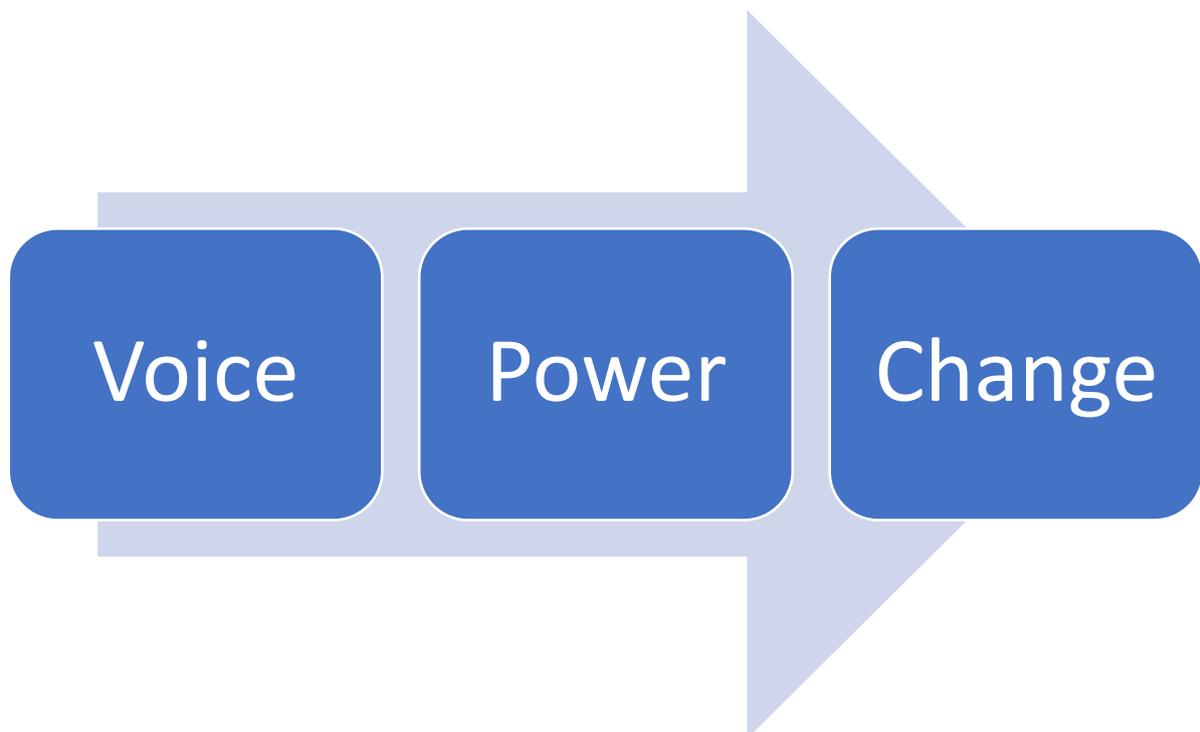


Disability advocacy research in Europe: emerging fieldwork

Year 2 Research Report



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This Research Report is provided by the Research Committee to showcase the emerging fieldwork of the 14 Early Stage Researchers (ESRs) employed on the Marie Skłodowska Curie Research Training Network on Disability Advocacy Research in Europe (DARE).

The DARE Project is co-ordinated by the Centre for Disability Law and Policy at the National University of Ireland, Galway, with the collaboration of partner institutions: the Institute for Social and Political Sciences (Portugal), Maastricht University (Netherlands), University of Leeds (UK), the European Disability Forum, the European Association of Service providers for Persons with Disabilities, the University of Iceland and Swiss Paraplegic Research.

The ESRs were invited to submit short working papers based on any aspect of their individual research projects during the second year. These chapters are based on methodological challenges, practical experiences and lessons learned from their fieldwork (examples from their research findings may be the subject of future research report publications in Year 3).

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1 Co-producing research with young disabled people in the context of the COVID-19 pandemic

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Abstract

This paper focuses on the process of research co-production with young disabled people as part of a doctoral research project on disabled children's participation in healthcare decision-making. The COVID-19 pandemic has dictated the way in which the research is conducted including the methodological approaches to research co-production. However, it has not only constrained the possibilities of research fieldwork but has also provided new opportunities for engagement with the communities benefiting from the research. The paper offers an overview of the methodological approach used in the initial stages of research co-production with 12 young disabled people mobilised to contribute to the research process and to form the Youth Research Advisory Board (YRAB). Shifting the engagement with young disabled people to online spaces allowed a diversity of voices, including young people with diverse impairments, from different geographical locations to come together and use their lived experience to shape the research agenda.

Introduction

The UN Convention on the Rights of the Child (UNCRC) (1989) by virtue of its Article 12 has entitled children to the 'right to be heard' in all matters that affect their lives. Being at the same time a right and the general principle applicable across all other rights, it has arguably been, the main driver of increasing attention to children's participation in research (Holland et al., 2010). The heightened interest of researchers on how to include children in different phases of the research process has also been spurred by new theoretical and methodological approaches developed within the interdisciplinary field of childhood studies (James, 1998). Such approaches heralded by the new sociology of childhood were underpinned by the view of children as competent social actors endowed with an agency to influence and shape their environment and contribute meaningfully to a generation of scientific knowledge (James and Prout, 1990; Prout, 2002; Prout, 2005).

In the last decade of the 20th century, the new sociology of childhood made an important step towards recognition of the child as a research subject rather than an object which characterized previous research endeavours mainly in the field of development psychology (James and Prout, 1990; Mayall, 2000; Prout, 2011). This epistemological shift posited a child as an important source of knowledge and a being with important views worth researching in its own right. In the previous decade, social researchers have been trying to make a step beyond the involvement of children as research subjects and informants and to create additional space and opportunities for children's participation in different stages of the research. This process in which children are given opportunities to shape the research agenda and to participate to some extent in research implementation is referred to as research co-production (Bell and Pahl, 2017; Cuevas-Parra, 2020). These changes have simultaneously been spurred by increasing attention to a human rights-based approach to child participation drawing from the requirements of CRC Article 12. In an attempt to interpret the normative content of Article 12, Lundy proposed a model of child participation which clarifies that its full implementation does not only mean that children are given the chance to voice their opinion if they have it. Rather, it entails a positive

duty of adults to act proactively and create a safe and encouraging environment for children to express their views, provide appropriate information and facilitate the expression of children's views, ensure that children's views are listened to, taken seriously and acted upon, when appropriate (Lundy, 2007).

This paper draws from the research project 'Disabled Children's Participation in Healthcare Decision-Making' and offers an insight into the process of research co-production with the group of young disabled people recruited as the members of the YRAB set up with an aim to get involved in the research process starting from the phase of fieldwork preparation. The next section will briefly explore the concept of research co-production unravelling the core ideas underpinning the concept and the value it may add to knowledge production. In the subsequent section, the methodological approach to research co-production with the group of young disabled people will be examined explaining the process and the mode of involvement of young disabled people in the initial stages of the research highlighting the challenges and opportunities that have arisen in the context of COVID-19 pandemic.

Research co-production with disabled young people

Co-production of research is a vaguely defined concept signifying different degrees of involvement of research participants in various stages of the research process. In the context of research co-production, research participants or those who are supposed to benefit from research findings are no longer occupying the position of research subjects who are merely allowing the researcher to obtain an insight into their living experiences but are rather acting as co-researchers by sharing their expertise to contribute to the generation of knowledge. As Cahill puts it:

Engaging young people fully in the research process offers a starting point for a more inclusive research agenda, one which recognizes young people as social actors and creates an opening for their concerns to influence new knowledge production. (Cahill, 2007, p. 309)

Disabled children and young people are a group that faces an increased risk of being excluded from participation in research and when their lives are researched their views are often solicited through family members or other adults as proxies (Curran and Runswick-Cole, 2013; Runswick-Cole et al., 2018). The rigidity of research methods or ethics procedures and overreliance on cognitive abilities and competence to participate, all act as the reasons for the lives of disabled children being under researched (Priestley, 1998; Davis and Watson, 2000; Tisdall, 2012; Stafford, 2017). However, the researchers have been increasingly demonstrating the possibilities of direct involvement of disabled children in research, adapting the research methods and seeking to create opportunities for authentic representation of disabled children's voices. The emerging interdisciplinary field of disabled childhood studies has underscored the value of contributions that disabled children can make in the research process (Curran and Runswick-Cole, 2013; Abbott, 2013; Liddiard et al., 2019). In this research project, the young disabled people are involved in research co-production by means of participation in an advisory body – the Youth Research Advisory Board. In their advisory capacity young disabled people (aged 15 - 35) were asked to reflect on their childhood experiences of participation in healthcare decisions and inform the process of development of research tools. Such research advisory groups are increasingly used in social research to benefit from the assistance of young people to share their life experiences related to certain research topic or to share their views on how to

create or adapt research methods to be effective and engaging for young research participants (Collins et al., 2020). It is exactly the latter task for which the YRAB was set up in this research project and in the next section I will set out to describe how the research co-production was methodologically conceived to fulfil this task.

Methodology of research co-production

The co-production activities in this phase of the research were designed so to include a series of online consultation meetings with young disabled people. The purpose of these online meetings was to talk about their opinions on key topics to be included in conversations on disabled children's participation in healthcare decision-making with future research participants – disabled children and young people, their parents and healthcare professionals in England and Serbia. For such purposes, the intention was to form the YRAB composed of disabled young people (aged 15 to 35) from different countries, meaning that the members of the YRAB would be different people than those recruited as research participants in the later phase of data collection in England and Serbia. In the case that the young person from England or Serbia where the data collection is going to be conducted, who at the same time matches the sampling criteria, applied for a membership in the YRAB they would have been informed that their membership in this advisory body would preclude them from participation in data collection process as the engagement in the tasks of the YRAB would likely distort their views on the subject. In such case they would have had the choice to opt either to membership in the YRAB or to become the research participant in data collection phase.

Recruitment of the members of the Youth Research Advisory Board

The researchers have been highlighting difficulties associated with the recruitment of children to participate in the research process including the need to work with different stakeholders and gatekeepers to obtain access to children, such as parents and their associations or institutions such as education facilities (Powell et al., 2020). Since the Lumos Foundation is a non-academic partner in this research project they were approached with the proposal to include the group of young disabled people they are working with, in the research co-production process. As Lumos, at that point in time, had the running project focused on support to self-advocacy of young disabled people in Bulgaria who had already been expressing a desire and an interest to learn more about research, Lumos presented an opportunity to join the research to this group of self-advocates. As a result, 5 young disabled people aged between 21 and 28 decided to join the YRAB.

Since the consultation activities with the YRAB members from Bulgaria were conducted as part of the Lumos's ongoing self-advocacy program with disabled young people, these activities adhered to Lumos's safeguarding policy for work with children and young people. That meant that ethics approval was not sought from the Research Ethics Committee of the University of Leeds, but the rules of procedure of Lumos for engagement with young people were followed including a provision of training on safeguarding policy to the researcher, mandatory enhanced Disclosure and Barring Service check before engaging in work with young people and arrangements to store the recorded data securely in Lumos's organisational data storage system. The involvement of young people in research necessarily begs consideration of the balance between their participation rights and the right to protection (Mayne et al., 2018; Liabo et al., 2018). Lumos has also provided support by their Child Participation Officer from Bulgaria with extensive experience of direct work with the group of young disabled people selected to take part in consultation meetings. The recruitment of people

was thus constrained by the availability of Lumos's resources and its limited work with young disabled people at that moment in time (the only active self-advocacy group of young disabled people was the one in Bulgaria). Such constraints meant that 5 young disabled people selected by Lumos were non-English speaking youngsters with no direct experience of impairment-related orthopaedic surgeries, a type of medical intervention which is the subject of this research project. However, it was decided that their contribution would still be valuable given that they could offer important reflections on participation in individual healthcare decisions understood more broadly.

Given the above listed constraints, a decision was taken to form another group of young disabled people to join the Youth Research Advisory Group. The open call was announced for interested young disabled people aged between 15 and 35 and the call was disseminated through the European Network on Independent Living (ENIL) and its Youth Network – largest pan-European network of young disabled people and their channels of communication. Seven young disabled people aged from 21 to 32 were recruited from 6 different countries including Montenegro, Serbia, Belgium, Turkey, Switzerland and Brazil. Four out of seven young people which signed up to join the YRAB had personal experience of impairment-related orthopaedic surgeries while others had an experience of other types of impairment-related surgical interventions. The application called included an information sheet with the project details and the role of the YRAB accompanied with the application form which among others included questions on reasons why wanting to join the YRAB, what makes them interested in the topic of disabled children's participation. Some of the answers are indicative of strong linkages between the personal experience of medical interventions in childhood and their interest to join the research on this topic. A young disabled woman stated following in her application:

I went through surgeries and hospital stays myself and I remember that there was no communication with the children. I remember being in hospital for days not knowing fully why then taken abruptly one morning to surgery by force and then waking up with a fixator by Wagner in my leg without any understanding of the surgery and the whole process of it. That's how it was done in the 90's. In general all of my hospital stays were marked with neglect and even abuse by the hospital workers (yelling, slapping my face, intimidation and such). And usually the children and the parents are left at mercy and will of the medical professionals as if they don't have a sense of agency on their own. I want to change that. It should be mandatory for children to have at least one counselling with professionals about what is going to happen with their bodies and doctors and nurses should explain things at their level of understanding before surgery and hospital stay. It would mean a lot less trauma and a lot more recovering and healing.

This quote highlights the motivation of young disabled people to draw from their personal experiences and recognise the key changes which ought to take place to enable meaningful participation of children and young people in healthcare systems. Despite the fact that the participants recruited for the YRAB are all young disabled adults over 18 rather than children, their contribution to the research process is significant as they could critically reflect on the events from their childhood and think of the instances when their participation was constrained or enabled by adults, parents and health professionals alike. In hindsight, they would recognise the barriers to participation they were facing and the enabling factors which could have improved their participation experience. The next section will lay out the methodological

approach used during the online meetings of the YRAB to elicit the views of young disabled people and use those views to map out the key topics to be included in the data collection phase.

Methodological approach to research co-production with the YRAB

The element of co-production in this research project has been built in the phase of research study design. While the research problem and research questions had already been identified and formulated, in the research study design phase the opportunity was envisaged for young disabled people to join the research process and contribute by helping to develop the interview guides to be used in the data collection phase for the interviews and focus groups with disabled children and young people, their parents and healthcare professionals. The participation of young disabled people was enabled through a series of online meetings. They were divided into two groups – the first group gathering those young people from Bulgaria recruited through Lumos and the second group recruited internationally through an open call for recruitment.

The reasons for division into separate groups are multiple. The working method differed between the two groups in so far as the work with young disabled people from Bulgaria was mediated by the Child Participation Officer from Lumos who has an ongoing relationship with the group of young disabled people meeting regularly with them as part of Lumos's self-advocacy project aimed to empower young people. The Child Participation Officer acted not only as the gatekeeper but also as an important source of support helping to schedule the meetings, provide support to young people to connect to Zoom meetings, resolve technical difficulties, communicate with them in their mother tongue and through the phone when needed and conducting a debriefing with young people after online sessions. Secondly, the group of young disabled people from Bulgaria was composed of non-English speaking young people and the work was conducted with consecutive translation which dictated the pace of conversation. Thirdly, having an experience of previous work with that group of young people, the Child Participation Officer warned against asking young participants to draw from their personal experience of healthcare participation because some of them have negative and traumatizing experiences of denial of access to healthcare either caused by their experience of institutionalization in childhood or due to poor access to healthcare during the period of a pandemic. This highlights the importance to consider a potential sensitivity of the topic for research participants making the corresponding adjustments in research design and methods. The topic of healthcare participation may not be traumatizing per se. Rather, sensitivity is context-bound, culturally determined and experienced subjectively depending on the previous individual lived experiences and perceptions (Powell et al., 2018; Powell et al., 2020)

Throughout four months from December 2020 to March 2021, four 1.5 – 2 hour long online sessions were held with the group of five young people from Bulgaria and three online sessions with the group of young people recruited internationally. The groups were meeting separately for several reasons. First, the group of young people from Bulgaria were meeting under the auspices of Lumos and the members have already known each other for long time, having established a safe working environment and relationships of trust. Being participants in Lumos's programs, Lumos was able to provide a support worker, present there on the field, which helped young people to prepare for the session and was there to help with a debriefing and any other type of support when needed. Second, the working methods of two groups differed as it was recommended by Lumos's support worker to avoid to the extent possible detailed talks about personal experiences of young people in terms of access to healthcare services due to traumatizing experiences of Bulgarian group members. Third, the work with

Bulgarian non-English speaking youth required a presence of translator which affected a dynamic and pace of conversations. Finally, the online discussion with 10+ young people was considered less than optimal because the work with a smaller group of young people would give more space and time for everyone to express their views.

The first session in both of the groups was dedicated to the introduction of the research project and an explanation of the whole research process and methods which are going to be used. This session was also used to explain the role of the YRAB and to obtain the informed consent of young people to take part in the next sessions and for the upcoming sessions to be recorded. In the following sessions, to avoid the stories of personal lived experience, the participants were given the following imaginary scenario to stimulate their reflections:

A teenager, 12-year-old girl, with cerebral palsy is attending a medical appointment together with her parents at the doctor's office – an orthopaedist. They visit a doctor because they would like to consult if anything can be done to improve the functionality of her body.

On the basis of this scenario the participants were engaged in a discussion of questions revolving around topics such as desirable behaviour of doctor in such situations, the type and amount of information to be given to a girl, how the girl might feel in such a situation and what might she want to know and ask her parents and a doctor, who might be deciding on what is best to do regarding her treatment, what might help the girl to feel less scared and more relaxed, and similar. The fourth and last session was used for reflections and debriefing on the whole series of sessions to elicit young people's views on what they learned in the process. In addition discussions were also focused on what they liked or what if anything had been challenging for them and to discuss the opportunities for further engagement in the research process.

The working method with the YRAB member differed only slightly for above described method used with a group from Bulgaria, in so far as the participants were asked to think of or share the personal experiences of medical interventions in their childhood and to reflect on what kind of information was important to them to receive and know about, who they referred to for such information, whether they were given an opportunity to voice their opinions and influence the decisions, and similar. Participants' answers were asked to identify the key topics to be represented in the interviews and focus groups during the data collection phase and to propose potential questions for the interview and focus group guides. The draft of the interview and focus group guides was shared with participants for validation asking their feedback and opinion if the questions accurately reflect what they deemed as important to be included.

Conclusion

This paper has shown that the COVID-19 pandemic has opened up new opportunities for engagement with young disabled people in the research process. Orientation to digital methods has enabled the young disabled people from different countries to come together and join the YRAB, a consultative body set up to inform the research agenda and contribute to the development of research tools to be used later on in the phase of data collection. Moving the fieldwork to an online environment has helped to move across geographical boundaries and to create the opportunity and safe space for young disabled people to share their experiences and thoughts about the research topic and recognise the commonalities they share even though they are coming from different localities. However, it also brought up certain limitations, particularly because of the digital exclusion. An expectation that the young disabled people

who decide to join the YRAB will have the access to computer equipment and skills needed to join and participate in the online meetings where the working language is English has led to such composition of the YRAB where most of the members are well-educated young disabled people, some of them highly experienced in activism or even with aspirations to engage in academia. Such limitations were partly mitigated through the involvement of a group of non-English speaking young disabled people from Bulgaria, participants in programs of Lumos Foundation, among which some are former or present users of residential care services. A further limitation relates to an age-cohort of Youth Research Advisory Group members which includes an age range from 21 to 32. This means that in some discussions it became evident that the participants are occupying the position of adults justifying the exclusion of children from participation in healthcare decision-making processes because of their relative immaturity. This opened up the questions of whose voices are being heard in the process of research production and if the research on children's participation can really be considered as genuinely co-produced since the research agenda is influenced by young disabled adults rather than disabled children themselves?

Despite the limitations, the value of research co-production with disabled young people has proven to be significant as the process of online consultations with the member of the YRAB led to rich discussions drawing from young people's personal experiences of participation in individual healthcare decision-making processes. These discussions provided a fertile ground to develop the set of provisional questions to be used in the interviews and focus groups with disabled children and young people, their parents and health professionals in England and Serbia in the data collection phase. In that way the research agenda is influenced to some extent by disabled young people as the topics which are important for them will be the subjects of conversations held with research participants throughout data collection.

The YRAB members have also expressed a desire to take part in further research activities after the process of data collection. The potential of YRAB for research co-production in later phases of the research will be used in terms of their participation in the process of data analysis by working together to analyse anonymised interview excerpts and recognise key themes and patterns coming up in the texts or by taking part in dissemination activities such as jointly written blogs, conference papers or webinars and similar events.

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2 Researching sensitive topics during Covid-19: methodological challenges and adaptations

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Abstract

For qualitative researchers, who relied on face-to-face interaction to collect data, Covid-19 wreaked havoc on their research plans and methods employed to collect and analyse data. In addition, research of sensitive nature, such as the one presented here, also would have to consider the new circumstances of participants who may be affected by increased health concerns, higher levels of social isolation and/or experience of intensified feelings of loneliness in response to physical distancing measures. This paper will discuss methodological challenges faced in my on-going study, which aims to explore the experiences of women and girls with disabilities and of those that support them through detection, investigation, and prosecution of gender-based violence. It will offer personal reflections on the challenges in adapting the research plans to the circumstances due to Covid-19, the sensitive nature of the research topic and as a disabled researcher.

Introduction

In March 2020, the COVID-19 pandemic swept through Europe altering everyday life for everyone. To qualitative researchers, who relied on face-to-face data collection, it upended their research studies and left them facing the dilemma of having to hit pause or go online. I certainly faced such dilemma as an early-stage researcher, exploring the experiences of women with disabilities and of those that support them thorough detection, investigation, and prosecution of gender-based violence. When researching such sensitive topic and relying on a marginalised group of disabled women as key participants—regarded by the law as vulnerable and at risk during the pandemic—there is a lot of methodological and ethical implications to consider. Disabled women have already been shown to be at higher risk of experiencing violence (Hughes et al., 2012; Krnjacki, et al, 2016; UNFPA, 2018). Recalling and talking about violence is not easy to do in regular circumstances, let alone during a pandemic that marginalizes them even further than before. Being classified as part of the ‘high risk’ group during a pandemic can cause additional stress and fears, intensified feelings of loneliness in response to physical distancing measures and increased psychological distress (APA 2020).

As I was preparing to start my data collection, there was no available research on the specific impact of COVID-19 on disabled people nor women. Nonetheless, I had to consider the new and different circumstances and its impact on my target participant groups very carefully when making decisions about the best way forward. Important to state, however, as I was doing this rethinking there was no available methodological resources and discussions on how to adapt data collection methods to the conditions imposed by the COVID-19 pandemic, as there is now (e.g., Lupton 2020; Taylor et. al. 2020). Nor was there any precedents regarding researching similar sensitive topics and using online methods. not knowing how long these necessary restrictions were going to be in place, I had to explore the option of continuing data collection through online platforms and gauge their methodological fit to sensitive research.

This paper will discuss methodological challenges faced in my on-going research. After providing a brief overview of the study and the originally planned qualitative methodology, the

paper will offer some personal reflections on the challenges I faced in adapting the research plans to the back-then circumstances as a result of the restrictions posed by Covid-19, the sensitive nature of topic and as a disabled researcher.

Research description and qualitative methods.

This on-going research focuses on violence against disabled women in Iceland and UK. It aims to gain in-depth knowledge through exporting the lived experiences of disabled women in the context of detection, investigation, and prosecution of gender-based violence directed against them. This interdisciplinary research employs a human rights approach in combining disability studies, gender studies and disability law and policy to gain a comprehensive and holistic view of the topic under study. The human rights approach is both driven and supported by the CRPD (Quinn & O'Mahony, 2017), and recognizes disabled people as rights holders (Kanter, 2015). This research focuses on the actualization of CRPD's right to freedom from violence (Art.16) and access to justice (Art.13) for disabled women (Art.6) and the analysis of the interlinking between these three Articles and of how the right to access to justice and to be free from violence stated by them have materialized in the lives of disabled women in Iceland and UK.

Moreover, the human rights approach recognizes the importance of "embedding lived experience in rights-based claims and in the development of social justice theories" (Degener, 2016, p. 6). To this end, this research employs a qualitative methodology to gain an in-depth insight of the actual experiences of women with disabilities and of those supporting them through detection, reporting and prosecution of gender-based violence. The data is to be primarily collected through qualitative interviews and document analysis. But before I discuss the originally planned methods, I will first outline the three groups of participants.

Participants.

There are three groups of participants: (1) Disabled women, (2) professionals/experts working in the support frameworks aimed at disabled women who have been subject to violence and individuals working within the justice system in the reporting/prosecuting structures, and (3) experts working in the disability field. Participants will be identified through different networks and recruited using purposive sampling, which allows for the selection of people who have experience of relevance to the study at hand and can, as Creswell points out, "purposefully inform an understanding of the research problem and central phenomenon in the study" (Creswell, 2007, p. 125). The disabled women will include those who have managed to go through the justice system up to the courts, and those who did not choose or manage to do so. All the disabled women will be adults over the age of 18 who have experienced violence of some kind, and have different impairments, sexual orientation, and ethnic backgrounds. The professionals/experts will include professionals that support the disabled women throughout the process of reporting and/or prosecuting violence (rights protectors officers, social service staff, women's shelter staff, and disability lawyers), and professionals working within the justice system (police officers, lawyers, prosecutors and judges). The third group, experts working on the disability field, will be interviewed to build background knowledge in the service and justice structures in Iceland and UK.

In the UK, participants are planned to be recruited through the required non-academic secondment with an NGO.

Interviews and document analysis

The main research method will be in-depth interviews with 36 participants. Each interview will be recorded, last about 1 – 2 hours and conducted at a place of the participant 's choosing. Two interview guides have been developed: one for interviews with disabled women and another for professionals/experts. The questions will be open-ended and exploratory in nature, investigating the experience of violence by disabled women, the types and context of violence, as well as exploring the experience of supporting somebody who has been subject to violence, or working in the detection and reporting structures of violence. In addition, the interviews address issues such as support services and structures, access to justice structures, the credibility of disabled women when reporting violence, legislation, and public policies.

Given the types and in-depth questions asked, the participants may experience discomfort or distress when discussing the violence suffered within their own life, or the life of someone who they have supported as part of their job. Thus, acknowledging how sensitive the topic is, measures to minimise the distress caused to the participants, would have to be put in place, as outlined in section 1.4.

In addition to interviews, analysis of court documents, laws, policies and international human rights treaties, CRPD and CEDAW, will also be conducted.

Grounded Theory Approach

Grounded theory approach will be used to guide the analysis of the interview data (Charmaz, 2014; Padgett, 2017). This approach aims to generate theories, concepts, and hypotheses from the data (Creswell, 2007; Taylor et al., 2016) and calls for ongoing data analysis from the beginning and alongside the data collection (Bogdan and Biklen, 2007).

Ethical challenges and measures

Addressing the very sensitive topic of violence against disabled women, who have been historically and are regarded by the law as a vulnerable group of people, falls under research that addresses ethically sensitive subjects. There are three major ethical issues in this research: obtaining informed consent, the sensitivity of the topic and emotional distress in recalling difficult events and memories, and the protection of the anonymity of the participants. Measures to overcome these challenges were identified in accordance with the ethical guidelines of the University of Iceland. First, the research protocol was designed to raise awareness about this sensitive topic at the information stage and to emphasize consent as a continuing process rather than a one-off decision. The initial recruitment e-mails and casual contact/conversations with potential participants will include a description and explanation of the purpose of the study, what participation entails, and offer to answer any questions they may have. This information will be provided verbally and in written format, as appropriate, including in an easy-to-read format. All participants will be informed that they could become emotional, and they have every right to stop at any point, take a break, can refuse to answer any or all questions and withdraw from participation at any point without giving a reason, and without incurring any negative consequences. Second, all the participating disabled women will be offered a free session with a counsellor or a psychologist of their own choice following their interviews, to whom they may reach out if they need support. Third, to protect the anonymity of participants, personally identifiable information will not be used. Only pseudonyms will be used when the interviews are transcribed and when findings are published or presented. All the research data, contact information, and court documents will be kept

strictly confidential, and stored in accordance with data protection procedures of the University of Iceland, and the data management policy and plan by the DARE project based on the European Code of Conduct for Research Integrity.

The ethical application and measures, which included the above original research plan, were submitted for review to the University of Iceland's Scientific Ethics Committee. Approval was received on the 7th of April 2020. Following that, the data collection was scheduled to start on the 1st of May 2020. However, due to the public health concerns caused by Covid-19, the data collection had to be postponed, and the research study and I as the researcher faced several challenges. Those and the adaptation will be discussed next.

Challenges and adaptations

When Covid-19 pandemic swept through Europe, universities had to go virtual and faculty staff had to work from home. As a screen-reader user, I had worked sometimes remotely before Covid-19, and thus, this was not an issue for me. Receiving the ethical review approval in April marked the transition to the plan for second year of my study: data collection. Given the restrictions posed by Covid-19, and the research relying on face-to-face interaction to collect data, I had to consider hitting pause or shifting to remote data collection. Part of such consideration was also the fact that both the disabled women were formally identified as vulnerable, and the topic was sensitive. From the outset of the pandemic, those with underlining conditions were categorized as part of 'high risk group', which would include some disabled women. Consequently, the data collection was postponed to begin in August 2020, with the hope that collection of interview data would be possible. After all, the situation in Iceland had been managed quite well and it looked promising.

Struggling to find resources on how to adapt sensitive research into online methods, and not knowing how long the restrictions were going to be in place, I began thinking creatively about how to modify the research methods to collect and analyse data. Together with the wonderful support from my supervisor, a close watch on the Covid restriction and some tweaking, adaptations to the research and some data collection was still possible, as it will be outlined below. Although there was no need for ethical amendments, I still faced many challenges.

Sampling and recruitment.

In April 2020 when the data collection was postponed, I decided to focus for the next few months on announcing the study and recruiting potential participants. As most of the relevant local conferences and DPO events were cancelled, it became difficult to establish connections and recruit participants. Feeling determined, however, I started spreading the word about my research and calling for participants on social media platforms, as well as asking people who my supervisor and I knew to introduce me and my research to potential participants and key individuals in the disability field and disability rights-networking mimicked on the phone and email. People were also asked to share my call for participants in their own social media accounts, and DPO newsletters. Each post included information on the research and my contact details. Due to the sensitive topic, potential participants were asked to contact me directly by private message on Facebook, phone or email. Even though reaching members of the disability community was still possible in Iceland, it became a slower process. Nonetheless, it worked.

Few people reacted to my call for participants: some asking questions and others confirming their participation. In answering them, I included the consent and information sheet. From the outset of the research, I made sure that both informed-consent and information sheet are

accessible, including to screen-readers, and had the option for disabled women to sign the consent form online or in person before starting the interview. Given the circumstances, the latter option was extended to the rest of participants. Hens, providing information and ensuring informed consent through online means was not an issue. The challenge consisted of conducting the interview itself.

