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‘Can you tell me what ethics means?’: collaboration, voice, and consent in (inclusive) research with people with learning disabilities

Gareth M. Thomas (Cardiff University, UK)

Abstract

Accounts of doing ‘inclusive research’ – in which people with learning disabilities are considered as major stakeholders in the research agenda – have proliferated in recent years. These largely focus on the *process* of such pursuits, including project planning, research design, data collection, and disseminating results. Yet, whilst scholars have identified the challenges of doing inclusive research, they rarely sketch out the more messy, and everyday, ethical moments when doing research with people with learning disabilities. Drawing on an ethnography in two settings run for and/or with people with learning disabilities in the UK, I ponder the use of an advisory committee, the notion of ‘voice’, and the consent process, to explore how my experiences complicate the philosophies of, and desire for, *inclusivity*. I conclude by urging researchers attempting to work inclusively to put their approaches under the microscope, in ways that can support others to fine-tune their practices.

Keywords

Advisory committee; consent; ethics; ethnography; inclusive research; learning disabilities; qualitative methods; reflexivity; voice

1. Introduction

Research has a poor history of centring the voices and experiences of people with learning disabilities¹ (Cluley 2017; Kaley et al. 2019; Locock et al. 2022; Nind 2014; Northway 2000; Ryan et al. 2023). Typically, research was conducted *on* people with learning disabilities and focused on pathology grounded in a tragedy understanding of disability. Indeed, contributions in disability studies lament the tendency in research to misunderstand disability, to overlook the input of disabled people, and to disregard and exacerbate, rather than address, disablist structures (Oliver 1992). Disabled people, in turn, are often undervalued both as knowledge producers and as learners (Mikulak

et al. 2022). They are not so much 'seldom heard', Locock et al. (2022: 2160) suggest, as 'seldom listened to, easily ignored or not even thought about'.

We have, in response, observed a radical reforming of research enterprises, including the emergence of the 'inclusive research' paradigm – and particularly so in the Global North. Whilst different definitions of inclusive research have been put forward, in this article, I use Walmsley et al.'s (2018: 758) description:

- 'Research that aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives.
- Research based on issues important to a group, and which draws on their experience to inform the research process and outcomes.
- Research which aims to recognize, foster and communicate the contributions people with intellectual disabilities can make.
- Research which provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.
- Research in which those involved in it are "standing with" those whose issues are being explored or investigated.'

Broadly speaking, inclusive research is coined as shorthand for research that involves people with disabilities as active participants (Walmsley 2004). This can include, but may not be limited to, project planning, research design, data collection and analysis, and disseminating findings. Broadly speaking, inclusive research – aligning with the mantra *nothing about us, without us* – recognises people with learning disabilities as experts in their own lives. It emphasises doing research *with* and *by*, rather than *on*, people with learning disabilities, and considering them as major stakeholders in the research agenda (de Haas et al. 2022; Kaley et al. 2019; Mikulak et al. 2022; Nind and Vinha 2014; Strnadová and Walmsley 2018). Stemming from the social model of disability which pursued bringing research under the control of disabled people (Oliver 1992), and sharing connections with the self-advocacy movement that celebrates the power of people's voices and choices, inclusive research is promoted 'as the right way to redress the hermeneutical injustice of their voices and theorising being excluded from the processes of knowledge production' (Milner and Frawley 2019: 382).

Using a range of methodologies, such as ethnography (Mikulak et al. 2022), interviews (Hollomotz 2018), and 'creative methods' like video (Kaley et al. 2019) and photovoice (Cluley 2017), researchers value a drive to involve people with learning disabilities in the design and conduct of projects in ways that represent their experiences and value different ways of knowing. This, it is asserted, both improves the research itself and helps to build confidence in people with learning disabilities (Nind 2017; Tuffrey-Wijne et al. 2020). According to Bigby et al. (2014), inclusive research can take on different forms, including 'advisory' (where people take on a consultative role, such as being on an advisory committee), 'leading and controlling' (where disabled people lead the

research), and ‘collaborative’ (where both people with and without disabilities cooperate as a research team). Whatever its form, inclusive research values involving people with learning disabilities during the research process, and implementing more transparent and accessible processes of doing research (Mikulak et al. 2022).

Examples of inclusive research are plentiful and instructive, and so I avoid rehearsing the same arguments here. Rather, I intend to acknowledge its general sentiments and principles, guided by the notion that people with learning disabilities hold the right to be involved with issues affecting their lives and can benefit from participating in this way (Bigby et al. 2014). However, there are various challenges with doing this work. This includes: little guidance on both the practicalities of doing inclusive research and offering appropriate training to researchers with learning disabilities (Walmsley 2004); the lack of resource and support available, which increases confidence gaps between and among researchers (Mikulak et al. 2022); rigid academic structures, including tight deadlines, inaccessible payment structures, and regulatory ethics procedures (Carnemolla et al. 2022; Leishman et al. 2023; Tilley et al. 2022); the pragmatic difficulties of working as collaborators, such as when undertaking data analysis and writing publications (Seale et al. 2015; Strnadová and Walmsley 2018); the troubling power asymmetries in which people with learning disabilities are sidelined in certain aspects of research (Milner and Frawley 2019); few assessments on the feasibility, rigour, and impact of inclusive research (Bigby et al. 2014); the time needed to build strong relationships (Chalachanova et al. 2021); the cumbersome nature of working in big teams (Walmsley et al. 2018), and; the written and spoken culture of research excluding people with profound and multiple learning disabilities (Cluley 2017; Kaley et al. 2019; Tilley et al. 2022). According to Locock et al. (2022: 2609), meaningfully involving people affected by research in its design, management and dissemination ‘requires skills, time, flexibility and resources’.

