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with adults with learning disabilities

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Reflecting on an unexpected challenge in obtaining ethical approval for research with adults with learning disabilities

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Abstract

Obtaining ethical approval for my PhD research with adults with learning (intellectual) disabilities presented an unexpected challenge of learning to work with two sets of guidance: the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and the Ethical Conduct in Human Research and Related Activities Regulations (HRR). The CRPD binds States Parties to progress equal rights for people with disabilities of which Article 12, equal recognition before the law, disconnects mental capacity from legal capacity. The HRR protects participants, researchers and institutions and recognises mental capacity as a component of informed consent. In applying the CRPD and the HRR as complementary safeguards, and looking through the lens of edgewalking, I gained an appreciation for positively encountering complexity and incorporating multiple points of view. This article will describe how my challenging experience enabled skill building to develop a more strategic academic voice and will be of interest to student and other researchers.

Keywords

Consent; CRPD; inclusive research; research ethics

Introduction

This article unpacks experiences gained in PhD research to offer new insights about ethical research with adults with learning disabilities in New Zealand. My PhD research is about redefining literacy for adults with learning (intellectual) disabilities in New Zealand. Data collection involves a series of weekly Zoom or in-person group workshop sessions with adults with learning disabilities, using an inclusive participatory action research methodology (Ollerton, 2012). Including adults with learning disabilities as research participants aims to gain perspectives currently missing from the literature on this topic, and to uphold the disability rights movement dictum “nothing about us without us” (Charlton, 1998). While people with learning disabilities have been researched “on” within positivist inquiry, the social model of disability heralded new paradigms for research “with” and “by” people with learning



disabilities and generated new ethical dilemmas (Milner & Frawley, 2019). One particular issue is balancing autonomy with protection (Douglass, 2016; Douglass & Ballantyne, 2019) for a group that is not inherently vulnerable (Doody, 2018) but whose members are more likely to experience vulnerability (Bracken-Roche et al., 2017).

Obtaining ethical approval for PhD research normally comprises expected challenges, but my experience was unexpectedly challenging because I had to navigate two sets of guidance: the *Convention on the Rights of Persons with Disabilities* (CRPD) (United Nations, 2007), and the *Ethical Conduct in Human Research and Related Activities Regulations* (HRR) (University of Waikato [UoW], 2008). I commenced the approval process with an unexamined bias for, and an advocacy informed understanding of, the CRPD. However, the increased level of detail required for PhD research, and the standards of University of Waikato Human Research Ethics Committee, obliged me to revisit my understanding of the CRPD through wider reading. I will describe how this process enabled me to build a more nuanced and neutral academic voice that acknowledges and transcends my personal ideologies. Then, I will consider my experience alongside Stewart-Withers' (2016) interpretation of *edgewalking*, the practice of contending with competing claims and building bridges between multiple realities. In this article, I reflect on learning the boundaries of academia and advocacy while cultivating accessibility and agency for participants in my research.

Research with people with learning disabilities

Historically, many people with learning disabilities have encountered research as subjects (Milner & Frawley, 2019; Walmsley & Johnson, 2003) and injustices have occurred involving both participation in and exclusion from research (Bracken-Roche et al., 2017). Then, *inclusive research* developed as a methodology that involves, rather than acts on, people with learning disabilities (Walmsley & Johnson, 2003). Inclusive research uses the *social model of disability*, which understands disability as constructed through interactions between an individual with impairment and barriers that exist within society (Oliver, 1990), transforming how people with learning disabilities take part in research (Walmsley & Johnson, 2003).

Convention on the Rights of Persons with Disabilities

New Zealand ratified the CRPD in 2008, progressing equal rights for people with disabilities within the canon of human rights conventions. The CRPD grants people with disabilities “equality and non-discrimination” (United Nations, 2007, Article 5). Where individuals meet recruitment criteria, equality and non-discrimination encompass participation in research (Nilsson & Broström, 2019).

