SAGE researchmethods cases

Researching Inclusively With People With Learning Disabilities in Prisons

Abstract

Very little is known about how people with learning disabilities symbolically engage with imprisonment and discursively account for it within their wider self-narratives. Although there is little published research on this, literature shows that this group are over-represented among prison populations worldwide and that their needs are simply not being met during their incarceration. My doctoral research set out to address this gap in literature by exploring how people with learning disabilities make sense of and adapt to imprisonment. Informed by prison sociology and learning disability studies, I used qualitative methods to research inclusively with people with learning disabilities while being appreciative of the challenges of researching within prison. This case study draws from my PhD fieldwork experiences to highlight some of the key methodological challenges of carrying out work of this kind. It comprises three sections: the first outlines the research design—the research background, methods, access negotiations, and ethics; the second section provides a reflection of the fieldwork process in action; and the final section offers some practical methodological tips to inform future research practice in this area.

Learning Outcomes

By the end of this case, students should be able to:

- To explain the principles of inclusive research, and consider design implications for researching inclusively with people with learning disabilities
- To illustrate the complexities of planning and carrying out research within a prison environment
- To summarize the ethical considerations for research considered "high risk," and critically recommend practical approaches to facilitate this kind of research.

Research Design

Research Background, Aims, and Objectives

This original piece of research was conducted to address two gaps in academic literature: the lack of existing prison sociological studies which had (deliberately) included the views of people with learning disabilities about their experiences of imprisonment, and, the lack of existing learning disability studies that had spoken to this group about their experiences or understandings of the criminal justice pathway when accused or convicted of a crime. People with learning disabilities in prison are often referred to as a "hidden" population as there are no cohesive figures on the population, nor standardized practices of identifying their needs. Although very little is known people with learning disabilities' prison experiences, an influential

Prison Reform Trust report (Talbot, 2008) indicates that this group are especially vulnerable among prison populations as they often: experience high levels of bullying and fear victimization, worry that prison staff do not understand their needs, are unaware of how to access healthcare or make formal complaints, and have little contact with their families outside.

My doctoral research approached this unique intersection with the aim of exploring how people with learning disabilities experience and make sense of imprisonment. The study set out to contribute significantly to knowledge about this group and the ways they adapt to imprisonment by conceptually, empirically, and methodologically bridging together two distinct fields of study: learning disability studies and prison sociology. To achieve the research aim, I constructed three key objectives:

1. To examine how people with learning disabilities discursively account for their incarceration and make sense of this within the wider context of their lives and self-narratives
2. To explore the key challenges faced by people with learning disabilities while in prison to investigate how they adjust to the demands of prison life and of being a prisoner, and to look at how prison, in turn, affects their sense of self and of self-worth
3. To gain an understanding of participants' overarching interpretations and experiences of the criminal justice pathway as a person with learning disabilities.

I was fortunate to be supported through a collaborative PhD studentship between the Economic and Social Research Council and Cornerstone—a Scottish third sector organization that support adults with learning disabilities. I worked closely with one of Cornerstone's Community Justice service areas, "Positive Tracks," which provides tailored daily living support to people with learning disabilities who have recently been liberated from short-term custodial sentences. Cornerstone had pre-existing partnership arrangements with the Scottish Prison Service (SPS); this meant that I had supported access to the prisons to carry out my research. To address the research aim and objectives I set myself, I spent 6 months (April 2013-September 2013) designing the research, negotiating access to my intended research sites with the SPS, and securing full ethical approval for my "high risk" research from both SPS and the University of Glasgow College of Social and Political Sciences. Then, I spent 9 months (October 2013-July 2014) fully immersed in the fieldwork process: I interviewed 25 men and women with learning disabilities a cumulative total of 72 times and across five research sites (four prisons and one community-based support program for recently liberated people with learning disabilities). This case study presents an overview of the research design, the key ethical considerations that affected the planning, my reflections on the fieldwork process, and finally, some practical reflections to help inform future research.