Moreover, for Walmsley et al. (2018), despite many years of inclusive research being discussed, few scholars address the question of its added value. As well as costing more money, taking more time, and involving more people than acting as individual researchers, the convention in inclusive research has been to ‘play down the skills of the researcher’ (Walmsley 2004: 68). For Walmsley (2004: 66), researchers should recognise the power imbalances that are otherwise camouflaged through a rhetoric of participation; ‘one of the keys to progress is to clarify what roles supporters of inclusive research can play, and how we can develop our skills – and help new entrants develop theirs’. Likewise, Bigby et al. (2014: 10) – whilst remaining supportive of the approach – warn against seeing it simply as ‘a panacea’; it ‘cannot be the universal remedy for including perspectives of people with intellectual disability, or for the generation of knowledge about their lives, policy or services they use’. They claim not all research lends itself to an inclusive approach, and there should be room for research topics that are important, but may not be identified by people with learning disabilities as such. Researchers must, they urge, be cautious to ‘avoid conformity at any cost, since this

will inevitably foster tokenism and risk abandonment of important areas of research... the value of inclusive research should not be assumed or overrated' (2014: 10).ⁱⁱ

There is a glut of research, then, both celebrating inclusive research and highlighting its possible challenges. However, scholars frequently focus on the process, rather than the more messy 'ethically important moments' (Guillemin and Gillam 2004: 262), of doing research with people with learning disabilities (the former includes, for example, complications with collaborative research teams, obstructive ethical committees, and institutional barriers for payment and training – see above). Proscriptive instructions and descriptive outlines of inclusive research processes are favoured over delving into the everyday ethical predicaments of research, the positionality of the researcher/s, and their relationships with/to participants. This is where I make my intervention.

I begin this article by outlining the background to my research project: an ethnography in two settings run for and/or with people with learning disabilities in the UK. From here, I reflect on three major aspects of the study. First, I ponder my use of an advisory committee, sketching out what I see as the troubles of using this approach (within the context of my study). Second, I reflect on the thorny issue of 'voice' in my project, and particularly my own ethnographic voice in telling stories from the field. Third, I discuss the worries that I had around the 'consent' process, with participants *undoing* standard research practices in ways that could be both unsettling and productive.

In many ways, my arguments are not limited only to the inclusive research paradigm. Indeed, I have had many of the same research experiences in 'non-inclusive' projects. Yet, these experiences are crucial to report since such troubles – around collaboration, voice, and consent – are, as I hope to show, frequently magnified when attempting to work inclusively. Moreover, accounts of inclusive research are commonly guilty of both focusing on 'process' (i.e. design, collection, and dissemination) and producing distant and sanitised descriptions of methodological design and practice. This neglects more reflexive tales which detail the *doing* of research with people with learning disabilities. Reflexivity is firmly embedded in the discourses of social scientific, and particularly ethnographic, research. Research is a pragmatic, intellectual, and emotional accomplishment; we must, therefore, reflect on how 'fieldwork affects us, and we affect the field' (Coffey 1999: 1). We should not see reflections as egotistic self-indulgence, or even as confessional acts of contrition, but rather as crucial statements that render researchers visible, and reveal the messy and situational nature of our engagements (Guillemin and Gillam 2004).

With such reflections often absent in the inclusive research literature, I address this by sharing dilemmas, anxieties, and tensions that shaped my own research experience when doing research with people with learning disabilities. Here, I attend to my own 'discomfort' during and after the project, as a productive entry point to consider the affective intensity of research praxis (Chadwick 2021). Indeed, Hammersley and Atkinson (2007: 151) remind us how 'feelings of personal conflict, anxiety, surprise,

shock, or revulsion are of analytical significance', and how 'various forms of embodiment in the field shape, enable, and restrict our sociological engagements and knowledge production'. Not recognising this, Walmsley (2004: 65) warns when urging for more transparency in research, means that the inclusive research agenda 'will be trapped in a cycle of sentimental biography or individual anecdotes'.

2. Research background

This article reports on my experiences of doing an ethnography in two settings run for and/or with people with learning disabilities: a professional theatre company and a community café. The intention of the project was to consider how people with learning disabilities and their allies (parents, support workers) navigate (and possibly confront) dominant oppressive narratives and articulate their lives in more affirmative terms. It involved exploring: 1) how people reflect on hurtful cultural representations of people with learning disabilities, and what outlets are available to offer alternative stories; 2) the ways in which people with learning disabilities craft identities which celebrate their worth and humanity; 3) the major barriers to this. The project's focus was guided by an acknowledgement that research agendas are too commonly underpinned by gross, pejorative assumptions of impoverished lives when it comes to people with learning disabilities (Ryan 2021). The study received ethical approval from [Anonymous].

