rhetoric into client-centred practice”.

**Limitations and Recommendations for Future Research**

People with intellectual disabilities are often seen as a vulnerable client group (Hall 2013); however this attribution of vulnerability can reinforce stereotypes of people with disabilities (Ballinger and Wiles 2006). Concerns stem primarily from queries regarding informed consent, voluntary decisions and the nature of their participation in the research (McDonald and Kidney 2012). Efforts were made to manage the impact of this potential limitation through the presence of a supporter during all interviews with self-advocates, and distributing accessible information regarding the nature of the project (Hall 2013). Future research could
potentially explore the impact of stereotypes pertaining to people with intellectual disabilities on ability to participate in inclusive research practices. This study also focused solely on the experiences of people with intellectual disabilities. While it has added an Irish perspective to existing literature on power relations, there is still a gap in knowledge to be addressed regarding utility of inclusive research with people with a variety of disabilities. Finally, the most significant limitation of this study is the fact that it is not an inclusive project. Considering a key finding was that academic research standards can create a barrier to inclusive research, this study risks becoming the very type of research that it aims to challenge. It is hoped that future research could focus on re-visiting the aims of this study using an inclusive approach.

Conclusion

This study illuminated experiences of engaging in inclusive research in an Irish context. It has added to the knowledge base surrounding definitions of inclusive research from the perspectives of self-advocates, their supporters, and academic researchers. In their view, inclusive research occurs on a continuum and researchers should be fluid in their beliefs, while remaining mindful of tokenistic engagement. Finally, this research also contributes to the ever-growing body of literature on the inherent power relations of research; reminding us that as academics, we must not lose the unique value of inclusive research in meeting the stringent standards of an academic world.
**Key findings**

1. Inclusive research can be understood upon a continuum, which ranges from partnership to complete control.
2. Inclusive research can tackle the power imbalance between policymakers and people with intellectual disabilities in Ireland.
3. Academic research standards can perpetuate power imbalances that create barriers to engagement in inclusive research.

**What the study has added**

This study provided a range of different perspectives on definitions of inclusive research in Ireland. It illuminated different experiences of engaging in inclusive research and highlighted that many people believe that it provides a platform for self-advocacy in an Irish context. The findings also provide further evidence of barriers to inclusive research created by well-intentioned academic research standards. Occupational therapists are well positioned to support people with intellectual disabilities to participate in decision-making around policy development and service provision, as outlined by the Convention on the Rights of Persons with Disabilities (CRPD).

**Acknowledgements**

This research was undertaken as part of the requirements towards the MSc in Occupational Therapy qualification at the University of Limerick. Gratitude is extended to the participants who gave their time freely to partake in the research. Sincere thanks are also offered to academic staff of the Occupational Therapy Department for imparting their knowledge, and in particular to the author’s research supervisor, Dr. Nancy Salmon, for her support and guidance in the completion of this study.
References


