'Working together is like a partnership of entangled knowledge': Exploring the sensitivities of doing participatory data analysis with people with learning disabilities

Abstract

While there have been significant developments in the field of inclusive research with people with learning disabilities, there is limited knowledge about the ways inclusive research teams have conducted participatory data analysis. The authors argue this is inherently tied to the sensitivities involved in the inclusive research process. In this article we present the experiences of two inclusive research teams (from the UK and Australia) who developed ways of working together to collaborate on data analysis. Both studies touched upon sensitive topics and crossed disciplinary boundaries. One was an evaluation of a series of history workshops with young people with learning disabilities; the other was an exploration of effective models of peer support for parents with learning disabilities. The authors explore different approaches to data analysis in inclusive research teams, and reflect on the politics of 'sensitive' research in this field, especially in relation to expectations of funders, ethics committees, and stakeholders.

Introduction

Inclusive research with people with learning disabilities, where people participate as active co-researchers (rather than as research subjects) has become a central tenet of the disability rights movement ambition "Nothing about us, without us". While there have been significant developments in the field of inclusive research with people with learning disabilities (see Strnadova and Walmsley, 2017 for a recent overview), there is limited knowledge about the ways inclusive research teams have tackled data analysis (Seale et al., 2015). It has been argued that a transparent data analysis process in inclusive research is important for establishing

whether the presented research is both 'good science' and good inclusive research (Nind, 2011). In this paper, we argue that the lack of transparency concerning data analysis in inclusive research is inherently tied to the sensitivities involved in this aspect of the research process. Analysis is the point at which some aspects of data are emphasised and privileged over others. Interpretation occurs, drawing particular voices and perspectives to the fore, while others fade into the background. It is an active process: decisions are to be made. What is the most insightful data, and why? How might different pieces of data connect and what patterns can be observed? What data is to remain uncoded, ignored, left for another day? During data analysis we build upon or challenge existing theory; sometimes new theoretical frameworks and ways of seeing the world emerge. It is when knowledge is both produced and organised. However, in many inclusive projects, data analysis is usually the point at which academics assume greater power and control over the research process. This raises sensitive questions about the integrity of the inclusive research endeavour, the nature of relationships between different research stakeholders, how power and decision-making is shared, and who ultimately 'owns' the research (Hoggart, 2017).

This article presents the experiences of two inclusive research teams from England and Australia, who each developed ways of working together to collaborate on data analysis. Both projects adopted qualitative methods and addressed what might be described as 'sensitive topics'. This is not unique, as inclusive research often deals with research topics that can be sensitive to people with learning disabilities – such as contraception (Ledger et al., 2016), ageing (Strnadová et al., 2015) and social inclusion (Iriarte et al., 2014). The English research was an evaluation of *MADHOUSE re:exit*, a project designed to raise awareness of the history of institutionalisation of people with learning disabilities and to reflect upon ongoing experiences of social isolation (Walmsley et al., 2018). A team that involved three University researchers and two co-researchers with learning disabilities conducted the evaluation. The

Australian project explored effective models of peer support for parents with learning disabilities, with a research team comprising three University researchers and one researcher with learning disabilities (Collings et al., 2019; Strnadová et al., 2019).

Our aim in this paper is to add an original contribution to the methodological debates in inclusive research for people with learning disabilities, across different international contexts. Emboldened not only by the focus of this special issue, but also Nind's (2011) appeal for more nuanced dialogue about the tensions involved in participatory data analysis, we discuss the deep (and often unacknowledged) sensitivities involved when doing this interpretive work together. We share our reflections, struggles and achievements of participatory data analysis, including consideration of the 'sensitive approach' that may be required to support meaningful co-analysis in such projects.