Data collection

Recalling and talking about violence is not easy to do in regular face-to-face circumstances as it might trigger difficult memories and emotional discomfort for disabled women, let alone during a pandemic that marginalizes them even further than before. Similar to the rest of the population, disabled women were isolated and in addition, some have underlying health issues that classified them at higher risk for the pandemic. Being classified as ‘high risk’ can cause additional stress and fears, intensified feelings of loneliness in response to physical distancing measures and increased psychological distress (APA 2020). Although there was no available research on the specific impact of COVID-19 on disabled people when I started considering the adaptations, in October 2020 the Covid-19 Disability Rights Monitor report emphasized the dramatic increase in gender-based violence against disabled women and girls including rape, sexual assault, and harassment at the hands of enforcement authorities or family members during the pandemic (2020, p.37). Therefore, there was a lot to consider while trying to figure the next steps.

Feeling stuck and not convinced about online methods, I began to think about ways in which I could accommodate safe social distancing practices and conduct the interviews in person as originally planned. As the pandemic was being extremely well managed in Iceland, it was possible for me to conduct in-person interviews. Keeping in mind that some disabled women may be living in environments where they are subjected to harassment, violence or surveillance, building trust and providing a comfortable, private, confidential and accessible space, was my priority. After much consideration, I decided that having optional locations, which accommodated the social distancing measures and accessibility needs of participants, was the best solution. This was possible because the research protocol was designed to have the interviews at the location of the participant’s choosing, which was adapted to include online platforms. In total five interviews were conducted in person between September-December 2020: two at participant’s home and three at my supervisor’s office at the University. Although my research questions remained the same, I was very aware of different circumstances of participants, including privacy issues, health concerns and the implication of talking about a sensitive topic on top of the pandemic.

When I received a refusal to have the interview in person nor online due to health concerns by the potential sixth disabled woman, and a general lack of responses, I realised that maybe for some people being interviewed during the pandemic is too difficult. I decided to solely focus on the second and third group of participants. Seven interviews were conducted with professionals in person: three at participant’s work meeting rooms, three at participant’s office, and one at my supervisor’s office. As working remotely became the norm, more and more people were using online platforms. All of them had their personal workspaces at home, which meant that privacy was not an issue and the fact that their work involves talking about violence, the sensitivity of the topic did not affect them as much as the disabled women. For those professionals, who did not want to conduct the interview in person, using online platforms meant that I could still interview them. Five interviews with six professional participants were

conducted via Microsoft-Teams platform. However, online is not for everyone. Despite choosing to conduct the interview online, one of the lawyer participants had no idea about using any online platforms. To keep her participation, I offered to and showed her how to set up and use Teams for the interview. All 12 interviews with professionals/experts were conducted between October-December 2020.

While acknowledging the opportunity to continue data collection through online platforms, I was concerned about the quality of online data collection due to factors that could affect participants' performance, including the stress from working at home through the pandemic, energy drain and loss of concentration.

Finally, collecting policy documents and other written materials for analysis, was not directly impacted by Covid-19 as it involves secondary data. However, most of these are in Icelandic and as a non-Icelandic speaker, I had to get someone to translate them, which took a long time.

Data analysis

Having some data collected and in light of the Covid circumstances, I decided in January 2021 to focus on data analysis and temporarily stopped trying to recruit participants. Doing data analysis alongside data collection is part of the grounded theory approach. This was methodologically appropriate and feasible to conduct given the Covid restrictive challenges to recruitments.

Being a screen-reader meant that the analysis is done electronically. The data analysis: observers' comments, coding, and analytic memos, is on-going. Coding was difficult as most approaches to coding that I came across involved visual methods i.e., colours. None of such methods were accessible to me. This was not a Covid-19-related challenge as I would have faced the same difficulty if Covid-19 had not happened. The relevance, however, is that due to isolation imposed by Covid-19 I did not have the network of PhD students and other researchers to ask about different coding methods. Left with no other choice, I had to come up with an innovating accessible way of coding. This took a long time and patience. But I did manage to come up with a way to code data that worked for me: using keyboard symbols, which would be read out by the screen-reader software.

Conclusion

This paper has emphasised practical implications in adapting research methodologies and data collection methods to the conditions imposed by the COVID-19 pandemic. Drawing from my on-going qualitative research study, it has offered some personal reflections on the challenges faced in adapting my research plans to the pandemic circumstances, in moving elements of research methods to the online field, and as a disabled researcher. Using online research tools may offer new opportunities. However, in research concerning sensitive topics, I do not see online methods as adequate substitution for research design and in-person data collection.

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3 Research inclusion for persons living with dementia

Ainsley K McLean

Abstract

The purpose of this chapter is to highlight the importance of acknowledging the joint endeavour between the participant and researcher in research inclusion. The authentic voice and experience of persons living with dementia are rarely captured in research, thus, noticeably absent in the literature. Consequently, dementia-specific research focuses on the person rather inclusion with the person. While it is undoubtedly clear that researchers need to be ethically and legally mindful of gaining meaningful consent from persons living with dementia, it is not always entirely clear how to go about it in the first instance. This chapter contends that all persons with disabilities (including dementia) possess full legal capacity, equal with others before the law, as guaranteed by Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In its novelty, this chapter will explore how best to support a person living with dementia to exercise their legal capacity to participate in research by highlighting practical examples of my PhD project.

First, the chapter will briefly explain why persons living with dementia are unnecessarily excluded from participating in research. Secondly, it will highlight what a human rights approach to include persons living with dementia requires. Specifically, Article 12 of the UNCRPD. And finally, how I work to achieve this in my research by drawing on accessible formats to ensure greater inclusivity towards the consent process for persons living with dementia to participate in research

Introduction

The purpose of this chapter is to ‘create a moral space by acknowledging the joint endeavour between the participant and researcher in the interpretive inquiry’¹. The authentic voice and experience of persons living with dementia are rarely captured in research, thus, noticeably absent in the literature. Consequently, dementia-specific research focuses on the person rather than being conducted with the person. While it is undoubtedly clear that researchers need to be ethically and legally mindful of gaining meaningful consent from persons living with dementia, it is not always entirely clear how to go about it in the first instance. This chapter contends that all persons with disabilities (including dementia) possess full legal capacity, equal with others before the law, as guaranteed by Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In its novelty, this chapter will explore how best to support a person living with dementia to exercise their legal capacity to participate in research by highlighting practical examples of my PhD project.

First, the chapter will briefly explain why persons living with dementia are unnecessarily excluded from participating in research. Secondly, it will highlight what a human rights approach to include persons living with dementia requires. Specifically, Article 12 of the

¹ Brooker, D (2007). *Person-centered dementia care: making services better*. Jessica Kingsley: London

UNCRPD. And finally, how I work to achieve this in my research by drawing on accessible formats to ensure greater inclusivity towards the consent process for persons living with dementia to participate in research.

Why excluding people with dementia from research is a problem

This section will provide a contextual background on why persons living with dementia are unnecessarily excluded from participating in research and why this is a problem.

The exclusion of persons living with dementia in research leaves a significant gap in the empirical understanding of those with lived experiences. Therefore this unique perspective is rarely captured in the research. The exclusionary process of denying participation in research to persons living with dementia primarily focuses on the presence of cognitive deficit or impairment - The inability to make a decision, reason, or even comprehend information that is being shared is all brought into question.

Many people living with dementia have expressed their will and preference to participate in research yet are routinely denied or unnecessarily excluded.² First, it is essential to understand that dementia is not synonymous with incapacity.³ In essence, not all persons living with dementia lose the capacity to make decisions about participation in research.⁴ As researchers it is important to expand ‘consent methodologies to include rather than exclude persons living with dementia’⁵ Further, it is important to understand that an individual’s ability to make a decision is not immediately relinquished when an individual develops dementia, including the ability to understand the purpose and consequences for participation in a research study.⁶ In addition, researchers often exclude people with dementia because of concerns around ethics

² Brosnan, L & Flynn, E (2017). Freedom to negotiate: A proposal extricating ‘capacity’ from consent’. *International Journal of Law in Context* (13) 1 p 13.

³ Palmer, B. W., Harmell, A. L., Pinto, L. L., Dunn, L. B., Kim, S. H., Golshan, S., & Jeste, D. V. (2017). Determinants of capacity to consent to research on Alzheimer’s disease. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 40, 24-34.(33)

⁴ Ibid, n F5.

⁵ O’Rourke M., H., Duggleby, W., Fraser D., K., & Jerke, L. (2015). Factors that affect quality of life from the perspective of people with dementia: A met synthesis. *Journal of the American Geriatrics Society*, 63, 24–38; Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, 13, 709-716.

⁶ Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations*. Philadelphia, PA: Jessica Kingsley., Holland, S., & Kydd, A. (2015). Ethical issues when involving people newly diagnosed with dementia in research. *Nurse Researcher*, 22, 25-33; Palmer, B. W., Harmell, A. L., Pinto, L. L., Dunn, L. B., Kim, S. H., Golshan, S., & Jeste, D. V. (2017).

approval and the confidence to include persons living with dementia in a meaningful way. Furthermore, many ethical committees also consider persons living with dementia as ‘vulnerable populations’. According to Hellstrom et al., such perceptions frame an individual as too challenging or unattainable, resulting in exclusion.⁷

Capacity to Consent to Research Participation: A Rights-Based Approach

This section will briefly outline what a human rights approach looks like when including persons living with dementia—specifically, the applicability of Article 12 of the UNCRPD, as it applies to my research. As previously highlighted, many persons living with dementia are often perceived to lack the capacity to consent based on the presumption of cognitive deficit and consequently excluded from participating in research. Traditionally, most researchers have ‘relied on an extension of the competency-based informed consent methods when it comes to interpreting an individual’s capacity to consent.’⁸

In this particular section, I focus on supported ability rather than a cognitive deficit, following the UN CRPD rights-based approach. The Convention has been integral for developing a rights-based approach towards capacity for persons living with dementia. The Convention enables the individual to make choices and have their decisions respected on an equal basis with others, as guaranteed by Article 12 of the UNCRPD. Further, it recognises an individual’s decisions to have legal effect or validity. Article 12 also recognises universal legal capacity, whereby all persons, regardless of disability or decision-making skills, inherently possess the legal capacity.⁹

Competency based methods usually rely on the premise of mental capacity, which is concerned with the decision-making process of the individual. Mental capacity tends to focus on deficit rather than supported ability. What this means is that mental capacity refers to a ‘combination

⁷ Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14, 608-19; Jeste, D. V., Palmer, B. W., Appelbaum, P. S., Golshan, S., Glorioso, D., Dunn, L. B., ... Kraemer, H. C. (2007). A new brief instrument for assessing decisional capacity for clinical research. *Archives of General Psychiatry*, 64, 966-974.

⁸ Dewing, J 2008 Process consent and research with older persons living with dementia. *Research Ethics Review* Vol 4, No 2, 59-64.

⁹ Committee on the Rights of Persons with Disabilities (2014), General Comment No.1 – Article 12: Equal Recognition Before the Law. UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session, April 2014.

of cognitive disability, impairment and a person's extent of understanding of consequences of their action.¹⁰

Often legal and mental capacity are confused by researchers, yet, there is a clear distinction between the two. The concept of legal capacity is very distinct from mental capacity for several reasons. First, mental capacity may fluctuate, whereas legal capacity does not; it remains constant. Legal capacity is a 'key concept in international human rights law'¹¹ to which a legal personality is established— 'this is the ability to bear rights and duties under law, and legal capacity – concerns, how one can exercise, claim or defend those rights, and the assumption of legal liability.'¹² Legal capacity has two essential strands:¹³ 'The first, legal standing and the ability to hold rights and to be recognised as a legal person before the law and the second is legal agency simply, by virtue of being human to act on those rights and to have those actions recognised by the law.'¹⁴

Article 12, paragraph 3, recognizes the right of persons living with disabilities to be supported in the exercise of their legal capacity. "Support" is a broad term that encompasses both informal and formal support arrangements of varying types and intensity.¹⁵ For example: in my research, to help support a person living with dementia to exercise their legal capacity in the consent process.

¹⁰ De Bhailís, Clíona, & Flynn, Eilíonóir. (2017). Recognising legal capacity: commentary and analysis of Article 12 CRPD. *International Journal of Law in Context*, 13(1), 6-21 (10).

¹¹ De Bhailís, Clíona, & Flynn, Eilíonóir. (2017). Recognising legal capacity: commentary and analysis of Article 12 CRPD. *International Journal of Law in Context*, 13(1), 6-21

¹² Series L, Nilsson A. Article 12 CRPD: Equal Recognition before the Law. In: Bantekas I, Stein MA, Anastasiou D, editors. *The UN Convention on the Rights of Persons with Disabilities: A Commentary*. Oxford (UK): Oxford University Press; 2018.

¹³ Byrnes, A (2008) Monitoring the fulfilment of CRPD Rights in Australia: Issues and Challenges (paper presented to Queensland Advocacy Inc Human Rights Seminar, Brisbane, 20 August 2008) as cited in Marcia H Roux, Lee Ann Basser and Melinda Jones (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhoff Publishers, Leiden, 2011) at 482.

¹⁴ Steele, Linda & Swaffer, Kate & Phillipson, Lyn & Fleming, Richard. (2019). Questioning Segregation of People Living with Dementia in Australia: An International Human Rights Approach to Care Homes. *Laws*.8. 18.

¹⁵ CRPD/C/11/4 2014 para 15 <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

I considered the following supportive guidelines from the Centre for Economic and Social Research on Dementia, the IDWG and the Alzheimer's Society of Ireland, to help provide accessible consent checklist, which include:¹⁶

- i. The consent process is continuous and should be continually reviewed.
- ii. Clear and accessible information should be provided to the person to ensure that they understand what is being asked of them.
- iii. Spend time getting to know the person to ensure that they are comfortable with you and trust you.
- iv. Written consent is particularly important, but also be mindful of other forms of consent - verbal consent on audio recordings.

As a researcher, I also need to be mindful of fluctuating levels of understanding and communication in the ongoing consent process. For example, what plan do I have to ensure the safeguarding of my participant? In other words, a person agrees to participate, and I am confident that they are providing informed consent, but later their cognitive skills decline. Their supporter states they wish to withdraw. These ethical implications are all genuine, and therefore, as an ethical researcher, I need to have a strategic plan to deal with this, should it arise.

How I work to achieve inclusivity for persons living with dementia in my own research

This section explores the practical elements of what approach and method I applied to my research to enable persons living with dementia to participate in my research. The Centre for Economic and Social Research on Dementia, the Irish Dementia Working Group and the Alzheimer Society of Ireland have developed guidelines that underpin a broad set of principles that inform researchers like myself on including people living with dementia in research. The purpose of these guidelines¹⁷ is to provide practical guidance to ensure the participation of persons living with dementia in policy and research. Further, collaboration with advisory groups such as the Irish Dementia Working Group (IDWG) is instrumental in ensuring that I adhere to best practices, especially when it comes to amplifying the voice of people living with dementia. The following guidelines I adopted throughout methodological design of my PhD:

Interaction

The overall experience of participating in research for persons living with dementia should be enjoyable. Having a calm and caring manner helps to create a supportive and encouraging atmosphere. There are several practical ways I aimed to achieve this; first, as a researcher, I must be organised and well prepared ahead of time. I also acknowledge the importance of minimising unnecessary disruptions as this can be a trigger for distress for persons living with dementia (sensory overload). I also need to provide adequate privacy and ensure that distracting

¹⁶ Centre for Economic and Social Research on Dementia, Irish Dementia Working Group, and the Alzheimer's Society of Ireland (2020) Hear our voice: guidelines for involving people with dementia in policy, advisory, consultation and conference activities, Galway, NUI p

¹⁷ Ibid, n 19.

noises and interruptions are limited. Secondly, I allow time for the person to get settled and comfortable; this can be as simple as making sure the temperature in the room is satisfactory. Further, it is also about respecting the individual as their person with their own unique experiences.

Communication

First, I will ask each person how best to communicate with them and then frame any future interactions. For example: how a person chooses to identify. Secondly, I establish the best mode of contact; is this from a phone call, text, email, in person or over virtual platforms such as zoom.

Generally, after the initial contact, I will send a reminder message just before the interview is due to take place. Thirdly, it is recommended by the IDWG that I communicate what is expected of the person - what the consultation or discussion will entail. Further, many people with dementia do not usually have much experience with this activity due to historical exclusion. Therefore, it is essential to communicate the process step by step if necessary. I would offer a trusted support person also to participate if the person feels more at ease. I am also mindful that all written communication might be inaccessible due to visual disabilities. In this case, I will offer a large-print information and consent form primarily designed to follow accessible best practices. For example, red and green print as dichromacy colours is the choice for persons with visual impairments.

Providing Accessible Information

As listed above, I ensured that all written communication (consent and participation information sheet) is accessible. I have achieved this in several ways. First, I offer three format types; general, easy-read and large print. As recommended, I am conscious of the volume of written material provided as this can overwhelm participants with too much detail. I emphasise important language, for example, the right to withdraw from the study at any time. The IDWG also advises that language is short and to the point. Further, 'avoid using the contribution of participants in an opportunistic or sensationalist way.'¹⁸

Venue

Choosing an appropriate venue during a COVID era has been one of the biggest challenges to my PhD. Due to government public health guidelines, interviews have occurred online. Although this is not preferable, the Centre for Economic and Social Research, IDWG and Alzheimer Society of Ireland have published a set of guidelines on how to navigate online platforms for persons living with dementia. First, if the meeting takes place on zoom, Microsoft teams, I need to establish whether the person with dementia has access to the internet and a device to join the call and feel comfortable using this platform. If not, or it would cause unnecessary duress, I would offer a phone call as an alternative. It is also essential to take the time to talk through the platform and use it. The process itself needs to reflect a gentle pace

¹⁸ Centre for Economic and Social Research on Dementia, Irish Dementia Working Group, and the Alzheimer's Society of Ireland (2020) Hear our voice: guidelines for involving people with dementia in policy, advisory, consultation and conference activities, Galway, NUI

similar to that if it was in person. As advised, I would look for visual clues of distress; if this is the case, we recommend discontinuing the interview and discussing other participating options. I would also offer support and determine what type of support the person with dementia may want or need to participate. Is this a support person for comfort or tech support?

Conclusion

Traditional competency-based assessments of capacity have unnecessarily excluded persons living with dementia from participating in research. This chapter has contended that all persons living with dementia possess full legal capacity, therefore they are meaningful holders of rights, equal before the law, as guaranteed by Article 12 of the UNCRPD. Further, not all persons living with dementia lose the capacity to decide on participation in research; it is imperative to highlight that dementia is not synonymous with incapacity. The overall purpose of this chapter was to highlight how to include persons living with dementia in research. This chapter has discussed various methods and approaches on how to do this from a practical level. Various ethical concerns such as fluctuating levels of understanding and exclusion based on perceived difficulties with ethical committees have also been discussed.

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4 Branding a paradise? Exploring Iceland's nation branding efforts after crisis

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Abstract

Iceland has shown itself to be remarkable in its national response to crises. In particular, Iceland has been successful in identifying unique and marketable national resources- whether it be tourism, gender equality or biotechnology- to bolster post-crisis recovery efforts. Using the concept of nation 'branding', this short chapter reflects on two of Iceland's most recent national crises, the post-2008 economic collapse and the current COVID-19 pandemic, and the national 'brands' as a feminist and genetic 'paradise', that have emerged. Drawing on the lived experiences of Icelanders within the feminist and disability rights community, this chapter explores how the criticisms and questions from members of these communities highlight larger issues associated with national identity trends of tourism, feminism, and genetic research.

Introduction

In recent years, Iceland's severe and unique landscape has been marketed to the international community as the exotic island on the arctic circle. With a mystical connection to nature, Iceland's population can be seen as equally invested in social equality as in its historical Sagas, populated by faeries, hidden people and trolls. Icelandic nature has also been noted to play a prominent role during post-national crisis. After one of the most significant economic collapses in Icelandic history in 2008, the volcano Eyjafjallajökull erupted in 2010 and blanketed half of Europe for a month in ash. While less dramatic, but no less spectacular, earthquakes shook Iceland for weeks in early 2021 until the volcano Fagradalsfjall erupted, just as Iceland was coming out from the third wave of the COVID 19 pandemic. Among many factors, the eruption in 2010 has been said to have jumpstarted the incredible rebranding of Iceland as a prominent tourist destination – a key factor in the recovery of a devastated economy (Loftsdóttir, 2015). The 2021 eruption is equally expected to boost a post-COVID 19 economic recovery.

Icelandic nature's mystic reaction to national crisis, while playful to note, has triggered what has been called national 'rebranding' efforts aimed at repairing economic and reputational damage. Using the concept of nation 'branding', I look at two of Iceland's most recent national crises, the post-2008 economic collapse and the current COVID 19 pandemic, and the national 'brands' that have emerged (and arguably are emerging). Academics have already traced Iceland's emergence as an international feminist and tourist 'paradise' after the 2008 economic crisis with intentional and unintentional nation 'branding' efforts and have additionally documented domestic criticisms that have come from trying to maintain this identity. (Einarsdóttir, 2020; Erlingsdóttir, 2021; Ingimundarson, Urfalino, & Erlingsdóttir, 2016; Jóelsdóttir & Wyeth, 2020).

Using a similar framing, the COVID 19 crisis has similarly served as an opportunity to showcase Iceland's achievement around its scientific advancement in genetic collection and sequencing, to the point of earning the moniker of a 'paradise' for geneticists (Kirby, 2014). Particularly looking at the foremost genetics company in Iceland, deCODE genetics-in collaboration with Icelandic authorities- has taken on a significant role in screening and sequencing COVID 19 tests.

Like the domestic criticisms of the feminist and tourist paradise identities, the acceleration and seeming alignment of genetics research with the Icelandic national identity has caused increasing domestic concern. If these waves of national branding are analyzed through the viewpoint of disabled people and activists in Iceland, it provides a unique opportunity to explore the emerging ethical implications of these brands for Iceland, especially as we currently navigate the COVID 19 pandemic. The experiences of disabled people and those working within disability rights referenced in this short chapter are part of a larger research project exploring the bioethical implications and factors that influence choices around prenatal testing, diagnosis of fetal impairment and abortion.

Connected Research

This paper draws on qualitative research (Charmaz, 2006) exploring the bioethical implications and factors that influence choices around prenatal testing, diagnosis of fetal impairment and abortion, from a disability rights perspective. It is a part of a larger project, Disability Advocacy Research in Europe (DARE), funded by the Marie Skłodowska Curie grant program. The research has focused on interviewing three categories of individuals in Iceland, including: [1] individuals and couples who have or are currently going through the reproductive process, including parents with and without disabilities [2] medical professionals and policy makers, and [3] members from the feminist and disability advocacy communities. The data collection is still ongoing. The 12 interviews this paper draws on were collected between March 2020 and April 2021 and include all three categories of informants. Initial data analysis, using a grounded theory approach (Charmaz, 2006), identified interesting themes where participants, in particular disability rights activists and feminists, criticize or question issues associated with national identity trends of tourism, feminism, and genetic research. Exploring these connections, the paper places the study in the larger national political, economic, and cultural contexts of national branding efforts in Iceland.

Crises Driven Nation Branding

As previously noted, the theory of nation branding provides a useful lens to view these significant socioeconomic changes. As a theory, nation branding, indicative of its name, often uses marketing, media and public relations (sometimes literal PR companies) to commodify a country's unique resources and culture in an increasingly globalized world (Teslik, 2007). Nation 'branding' further described by Aronczyk (2014), has become increasingly used in European states "as a form of soft power: gentler than sticks, less coercive than carrots, the creation of a conscious strategy that draws on a nation's territorial, cultural, and commercial specificity promises to attract broader international legitimacy than the use of traditional power resources."(pg. 1)

Icelandic feminist scholars (Einarsdóttir & Pétursdóttir, 2017; Erlingsdóttir, 2021; Loftsdóttir, 2015) have connected specifically the creation of a feminist national identity and development of an ideal tourist destination with the practice of nation branding. For Iceland the confluence of the collapse of the economy in 2008 and the financial impact throughout Europe from the subsequent volcanic eruption in 2010, created a national identity crisis. Identifying the need to highlight Iceland as an exotic-yet safe- tourist destination, the Icelandic government and public relations companies intentionally constructed the successful 'Inspired by Iceland' campaign which had, until COVID 19, brought in up to 2 million tourists per year (Einarsdóttir, 2020). Parallel to the intentional construction of a national identity as a tourist destination, Iceland underwent a political rebranding as a feminist, predominantly female led nation. While both

identities are seen as largely positive, Iceland is experiencing many of the significant drawbacks to nation branding, notably the imperative of its citizens to ‘live the brand’ and “reinforce the tenets of the ‘new and improved’ national character” (Aronczyk, 2014, p. 1). As detailed below, many Icelanders find it increasingly difficult to negotiate the relationship between the internationally promoted image of Iceland and the domestic reality.

Business Vikings to Equality Warriors?

Following global trends towards increasingly *laissez faire* economics, Iceland spent the early 2000’s privatizing banks, eroding monitoring institutions and promoting widespread deregulation (Erlingsdóttir, 2021). Seen as a backlash to the significant feminist inroads made by the women’s movement in Iceland during the 70’s and 80’s (Styrkárssdóttir, 2013), the first decade of the 21st century saw increasing trends towards neoliberal policies that earned such monikers as “the era of masculinities” (Erlingsdóttir, 2021; Loftsdóttir, 2015) and the land of the “business Vikings” (Einarsdóttir, 2020, p. 141). Following the 2008 collapse, these neoliberal economic practices were widely associated with masculinity and patriarchal capitalism seen to pervade Icelandic economic and political institutions. Political scientists Einarsdóttir and Pétursdóttir (2017) remark on how masculinity was embedded and reinforced pre-2008 by the interplay between Icelandic financial, political and leading media institutions, and how “the Icelandic financial collapse reveals how masculinities are continuously renegotiated, reflecting tensions between various forms and images of male power” (p. 48). In response, Iceland saw the pathway towards repairing their severely damaged international reputation and domestic trust in institutions, as decisively female led. In true Icelandic fashion, academics Styrkárssdóttir (2013) and Ingimundarson et al. (2016) have compared the waves of women’s democratic enfranchisements throughout the twentieth century in Iceland with natural upheavals, such as earthquakes or volcanoes.

Erlingsdóttir (2021) notes that, since 2008 “gender equality has been a central focus of Icelandic government policies, playing a major role in domestic reconstruction efforts and nation-branding abroad.” (p.91). Thus, beginning in 2009, the first Icelandic female and openly gay Prime Minister took office, some top banking and economic institutional male leadership was replaced by women, and the number of women in Parliament increased to 40%, (Einarsdóttir, 2020; Ingimundarson et al., 2016). In continuation, Iceland elected Katrín Jakobsdóttir in 2017 as Europe’s youngest female prime minister of a government which, through a strong women’s movement and cross- party collaboration, pushed through successive gender equality legislation including; extended parental leave, reformed abortion legislation, and increased support for corporate female leadership and transgender rights (Ingimundarson et al., 2016). This rapid transformation in many ways was seen to be the “a key factor in reversing [Iceland’s] negative image after the financial collapse.” (Erlingsdóttir, 2021, p. 91). The branding of Iceland as a ‘feminist paradise’ has been further solidified by ranking the most gender-equal nation for twelve consecutive years on the World Economic Forums’ Global Gender Gap Report (GGG) and through leading feminist foreign policy campaigns (Jóelsdóttir & Wyeth, 2020).

Criticisms of the GGG index mirror closely national criticisms towards Iceland’s gender equality brand. The GGG index has been largely criticized for the relatively limited scope in which they measure gender equality. There is acknowledgment that Iceland has made rapid advancement towards gender equality in key categories included in the GGG, like female economic opportunity, educational attainment, health, and political representation, yet neglects

critical issues of safety, access to justice and whether these advancements reach all women equally (Jóelsdóttir & Wyeth, 2020; Wyeth, 2021). The lack of intersectionality and the lack of inclusion of minority identities within the mainstream feminist movement has been a strong advocacy point for many women with disabilities.

Disabled feminists have noted that there is a strong push to maintain the ideal of Iceland as a feminist paradise, and as a result the real and complex experiences of many women in Iceland with multiple and intersecting identities are largely suppressed. As Embla Ágústsdóttir wrote for the disabled feminist organisation Tabu, “[...] with so much of the advocacy in Iceland, I have to be disabled on Monday, queer on Tuesday, and a woman on Wednesday.” (Haraldsdóttir & Ágústsdóttir, 2020). Disabled leaders such as Haraldsdóttir and Ágústsdóttir (2020) have remarked that to publicly criticize the feminist movement on its lack of intersectionality or policies, is to automatically be labelled and dismissed as ‘antifeminist’ and ‘regressive’. For those that publicly push back on the feminist paradise identity in Iceland, they often feel that by criticizing aspects of the feminist movement they are criticizing Iceland as a whole.

Leading disability rights and feminist activists reiterated such sentiments from Haraldsdóttir and Ágústsdóttir (2020), and have additionally noted the strong conflation between feminism and nationalism in the public sphere, where to be labeled ‘antifeminist’ equates to being ‘un-Icelandic’. These same issues came up in my interviews with disabled activists, members from the feminist movement and policy leaders, when discussing the topics of prenatal testing and the recent reform of the national abortion legislation. Many addressed the connections between feminism and the national identity. For example, a leader in the women’s movement stated:

In the past, when I have brought up any concerns about the scope of [the abortion bill] and its impact on how we think about disabled people, I immediately was said to be against women and to be against Iceland. Can you imagine? Me, being called against women and Iceland! (Feminist Leader 3, 2020)

In a subsequent interview with a prominent disability rights activist, they stated, “I have criticized, in some public spaces, why so many people are having [pre-natal testing] so much, and immediately I’m asked if I’m religious and in Iceland there is a feeling that if you are called religious it means you are not progressive” (Disabled Leader 2, 2020). Recent feminist-led discussions around the reformed abortion legislation and prenatal testing have intensified this feeling of exclusion and shrinking space for criticism of feminist policies and culture among disability rights activists and other feminists. The views and concerns from disability rights activists and critical feminists reflect the repercussions of developing such a commercialized national brand. This reflects one of the more significant drawbacks as identified by Aronczyk (2014), such criticisms put the cultivated brand in jeopardy when citizens can no longer “reinforce the tenets of the ‘new and improved’ national character.” (pg. 2)

An Island ‘Led by Science’

The COVID 19 pandemic has showcased Iceland’s other brand of exceptionalism during crisis, as a global leader in scientific progress. With the combination of having a small population, its geographical remoteness, a depoliticized crises response, and a crucial history in genetic tracing and genomics, Iceland was able to swiftly and effectively curb the impact of the COVID 19 pandemic. So much so that starting in April 2020, international media declared Iceland had

won COVID 19 with headlines such as; “How Iceland hammered COVID with science” (Scudellari, 2020) and “How Iceland Beat the Coronavirus” (Kolbert, 2020) , among others.