Research was carried out over a fifteen-month period. I carried out observations of the research sites as well as doing interviews with staff at each site and parents of people with learning disabilitiesⁱⁱⁱ. For this article, I focus on my experiences of carrying out ethnographic fieldwork, defined here as a form of inquiry in which one is 'immersed personally in the ongoing social activities of some individual or group for the purposes of research' to acquire a level of understanding to share with outsiders (Wolcott 2005: 58). This involved 'deep hanging out' (Geertz 2000: 107) in both sites. The professional theatre company ran performance training courses with sessions running every week. During my project, I actively participated in many of the sessions, in which people with learning disabilities were trained in (among other things) dance, theatre, improvisation, clowning, role play, and audition preparation. The café was a pop-up community site which ran several days a week in different sites. I did fieldwork in the busiest setting, working alongside team members to take orders, to make drinks and plate-up baked goods, and to serve these to customers. I was regularly an active participant in various scenes, but I resisted asking outright questions to people until the latter stages of my stay. After building relationships for some time, I was in a position where I felt more comfortable and confident to ask direct questions to people in each site to, essentially, corroborate, or not, my observations.

The ethnographic fieldwork unfolded as follows. First, I spent approximately 6 months planning visits with gatekeepers at each site. This time was important given my limited experience in these settings, and my gatekeepers' unfamiliarity with both sociological research and ethnographic observations as a method. Moreover, there was a need to build trust and a sense of familiarity (over several meetings) before the study began.

Caine et al. (2009: 491) define this process as 'preliminary field-work': 'exploration, reflexivity, creativity, mutual exchange and interaction through the establishment of research relationships with local people'. My own preliminary fieldwork also involved recruiting members for an advisory committee. Ethnographic research has, historically at least, been a solo endeavour. As such, it arguably pushes against inclusive research paradigms (which often emphasise collaboration). One attempt to be 'inclusive' in this study involved establishing an advisory committee. Later in this article, I describe both the make-up of this committee and my experiences of doing it. From here, I negotiated start dates with each site and provided a rough estimation of when I would be leaving (project funding largely stipulated this). For the first few weeks at each setting, I made no attempt to 'collect' data, instead focusing my efforts on introducing myself to people and familiarising myself with each setting. Once settled, I began what I considered as the data collection process, which continued for 15 months.

Ethnographic observation was selected as the primary method for two main reasons. First, this was recommended by gatekeepers at the research sites. Questionnaires, in particular, were singled out for criticism; potential participants, they felt, did not always feel comfortable or capable of completing them, and they abstracted the vital context within which they lived. Equally, while interviews were identified by gatekeepers as an appropriate method for people with learning disabilities, they conceded that this would only be relevant for *some* individuals in each site, given a discomfort that some people might have with talking one-on-one (Kaley et al. 2019).

My decision, then, was guided by recommendations from people in the settings to 'be in the room' (their term) and not disturb the normal rhythms and routines of each site. This would also allow me to familiarise myself with the individuals themselves on their own turf. Since I felt that it was crucial for me to spend time building relationships and familiarity with people, I spent lots of time immersing myself into the culture of each setting on an informal level. This is not to suggest that I share experiences with people with learning disabilities; the extent of this – with myself being a nondisabled, White, male, middle-class researcher – is highly debatable. Nonetheless, this method allowed me to 'get to know' people, thus 'mirror[ing] a key component of the social model of disability—disabled people boast expertise about disablement and nondisabled researchers can only hope to learn from these experts' (Goodley 1999: 28).

I also selected ethnography as it was a method that I had experience in. Ethnographic fieldwork allows researchers, Bosk (1985: 14) claims, to 'see social life as we live it... It provides us with soft data – observations, intuitions, and comments – for rethinking some very hard questions about what it means to be a member of society'. Fieldwork, Bosk advances, 'supplies precisely what other methods of research drop out – the experiencing individual as a member of a community and the set of shared meanings that sustain that individual's action in an uncertain world' (1985: 14). I was guided by an interest in producing an in-depth description of each site and the lives of people within them. It meant I could seize 'the unscripted, unrepeatable, and often unutterable

stuff of existence' (Desmond 2007: 288). At its heart, then, an ethnographic approach allowed me to participate in the everyday life of social worlds occupied by people with learning disabilities and their allies. Equally, ethnography is heralded as an ethical form of engagement since it is based on a shared commitment to people, compared to the 'ethical shakiness of the hit-and-run approach of far too much social investigation' (Atkinson 2015: 173). I refrain from describing other methods in such terms, though I acknowledge the notion that ethnography is a deeply 'social' and 'humane undertaking' (2015: 173).

In what follows, I reflect on my experiences of doing research with people with learning disabilities. More specifically, I discuss my use of an advisory committee, the notion of 'voice', and the consent process, to capture how my own experiences complicate the principles of, and desire for, inclusivity in my research practices.

3. 'Can you tell me what ethics means?': the advisory committee

I formed an advisory committee with three people with learning disabilities from a self-advocacy organisation, one member of a learning disability national charity, and two academic colleagues with experience of doing research with people with learning disabilities. The committee met three times (online) over the course of one year, and members were remunerated for their time. The committee offered advice on the broad directions of the study as well as specific issues brought to the group. We discussed all aspects of the project, and members provided input and feedback on a range of topics, including (but not limited to): the project website; issues of anonymity and confidentiality; the phrasing of (co-created) information sheets and consent forms; who may be excluded due to the research design; feedback on findings; the structure of an end-of-project workshop, and; how to share findings (and who with).