Research Methods: Multiple and Semi-Structured Interviews

One of the key features of the study design was to centrally include the accounts of people with learning disabilities, and avoid excluding them from research "about" them. Existing academic research in this area has mainly sought to estimate how many people with learning disabilities are in prison (quantitative studies), consulted only the professionals who work with the group (exclusive studies), or evaluated behavioral treatment programs for prisoners with "complex needs" (pathologizing studies). It was essential, therefore, that my research design involved qualitative research methods that directly consulted the prisoners with learning disabilities themselves. Qualitative interviewing recognizes participants as experts of their own lives, experiences, and perspectives; this is extremely useful when interviewing groups of people who may feel routinely excluded, oppressed, or marginalized—such as prison populations and/or people with learning disabilities.

As research methods should be selected in relation to the research task, I decided to use qualitative interviews to provide a platform for people with learning disabilities in prison to share how imprisonment shapes, or is shaped by, their wider lives as disabled people, along with an exploration of their interpretations of the daily demands of prison life. Qualitative interviews produce rich and detailed data, and encourage new or unexpected accounts to emerge (Silverman, 2010); I felt that this was important given that very little research had been previously carried out in this area. A flexible approach seemed to be most appropriate for researching with people with learning disabilities within such a highly controlled environment; I decided that a semi-structured interview approach carried out over a series of shorter interview sessions would best suit this study. Semi-structured interviews are pliable in their nature and offer space to recognize, respond to, and be inclusive of the needs of participants with differential communication styles. The conversation-like style of semi-structured interviews was appealing not only to encourage the conversation to flow freely (Fylan, 2005) but also to acknowledge participants as the experts of their own realities by offering more control over the interview content (England, 1994).

To avoid the potentially disabling barriers that longer interviews may present to some people with learning disabilities (Nind, 2008; Stalker, 1998; Walmsley and Johnson, 2003), I gave all participants the option of completing the interview in multiple shorter sessions as opposed to one longer interview. Frequent and/or shorter interview sessions allow topics to be covered at a slower pace, offering more time to the participant to reflect on their experiences (Atkinson, 2004; Booth & Booth, 1996; Matteson & Lincoln, 2009: 660); this was particularly useful among participants whose cognitive impairment impacted upon their memory or sequencing of events. Participants can clarify comments from earlier interviews, and the researcher can revisit topics

to better comprehend phenomena (Charmaz, 2003; Matteson & Lincoln, 2009).

Multiple interviews also allow the participant and researcher to get to know one another better (Thomas & Woods, 2003). This approach helped with the complexities around researching within a "low trust environment," such as the prison (Liebling, 2004, assisted by Arnold), particularly as gaining trust as an outsider can be difficult (Jewkes, 2014). Prison research can also be emotionally draining or harrowing, met with hostility and suspicion from participants, frustrating for participants, and constrained by external forces such as time, access, or funding bodies (Liebling, 1999). I felt that multiple interviews could help mitigate some of these issues through familiarity and building rapport over time. This approach also supports the researcher's "slow and deep immersion" in the research environment (Beyens, Kennes, Snacken, & Tournel, 2015: 67). Charmaz (2003) also highlights that multiple interviews can strengthen the data analysis process as the researcher constantly reviews the emerging data.

Negotiating Access and Gatekeeping

In terms of inclusion criteria for participation, the study required that the individual was in prison at the time of research (21 participants), or had been recently liberated from custody and were being supported by Cornerstone in the community (4 participants), and had been identified with a learning disability (n = 25). The former was straightforward, however, the latter required much more consideration and care. The conceptualization of "learning disability" is highly contested. This not only affects the terminology used, but also the way in which learning disability is identified; screening tools or diagnostic criteria may vary among practitioners and institutions. I used a deliberately loose definition of "learning disability" to avoid the adverse effects of inclusion/exclusion criteria at the margins, and also extended its application to include participants on the autistic spectrum (including Asperger's syndrome) as well as those with acquired brain injury.

It was agreed that I would work closely with Cornerstone support staff and an appointed SPS operations officer in a managerial position within each establishment in order to identify potential participants from the former, and negotiate an appropriate time and space to conduct the interviews through the latter. However, as I was spending quite a substantial amount of time within each establishment, prison officers began suggesting individuals who may be eligible and willing to take part in the research project and the final sample quickly emerged through this practice. I did "warm up" sessions (discussed below) with potential participants ahead of interviews, preferably on a separate day, to establish whether or not they were eligible to take part and to allow them time to decide whether they wanted to participate in the research.