In tandem, Iceland’s international identity as a leader in gender equality seemed to seamlessly intertwine with this new national brand, topping lists of female-led countries with effective COVID 19 response. While the country still experienced waves of infection, deaths, and economic hardship, Iceland differentiated itself with its extensive expertise in genetics and genome sequencing. After decades of experience collecting and sequencing the health data and genetic material of Icelanders, Iceland’s foremost genetics company, deCODE genetics, rapidly took over much of the COVID 19 testing and responsibility for screening the general public (Scudellari, 2020). While there was initial hesitancy from the Icelandic Data Protection agency regarding a private company’s role in a public health emergency, by March 2020 deCODE was permitted expansive access to public health information and spearheaded contact tracing efforts. As he repurposed much of the company’s labs into a COVID-19 testing and sequencing centres, deCODE’s CEO, Kári Stefánsson stated, “It almost looked like these 24 years preceding COVID-19 had just been a training session, [...]. We dove into this full force” (Scudellari, 2020, p. 7). COVID 19, as reflected in Stefansson’s comment, can be seen as a pivotal event for Iceland’s recognition as a global leader in genetic research.

At the time this chapter is written Iceland is going through the fourth wave of COVID 19 infections. As such, the relationship between its growing popularity as a global leader in genetic research and what that may mean for a future national brand is still evolving. However, the positive role that Iceland’s genetic research, and specifically the company deCODE, has had during the COVID 19 pandemic creates the potential for Iceland to develop and profit from another national branding process. By briefly tracing the way that the feminist and tourist ‘paradise’ brand evolved and the subsequent challenges for domestic criticism, we can draw similarities in the way genetic research has evolved in Iceland and the potential shrinking space for domestic critique.

To trace the growing prominence of genetic research in Iceland, it is useful to understand the how deCODE Genetics monopolized Iceland’s genetic data and has since become intertwined within governmental and health institutions. As a privately owned company deCODE’s trajectory towards collecting and analyzing nearly the entire Icelandic populations DNA has not been without controversy. In early 1998, deCODE announced it was going to map the genome of the Icelandic people as part of a larger medical database (Pálsson & Rabinow, 2001). After almost a year of national debates, the Icelandic government passed a bill that authorized deCODE to construct a national medical database, for commercial use as well as to support the national health system (Eischen, 2001). Early criticisms included demands for further assurances in data privacy and usage, increased consent protocols and further monitoring mechanisms to ensure public health data would not be used for private enterprises. While initially hesitant, national polls saw that by 2000, 81% of the population supported the database (Pálsson & Rabinow, 2001). What many Icelanders were not aware of when this bill was passed and when deCODE obtained the license, was the presumed consent clause. This clause meant that Icelanders had to intentionally opt out of the database in order for their medical and genetic material to not to be used (Pálsson & Rabinow, 2001).

This criticism was revived in 2018 when Stefánsson claimed that he has fully sequenced the DNA of 60,000 Icelanders and partially sequenced 180,000, allowing his team to map most of the Icelandic population of 330,000 (Leavenworth, 2018). With this level of sequencing deCODE has been able to identify carriers for such diseases as BRCA2, a gene linked to developing breast cancer in 86% of women that have it (Leavenworth, 2018). Icelandic data regulators have continuously blocked deCODE's desire to reach out to individuals that they identify with certain genetic conditions, including BRCA2 (Leavenworth, 2018). In his typically mercurial fashion, when asked about the ethics of consent and providing information to individuals about their genetic data, Stefánsson stated,

There is a tradition in Icelandic society to save people who are in life-threatening situations, without asking them for informed consent. Should there be a different rule if the danger is because of a mutated gene? [and] If someone falls into the harbor, does he need to sign an informed consent before you pull him out of the sea? (Leavenworth, 2018, p. 13).

While there clearly has been regulatory push back on the scope of deCODE's authority and liberty in using Icelanders' health data, there has been historically a strong political endorsement for such genetic research and scientific advancement. From early on, Iceland's first female President Vigdís Finnbogadóttir pushed the Icelandic public to embrace scientific advancement and this widespread collection of genetic and health data with the fundamental aim of preventing disease and impairment. As seen with the rapid institutionalization, from the early 2000's, of prenatal testing aimed specifically to identify chromosomal and other fetal impairments, there has been an increasing push to prevent perceived impairment and disease at all levels (Gottfredsdóttir, Sandall, & Björnsdóttir, 2009).

While Stefánsson is renowned for eliciting controversy with his views on bioethics, Iceland has evolved to share many of the same values with regard to the identification of disease and impairment, and its prevention. During the early debates regarding the introduction of prenatal testing for all pregnant women, a leading health official compared screening for impairments with preventing traffic accidents, saying: "Why wouldn't you prevent a car crash if you could?" These positive associations between Icelandic scientific progress with disease and impairment prevention – and by proxy deCODE's leadership in these areas – have only been reinforced and solidified within the COVID 19 pandemic. Iceland's Prime Minister Katrín Jakobsdóttir has been widely praised for turning over the national pandemic response to public health authorities, ensuring politics takes a backseat (Kolbert, 2020). deCODE's remarkable ability to widely test and contact trace, thereby being the first nation to identify how the COVID 19 virus was being spread by asymptomatic patients, has not only saved lives but has solidified its prominent role in Icelandic public health response and influence on future national health policies (Leavenworth, 2018).

For many that have seen Iceland's trajectory regarding ethical debates on the advancement of biotechnology – such as prenatal screening and genetic sequencing – it is concerning to see the increased uncritical trust in such institutions as deCODE. For many disabled rights activists and bioethicists, the increasing uncritical culture around using biotechnology to eliminate or reduce impairment and disease has the potential to decrease Icelandic social diversity, particularly in disability. Along with others who are critical around the practices of prenatal screening and genetic sequencing, disability rights activists have found themselves labelled

once again 'regressive', and being 'anti-science' when bringing up concerns publicly as was stated by one of the disabled parents who participated in this study. Many disability rights activists and feminists have felt similar negative reactions when criticizing mainstream feminist policy, as when criticizing Iceland's use of biotechnology.

The current COVID 19 pandemic has only heightened such issues for many within the disability community. The link between Iceland's prominence in genetic research, and deCODE's positionality as a trusted and increasingly uncriticizable institution, has caused a shrinking space for critique or pushback. A disabled activist stated in an interview in November 2020,

My doctor has learned not to ask me to test for anything, even when I was pregnant, she knew not to push prenatal testing and definitely never pushed for a [genetics] test for my disability. But I see more people testing for COVID research [submitting DNA], and my doctor asked me if I wanted to go get tested. [...] But it's hard to say no because it could help everybody [in COVID]. (Disabled Parent 4, 2020)

Concluding Remarks

Iceland has shown itself to be remarkable in its national response to crises. However, the way that Iceland has branded its areas of exceptionalism, whether it be as a tourist, feminist, or genetic 'paradise', has created an environment where such imagery increasingly cannot be criticized. As we enter the second year of the pandemic, Icelanders within the disability movement see the rapidly growing trust in the work of deCODE and Iceland's growing affinity as a global leader in genetic research. Yet, more so than ever, there is a muted dialogue on what this means for the future of how genetic data and research will be able to be monitored and discussed.

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5 Challenges and opportunities identified during the COVID-19 pandemic: constructing a qualitative research project

Marissa Diaz

Abstract

In light of massive global shifts caused by the COVID-19 pandemic, academics have been presented with an opportunity to adjust their methodologies and expand beyond traditional means of methodology construction, recruitment, data collection, and collaboration with co-researchers. An example of this is presented in this chapter, which describes the process of developing a research project almost entirely during the pandemic. While the research question was conceived pre-COVID-19, I shifted the entire research process online very early in the process and decided on using a focus group to collect data using Zoom. With an aim to identify perceived barriers and facilitators to end of life care services by people with intellectual disabilities, I identify many challenges whilst achieving some of these early major research milestones entirely online. While acknowledging the challenges of working through this medium, opportunities for future research are abundant, especially within the realm of disability studies.

Introduction

Since first identified in the winter of 2019, COVID-19 challenged and confounded the world. In addition to the massive loss of life, many people's lives changed within the span of a few months. Travel came to a near-complete standstill, both domestically and internationally. The threat of an unfamiliar virus forced many people to stay home, sheltered away from the possibility of contracting the disease. A variety of public health provisions implemented on a country-by-country basis had a direct impact on face-to-face research, making it virtually impossible to conduct. This situation, unfortunately, continues today.

Academics, particularly those specializing in qualitative research, have found themselves in new territory – when confronted with the obligation to stay home, how does fieldwork happen? With the exception of academics who work with digital ethnography – which occurs within digital mediums and involves the study and analysis of virtual realities such as social media pages and chatrooms [1] – many have had to shift away from face to face discussions to indirect forms of communication, through either telephone or video. Bound by contracts and/or funding deadlines, waiting out the pandemic was not an option. This time of great uncertainty illuminates many complications with conducting such research during a global pandemic; this chapter focuses on the time *before* data collection. Three of these challenges – Tailoring Qualitative Methods to the Virtual Realm, Recruitment, and The Role of Co-Researchers – are described with references to the literature. My own experience during COVID-19 is outlined, focusing on my original research plans and how they shifted as a result of the pandemic. Opportunities for innovation are mentioned in brief in the conclusion.

By the beginning of 2020, I was in the earliest stages of my PhD. Originally, I proposed doing an ethnographic research study based in at least one Irish hospice. I wanted to observe barriers and facilitators to access by persons with disabilities in-person. I familiarized myself with the challenges of conducting an ethnographic study, both generally [2, 3] and within clinical settings in specific [4, 5]. There are numerous challenges in conducting research in palliative care settings [6, 7]. However, I grew familiar with an established evidence base that showed

observational research was not only possible, but also contributed to the field in a manner that interviews couldn't [8]. I had contact with the appropriate organizations in order to make this study happen and we began lightly discussing how to make my plans a reality. I considered many aspects of the research, including recruitment, situating myself within the physical world that I wanted to observe, and what data I wanted to analyze (e.g. participant observation only or adding tangible documents – such as medical records – to the analysis). While I knew that such research would not be easy, I had multiple resources to pull from and studies to base my methodology on.

The pandemic was just starting to take form in Europe at the time I was refining my research question. I focused on what population was most in need of attention; where was there a need for further research? After another literature review and discussions with experts, I came to the conclusion that people with intellectual disabilities was a population that experienced a wide variety of barriers and facilitators to palliative care, specifically at end of life [9]. These barriers and facilitators are connected to larger issues that prevent this population from being fully included in society and being able to voice their opinions, beliefs, and needs. This population is often assumed to be unable to make decisions for themselves, leading to others making decisions for them, including at end of life [10]. As of this writing, most qualitative studies on the topic of death and dying that include people with disabilities usually discuss bereavement or the concept of death itself, not so much palliative care as a service [11]. Qualitative studies have shown that people with intellectual disabilities are able to give their opinion on end of life care [12], but most research focuses on the perspectives of the carers and professionals involved in their lives.

As my research question began to take on a more solid form, I know that my methodology must also change in response to the pandemic. As the stay-at-home orders were extended all over the world, I realized that conducting an ethnographic research project was not possible. Certainly not in my case – being around hospice patients while a new virus spread like wildfire did not seem like a wise or morally justifiable possibility. With Zoom meetings becoming the new medium for every social setting, I knew that I would have to *readjust my methodology to take place within the virtual realm*. While I knew that this was hypothetically possible, conducting interviews with this population already comes with numerous challenges. I realized that conducting research with this population *online* was uncommon, thus providing me with an additional challenge of adapting my methodology and making it novel.

Without the possibility of conducting research in a physical space, I knew that my method of *recruitment* would also have to change. Originally, my contacts at the European Association of Palliative Care (EAPC) and Trinity Dublin College were open to assisting me in finding the appropriate hospices. Moving online thus shifted my method of recruitment online, since it was impossible to me to go anywhere to physically engage with stakeholders, gatekeepers, or potential participants. Finding enough participants and establishing the validity of my qualitative research will be imperative for its success.

Including co-researchers with intellectual disabilities is not only important for balancing power dynamics, but I wished to include people in discussing a topic that has often been shielded away from them. While I met three interested co-researchers through my contact at the Inclusive Research Network (IRN), continued meetings via Zoom has been challenging due to a lack of clarity on when I will be able to see them in person. Clarifying the *role of co-*

researchers using only remote means (such as e-mail, SMS, and video calling) has proven challenging, specifically with regards to matters that are specific to this population.

Since COVID-19 first appeared soon after I began my PhD, I was forced to confront certain challenges that preceded data collection. Below I elaborate on the aforementioned three points in descending order; arranged from when I first observed the challenges as I continued my PhD journey. While these points are certainly not representative of every challenge posed to the qualitative researcher during a pandemic, they are just a few of the many issues that complicated the preservation of my research project.

Three Impacts on Qualitative Methodology – The Effects of COVID-19

Tailoring Qualitative Methods to the Virtual Realm

It is certainly not unheard of for qualitative research to be conducted online or via telephone. When the study is carefully planned and executed with precision and care, qualitative research conducted outside the shared physical arena expands the potential for collaboration between people who are physically far away or otherwise unable to meet. With the popularity of software such as Skype, Zoom, and Microsoft Teams exploding after the pandemic spread, it seemed logical for me to adapt my own methods to be conducted through these mediums. Conducting qualitative research via video calls has its pros and cons. Ease of access, low costs (especially for free accounts), and virtually no travel requirements can benefit both the researcher and the participant [13]. However, one could argue that these benefits can also work against participation in research. Other researchers have made note of the phenomenon of absenteeism when using online interviewing methods [14]; quite simply, it is very easy to not show up to an online call. Technical difficulties can also plague a discussion held via video call and navigating such software may require a degree of computer literacy [15] which is not possessed by everyone. However, due to the proliferation of video calls as the default setting for social gatherings after the pandemic, one could assume that most people have grown more competent in using software like Zoom [16]. However, while using video calls can enable researchers to go where it would be difficult or physically impossible to go otherwise, this methodology inherently leaves out anyone without both an electronic device that supports such software and a stable internet connection. While it is possible to conduct qualitative research this way, there are issues that remain relatively unexplored.

There are numerous complexities with conducting qualitative research with people with intellectual disabilities with traditional (i.e. in-person) methodologies; there are too many to discuss each thoroughly. In this chapter I wish to focus on issues concerning communication when interviewing, since this will be when I utilize online methods the most during my research study. The root of many of the below issues is the power imbalance between the researcher and participant, requiring reflexivity and flexibility from the former. In order to avoid being a "parasite", researchers like myself must adapt their methodology in order to respond to the needs of disabled people [17].

Communication with people with intellectual disabilities in qualitative research illustrates methodological challenges for the researcher, including (but not limited to):

- When research is conducted by non-disabled researchers, there is a risk that people with intellectual disabilities *feel pressured to give the "right" answer as opposed to what they actually think* [18].

- People with intellectual disabilities may also be *socially conditioned to acquiescence*; responding "yes" to "yes or no" question [19].
- With this population, sometimes a misinterpretation occurs, with the research participant *identifying the researcher(s) as a friend* [20].

Keeping in mind the aforementioned challenges, my biggest concerns are twofold. I am concerned with gaining and maintaining rapport between participants and myself. I am also concerned with transferring my material in Easy Read, traditionally presented in a more tangible format, via Zoom.

Responding to the Challenge

Given that there is no research on presenting Easy Read materials via Zoom, I decided to conduct some pretests in order to test my methodology. Presented as PowerPoint slides via Zoom, I narrated the Easy Read information as I conducted the focus group. Text and pictures accompanied everything that would occur in a normal focus group (such as opening the discussion with information about the research followed by the questions themselves). In order to not take up too much of the participants' time, the pretests were limited to one hour (both ended up taking less than 40 minutes).

Within the focus group itself, I structured the questions in response to problems identified in the literature. For example, there are no "yes or no" questions within the focus group, but rather more open questions using the words "why" and "how". In addition, I stress at the beginning of the focus group that there are "no right or wrong answers". It is difficult to ascertain if the participants truly internalize this idea, but it is important to point out that I am not testing the participants, but rather interviewing them.

With regards to establishing boundaries between myself and the participants, I have struggled in how to approach this, especially through an online medium. While it has been argued that being online merely shifts the encounter between researcher and participant to a different realm, unchanging the potential for rapport and emotional connection [21], aforementioned technological and absenteeism issues gave me pause. I also struggled with the idea of establishing intangible boundaries in an intangible space with this specific population. Other research has pointed out that, due to their relatively small social networks, people with intellectual disabilities often can see researchers as a friend and struggle with the end of the research relationship [22]. While my own research is a one-off focus group, they are also invited to talk with me via Zoom after the focus group for more information or to discuss their feelings about the topic of conversation. In contrast to other qualitative research, which often takes place in their homes or other familiar places, my research is only online, which hopefully mitigates this boundary issue. However, going online ironically creates new barriers to those who lack internet service.

Recruitment

Recruitment can take many forms – through physical letters to emails to recruitment posters displayed in public places. However, trying to recruit participants from another country was intimidating. In the beginning of 2020 I had no option to meet anyone in person, nor did I imagine (at the time) ways for me to introduce myself in a way that would engender trust and rapport. In addition, the thought of recruiting participants during this time felt awkward and

almost wrong. How could I manage to recruit participants to take part in a study about end of life when everything felt so apocalyptic?

Recruiting people with intellectual disabilities for my project must also be done with care, particularly with sensitive subjects. Not only was I faced with recruiting participants in another country, but those who may be difficult to reach. Savage, et al. [23] list three issues when it comes to recruiting people with intellectual disabilities for end of life research:

- *Carers are protective of potential participants* due to past exploitation and abuse;
- Researchers are unlikely to make individual contact with participants, thus *relying on agencies that are already in need of more support*;
- Moreover, *flyers and advertisements may not be effective in recruiting from this population* due to literacy difficulties.

Responding to the Challenge

Recruitment will take place entirely online and will be facilitated through my connections with the Inclusive Research Network. Similar organizations will be contacted with accessible information for both the participant and, if they choose to include them, their supporters.

There are four forms that will be given to participants after establishing that they are interested in taking part in my research. The first will be an information form for both the participant. If the participant chooses to include their carer, they will also receive an information form. Both forms will highlight that participation is voluntary and that the participants can leave at any time.

To ensure that the supporters will be supporting the participants as opposed to speaking *about* them, they will be given a guidance document to clarify their role in the focus group. Said document will stipulate that the supporters agree to:

1. Assist the person with an intellectual disability in sharing their perspective on accessing end of life care. Supporters have a personal relationship with the person, and understand their communication well, and this could be beneficial to drawing out key insights.
2. Refrain from answering on behalf of the person with an intellectual disability. In order to make my research truly reflective of the perspectives of persons with intellectual disabilities, it is imperative that I hear their thoughts, even if they are incomplete.
3. Supporters may ask me to repeat, or clarify a question, or rephrase the question in a way that the person with an intellectual disability may be better able to understand. If I do not understand the answer the person with an intellectual disability has given, I may check with the supporter to help me to understand the person's communication.

The Role of Co-Researchers

Until recently, people with intellectual disabilities have not been involved in research about them. Research has traditionally done *to* them as opposed to *with* them, with those in positions of power refusing to include them. While more research has included people with intellectual disabilities in the research process, not all such research is inherently *inclusive*. Ideally, people with intellectual disabilities are not just participants in research, but are just as involved as contributors as those without intellectual disabilities [24].

At the time of this writing, I have only assembled my team of co-researchers; since I have not obtained ethical approval for my study. However, I have already identified some concerns of my own that I have found in the work of other researchers who have covered the unique challenges of having people with intellectual disabilities as co-researchers. Below are some of the issues Di Lorito et al. [25] identified that I have encountered and considered myself:

- *Establishing and maintaining trust and rapport with the co-researchers.* Without an opportunity to physically meet them, I will have to establish a professional relationship with my co-researchers, while prioritizing their needs. This will all have to be done online.
- *Not overwhelming them with emails or other communication regarding the study.* Some people with intellectual disabilities need more time to take in a lot of information and I do not wish to cause undue stress. In addition, they may need information presented in a visual format as opposed to just text.
- *Exploring how they wish to be involved with the research and to what extent.* Not everyone will want to be part of the research in the same way and I need to clarify their roles.

Responding to the Challenge

From the beginning, I was nervous about establishing rapport with my co-researchers. Thanks to my introduction to the IRN from my co-supervisor who had worked with them in the past, trust was established in part due to my relationship with someone else that they trusted with research. I believe that her endorsement was crucial to my acceptance by those interested in the research topic. In addition, I began sending emails and SMS that were more casual in nature in order to get to know them as colleagues. Without the chance to get a coffee or set up a similar casual meeting, I knew that I should set up opportunities for us to discuss common interests, such as poetry, fashion, and film.

I did not want to overwhelm my co-researchers with emails, particularly if the information was not relevant for them. Similar to my focus group, I always conduct my meetings with co-researchers with Zoom open to an Easy Read PowerPoint presentation that matches the topic and content of what I am saying. Exploring software other than Zoom is a possibility, but that means I would have to attempt to train co-researchers from abroad, which is not realistic. Therefore, I share information and hold meetings via Zoom with Easy Read, providing the presentation in advance in case they want to print it. Should I be sharing information via email, I have learned that it is best to include an Easy Read document that matches the content of the email for clarity, mirroring what other researchers have done in-person [26].

While clarifying the research roles is an important task, these roles do not need to be set in stone. A systematic review suggests that flexibility from the researcher without intellectual disability needs to be married with good planning; both are required for allowing co-researchers with intellectual disability to express what they wish to do with the study while acknowledging their voice and needs [25]. Therefore, I will clearly label everyone's role in Zoom meetings while re-iterating that these roles are not binding and that they can leave at any time. For roles that involve more of a time commitment (such as data analysis), I must organize time and resources to train interested co-researchers [27].

Conclusion

As of this writing, the pandemic marches on, albeit much more slowly than in the past in countries with access and means to distribute vaccines. Due to the global reach of COVID-19, the challenges identified in this paper are likely neither unique nor completely novel. In the near future, there will be no lack of papers, books, and conferences on the impact of COVID-19 on qualitative research. However, current researchers do not have the benefit of hindsight; there will never be a 2020 without COVID-19, and thus we are condemned to contend with its presence and repercussions.

However, COVID-19 may have forced us to refine methodologies and confront issues that were deemed "too challenging" in the past. We do not know enough about the effects of using video calls in qualitative research, but what we do know is that the use of these technologies shake the foundations of our assumptions about interviewing [14]. Disrupting said assumptions by using different research methodologies is crucial for gaining new perspectives, particularly from people who have historically been marginalized [28]. While conducting qualitative research with people with intellectual disabilities through an online medium may seem too "challenging" to others, it is important to remember that, up until very recently, attempts to capture this populations' voice were left out of qualitative research completely, in part due to perceived challenges. As time marches on and research continues to expand in scope, our methodologies must also respond to shifts in technology and the needs of the participants and co-researchers.

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6 'Wishing that we don't feel anxious is like wishing for peace in the world': Reflexivity as part of participatory research methodologies

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Abstract

This paper explores reflexiveness as part of participatory research methods. My co-researchers came as a group or have built a group around our research project, in which my role is not identical but with different responsibilities and as a non-disabled academic PhD student. I use an ethnographic methodology to observe our work together, and reflexiveness as a way of observing my role and actions within the group. Reflexiveness helps researchers think about transparency in the relationship, how they are contributing, and impeding and interpreting the research process. Participatory research or emancipatory research often seeks to change the relationship participants have with research and knowledge, but it also transforms the researcher. Through reflexive processes, in which the researcher notes her responses to the participatory project and its members, the researcher continuously considers ethical dilemmas, power relationships and whose wish, concern or need the process is addressing.

Introduction

Research is not value free, nor is the researcher. In participatory research, the researcher is required to forego any claim of objectivity and commits to social justice values (Garoian & Gaudelius, 2008). The researcher needs to be aware of how she influences the research process, the power relationships and how the process affects her. In my PhD research project, I conduct two co-researched projects, one with a group of people with intellectual disabilities and one with autistic women. I document the research process through an ethnographic methodology, in which I record my actions and the work together. In this chapter, I share some initial findings through reflexivity in my autoethnographic research project.

Reflexivity in research

Participatory research and autoethnography as methods acknowledge the crisis of representation in social sciences (Prasad & Prasad, 2019). Qualitative research has been said to be about "*implementing the goals of social justice and radical, progressive democracy*", and aims to "*expose and critique the forms of inequality and discrimination that operate in daily life*" (Garoian & Gaudelius, 2008 in Giardina & Denzin, 2010, pp.15-16).

However, implementation of these goals and exposing the daily life experiences of inequality and discrimination require not only a different methodology to produce knowledge, e.g. participatory research, but also reflexivity on behalf of the researcher in order to acknowledge how her role contributes to these inequalities.

The role of the researcher in participatory research methods is different from traditional research. Participatory research methods require researchers to adopt a "*more reflexive stance*" (Chappell, 2000). The researcher is expected to facilitate the research, assist to develop an emergent inquiry, train or provide technical assistance to the lay researchers and design strategies so that people may both speak and be heard accurately (Schwartz and van der Sande, 2011).

The self is part of research and more so in (auto)ethnographic research. Autoethnographic projects, focus on the following core ideals:

- “Recognizing the limits of scientific knowledge (what can be known or explained), particularly regarding identities, lives, and relationships, and creating nuanced, complex, and specific accounts of personal/cultural experience
- Connecting personal (insider) experience, insights, and knowledge to larger (relational, cultural, political) conversations, contexts, and conventions
- Answering the call to narrative and storytelling and placing equal importance on intellect/knowledge and aesthetics/artistic craft
- Attending to the ethical implications of their work for themselves, their participants, and their readers/audiences. “ (Adams, Holman Jones & Ellis, 2015, p.27)

Ethnographic or participant observation research methodologies, especially as an active participant, poses the risk of “*losing the sense of being a researcher and become wrapped up in the worldview of the people they are studying*” (Bryman, 2012, p. 445). To prevent this from happening, the researcher must work on developing critical awareness and a reflexive approach. This skill has been described by Reason (1994) as “*a quality of awareness in which we do not suppress our primary experience; nor do we allow ourselves to be swept away and overwhelmed by it; rather raise it to consciousness and use it as part of the inquiry process*”. Ways to develop critical subjectivity include (Reason and Rowan, 1981 in Reason, 1994):

- “cycling and re-cycling between action and reflection so that issues are examined several times in different ways;
- exploring the authenticity of participation within the group;
- using self-development methods to look at the impact of unacknowledged anxiety;
- establishing norms whereby group members can challenge unwarranted assumptions;
- etc.“

A research paradigm will determine how a research project is shaped. A research paradigm is “*the basic belief system or worldview that guides the investigator*” (Guba & Lincoln, 1994, p. 105). Reflexivity requires researchers to be aware of their basic belief system. Transparency is essential in any research project, but more so in participatory. Jungmeister proposes a set of questions to promote reflexivity:

- ‘What is the researcher’s understanding of reality, are there alternatives?
- What are the consequences of the understanding of reality for the research process?
- Do the research paradigms fit with the research questions, or which research paradigms are optimal for knowledge acquisition to answer the research questions?
- What are the advantages and disadvantages of the research paradigms?
- How can the disadvantages be compensated for?
- Does the research methodology fit with the selected research paradigm?
- What are the implications of this?’ (Jungmeister, 2016, p.72)

Research changes the researchers (Etherington, 2004). More so in participatory research, where researchers invite a specific group, to get involved in researching, and facilitates the participation and decision-making process. The academic researcher holds responsibility and power over the research process. In ethnography, researchers are also concerned with the

researcher-researched relationship, which will also be addressed through the reflexive process (Creswell, 2007). Reflexivity needs to be part of the research process to attain quality of the research and an ethical relationship with participants (Lynch, 2008). Reflexivity and objectivity are closely related but not identical (Davies, 2002). Reflexivity means examining our values, the beliefs one holds and social position from which one benefits (Strega and Aski-Esquao, 2009) and turning on ourselves (Davies, 2002).

Reflection means thinking about something with some distance or critical thinking. It involves considering underlying assumptions, making new connections and may lead to coming up with a new understanding of an issue or a new way of solving an issue (Jungmeister, 2016). Reflexivity refers to a “*more immediate, ongoing, subjective, self-conscious*” process (Jungmeister, 2016, p.1), in which the researcher explores her own role, beliefs and actions. These views and beliefs will guide the researcher’s choices (Etherington, 2004), after all. Reflexivity is awareness on how the researcher responds to participants (Etherington, 2004) and how her beliefs influence the actions and ultimately, the research. To be reflexive, one needs to be aware of the personal, social and cultural context (Etherington, 2004) and subjective feelings and attitudes (Jungmeister, 2016).

Sharing power requires transparency and sharing knowledge (Foucault 1980 in Etherington, 2004). Researchers need to disclose the values and beliefs behind their decisions and take responsibility for those views (Etherington, 2004), which they must be able to identify them accurately. Reflexivity is key in that task. In order to do so, a reflexive journal can be used to map values and actions (Van der Sande and Schwartz, 2011, Jungmeister 2016).

Preliminary research findings

This project began in October 2020, with an inverted job offer¹ for people with disabilities to hire me to conduct a research project together. I held different information sessions over zoom. After two months, a group of persons with intellectual disabilities and a disabled person’s organization (DPO) of autistic women decided to accept my offer. We put together a research agreement, that was reviewed and discussed during four weeks. Due to covid 19 and geographical dispersity, we meet online on a weekly basis to discuss our projects and research methodologies. These meetings are recorded and I take notes after the meetings. I also write down my reactions and thoughts around issues that were discussed or situations that came up during our collaboration between meetings. During the period of our collaboration, we introduced three sessions to discuss the work dynamics, participant needs and general satisfaction of the group.

Sharing power and sharing responsibility

One of the goals of participatory research to share power over the research process. In my initial beginnings, I attempted to share power and responsibility by leaving enough space for conversations to spark and let others take over the leadership. However, participants did not

¹ I thank Cliona De Bhailís for this idea. It meant sending out a job offer under which I offered my services to conduct a research project with co-researchers, who would choose the research topic, conduct the data collection, do the analysis and write up. Ownership over the findings was to be shared.

seem interested in taking over the leadership of the research the way I had imagined. I felt the responsibility was delegated on me and tried to return it to the group, which created an unnecessary pressure. A similar experience of pressure on a co-researcher is described by Bigby and Frawley (2010). I then realized that I had to create more structured forms of participation and to accept different levels of involvement depending on the task or activity. In my head, holding power meant being responsible for a decision or step within the research, but some did not seem too interested in these steps or details. I assumed this could be due to lack of knowledge or information (maybe also stigma?). Other authors have described the challenge of remaining a facilitator rather than doing the research task (Chapman, 2005), or the lack of structure to support researchers with intellectual disabilities (Bigby & Frawley, 2010). Bigby and Frawley also found that their co-researcher initially showed little interest in writing or analysing the research process (Bigby & Frawley, 2010). Examining this further, I realized that power does not necessarily require executing every task, but being able to choose what tasks and decisions one is interested in or which ones they would like to delegate because they seem uninteresting or cumbersome. In activities that were delegated, I reinforced transparency and left enough time to review each decision, which makes the process slower than initially planned, but allows participants to review decisions and express their opinions on them. Delegation requires information on the decision to delegate and mainly trust in the person (in this case, me). Trust and delegation, on the other hand, requires accountability and transparency. I included debates with different options and voting on decisions, which were discussed in different sessions with the possibility to revoke decisions. This meant that at times, the research process took different directions than the ones I had wished for or thought best. Linked to this idea, I realized through reflexivity and a session to review our working process with each group that the aim of the research project as a group, my objective, and each individual motivation to participate was different. During these shared reflective sessions, I consciously avoided the group praising me or comforting me, but tried to formulate forms of criticism or possibilities of suggestion anonymously or in form of advice on how to move forward.