Using Bigby et al.'s (2014) typology of inclusive research, this project fell under the banner of 'advisory' (rather than people with learning disabilities formally being part of a research team). This may cause some to label it, inherently, as *not* inclusive for this reason. Funding stipulations meant I was the primary researcher. In addition, payment for a co-researcher would have been complicated for two reasons. First, there was not enough money to adequately remunerate another researcher for what they would have deserved. Second, some members of the self-advocacy organisation warned me that payment would thwart people's welfare benefits. Throughout the project, participants – and particularly parents – were panicked by the prospect of losing disability welfare benefits in an austere context of diminishing resource. If doing my research threatened this, and with no long-term strategy in place to mitigate any loss of funds, I felt that it was unfair, even unethical, for me to recruit people to participate in this manner. I opted, thus, to use an advisory committee to involve people with learning disabilities, but in ways that, I hoped, would not appear to be tokenistic or exploitative.

Even so, like Leishman et al. (2023), I have lingering anxieties and critical reflections about the advisory committee format in the project. One was I had possibly assumed,

as Frawley and Bigby (2011) warn, a ‘learning disability perspective’. This played out in the final committee meeting, where two members of the self-advocacy organisation were unable to attend due to their carers not being available at the specified time. The response from the self-advocacy organisation was to ask another member to take their place for the meeting, despite not previously holding this position (though they were involved with the study in its initial planning stages). This decision was understandable and appreciated, since it allowed the committee meeting to avoid postponement – and the invited person did make a telling contribution. Nonetheless, such an invitation also risks casting all people with learning disabilities in homogenous terms, and presuming that what one member says counts for others too.

Moreover, I felt that the advisory committee was more led by me than intended. For instance, I set the agenda and chaired the meeting (I also remained in charge of the budget and was accountable to the project funder). This decision was taken to balance both discussing the project with members and also not placing too many demands on them. There was also a long time between meetings, so I wondered whether people still felt connected to the project. With busy lives and competing demands, it became a lot to ask for members to remember the intricacies of this particular project.

Another related concern was about the co-production of materials. Project information sheets and consent forms were designed with people with learning disabilities and other advisory committee members. However, institutional demands to include details on data protection and research governance meant they became more cumbersome and unclear than I would have wanted. The long length of these documents was picked up by committee members; my only retort was this was required for ethical approval. Members appeared to accept this explanation, but felt people with learning disabilities were subsequently less likely to read them. Deviating from their recommendations to keep documents under a certain number of pages fuelled a worry I had that the group may appear tokenistic and as rubber-stamping in ways that did not seemingly perceive them as partners. Likewise, I recognised how I was the one who designed the project – and the one who is analysing data and writing for publication. Whilst the project was shaped in conversations with gatekeepers and advisory committee members, it was also shaped by funding stipulations (i.e. I was funded to do *this* project). As such, whilst I attempted to avoid making a Procrustean bed for data and, so, entered the field with some flexible research interests, I equally could not cover everything that people might have thought was important.

The advisory committee also exposed me to my own assumptions and limitations as a researcher. I was aware of needing to avoid unfamiliar academic words (Mikulak et al. 2022) and creating documents in an easy-read format. For example, it was decided, with advisory committee members, to replace ‘ethnography’ with another description for what I was up to (since it was felt that not everyone would know what this means). Yet, I was not always successful with this. The following extract is taken from my notes following the first advisory committee meeting:

I have given an outline of the consent process. I ask the advisory committee if they have any questions. Roger (self-advocacy group member) raises his hand: 'Thanks [Anonymous]. I have a question for you [Roger smiles and points at me]. Can you tell me what ethics means?' I pause for a few seconds and, then, stumble my way through a clumsy answer. I add, 'I'm finding it hard to explain actually!' The committee members laugh, with Roger exclaiming 'Aha! You see? If it's hard for you, it's going to be hard for me and everyone else too!' I chuckle, attempt to recompose myself, and offer an explanation that ethics is related to the harm a study might cause, so the job of an 'ethics committee' is to try to ensure that people are not harmed by taking part in research. Roger nods, with himself and the rest of the team seeming to accept this explanation. The meeting continues.

Roger's rightful assertion about my use of the term ethics, whilst delivered in a playful and generous way, was disarming. I had used a term without due consideration of how it would be understood by people who may not have much/any research experience. This exposed a limitation on my part; I had made assumptions about terms that were an everyday part of my working-life, but were not always translatable in other contexts.

To be clear, the anxieties sketched out above were my own; they were not stated by advisory committee members (though this is not to claim they *also* did not feel them). My point, here, is that my efforts to meaningfully engage with an advisory committee, and to *be inclusive*, were not always effective. Next, I discuss the 'ethically important moments' (Guillemin and Gillam 2004) that emerged when carrying out data collection with people with learning disabilities.

4. The issue of 'voice'

Accounts on inclusive research frequently lament, historically, the denial of the 'voices' of people with learning disabilities in research (Milner and Frawley 2018). The inclusive research paradigm, then, is heralded as a welcome and much-needed antidote to this shortcoming, though some claim that the 'voices' of people with multiple and profound learning disabilities are often lost here (Cluley 2017; de Haas et al. 2022). However, we know little about how notions of 'voice' play out in research itself when working with people with learning disabilities. In this study, the notion of 'voice' is complicated in two major ways.