In terms of gatekeeping, the SPS made it clear from the outset that the research was subject to

local management:

> You should note that access is also conditional on individual establishments being willing and able to accommodate any potential demands that may be made on staff time and resources as a consequence of the study (SPS Research Access and Ethics Committee [pers. comm., August 2013]).

To minimize my disruption to local regimes, I maintained contact with the SPS via email throughout the fieldwork to notify them of my progress, and to initiate access to the subsequent prison. I was then introduced to a local management contact and negotiated my access at this point; this was a smooth process throughout, although access differed from prison to prison.

Some Ethical Considerations

I anticipated a tricky and lengthy ethics application process due to the "high-risk" nature of the research, and so took great care to anticipate and address each potentially "risky" element of the study. I applied for ethical approval as a phased process from the University which I clearly indicated in a supporting letter addressed to the chief ethics officer at the University, and began by asking for approval to interview previously incarcerated people with learning disabilities in the community. I then approached the SPS Research Access and Ethics Committee to negotiate access before applying for ethical approval to interview in prison from the University. While this was a successful and fairly swift process once underway, I've detailed below three broad areas where additional consideration was required: interviewing people with learning disabilities, the limits of confidentiality, and approaching sensitive subject matter.

Interviewing People With Learning Disabilities

People with learning disabilities are often excluded from research that concerns them. Qualitative research methods, such as interviews, can be inclusive when carried out with, rather than on, people with learning disabilities. Interviews can encourage participants with learning disabilities to realize the validity in their points of view (Atkinson, 2004) and acknowledge their expertise in their own lives and experiences (Stalker, 1998). While Goodley (1998) maintains that there is no correct way to interview people with learning disabilities since they are not a homogenous group, flexible interview approaches can support individuals with learning disabilities to participate (Walmsley & Johnson, 2003). Although some researchers caution that there can be specific methodological challenges of interviewing people with learning disabilities, others have shown that this is not the case (Booth & Booth, 1996; Goodley, 1998; Stalker, 1998). Booth and Booth (1996) highlight four challenges that can arise during qualitative interviews with people with learning disabilities: inarticulateness, unresponsiveness

to open questions, difficulty generalizing or thinking in abstract terms, and, difficulty with time and temporal succession. They advise using direct questions without abstract temporal conceptualization to overcome those concerns (Booth & Booth, 1996). However, Goodley (1998) while affirming that direct questioning can be useful, shows that at other times a loose conversational approach, which includes probing from the researcher, can be successful. While Lewis (2004) found that the format of questions can be more constraining than a narrative account, Booth and Booth (1996) found that reactive responses to specific questions were more successful than asking participants for long narratives of uninterrupted speech. Some researchers have successfully used props, such as visual aids, cue cards, or talking mats, to better support people with learning disabilities to talk about their opinions and experiences in interviews (Atkinson, 2004; Stalker, 1998; Swain, Heyman, & Gillman, 1998).

I created "plain language" information sheets and consent forms with specific information related to the location of interviews (i.e., in prison or in Cornerstone's offices). These were accompanied by "Easy Read" equivalents on which I consulted Cornerstone staff before circulating. During the initial "warm up" meeting, I gave both "plain language" and "Easy Read" information packs and consent forms to all participants, and discussed the form of each version to allow participants to select the most appropriate version for themselves. I read aloud the preferred option with every participant. This process allowed me to include one participant who self-identified as "illiterate"; I secured his verbal consent as approved in my ethics application. I used an ongoing process of consent, although participants only signed one consent form before the first interview. Before each new interview, I verbally reiterated the consent agreement and reminded participants that they did not have to answer questions without any explanation if they did not wish. This made sure that participants were always well-informed, but not overwhelmed by excessive paperwork. This also served to maintain boundaries in the research relationship.

The Limits of Confidentiality

I provided participants with a limited degree of confidentiality and explained this during the "warm up" session but also ahead of each subsequent interview session, as outlined in the British Society of Criminology's (BSC, 2015) Ethical Code of Conduct. Confidentiality was always afforded unless participants informed me of their intention to harm themselves or others, or plans to commit new offences. I also explained that I would interrupt them if I felt that the limit had been reached. Some participants discussed previous offences which they had not been convicted of; these were usually petty offences so I decided not to act on this information.