The research space and its use

The groups gathered on a weekly basis over zoom. I am the only non-disabled person in these meetings. It was important to let participants own the space and shape it to their preferences. However, at times these preferences did not lie with the research project, but with other group or personal needs. Qualitative research methods tend to take up a narrative approach and difficult topics and emotions can come up. Participants are considered experts (Schwartz and van der Sande, 2011) and the researcher is in a more equal position, of learning and acknowledging expertise. However, there is a risk of confusing the research space with a therapeutic space or for other purposes. At times, the groups slid into more personal experience sharing moments or with issues their organisations or other members were facing, which were not always in line with the purpose of the research project. My role as a researcher was difficult to determine when these situations occurred, and I specifically refrained from giving any advice on personal situations. However, constructing knowledge and equal relationships does require mutual opening up (Behar in Etherington, 2004). Thus, I opted for creating spaces for informal conversations at the beginning and end of the sessions, using an emotional and energy thermometer or for sharing personal stories, and separating these spaces from the actual research discussion.

During the group reflexivity sessions, the group decided to agree on topics that could be discussed during our meetings and in the shared communication channels. Some participants also raised with me the need for a more structured environment to increase participation and stay on topic. I found that, at times, I had failed to facilitate the research process and participation adequately. Figuring out what had happened and how to deal with my feelings were addressed through the reflexive diary keeping and individual conversations with co-researchers, as well as incorporating immediate anonymous feedback surveys on zoom.

Identifying privilege

The first thing always required by reflexivity is to acknowledge privilege. I am a highly privileged non-disabled academic researcher, with work experience in different fields, including working as a support worker for adults with disabilities. This type of statement seemed a bit empty for me. However, the words came back to me at different moments of the research process, when I recognized I have had access to training, contacts, ideas, resources and experiences in a way that have shaped my way of thinking, of solving problems and my person. Privilege assumes certain things for granted, which are not, even though at times I have not always seen them. To understand whether I was acting out of privilege, I came up with a rule of testing whether I would behave the same way if a request or a pending task came from a superior. I identified that at times, I was not being as up to standard as I thought I would. I assumed people had time and space in their weekly routine to reflect on our work, bring feedback to our meetings or read the summaries I sent. However, I found that it is an (academic) privilege to have time and mental space to reflect on things. Self-reflection was also found challenging in Bigby and Frawley's experience (2010). Participants may not have the time or more concerning issues that occupy them. I decided to build in time for individual and collective reflection as an explicit part of participatory research.

Identification of paternalistic feelings

Throughout the research process, difficult emotions or evidence of rights violations came up. Further, the urgency to uncover and properly document these situations fueled the research with motivation of participants to engage with the project. The expectations of the research rose and at some point, I felt I could not accomplish or promise what I assumed they were hoping for. I started feeling responsible for how people felt and dealt with the research, regardless of how much information I was providing. Through the writing, I identified paternalistic feelings to protect from disappointment. One of those moments was pointed out to me by one of the participants, who stated: '*Wishing that we don't feel anxious is like wishing for peace in the world*'. At that moment, I realized I was having paternalistic attitudes towards them, in my attempt to avoid discomfort at all costs. Research is not a trouble free and smooth process. Discussing systematic violations of human rights is not either. I cannot avoid pain in research and in discoveries, or difficult conversations. We can construct a safe space in which people can have those conversations, which is on what I tried to focus, as well as finding ways of discussing them in more abstract ways.

I also identified what I considered internalized oppression in my co-researchers, but I realized it is not my place to raise it, point it out or even write about it. I can only provide opportunities to explore these ideas in a different framework and to do research related activities under the framework of the Convention on the Rights of Persons with Disabilities.

Not judging the motivation of co-researchers

One of the risks I identified early on is the temptation to study my co-researchers rather than the process or my influence over it. I caught myself considering what their motivation to pursue this project was. It is not my place to consider or judge that, but it nonetheless crossed my mind. I realized stigma goes both ways, thinking negatively or attributing unrealistically positive attributions to and expectations from people with disabilities, such as a pure commitment to advocacy.

Conclusion

Reflexiveness in my research has proved to be essential to tackle the task of supporting and contributing to a participatory research project. It has helped me identify prejudices and redefine my role throughout the process. It has also improved my facilitation skills and increased my search for and use of different participation methods instead of using default working methods.

One of my main conclusions is that I get much more out of the co-researched projects than I can ever write about, thank, or return to my co-researchers. Secondly, my co-researchers have trusted me and my expertise. This trust needs to be honoured far beyond the chance to participate or being paid. Their trust is also where power is returned to me. This power must be subject to transparency, accountability, and the possibility to be reviewed at any stage without causing trouble. Reflexivity is, for me, key to hold oneself accountable first, to improve participation and to identify what needs to be raised explicitly with the group, and what one has to deal with oneself, instead of burdening co-researchers with it.

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7 A methodological approach to investigating DPOs' attitudes towards case law on disability

Radina Ugrinova

Abstract

The present paper presents a methodological approach to investigating the attitudes of Disabled Persons Organizations (DPOs) towards judicial understandings of the concept of disability. In particular, the paper discusses the methods applied in a study investigating the attitudes of European DPOs towards the case law of the European Court of Justice (CJEU) regarding the concept of disability in an employment context. The study presents an approach which combines the use of online focus groups with thematic analysis as methods for data collection and analysis of the views of DPOs.

Introduction

The study presents an approach which combines the use of online focus groups with thematic analysis as methods for data collection and analysis of the views of DPOs. The methodological approach presented here provides an outlet for investigating not only the perceptions of DPOs towards the CJEU's case law but also for an assessment of whether there exists a discrepancy in the manner in which disability is perceived by the CJEU, on the one hand, and by DPOs, on the other. The study builds on the work of Nowell et al.,¹ as well as of Massey,² to describe the manner in which focus groups and thematic analysis will be combined and used to investigate how European DPOs respond to the case law of the CJEU.

The discussion proceeds as follows. Firstly, the study provides a description of the background of the present paper: a study investigating the views of European courts and DPOs regarding the meaning of the concept of disability. The methodological approach outlined here will be applied in this context. Secondly, the study provides an overview of the use of online focus groups to gauge the views of the DPOs regarding the case law of the CJEU. The paper discusses three types of data which may emerge from the focus groups, as well as how these data will be used in the analysis. Finally, the study provides an overview of the manner in which thematic analysis will be used to interpret the data collected during the focus groups. The study outlines a six-step approach which will be applied to the data and which will guarantee sufficient rigor of the final analysis.

Research Background to the Proposed Methodological Approach

The large study briefly outlined above comprises of three parts. The first part focuses on the case law of the CJEU and the understanding of disability embedded therein. The analysis is carried out in the context of the model of disability enshrined in the Convention on the Rights of Persons with Disabilities (the CRPD). The aim of the analysis is to investigate how the

¹ Lorelli S. Nowell , Jill M. Norris , Deborah E. White , and Nancy J. Moules, 'Thematic Analysis: Striving to Meet the Trustworthiness Criteria' (2017) 16 International Journal of Qualitative Methods 1.

² Oliver T. Massey, 'A Proposed Model for the Analysis and Interpretation of Focus Groups in Evaluation Research' (2011) 34 Evaluation and Program Planning 21.

concept of disability is understood by the CJEU in the context of EU employment non-discrimination law. Among other conclusions, the author argues that in some decisions the Court struggles to apply a social model of disability in its case law.

The second and third parts of the study build on this analysis. The second part examines how domestic courts respond to the case law of the CJEU and understand the concept of disability in an employment context. The third part of the study focuses on the perceptions of European DPOs of the case law of the CJEU with a view of gaining an understanding into how DPOs shape their advocacy programs. This third part forms the research background of the present paper. The methodology outlined below will be applied in the context of this part of the research. The study adopts a methodological approach which combines the use of online focus groups as a data collection method with thematic analysis as a method for analyzing the views of DPOs. This approach is defined below.

The Use of Focus Groups: Three Types of Data

Focus groups here are defined as ‘carefully planned discussion[s] designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment’, which combine elements of interviewing and participant observations.³ Since the focus groups in the present research will be conducted online (see below), the focus of the analysis in this instance will fall on interviewing and gauging DPO’s views of the CJEU’s case law. Focus groups offer an opportunity for the researcher to collect data regarding attitudes and opinions which is more robust and rich compared to survey methods.⁴ Massey states that there are three forms of qualitative analysis associated with focus groups: grounded theory, phenomenological approached and thematic analysis.⁵ Thematic analysis will be used to examine the attitudes and opinions of the DPOs concerning the understanding of disability embedded in the case law of the CJEU.

The focus groups will be conducted in the following manner. The author will contact potential research participants with the assistance of European Disability Forum during the months of June-August 2021. The participants targeted for the research are representatives of European-level DPOs who have a sufficient understanding of European disability policy and some understanding of European employment non-discrimination law. Once informed consent has been acquired from a sufficient number of participants, the latter will be divided into three focus groups. Each focus group will include 5-7 participants and will last approximately 2 hours. The focus groups will be conducted online, via the medium of Zoom. The participants will be presented with two case study scenarios based on existing decisions produced by the

³ Massey (n 2) 21.

⁴ *Ibid* 21.

⁵ *Ibid* 22.

CJEU. The author will have prepared specific questions for the participants related to the definitions of disability embedded in the case scenarios and their opinions on these. However, the discussion will also be guided by the spontaneous reactions of the participants to the case scenarios. The resulting data will then be analysed using thematic analysis.

Massey suggests that three types of data may emerge through the use of focus groups and thematic analysis: articulated data, attributional data and emergent data. Articulated data is defined as the ‘data that arises in direct response to the questions and prompts provided in the discussion guide’.⁶ In the present study such data will derive from the questions prepared by the researcher regarding the definitions of disability in the case scenarios, as well as the spontaneous reactions of the participants to the scenarios. Attributional data is defined as data derived ‘from comments and discussion that relate to a priori theories, operating hypotheses, or research questions that the evaluator brings to the study’.⁷ These data will be derived in the study from the theoretical basis of the research in the field of disability. Emergent data is data ‘that contributes to new insights and hypothesis formulation and is the unanticipated product of individual comments and exchanges among group members’.⁸ The author will use emergent data heavily in the drafting of the final report.

The Use of Thematic Analysis: A Six-Step Approach

The study will use thematic analysis to examine how DPOs view the concept of disability embedded in the case law of the CJEU. Thematic analysis here is defined as ‘a method for identifying, analysing, organizing, describing, and reporting themes found within a data set’ which can ‘be widely used across a range of epistemologies and research questions’.⁹ This approach to data analysis suggests that qualitative analysis involves the search for common themes emerging from group dynamics and the open interplay among participants. These themes may reflect a range of individual attitudes, opinions, and beliefs, as well as touching on otherwise unarticulated norms and social values.¹⁰

Nowell et al. outline several advantages and disadvantages with regard to the use of thematic analysis. Among the advantages of this approach, the authors cite its flexibility and the ability to modify the approach to fit the needs of a variety of studies, its ability to provide ‘a rich and detailed, yet complex account of data’, as well as its accessibility to early-stage researchers.¹¹ However, the approach also has certain disadvantages in the form of the possibility of some ‘inconsistency and a lack of coherence when developing themes derived from the research

⁶ Massey (n 2) 23.

⁷ *Ibid* 23.

⁸ *Ibid* 23.

⁹ Nowell et al. (n 1) 2.

¹⁰ Massey (n 2) 22.

¹¹ Nowell et al. (n 1) 2.

data'.¹² It is important to note that '[c]onsistency and cohesion can be promoted by applying and making explicit an epistemological position that can coherently underpin the study's empirical claims'.¹³ To provide such consistency and cohesion, the present study will take two steps. The first one is to clearly stipulate the theoretical basis of the research, i.e. a disability studies perspective focused on an examination of the model of disability applied by the CJEU (see above). The second step adopted will be to use the six-step approach to thematic analysis presented by Nowell et al. to guarantee a rigorous approach to the data analysis.

Nowell et al. define these six steps as 'phases'; they are the following. Firstly, phase one stipulates that the researcher familiarize herself with and immerse herself in the data collected through the focus groups.¹⁴ This immersion is achieved through an active search for meanings and patterns¹⁵ which emerge from the discussions with the DPOs. The researcher will read through the entire data set to identify overarching ideas and patterns in the testimonies of the research participants and will build on this process in the next five steps.

The second phase concerns developing initial codes.¹⁶ During this phase the researcher will develop a codebook and will systematically code the statements provided by the research participants during the focus groups. The researcher may also use the method of reflexive journaling during this stage, as recommended by Nowell et al., in order to further refine the codes and to keep track of how the various parts of the data relate to each other.¹⁷

The third phase of the data analysis consists of sorting through the data in search for themes.¹⁸ A theme is defined here as 'an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations [and] captures and unifies the nature or basis of the experience into a meaningful whole'.¹⁹ During this stage of the data analysis the researcher will rely both on the raw data produced during the focus groups, as well as the theoretical perspective on which the study is based, i.e. the specific understanding of the concept of disability embedded in the CJEU's case law and the resulting model of disability embedded therein. Thus, the researcher will combine an inductive approach to the data analysis with a deductive one.

¹² Nowell et al.(n 1) 2, citing Immy Holloway and Les Todres, 'The Status of Method: Flexibility, Consistency and Coherence' (2003) 3 *Qualitative Research* 345.

¹³ *Ibid* 2.

¹⁴ *Ibid* 4-5.

¹⁵ *Ibid* 5.

¹⁶ *Ibid* 5-8.

¹⁷ *Ibid* 7.

¹⁸ *Ibid* 8-9.

¹⁹ Lydia DeSantis and Doris Noel Ugarriza, 'The Concept of Theme as Used in Qualitative Nursing Research' (2000) 22 *Western Journal of Nursing Research* 351, 362.

The fourth phase consists of a review of the themes which will emerge in the previous phase.²⁰ This process will entail a review of the coded data and a refinement of the themes identified through the initial codebook with the aim of reviewing the accuracy of the initial codes and the validity of the resulting themes, as well as the extent to which they accurately reflect the statements provided by the DPOs during the focus groups. During this phase the data will be collapsed into a more condensed and manageable set of statements. The researcher will be able to build a comprehensive and exhaustive idea of the data set and how the various themes and patterns identified therein fit with one another.

Afterwards Nowell et al. propose the fifth phase of the data analysis – the defining and naming of themes.²¹ This phase stipulates that the researcher conduct a detailed analysis of each theme to uncover the underlying ‘story’ behind them and to further refine them. At this stage the researcher can also consult with her supervisors, who will provide feedback on the coherence and accuracy of the themes the researcher has produced. However, this phase may not be relevant to the present research because the author is not seeking to understand a process but views/perceptions. For this reason, this phase of the proposed approach will be omitted and the author will move on to the next phase.

Finally, the author will conduct the final analysis of the data and produce the final report.²² This stage of the research process will entail ‘a concise, coherent, logical, non-repetitive, and interesting account of the data’.²³ The researcher will aim to articulate clearly the themes which were used during the data analysis and what each theme means within the broader context of the focus groups. The researcher will report on codes and themes which emerged during the research process, as well as how these were developed and used. Additionally, she will report on the interpretation of the patterns and themes, and theorizations on how the themes relate to one another, to relevant literature and to the first two parts of the large-scale study (i.e. the interpretation of the concept of disability by courts). The researcher may also make references to her reflective journal.

Conclusion

In conclusion, the present paper presents a methodological approach to investigating the views and attitudes of DPOs towards the case law of the CJEU in relation to the concept of disability. The proposed approach combines the use of online focus groups with thematic analysis. The aim of the approach is to gain a sufficiently deep understanding of the manner in which DPOs react to the CJEU’s case law, as well as to guarantee flexibility, as well as a rigorous assessment of the various forms of data collected through the focus groups.

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DeSantis, L., and Noel Ugarriza, D., ‘The Concept of Theme as Used in Qualitative Nursing Research’ (2000) 22 *Western Journal of Nursing Research* 351

²⁰ Nowell et al. (n 1) 9-10.

²¹ *Ibid* 10.

²² *Ibid* 10-11.

²³ *Ibid* 10.

- Holloway, I., and Todres, L., 'The Status of Method: Flexibility, Consistency and Coherence' (2003) 3 *Qualitative Research* 345
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8 Research participants and researchers with communication-support needs: methodological and ethical considerations raised by online interviews

Edmore Masendeke

Abstract

Conducting an online interview is different from conducting an in-person interview. While some of the methodological and ethical issues are similar, how you address them is sometimes different. Furthermore, there are several additional methodological and ethical issues which need to be considered when conducting online interviews. While there is growing literature on online interviews during the COVID-19 pandemic, there has been little focus on how to conduct online interviews with or as a person with psychosocial disabilities, a person with intellectual disabilities or a person with communication support needs in this literature. This chapter critically reflects on the methodological and ethical issues I considered in the preparation of my online interviews with people with psychosocial and intellectual disabilities who have communication support needs in court contexts. It takes into account that some of the interviewees and I, as a disabled researcher myself, will require support with communication during the interviews. This helped me identify the supports that may be required to ensure that interviews and I are able to effectively participate during the interviews.

Introduction

The COVID-19 pandemic has shifted a lot of in-person research online amid travel restrictions and social distancing requirements. While this has enabled some of the research which was initially planned to involve in-person interaction to continue, the shift has necessitated a rethink of the ways researchers interact with research participants and conduct their research.²⁴ In some instances, it has necessitated the development of new and improved ways of interacting with research participants and conducting research.²⁵ Furthermore, it has required researchers to

²⁴ Majella Dempsey and Hillary Tierney, 'Ethical challenges in educational research during the pandemic: implications for interviewing in the online environment' in Brian Mooney (ed) *Ireland's education yearbook 2020* (Education Matters 2021) 272 <<https://irelandseducationyearbook.ie/downloads/IEYB2020/YB2020-Higher-Education-9.pdf>> accessed 5 June 2021.

²⁵ Majella Dempsey and Hillary Tierney, 'Ethical challenges in educational research during the pandemic: implications for interviewing in the online environment' in Brian Mooney (ed) *Ireland's education yearbook 2020* (Education Matters 2021) 272 <<https://irelandseducationyearbook.ie/downloads/IEYB2020/YB2020-Higher-Education-9.pdf>> accessed 5 June 2021; Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' *Journal of Enabling Technologies* (forthcoming).

consider the application of traditional ethical principles in an online environment and, at times, to consider new ethical challenges related to online research. Thus, the shift of in-person research online has had different methodological and ethical implications for how research is conducted.

This chapter looks at the methodological and ethical implications of doing research online. It focuses on the interview as a method of data collection. While there is growing literature on online interviews during the COVID-19 pandemic, there has been little focus on how to conduct online interviews with and/or as a person with psychosocial disabilities, a person with intellectual disabilities or a person with communication support needs in this literature. Therefore, the ‘unique ethical and methodological challenges’ of online interviews with or as a person with psychosocial disabilities, a person with intellectual disabilities or a person with communication support needs ‘have not been well explored in the literature.’²⁶

It is against this background that this chapter critically reflects on the methodological and ethical issues I considered in the preparation of my online interviews with people with psychosocial and intellectual disabilities who have communication support needs in court contexts. It takes into account that some of the interviewees and I, as a disabled researcher myself, will require support with communication during the interviews. This chapter has three sections. The first section explains the purpose of my research; who I will be recruiting as interviewees and their support needs; and my support needs. In the second section, I reflect on the methodological and ethical issues that I considered in my preparations for my research interviews. The third and final section is the conclusion.

The research, the research participants and the researcher

To find out about the experiences of defendants with psychosocial and intellectual disabilities who receive support with communication during court proceedings in England and Ireland, I plan to interview past defendants with psychosocial and intellectual disabilities who received this kind of support. These are people with psychosocial and intellectual disabilities who, as defendants, had someone other than their legal representative – an intermediary²⁷ or personal advocate²⁸ – help them understand and answer questions or understand what was happening

²⁶ This was noted by Miller and van Heumen in their paper on inclusive online research with people with intellectual and developmental disabilities during the COVID-19 pandemic. Sara Michelle Miller and Lieke van Heumen ‘Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations’ *Journal of Enabling Technologies* (forthcoming).

²⁷ The Youth Justice and Criminal Evidence Act 1999 in England and the Criminal Evidence Act 1992 in Ireland provides for the use of intermediaries by court participants who have communication disabilities. The role of an intermediaries is to facilitate communication between these court participants and the court.

²⁸ The Comhairle Act 2000 and the Citizens Information Act 2007 in Ireland contain the provisions for ‘personal advocates, Anecdotal evidence suggests that advocates from organisations such as the National Advocacy Service

during court proceedings. This could have been because, without this support, they would not be able to (1) understand the questions, (2) relay their responses in a way that the court understands, (3) follow the proceedings or (4) understand the consequences of their decisions.²⁹ This could also have been because, without this support, they would have been more vulnerable to acquiescence, more likely to be compliant or more suggestible than others.³⁰ Thus, this support was provided to mitigate against possible difficulties in communication that could have arisen from environmental factors such as the type of questions presented to a witness, their framing and the setting in which they are asked.³¹

As in court, difficulties in communication can arise due to the same environmental factors when doing research interviews with the same group of people.³² Therefore, this is something which researchers need to take into consideration as they are the ones who are responsible for providing the accommodations which participants may need to effectively participate in research.³³ Accordingly, I took these issues into account in my preparations for the interviews.

However, these preparations did not only involve thinking about the accommodations which my interviewees may require. They also involved making accommodations for myself, the researcher, as I am a person with cerebral palsy. My speech is slurred, and it can sometimes be difficult to understand for people who are not familiar with how I speak. Therefore, my personal assistant will attend the online interviews with me and help me communicate with participants during some parts of the interviews. Particularly, he will support me in three ways. First, he will help me conduct the oral consent process so that it is completed in a timely manner.

support disabled people accused of crimes or disabled defendants navigate their way through complex legal proceedings based on these provisions.

²⁹ Glynis H Murphy and Isabel CH Clare, 'The effect of learning disabilities on witness testimony' in Anthony Heaton-Armstrong, Eric Shepherd, Gisli H Gudjonsson and David Wolchover (eds) *Witness Testimony: Psychological, Investigative and Evidential Processes* (OUP 2006).

³⁰ Glynis H Murphy and Isabel CH Clare, 'The effect of learning disabilities on witness testimony' in Anthony Heaton-Armstrong, Eric Shepherd, Gisli H Gudjonsson and David Wolchover (eds) *Witness Testimony: Psychological, Investigative and Evidential Processes* (OUP 2006).

³¹ Neta Ziv, 'Witnesses with mental disabilities: Accommodations and the search for truth' (2007) 27(4) *Disability Studies Quarterly* <<https://dsq-sds.org/article/view/51>> accessed 29 August 2021.

³² Andrea Hollomotz, 'Successful interviews with people with intellectual disability' (2018) 18(2) *Qualitative Research* 153; Lisa Brophy et al, *People making choices: The support needs and Preferences of people with psychosocial disabilities* (Mind Australia 2014) <https://minerva-access.unimelb.edu.au/bitstream/handle/11343/52597/Mind_ResearchReport_People%20Making%20Choices_%20Final%20Report.pdf> accessed 3 June 2021.

³³ Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' *Journal of Enabling Technologies* (forthcoming); Lisa Brophy et al, *People making choices: The support needs and Preferences of people with psychosocial disabilities* (Mind Australia 2014) <https://minerva-access.unimelb.edu.au/bitstream/handle/11343/52597/Mind_ResearchReport_People%20Making%20Choices_%20Final%20Report.pdf> accessed 3 June 2021.

If I do it myself, the process will take a lot more time to complete because my speech is slow. Second, if a participant cannot or finds it difficult to understand my voice, my personal assistant will repeat what I have said to participants – as necessary. Third, he will maintain notes of participants' responses throughout the interview. Thus, the support I will receive from my personal assistant will to some extent affect how I interact with research participants and conduct my research. This is reflected in the following observations on the methodological and ethical issues I considered in preparation for my interviews.

Methodological and ethical considerations

My original goal was to have in-person interviews with research participants. My preparations for the in-person interviews involved a careful consideration of how I was going to interact with my research participants and conduct my research. Moving these interviews online saw me reimagining my interaction with participants in an online environment. Some of the issues which I have had to reimagine include how I may go about building rapport with interviewees; facilitating communication with interviewees and support providers; obtaining informed consent from interviewees; ensuring confidentiality, privacy and security of data; and ensuring that participation is as autonomous as possible. I reflect on these issues in turn in the remainder of this section.

Building rapport with interviewees

Studies suggest that researchers sometimes need to spend time with participants with communication support needs before the interview to build rapport and/or learn how they communicate.³⁴ This can also be achieved through prolonged engagement.³⁵ Therefore, in situations where it will be required, I will break my interviews into multiple sessions for prolonged engagement. In addition to talking about the research and what participation involves, I will use the initial sessions to build rapport with potential interviewees, to learn how they communicate and to find out if they have support needs. In turn, potential interviewees will get to hear my voice and speak with me before the actual interview. This may increase their familiarity with my voice and how I speak, potentially reducing the need for my personal assistant to repeat what I say during the interview.

While three sessions are anticipated – initial contact, consent process and main interview – the number of sessions that will be held with each interviewee will depend on several factors including the interviewees' preparedness, preferences, and abilities. This is because these short multiple sessions are also 'designed to accommodate participants with a shorter attention span

³⁴ Hanne Marie Høybråten Sigstad and Veerle Garrels, 'Facilitating qualitative research interviews for respondents with intellectual disability' (2018) 33(5) *European Journal of Special Needs Education* 692.

³⁵ Hanne Marie Høybråten Sigstad and Veerle Garrels, 'Facilitating qualitative research interviews for respondents with intellectual disability' (2018) 33(5) *European Journal of Special Needs Education* 692.

or who might experience interview fatigue' especially online.³⁶ Accordingly, some participants may find it too tiring to have the interview in one session, while others may be able and willing to have the interview as one session. Therefore, this is an accommodation which will be applied on an individual basis.

Before meeting them online, I will ask potential interviewees to choose the online platform they want to use as part of the process of building rapport. Studies suggest that research participants' familiarity with the Voice-over Internet Protocol (VoIP) platform being used contributes to building trust and rapport in online research.³⁷ Studies also suggest that research participants' and researchers' ability to see each other on videoconferencing platforms and the screen and file sharing capabilities of these platforms also contributes to building trust and rapport in online research.³⁸ While there are many VoIP different platforms, participants will be encouraged to choose either Zoom, Microsoft Teams, Skype or Blackboard Collaborate because the University of Leeds has licenses for these platforms and therefore offer better security. Participants will also have the option of switching on their cameras or switching it off during the interview. This may however limit access to non-verbal communication. Potential participants will also be given the option to have interviews conducted by phone as some of them may lack access to necessary electronic devices, the internet or training on how to use VoIP platforms.³⁹

Facilitating communication with interviewees and support providers

As mentioned above, in addition to building rapport, I may also use the initial sessions to learn how potential participants communicate and to find out if they have any support needs. The latter includes finding out whether they want Easy Read material and whether they want to attend the interview with a support provider to facilitate communication or provide emotional support during the interview. In relation to facilitating communication, support providers will be expected to assist interviewees in sharing their perspective on their experience of being supported by an intermediary or personal advocate in court. This can be by asking me to repeat

³⁶ Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' *Journal of Enabling Technologies* (forthcoming).

³⁷ Mandy M Archibald, Rachel C Ambagtsheer, Mavourneen G Casey and Michael Lawless, 'Using zoom videoconferencing for qualitative data collection: perceptions and experiences of researchers and participants' (2019) 18 *International Journal of Qualitative Methods* 108.

³⁸ Mandy M Archibald, Rachel C Ambagtsheer, Mavourneen G Casey and Michael Lawless, 'Using zoom videoconferencing for qualitative data collection: perceptions and experiences of researchers and participants' (2019) 18 *International Journal of Qualitative Methods* 108.

³⁹ Geraldine Foley, 'Video-based online interviews for palliative care research: A new normal in COVID-19?' (2021) 35(3) *Palliative Medicine* 625; Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' *Journal of Enabling Technologies* (forthcoming).

or clarify questions to interviewees or rephrasing questions in a way that interviewees may be better able to understand. If I do not understand interviewees' responses, after several attempts to do so, I may check with support providers to help me to understand interviewees' responses. Since support providers may have a personal relationship with the person and may understand their communication better than me, this could be beneficial to drawing out key insights from the interview. However, I will ask support providers to refrain from answering on behalf of the person that they are providing support to. To make my research truly reflective of the perspectives of persons with psychosocial and intellectual disabilities, it is imperative that I hear their thoughts, even if they are incomplete.

While support providers and my personal assistant will be there to assist us, my goal will be to speak directly with interviewees as much as possible during the interview. I will use plain language to ask questions and may share my screen to show participants images and short sentences which describe the interview questions and topics during the interview. Also, cognisant that paraphrasing or summarising participants' responses may result in researchers bringing in their own conceptual views into the research,⁴⁰ I will use the interviewee's words, as much as possible, to verify my understanding of participants' responses and ask follow-up questions.⁴¹ In addition, I will follow-up yes/no responses with open questions to allow participants to add detail to their responses.⁴²

A possible limitation to interviewing online could be that I will not be able to detect participants' non-verbal communication, especially if they opt to keep or turn their cameras off. Therefore, I will need to be attentive for any indications of wariness, doubt or distress from participants. If I sense any indications of wariness, doubt or distress, I will acknowledge that I have noticed these signals and ask them if they want to stop or continue the interview. If participants want the interview to stop for any reason, I will ask them if they want to continue the interview at another time or to withdraw from the interview at that point. If participants are feeling distressed, I will provide them a list of support providers who they can reach out to for support.

Obtaining informed consent

An important consideration was the process of obtaining informed consent. As Harries highlights, consent can only be valid if a person understands what the research is about, the consequences of participating in the research and can give their consent freely.⁴³ Before the

⁴⁰ Hanne Marie Høybråten Sigstad and Veerle Garrels, 'Facilitating qualitative research interviews for respondents with intellectual disability' (2018) 33(5) *European Journal of Special Needs Education* 692.