In the spirit of transparency, we believe it is also important to detail the process of how we conceived and wrote this article. It was the University researchers who first considered the possibility of submitting a paper about participatory data analysis for this special issue. We then discussed the idea with our co-researchers with learning disabilities who agreed we should go ahead. The University researchers undertook a review of the literature and broadly agreed a focus and outline for the paper. Sue Ledger and Paul Christian from the history project, and Iva Strnadová and Julie Loblinzk from the parenting project, then met to discuss their experiences of doing data analysis together, basing their discussions around a set of core questions that were agreed amongst all seven authors. We decided to include extracts from the meetings within the main body of the article, so that readers can see how these conversations unfolded. In the context of community heritage exhibitions, Graham (2019) has argued that the 'radically specific' reflections of people with learning disabilities are often at risk of being hidden within the big ideas or headlines of curatorial practice. We argue that such 'interpretive hierarchies' (Serrell, 2015) are also at play in the curating of articles like this, where space

must be dedicated to theoretical considerations and conceptual ideas. For this reason, direct contributions from all the researchers are identified in the main body of the article. The lead author drafted the discussion section (a further layer of analysis in the development of our argument) and the first draft of the paper was then refined by all the other named authors. This approach to co-writing mirrors and builds upon previous co-written publications we have been involved in (Brownlee-Chapman et al. 2018; Strnadová et al., 2019). We acknowledge its imperfections, notably that it can be challenging to provide a rigorous account of the research process and findings when making space for stakeholder perspectives to be included. But we argue that we must strive towards different ways of communicating knowledge and experience, in order to challenge the boundaries of what constitutes accepted (and respected) practice within academic publications. We appreciate that this paper may be of greatest interest to those conducting inclusive research with people with learning disabilities. However, we hope the detailed explications of our data analysis processes, alongside our critical reflections, will be relevant for anyone engaged in participatory research with so-called 'marginalised' groups.

Participatory data analysis with people with learning disabilities: What we know from the literature

While the breadth and depth of inclusive research with people with learning disabilities has experienced notable expansion in recent years (Bigby et al., 2014; Nind, 2014; Strnadová and Walmsley, 2017), the process of doing data analysis together continues to be underreported. For us, participatory data analysis offers opportunities to resist the 'power takeovers' (Deleuze and Guattari, 1987: 8) of professional discourses about learning disability (including those produced through the academy), strengthening scope for what Roets et al. (2007: 325) have described as 'epistemological innovation'; a multiplicity of perspectives and truths. Data analysis offers people with learning disabilities the potential to become not

just producers and users of knowledge, but also interpreters of knowledge, bringing their own wisdom, experience and judgement to bear.

But this begs the question: how best to achieve this aspiration in an ethical, rigorous and sensitive way? If we acknowledge, as many colleagues involved in inclusive projects do, that research offers pathways to disrupt marginalising discourses and unequal social structures; then the act of data interpretation is worthy of close attention. As Nind has argued 'it is through active participation in understanding the world through research that participants benefit from a transformative experience' (2011: 354). And yet why do so few inclusive projects talk about participatory data analysis? We agree in part with Nind's (2011) suggestion that the power and status that is associated with data analysis may make it harder for academics to relinquish. But we also suspect that it is uncertainty about how to do this process well (and sensitively), combined with anxiety about how best to write about it, that explains the scant coverage in the literature.

There are some emerging accounts of participatory data analysis with people with learning disabilities. Nind and Seale (2009, cited in Nind, 2011) undertook concurrent data collection and analysis with participants/co-researchers through a series of workshops. A different method was adopted in the Voices for Change project (Stevenson, 2011). The author describes how she collaborated with a small group of people to analyse and code the transcripts of young people with learning disabilities who had participated in a project about their life goals. Williams, Ponting, Ford, and Rudge (2009) described their use of conversation analysis to analyse the video stage of their Skills for Support study. The two researchers with learning disabilities, who had experienced interactions similar to those portrayed in the videos, participated in data analysis by identifying important parts of the videos. Frankena et al. (2019) described using Membership Categorisation Analysis (MCA) in an inclusive project that explored the roles, activities and relationships in participatory

projects, enabling co-researchers to 'take the lead' (2019: 725) in analysing data. The Building Bridges Team described their visual coding process on a project exploring community inclusion (Moony et al., 2019). Following 'discussion group' meetings, the academic supporter compiled a list of reflections that were then translated by a co-researcher into picture cards. The picture cards were subsequently used by the wider team to identify key themes in the data.