First, the research design, whilst intended to 'recognise, foster, and communicate the contributions' of people with learning disabilities, might not have adequately done so (Walmsley et al. 2018: 578). As mentioned earlier in this article, I refrained from asking participants outright questions until the latter stages of fieldwork (i.e. once participants had known me for some time). In agreement with gatekeepers, I invited participants (who agreed to this) to chat one-on-one about my project. Whilst several of these chats were seemingly successful, others were not; some conversations were stilted and, for me, difficult to navigate. Long pauses by participants occasionally became punctured by my interruptions. Reflecting back on these conversations, it is entirely possible that

people were simply pausing to gather their thoughts, rather than necessitating a further prompt (as I had concluded). I also felt my questions to people, at times, were not fully understood, which points to a limitation on my, rather than their, behalf. Finally, some participants, on occasion, appeared to be uncomfortable with the encounter. A handful of participants, for example, were very talkative and welcoming during my time at the respective setting, yet not so during (formalised) one-on-one conversations. Consider the following extract from my fieldnotes towards the end of fieldwork in the café, where I asked Graham, an affable and gregarious team member, if he could tell me about his café experiences:

Graham and I walk towards the chairs. His demeanour is, as usual, chirpy and enthusiastic...I ask Graham about when he started at the café and follow this up with several other questions. It is clear to me that, since we have sat down together and with my notepad in front of me, Graham's demeanour has become more serious. Usually warm and confident, he now seems solemn and uneasy. Sensing this, I close the notepad and ask Graham 'are you doing OK?' He answers 'I'm fine'. I probe him a bit further, before he says 'I've got a headache'. I tell him I will get him a drink...I inform Lauren, another team member, about what happened. 'Ah', she replies, 'sometimes Graham does this. I think he struggles with questions that aren't yes and no answers'...I take a glass of water to Graham. I thank him for talking to me, say I don't have any more questions for him, and leave him. A minute or so later, I see Graham standing by the front of the café greeting people, with his usual cheerful demeanour.

I do not intend to dissect whether Graham did, or did not, have a headache – which was seemingly the reason for Graham to cut short our conversation. What is important, here, is that despite intending to design a study that sought to include the experiences and perspectives of people with learning disabilities, this was not always fruitful. My relationship with Graham did not seem to be soured by this experience; his warmth with me continued following this episode, even minutes later. Yet, it exposed me to the realisation that my practices may have inadvertently excluded people, even those with whom I had already spent a considerable period of time. My emphasis, as well, on having verbal conversations may have excluded people whose form of communication is not verbal. My ethnographic approach, hopefully, mitigated this by *being alongside* people with profound and multiple learning disabilities (de Haas et al. 2022), but I felt that I did not always succeed with this approach.

The second way in which 'voice' is complicated in this study is the use of ethnography itself. Ethnography, in its conventional form, involves sharing fieldnotes from field encounters. Appreciating the deconstructionist cliché of 'culture as text', I am aware that my arguments are an impressionistic sketch laced with my own interpretations. Questions of ethnographic authority and the limits to a researcher's arguments are common, yet such concerns are arguably intensified when working with people with learning disabilities. Indeed, writing and sharing fieldnotes may have simply elevated my own voice, as the privileged non-disabled academic researcher, whilst falling into

the trap that many before me have too: excluding the lived experiences of people with learning disabilities, as told by *them* rather than through a *proxy*. As a scholar guided by the principles and sentiments of critical disability studies, I endeavour to centre the experiences of people with learning disabilities, as agents in their own lives and as competent social actors. However, I arguably only do so via *my* ethnographic voice. In this study, then, there is the possibility that my study design imitates a research culture privileging cognition and a gold standard of verbal and written communication (Bigby et al. 2014; Locock et al. 2022).

Likewise, when it comes to publishing the study, there are points of contention. In the inclusive research literature, accounts of publications are mostly limited to a discussion of co-authorship (Leishman et al. 2023; Mikulak et al. 2022) and how, in some cases, such activities might exclude people with more complex impairments (Walmsley et al. 2018). However, little has been said about the politics of publication regarding the lives of people with learning disabilities. In this project, for instance, the issue of 'harm' is pronounced, particularly in a historical context where people with learning disabilities have been hurt in the name of research. One major focus of this project is disrupting deficit-focused narratives and the cultivation of more positive accounts by people with learning disabilities and their allies. Yet, some people may suffer through publication, with it possibly exposing people to feelings of exploitation, betrayal, and abandonment (Anonymous). Indeed, in this study, there were moments where tensions emerged and participants identified negative treatment by others as well as the disablist structures impeding their lives. How could I talk about these matters without being a *tertius gaudens*, that is, they who benefit from the conflict of others? How could I identify the hold of disablism in the lives of disabled people without tightening its grip? Do I have the authority to tell such stories *on behalf of* participants, with their own voices possibly being diminished?