⁴¹ Hanne Marie Høybråten Sigstad and Veerle Garrels, 'Facilitating qualitative research interviews for respondents with intellectual disability' (2018) 33(5) *European Journal of Special Needs Education* 692.

⁴² Hanne Marie Høybråten Sigstad and Veerle Garrels, 'Facilitating qualitative research interviews for respondents with intellectual disability' (2018) 33(5) *European Journal of Special Needs Education* 692.

⁴³ John Harris, 'Time to make up your mind: why choosing is difficult' (2003) 31 *British Journal of Learning Disabilities* 3.

interview session(s), I will send potential participants copies of my information sheet⁴⁴ and a consent form by email. If a potential participant requests Easy Read material, I will send them three handouts explaining the information in the information sheet and consent form and the sorts of questions they might be asked during the interview in plain language with accompanying illustrations. These handouts are designed to support potential participants' comprehension of information about the research and provide consent.⁴⁵ Potential participants will be asked if they have read and understood the information in these documents at the beginning of the consent process.

If a potential participant has not read the documents, I will ask them if they would like to take some time to read the documents on their own or for someone to read out the documents to them. If they want someone to read out the documents to them, either their support provider or my personal assistant will read the documents to them. Potential participants will be encouraged to seek any clarification, ask any questions, express any worries, or concerns they may have regarding the research. If participants have any questions, worries, or concerns, I will address them as best as I can.

To ensure potential participants have the capacity to provide informed consent, I will remain attentive and alert to the possibility that they may have some doubts about taking part, confusion about what it will involve or any discomfort whatsoever about the research. If any confusion or discomfort continues, despite my attempts to clarify what the research is about and what participation entails, I will acknowledge that I have noticed these signals and advise them that there is absolutely no need for them to take part if they are not 100% clear about the project and happy to go ahead with the interview. In these situations, I will try to create space for potential participants to feel that they have decided against taking part rather than feel that I have rejected them. While being sensitive to their concerns and their feelings, I will also be firm should a situation arise in which a potential participant remains very keen to take part despite seeming to be confused about what taking part would involve. This will be done before obtaining their consent.

To obtain potential participants' consent, I will ask them for permission to start recording the session and my personal assistant will read them statements, from the consent form or corresponding Easy Read handout, which they can either agree to or decline. These statements are about whether they have read and understood what the research is about and want to participate in

⁴⁴ The information sheet explains what the research is about, why their participation is necessary, what they will be asked to do, what will happen to the information they provide, how that information will be used, and how and to whom it will be reported. It also has informed about the retention, sharing, and any possible secondary uses of the research data.

⁴⁵ Katherine E. McDonald et al, 'Is safety in the eye of the beholder? Safeguards in research with adults with intellectual disability' (2016) 11(5) *Journal of Empirical Research on Human Research Ethics* 424; Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' *Journal of Enabling Technologies* (forthcoming); Lisa Brophy et al, *People making choices: The support needs and Preferences of people with psychosocial disabilities* (Mind Australia 2014) <https://minerva-access.unimelb.edu.au/bitstream/handle/11343/52597/Mind_ResearchReport_People%20Making%20Choices_%20Final%20Report.pdf> accessed 3 June 2021..

the research. The recording will be stopped at the end of these statements as it will be stored separately from the recording of the interview responses for security reasons.

Though consent will be obtained before an interview, I will ask participants if they want to stop or continue the interview at the start and during every session of the interview, providing opportunities for participants to withdraw from the research at any time.⁴⁶ This will be done to ensure that informed consent is a process that is confirmed throughout the interviews.⁴⁷

Confidentiality, privacy and security of data

There are additional considerations in relation to privacy, confidentiality and security of data which are brought about by online interviewing.⁴⁸ For instance, there may be more reliance on participants' judgement in relation to privacy issues. Therefore, I will encourage participants to find a private space to be during their interviews to protect their own privacy and the privacy of their support providers.⁴⁹ I will also discourage participants and support providers from sharing or making any recording of whatever is discussed in the interview. In relation to the security of data, I will use paid-up videoconferencing platforms as they tend to operate securely.⁵⁰ I will record the interview using software that does not store data in the cloud. Soon after creating the data file, I will password-protect it and store it on a secure location on the university drive.

Autonomy

Another important consideration was participants' autonomy in relation to their choice and control over the technical devices and videoconferencing platforms that will be used for the interviews as well as the scheduling of the interviews. Participants will choose the devices and videoconferencing platforms they want to use for the interview. However, depending on their familiarity with technological devices and videoconferencing platforms, some participants may need assistance to use these technical devices or videoconferencing platforms. Those who assist participants in this manner will be requested to only assist participants in the operation of the technical devices or videoconferencing platforms. They will also be requested to respect participants' privacy by allowing them to continue with the interview on their own unless participants also want them to provide communication or emotional support during interviews.

⁴⁶ Majella Dempsey and Hillary Tierney, 'Ethical challenges in educational research during the pandemic: implications for interviewing in the online environment' in Brian Mooney (ed) Ireland's education yearbook 2020 (Education Matters 2021) 272 <<https://irelandseducationyearbook.ie/downloads/IEYB2020/YB2020-Higher-Education-9.pdf>> accessed 5 June 2021; Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' Journal of Enabling Technologies (forthcoming).

⁴⁷ Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' Journal of Enabling Technologies (forthcoming).

⁴⁸ Geraldine Foley, 'Video-based online interviews for palliative care research: A new normal in COVID-19?' (2021) 35(3) Palliative Medicine 625

⁴⁹ Sara Michelle Miller and Lieke van Heumen 'Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: technological adaptations' Journal of Enabling Technologies (forthcoming).

⁵⁰ Geraldine Foley, 'Video-based online interviews for palliative care research: A new normal in COVID-19?' (2021) 35(3) Palliative Medicine 625

These measures will be taken to ensure that research participants' participation is as autonomous as possible and not influenced by support providers. Participants will also be asked when they want to have the interviews and whether they want the interview to be held as one session or multiple sessions.

Conclusion

Based on my on-going research, this chapter offers a critical reflection on the methodological and ethical challenges of conducting online interviews with or as a person with psychosocial disabilities, a person with intellectual disabilities or a person with communication support needs. Accordingly, I considered how I propose to tackle certain processes in my research, taking into account that some of the interviewees and I will require support with communication. On the one hand, it involves the application and modification of traditional methods and ethical principles, and on the other, it imposes new methodological and ethical challenges for the researcher. This also helped me identify the supports that may be required to ensure that interviews and I are able to effectively participate during the interviews. Some of these supports may applied in research involving a research participant or researcher who has communication support needs.

9 Do persons with disabilities in Mozambique participate and own development cooperation programs?

Jorge Manhique

Abstract

In recent years, the issue of ownership of development cooperation programs has taken centre stage among donors and recipient Governments. This interest has been driven by a ‘shared concern [between donor and recipient countries] for making aid more effective’.⁵¹ Previous research on disability and development have exposed the precarious condition in which persons with disabilities live, revealing the systemic inequalities between those with and without disability. This kind of research helped to make the case for increasing funding for persons with disabilities through International Cooperation (IC), especially to the poorest regions of the world. Yet, we know from previous research that IC may produce perverse results by weakening democratic processes in recipient countries. Still unexplored in the literature on disability and development are the conditions needed for IC to enable the flourishing of democratic culture in recipient countries. This paper contributes to this debate by examining the extent to which those programs contribute to support dialogue between Civil Society Organizations (CSO) in general (and DPOs in particular) with State institutions. The paper focuses, primarily, on two ongoing projects in the domain of gender-based violence and social protection, both funded by the European Union (EU) and implemented in Mozambique. The paper draw from the perspective of key stakeholders involved in the implementation of those programs, collected through semi-structured interviews to underline the centrality of the political economy analysis and data disaggregation to ensure participation and ownership of development programs by persons with disabilities in Mozambique.

Introduction

Previous research on disability and development has exposed the precarious condition in which persons with disabilities live, exposing the systemic inequalities between those with and without disability.⁵² This research was instrumental in raising awareness among development

⁵¹ T Carothers ‘The deeper struggle over country ownership’ in OECD *A Governance practitioners’ notebook: alternative ideas and approaches* (2015).

⁵² N Groce, N Kett, M. Carew, M. Lang & R. Deluca, ‘Bridging the gap examining disability and development in four African countries’ (2018, March). <https://reliefweb.int/report/world/bridging-gap-examining-disability-and-development-four-african-countries-0> (Retrieved: 10 May 2021). UNDSA *Realization of the rights of persons*

actors of the plight of persons with disabilities all over the world, with particular focus in the so-called ‘Global South’ where an estimate of 80% of people with disabilities live. This was complemented by other sets of research pointing to gaps in funding to disability issues suggesting, for instance, that less than 0.5% of all Official Development Assistance (ODA), between 2014 and 2018 (or \$ 3.2 billion) aimed at disability inclusion⁵³ and only 3% of OECD human rights funding, in 2017, went to disability rights issues⁵⁴.

One of the guiding principles in IC is the ownership of development programs.⁵⁵ However, in practice, IC can produce perverse results. Studies that assessed the participation of persons with disabilities in national Poverty Reduction Strategy Papers (PRSP) indicate that while in theory the PRSP process aimed to enhance ownership participation and accountability, its design and implementation suggest that Governments were more concerned about satisfying donor conditionalities and deadlines than genuinely committed to meaningful involvement and accountability toward their citizens.^{56 57} In this sense IC may contribute to democratic deficit. Conversely, development agencies can leverage their influence by establishing bridges between CSO more broadly and the recipient Government.⁵⁸ As such, it is important to question the very nature of IC and discuss the type of cooperation and conditions that support the flourishing of democratic culture. This paper contributes to this debate by examining the extent to which those programs contribute to support dialogue between CSOs in general (and DPOs in particular) with State institutions.

This paper proceeds as follows: the first section presents and discuss different commitments – from Rome to Accra on aid effectiveness and the underline principles of ownership and participation. In the second section, the findings are presented and discussed. The paper concludes by highlighting three things that are important to ensure ownership of the development cooperation programs by persons with disabilities, namely: the centrality of

with disabilities by, for and with persons with disabilities, UN flagship report on disability and development (2018) <https://www.un.org/development/desa/disabilities/publication-disability-sdgs.html> (retrieved: 10 May 2021).

⁵³ D Walton ‘Fact Sheet: Disability-inclusive ODA: Aid data on donors, channels, recipients’ (2020) <https://devinit.org/resources/disability-inclusive-oda-aid-data-donors-channels-recipients/> (retrieved 12 May 2021).

⁵⁴ CANDID ‘Advancing Human Rights: annual review of Global foundations grantmaking’ (2017) <https://www.issuelab.org/resources/36686/36686.pdf> (retrieved: 24 May 2021).

⁵⁵ Paris Declaration on Aid Effectiveness (2015).

⁵⁶ T Mwendwa, N Muragira, & R Lang ‘Mainstreaming the rights of persons with disabilities in national development frameworks’ (2009) *Journal of International Development*. 21, 662–672.

⁵⁷ AK Dube, ‘Participation of disabled people in the PRSP/PEAP process in Uganda’ (2005) *Disability Knowledge and Research Program* <https://gsdrc.org/document-library/participation-of-disabled-people-in-the-prspspeap-process-in-uganda/> (retrieved: 24 May 2021).

⁵⁸ D Fritz, U Miller, A Gude, A Pruisken, & D Rischewski, ‘Making poverty reduction inclusive: experience from Cambodia Tanzania and Vietnam’ (2009) *Journal of International Development*. 21, 673–684.

political economy analysis, disability data disaggregation and the establishment of mechanism for [disability] inclusion.

Aid effectiveness: from Rome to Accra

In the turn of the millennium, and in the framework of the Millennium Development Goals, donor and recipient countries came together to address the issue of aid effectiveness, that is: how to maximize the impact of aid in recipient countries. In 2003, in Rome, developing and donor countries responsible for promoting development and heads of multilateral and bilateral development institutions came together in the framework of the Development Assistance Committee (DAC) to outline, for the first time, the principles of aid effectiveness.⁵⁹ The Rome Declaration paved the way to the Paris Declaration on Aid Effectiveness in 2005. The Paris Declaration is built over five core principles, that is: Ownership, Alignment, Harmonization, Managing for Development Results, and Mutual Accountability.⁶⁰ Each principle is operationalized by a set of indicators. The principle of Ownership, arguably the cardinal principle of the Declaration, states that recipient countries must ‘exercise effective leadership over their development policies, and strategies and co-ordinate development actions’. In addition, the Declaration states that recipient countries must do so ‘in dialogue with donors and encouraging the participation of civil society...’.⁶¹

The Rome and Paris Declaration did galvanize both donors and recipient countries to introduce reforms aimed to make the aid industry more effective. For instance, recipient countries embarked on the process of drafting PRSP. The aim of PRSP was to foster local ownership of development programs; participation of local actors, especially groups in vulnerable situations; and accountability and transparency through functional and capable governance systems.⁶² Despite the new dynamics brought by the new discourse on aid effectiveness, critics pointed out the excessive focus on procedures to promote ‘harmonization and alignment’ between donors and recipient countries.⁶³ While this is important, excessive focus on procedure may overlook the fact that ‘aid effectiveness is a political issue.’⁶⁴ In this connection, prominence

⁵⁹ Rome Declaration on Aid Effectiveness (2003).

⁶⁰ OECD, Paris Declaration on Aid Effectiveness (2005)

⁶¹ Idem.

⁶² M Elkins, S Feeny, & D Prentice ‘Are poverty reduction strategy papers associated with reductions in poverty and improvements in well-being?’ (2018) *The Journal of Development Studies*, Vol. 54, No. 2, 377–393. DOI: <https://doi.org/10.1080/00220388.2017.1299140>

⁶³ ECOSOC ‘Background Study for the development Cooperation Forum: Toward Strengthened Framework for Aid Effectiveness’ (2008).

⁶⁴ KA Paksi ‘Aid Effectiveness Agenda and the Politics of Ownership in Donor-Recipient Relationships’ (2019) *Islamic World and Politics* Vol.3. No.1 January-June.

must be placed on ‘the factors on both sides of the aid relationship that can work against more effective delivery and put in place incentives that support it’.⁶⁵

Like ownership, participation in the design and implementation of development programs has emerged as a crucial principle of aid effectiveness.⁶⁶ This stems from the belief that ‘aid will be most effective if its ultimate beneficiaries are consulted and engaged in defining its priorities’.⁶⁷ Critics have pointed out that the process that led to the Paris Declaration was ‘State centric’, did not engage the ‘full range of stakeholders’, notably CSO.^{68 69}

The Accra Agenda for Action (2008) attempted to address some of this criticism in at least two ways. First, the Accra Agenda for Action sought to ‘broaden country-level policy dialogue on development’ by explicitly calling on recipient governments to work more closely with parliaments, local authorities and CSO in preparing, implementing and monitoring national development policies and plans.⁷⁰ This was complemented by donors' commitment to support efforts to increase the capacity of all development actors (mentioned above) including ‘research institutes, media and the private sector – to take an active role in dialogue on development policy’.⁷¹ Second, the Accra Agenda for Action has put an emphasis on the need to create ‘strong institutions, systems, and local expertise’, a necessary condition to enable recipient countries to ‘fully own and manage their development processes’.⁷²

Program characterization

This paper is part of an ongoing research project which revolves around inclusion and participation of persons with disabilities in IC development programs. The project focuses, primarily, on two European Union funded development project in the domain of gender-based violence (Spotlight Initiative) and social protection in Mozambique.

The Spotlight Initiative (SI) is a multiyear program covering 28 countries across five regions of the globe.⁷³ Mozambique is one of the beneficiary countries in the African region. The focus of the program varies across region. The African program focus on ‘sexual and gender-based violence (SGBV), early marriage (with linkages to the eradication of harmful practices) and

⁶⁵ ECOSOC, (n 13).

⁶⁶ F Zimmermann ‘Ownership in Practice’ (September 2007)

⁶⁷ F Zimmermann (n 17) p. 6.

⁶⁸ ECOSOC, (n 13) p.3.

⁶⁹ F Zimmermann (n 17).

⁷⁰ The Accra Agenda for Action, 2008, para.13a.

⁷¹ The Accra Agenda for Action, 2008, para.13b.

⁷² The Accra Declaration, 2008, para. 14.

⁷³ Africa (8), Asia (4), Caribbean (6), Latin America (6) and Pacific (4).

sexual and reproductive health rights (SRHR)'.⁷⁴ The program is implemented by five UN Agencies⁷⁵ in collaboration with Government Agencies and CSO. In Mozambique the program covers 3 provinces. The program is also implemented at central level (capitol) covering, especially, legislative related work. With EU seed funding totalling 500 million euros for a period of 4 years (2019 – 2022), the SI is thought to be the 'largest global effort to end all forms of violence against women and girls'.⁷⁶

The second project, *Monitoria Comunitária Independente (MCI) ao Programa de Subsídio Social Básico (PSSB)* is a five-year (2018 – 2023) project implemented by a consortium led by *Plataforma da Sociedade Civil Moçambicana para Protecção Social (PSCM-PS)*. The project aims to improve the quality and impact of social protection programs and promote their transparency through awareness raising, access to information and active citizen participation in the accountability of social protection programs, with an emphasis on the PSSB. The project model uses a network of Community Social Protection Committees. The composition of each Committee varies between 25-40 community members. With funding of 2.500.000,00 euros from the EU through the Support Program of Non-State Actors (PANNE II), the project is being implemented in 6 provinces and a total of 10 districts.

In common, these projects have an explicit commitment to 'Leaving no one behind' (LNOB), meaning 'end[ing] extreme poverty in all its forms, and reducing inequalities among both individuals and groups'.⁷⁷ To operationalize this commitment, 'explicit and pro-active attempts are needed to ensure that populations at risk of being left behind are included from the start'.⁷⁸

Research approach and methods

As alluded above, this paper is part of an on-going research project. Qualitative approach was used to gauge stakeholders perspective on inclusion and participation in programs under review. The preliminary data used in this article was collected through semi-structured interviews. A purposive sampling approach was used to recruit research participants. Stakeholders recruited include EU Delegation representatives in Mozambique, UN Agencies, a network of local CSO implementing the projects, and Government official. In addition, representatives of OPDs were also recruited to participate as informants (see table below). Stakeholders were asked to reflect on the strengths and challenges of the programmes under review, including factors affecting the inclusion and participation of persons with disabilities and the extent to which those programs contribute to support dialogue between CSO in general (and DPOs in particular) with State institutions. By State institutions we mean the executive, legislative and judiciary. In total 22 interviews were analysed for this paper. All respondents were anonymized. The quotations presented in this paper reflect patterns, rather than individual responses.

⁷⁴ Spotlight Initiative Country Program Mozambique (2018) <https://spotlightinitiative.org> (retrieved: 14 April 2021).

⁷⁵ United Nation Children Fund (UNICEF); United Nation Development Program (UNDP and United Nation Women (UNW) and United National Population Fund (UNFPA).

⁷⁶ Spotlight Initiative <https://spotlightinitiative.org> (retrieved: 14 April 2021)

⁷⁷ E Stuart & E Samman "Defining 'leave no one behind'" (2017).

⁷⁸ Stuart & Samman (n 32).

Informants identified as	
Women	16
Man	8
Age Group	
18-34	5
35-44	10
45-54	7
55-64	2
Entity/type of informant	
Persons with disabilities	12
UN Agencies	5
Donor	2
Mainstream CSO	4
Government official(s)	1

Findings

The data analysed thus far have revealed the factors that limit the participation of those with disabilities hence preventing them from owning the policies and laws that development cooperation program aim to influence. These obstacles are clustered around two major themes:

The institutional framework

Freedom of association and assembly are constitutionally guaranteed in Mozambique. The exercise of the rights to assembly is subject to prior notification to authorities, a loophole which the government has taken advantage of, to misinterpret as contingent to authorization, and effectively ‘disallow protesters’⁷⁹. While most NGOs can operate without significant legal restrictions, human rights defenders and members of groups perceived as critical of the government policies are systemically object of intimidation. Journalists and researchers are harassed, intimidated, arrested, and detained for reporting on the conflict in Cabo Delgado - a region in the north of the country which has been targeted by terrorist groups since 2017.⁸⁰

Disability issues are not, so far, perceived as sensitive issues, and thus OPDs feel relatively comfortable to challenge government policies. However, the general climate of intimidation, the lack of framework to enable CSO groups to participate in public policies debates, and the limited access to information which impacts disproportionately those with hearing impairments make it difficult for OPDs to participate and own development programs, public polices and legislative processes, even when there is a commitment to LNOB. OPD leaders have reported

⁷⁹ Freedom House, Report Freedom in the World 2021: Mozambique. Retrieved: <https://freedomhouse.org/country/mozambique/freedom-world/2021>

⁸⁰ US State Department. 2020 Country Reports on Human Rights Practices: Mozambique. Retrieved <<https://www.state.gov/reports/2020-country-reports-on-human-rights-practices/mozambique/>>

difficulties in obtaining legal registration because of the high fees involved, which impacts on their ability to operate and obtain funding.

Because of this, recently the former representative of the Mozambican Bar Association called for a ‘law of laws’ to be passed:

‘that is, a law that more clearly defines the process of drafting laws, which, [...] clearly defines the way in which civil society participates in the process, establishes a mandatory period in which proposals must be available to the public for consultation and contributions, and imposes the obligation to explain the rationale of policy choices. Only then will the recipients of the laws [the citizens] be able to own them [policies]’⁸¹.

Program design

The review of program documents and other related materials (attendance sheet, budget, etc.) combined with interviews with stakeholders involved suggests that, despite the commitment to LNOB, there is little in those programs to ensure the fulfilment of the said commitment. For instance, the programs under review do not reflect on how the problems identified affect persons with disabilities, including women and girls, and how the proposed actions will address the identified problems. As a result, there is no specific indicators nor budget line for support and accommodation, and the monitoring and evaluation tools do not reflect a disability dimension. Stakeholders, involved in the implementation of the SI do recognize this incongruence, and suggest that this must be the case because the main donor (EU) did not emphasize disability issues in the call for proposals:

‘UN agencies are usually good in complying with donors’ conditions. So, I think that these issues [disability inclusion] was not highlighted in the EU call. Rather, the emphasis was on GBV’

However, irrespective of the donor’s requirements, UN agencies have an institutional obligation to ensure disability inclusion. The UN Disability Inclusion Strategy provides guidance to agencies within the UN system to advance disability rights as promoted in the CRPD and other agreed international legal and policy commitments.⁸² When asked about how the UN Disability Strategy informs the implementation of the SI, the stakeholders demonstrated not being familiar with the Strategy.

Findings also show how political commitments turn to be empty buzzwords without meaningful and tangible measures. The following statement from one informant makes the point clear:

⁸¹ Cerimónia de Abertura do Ano Judicial 2019- Intervenção do Bastonário, Flávio Menete. Retrieved <<https://www.oam.org.mz/cerimonia-de-abertura-do-ano-judicial-2019-intervencao-do-bastonario-flavio-menete/>>

⁸² UN Disability Inclusion Strategy. Retrieved <https://www.un.org/en/content/disabilitystrategy/>

‘The problem is that LNOB is just a commitment and not a target... it would be good if it was a target. But in the real world, it would be difficult to materialize in a project with 2 years of implementation’

This quote also illustrates the difficulties of designing and implementing a program aimed to include all the marginalized communities in a context where both expertise and resources are limited. For instance, the SI is dominated by women and feminist organizations with little or no expertise on disability rights. They tend to work together such that when asked about how the leading organization went about to form one of the consortiums implementing the SI, the response was that it was based on their previous experience of ‘working together and on similar issues’. In this context, it is hard for outsiders – namely OPDs who are traditionally marginalized - to be invited for such platforms.

The governance and implementation structure of both programs include representatives of groups considered marginalized. The SI has at the governance level (National Civil Society Reference Group) a woman with disability, who was deliberately recruited to represent persons with disabilities (representative of other groups such as LGBTIQ were also recruited). Among others, they are tasked with providing advice on their areas of expertise. The presence of a person with disability is frequently presented as testament of the program’s commitment to disability inclusion and LNOB, but in practice, their appointment amounts to tokenism representation, as the person is limited in what she/he can do to further disability inclusion given the lack of structure and space to advance the cause.

This is also true for the MCI project. Despite having a FAMOD delegation as an implementing partner in Niassa province, persons with disabilities are not adequately represented within the Committees. From eight existing Committees in Niassa province, only one has a member who identified himself as person with disability – the Mepapa Committee. There are several reasons for this. First the Committees were originally established by the District Services for Women Health and Social Action as Children’s Protection Committees; and others were established as Water Committees (Comités de Água). Membership to these Committees “was volunteered based... there was no precondition attached, except that there must be representative of children’s”, as observed by one representative District Social Services reflecting on the Children’s Committee. The MCI project capitalized on the existing structures – instead of creating new committees - and to avoid duplication, expanded them to include aspects of social protection. Yet, in doing so, the project did not pay attention to the configuration of these committees, so that members remained largely the same, and persons with disabilities are seen only as beneficiaries that “must be taken care of” and not as active participants in project implementation. Second, there is a lack of understanding of social protection from a disability rights perspective among the committee members, who were only trained on aspects of PSSB –eligibility criteria, target groups, among others. Finally, MCI does not collect disaggregated data on disability, making it difficult to know, objectively, which groups of persons with disabilities are beneficiaries and participate in the project implementation.

Implementing organizations of the SI were recruited through a call for proposals put forward by UN Women. The requirements and the process itself proved to be exclusionary for most local organizations, including those of persons with disabilities. To begin with, the call was published in English and the proposal had to be submitted also in English (in a country where

the official language is Portuguese). The proponents had to be legally registered to be eligible.⁸³ There was a possibility to apply as a consortium, and indeed at least one group - led by Women and Law in Southern Africa (WLSA Mozambique) – applied, which enabled small organizations, including community-based organizations, to participate. Yet, because the guidance from the call did not go far to address issues of disability representation (as it did in relation to community-based organizations), coupled with the proponent lack of awareness, the consortium does not include OPDs. As a result, there is no OPDs among the implementing organizations of the SI.

Because of this, both projects under review failed to address existing unequal power relations not only within the disability movement, but more generally. For instance, persons with physical disability - largely ex-combatants with disabilities or mine survivors-are likely to be the beneficiaries of the PSSB. As observed by one government official, ‘Niassa is a land of ex-combatants’. Ex-combatants with disability are relatively privileged within the disability community because they also receive specific benefits derived from their contribution to the colonial and civil wars. Those who participate are individuals who are relatively more privileged in the community. Even the person with disability who is member of the committee is so because he is as local leader (Secretário de Bairro). As he puts it “I had to be part of the Committee because I’m a local leader, which means I have to know what is being discussed and represent the community”.

Both projects achieved impressive results. Over the past 3 years, the MCI project contributed to consecutive increases of subsidies to PSSB (except for 2020), raising the share of GDP, from 0.3 in 2015 to 0.7 in 2019, and increasing the number of beneficiaries with disabilities from 4% in 2014 to 5.3% in 2019.⁸⁴ Moreover, the project established local and national forums where government, donors and CSO came together to discuss social protection issues. Likewise, the SI, ‘strengthened partnerships with civil society government institutions and the EU Delegation, bringing these diverse stakeholders together’ at provincial and national level and facilitated ‘consultations that led to the passage of key legislation such as law on child marriage’.⁸⁵

This has contributed to ownership of these laws by some groups, mainly women and feminist organizations who directly participate in the project implementation, in the case of the SI. Conversely, because representative organizations of persons with disabilities are not included

⁸³ UN Women (2019). Call for Proposal EVAWG MZ 2019/001 on Ending Violence Against Women and Girls (2019)

⁸⁴ INAS, Relatório Anual, 2019. Oxford Management Policy & OIT, (2014), Avaliação da Estratégia de Segurança Social Básica: documento de síntese.

⁸⁵ Spotlight Initiative (2019) Mozambique Annual Narrative Report.

in the project implementation, they are likely not to own the policies and laws that the project seeks to influence.

Conclusion

These data suggest three aspects which need to be considered to ensure the participation of persons with disabilities and, ultimately, their ownership of laws and policies that these programs seek to influence.

First, the findings highlight the centrality of political economic analysis in development cooperation and participation as pointed out in relevant literature.⁸⁶ Political economy analysis, provides ‘a more detailed and systematic analysis of the context, and a better understanding of who participates, in what activity, and for what motives’.⁸⁷ For instance, the political economy analysis of the CSO would have pointed out the fact that, given the history of exclusion and stigma toward disability, the disability movement is still somehow disconnected from the mainstream. It would have also pointed out to the heterogeneity and diversity within the disability movement and the fact that there are some groups more marginalized than others.⁸⁸ This realization would have led to specific strategies and incentives to engage persons with disabilities through their representative organizations or other means. The lack of this understanding perpetuates the domination of mainstream groups who are more organized and claim to ‘speak for those without voice’. In this sense, development programs contribute to perpetuate, rather than challenge, the status quo by not addressing the power relation within CSO and society more broadly.

Second, the findings also highlight the centrality of data disaggregation if development community are serious about LNOB. LNOB need to be more than simple commitment. There must be concrete activities and indicators on disability, and a system of monitoring and evaluation able to capture and make sense of the data that is collected.

Third, there is a need to move beyond disability awareness to more concrete actions aimed to support disability inclusion in practice. This involves setting up a mechanism - such as a disability focal point or desk - and tools - such as guidelines - to support disability inclusion. This would mean rethinking the typical framework of personnel working in traditional development agencies, by, for instance, including disability focal points with the aim of bringing in the expertise needed on these issues.

⁸⁶ OCDE, 2007.

⁸⁷ NORAD (2013) Framework for Analysis participation in Development.

⁸⁸ Westminster Foundation for Democracy ‘Towards Social, Economic and Inclusive Policies for People with Disability in Mozambique’ (2020).

10 Using audiovisual conference technology in qualitative research: lessons learned from the study

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Abstract

Semi-structured interviews are relevant research method that allows the researcher to solicit narrative accounts of individual experiences. Researchers use online semi-structured interviews for data collection in qualitative studies, particularly during Covid-19 pandemic. Based on the empirical work carried out for the study *'Voting Matters: An Analysis of the Use of Electoral-Assistive Devices through the Lens of the United Nations Convention on the Rights of Persons with Disabilities'*, this paper discusses four main aspects of online semi-structured interviews implementation: (i) using Voice over Internet Protocol (VoIP) as an adaptation and methodological alternative to conduct interviews during the COVID-19 pandemic; (ii) brief content-based literature recommendations for using VoIP in qualitative research; (iii) use of the Zoom platform; and (iv) four main lessons learned from using Zoom for individual and focus group coordination. This paper concludes that VoIP is a promising technology to host individual and focus group interviews for a qualitative study. Lessons learned described in this paper might be useful for researchers considering VoIP to carry out individual and focus group data collection in qualitative research, mainly during the coordination phase.