While there is now wide acceptance that people with learning disabilities can participate in research design, data collection and dissemination (Nind, 2014; Walmsley et al., 2018), Nind argues:

> 'we need to push on to say that people with learning disabilities can do data analysis too, not in the sense of romantic idealism or positive spin, rather of finding out what can be achieved by exploring ever-more sensitively supportive approaches to breaking down barriers, opening up possibilities and achieving access' (2011: 355).

In the following two examples of participatory data analysis, we set out the ways in which we attempted to address the ethical and quality challenges posed by Nind, and the sensitive terrains that were navigated in the process.

Doing data analysis together: Practices and reflections from two inclusive teams

Here we present the research teams' reflections about the participatory data analysis process, captured across a number of meetings based around the development of this article. What follows are the edited accounts of these conversations, based around a set of pre-agreed questions. The questions we posed to each team were:

- How did you do the data analysis together?

- What part(s) of the data analysis process felt sensitive to you?

- Why did this feel sensitive?

- How did you deal with this?

- What difference did doing the analysis together make to what you said about your research?

The accounts below were jointly compiled by the teams, but also include direct quotes from individual researchers to reflect their perspective. Direct quotes are presented in italics and are included where a member of the team felt it was important for their reflections to be captured verbatim. For more details on the two projects, please see Walmsley et al. 2018 and Srnadova et al, 2019.

Inclusive Evaluation of MADHOUSE re:exit (England)

How did you do the data analysis together?

The evaluation of the *MADHOUSE re:exit* programme was conducted by a team comprising of two experienced researchers, Sue Ledger and Jan Walmsley, and two co-researchers with learning disabilities from theatre company Access all Areas, Paul Christian and Zara Jayne Arnold, with input and advice from Liz Tilley. Prior to working as an inclusive team, we had gotten to know each other quite well as Sue and Jan had led workshops on learning disability history for the theatre company. Paul and Sue had also previously worked together with Access all Areas in making a film called *No Longer Shut Up.* The co-researchers received basic training in research methods from Sue and Jan.

The main piece of collaborative data analysis we undertook related to history workshops that Access all Areas had delivered to people with learning disabilities. The data we analysed together included:

- Observation notes made in notebooks kept by evaluation team;

- Photographs from workshop sessions;

- iPhone and iPad film recordings from the workshops and evaluation session;

- Session aims from workshop leaders, who were members of Access all Areas (the 'wall of what we wanted to do');

- Interviews with the *MADHOUSE re:exit* programme leaders about the workshop aims, planning and activities;

- Data from a de-brief interview with a life history workshop leader;

- Paul's audio recording of his immediate reflections following the workshops.

We undertook a thematic analysis of our data adapted from an approach outlined by Zeibland and McPherson (2006) and also drawing on coding systems outlined by Braun and Clarke (2006). We worked systematically through the data using post it notes to identify key segments of data. This was followed by the shared naming and clustering of codes which finally developed into thematic maps.

Prior to this coding process we analysed the 'wall of what we wanted to do' and extracted the aims as identified by workshop leaders. A large piece of paper was used to represent the 'wall', with paper 'bricks' stuck on. These bricks were made by the Access all Areas History workshop leaders, and clarified what leaders wanted to achieve in the session. As evaluators it was important for us to understand what the leaders wanted to happen. For workshop leaders it was important to know whether findings from the analysis showed if their original aims had been met. This data could then feed into the planning of the next

workshop series. We also made a note of the aims as headings to use in our analysis, and if data related to these aims we coded the extract to these pre-determined headings. Alongside this approach we remained open to new themes arising from the data.

When this data analysis process was underway, we developed numerous sheets of paper with different headings and placed coded extracts (with respondent identifiers) under each. Jan and Zara read out what they had seen from their notebooks and Paul shared his verbal reflections and audio recording from the session. Sue, working with Paul, then recorded the main points on sticky post-it notes and placed these on a large piece of paper. The team then discussed these together. We all decided quite easily how things should be coded and what key words to use on the post-it note along with the data extract. If a piece of information didn't fit easily with one of the headings on the paper, we made a new theme and put it in there. Some data extracts were coded to more than one theme.

