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"Ethno...graphy?!? I can't even say it": Co-designing training for ethnographic research for people with learning disabilities and carers

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Accessible Summary

- We are a team of academic researchers, people with learning disabilities and carers. We worked together to design training materials for people with learning disabilities and carers to work as co-researchers on research projects.
- The training was for doing a type of research called ethnography. When you do ethnography, you spend time with people to learn about their lives.
- In this article, we describe what we did and what we learnt.
- We think more people with learning disabilities and carers should be involved in research but many do not have the confidence to do it. Training can help with that.
- We also think that ethnography is a type of research that can be easier to do than other types of research. This is because ethnography uses the skills lots of us already have the following: watching, listening and talking to people.

Abstract

Background: There is a strong ethical case and an urgent need for more participatory research practices in disability research but a lack of resources to support this. It is important to involve people with learning disabilities and carers at all stages, including when designing training for co-research.

Methods: We co-developed training materials to support people with learning disabilities and carers to work as ethnographic co-researchers and for academic researchers to facilitate co-research. We focused on what people with learning disabilities and carers thought was important to learn.

Findings: Whilst not all types of research methods are easy to democratise, ethnographic observation is a research method that lends itself well to participatory co-research.

Conclusions: For people to be able to meaningfully participate, research processes need to become more accessible and transparent. Training that considers the needs

and priorities of people with learning disabilities and carers and addresses the confi-
dence gap is key for meaningful co-research.

KEYWORDS
co-research, inclusive research, participatory research, people with learning disabilities

1 | INTRODUCTION

Despite considerable policy developments and research focusing on the lives of people with learning disabilities across decades, an estimated 1 million people with learning disabilities in England remain disadvantaged in terms of relationships, employment, health and wellbeing (Bates et al., 2017; Forester-Jones et al., 2010; Hatton et al., 2016). Inclusion is a core principle of Valuing People—the government's policy framework for learning disability (Department of Health, 2001). However, people with learning disabilities continue to face exclusion in daily lives (Fulton et al., 2021; Harrison et al., 2021). People with learning disabilities have historically also been excluded from doing research and have instead been relegated to be the subjects of research (Lester & Nusbaum, 2018). However, there has been a move towards democratisation of research practice across two decades that offer more inclusive approaches for people with learning disabilities and other marginalised groups (Fletcher-Watson et al., 2019; Garcia Iriarte, 2014; Johnson, 2009; Nind, 2014; Ramcharan et al., 2004; Warwick, 2020). One way this has been happening is through participatory research (Bourke, 2009; Nind, 2014, 2017). Participatory research is "a research process which involves those being researched in the decision-making and conduct of the research, including project planning, research design, data collection and analysis, and/or the distribution and application of research findings" (Bourke, 2009, p. 457). Participatory research is inclusive and adaptable, allowing for the research environment, methods and dissemination to take forms and routes "to permit the widest and most accessible engagement" (Fletcher-Watson et al., 2019, p. 944). "Co-research" is a type of participatory research, "defined as research carried out 'with' or 'by' members of the public rather than 'to,' 'about' or 'for' them" (Di Lorito et al., 2018, p. 670). However, for people to be able to contribute meaningfully and to overcome a confidence gap that might exist in the face of academic processes, they need access to training. We argue that this training should also be designed in collaboration with people with learning disabilities and carers.

There is much discussion about the emancipatory potential of participatory co-research in relation to disability, but very little is done in terms of facilitating this in a practical way. To be involved as co-researchers, it is essential that people can access the knowledge and tools that researchers use (Strnadová et al., 2016). It is also important to acknowledge that offering adequate training and support requires extra planning, time and resources (Burke et al., 2003; Flood et al., 2013; Kramer et al., 2011). Whilst most academic researchers learn how to conduct research through formal training, co-researchers are typically expected to learn on the job. There remains

little knowledge or practical advice for how to support people to do the job of co-researchers (Tuffrey-Wijne et al., 2020). There is also debate around the role of formal research training which might "train away the difference" that is being brought to the research project (Nind et al., 2016).

We suggest that the lack of knowledge and/or practical advice may dissuade academic researchers from actively engaging in co-research. Academic researchers might also lack the know-how around appropriate resources for co-research and ensuring the relevant ethics approvals. Lack of knowledge and support exacerbates the confidence gaps between and among co-researchers and researchers, creating and reinforcing barriers to participation and, by extension, inclusion. In addition, the risk is that if people are not supported to develop appropriate skills and confidence as co-researchers, their contribution might become tokenistic.