Introduction

International human rights law, and particularly Article 29(a) of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, 2006), sets out the obligation for States Parties to ensure that all persons with disabilities can effectively exercise a secret and independent ballot through *inter alia* positive measures, such as the provision of assistive and new technologies. Against this background, the study *'Voting Matters: An Analysis of the Use of Electoral-Assistive Devices through the Lens of the United Nations Convention on the Rights of Persons with Disabilities'* compiled an inventory of electoral-assistive devices which are already use. The extent to which these electoral-assistive devices are available to voters with disabilities in elections, and used by them in practice, was examined through semi-structured interviews conducted with persons with disabilities and election officials from England and Spain in the period September 2020 to March 2021. Interview guides were prepared based on the analysis of the legal and policy measures adopted by England and Spain to implement Article 29(a) UN CRPD.

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This study was conducted during the COVID-19 pandemic, when countries, including England and Spain, adopted various measures to slow the spread of the virus. Measures taken included limiting travel, quarantining citizens, and cancelling gatherings. These measures challenged the original modality of in-person interviews as proposed in the first ethics submission to the Ethical Review Committee Inner City Faculties (ERCIC) at Maastricht University (reference ERCIC_165_11_12_2019). Face to face interaction based on the physical presence of research participants and the researcher, with an appointment to collect data, was no longer possible and adaptation and methodological alternatives were required. Accordingly, a revised ethics application was made before the ERCIC in June 2020. The ERCIC was consulted regarding a proposed amendment to change the initial methodological approach (in-person interviews) to an online approach during the COVID-19 pandemic.

The ERCIC concluded that there were no ethical objections to the execution of the research project as amended. An explanation on the interaction with research participants of the interviews, which was conducted entirely through ‘virtual networking’ is provided below.

Voice over Internet Protocol (VoIP)

In the study ‘*Voting Matters*’, using VoIP technology was proposed as an adaptation to the methodology. VoIP is a method and group of technologies for the delivery of voice communications and multimedia sessions over Internet Protocol (IP).² It facilitates voice calls through a broadband Internet (or high speed) connection instead of a regular (or analogue) phone line.³ Elixmann et al.,⁴ define VoIP as the delivery of voice services over networks based wholly or partly on IP. In short, VoIP services convert people’s voices into digital signals that travel through the Internet. It connects people through virtual networking. VoIP also takes the center stage of recent debates on the implementation of qualitative research in the context of infectious epidemics, where face to face interaction with research participants needs adaptation and methodological alternatives.⁵

² Internet Protocol (IP) is the main communications protocol in the Internet Protocol Suite that has a routing function. Such a function enables internetworking and delivers ‘packets’ of data from the source host to the destination host based on the IP addresses. See VoIP-info.org, ‘What Is VoIP?’ (2015) <<https://www.voip-info.org/what-is-voip/>> accessed 26 May 2020.

³ Voice over Internet Protocol (VoIP) is also called ‘IP telephony’ see Federal Communications Commission, ‘Voice Over Internet Protocol (VoIP)’ (*Disability Rights Office*, 2019) <<https://www.fcc.gov/general/voice-over-internet-protocol-voip>> accessed 25 May 2020.

⁴ Dieter Elixmann, Scott J Marcus and Dr Christian Wernick, *The Regulation of Voice over IP (VoIP) in Europe* (Cullen International Wik Consult 2008), 1.

⁵ See for instance Cecilia Vindrola-Padros and others, ‘Carrying Out Rapid Qualitative Research During a Pandemic: Emerging Lessons from COVID-19’ (2020) 30 *Qualitative Health Research* 2192.

Brief recommendations for using VoIP in qualitative research based on a literature review

VoIP technology has increasingly been recognized as a scientific process for research inquiries.⁶ Weller⁷ identifies two main advantages of using VoIP in qualitative research. Firstly, VoIP facilitates convergence of voice, data, and video calls to landlines and mobile devices, which enables low-cost data collection in real time across the Internet. Secondly, VoIP allows recording video and voice calls. The voice recording function offers the same voice-to-text function as portable audio recorders, which is useful when analyzing the data with other software like Atlas Ti or NVivo.⁸

According to introductory texts, the novelty of using VoIP in qualitative research results from five principal VoIP's features: (i) software with VoIP requires informed consent from users.⁹ Usually, software with VoIP asks the interlocutor (research informant or participant) to consent to joining the meeting and connecting computer video and audio. It also gives the organizer (researcher) the option to activate video and audio recording functions; (ii) VoIP offers participants an opportunity to share information that they might not feel comfortable sharing in person;¹⁰ (iii) VoIP allows participants to exit the virtual meeting-session whenever they want;¹¹ (iv) VoIP has the potential to engage in research with hidden populations, and the comfort of participating from a convenient location without the need to travel;¹² and (v) VoIP makes it possible to make the best use of the information contained in the video calls.¹³ Non-verbal data are visible and do not depend on the researcher's sparse notes nor his or her memories.¹⁴ The authors assert *'The body movement's analysis offers, after the event, precious observations with the necessary condition that the exploitation of each case will be made with the same rigorous methodological protocol.'*¹⁵

⁶ See for instance Bertrand and Bourdeau (n 5); N James and H Busher, *Online Interviewing. Qualitative Research* (4th edn, UK: SAGE Publications Inc 2016); Henrietta O'Connor and Clare Madge, "Focus Groups in Cyberspace": Using the Internet for Qualitative Research' (2003) 6 *Qualitative Market Research* 133.

⁷ Susie Weller, 'Using Internet Video Calls in Qualitative (Longitudinal) Interviews: Some Implications for Rapport' (2017) 20 *International Journal of Social Research Methodology* 613, 613-625.

⁸ *ibid.*

⁹ Kimberly Nehls, Brandy Smith and Holly Schneider, 'Video-Conferencing Interviews in Qualitative Research' in Shalin Hai-Jew (ed), *Enhancing Qualitative and Mixed Methods Research with Technology* (IGI Global 2014), 140-157.

¹⁰ O'Connor and Madge (n 63), 134.

¹¹ Bertrand and Bourdeau (n 56), 75; Cory R Woodyatt, Catherine A Finneran and Rob Stephenson, 'In-Person Versus Online Focus Group Discussions: A Comparative Analysis of Data Quality' (2016) 26 *Qualitative Health Research* 741, 743.

¹² Weller (n 64), 620.

¹³ Bertrand and Bourdeau (n 56), 73.

¹⁴ Bertrand and Bourdeau (n 56), 73.

¹⁵ *ibid.*, 10.

Accordingly, previous studies have used technologies, including VoIP software to conduct online focus groups and online interviews.¹⁶ O'Connor and Madge¹⁷ argue that online and face-to-face interviews are similar for the researcher. Both can be considered '*conversations with a purpose*'.¹⁸ Similarly, a recent study by Woodyatt et al.,¹⁹ comparing online focus groups to in-person focus groups, concluded that online focus groups have the potential to produce a similar number of emerging themes and may be advantageous when discussing sensitive topics.²⁰

Other authors agree that there are important limitations to consider when conducting online focus groups and interviews including: (i) the need for participants to have a device that can run VoIP (computers, mobile devices, etc.);²¹ (ii) potential security and privacy risks;²² (iii) potential interruptions;²³ and (iv) technological difficulties.²⁴ Wettergren et al.,²⁵ suggest that these issues can be managed through solid research protocols. Following Wettergren et al.'s idea, the next section explains the specific software with VoIP properties that was used in this study.

Use of Zoom Platform in the study 'Voting Matters'

Zoom is a video communication enterprise with a reliable cloud platform for video and audio conferencing, collaboration, chat and webinars across mobile devices, desktops, telephones, and room systems.²⁶ This study used Zoom to coordinate online focus groups and individual interviews. It is noteworthy, however, that SURF Videobellen, a Dutch videoconferencing service like Zoom, was initially used to carry out pilot interviews due to its availability at Maastricht University (UM). However, the service provider SURF discontinued SURF Videobellen and UM advised PhD students to start using Zoom in their research.

For present purposes, there are four main reasons for using Zoom. Firstly, UM offers its PhD researchers access to Zoom through a private subscription, which helps to reduce security and privacy risks. Secondly, Zoom data storage settings can be administered by the researcher of this study using her private account. Thirdly, Zoom makes for easy conferencing even with users that are not part of the company account and through computers, tablets, or mobile devices. Fourthly, Zoom provides features such as multiple screen sharing to support web-

¹⁶ See for instance O'Connor and Madge (n 12); Woodyatt, Finneran and Stephenson (n 17); James and Busher (n 12); Nehls, Smith and Schneider (n 15).

¹⁷ Henrietta O'Connor and Clare Madge, "Focus Groups in Cyberspace": Using the Internet for Qualitative Research' (2003) 6 Qualitative Market Research 133, 137.

¹⁸ *ibid.*

¹⁹ Woodyatt, Finneran and Stephenson (n 17).

²⁰ *ibid.*

²¹ *ibid.*

²² Weller (n 13).

²³ Donna J Reid and Fraser J. Reid, 'Online Focus Groups' (2005) 47 International Journal Market Research Society 131.

²⁴ Jeanine Stancanelli, 'Conducting An Online Focus Group' (2010) 15 The Qualitative Report 761.

²⁵ Lena Wettergren and others, 'Online Focus Group Discussion Is a Valid and Feasible Mode When Investigating Sensitive Topics Among Young Persons with a Cancer Experience' (2016) 5 JMIR Research Protocols 1.

²⁶ <https://zoom.us/about>

based presentations, translation services, and interpreting services for persons with hearing impairments.

Lessons learned from using Zoom Platform

Based on the data collection process in the study ‘Voting Matters’, VoIP technology has offered the researcher a promising alternative means to carry out semi-structured interviews in the form of focus group and individual interviews. Coordinating and hosting online semi-structured interviews is challenging; however, coordinating individual interviews with election officials and focus groups with persons with disabilities located in two European jurisdictions (England and Spain) presented a set of unique circumstances to navigate. The research participants were geographically dispersed, and their schedules varied. Moreover, certain research participants required reasonable accommodations and other individualized supports. These combined individual-arrangement characteristics form an array of individual and focus groups scheduling challenges.

This section describes four main lessons learned from the use of the Zoom platform as an innovative method for collecting qualitative data.

Testing and retesting the Zoom Platform

Before using the Zoom platform to host individual or focus group interviews in the study ‘Voting Matters’, the researcher carried out numerous practice sessions to gain an understanding of, and develop practical skills in, the use of the video conferencing software application. This enabled the researcher to schedule and launch Zoom Meetings properly, as well as to develop practical skills in using certain relevant Zoom’s features, such as screen sharing, recording, and managing breakout rooms. During the practice sessions, the researcher became familiar with the videoconference service functioning. This knowledge helped the researcher to elaborate a ‘getting started guide for new Zoom users’ and a list of frequently asked questions, including common problems users come across. Both documents -the user guide, and the frequently asked questions list- were part of the information sent to potential participants to request consent and were designed in accessible formats. These documents included a description of the Zoom platform to be used in the sessions and the hardware required to participate (desktop or laptop computers, tablet, or mobile device). The user guide contained an individualized URL and instructions about how to join the individual or focus group interview. The researcher shared these documents with participants to properly inform them on how to access the meeting space. This practice helped participants to make an informed decision about their participation in the study. The guidelines also served to promptly answer some of the most common questions users could potentially have about Zoom before the date of the interview. This reduced the time allocated to answering these questions at the beginning of each session. This experience validated the importance of carefully testing and retesting a VoIP conference service to determine its reliability for research purposes.

Establishing Effective Lines of Communication

The primary mode of communication with participants to coordinate interview sessions was email. Nevertheless, during the coordination of the individual and focus groups interviews, some participants did not respond to the researcher’s email of confirmation in a timely manner. By virtue of the fact that people’s reliance on mobile phones and mobile applications is extensive, the researcher considered it valuable to know phone numbers of participants (in addition to their email addresses) to communicate with them more expeditiously (where

necessary). Therefore, text and WhatsApp messaging and phone calls were adopted as the secondary mode of communication to follow up with participants during the individual and focus groups coordination process. Participants indicated that because they did not always have access to their emails, text message and phone calls reminders sent by the researcher on the morning of their scheduled session were especially helpful. The researcher learned that when scheduling interviews with geographically dispersed research participants, asking them to identify their preferred mode of contact could save time and mitigate challenges associated with arranging sessions.

Establishing responsiveness

During individual and focus groups interviews coordination several points of contact occurred between the researcher and each participant. Initial correspondence typically occurred via email. In most cases, communication also took place by phone, followed by several additional points of contact, usually via text and WhatsApp messaging. On the day prior to and the morning of each scheduled individual and focus group interview, the researcher sent text reminders to participants. In doing so, the researcher learned that having multiple points of contact with participants helped to develop a favorable rapport between participants and the researcher, which facilitated introductions and social exchanges before starting each session. This also stimulated a more open and friendly discussion.

Connectivity: Access to the Zoom meeting

As explained above, the researcher sent an email to participants before the meeting containing an individualized URL and instructions about how to join the session. The researcher also encouraged participants, via a morning text or WhatsApp message reminder, to watch for and open the pending invitation access email, and to click on the embedded URL at least 5 minutes before the scheduled start time. The 5-minute lead time allowed the researcher and participant to establish a connection and address any technical challenge prior to the session start time.

Some focus group participants could not maintain a video connection or were only able to establish an audio connection. These participants were not excluded from the focus groups in accordance with the focus groups protocol established in the study 'Voting Matters'. Even though video images were a relevant element for measuring the level of group engagement and communication, the breakdown of video connectivity was not deemed sufficient to justify exclusion of a participants' valuable contributions to the group discussion. In most of the focus groups, participants shared their webcam images during the entire session. It is also noteworthy that computer video and audio connection was substantially better than tablet or mobile device connection. This finding might be useful for recommending other researchers to encourage participants to use laptop or desktop computer with a solid wireless signal or Internet connection (where available).

The researcher learned of the relevance of having extra time at the beginning of each session, to control any potential technical challenges and address them properly. She also learned the importance of allowing participants to take part in the session through video or audio connection, depending on their individual preferences and possibilities.

Conclusion

Using Voice over Internet Protocol (VoIP) expanded the options for participant recruitment and data collection methodology in the study 'Voting Matters'. It was possible to reach and

include research participants from England and Spain during the Covid-19 pandemic. VoIP offered a suitable venue for online semi-structured interviews that supported research participants engagement and interaction in the data collection processes. VoIP provided a communication technology to host individual and focus group interviews for geographically dispersed groups of research participants from England and Spain.

Available literature in this field confirms this positive evaluation of using VoIP for data collection in qualitative research. Furthermore, new knowledge emerged from lessons learned while using Zoom platform for data collection in this study, particularly during the coordination of individual and focus group interviews. Other researchers considering using VoIP to carry out online semi-structured interviews data collection in qualitative research might find useful the following four lessons learned: (i) test and retest the chosen videoconference service to determine its reliability for research purposes; (ii) establish multiple and effective lines of communication with participants to confirm interview appointments; (iii) establish multiple points of contact to facilitate introductions and social exchanges before interview sessions; and (iv) encourage participants to access the virtual meeting space before the scheduled start time to identify and address any potential technical challenge, as well as to allow participants to establish audio or video connection depending on their individual preferences and needs.

11 Literature in action – placing the European Disability Rights movement within social movement scholarship

Claudia Harris Coveney

Abstract

This article will track the ascent of disabled European citizens and their organisations into the sphere of European governance, via the creation of an EU-level civil society organisation called the European Disability Forum. It is based on initial reflections of the data-collection phase in a research project titled: ‘A history of European disability movements: Civil society, social movements and opportunities for counterhegemonic resistance’. The research is part of the Disability Advocacy Research in Europe (DARE) project. The data consist of semi-structured interviews and documentary analysis linked to the partner organisation of the research, the European Disability Forum. The article places the story of the organisation within the social movement literature. It first locates the creation of the research’s focal organisation within the theory of political opportunity structures and its criticisms. It argues that while ‘political openings’ did indeed play a role in the successful creation of this organisation, the mobilisation strategies of the movement were what allowed these opportunities to be seized upon. An overly structural perspective does not acknowledge the agency and strategic power of actors involved in social movement struggles. Therefore the article acknowledges the opportunity structure at play in this organisation’s story as well as in individual agents that seized on and mobilised resources. The article then reflects on some initial findings of the research, primarily contested accounts, and concludes by asking where these might fit into social movement literature.

Contexts and methods

The present article focuses on the disabled people’s movement (DPM) in Europe. From the movement, a smaller collective prompted the creation of the European Disability Forum (EDF). The collective contained members of European disabled people’s organisations (DPO) networks, national Member State DPOs and members of international disability networks like Disabled People International (DPI). This collective was calling for a European-level DPO with stable funding that would represent the voice and interests of disabled European citizens at the European level. The organisation initially appeared as an internal advisory board within the European Commission, as part of a pilot programme aimed at addressing the exclusion of disabled people in the European Community, before achieving independence. The data discussed in this article were collected via interviews with past and present members of the EDF, particularly those who spoke about the very early years of the organisation. It also uses archival information provided by Professor Lisa Waddington from the period before and during the EDF’s separation from the European Commission. While the focus of the research project is primarily on three campaigns that the organisation has run, the present article focuses on some initial findings that are not directly linked to this. The next section will connect the activity of the collective of disabled activists pushing for representation at the European level with concepts of contentious politics and structures of political opportunity.

The DPM, social movements and collective action

The disabled people's movement (DPM) has a long and rich history. It contains many factions, regionally and politically, with some aiming for more radical systemic overhaul and others demanding rights recognition within a current system (see for example Dreidger, 1989; Oliver & Campbell, 1996). As an international social movement, it tells many stories of the creation of collective disabled identities and contentious collective activity, challenging attitudes and structural excluding barriers (Tarrow, 2011: 7). With this in mind, it is helpful to consider the roles of actors within a movement. Groups within a movement are formed based on perceptions of how best to realise their goals, and what societal changes are needed to do so (Carroll & Ratner, 2001). Tilley's summation of social movements not as a cohesive, homogenous groups feels pertinent in conceptualisations of the DPM. Social movements should rather be viewed as 'bounded, contingent, interactive performances by multiple and changing actors' (1999: 256).

Collective action exists outside of social movement activity. Be it brief or sustained, institutionalised, disruptive or dramatic, it occurs regularly within an institutional framework. It becomes more synonymous with social movement activity when it is contentious. Contentious politics are used by people who lack regular access to representative institutions, in the name of new or unaccepted claims and who behave in a way that challenges authorities (Tarrow, 2011: 29). Such authorities are responsible for creating and sustaining law and order, and setting societal norms. The aim of challenging the authorities is to force change to laws and norms. This can be connected to the idea of counter-hegemonic resistance: groups can challenge cultural hegemonic structures through contentious politics and through this create changes that move society towards a more acceptable condition, according to the aims of the movement (Gramsci, 1971; Oliver, 1990). The creation of the EDF, and wider campaign for recognition by disabled activists in Europe began with contentious political action – this was a group who engaged in, alongside protest activity, strategic lobbying, and building alliances of support with MEPs who made up the Disability intergroup in the European Parliament. The following quote is from an interview with a disabled activist involved in the very early years of the EDF:

“And I think it was thanks to the relationship we had built with European Parliament ... they created the pressure on the European Commission ... the European Parliament used their budgetary powers to force the European Commission system to have the budget line, a separate budget line for independence.”

Structures of political opportunity

To what extent should a group's success or failure be explained by the 'structures' of a given political system? To place the story of the EDF within the literature of political opportunity structures is to weigh in on the 'structure/agency' debate of sociology. Structural approaches to social movement scholarship emphasize the role of resources, political structures, organizations, and networks (Goodwin & Jasper, 2004). Eisinger (1973: 25) defined political opportunity structure as 'the degree to which groups are likely to be able to gain access to power and to manipulate the political system'. As the story of the creation of the EDF demonstrates, opportunities must be recognised and seized upon by activists. The agency of groups can become lost in structural explanations (McAdam, McCarthy & Zald, 1996: 25; Polletta, 1999). This approach is also in danger of viewing opportunities as being created in a vacuum, whereas they are often the result of action by agents of social change. Suffice to say,

the degree to which a state system (consciously or unconsciously) allows social movement groups to achieve influence and change is a crucial factor in success for movements. Open and closed structures intersect with high and low capacity to implement policies, the strategies of movements are affected by their institutional policy. In 'open' phases of a political systems, social movement groups might face a greater range of opportunities to work closely with state actors (Kischelt, 1986; Tarrow, 1996). The following section described this fluctuation in the context of the European Community, and the result for disability rights activists in Europe. It is based on the previously referenced data collected for the ongoing research project

Structure & agency in action – European democracy, civil society and the EDF

In the last decade of the 20th century, several important changes were taking place in the European Community that created opportunities for the European DPM. The first was that the European Union had faced several rebellions against the Treaty on European Union (TEU), specifically the 1992 Maastricht Treaty. This Treaty laid much of the fundamental groundwork to integrate Member States into a single European institutional framework – for example the creation of a single European currency. The following amending treaty, the Amsterdam Treaty signed in 1997, transferred some national powers to the European Parliament and expanded the scope of European jurisdiction to European citizen rights in employment, specifically naming minority groups to protect against discrimination. These changes were designed to better realise the concept of European citizenship and increase the democratic functions of the Union. Part of this involved creating spaces for non-government groups to interact formally and informally with the European institutions. The Maastricht Treaty signalled a shift away from unspoken agreement between the public and national governments to shift parts of Member State decision-making to the European level. This consensus faded away in the early 1990s as critical engagement with European integration increased (Hooghe & Marks, 2008). This was evidenced by the increased public debate in Member States about European integration which resulted in more political and scholarly attention towards the democratic nature of the EU.

As well as increasing scope being gradually given the European Parliament, civil society became an important tool for increasing the democratic functioning of Europe. This was a sphere in which independent organisations representing the interests of European citizens could communicate directly with the European Institutions. The prominence of NGOs in European decision-making has increased since the Maastricht Treaty and led to the creation of a funded 'Social Platform' of EU civil society organisations. Their increasing presence in policy can be tracked, as Kohler-Koch (2012) describes, via the changing terminology used in Commission documents about its relationship with these organisations – from 'involving civil society' to 'co-production of policy'.

Another important change was the action being taken by the European Union bodies to address the vast inequalities faced by disabled European citizens. The decade of 1980 was an important one for disability rights movements around the globe. Alongside the production of the UN Standard Rules, the European Commission was running thematic workshops and pilot programmes from 1982 - 1986, and 1988 - 1991 respectively. The first pilot programme was a network of Community action programs, mostly focused on vocational training for persons with disabilities to promote their inclusion in the labour market. The projects also involved consultations between project managers and departmental figures from national-level governments, acknowledging the need for support from non-governmental organisations. Innovative learning exchanges examined action taken at the national level towards the

promotion of independent living, education and employment, and coordinated the sharing of best practices by Member States. The programmes were part of a shift in the approach to addressing the inequality and oppression faced by persons with disabilities in Europe. They promoted the move towards supranational support and coordination for Member State governments. The programmes also included more promotion of social integration and independent living, recognising areas outside of the labour market where persons with disabilities face discrimination and unequal opportunities. However, they were mainly consultations between experts and governmental actors. The European DPM collective were not given due space in the programme and the voice of disabled people themselves was not heard. From an interview:

“It was really this tendency to pay more attention to service providers and experts, if it were up to the European Commission. Under the first pilot programme we had nothing basically. Other than a bunch of angry disabled people including myself that weren't involved in consultation.”

In 1993, the third programme was launched that included an arm of representative disability organisations: 12 pre-existing national disability councils from EU Member States, and European non-governmental organisations (ENGOS) that promoted the interests of persons with disabilities. It was a much more comprehensive programme than its predecessors, and shifted the voice of persons with disabilities to the centre of its activities. This programme sought to create a ‘Community-level’ policy to complement national level actions aimed at equalising opportunities for persons with disabilities, and increase co-ordination between member states in the area. It also placed focus on increasing the capacity of pre-existing representative DPOs, carrying out applied research, and information campaigns. Interviewees acknowledged the role of the open, changing structures here:

“When the European Parliament started to make a budget line available for projects led by disabled people organizations ... this exchange of experiences and the fact that we could start having our own projects, that lead to more awareness. It was indispensable. We're very grateful to the intergroup of European Parliament. You probably heard, this is the oldest intergroup in European Parliament, the very first that ever existed, and I think that's the informal network of European parliamentarians that created the right conditions.”

More importantly, successful lobbying had led to the internal advisory group within the Commission becoming an external, independent organisation made up of the network of European and national DPOs within the Member States. This organisation would advise on Community policy related to the field of disability and would receive funding from the Commission. In 1996, the EDF became independent. Since this time, its membership has grown to more than 100 organisations and its political reach has continued to expand, from its involvement in the drafting of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and implementation in Europe to the prompting of two decade-long specific European Disability Strategies and the mainstreaming of disability interests into all policy areas within the European Union’s jurisdiction. The ever expanding Annual Reports evidence the wide range of advocacy activity the EDF engages in.

Reflections

The creation of a European public sphere to increase democratic functions in the EU and the increase in representative bodies to operate within this sphere created an opportunity for the EU DPM to occupy a space there. The European Union was consciously opening itself up to citizens, creating spaces for them to voice their interests and participate in democratic processes. This opening up was in response to public pressure placed on the European institutions. Organisations like the EDF needed to become included in such processes, after decades of being spoken on behalf of, also required a highly strategic approach. The EDF is the culmination of a 15-year campaign for voice, recognition and inclusion. The result is a highly strategic organisation that operates from its embedded position within the structures of the EU.

The position of this organisation is strong – it has been instrumental in the introduction of legislation targeting anti-discrimination in employment, independent living and accessibility, to name a few examples. It has also orchestrated regular events that other European NGOs are not privileged to, such as the European Disabled People's Parliament and meetings with all three Presidents of the European Institutions. With the increased strategic power of the EDF, more opportunities have appeared for it to voice the interests and concerns of disabled people in Europe. Increasingly it is being called upon as an expert advisor on disability policy.

Despite close communication and work over the past 25 years, in a position of high access to figures of influence within the European institutions, the EDF is still fighting for basic human rights for its community. Disabled people in Europe still don't all have the ability to exercise their right to vote, still can't completely exercise their right to free movements around Europe because of discriminatory transport factors, still can't enter all public buildings due to accessibility issues, and see new inaccessible public buildings being built with European structural funds. Many continue to reside in institutions, segregated from their communities, experience disproportionately high rates of unemployment, are still committed to employment in sheltered workshops (increasingly so in some Member States like Germany), and still cannot always attend mainstream education. The EDF has proven its competence repeatedly in navigating the labyrinthine processes of European policy and its ability is not in question. Rather, attention can be called to political opportunity structures and their outcomes. Further research into outcomes of political opportunity structures being seized would provide more clarity to questions of the types of success a social movement can achieve through engagement with the state.

Another area that would benefit from further research is that of selection. Social movements, as stated at the start of this article, are the combination of many groups and frequently changing actors. The organisation examined here represents one culmination of the EU DPM. It serves the purpose of formal representation at the EU civil society level and maintains an influential position in monitoring policy to ensure the needs, interests and concerns of disabled people are present in European decision making. Through campaigns and lobbying, counterhegemonic resistance and social change is possible through these mechanisms, as the work of the EDF shows. This work occurs alongside activity by more radical factions of social movements who would not be accepted in civil society spheres, sometimes complementing one another, and sometimes 'bumping up' against one another. The EDF works to represent the interests of all disabled people around Europe. An obvious tension lies between which organisations are selected by the state to be included in the civil society sphere and the EDF's task in making

sure the spectrum of the movement's views are heard at the European level. It would benefit from further academic attention.

Conclusions

This article was written based on initial reflections from the data-collection phase of a current research project. It is a collaborative endeavour with its partner organisation also being the focal point of the research. The article placed the story of the organisation's creation within the 'political opportunity' school of literature to raise questions of structure and agency in social movement activity. It then turned to questions of the outcomes of social movement activity with the state, and the task of the EDF to represent the entirety of the movement's voice at the European level. It finally called for further academic attention in these areas to shed more understanding onto the area of social movement activity in civil society arenas.

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12 Women with Disabilities involved in Activism and Social Movements in Europe: Some initial reflections following Data collection

Aoife Price

Abstract

The chapter focuses on some of the initial reflections that I as a researcher have following data collection. My research focuses on women's activism in social movements throughout Europe with a focus on the disability and the women's movement and the relationship between them. I will first explain a bit about the background to my research and set the context before discussing how I collected the data and the practicalities of that. Following that I will discuss some of the demographic information I received from participants and how I believe it will enhance the study. Finally, I will reflect on my own positionality and disclosure and the impact I believe this had on participants and their participation in the study. Following completing of data collection, it is a good time to pause and reflect on the research prior to starting analysis. It is important to understand aspects of the overall population and the context to interpret the narrative in its entirety. It is for that reason that I have chosen to look at these aspects of the research for the end of year chapter.

Research aims and objectives

My research examines disabled women's activism in social movements throughout Europe with a focus on the disability and the women's movement. Through hearing directly from disabled women about their experience I believe that I will be able to address the aim of the study which is to understand participation and how to best include disabled women in social movements.

The objectives of the study are to:

Explore:

1. The meaning and purpose of participation and involvement.
 - Experiences of participation in both movements and beyond.
 - Relationships between movements as the women see it.
 - Hopes going forward.
2. Trace the emergence of the voice of women with disabilities/disabled women in social movements and the impact of that at different levels (local, national & international).
3. Reflect on how social movements can best facilitate and work together to enable the voices of women with disabilities/disabled women.

Context and background

We began to see the emergence of the disability movement since the 1970s. The creation and growth of Disabled Peoples Organizations (DPOs) was significant. They drew strength and were influenced by the rise of feminist, civil rights and anti-racist movement in setting their aims and refining their tactics. The disabled people's movement was run predominantly by men and women have argued that disabled women's issues were sidelined. Male leaders did not always regard disabled women's rights as worthwhile campaign issues. In efforts to address this Disabled Women began to organize together, however this was often disrupted and discouraged

by disabled men. Similarly, to feeling sidelined in the disability movement women often felt but their concerns were not heard in the feminist movement, and they have struggled to find their place in both movements. However, in recent times we have seen that disabled women are finding each other and forming groups to relate to and share experience with. This has led to the development of some political organizing and what could be called a disabled women's movement. The Beijing conference in 1995 marked a watershed in terms of disabled women's inclusion in the women's struggle for rights. It laid the ground for a growing group of disabled women who would become involved in campaigning for the rights of women in the development of the CRPD. The convention has led to greater clarity about the breath of possibilities for disabled women to build movements within and across countries¹.