Paul: *It made me feel included that I was saying the words and you were transcribing it. A research word! It helped that I could see exactly what you were doing. I felt included. If you had done something wrong I felt I could easily tell you and talk to you and Jan and Zara and then I wouldn't feel like I had been ignored. I felt my points counted this way and I could see them being written down and included. It just shows people how serious our views and thoughts are and how it means so much to us. I think being able to see the whole process was very important and it is very important that you can stop and talk openly with people like you and Jan who are helping us make sense of the data. It is important that you feel really listened to and that it is not going to cause any difficulty if you don't agree or don't understand what is being said or what is being done.*

What part(s) of the inclusive data analysis process felt 'sensitive' to you?

Sue: *One issue in data analysis that felt sensitive to me was that I took the lead in doing the writing of data extracts on the post-it notes. Paul and I were choosing the words together with Jan and Zara feeding in too, but I was doing the actual writing on the post-it notes which did, for me, feel a bit controlling at the time. Everyone was happy for this to happen – we agreed this was best as I had hadn't been evaluating at this workshop, but on reflection (and with more time available) it might have been good to share this role around.*

Paul: *Yes but it worked because we could all see what you were writing and drawing and what you were doing. I could change the words if I wanted to and I remember I did this. I never had a chance to explore this researcher side of me before and it really helped me to talk about these kind of issues with other people and for them to listen. I'll be honest it sounded a bit jargon - the term 'data analysis' - but when we started doing it I understood the concept. I think that was the best method at the time – it was done in a fashion that was cut up into small bites of information and that helped me to click on to what people were saying.*

Sue: *I would like to have had the time to try out some ways of presenting the first stage data analysis, like mind maps and flow charts and then had another team session to re-visit the coherence of our coding, categories and themes together. When I started to think how we could do this I estimated that this would have added a further two days of work to our data analysis schedule. As there were four of us this would be more expensive for funders but in my view very worthwhile in terms of the deepening the inclusive analysis process and findings.*

Why did this feel sensitive?

Paul: *Because this was analyzing data from a workshop about learning disability history and about people's lives today. In this way the actual data, it's dragging up the things that excluded us from the events in the past that somehow have still made it into our present. This has made a permanent scar on our hearts. In our team if someone in power hadn't listened when we were talking about the data it would be like a re-activator or reminder – if someone ignores us and doesn't really take careful note of what we are trying to say it can reactivate the wound which ultimately puts us back to the beginning. That didn't happen in our team, that was a very good thing. It felt we were all on a level. But I think we did need more days in our programme to give us more time to do our data analysis. I found it very interesting, the thinking and sorting out what we saw and heard in the sessions and what they meant. We would need more money to actually do more of this properly.*

Sue: *I think that you have raised for me what is the greatest tension in doing this work together. In our analysis session I think you and Zara both saw things, certainly in terms of performance, that I might have missed as I don't have a performance background. I was also very aware of the sensitive and painful issues that some participants were raising – like how people are still experiencing a lot of bullying and name-calling. This is really important data to capture and, as you say, to you and Zara it is deeply personal and it seems crucial to include your input, your reflections based on your own lived experience. Yet it feels very uncomfortable and inappropriate to be rushing the processing of this sensitive material because we have to deliver our findings on time. I also wonder if there is more pressure on us to prove ourselves as an inclusive team? In the past people have questioned whether people with learning disabilities can really do data analysis.*

How did you deal with this?

Paul: *We dealt with this by talking about it and thinking about how we would make the best use of the time we had. We also talked about how we can make a case for more time in the future – like writing this article. We are speaking about how we can make the case for people to be trained and involved in research.*

Sue: *We discussed the tensions openly. It feels risky but it needs to be said as there is a real danger of pretending to do things inclusively. When we had to cut corners we decided to explain this openly. It is much more respectful. If we as an inclusive team acknowledge the limitations of working under existing time constraints we can think together about how to work in the future in a way that can capitalize on using your time and the expertise you bring to thinking about the data and to the interpretation and analysis process.*

What difference did doing the analysis together make to what you said about your research?