Notably, some research methods lend themselves more readily than others to participatory approaches and co-research (Strnadová et al., 2016, p. 58). We argue that ethnographic observation is such an approach, as it relies on skills many of us already have. In this paper, we discuss our experience of working together as a team of academic researchers, people with learning disabilities and carers to design training materials for people to work as co-researchers on ethnographic research projects, with focus on ethnographic observation. We also share what we learnt in the process.

Our guiding principle for this work was to find out what people with learning disabilities and carers thought would be helpful for them to learn and know to be able to work as co-researchers. We took a collaborative approach to this task, and this article is an extension of this. We argue that for co-research to be meaningful and productive co-researchers need to be better supported and prepared. We also argue that academic researchers have to *proactively* offer that support and facilitate preparation. Based on our collaboration, we developed a set of resources (see Appendices S1–S4) that reflect this and support people with learning disabilities and carers to become co-researchers, as well as supporting academic researchers to better facilitate ethnographic co-research. Whilst our work focused on ethnographic observation, our insights around research processes and training are applicable more generally and contribute to the growing field of co-research literature.

1.1 | The why and how of co-research

There is a strong ethical imperative for participatory research as a more equal way of doing research. This should be enough to legitimate

participatory approaches, as Williams et al. (2020, p. 4) point out: "a democratic rationale does not require a sound evidence-base to justify the normative desirability of co-production." In addition, co-research produces richer results as it is more relevant to the people the research is about. The quality of data is improved because co-researchers can act "as catalysts and role models when interviewing people with learning disabilities or facilitating focus groups of people with learning disabilities" (Butler et al., 2012; Tuffrey-Wijne et al., 2020, p. 302). Involving people with learning disabilities as co-researchers can also benefit people's personal growth by boosting their confidence (Tuffrey-Wijne et al., 2020). We expand this point and argue that overcoming the confidence gap is also key to successful co-research.

However, whilst people with learning disabilities are involved more often as co-researchers (Herron et al., 2015; Nind & Vinha, 2014; O'Brien et al., 2014), there remains little knowledge or practical guidance for how to support people to develop skills to do the job (Tuffrey-Wijne et al., 2020). The small amount of training that has been done is designed by academic researchers, teaching what they think people should know, rather than actively co-designed with people themselves. Existing training is also delivered by researchers. Together, this means training is underpinned by researchers' assumptions, and not by what people with learning disabilities and their carers actually want or need to know to be able to participate as research partners. There is a risk that existing skills and knowledge—the reasons people with learning disabilities and carers are valuable co-researchers—are de-emphasised in favour of the skills researchers think are important, again prioritising particular knowledge (see also Nind et al., 2016).

1.2 | Theoretical underpinnings

Whilst practical in nature, our project was informed by a particular understanding of disability; theoretically, our work is indebted to and builds upon critical disability studies (Goodley, 2018, 2021; Goodley et al., 2019). The main insights from critical disability studies relevant here are attentiveness to conditions of exclusion and inequality that disabled people are subjected to and demands for accountability and inclusiveness in disability research:

> A critical disability studies scholar asks difficult questions about the possibilities of representation and accountability of scholarship and activism to all disabled people. And this newfound criticality seeks to challenge some of the starting assumptions of disability scholarship, founded at a time when some groups of disabled people were not present in deliberations as to its potential meaning (Goodley, 2018, p. 6)

Co-designing training for co-research is to work against the grain of assumptions around who should be included and in what ways in the research process. To study disability critically is to also acknowledge academic researchers' complicity in and at times personal and institutional investments in the very processes that make research and its outputs inaccessible to its "subjects." It means that academics need to come to terms with their own discomfort around (reluctantly) standing in for institutional power of academia, with its hierarchical and ableist nature (Brown & Leigh, 2018; Dolmage, 2017).