General comment number 3² from the United Nations Committee on the Rights of Persons with Disabilities (CRPD) looks at article 6, focusing on women and girls with disabilities. In point 60 they make a comment on the participation of women in political and public life stating the voices of women and girls with disabilities have historically been silenced, and thus women and girls with disabilities are disproportionately underrepresented in public decision making. The CRPD Committee has urged state parties to take measures to make sure that women with disabilities are enabled for participation in public decision making including in the cases of Armenia³, Luxembourg⁴, and Seychelles⁵. The CRPD committee also emphasises the importance of state support and encouragement of the establishment of organisations of women and girls with disabilities, as well as the participation of women with disabilities in leadership roles of disabled people's organisations⁶

Data collection

Pilot interviews

I wrote my initial interview guide and tested it through a pilot interview in October with a DARE colleague who has been involved in activism and met all the criteria of the study apart from being European so was an ideal candidate for this. Piloting is sometimes referred to as

¹ Janet Price, *The seeds of a movement: Disabled women and their struggle to organise* (Changing their world, 2011)

² Committee on the Rights of Persons with Disabilities, *General Comment No.3 (2016) on women and girls with disabilities* (United Nations 2016)

³ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Armenia* (United Nations 2017)

⁴ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Luxembourg* (United Nations 2017)

⁵ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Seychelles* (United Nations 2018)

⁶ Committee on the Rights of Persons with Disabilities, *General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention.* (United Nations 2018)

pretesting or trying out of a particular research instrument⁷. One of the aims of conducting a pilot interview is to increase the quality of the research⁸ and should be viewed as a crucial part of the research⁹. The focus is not to simply justify the method, but it is about modifying questions and the procedure¹⁰ to figure out what works best and how to get the most from interviewees. The schedule was far too detailed, and we did not get close to finishing the interview after two hours of conversation. I reflected on this, and I decided to shorten the number of questions significantly and focus on broader and more open questions. I then piloted an improved version of the schedule with a colleague in the European Disability Forum who met all the criteria of the study, and this interview went much smoother and ended within a reasonable time frame. I was happy to move forward and start recruitment at this point. In the end the final interview guide asked about their background and history as well as questions about views on the disability and women's movement and the relationship between them and about their understanding of social movements and what activism means to them, all questions that were covered in the initial schedule but this time by asking less and more open and broad questions that would provide me with an understanding of participants views and activism.

Recruitment and selection

I recruited people in several different ways. Through the European Disability Forum (EDF), European Women's Lobby (EWL) and through reaching out to people who had been personally recommended to me via colleagues from the EDF Women's committee and through the Disability Advocacy Research in Europe (DARE) project. I also found some people of interest online and reached out directly to them. In total I recruited 53 eligible participants from 23 countries. In a few cases people did not meet all the eligibility criteria and therefore I did not interview them. The eligible criteria included (1) identifying as a disabled women/women with disability, (2) being from or located in Europe, and (3) being over the age of 18. I used the process of purposeful sampling to recruit suitable participants. Purposeful sampling is a technique widely used in qualitative research for the identification and selection of rich cases¹¹. It involved identifying and selecting individuals that are especially knowledgeable in the area of study¹². In the case of this research I had an inclusion criterion that women needed to identify as a person with disabilities/disabled person to take part in the research so the call was

⁷ Therese. L. Baker, *Doing Social Research* (McGraw-Hill 1994)

⁸ Greta Björk Gudmundsdottir and Birgit Brock-Utne, 'An exploration of the importance of piloting and access as action research' (2010) 18 *Educational action research* 359

⁹ Yujin Kim, 'The Pilot Study in Qualitative Inquiry: Identifying Issues and Learning Lessons for Culturally Competent Research' (2011) 10 *Qualitative social work : QSW : research and practice* 190

¹⁰ Gudmundsdottir and Brock-Utne, 'An exploration of the importance of piloting and access as action research'

¹¹ Michael Quinn Patton, *Qualitative research & evaluation methods: integrating theory and practice* (Sage Publications 2014)

¹² John W. Creswell and Vicki L. Plano Clark, *Designing and conducting mixed methods research* (2nd edn, SAGE Publications 2011)

quite specific. In addition to knowledge and experience willingness to participate was an important factor¹³. I believe that more people made themselves available when they knew that it was only one interview, and they could do it from their own home over Zoom. Most were working from home at the time and with lockdown over most of Europe because of the global pandemic, people had some additional spare time. I believe that many were more willing to give me their time because of this. The nature of interview samples has changed as more flexible options for interviews can happen and travel barriers are removed which results in a wider social and geographical involvement¹⁴. I would have liked the opportunity to meet the women I interviewed but making the most of the current situation I believe I reached a broader and more diverse population which I am grateful for. The interview period started in October 2020 and ended in April 2021. I continued to recruit once I started interviewing but once I got many acceptances, I decided to cease active recruitment.

Practicalities

The practicalities of organizing and carrying out the interviews took a lot longer than I expected. I had a lot more participants to deal with than I initially thought I would have. From October 2020 to April 2021, I gave most of my time to organizing and carrying out the interviews. Most interviews went to plan with no technical difficulties however in one case we had to move to a written submission because the connection would not work at all and we had rescheduled already on two occasions. Participants selected the time and date that suited them, in some circumstances people need to change the date and time at short notice and this was always facilitated. I was flexible with my time. I worked into the evenings and at weekends over the period as I was aware that this may suit some participants best. Interviews generally lasted 1 hour and 30 minutes with some lasting longer or shorter than this.

Ethical Considerations

There were several ethical considerations to be managed during the research. These were addressed within the ethical application. These included risks to both the participants and the researcher including but not limited to distress, misinterpretation of the persons experience, informed consent, withdrawal from the study, disclosure of sensitive information, the non-anonymized nature of the data, and personal management of data. In terms of a code of practice I took guidance from NUIG protocols as well as the Social Research Associations code of practice for safety of social researchers.

¹³ Bernard H. Russell, *Research Methods in Anthropology: Qualitative and Quantitative Approaches* (Blue Ridge Summit: Rowman & Littlefield Publishers 2017)

¹⁴ Elizabeth Salerno Valdez and Aline Gubrium, 'Shifting to Virtual CBPR Protocols in the Time of Corona Virus/COVID-19' (2020) 19 *International journal of qualitative methods*

In a small number of cases interpretation was used. The consent and information sheet were translated into German Spanish and Italian. I am confident that these translations were accurate. Interviews were also carried out in those languages as well as in Romanian and Croatian and although this allowed for wider participation, I cannot be fully sure that all interviews were interpreted 100% accurately word for word.

COVID context and impact

I believe that the COVID situation presented many opportunities as well as challenges. At first, I was reluctant to interview online but when I knew there was not another option, I embraced it and believe it worked well. It meant that I could reach much more women that I would have been able to in person. For example, I interviewed 53 women from 23 European countries, and this may not have been possible to do in person. With a change to my initial plans, I moved to online interviews over Zoom. Patlow¹⁵ notes that online interviews have been technically challenging for people with disabilities. I did not find this the case. Others expressed concerns about the relationship between interviewee and interviewer and that this may be impacted by the move to online interviews. O'Sullivan et al¹⁶ finds that being able to maintain research relationships at a distance has been a consideration and challenge in the recruitment and retention as well as in building trust. Although this was a major concern of mine as noted above, I believe that I have built and sustained relationships with those I interviewed. I spent a lot of time making myself known and available to participants. This included an open conversational tone from the outset as well as being available to talk online or over the phone relating to any questions or concerns. I will work to continually update and inform participants of the progress of the project as well as being available and open to discuss ideas about future dissemination.

¹⁵ Emma Partlow, 'Prioritizing Inclusion, Ethical Practice and Accessibility During a Global Pandemic: the Role of the Researcher in Mindful Decision Making' in Helen Kara and Su-Ming Khoo (eds), *Researching in the Age of COVID-19: Volume II: Care and Resilience*, vol 2 (Bristol University Press 2020)

¹⁶ Katriona O'Sullivan and others, 'Exploring the Impact of Home-Schooling on the Psychological Wellbeing of Irish Families During the Novel Coronavirus (COVID-19) Pandemic: A Qualitative Study Protocol' (2020) 19 *International journal of qualitative methods*

Results and information on research participants

Research participant mapping



Ireland	13
UK	10
Serbia	3
Turkey	2
Spain	2
Poland	2
Malta	2
Hungary	2
Germany	2
Croatia	2
Switzerland	1
Sweden	1
Romania	1
Norway	1
Netherlands	1
Moldova	1
Latvia	1
Italy	1
Iceland via Ireland via Albania	1
Iceland	1
Finland	1

Belgium	1
Albania	1

I managed to have conversations with participants throughout in Europe. This was made possible through my work and position with the European Disability Forum as well as my connections through the Disability Access Research in Europe programme and at the Centre for Disability Law and Policy (CDLP) at National University of Ireland, Galway. The European Women’s Lobby and the National Women’s Council of Ireland also helped in spreading the word and gaining participants. I believe the diversity and variety of countries and participants examined will add a lot of substance to the analysis as well as the ability to draw comparisons across the region.

Age range among participants

In terms of age, participants ranged from 22-76, with an even distribution in each age category as can be seen below. This distribution and good mix of age ranges will allow for different levels of experience as well as generational comparisons. It also allows for reflections on how things have changed or if they have changed for the younger generation and how things might be differing for them and their participation into the future. I was delighted to interview young women still at university and involved in the student movement as well as people who are veterans of the disability movement, all who had an important contribution to make to this study.

under 25	4
25-35	13
25-45	12
45-55	12
55-65	8
over 65	4

Type of impairment

People identified as having different impairments. Important to note when referring to multiple impairment - many who had psychosocial disabilities identified here as well as people with neurodivergent or with cognitive and learning disabilities. Some had a combination of these and a physical disability. Asking about type of impairment was a tricky one as I did not want to categorise people by disability or impairment, but I also wanted to ensure that I had people who had different experiences and disabilities and therefore that is why I asked this question. It also filtered out some people who wanted to take part but did not identify as having a disability themselves but were the parent or carer of someone with a disability and therefore did not meet the eligibility criteria. People interviewed identified as having many different types of impairments including physical disability, multiple impairment, visual impairment, intellectual disability, deaf, deafblind, autism, psychosocial disability, neurodiverse, a small number of people preferred not to answer this question but identified as having a disability.

Physical disability	25
Multiple impairment	9
Visual impairment	6

Intellectual disability	4
Deaf	3
Deafblind	1
Autism	1
Psychosocial disability	1
Did not say	3

Sexual orientation

Many of the participants in the research identified as part of the LGBT+ community and they have highlighted this as an important element. This was not a specific question in the research and emerged naturally through the interviews. LBT women may face multiple discrimination through homophobia within disability communities and services, therefore this will be important to focus on in the analysis as well as the space for LBT women within the disability and LGBT movement and if it will be possible to draw comparisons with disabled women's place in the women's movement and the LGBT movement¹⁷.

Reflexivity

Positionality

I think it is important for me to address my own positionality when it comes to the research as I am very much connected to the research on a personal as well as an academic level. I identify as a disabled researcher and as a disabled woman. This is an identity that has been with me since I was very young. I have been involved in social movements of one kind or another for as long as I can remember, and I believe that they are important parts in my life and informing the person I am today. Since beginning the PhD, I have had the pleasure of meeting women from all over Europe and beyond through my work with EDF, CDLP, DARE, EWL and Disabled Women Ireland (DWI) and I believe that my interaction with these women has strengthened further my identity as a disabled woman and as a disabled researcher. I am proud to be part of a vibrant disabled women's community and believe that great change can be created through working together and supporting each other. I consider myself as having a dual identity as being both a researcher and a member of the community. I would be what is considered an 'insider researcher'. This is not uncommon in research¹⁸¹⁹. The approach is where the researcher positions themselves in their research so shared experiences and understandings better explain the research topic²⁰. Such positioning is not simply a source of

¹⁷ Spanish National Organisation of the Blind (ONCE), *General Discussion on Women and Girls with Disabilities* (Committee on the Rights of Persons with Disabilities 2014)

¹⁸ Paul Hodkinson, 'Insider Research' in the Study of Youth Cultures' (2005) 8 *Journal of youth studies* 131

¹⁹ Jodie Taylor, 'The intimate insider: negotiating the ethics of friendship when doing insider research' (2011) 11 *Qualitative research* : QR 3

²⁰ Sue Wilkinson and Celia Kitzinger, 'Representing Our Own Experience: Issues in "Insider" Research' (2013) 37 *Psychology of Women Quarterly* 251

bias but can provide valuable insight. Being part of a community can give a greater understanding of viewpoints to formulate appropriate questions that might not occur to those from outside²¹. The shared experiences between the researchers and participants can give an insight and understanding of the data that may go unnoticed by other researchers, potentially leading to more reliable data interpretation²². I believe my position very much influences my research and the entire process of how I go about things from recruitment to selection of participants right through to analysis of the data and writing up. I think that people were more willing to interview given my peer status and past and present involvement in disability activism. This is a key feature in disability studies, and some have claimed that scholars not involved in activism to support disabled people or actively right oppression are simply adding to their repression²³. Both feminist and disability studies point to the danger of empirical detachment from the process arguing that researchers must locate themselves within the research and reflect on their influence and positionality²⁴, and that the research is an embodied experience²⁵.

Disclosure and building rapport

I made the decision to disclose my disability from the start. This is something that I had always planned to do and indeed think it would be impossible not to give in my online profile and work to date. When I emailed potential participants about the project, I let them know a little about my background and work to date. I think that this helped in terms of participants getting on board and agreeing to participate in the study. Building rapport was something that was particularly important for me in terms of respecting the participants and keeping them engaged. I built this by adopting a friendly open conversational tone prior to the interview. I was available to answer any questions or concerns that the potential participant may have. I also kept the conversation open, and participants engaged post interview. I believe it is very important to keep participants engaged.

Conclusion

In this paper, I have outlined the data collection process in detail from piloting the interview to recruitment and selection of participants. I explain a little about some details of the participants including what countries they are from, their age range, impairment type and sexual orientation. Finally, I outline my own positionality within the research and how I feel this had an impact on the recruitment, selection, and retention of participants. I was delighted to receive such a diverse range of participants and am very grateful for the time that they gave to this project.

²¹ Michael C. LaSala, 'When Interviewing "Family": Maximizing the Insider Advantage in the Qualitative Study of Lesbians and Gay Men' (2003) 15 *Journal of gay & lesbian social services* 15

²² Madelaine Smales and others, "'Surviving not thriving": experiences of health among young people with a lived experience in out-of-home care' (2020) 25 *International journal of adolescence and youth* 809

²³ Mike Oliver, 'Changing the Social Relations of Research Production?' (1992) 7 *Disability, handicap & society* 101

²⁴ Erica Burman, 'Engendering development: Some methodological perspectives on child labour' (2006) 7 *Forum, qualitative social research*

²⁵ Robyn Longhurst, 'Becoming Smaller: Autobiographical Spaces of Weight Loss' (2012) 44 *Antipode* 871

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13 How do we assess the transformative potential of participatory systems?

Colin Caughey

Abstract

The UNCRPD places extensive obligations on state parties to develop participative processes in order to provide disabled people and their representative groups with opportunities to engage in and influence the policy making process. The drafters of the UNCRPD had significant faith in the transformative potential of such processes. However, in practice many states have developed participatory systems which are largely tokenistic, and which therefore do not afford disabled people and their representative groups with meaningful opportunities to influence change. This article considers how participatory systems can be critically analysed to determine whether they present a genuine opportunity to affect change. Drawing on the jurisprudence of the UNCRPD Committee, I propose a framework to conduct critical analysis of participative systems, which will inform ongoing discussions on how states can develop systems which are truly participative.

Introduction

The participatory provisions of the CRPD, which obligate states to ensure the effective participation of persons with disabilities and their representative groups in the policy development process is seen as one of the most progressive elements of the CRPD.¹ The development of participatory processes that will lead to a new form of disability politics is seen as the route toward the emancipation of persons with disabilities.² However there is a significant risk that States will co-opt the participative language of the CRPD and develop participatory arrangements which are largely ritualistic giving participants the impression that they are being influential without actually allowing them to impact the outcome or engage with the real decision makers.³ Indeed if not appropriately designed participatory systems can perpetuate systems of oppression.⁴

Reflecting on the experience in the UK Mike Oliver and Colin Barnes noted the dilemma faced by the disability movement *'To get too close to the Government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise'*.⁵ Their comments underscore the need to develop a

¹ Lord/Stein 2008: The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities (2008)

² Quinn, G. (2009b). The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability. *Texas Journal on Civil Liberties & Civil Rights*, 15(1), 33–52.

³ Robert F. Drake: Disabled people, voluntary organisations and participation in policy making *Policy & Politics* vol 30 no 3 373-385, pg 376

⁴ Paula Hyde and Huw T.O. Davies Service design, culture and performance: Collusion and co-production in health care *Volume 57(11)*: 1407–1426

⁵ Mike Oliver and Colin Barnes, 'Disability Politics and the Disability Movement in Britain: Where did it all go wrong? June 2006 Available at: <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-Coalition-disability-politics-paper.pdf> <accessed 10 June 2021>

framework for the assessment of participatory processes to determine if they are offering persons with disabilities and their representative groups a genuine opportunity to influence. This article will consider whether it is possible for disability researchers and advocates to critically assess participatory systems to determine if through participating a social movement organisation can enhance its influence.

I will first consider the obligation placed on member states by virtue of UNCRPD Article 4(3). In doing so I will set out guidance provided by the CRPD Committee. I will then review existing literature on the classification of participatory systems. In doing so I will demonstrate how the absence of an established methodology for assessing the level of influence of an organisation continues to present a significant challenge to researchers.

Drawing on guidance provided by the CRPD Committee I will put forward a ten point methodology for critically assessing whether a participatory process is compliant with the CRPD. In concluding I will highlight the need for the methodology to be refined to meet the need for a workable methodology to inform decision making by persons with disabilities and their representative groups.

Legal Framework: Participation

Participation is a general theme of the CRPD, the preamble notes that participation, “*will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty*”. The CRPD protects the right to participation generally and specifically in the contexts of the implementation and of monitoring the Convention.

Article 4(3) includes a specific obligation on Governments to ‘*closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations*’ in the design and implementation of policies relating to the CRPD. By way of General Comment Number 7 (GC7) the UNCRPD Committee have elaborated on the scope of the duty and on how states should execute it.⁶

The Committee have made clear that states are required to develop “*formal procedures of engagement and liaison with*” persons with disabilities and their representative groups.⁷ Consultation processes should be conducted in a “*meaningful and timely manner*” providing a real opportunity to influence the outcome.⁸ The CRPD Committee require State Parties to

⁶ CRPD General comment No. 7 (2018) on the participation of PWDs, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention CRPD/C/GC/7 9 November 2018

⁷ Ibid para 35

⁸ Ibid para 22

ensure that consultation exercises are accessible and that reasonable accommodations are made.⁹

Within GC7 the CRPD Committee provide a clear definition of organisations which are truly representative of persons with disabilities which Governments and others much adopt. The CRPD Committee make clear that priority should be given to the views of persons with disabilities and their representative groups when addressing issues directly related to them.¹⁰

The CRPD Committee are clearly conscious of the risk that engaging in participatory mechanism may lead to the voice of organisation being curtailed and provide that Governments must not “*condition or prevent organizations of persons with disabilities from freely expressing their opinions in consultations and throughout decision-making processes*”.¹¹

The public officials responsible for the consultation exercise should seek to obtain “collective agreement on procedures”.¹² The processes for the consultation exercise should “*allow for reasonable and realistic timelines taking into account the nature of the organizations of persons with disabilities*”.¹³ Disability representative organisations may need to consult with their members before providing a view on a specific proposal and they should be allowed time to do so.

The CRPD Committee emphasise that public officials responsible for engagement should be appropriately trained. Political scientists have highlighted that whilst often overlooked it is important that bureaucrats are appropriately trained in managing participative processes.¹⁴

The CRPD Committee emphasises that processes should be subject to “periodic evaluations”.¹⁵ Indeed throughout the consultation processes the Committee suggest that “*States parties should appoint persons with the role of following up on attendance, noticing underrepresented groups, and ensuring that accessibility and reasonable accommodation requirements are met*”.¹⁶

With respect to the outcome of consultation process the Committee have made clear that “*Public authorities leading decision-making processes have a duty to inform organizations of persons with disabilities of the outcomes of such processes, including an explicit explanation in an understandable format of the findings, considerations and reasoning*

⁹ ibid Para 45

¹⁰ ibid para 23

¹¹ Ibid Para 43

¹² Ibid Para 47

¹³ Ibid Para 47

¹⁴ Newman, J., Barnes, M., Sullivan, H. and Knops, A. (2004) ‘Public participation and collaborative governance’, *Journal of Social Policy*, vol 33, no 2: 203–23 pg212

¹⁵ ibid para 47

¹⁶ ibid para 54

of decisions on how their views were considered and why".¹⁷ It is notable that the Committee does not suggest that persons with disabilities and their representative groups should have control over the outcome.

The CRPD Committee give consideration to how to support the growth of the disability movement. The State party should ensure that persons with disabilities are not restricted from establishing their own representative organisations and should make ensure there is appropriate and sufficient resources to facilitate their operations.¹⁸

Classification of Participation

Whilst persons with disabilities have often been excluded from participatory processes it should be noted that the development of participatory processes is not novel.¹⁹ Political scientists note that governments are adept at designing participative systems which achieve the objectives of the state.²⁰ As new approaches to governance have developed states have developed more sophisticated technologies of participation.²¹

States often develop participatory processes to sustain and legitimise pre-existing systems. Representative governments must demonstrate that they are reflecting the goals and preferences of their citizens to ensure they maintain their legitimacy and to support processes of reforms.²² The outcome of consultation or participatory exercises can provide a Government with evidence of consent or support from the public which can be valuable when convincing the legislature to support the passage of a Bill.²³ Participation exercises can also be developed to appease or co-opt social movement organisations that may otherwise engage in disruptive protests.²⁴ States may also develop participatory mechanisms to provide an opportunity for state officials to draw on and learn from external expertise.²⁵ Persons with disabilities and their representative groups can uniquely contribute to the development of disability policy through sharing their experiential knowledge.²⁶

Social movements engage with the state because they want to shape or influence the outcome of the process. In the context of the CRPD many states have developed participatory

¹⁷ *ibid* 23

¹⁸ *ibid* 63

¹⁹ Erik Lundberg (2013) Does the Government Selection Process Promote or Hinder Pluralism? Exploring the Characteristics of Voluntary Organizations Invited to Public Consultations, *Journal of Civil Society*, 9:1, 58-77

²⁰ *Ibid*

²¹ See further Fung A (2006) Varieties of participation in complex governance. *Public Administration Review* 66(S1): 66–75.

²² Catt, H. and Murphy, M. 2003, 'What voice for the people? Categorising methods of public consultation', *Australian Journal of Political Science*, vol. 38, no. 3, pp 418

²³ Chris Skelcher Navdeep Mathur Mike Smith The Public Governance of Collaborative Spaces: Discourse, Design and Democracy Volume83, Issue3 August 2005 (573–596) pg 581

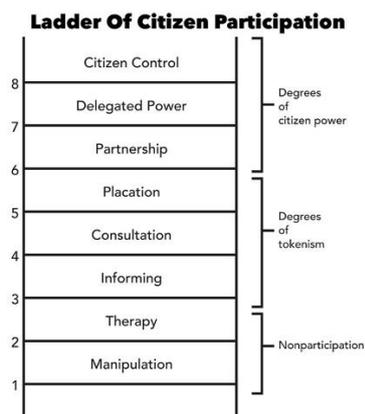
²⁴ Jan-Peter Voß and Nina Amelung Innovating public participation methods: Technoscience and reflexive engagement *Social Studies of Science* 2016, Vol. 46(5) 749–772 pg 754

²⁵ George Anderson, 'The new focus on the policy capacity of the federal government' (1996) 39(4) *Canadian Public Administration*, 469

²⁶ Merry Smith, Evidence- based policy, knowledge from experience and validity *Evidence & Policy*, vol 16 no 2 305–316

mechanisms for the development and monitoring of national disability strategies.²⁷ The extent to which these participatory mechanisms have influenced the outcome is a subject of debate.²⁸ Whether an organisation should or should not take up an opportunity to participate in a particular mechanism is often a source of contention within the disability movement.²⁹

There is a lack of guidance for social movements to assess whether offers made by the state to participate present an opportunity to influence. In 1967 developed a framework for the categorization of forms of participation which continues to be utilised today.³⁰ Arnstein categorises participation into eight rungs of a ladder which are categorised as, ‘non-participation’, ‘degrees of tokenism’ and ‘degrees of citizen power’.



Arnstein focuses on the degree to which an offer to participate is an offer to share power. Arnstein stated that “citizen participation is a categorical term for citizen power”³¹. The highest category of participation focuses on the degree to which power is shared with participants. Influenced by the writings of Arnstein some disability advocates have criticised participatory processes that have not handed control over to representative organisations.³²

The general duty to ‘consult with and actively involve PWDs’ contained in Article 4(3) in my view lies somewhere in between the fourth category, consultation, and the fifth category, placation. Arnstein warns that, “if consulting them is not combined with other modes of participation, this rung of the ladder is still a sham”.³³ Placation is defined by Arnstein as ‘a

²⁷ Combined second and third periodic reports submitted by New Zealand under article 35 of the Convention pursuant to the optional reporting procedure, due in 2019 CRPD/C/NZL/2-3 para 326

²⁸ John Pring Pressure mounts on Tomlinson as second DPO letter raises disability strategy concerns 4th February 2021 Disability news service

²⁹ Ellen Clifford, ‘The War on Disabled People’ (Zed Books, London) 2020 pg 280

³⁰ Arnstein, Sherry. 1969. A Ladder of Citizen Participation. Journal of the American Institute of Planners 35(4): 216-24.

³¹ Arnstein ‘Ladder of Citizen’ (n. 30) p 217

³² Lana Moriarity and Kevin Dew, ‘The United Nations Convention on the Rights of PWDs and Participation in Aotearoa New Zealand’ (2011) 26 Disability & Society 685. pg 686

³³ Arnstein ‘Ladder of Citizen’ (n. 30) p. 219

higher level tokenism because the ground rules allow have-nots to advise, but retain for the powerholders the continued right to decide'.³⁴ The obligation on states to provide funding and support the development of representative groups may be seen as examples of placation. Despite this obligation is still likely to be categorised by Arnstein as 'tokenism'.

The CRPD Committee in GC7 have not suggested that Governments are actually required to transfer power to representative groups. In my view GC7 can be seen as an attempt by the CRPD Committee to require states to develop processes which reflect a process of co-production.³⁵ Conceptualising offers of participation as forms of co-production encourages a focus on the development of a shared outcome rather than the allocation of power.

The Committee seek to strengthen the capacity of representative group to influence the outcome through ensuring the processes of production are accessible and that the representative groups are well resourced. When it comes to the development of public policies which may be classed as 'collective goods' the allocation of decision making power to a selection of representative groups would in my view neither reflect good policy making approaches nor would it be.³⁶

Taking note of literature relating to co-production in contrast to Sherry Arnstein's proposition I take the view that an offer to participate is an offer to exercise soft power.

New Framework

I have attempted to set out that a categorisation of participatory processes which focuses on the allocation of power is of limited value when it comes to assessing participative processes for the development of public policies. In my view commentators should focus on the extent to which a participatory system offers participants a genuine opportunity to influence the outcome. The CRPD Committee in GC7 have described a number of features of an Article 4(3) compliant system. Informed by GC7 I believe it is possible to develop a framework for critically assessing participative systems.

An important precedent has been set by Priestly and Stone who have developed a methodology to assist disabled people to assess whether research projects are truly emancipatory.³⁷ The methodology rests on six core principles of emancipatory research, which individuals can assess a research project against to inform a decisions as to whether or not they wish to contribute.

Building on this model I believe a methodology can be developed to assist disability advocates to assess whether an offer to participate is potentially transformative. This methodology would be equally valuable to disability researcher critically assess participative systems. This

³⁴ Arnstein 'Ladder of Citizen' (n. 30) p217

³⁵ Jacob Torfing, Eva Sørensen, and Asbjørn Røiseland Transforming the Public Sector Into an Arena for Co-Creation: Barriers, Drivers, Benefits, and Ways Forward Administration & Society 2019, Vol. 51(5) 795–825 pg 804

³⁶ Bovaird T, Stoker G, Jones T, Loeffler E, Pinilla Roncancio M. Activating collective co-production of public services: influencing citizens to participate in complex governance mechanisms in the UK. *International Review of Administrative Sciences*. 2016;82(1):47, p.

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³⁷ Stone, E. and Priestley, M. (1996) *Parasites, pawns and partners: disability research and the role of non-disabled researchers*. British Journal of Sociology, 47 (4). pp. 699-716.

methodology looks at the features of the systems to determine if participants will be provided with a genuine opportunity to influence the outcome. Below I set out the ten essential features of a participative process which have been developed with reference to GC 7.

- Participative processes should only be offered when there is a meaningful opportunity to influence the outcome
 - At what stage of development is the proposed policy?
 - Will participants have access to the decision maker ?
- Representative groups should have an opportunity to influence the design of the participative process
- The process and timelines for seeking inputs and views should afford representative organisations an opportunity to consult their members
- Public officials responsible for managing participatory processes should be appropriately trained
- The process should make provision for reasonable accommodation
- There must be no restrictions on the ability of a representative group to raise issues of concern or interest within the process or outside of it.
- Decision makers should be required to explain how the views of participants have been taken into consideration and give reasons for their decision.
- If participants are not satisfied with the process they should have the opportunity to complain to an external body
- Participatory processes should be accompanied by state efforts to facilitate and fund representative organisations
- The process should be subject to periodic review.

The value of this framework can in my view only be tested in practice. In keeping with GC7 the framework covers the process of participation rather than the outcome.

Conclusion

I am aware that many of the features set out in this framework are somewhat open ended. A participatory system is likely to contain some but not all of these features. In setting out these features I am attempting to provide a method for disability advocates and researchers to assess offers of participation and to critically assess their compliance with the CRPD to inform their own decision making.

The existing analysis of Article 4(3) does not consider its application in different contexts. Whilst key disability actors have put forward expansive interpretations of the breadth of the right to participation, there is a lack of research into state practice. There is a need for research to what impact Article 4(3) is having on government bureaucracies responsible for the development of participatory systems. Whilst there are a number of publications looking at participative systems there is currently a dearth of empirical evidence on their impact.³⁸ State Parties to the CRPD are increasingly developing participative processes in particular when in

³⁸ Rowe G and Frewer LJ (2000) Public participation methods: A framework for evaluation. *Science, Technology & Human Values* 25(1): 3–29.

the development of disability strategies. These processes should be critically assessed to identify examples of good and bad practice and to build up a body of empirical evidence that can inform further research driving up levels of professionalism in policy professionals.

In keeping with the concept of co-production disability researchers need to give greater consideration to how accessible participatory processes can be mainstreamed as an essential stage within policy making systems. Whilst the proposed framework is inevitably imperfect and will require revision I believe it puts forward a basis for further discussion.