Paul: *Working together is more like a partnership of entangled knowledge that helped to understand these strong issues. It helped to feedback to one another and to have debates on the issues. I think that as performers we bring our own knowledge and passion that drives it forward. It enables us to move forward and understand things that they (Sue and Jan) wouldn't have thought they would understand and so they are teaching themselves in the process. Even though it was the same goal – doing really good data analysis – we all brought different perspectives to the table. We all have different eyes and we all travel on different paths – so we all saw different things.*

Peer support for parents with learning disabilities (Australia)

How did you do the data analysis together?

The study was co-designed and co-produced by academic researchers (Iva Strnadová, Susan Collings, and Joanne Danker) and a researcher with intellectual disabilities (Julie Loblinzk). Three of us (Iva, Susan, and Julie) conducted the interviews, either in tandem (mostly Iva and Julie) or individually (Iva or Susan). We analysed the data in two different ways and teams. This was due to time constraints. We knew that we needed to submit an article to a high-quality peer-reviewed journal within 18 months of commencing the study (this was a condition of being funded). The first year was spent developing and obtaining ethical approval, recruiting participants, conducting and transcribing the interviews, and making a start on data analysis. It was these 12 months that we were funded for. Most of the data analysis was conducted after the initial 12 months of the study, and given our previous experiences of doing data analysis inclusively, 6 months was not long enough to analyse the interviews and write a high quality article. Therefore, the data analysis was conducted by Iva, Susan, and Joanne, and in parallel by Iva and Julie. This allowed us to meet the funding conditions, and still engage in inclusive data analysis. What we describe below is based on the data analysis conducted by Iva and Julie. The actual inclusive data analysis took place in the following stages:

- We printed out all transcribed interviews (in font size 14, double-spaced).
- We listened together to each interview, while reading it in a printed version.
- We used highlighter pens to highlight main topic that each parent talked about.
- We also wrote our comments on the printed interviews.
- After listening to an interview, we discussed the main topics covered in that interview, and then summarised it. These discussions were recorded and transcribed and became a part of data.
- From each interview we had 1-2 pages of main topics in dot points.

Julie: *We also did some of the interviews separately and I emailed the main points to you.*

In the next stage, we used highlighters to group the main headings together (e.g., purple was for parents' preferences, yellow for issues they experienced). After that we used a butcher paper [an Australian expression for a kraft paper] to create mind-maps for each heading. We totalled the number of participants that mentioned each topic.

Julie: *Mind-mapping is the best. As we were playing to our strengths, I was happy to do the writing on the butcher paper.*

Based on the mind-maps, we created a one-page overview of the main themes. Under each theme we listed sub-themes, in order of frequency that these were mentioned (from most to least). After that we summarised the key findings in a narrative.

This extensive description of our data analysis process is important, as it also gives an indication of how much time was needed for data analysis, which went beyond the funded period of the project. This was a particularly sensitive issue for **Iva:** *As an academic researcher, I am in a privileged position compared to Julie. Conducting research and writing publications is reflected in my workload, and thus I am getting paid for my research work even beyond the official funding for a research study. However, this is not the case when it comes to Julie, who conducted data analysis with me after the funding for this study ceased. I found some opportunities to pay Julie for her work, but it was not enough. Julie was happy to continue with data analysis and writing up the findings beyond what she was paid for, as she has been very passionate about the research work and the potential impact it can have, however, I felt terrible about this financial aspect of doing inclusive research.*

Despite this sensitive (and ethical) issue, the data analysis process was a new experience for Julie, and a positive experience for both Iva and Julie.