2 | THE TEAM AND THE PROJECT

The team came to this work through different paths. PB is a Consultant at My Life My Choice and a co-researcher, LD supports PB, JC is a self-advocate and Director of Together All Are Able, KL and SB are a family carers, AV is a family carer, co-researcher and a PPI lead, SR is a sociologist, CA is a medical anthropologist, and MM is qualitative researcher with background in gender studies. Members of this team (AV, SR, MM, PB) were working on an ethnographic study exploring how people with learning disabilities and their family carers can be better supported in later life.[1] When looking for training to support co-researchers on this project, they identified the gap we outline above—training is scarce and researcher designed and led, which reproduces many of the inequalities of a "typical" research process. To avoid this, SR, AV and CA developed a successful funding application to co-design a training resource with, and for, co-researchers. MM was recruited to work as a researcher on the project. JC, PB, KL and SB were invited to join the team as people with learning disabilities and carers.

2.1 | The process

We had three online meetings to develop the initial resource. The first two were two hours, and the third was half an hour. We had an open agenda for the first meeting with focus on "The *What? Why? and How?* of research". To mitigate power imbalance where possible, we thought it was important academics did not take the lead. AV, an experienced facilitator, chaired the meeting. After introductions, we had an open discussion about research. Rather than grounding discussion in "academic" research, we talked about the skills we have and use every day to find things out. We shared that we might research what the parking rules are in our area, for example, or what types of food would be best for tube feeding our children. We talked about using the Internet, talking to people and asking questions to help us find things out. The discussion was free-flowing, and we found we all had skills to find things out and used these confidently in our daily lives.

We moved to discussing ethnographic research specifically. At this point, nonacademic team members said not only had they never heard of "ethnography," it was also difficult to say the word

and remember it. It was an unfamiliar academic term presenting a stumbling block in the team's confidence that people with learning disabilities and carers do, and can, do research.

Through discussion the team unpicked the core elements of "ethnography": asking questions, looking, listening and "hanging out/spending time" with people to find out about them and their lives (see Appendix S1). We decided these were things many of us already do well. Some of the team, for example, were involved in quality checking inpatient units and said they made visits and filled out structured questionnaires. They also observed, listened and asked questions. Other team members talked about when they used these skills to find things out and said "it's something you do without realising". Therefore, although the word "ethnography" sounded difficult and inaccessible, the process was a familiar one.

As the practices of ethnography felt familiar, the team identified a gap in confidence rather than a gap in skills. Although people with learning disabilities and carers felt that they had these skills, they were (a) less confident that their skills, knowledge and experience would be valuable, or valued, when working as a co-researcher, and (b) unsure when and how to use skills in listening, asking questions and observing in the context of "ethnography".

When asked what would help develop this confidence, people stressed the need for clear guidelines that would explain the "steps" in an accessible way, outlining where and when to apply those skills. We discussed a document that could be freely available and easily accessible. The team also spoke about the value of being involved in every step, trust and of working together (in the meeting notes, MM has circled and underlined "togetherness" as something everyone felt was important). This togetherness is highlighted in existing literature (see, e.g. Warren & Boxall, 2009). Other key things identified to take forward were being flexible and avoiding jargon, and difficult words.

After the meeting, MM and CA collated the information in the notes from the discussion into a series of draft documents. The first explained what ethnography is, the second the process of doing ethnography "as" a co-researcher, and the third explained doing ethnography "with" a co-researcher to emphasise that this is an activity undertaken together. These were reviewed by SR and shared as an easy read version with the full team.

The second meeting focused on feeding back on draft documents and sharing experiences of the mini-ethnography. We talked about each document, together suggesting changes. The team felt it was important to make sure the materials were clear and accessible. For example, the initial draft on "doing ethnography with a co-researcher" had mentioned making sure people "felt comfortable". The team said this was not specific enough… was this "physically comfortable in their environment", "comfortable with what they needed to do" or both? We also wondered if the word "ethnography" should be used at all, as its unfamiliarity may feed into a confidence gap, but decided it should be used, as long as it was explained clearly.

We also discussed asking questions in ethnography. The team were keen that it was clear you do not have to ask questions, and if you do it is more like having a chat rather than asking a list of questions in a specific order. We decided it may be difficult to think of questions when you are in a new environment and discussed what questions people could ask (see Appendix S2).

Finally, we spoke about how the documents 'doing ethnography as a co-researcher', and 'doing ethnography with a co-researcher' should be closely aligned, like a mirror image showing both sides of the process (see Appendix S2 and S3). We felt it was important these two documents showed clearly the responsibilities of researcher and co-researcher at each stage of the process. The team wanted the documents to support the co-researcher to feel valued, and more confident.

The third meeting provided opportunity for final feedback and discuss timelines for the final version of the resource.