Several articles in the CRPD imply rights and protections for research participants with disabilities, of which Article 12 has particular salience to consent for people who have learning disabilities (Mirfin-Veitch, 2016; Nilsson & Broström, 2019). Article 12 sanctions equal recognition before the law, confirming the right to legal capacity for people with disabilities (United Nations, 2007). This approach drives a wedge between *legal capacity*, the recognition of decisions as legally effective by others, and *mental capacity*, the cognitive abilities of the decision-maker, asserting that the former cannot be contingent on the latter (Nilsson & Series, 2018).

States Parties are responsible for providing support to realise Article 12, and safeguards to avoid abuse (United Nations, 2007). People with learning disabilities can experience difficulty understanding, remembering and weighing information, foreseeing consequences and communicating decisions (Office for Disability Issues, 2017). Therefore, some research participants may require *support for decision-making*, such as environmental and informational adaptations (Mirfin-Veitch, 2016), and *supported decision-making*, which exists when the “presence of support extends a person’s ability for decision making” (Office for Disability Issues, 2017, p. 3). Support for decision-making and supported decision-

making processes aim to empower adults with learning disabilities to maintain control in their lives (Mirfin-Veitch, 2016; Office for Disability Issues, 2017).

Human research ethics in New Zealand and regulations at the University of Waikato

New Zealand law charges universities with ensuring the ethical conduct of their researchers who are working with human subjects (Gillett & Douglass, 2012; West-McGruer, 2020). These research ethics requirements draw on Western biomedical standards and closely align with existing legislation (such as Health and Disability Commissioner, 1996; Ministry of Health, 2002) (Stewart-Withers, 2016; West-McGruer, 2020). As a result, research ethics in New Zealand presume competence, recognise mental capacity as a component of legal capacity, and have a best interest standard for research with people thought to lack capacity for consent (Douglass, 2016; Douglass & Ballantyne, 2019; Mirfin-Veitch, 2016).

The HRR outlines the ethical research policies of the University of Waikato (where I am undertaking my doctoral study) in line with guiding frameworks. Regarding consent, the HRR uses “reasonable judgement” to decide if a prospective participant is capable of giving informed consent, or, if proxy consent should be sought “from the person who has responsibility for the prospective participant's welfare” (UoW, 2008, Article 9.4.e). When proxy consent is sought, researchers “must make all reasonable effort to involve the prospective participant themselves in the process and the decision about consent” (UoW, 2008, Article 9.4.f).

An unexpected challenge

The wording of the HRR was unexpectedly challenging for me and prompted a series of questions. I wondered, “if a prospective participant is reasonably judged incapable of giving informed consent” (UoW, 2008, article 9.4.e), what constitutes “reasonable judgement”, whose judgement should be involved, and how would I know if someone was incapable of giving informed consent? As Douglass (2016, p. 12) says, “Capacity can be difficult to assess, may not be clear-cut and involves value judgements about people’s preferences and beliefs.” People with learning disabilities are, as Nilsson and Broström (2019, p. 8) argue, “more vulnerable than others, all else being equal”, and their capacity to consent has been examined in many forums. If required to obtain proxy consent, I was unsure what that would entail, or where it would fall on a spectrum of decision-making approaches in light of the CRPD call for a paradigm shift from substitute decision making to supported decision-making (Mirfin-Veitch, 2016). The HRR states proxy consent must come “from the person who has responsibility for the prospective participant's welfare” (UoW, 2008, Article 9.4.e). However, as more people with learning disabilities are living self-directed lives in the community, I was unsure whom, if anyone, would have responsibility for their welfare.