Approaching Sensitive Topics

A third ethical consideration during the research design was whether, and how to respond if, the interviews touched on sensitive topics and led, in turn, to emotional upset. I discussed the implications of this likelihood fully with my supervisors ahead of interviews and became familiar with supports and services available to the participant: there was a Listener service in each of the prisons which consisted of prisoners who were trained by the Samaritans to support other prisoners, and, Cornerstone staff and trusted prison officers could be identified by the participant for specific advice or support beyond the interview. My own supervisors and a key senior contact at Cornerstone were available throughout the fieldwork process for debrief sessions.

Fieldwork Reflections

Multiple and Semi-Structured Interviews in Action

Ahead of interviews, I developed a broad topic guide and organized questions into three thematic areas corresponding to the stages of the criminal justice pathway an accused person faces: (1) general discussion about life prior to first conviction; (2) arrest, court proceedings, and sentencing; and (3) imprisonment, prison life, and hopes for the future. As already described, I gave participants the decision to complete the interview in one longer session or in multiple shorter sessions; all participants elected for the latter, however on occasion extrinsic or unavoidable circumstances prevented individual participants' committal to the full interview process. Most participants' interviews were completed in three sessions; the content of each interview corresponded to the three thematic areas identified on the topic guide. All interviews were bookended with a "warm up" and "cool down" sessions, discussed below.

The research methods were extremely successful in eliciting deep, meaningful, and reflexive views and perspectives from the participants. I was extremely flexible with my time throughout the fieldwork process to account for participants' family and friends' visits, court appearances, social work meetings, health appointments, wellbeing needs, and any other prison-based activities. On the whole, though, participants were keen not to miss the interviews.

As I used multiple short semi-structured interviews, I ensured that I spent time "warming up" and "cooling down" with those who participated in the research separate to the interviews. The main purpose of the former was to make sure that sufficient time was dedicated to explaining the research and obtaining consent from the participant and allowing them to ask any questions, however over and above this, I found this time invaluable in terms of getting to know the individual and their communication style. After this preliminary meeting, I recorded initial thoughts and a few key points which we spoke about in my fieldwork diary so that I could relay this to contextualize our subsequent meeting; I found this to be a useful practice after each

interview as it helped to maintain the pace, focus, and linear succession of interviewing more than once. Although I never had the topic guide visible during interviews, one participant requested that I print the research topic guide in a larger font and bring this along so that they could follow the focus of the narrative without going off-topic too much.

Inclusive Interviewing Strategies

Although some researchers have cautioned that there can be specific methodological challenges of interviewing with people with learning disabilities, I found that the "warm-up" session was useful to help me understand more about each individual's communication styles and preferences. Some of the more specific, and subtle, communication preferences came to light when I listened back to the audio recording prior to the subsequent interview. I discovered that some participants preferred to narrate the story of an event in a temporal order without interruption, while others found this abstract style difficult and were open to specific time referents, such as "your first prison sentence," "your most recent arrest," or "Mondays." I added my thoughts to the notes in my fieldwork diary and always decided the first question of the subsequent interview in advance, then adapted the rest of these later interviews to follow wherever the participant took me. This process of re-listening gave me time to consider the appropriateness of my questions, or style of questioning, and improve on my interviewing technique specific to that individual before meeting again.

Access and Gatekeeping

One of the most challenging aspects of the research was the inconsistency in access, despite the benefit associated with working within such a unique partnership synergy. The four penal establishments differed in their local management, entrance security procedures, and ease of access with a dictaphone. The interview locations were often unsuitable or not conducive toward a productive or positive research experience for the participant. Most notably impacted were interviews conducted within the Agents Visitation booths in Prison A, the social work office in Prison C's Links Centre, and the doctor's room in Prison D; participants held preconceived notions of each of these locations due to prior dealings. In those instances, it was imperative for me to set expectations and marshal boundaries efficiently as those three rooms represented another experience to the participants: meeting their lawyer, and receiving disappointing news; meeting a social worker, and receiving disappointing news; or meeting the doctor, and receiving disappointing news. Some locations were noisy or suffered from echoes due to the room size or concrete interior; this disrupted the audio recording quality and, in turn, affected the accuracy of transcription. Some research sites were visible to other prisoners passing by; this concerned me in terms of potentially forcing the participant to disclose the purpose of their meeting with

me to their peers.