2.2 | Mini-ethnography: Living with pets

After the first meeting, it was clear ethnography is not a type of research people are familiar with. The team shared that they felt they had the skills to carry out ethnography but not the confidence that these skills could be considered "research" skills. By putting these skills into practice, we thought we could discover together if existing skills were indeed enough and, if not, the people with learning disabilities and carers could share which skills they would like to learn and/or develop further. Because we were working during the 2020 COVID-19 lockdown, we had to be creative choosing a topic that would be feasible online and engaging, but also not too emotive, so that the people could practice their ethnography skills in a relaxed way, rather than dealing with sensitive or personal issues. The academic researchers are pet owners and were happy to be studied.

People with learning disabilities and carers were invited to conduct 3 sessions (10–20 mins each) on the topic *Living with pets during the pandemic*. The mini-ethnography was conducted via an online platform people felt comfortable using. The instructions sent by email in easy read were to observe the pet and their owner and ask questions. People were encouraged to be creative, have fun and to mix it up by, for example, talking to their participants at different times of the day or week, to observe different activities (play, feeding, etc.). People were encouraged to take notes in a format that worked for them. We thought that, if successful, this approach could be used by other teams doing ethnographic co-research (see Appendix S4). This practical research exercise offered opportunity to: build confidence, identify any gaps in knowledge or skills, practice existing skills and to build trust and rapport between academic researchers and co-researchers. It also offered the possibility to disrupt the power dynamic, with academic researchers becoming participants, answering questions and being probed about their lives. The pet ethnography was a success, exemplified in our reflections below. It revealed that the team had the skills to do ethnography. The team shared that the process built their confidence in their own skills, and to ask questions to find things out.

A valuable outcome that goes beyond the immediate skill-building logic of learning through doing was the development of trust; team members commented on how doing the ethnography made them more comfortable and at ease with the process of taking part in the project overall and how much they enjoyed getting to know their academic colleagues and their pets.

2.3 | Mini-ethnography: Reflections from co-researchers

We got to practice our skills of interviewing people. We were asked to find out about what it is like to have pets in lockdown. As we are sure you have found, living in lockdown has been tough. It has been tough for people, but it has also been tough for animals. SR told us about her dog, Bess. The family takes her on walks in the local parks, and it seems like every other family are taking their pets for walks too! Sara said Bess has gotten confused a few times and followed other families home! The vets have been very different too. Pet owners have had to drop off their pets for treatment and come back to collect them after. For some, like myself, we have found this rather impersonal. I have enjoyed this experience of practicing my interview skills, and now feel very ready to interview people about their experiences of growing older. If anyone wants to get to grips more with ethnography or interviewing people, I definitely recommend this!

What was also fun, was putting our discussions in to practice and conducting our own research—in our case 'pets in lockdown'. It made me more aware that talking about and actually doing the research are two very different things and that you need to be prepared to be adaptable as no situation is ever the same. Overall, it was a really interesting project, and has made me realise that research isn't just about asking questions—it's also the why and how!

To enable me to learn more about how to do this type of research, I took part in the Ethnography, Living with Pets… I learnt so much in a short amount of time and I found it interesting to reflect on this after carrying out this type of research… Whilst carrying out the Ethnography I need to be mindful of the sensitivity of any topics I ask questions about. It was interesting to hear how it made that person feel to be asked questions. I also know from this that I don't have to have knowledge to do this research and it's ok to ask questions.

3 | THE MATERIALS

Based on our meetings, follow-up meetings between CA, MM and SR and the mini-ethnography trial, we developed a set of resources (see Appendix S1–S4) to support people with learning disabilities and carers to become co-researchers and to support academic researchers to better facilitate co-research. We focused first on explaining what ethnography is (see Appendix S1), then broke it down into four steps (1. designing the ethnography; 2. planning the activities; 3. doing the ethnography; and 4. debrief). The aim was to capture what is expected of academic and co-researchers at each stage and what to pay attention to as research is planned and carried out to ensure that co-researchers can contribute meaningfully and confidently to data collection in ethnographic research. This led us to developing two separate "activity flows": *Doing ethnography as a co-researcher* (Appendix S2) and *Doing ethnography with a co-researcher* (Appendix S3) with clear guidance for each step. We also included *Tips on making information & processes more accessible* and instructions for a trial mini-ethnography, with *Living with pets* as one possibility and *Working from home* as an alternative (Appendix S4). We made the materials available in three versions, including easy read.