My supervisors strongly encouraged me to engage with research that unpacks the CRPD and problematise an otherwise straightforward reading of the CRPD articles. This process enabled me to identify my positionality, or, where my “personal and field life bleed into one another” (Billo & Hiemstra, 2013, p. 315). Specific feedback directed my attention to the academic debate surrounding terms and concepts. The CRPD is characterised by strategic ambiguity and key terms, such as legal capacity and support, which are not defined within the text, for example, as Nilsson and Series (2018, p. 384) articulate,

In the final analysis, much comes down to what ‘substituted decision-making’, ‘supported decision-making’, and ‘exercising legal capacity’ are taken to mean. These should be recognized as terms of art within the literature on universal legal capacity; it should not be assumed that they carry their intuitive or traditional meaning.

Ultimately, I was able to appreciate the common intent of the CRPD and the HRR and draw on the HRR as a protective counterbalance for the CRPD, as the latter lacks local and research specificity (Nilsson & Series, 2018).

My response

I responded to CRPD and HRR framings of capacity to consent by designing my recruitment and consent protocols to meet their calls for autonomy and safeguarding (Nilsson & Broström, 2019). I ensured each participant had a nominated support person who agreed to assist with supported decision-making. Participant autonomy was promoted by involving their support person to inform and enhance individually tailored recruitment and consent processes. Then, I conducted at least two home visits with each participant to gain rapport and better understand their preferences and needs. I focused engagement around *Easy Read* information and consent forms. *Easy Read* is a communicative format intended to be more accessible for adults with learning disabilities and align more effectively with their preferences (Chinn, 2019; for example see Newcombe, 2019). This style can contribute to an enhanced understanding of research processes for some people with learning disabilities (Hurtado et al., 2014). I asked participants if they wanted to consent independently or with support, providing illustrations of other serious decisions and encouraging them to decide whether to participate in line with how they normally make and communicate similar decisions.

I promoted participant protection by using a *Declaration for Supporters* (DfS) that works alongside the *Easy Read* forms and allows a support person to give consent for and/or agree to support someone to participate in this research. I made the DfS as unobtrusive as possible by fitting it on one page in black and white, contrasting with the nineteen-page full-colour image-rich and large font participant information and consent forms. The DfS provides an additional safeguard to mitigate vulnerability for those who chose to sign their consent form and constitutes proxy consent for those who chose their supporter to provide consent. These accommodations to the recruitment and consent process enabled me to implement a research-informed example of how the CRPD and HRR work together.

Edgewalking

Reflecting on my experience, I came across feminist psychologist Krebs (1999), who coined the term edgewalkers (sic) to describe people who embrace complexity and difference. These people identify and cultivate edgewalking qualities, such as an appetite for change, innovation and risk; and courage in welcoming unfamiliarity, ambiguity and dialogue. Stewart-Withers (2016) applied edgewalking to ethics review in a New Zealand context. In her analysis, edgewalkers bridge the biomedical paradigm regulating ethics committees with the visceral dynamic of working with people in social sciences, as I found myself doing to achieve ethical approval. For Stewart-Withers (2016, p. 40), self-awareness is an important component of edgewalking because “ethics in practice can generate high expressed emotion where people have a tendency to position themselves one way or the other”. I found myself edgewalking as I negotiated consent processes with stakeholders, including participants, their supporters, my supervisors, and the University of Waikato Human Research Ethics Committee; incorporated my experiences of living and working alongside many people with disabilities, and indeed, being disabled; appreciated the adaptability of words and phrases in the CRPD and the HRR; and ultimately created something new, integrating the CRPD and HRR as complementary safeguards. In all, confronting my previously held assumptions provided me with an opportunity to be an edgewalker and move forward with a new understanding of managing complexity.

Conclusion

Including adults with learning disabilities in research requires appropriately balanced measures and processes. The CRPD and the HRR were written for different purposes, sit within different legislative contexts and construct risks in different ways. This article considers their contributions to consent in my research within the context of inclusive research. Understanding two sets of guidance as complementary has empowered me to accept ambiguity and multiple points of view. This unexpected challenge enabled creative solutions to address tensions between my previous way of working and a new way of working, and personal growth in learning to be an edgewalker.

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