The issues of anonymity and confidentiality are important here too. In this project, the sites observed are unique and, so, raise concerns about the use of pseudonyms (i.e. their use may be rendered pointless). Equally, several gatekeepers of the groups said that they would prefer to not use a pseudonym for the group on the basis that *being known* is a kind of capital for them. The decision made was to not provide pseudonyms for the research *sites*, but to do so for *participants*. Whilst this approach was agreed to by participants during the consent process, this does not entirely assure anonymity. My solution has been to omit minor details that could possibly lead to the identification of people, but to be candid about how this does not guarantee that people will remain anonymous. Since working inclusively regularly involves collaborations between small groups of people, it is important for inclusive research accounts to give more serious consideration to the issues of anonymity and confidentiality. Staying with the dilemmas and troubles raised during fieldwork, I turn now to the consent process.

5. 'There's nothing wrong with me': gaining and maintaining consent

A focus on consent, relating to people with learning disabilities, often sketches out an assumed incapacity for them to give *informed consent* (van der Weele and Bredwold 2021), treating it as a static process occurring prior to a study beginning – and, often, as a barrier to participation itself (Schnellert et al. 2023). Such attention neglects the everyday ethical issues, particularly around consent, faced by researchers that cannot always be predicted by ethics committees or researchers (Santinele Martino 2022). I explore such experiences here.

Gaining and maintaining consent in this project was given serious consideration. After consulting with the research sites on the best way to carry out the research, I liaised with a self-advocacy group to co-design information sheets and consent forms for the observations and interviews. I was advised to also create a video providing information on the project and the consent process. This was because, members of the group told me, people will be more likely to engage with videos than easy-read documents (and especially due to the length of the documents – see above). These were subsequently shared with the advisory committee and research sites for feedback, before they were uploaded to the project website and sent to the research sites prior to my visit (along with the videos). From here, I organised to visit each site to go through this information.

At the theatre group, we watched a video providing information on the observational component of the project (~7 minutes long) and another video providing information on the consent procedure (~3 minutes long). Group members were then asked by the gatekeeper whether they had any questions for me. At the café, potential participants were asked to watch the videos in advance of my visit and ask me questions during the visit. From here, prospective participants could tell an organisation staff member, or me, if they would like to take part. The use of a proxy was to mitigate any discomfort people may have with declining the invitation to me directly. Prospective participants were told to take at least 24 hours to decide whether they wanted to take part. Consent could be verbal or signed, depending on their preference (verbal was most common). I then ensured, throughout the project, that people were reminded of why I was there (for instance, by inviting people to chat about my project at different moments), thereby recognising consent as a dynamic and 'live' process.

This method was discussed with, and approved by, the advisory committee and the gatekeepers. It appeared largely successful, with many people confirming their desire to take part. Some group members opted not to talk to me directly, but consented to me being present in the respective space. Although research mostly went smoothly, there were moments in which the approach for gaining consent was compromised. I describe two distinct, yet related, encounters where this played out. The first extract describes my first day at the theatre group in which we have watched the videos. I decided, with permission, to hand out printed consent forms a few hours later:

Aaron (theatre group member) immediately returns the form to me and says, 'Thanks [Anonymous], but I don't want this'. I respond: 'So, you don't want to take part in the project?'. Aaron replies, assuredly, 'No, I'm fine, there's nothing wrong with me'. This comment catches me off-guard. I reply, 'that's absolutely fine, Aaron, it's your choice whether you take part or not so please don't worry'. 'Sorry [Anonymous], Aaron replies. 'Please don't say sorry, Aaron. It's totally your decision and I'm fine with that', I say. He smiles and says 'Thanks mate', before walking away. Later, I tell Wilf (theatre group staff member) about Aaron not wanting to take part. He appears surprised. 'Really? That's strange because Aaron is usually very happy to talk to people about his life'. When I recount what Aaron said to me, Wilf replies: 'Ah, I wonder if he thinks you're a doctor, if we referred to you as Dr [Anonymous] at some point maybe, and he thinks that's what you're there for?'. Wilf says that he will 'talk' with Aaron to 'make sure he knows what you're doing'. I thank Wilf for the offer, but tell him 'I don't want to pressure Aaron to take part'. Wilf concludes the conversation by saying, 'OK, leave it with me'.

One week after these conversations, and during my next visit to the theatre group, Wilf approaches me: 'So, Aaron did think you were a medical doctor. I've explained what you're doing again and he's very happy to take part now'. This interaction troubled me. I was wary of Aaron being coerced to take part, but I also did not contribute to denying participation and silencing him. Our relationship from here onwards suggests Aaron *was* comfortable in my presence and *did* want to participate. Yet, I cannot rule out that Aaron, and others, felt coerced to participate. Access was granted to each site through gatekeepers. Although they would have consulted with members of their respective groups before I was allowed to join them, their general support of the project may have muted objections. My championing by gatekeepers may have perceived how others saw me and, in turn, limited complaints.

The encounter with Aaron raises questions about the consent process – as does the following interaction with Eric, a team member at the café. Over one week earlier, Eric was informed about the project (he was sent the videos and documents) and I ask him whether he has read/watched the materials:

Eric: Nah, but I know about your project. I'm in. It's fine by me.

Me: Did you want to look over the information together and go through it to make sure you agree to everything?

Eric: Nah. No need to. I'm happy you're here.

Me: Are you sure?

Eric: Yeah!

Me: So, you don't need to look over the information and you don't mind me hanging around?

Eric: [Nonchalantly and looking into the distance] Nah. It's fine. I'm as cool as a cucumber. [Eric smiles widely. He starts talking to me about football].