The developed materials are co-designed with many reiterations and revisions. We aimed for clarity and equity, with emphasis on what the co-researcher and academic researchers need to know for ethnographic co-research to work well.

4 | REFLECTIONS AND LESSONS LEARNT

In this section, we offer our reflections on how we found working on this project. We deliberately chose not to attribute the quotes below to different team members.

Co-researchers' reflections:

E-Eth-Ethnography—or however say it! Is about doing things with people and learning about their lives. L and I took part in a few meetings about this type of study. We found these meetings fun, chatty and a great of way of getting to grips with ethnography.

The co-research project I found really interesting. I was asked to come into it by SR. I was late joining it. This means I really can't say that much but it was good to meet new people and listening to their experiences. It has also been an opportunity for me to share my experience and learn something new. It will be interesting to see what happens next with this project. [I would like to see] More people with Learning Disabilities and or Autism become researchers. I know that family carers and people with learning disabilities can be excellent participants in research,

engaged and insightful. I know too that we make good researchers—bringing experience and questioning minds to quality of life issues. However, claiming the co-researcher training space—traditional academic territory—and the power and responsibility that comes with it, felt a little daunting. The University team were honest—they hadn't done this before either—and they were remarkably unfazed and openly excited... My feeling is our modest start through this project is part of a growing understanding that family carers and people with learning disabilities have the potential to be game changers in co-researcher training. My hope is that this way of working becomes 'good practice'—if it must be rated—or just the everyday way of doing things around here.

Working as a group meant that we were able to share and develop ideas that I hadn't necessarily even considered.

It was incredibly interesting to have discussions around how those with learning disabilities and their family carers can become co-researchers... The first points that I remember discussing were 'why am I joining the research, what is the research for, how will I carry out the research' and I feel that listening to other people's experiences and views and reflecting on my own thoughts was really interesting...

Academics' reflections:

The project underlined how important it is to work with people and how our role as researchers should involve a core strand of enablement and facilitation which is too often missing.

I was nervous but also excited starting this project, mainly because I really didn't know what the result was going to be. I teach research methods, and start sessions clearly sharing objectives of what we're going to learn together...this really flipped that round, and instead of talking about what we need to learn so we can do qualitative research, we talked about what we already knew, and what we thought we needed to know.

It was a bit unsettling to go into this project with no idea of what the end result might be, but I have had a lot of fun working on it. The meetings were creative chaos even though I do wish we had more time. I hope what we produced will help people with learning disabilities and carers become more confident researchers.

4.1 | Cost and time pressures

Co-research can increase the cost of research, and meaningful involvement can be difficult to reconcile with budgetary constraints, and tight deadlines that characterise much of academic research activity (Burke et al., 2003; Kramer et al., 2011). On our project, we were working with a very tight timeline of a few months which made it more difficult to plan meetings, process input from the meetings and ensure that information was available in easy read format. Whilst we were surprised at how much can be done in such a short time and on a small budget, we also felt that having more time would improve the experience for everyone involved. For example, we planned to have an easy read agenda for each meeting. However, the rapid timeframes, and limited funding, meant that for the second and third meeting, we were unable to receive the easy read agenda in time.

Careful consideration of costs is an important element in co-research. In particular, making sure that people are remunerated fairly *and* consistently for their work is key to meaningful co-research. With our project, we made sure everyone was paid for their work, including any additional and unanticipated tasks (e.g. conducting the mini-ethnography and contributing to this paper). We also paid costs of replacement care for the carers. With a limited budget, this required constant checking and re-evaluation pointing to the difficulty of balancing the demands of a small budget with a flexible research project.

Moreover, making sure that payments are processed smoothly is key to demonstrating commitment to co-research and establishing trust. Because payments are processed by a separate team within the university, it is worth making sure that relevant departments are aware of these payments so that they can be set up in advance, to avoid delays. The forms this team were required to fill out to claim payments were complicated and long. CA allocated time to fill out what she could and flag up the part of the forms that needed to be filled in, and those that could be left blank. These processes, however, were complex. It was often frustrating explaining to a process-driven finance team that some processes were not accessible. Researchers and finance teams should collaborate before a project starts to identify which parts of these processes can be altered or adjusted to increase accessibility.