Julie: *I have just started to do data analysis. … My previous experience with writing was with* [another academic] *– all we did were discussions and then* [he] *wrote it and I gave feedback to it before it was final. Working with you has been a lot different. It's positive, we work well together, we like our brainstorming together.*

Iva: *While I worked within inclusive research teams before, this has been a new experience for me too. Julie and I work very well together. Our collaboration developed gradually, from getting to know Julie in her work role at Self Advocacy Sydney, via Julie being a kind external help with recruitment in my studies focused on adults with learning disabilities and inviting Julie to guest lecture to my undergraduate and postgraduate students, to deciding that we would like to conduct research together on issues that are important to us. I think that this gradual getting to know each other in different aspects of our work (Julie's as a self-advocate, and mine as an academic researcher) helped to shape how we work as a team. Each and every decision is made together. Julie is a very independent and self-determined woman, so there is no feeling shy about our own opinion on either side. In my previous experience, I conducted inclusive research with co-researchers, many of whom lived in circumstances which did not allow for much self-determination or choice (like a group home). This was reflected in the way we worked together, with me and my academic colleagues shaping the approach and individual steps taken in these research studies. Julie and I work differently – we brainstorm how we want to do things together and we are not afraid to admit to each other when things don't work out. Being friends is also tremendously helpful. We know about each other's joys and sorrows, so to speak, which assists in mutual understanding and respect.*

What part(s) of the inclusive data analysis process felt 'sensitive' to you?

Iva: *The process of data analysis in terms of considerations of who has a power in this process was not sensitive for us. What we found sensitive, were the findings and what to do with them. This included issues of domestic abuse and violence, bullying, parenting rights and custody issues, and parenting skills and confidence. Some parents talked about a lack of self-confidence and accomplishments, and a few parents self-harmed as the way to deal with emotions, experiencing a lack of trust, people not caring for them, and feeling excluded. There was even a reference to feeling suicidal. These findings were – while not surprising – deeply disturbing.*

Julie: *The process wasn't sensitive; it was just what came out of it.*

Iva: *Government services are not supportive of parents with intellectual disabilities. Instead of helping parents to develop parenting skills, they tend to remove children from their custody. In cases of domestic violence, they would rather remove a child than help the mother and children.*

Julie: *Yet, all government services have to follow the National Standards for Disability Services, and Disability Services Act, which first came up in 1986.*

Iva: *How do you remember all of this?* [i.e. the year when the legislation came out].

Julie: *Because as a result of it I could speak up…I guess we learnt that the things that came out were sensitive. What people brought up. … People really didn't get the idea around peer support and there were a lot of issues that I thought would not come out so strongly (domestic violence and removal of children from custody). It is difficult as we can only report about it but cannot get involved. You can't go back…. It makes you want to jump right in and support, but you can't…We could not intervene and support them with developing skills and getting support.*

Why did this feel sensitive?

Iva: *It was because of the feelings of helplessness that Julie and I had, listening to (both during the interviews and from the audio recordings when analysing the data) disturbing experiences of domestic and family violence, as well as bullying experienced by the parents with intellectual disabilities.*

Julie: *A lot of parenting and DOCS* [Department of Community Services, Australia] *taking away children – I don't think DOCS fully understand these parents. One mistake and a child is automatically taken away.*

Iva: *I remember how it triggered for you a memory of being in a maternity hospital with your first child and being afraid that she will be taken away from your custody, as it happened to another mother who was in the same room.*

Julie: *It gave me things to think about. It gives reflection, to look at what is happening to you…If anybody is giving you information and it is not positive, you are going to feel towards that person. Especially if they are in a difficult situation. So, it depends what the person brings up. It can be something I can relate to as I went through it.*

Julie also brought up an important point of how having a voice, and having somebody to listen to your experiences, can have a cathartic effect.

Julie: *If you are good at interviewing and if you can bring something out, hopefully it can help them to feel better… I have learnt how it is positive that people with intellectual disabilities can be open in interviews, because it is different in mental health.*

How did you deal with this?

Julie: *Well, we did reflections. We talked about it.*

After each interview that we listened to and made notes about, we had a discussion about the main points brought up by the parent and our thoughts about it. We recorded these

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reflections as part of our data. This was very helpful not only from the perspective of understanding the data, but also dealing with some distressing issues we heard about. Still, this did not lessen our feeling of limited opportunities we have as researchers to do something about the disturbing findings.