In declining to engage with the research materials, Eric troubles conventional consent processes (though there is a recognition in ethnographic work that 'informed consent'

is unrealistic, and how research documents are more aspirational than pragmatic). In current accounts of inclusive research, careful attention is afforded to the process of gaining consent, particularly relating to co-producing easy-read materials. Yet, in this project, the careful and sensitive cultivation of the consent process were unimportant for some people. In Eric's case, I decided to include him in the project. He expressed a clear interest in taking part, and my denial of that might be seen as obstructing his agency to decide. Me making this call on his behalf would replicate research practices in which labels/expectations of vulnerability exclude people with learning disabilities. According to Northway (2014), we should resist applying the moniker of vulnerable to all people with learning disabilities, since the capacity to exercise autonomy and offer consent are highly variable.

A further dilemma around consent related to my positionality in each setting. The blurry lines of ethnographic research and the researcher role in learning disability research is documented elsewhere (Ginsburg and Rapp 2013). In this project, I was encouraged by the gatekeepers in each site to get involved, both to understand the setting and to build trust with people. My role was participatory; I joined in training sessions with the theatre group and I worked alongside team members at the café. This approach was often praised by participants. When I asked Lauren (café staff member) at the end of her interview whether she had anything to add, she said:

The fact that you've just jumped right in and got to know everybody and just assimilated yourself in what we're doing, that's so lovely. Because that's how you kind of get to know [café]. If you're just watching and not getting involved, then you wouldn't have been able to draw out the things that you have drawn out. But I have often felt really bad, like when you're doing the washing up and things like that [laughs], which is not what you're here for. But then, at the same time, that's the way the conversations start.

Whilst effective for ensuring my continued presence in each setting, I felt that this also meant that my role was unclear and confusing (e.g. Goodley 1999; van der Weele and Bredewold 2021). As well as being an active participant, I was also occasionally asked to 'stand-in' for staff at the theatre group, when a member of the team either wanted a toilet break or was needed elsewhere to attend to other matters (e.g. an upset group member, transportation issues). This role confusion also troubles the consent process, specifically in relation to whether people *really* knew what I was up to in these spaces (though the extent to which participants ever *really* know what researchers are up to is debatable).

I am not proposing solutions, necessarily, to the troubles raised here. My point instead is to highlight how a procedural focus on consent when doing research with people with learning disabilities, which is usually limited to the notion of capacity, has emerged to the detriment of attending to consent *in practice*. In many ways, the experiences documented above apply to my earlier research projects which do not involve people

with learning disabilities. However, a reckoning with such experiences in accounts of inclusive research is largely absent. Research is messy and unpredictable. As such, it 'becomes all but impossible to solicit consent to the research that is "informed" in the sense of being predictable and explicable before the research itself is carried out' (Atkinson 2015: 179). Scholars attempting to do inclusive research must, equally, be attentive to this.

6. Conclusion

I have, so far, outlined the various challenges and dilemmas raised in my ethnographic research with people with learning disabilities. I reflected on the advisory component of the project, and the issues of 'voice' and consent, to capture how my experiences complicated the claim to inclusivity. In so doing, I demonstrate the value of reflecting critically on our research practices. My intention is not to dismiss or undermine doing this kind of research. Nonetheless, we must continue to subject inclusive research to microscopic investigation, in ways that both avoid over-sanitised accounts and help (especially novice) researchers to fine-tune their own practices. Accounts on inclusive research too often focus on the process of ensuring inclusion, rather than considering how this can be complicated, and even *undone*, in messy research interactions. An obsession with process can, put simply, gloss over how attempts to be inclusive play out (and possibly, as in my project, fall down) in practice. My intention is not to offer a 'how-to' guide in terms of dealing with such issues in other research (though I have, where appropriate, given an account of what I did to mitigate particular situations). As such, I resist providing structured recommendations^{iv}. Nonetheless, I now offer four points for consideration when attempting to research inclusively in the future.

First, we must take reflexivity seriously. Self-conscious reflexivity is a vital feature of the research craft. This should not be seen as the sharing of bar-room confessionals that are ultimately futile and meaningless navel-gazing. I hope that, by considering the impact of the researcher in their endeavours, this encourages others to 'come forward with confessional tales about performing in (and messing up) their own shows' (Scott et al. 2012: 718). Sharing stories will, as Walmsley and Johnson (2003: 16) suggest, allow us to take retreat from the process of inclusive research and to have a 'frank and open debate' about issues raised when doing research with people with learning disabilities. As Goodley (1999: 42) says, doing this 'permits us to at least start unpicking the aims, directions, and findings of research and the researcher's role in their creation'.

Second, we must attend to what we mean by inclusion when doing inclusive research. All projects, where possible, should involve people with learning disabilities throughout the entire process (e.g. research design, data collection and analysis, sharing findings, and so on). However, it is disingenuous to suggest that this is always possible. Such work requires time, resource, training, expertise, experience and flexibility that are not easily available to researchers, and particularly unfunded and solo researchers (such as PhD students). We should consider how we can *meaningfully* involve people with

learning disabilities and, where this is not possible, to – as a bare minimum – do research that: intends to contribute to social change and improving their lives; is based on important issues and experiences that can shape the research process and outcomes; produces information to campaign for better conditions, and; ‘stands with’ people with learning disabilities and their allies (Walmsley et al. 2018). In determining whether a project is inclusive, it will be helpful for researchers to ask themselves the following question, posed to me by an advisory committee member when I shared an anxiety about my project being inclusive or not: ‘what would have happened if people with learning disabilities were not there?’ If they were ‘present’ in my project without making a meaningful contribution, they said, this might not count as inclusive research. However, if people with learning disabilities shaped the project in a meaningful and positive way, this can be perceived as inclusive. Future researchers might benefit from asking themselves a similar question.