14 Applying grounded theory in empirical legal research: challenges, added value, and lessons learned

Hanxu Liu

Abstract

Grounded theory has been employed in many disciplines; yet its application in legal research is underexplored. As a qualitative research tool, grounded theory allows researchers to develop theories that emerge from data evidence. This article examines how a constructivist grounded theory approach can be employed in data collection and legal analysis in an ongoing PhD study. By providing examples and commentary from a legal case study, this article elaborates on the lessons learned during the process of fieldwork and initial data analysis. For novice researchers, grounded theory is a complex methodology. Nevertheless, it provides valuable opportunities to facilitate the design of a research framework, and to analyse data flexibly and systematically, when there is a lack of candidate hypotheses at the outset. Discussion in this article has implications for researchers who seek to understand grounded theory and employ its concepts and processes in their legal research.

Introduction

Empirical research based on observations and experience about the world, also known as data, is becoming more and more prominent in contemporary legal research.¹ Data enables legal scholars to assess the gap between theories ('law on the books') and practice ('law in action'). Epstein and Martin argue that 'well-executed (legal) research with a data component is likely to make more important, influential, and, frankly, better contributions to policy and law because the study's authors can accurately gauge the uncertainty of their conclusions.'² In light of this, socio-legal scholars often adopt an interdisciplinary research approach by integrating sociological methods.³

Empirical legal research requires systematic data collection and analysis based on existing research methods.⁴ This article focuses on the context of qualitative research, which often concerns social studies that attempt to capture and interpret social phenomena and their

¹ Lee Epstein and Gary King, 'The Rules of Inference' (2002) 69 *University of Chicago Law Review*, 2-3. For an overview on the development of empirical legal research, see Peter Cane and Herbert M Kritzer, 'Introduction', *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010).

² Lee Epstein and Andrew D. Martin, *An Introduction to Empirical Legal Research* (OUP Oxford 2014), 4.

³ Peter Cane and Herbert M Kritzer, 'Introduction', *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010), 1.

⁴ Peter Cane and Herbert M Kritzer, 'Introduction', *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010), 4.

meanings in context.⁵ Unlike quantitative research methods,⁶ the researcher is the tool for data processing in qualitative research.⁷ Therefore, the researcher's skills and methods for data collection and analysis determine the 'reliability' of qualitative research findings.⁸

This article aims to introduce the application of grounded theory in the author's ongoing PhD study, titled '*Collective Voice in the Global Arena: Interactions with the United Nations*' (Collective Voice). This study examines the role of organisations of persons with disabilities in European countries (European OPDs)⁹ in the national and international monitoring of the UN Convention on the Rights of Persons with Disabilities (CRPD).¹⁰ As explained later, the author used grounded theory to guide the qualitative research in this study. Since its emergence in the 1960s, this qualitative methodology has been further developed and widely used in varied disciplines and topics of social research.¹¹ Grounded theory provides 'systematic, yet flexible guidelines for collecting and analysing qualitative data'.¹² However, due to the defining characteristics and various versions of grounded theory, junior researchers often experience difficulties applying its methodology.¹³ Moreover, early legal scholars encounter more challenges if not offered proper training in empirical research.¹⁴

This article is divided into three sections. Following this introductory section, the second section reviews the concept of 'grounded theory' and its application in legal studies. Next, the third section presents how a grounded theory approach is used in the Collective Voice and its

⁵ Lisa Webley, 'Chapter 38 Qualitative Approaches to Empirical Legal Research' in Peter Cane and Herbert M Kritzer (eds), *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010), 928-929.

⁶ For instance, questionnaire.

⁷ Lisa Webley, 'Chapter 38 Qualitative Approaches to Empirical Legal Research' in Peter Cane and Herbert M Kritzer (eds), *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010), 934.

⁸ Lisa Webley, 'Chapter 38 Qualitative Approaches to Empirical Legal Research' in Peter Cane and Herbert M Kritzer (eds), *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010), 934.

⁹ According to UN Committee on the Rights of Persons with Disabilities (CRPD Committee), Organizations of persons with disabilities refer to the organisations 'led, directed and governed by persons with disabilities'. For more on the definition and scope of OPDs, see Committee on the Rights of Persons with Disabilities, 'General Comment No. 7 (2018) on the Participation of Persons with Disabilities, Including Children with Disabilities, through Their Representative Organizations, in the Implementation and Monitoring of the Convention' (2018) UN Doc CRPD/C/GC/7, para 10-14.

¹⁰ UN General Assembly, 'Convention on the Rights of Persons with Disabilities' (2007) A/RES/61/106.

¹¹ John W. Creswell and Cheryl N. Poth, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (SAGE Publishing 2016), 82-83.

¹² Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014), 2.

¹³ Fahad M Alammar and others, 'Grounded Theory in Practice: Novice Researchers' Choice Between Straussian and Glaserian:' [2018] *Journal of Management Inquiry*.

¹⁴ For evidence and discussion concerns a lack of general understanding and training of empirical legal research methods in legal education, see Nuffield Report in Paddy Hillyard, 'Law's Empire: Socio-Legal Empirical Research in the Twenty-First Century' (2007) 34 *Journal of Law and Society* 266; and Peter Cane and Herbert M Kritzer, 'Introduction', *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010), 3.

implications of practical application in legal studies. The final section offers some general conclusions and reflections on applying grounded theory in empirical legal research.

Background: Grounded Theory and its Application in Legal Research

This section introduces the general design of grounded theory and its use in existing legal studies.

After six decades of application, theorists have provided plentiful manuals for conducting grounded theory research under its three main methodological branches.¹⁵ Discussion in this section highlights constructivist grounded theory because it was used in the to-be-presented PhD study in the next section.

Traditionally, grounded theorists aim to build theory from data through a systematic process of data collection and analysis from social research.¹⁶ Creswell and Poth suggest that theory can be ‘an explanation of something or an understanding that the researcher develops’.¹⁷ As many scholars have discussed the differences among the three variants, such differences often revolve around their philosophical stances,¹⁸ whether and when to conduct literature reviews and coding procedures.¹⁹ As a distinct genre of grounded theory, Charmaz thinks that researchers construct and interpret theories, which is built upon their knowledge and understanding from the research practice.²⁰ Still, the researcher’s presumption is continuously scrutinised and challenged by the awareness of the relativism and reflexivity of their actions during the research processes.²¹ In this way, constructivist grounded theory encourages the

¹⁵ The three branches are Glaserian (or known as traditional), Straussian (evolved) and constructivist method, which often associated with grounded theorist Charmaz. See more detailed discussion in Fahad M Alammam and others, ‘Grounded Theory in Practice: Novice Researchers’ Choice Between Straussian and Glaserian:’ [2018] *Journal of Management Inquiry*, 228. Ylona Chun Tie, Melanie Birks and Karen Francis, ‘Grounded Theory Research: A Design Framework for Novice Researchers’ (2019) 7 *SAGE Open Medicine*, 2, and John W Creswell, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (2017), 82-86.

¹⁶ Barney G Glaser and Anselm L Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Transaction Publishers 2009), 1. James E Herring, ‘Chapter 9 - Constructivist Grounded Theory: A 21st Century Research Methodology’ in Kirsty Williamson and Graeme Johanson (eds), *Research Methods (Second Edition)* (Chandos Publishing 2018), 226-227.

¹⁷ John W Creswell and Cheryl N Poth, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (SAGE Publications 2016), 84.

¹⁸ For instance, positivism (Glaserian and Straussian methods) v. constructivism.

¹⁹ For detailed discussion on these differences, see Fahad M Alammam and others, ‘Grounded Theory in Practice: Novice Researchers’ Choice Between Straussian and Glaserian:’ [2018] *Journal of Management Inquiry*, 229. Ylona Chun Tie, Melanie Birks and Karen Francis, ‘Grounded Theory Research: A Design Framework for Novice Researchers’ (2019) 7 *SAGE Open Medicine* 2-3.

²⁰ Charmaz, *Constructing Grounded Theory* (n 10). KC, 17. Ylona Chun Tie, Melanie Birks and Karen Francis, ‘Grounded Theory Research: A Design Framework for Novice Researchers’ (2019) 7 *SAGE Open Medicine*, 3.

²¹ Kathy Charmaz, ‘Constructionism and the Grounded Theory Method’ in James A Holstein and Jaber F Gubrium (eds), *Handbook of Constructionist Research* (Guilford Publications 2013), 403

researcher to raise critical questions and contest one's stances and bring new ideas.²² Charmaz suggests that theory building is not necessary for applying grounded theory, as it can simply provide an 'analytic handle' to conduct research.²³ Nevertheless, constructivist grounded theory shares the grounded theory family's typical traits, accepting core strategies for research processes, including theoretical (purposeful) sampling, coding, constant comparative analysis, memo-writing, and theory development.²⁴ According to Tie et al., it is appropriate to use grounded theory when 'little is known about a phenomenon' regarding a research problem, and for studies investigating 'in individual and collective actions and social psychological processes'.²⁵

As an inductive method, grounded theory emerges from the interplay between data collection and data analysis, which forms the iterative research processes, as illustrated in Figure 1.²⁶ The analytical process used in grounded theory is a constant comparative method.²⁷ Under this method, data collection and analysis are concurrent during the whole research process, as comparisons are made between each data analysis stage to advance theory development.²⁸ A more abstract and generalised understanding of the research, called a 'concept' or 'theory', emerges from the 'checked and refined' analytic processes.²⁹

Like other qualitative research designs, the researcher starts sampling to direct initial data gathering with appropriate methods suggested by the research problem.³⁰ Data will be coded from the beginning of the research.³¹ Charmaz recommends at least two coding rounds, namely

²² Kathy Charmaz, 'The Power of Constructivist Grounded Theory for Critical Inquiry' (2017) 23 *Qualitative Inquiry* 34. 36 and 39

²³ Charmaz, 'Constructionism and the Grounded Theory Method' (n 18). 401

²⁴ Kathy Charmaz, 'The Power of Constructivist Grounded Theory for Critical Inquiry' (2017) 23 *Qualitative Inquiry* 34; Fahad M Alammar and others, 'Grounded Theory in Practice: Novice Researchers' Choice Between Straussian and Glaserian:' [2018] *Journal of Management Inquiry*, 269; and John W Creswell and Cheryl N Poth, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (SAGE Publications 2016), 84.

²⁵ Ylona Chun Tie, Melanie Birks and Karen Francis, 'Grounded Theory Research: A Design Framework for Novice Researchers' (2019) 7 *SAGE Open Medicine*, 1. Robert Thornberg and Kathy Charmaz, 'Grounded Theory and Theoretical Coding', *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications, Inc 2014), 154 .

²⁶ Alammar and others (n 21).FMA, 229.

²⁷ Ylona Chun Tie, Melanie Birks and Karen Francis, 'Grounded Theory Research: A Design Framework for Novice Researchers' (2019) 7 *SAGE Open Medicine*, 3-4.

²⁸ Charmaz, *Constructing Grounded Theory* (n 10).KC, 7

²⁹ *ibid.* 3-4.

³⁰ See Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014), 22-54.

³¹ Charmaz, *Constructing Grounded Theory* (n 307), 3. Lisa Webley, 'Chapter 38 Qualitative Approaches to Empirical Legal Research', *The Oxford Handbook of Empirical Legal Research* (2010), 5.

initial coding and focused coding (Figure 1).³² The researcher conducts initial coding to construct ‘short, precise and active’ codes to data word by word, line by line, or incident by incident.³³ The constant comparative method compares data and data, data and codes, codes and codes, to find similarities and differences, which leads to sorting, clustering, and merging initial codes.³⁴ Based on initial coding, the researcher identifies focused codes to construct more abstract concepts to allow theory to emerge from data.³⁵ At this stage, the most common codes are selected as conceptual categories, and are constantly compared to generate and refine the concepts or theory that emerge.³⁶

³² Robert Thornberg and Kathy Charmaz, ‘Grounded Theory and Theoretical Coding’, *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications, Inc 2014), 156.

³³ More on initial coding and the three different techniques, see Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014), 124-132.

³⁴ Robert Thornberg and Kathy Charmaz, ‘Grounded Theory and Theoretical Coding’, *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications, Inc 2014), 158.

³⁵ Robert Thornberg and Kathy Charmaz, ‘Grounded Theory and Theoretical Coding’, *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications, Inc 2014), 158. Ylona Chun Tie, Melanie Birks and Karen Francis, ‘Grounded Theory Research: A Design Framework for Novice Researchers’ (2019) 7 *SAGE Open Medicine*, 5-6.

³⁶ Robert Thornberg and Kathy Charmaz, ‘Grounded Theory and Theoretical Coding’, *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications, Inc 2014), 159.

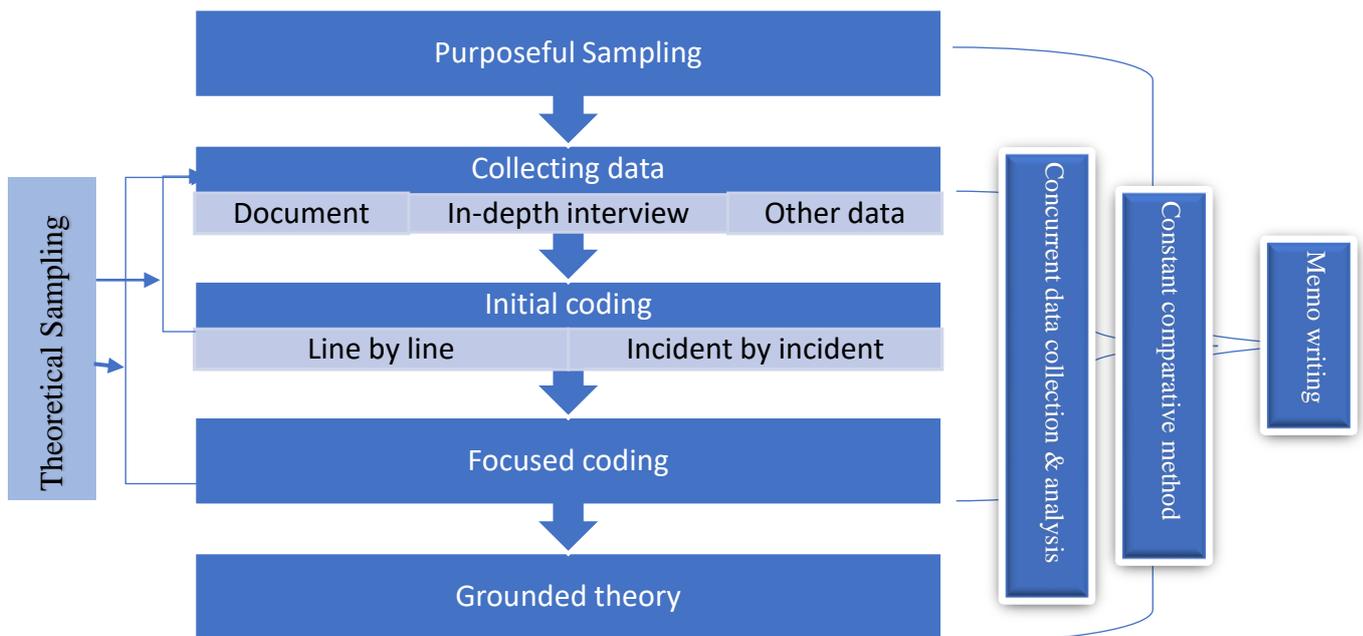


Figure 1 Basic research design framework under constructivist grounded theory³⁷

During each coding stage, using theoretical sampling allows the researcher to go back to the data collection and repeat the research processes (see Figure 1).³⁸ Theoretical sampling means the researcher pursues pertinent data to focus on specific tentative conceptual categories and their properties, aiming to fill knowledge gaps and saturate the categories, which have emerged from data analysis and coding.³⁹ Analytical notes or memos are produced throughout the research process, to collect and reflect the researcher's generalised ideas or questions that emerged from the data collection and coding (see Figure 1).⁴⁰ These ideas and questions further inform the processes of theorisation and theoretical sampling. This procedure is known as memo-writing, which is essential for theory development in grounded theory.⁴¹

³⁷ This chart is adapted and edited on the chart used in Ylona Chun Tie, Melanie Birks and Karen Francis, 'Grounded Theory Research: A Design Framework for Novice Researchers' (2019) 7 SAGE Open Medicine, 3.

³⁸ Charmaz K, Constructing Grounded Theory (SAGE Publishing 2014), 3.

³⁹ According to Charmaz, an example for theoretical sampling is to go back to interview participants and ask more focused questions. See Kathy Charmaz, Constructing Grounded Theory (SAGE 2014), 192-206.

⁴⁰ Creswell JW and Poth CN, Qualitative Inquiry and Research Design: Choosing Among Five Approaches (SAGE Publishing 2016), 187-189.

⁴¹ John W Creswell and Cheryl N Poth, Qualitative Inquiry and Research Design: Choosing Among Five Approaches (SAGE Publications 2016), 84.

Despite its acceptance elsewhere, few legal studies have used grounded theory methodology. This is unsurprising considering that the characteristics of grounded theory are frequently not aligned with the research design of traditional legal studies, in which empirics are regularly used to support legal analysis and hypotheses. Charmaz argues that grounded theory can be a useful tool when conducting critical inquiries that focus on marginalised groups and address power, inequality and injustice issues.⁴² In the same vein, legal scholars have discussed the use of grounded theory in critical race research and socio-legal research on women's legal positions in the context of the Global South.⁴³ In the latter studies, the grounded theory allows the researchers to rethink their presumptions and find new directions in empirical research by integrating data on the lived experience of local women with legal analysis in the process of theorisation.⁴⁴ Grounded theory is also adapted to other legal studies when assessing participants' views on legal issues, to address the context and background of such issues.⁴⁵

The Use of Grounded Theory in the Collective Voice

This section uses the example of a junior researcher's PhD study to demonstrate some of the practical considerations and difficulties faced while using constructivist grounded theory.

The Collective Voice study aims to examine the effectiveness of the processes, results and outcomes of interactions between European OPDs and certain UN human rights bodies, with a view to monitoring the national implementation of the CRPD.⁴⁶ Constructivist grounded theory approach is applied in this study's empirical research design, data collection and analysis, to investigate interaction processes among European OPDs, UN human rights bodies and other stakeholders in national and international CRPD-monitoring-related activities and their views towards such activities. It is called an 'approach' because the empirical research is guided by

⁴² Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014), 34.

⁴³ See Maria C Malagon, Lindsay Perez Huber and Veronica N Velez, 'Our Experiences, Our Methods: Using Grounded Theory to Inform a Critical Race Theory Methodology Education & Pedagogy' (2009) 8 *Seattle Journal for Social Justice* 253; and A. W. Bentzon and others, *Pursuing Grounded Theory in Law: South-North Experiences in Developing Women's Law* (1st edition, Tano Aschehoug 1998).

⁴⁴ A. W. Bentzon and others, 'Preface', *Pursuing Grounded Theory in Law: South-North Experiences in Developing Women's Law* (1st edition, Tano Aschehoug 1998).

⁴⁵ See Opi Outhwaite, Robert Black and Angela Laycock, 'The Significance of Cost Recovery for the Regulation of Agricultural Health: A Case Study in Pursuing Grounded Theory' (2008) 35 *Journal of Law and Society* 126, and B Courtney Doagoo, 'The Use of Intellectual Property Laws and Social Norms by Independent Fashion Designers in Montreal and Toronto: An Empirical Study' (Thesis, Université d'Ottawa / University of Ottawa 2017) <<http://ruor.uottawa.ca/handle/10393/36062>> accessed 2 June 2021.

⁴⁶ These European countries include 22 EU countries and the UK that have been reviewed at least once by the CRPD Committee under the procedure established according to CRPD Article 35, with a focus on four country studies, namely Denmark, France, Hungary and the UK. The examined UN bodies are the CRPD Committee and UN Human Rights Council.

the rationality and methods used in constructive grounded theory, but may not be considered a traditional or typical grounded theory study.

Grounded theory was considered as an appropriate method from the beginning of the research design for two reasons. First, there was little previous research done under similar research topics. Second, due to the current study's interdisciplinary and empirical characteristics, this study needs a robust empirical research design. The decision of adopting grounded theory approach also considered a disability study in Iceland, which used grounded theory to investigate the participation of local OPDs in the national policy-making process.⁴⁷ Constructivist grounded theory was chosen because it provides an ideal methodological tool to guide the complex empirical components in the current study by assisting the researcher to generate new ideas to answer the research problem. It also enables the researcher to examine data, theory, and legal analysis in a systematic, comparative and reflective manner.

The explanation and discussion on research design, method and data analysis are demonstrated in the following four subsections.

Research Design

After the literature review and legal analysis, empirical research is conducted through document analysis, intensive interviews, and non-participatory observations⁴⁸. However, observations had to be eliminated from the plan due to the cumulative impact of the worldwide pandemic.⁴⁹

At least two cycles of data collection and analysis were arranged. In the first cycle, data sources and types are decided according to the research problem, while applying convenience and snowball sampling.⁵⁰ For example, documents sources were selected from literature reviews of primary and secondary resources. Potential interviewees were identified and recruited through consultation with European OPDs, academic and non-academic partners, as well as colleagues in the DARE network and recommendations received from interviewees.⁵¹ Later, data

⁴⁷ Laufey Love, Rannveig Traustadottir and James Rice, 'Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing "a Seat at the Table"' (2019) 8 *Laws* 11.

⁴⁸ For non-participatory observations in *Collective Voice*, the researcher intends to observe public UN sessions held in Geneva.

⁴⁹ All research activities involving human participants have received approval from the Ethical Review Committee of Inner-City Faculties at Maastricht University.

⁵⁰ Lawrence A Palinkas and others, 'Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research' (2015) 42 *Administration and policy in mental health* 533.

⁵¹ The presented PhD study is supported by the DARE (Disability Advocacy Research in Europe) project. DARE is a new European-wide training network for early-stage researchers in the field of disability rights, which is funded by the European Commission's Marie Curie grant (No 814249).

collection will use theoretical sampling by seeking data from specific sources, mainly interviews, to fill knowledge gaps that emerged from the initial data analysis.

Research Methods

A triangulation of document, intensive interview, and non-participatory methods were chosen to cross-examine the research findings and answer the designated research questions.

Document analysis and its textual analysis are considered a valid exercise in grounded theory.⁵² Following Prior's suggestions, document analysis in *Collective Voice* explores both the meaning and functions of documents beyond the traditional content analysis approach.⁵³ Thus, the analysis extracts information from documents and explores the drafting process, function, and impact of certain documents in the context of the examined UN procedures and European countries.⁵⁴ Even though non-participatory observation activities were cancelled due to the pandemic, the researcher instead observed the public video records and broadcasts of a few UN sessions related to the research topic, supplementing the use of documentation.

After documents collection, intensive interviews were conducted. Interview participants were invited to engage in a gentle-guided conversation to explore their experience regarding the research topic.⁵⁵ An interview protocol was designed to include semi-structured topics and questions to be explored during each meeting.⁵⁶ Before recruiting interview participants, pilot research was conducted with a DARE colleague to test interview questions. The author also consulted a European regional OPD and other colleagues based in Geneva on the scope of the qualitative research and interview questions. Their valuable inputs contributed to the framing of interview questions and general research design.

Data Collection and Analysis

The collection and analysis of documents were conducted first, hoping that some preliminary results could inform later interview and observation topics. Meanwhile, all data were coded and analysed concurrently, as stated above in the flow chart (see Figure 1).

⁵² For more discussion on document analysis in grounded theory see Helen Hardman, 'The Validity of a Grounded Theory Approach to Research on Democratization' (2013) 13 *Qualitative Research* 635.

⁵³ Lindsay Prior, 'Documents in Social Research', SAGE Research Methods Foundations (SAGE Publications Ltd 2019) <<https://methods.sagepub.com/foundations/documents-in-social-research>> accessed 2 June 2021.

⁵⁴ For instance, how shadow reports are used in the CRPD Committee's official documents. For detailed explanation on different approaches of document analysis, see Lindsay Prior, 'Documents in Social Research', SAGE Research Methods Foundations (SAGE Publications Ltd 2019) <<https://methods.sagepub.com/foundations/documents-in-social-research>> accessed 2 June 2021, 6-13.

⁵⁵ Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014), 56.

⁵⁶ The interview protocol and questions considered the guide provided by Charmaz in Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014) page, 62-68.

Documents, including written and video records related to the UN CRPD monitoring procedures, were collected from the public UN database and websites. In addition, interviews were conducted in-person, during the author’s short visit in Geneva, or through online communication tools.⁵⁷ Interview participants comprised current and former staff or members from national, regional and international OPDs, UN human rights bodies and other stakeholders. After initial coding, the second round of interview data collection will be conducted based on theoretical sampling.

In terms of data analysis, two rounds of coding are planned for qualitative research in this study. A computer-assisted qualitative data analysis software, Atlas.ti, is used for coding in order to store and organise all data, and effectively manage and compare many codes.⁵⁸ A codebook with pre-determined codes is compiled to include concepts from previous literature reviews and legal analysis (see table 1). New codes arising from analysing documents, and interview transcripts, are also assigned to data.

Table 1 examples of pre-determined codes

Code name (short name)	Definition	When to use
National Consultation	Any evidence recognising the existence and arrangement of consultation procedures in the examined country related to Article 4.3 CRPD	Description indicates the existence/non-existence of such consultation procedure, such as its structure and legal status, and consultation activities, such as meetings and other events.
Country report drafting	Any evidence recognising OPDs are consulted during the preparation of the country report related to Article 34.3	Description indicates such consultation has been conducted or not conducted, including participant OPDs.
Timeframework	Any evidence referring to time frameworks provided for OPDs participation	Description of timing and dates of participation information.

⁵⁷ For instance, Skype and Microsoft Team. The selection of communication tool considers safety requirements, accessibility and participants’ convenience.

⁵⁸ For more discussion on computer-based coding and its application, see Fahad M Alammari and others, ‘Grounded Theory in Practice: Novice Researchers’ Choice Between Straussian and Glaserian:’ [2018] *Journal of Management Inquiry*, 234; and Johnny Saldana, *The Coding Manual for Qualitative Researchers* (2015), 21-26.

At the time of writing, the author has conducted initial coding of some documents and interview transcripts. All coded data were categorised according to themes and analysed in a specific order following the research questions. Under each category, documents and interview data are coded and constantly compared. Line-by-line coding is applied in initial coding. It means that a document or transcript is read sentence by sentence, then labelled with appropriate codes in the software.

Apart from coding, memo-writing is also used in data analysis. Following Charmaz's suggestions, memos are written in informal language, and are used as a personal research journal to capture analytical notes from data comparison and crystallise questions to pursue in the following research.⁵⁹ For document analysis purposes, memos were compiled under each code category, and then clustered by the coding order. In terms of the interviews, memos or short reflections were written immediately after an interview, then during the coding process. A memo or reflection often highlighted surprising information obtained from an interview and record the author's thoughts about possible improvement or future interviews. The second coding process of focused coding will mainly draw on codes and memos to sort and refine the ideas gathered.

Discussion

This last subsection provides some general remarks on the challenges, lessons learned, and added value in using the grounded theory approach in the above study. It is not the author's intention to look into technical issues in each step of applying grounded theory, which has been discussed in detail.⁶⁰ Instead, the author hopes to address some general implications for legal researchers who might feel reluctant to adopt this theory in their qualitative research.

From the discussion above, junior researchers may identify a steep learning curve in using grounded theory. The first challenge is to understand and choose the right version among grounded theory variants for one's study. After that, it also requires efforts in the form of relentless learning and training, back and forth reading and, possibly the most effective method, discussions with other methodologists. The Collective Voice would not be possible without generous knowledge sharing from other colleagues and senior researchers.

In the context of legal studies, researchers could exploit a practical use of grounded theory by adopting its core strategies to guide empirical research and by selecting appropriate methods that serve legal analysis. In this way, the researcher would not be distressed about fitting legal research into grounded theory's rigid framework.

⁵⁹ Kathy Charmaz, *Constructing Grounded Theory* (SAGE 2014), 161-165.

⁶⁰ For instance, see Fahad M Alammam and others, 'Grounded Theory in Practice: Novice Researchers' Choice Between Straussian and Glaserian:' [2018] *Journal of Management Inquiry*.

On the other hand, even equipped with thorough knowledge of theory, the most suitable research design might vary from person to person. Junior researchers could quickly feel overwhelmed by all available instructions on grounded theory. For instance, the author decided to minimise the size of the pilot research after considering the time constraints and advice received from other experienced researchers.⁶¹ In the end, it is up to the researchers to design a research framework balancing all limitations and options, and justify their choices. Still, like any new skills, researchers need to be prepared to confront new issues during their research and seek further guidance from literature and other researchers.

For legal researchers who consider using grounded theory in their empirical research, planning ahead of time is advisable. One should beware that acquiring skills in grounded theory methodology is a learning-by-doing experience and researchers should start the research design and data collection at the earliest stage of their research. It could be the case that the theory and instructions become more relevant and understandable once the inquiry process is launched. Most importantly, it is always beneficial to ask for help from other researchers and methodologists experienced in similar research areas from legal or other social science backgrounds.

Notwithstanding these difficulties, grounded theory added numerous benefits to the current study. Foremost, it provided a clear and well-developed framework for qualitative research from beginning to end, covering almost every step in a research process. Once equipped with the skill, researchers are more likely to feel confident in conducting empirical research, knowing that the data has been collected and analysed logically and consistently. In the *Collective Voice*, the author gained new ideas and perspectives from the data analysis that led to examining power dynamics between European OPDs and policymakers and tested the presumptions that emerged from previous desk-based research. Moreover, as one of the mainstream qualitative research methods, grounded theory shares many similar methods and techniques with other methods,⁶² which could benefit a researcher's research in the future.

Conclusion

This article has outlined the basic steps of grounded theory research and its application in a legal research case study. Some of the issues raised in the discussion might be shared among early-stage or even experienced researchers. It is hoped that the insights outlined above are helpful for other legal researchers, especially those interested in adopting grounded theory in

⁶¹ For some discussion on conducting pilot research in qualitative research, see Mohd Aliff Abdul Majid and others, 'Piloting for Interviews in Qualitative Research: Operationalization and Lessons Learnt' (2017) 7 *International Journal of Academic Research in Business and Social Sciences* 1073; and Baptista Nunes and others, 'Contextual Sensitivity in Grounded Theory: The Role of Pilot Studies' (2010) 8 *The Electronic Journal of Business Research Methods* Volume 73.

⁶² For instance, ethnography.

their qualitative empirical research in the fields of human rights and social justice. The qualitative research design and execution in the presented PhD study has its limitations, yet it shows how to balance research between legal analysis and grounded theory, considering time and resource constraints. Although grounded theory seems to be a complex methodology on the first impression, it enables the researcher to conduct solid empirical research, pursue emergent knowledge rather than a priori goals, and refine qualitative research skills. Legal researchers should learn to ‘tolerate ambiguity, confusion and lack of confidence at the early stage of their studies’, and feel comfortable to tailor grounded theory as an ‘analytical handle’ to meet their research needs.⁶³

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⁶³ Fahad M Alammar and others, ‘Grounded Theory in Practice: Novice Researchers’ Choice Between Straussian and Glaserian:’ [2018] *Journal of Management Inquiry*, 241.

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