Researcher Identity and Influence

As with any piece of research, it is impossible to deny the researcher's involvement or placement within the study. Becker (1967) argues that it is not a discussion of whether or not we should take sides, but, rather, it is the dilemma of whose side we are on; it is impossible to remain impartial in social science research, and to do so would deny our own humanity. I often felt extremely conscious of my own gender within the masculine fields generated by men's prisons, however I rarely felt threatened or insecure. My perceivable identity as a young female rendered me non-threatening in such a control-centric environment. Liebling (1992) notes the various advantages for female researchers within men's prisons, including their perceived vulnerability. Although when I was working with the female prison population, these exact qualities—being young and female—meant that I looked just like many others there.

My role as a student was useful in neutralizing power expectations. I explained my role clearly when I met potential participants, and was sure to describe what my role was not. I found that it was important establish clear boundaries and expectations, while presenting my research position in a relatable and non-threatening manner. Introducing myself as a student, rather than expert, allowed participants more opportunity to realize their expertise of their own experiences, lives, and social situation. Dressing informally also facilitated the communication of my student role, as noted in the fieldwork diary extract above. Equally, being a "student" in a specialized area also seemed to aide dynamics with prison staff and Cornerstone support workers. Perhaps it was because it was not their role which was under study that staff were so willing to contribute their perceptions, share their knowledge, and facilitate the progress of this study; the non-threatening role of "student," rather than researcher, became valuable cultural capital in such a scrutinized space.

My involvement in the research was tested on occasion with regards to the pastoral duties of a social science researcher. Marshalling the boundaries of involvement was imperative due to the nature and intensity of the interview process: a level of trust had been established over a period of time and, retrospectively, there was a danger that certain interviews could have been molded into counseling sessions. I managed boundaries effectively through precautionary techniques such as regularly reminding participants of my role as a researcher, the purpose of the interviews for my research study, and referring to the inclusion of multiple participants at different prisons. I used "cool down" sessions to explain what would happen next with the study, reassure participants of their anonymity, and reiterate the data security procedures. Reminding participants of my role as researcher also facilitated successful disengagement with

some participants. This also reduced misleading expectations of friendship beyond the research exchange, which Stalker (1998) highlights as a risk when doing research with people with learning disabilities over a longer period.

Methodological Insights for Future Research

I have outlined above what led me to this topic, how I designed the research, and how I navigated the field while ensuring that the research process was accessible to people with learning disabilities and being attuned to the demands of researching within a highly disciplinary and controlled environment. This section picks out some practical advice for those interested in researching with (not about) participants who are often excluded from research, at the margins, or in closed settings.

1. Consider doing a staged ethics application for "high risk" projects.
2. If research topics are likely to touch on sensitive subject matter, make time for regular debrief sessions with supervisors.
3. All participants are unique individuals, with unique communication styles and preferences: no single interview approach will work for everyone.
4. Keep a detailed fieldwork diary.
5. Try not to schedule too many interviews in one day—this is not only exhausting but over-running or unavoidable cancelations can have a detrimental impact.
6. When researching in prison, work with prison/service staff and management not against them. It is important to be willing to be accommodating to the existing prison regime, share research activity schedule with local management so they are aware of time, always make sure officers know where you are and vice versa, and, talk about the research with officers —they will likely have insights to offer.
7. Be aware of security measures and individual security concerns. Familiarize yourself with which items you might need permission to bring in to the prison, what you are permitted to give to the individual prisoner (i.e., pens, paper clips), the general mood in prison (i.e., any disturbances), and, sometimes, the general mood of the participant.

Exercises and Discussion Questions

1. Consider the research design. Which strategies make the research approach accessible for people with learning disabilities?
2. The participants in this study all had very different impairments which affected them uniquely, especially in terms of communication styles, abilities, and preferences. How might qualitative methods support individuals with learning disabilities?

3. Consider ways that you could make your research inclusive.

4. Summarize the key ethical considerations for carrying out research within highly disciplinary and controlled environments, such as a prison.

5. If a participant were to advise of their intention to harm themselves, what steps—under the limited agreement of confidentiality—would you take to ensure their safety?

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