Thinking about inclusion itself as a category also involves recognising how inclusion operates at different levels of granularity (de Haas et al. 2022). Indeed, as Walmsley (2004: 69) claim, ‘there is no one right way to approach inclusive research’. Flexibility is needed to allow for a variety of forms of participation (Kaley et al. 2019) and prevent including only certain voices that produces narrow disability scripts (Milner and Frawley 2019). As Nind and Vinha (2014: 108) argue, an ‘expansive vision of inclusive research is necessary for its sustainability’. This is also vital for considering ‘inclusivity’ in other settings. The inclusive research paradigm is often discussed in Global North contexts – reflective of how disability studies often remains Global North-centric in its theoretical and empirical undertakings (Grech 2011; Ingstad and Whyte 2007). We know little about how these principles and mantras translate to other environments, including within the Global South, where disabled people’s experiences and research infrastructures are likely to differ.

Third, researchers should remain vigilant to how our own research can exclude certain populations. For example, the written and spoken culture of research risks excluding people with profound and multiple learning disabilities (de Haas et al. 2022). Groups of people with learning disabilities will continue to be overlooked if researchers do not consider stepping outside the boundaries of conventional methodologies (Bigby et al. 2014). Research is poorer if we exclude certain people; we must ensure that research with people with learning disabilities remains flexible and creative, in ways that include a range of perspectives and experiences (Ryan et al. 2023). This need to be flexible, long championed by crip theorists and critical disability studies scholars, identifies the embodied and fluctuating nature of people’s lives.

Ethnography, others have argued, is a useful method for working collaboratively and with people at risk of exclusion when using other research methods (de Haas et al. 2022; Mikulak et al. 2022). I am wary of heralding it as a remedy to problems around the inclusion of people with learning disabilities; my experiences, as documented here, point to moments in which my attempts to be inclusive fell by the wayside. Equally, we

should acknowledge that doing ethnographic work requires time, money, training, and does not always satisfy 'the short-term needs of policymakers' (Atkinson 2015: 196). This means, perhaps, 'reimagining current models of research governance, funding, and processes to incorporate the time and flexibility that are essential for meaningful involved research' – and only then can research be perceived as 'truly collaborative, engaged, accessible and inclusive' (Locock et al. 2022: 2609)^v.

Fourth, we must 'keep a flexible vision of inclusive research and to keep learning and talking together' (Nind and Vinha 2014: 102). The challenge to 'get it right', Locock et al. (2022: 2612) say, can be daunting and there is 'potential for hurt and harm to ensue, both for the people they seek (or fail) to involve and inexperienced and experienced researchers'. It is important, then, to establish formal communities of practice providing guidance and support (Locock et al. 2022). Indeed, cultivating communities of care, collaboration, and championing is crucial to ensure that we, as researchers, continue to share experiences and learn how our practices can be improved. This article, in which I offer a few tales from the field as grist for the mill, is one step in this direction. Sharing such stories, I argue, has the potential to bring into sharper focus a variety of issues faced by researchers attempting to work inclusively. By doing so, researchers can make comparisons, develop better approaches, and learn from our mistakes.

7. References

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8. Endnotes

ⁱ I have opted for term 'people with learning disabilities' as this was the most commonly preferred term for participants in my research. However, I recognise how some people prefer 'disabled people' – and I have previously used the term in research publications – since it recognises how people with impairments are disabled by societal structures.

ⁱⁱ Similar challenges are identified in literature on patient-and-public involvement (PPI) initiatives and co-production. In their research on two health service 'transformation' programmes, Martin et al. (2018) found public involvement in programmes fell short of normative ideals and, occasionally, inadvertently reduced (rather than enlarged) public influence on health service reconfiguration decisions. Similarly, Oliver et al. (2019) spell out various 'costs' of co-productive research, whilst Williams et al. (2020) identify the structural factors which shape academia's failure to accommodate and support co-productive efforts.

ⁱⁱⁱ This also included four interviews with people with learning disabilities. I decided to mostly speak to people with learning disabilities during observations (so I could get to know people and build trust over time). But, where conversations were not possible during the observational phase of the project and people had expressed an interest in talking with me, I made sure that we did so later on via an online interview.

^{iv} Various authors do offer tips and recommendations in this regard, such as involving people with learning disabilities before, during, and after the research, the appropriate remuneration of people for their input, and offering training for people to work as collaborative research teams (Carnemolla et al. 2022; Leishman et al. 2023; Mikulak et al. 2022).

^v Any consideration of time and flexibility in our research practices must be attuned to the aftermath of research projects. Ending research is a crucial, yet often overlooked, aspect of the inclusive research process – particularly when working with people with learning disabilities who, although not always, might have limited social networks (for exceptions, see: Northway 2000, 2014).