Julie: *I would love to do something about it. If it was in my role, I would take it on as part of the self-advocacy. But that is restricted by the numbers.* [Self Advocacy Sydney is funded to support only up to 50 people with learning disabilities. Yet, this advocacy organisation covers the whole Sydney metropolitan area, and it is the only self-advocacy organisation in that region.]

We agreed though, that publishing the findings and thus giving parents the voice, can assist in gradually changing their situation.

Julie: *Thanks to that there is more awareness and it gets to stakeholders so that they can use the information.*

What difference did doing the analysis together make to what you said about your research?

Julie: *We would have probably come up with same findings, but the way it was presented would be different. It was more positive doing it in teamwork than separately.*

Iva: *Each of us brought our knowledge and experiences to data analysis, and we also played on our strengths. It allowed us to understand the data on a deeper level.*

Julie*: Finally, I want to say something about the amazing positive experience of working together. Doing the research together in this way works. It demonstrates how a co-researcher and a professor can be able to achieve completing the data analysis as a team. In future, hopefully professors and co-researchers can be involved more to explore topics important to people with intellectual disabilities.*

Discussion

The examples detailed in this paper speak to sensitive research issues in a number of ways. While there are some differences between the two examples, there are also a number of striking similarities. First is the issue of time and resources. Despite good intentions and an awareness of what is required to de-stabilise traditional power dynamics between 'academic' and 'co-researchers', time and money place constraints on the inclusive data analysis process. Both teams identified that collaborative interpretation would have been deepened further had there been time for an additional stage of analysis. The pressures of resources and demands to publish meant this final round of review had to be abandoned. Both teams identified this as a limiting factor in terms of extending opportunities for co-researchers with learning disabilities to be more thoroughly engaged in interpretative work. Having time to consolidate and reflect is important to everyone, but particularly for co-researchers, who are not only contending with managing new skills of data analysis, but also immersing themselves in data that may be deeply personal. It is also important to acknowledge that research papers are usually written after a project's completion, when funding has ceased. It is not uncommon for co-researchers to participate in writing activities without payment; this has implications for the scope and depth of participation and raises significant ethical issues regarding unpaid labour. We need a 'slow rhythm of reflection and action' (Fals Borda, 2013: 159) to undertake sensitive and robust participatory analysis, but the systems we work within do not always facilitate this.

The research teams both identified that participating in data analysis runs the risk of reviving past trauma. Both projects set out to address sensitive topics. But it is perhaps the immersion in that data, through the analysis process, that had a particular impact on co-researchers with learning disabilities. The data resonated with their own personal experiences, and that of people they knew. This reawakened memories of painful experiences. In Julie's case, it prompted a strong desire to reach out and help the participants

with whom she had spoken. As a peer advocate, Julie provides practical and emotional support to people with learning disabilities in her 'day job'. But as a researcher, focused on revealing, understanding and interpreting experiences, she did not have the same freedoms to 'act' as she might do in her advocacy role. These are ethical dilemmas that all social researchers may face, but for those with lived experience of the issues at hand, the frustration of not being able to intervene may be especially difficult. This alerts us to the potential impact on researchers who engage in data analysis in spite of - or indeed *because* - it resonates so deeply with their own personal experiences.

The potential for reactivating trauma through the analysis process can be heightened further if academic colleagues do not listen sensitively to their co-researchers' responses. Paul said: '*In our team if someone in power hadn't listened when we were talking about the data it would be like a re-activator – a reminder - if someone ignores us and doesn't really take careful note of what we are trying to say it can reactivate the wound'.* His words remind us that the everyday practices of doing data analysis – who speaks/listens when, and how - can also have significant impacts on co-researchers; as powerful as the data itself. Power (im)balances were managed carefully on both teams, with Paul and Julie stating that that they felt listened to, respected and valued. In turn, they also engaged with diligence and attention. In this way, participatory data analysis becomes a mutual exchange in which all parties must demonstrate sensitivity and care both towards the data, and to each other.

Such sensitivity may be strengthened by the nature of the relationships within teams. In both projects reported here, the researchers were already known to one other. They had worked together previously, and had developed trust, rapport and knowledge of each other's lives. This appeared to support a context in which members of the team felt they could be open and frank about their interpretations. However, inclusive research teams will often find themselves working together for the first time. We argue that teams must therefore be

prepared to invest time and energy in developing relationships, aiming to create a level of trust and psychological safety that seems to be crucial in enabling authentic collaborative sense-making to happen (Frankena et al., 2019). As Schwartz et al. (2019) have argued, this is likely to support the longer-term maintenance of inclusive research collaborations.

These two projects demonstrate that people with learning disabilities can learn to do data analysis and can benefit from the experience. In this way, we would argue that our research resists the 'incompetency discourses' (Nind, 2011) concerning people with learning disabilities that have dominated for so long. But perhaps more significantly, participatory data analysis in our projects also became a site for mutual learning. The process of acquiring skills and knowledge was a reciprocal one. The co-researchers learned how to code data; while the academic researchers learned how to view the data through a different lens. Drawing upon Gallacher and Gallagher's (2008) argument that we are all immature, developing and learning beings and researchers, Nind applies this to the inclusive data analysis process, suggesting it 'recognizes the vulnerability and potential of us all as we take risky steps forward' (2011: 359). This mirrors our experiences, and reminds us to be sensitive to the opportunities for growth and development for all members of the inclusive team.

Both of the projects involved analysing qualitative data. While the data sets were not small (26 interview transcripts for the Australian study; a varied set of ethnographic data for the English project), our experiences do raise questions regarding how well the methods detailed in this article would support participatory data analysis when working with much larger data sets.

Finally, these projects show us that collaborative sense-making is possible. We can and should be striving towards 'entangled knowledge' (Paul). Participatory data analysis enables us to 'lean in', listen to and value different ways of understanding the world (Thrift, 2008). The two projects described in this paper show that members of the team attended to

the stories, interactions, movements, pictures and words that emerged in the data in a multiplicity of ways. Participatory data analysis can help us to resist privileging those accounts that act as convenient 'tent holes and pegs' around which we can interpret the more complex and 'radically specific' accounts of people with learning disabilities (Graham, 2019). However, we acknowledge that in doing so, it might make our jobs of reporting to funders or policy-makers more difficult.

Conclusion

In this article we argue that the pressures of being seen to do 'good science' and 'emancipatory inclusive research' can serve to silence us when it comes to describing our experiences of participatory data analysis. The desire to demonstrate rigour and efficiency in the academy can make it challenging to approach the sensitivities of collaborative interpretive work in an honest and reflective way. Anxieties of power take-overs when working within an inclusive paradigm can further constrain our confidence to approach the process of data analysis in an open way. But to engage with our colleagues on these matters is, as Sue argues above, a mark of respect. Reflecting on the difficulties together also offers the possibility of jointly constructed solutions. We are reassured and encouraged by Nind's contention that 'difficulties do not belong to people, but rather the interactive spaces between them' (2011: 353). Our examples present two established research teams making genuine headway to negotiate the sensitivities of these interactive spaces. Both teams acknowledged imperfections in the process but their accounts demonstrate the potential for participatory data analysis to help us imagine and create new spaces for epistemological innovation.

We conclude our paper with a set of recommendations for researchers seeking to work inclusively on data analysis with people with learning disabilities or other marginalised groups:

1. Plan ahead – seek to get the additional resource that participatory data analysis will require, both in time and money;

2. Collect the data with an awareness that you will be analysing it inclusively;

3. Build trust between members of the research team – this takes time and effort and needs to be accounted for when developing research proposals;

4. Be imaginative - think of different ways to present data to support co-researchers to engage with the interpretive process;

5. Be prepared to be selective in the data you work on together;

6. Recognise, and celebrate the unique expertise everyone brings to the task;

7. Create opportunities for reflexive conversations about the process.

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