Lastly and importantly, whilst paying people *ad hoc* for the work of co-production is better than expecting people to contribute their time and labour for free, to truly democratise research, people with learning disabilities and carers should be offered research contracts alongside academic researchers. This would enable their sustained and long-term involvement with the research and give them more power and recognition in the process. Funding applications need to reflect these commitments.

5 | LIMITATIONS

Because of tight timelines, we relied on personal and professional networks when putting the team together. As result, people with

learning disabilities and carers involved had interest in research (through their work as self-advocates or other PPI engagement). Our insights might therefore not be applicable to all carers and people with learning disabilities, but rather are reflective of a particular group of people. More research is needed on training needs and views about the research processes of people with learning disabilities and carers who have not had previous experiences of research and/or self-advocacy.

Relatedly, the resources we produced are a result of intense, but short collaboration. A longer project, which allows for more meetings and more time between the meetings, could further enrich the materials developed.

The literature on which this paper builds points to several stages of research in which people can be involved; however, we specifically focused on data collection in ethnography, with acknowledgement of the importance of including co-researchers in the planning and undertaking of ethnographic observation (see Appendix S2–S3). We recognise that ethnography encompasses a broad area of practices and approaches that might not all be equally suited to co-research. However, in many other areas of ethnographic research, there might be potential for more democratic practices that include people with learning disabilities and carers in meaningful ways. We encourage and welcome further research into these.

Finally, ethical consideration was present in our group discussions and is reflected in the produced resources—for example in Appendix S1: Things to remember we included statements around sensitive topics (If you ask people questions, think how you would feel if you were asked these questions) and the need for flexibility (If people do not want to spend time with you it's fine. Leave and check if they are happy for you to return a few days later.) However, the scope of our project left no time for fuller exploration of how people with learning disabilities and carers can be included more fully in thinking through research ethics more comprehensively, a point that signals an important area for future interventions.

6 | CONCLUSIONS

Collaborations such as ours have important implications for co-research and what we have learned benefits research practice more widely. One of the key points is that when it comes to ethnographic and potentially other types of research a confidence gap that can exist between "professional" researchers and co-researchers is equally important to attend to as a skill/knowledge gap. A confidence gap can affect how co-researchers participate, negatively impacting how comfortable they are sharing their thoughts, asking questions, suggesting changes to processes and activities and making their needs (including support needs) known. We tried to capture these points in the resources we developed (see Appendices S1–S4). Building confidence is particularly pressing for people with learning disabilities who are systematically excluded from research and are undervalued as knowledge producers *and* learners. Addressing this gap through training and practices that build trust is therefore key to successful co-research. How this is done in practice can vary depending on a research project; in our case, our mini-ethnography was a pivotal part of the co-design process as it generated confidence and understanding, and disrupted the power imbalance within the team.

Providing people with learning disabilities and carers with training on how to do ethnography as co-researchers is key to bridge the confidence gap and to harness the benefits of their experience and knowledge. We argue that co-designing such training with people with learning disabilities and family carers offers opportunities for fostering trust and more equal research relationships, further helping to address this gap. It also allows for moving away from academic researchers' assumptions about what they think people should know and into an area of exploration of what people with learning disabilities and carers feel is important to know in order to get the job done. Further, it puts emphasis on skills and knowledge that people with learning disabilities and carers already have, the reason they are valuable co-researchers. We suggest that because ethnography is grounded in everyday life and mingling/hanging out which is something most of us do, it is particularly suitable for co-research. In that sense, there is also something paradoxical about ethnography as a word people struggle to say and a type of research, about which they might not even have heard, whilst being equipped with some of the key skills necessary to get the job done. Importantly, other social research methods grounded in everyday life have also highlighted that training in research skills is not necessary to make valuable observations, when people are well supported (Albert et al., 2018).

Furthermore, lack of research which includes the voices and centres experiences of people with learning disabilities and/or family carers leads to theoretical and methodological limitations (Fulton et al., 2021). We suggest that these outcomes are, in part, attributable to a lack of meaningful involvement of people with learning disabilities and family carers in research design and process. Because research impacts and informs policy, this feeds a vicious cycle, where the voices of people with learning disabilities and carers are not included in policy informing research, which results in further marginalisation of people with learning disabilities and their families. To change how research is done, meaningful involvement of people with learning disabilities and carers cannot be an afterthought. It needs to be built into the design of research from the outset; it also needs to be adequately valued, funded and remunerated.

For the academic researchers involved, this was a deeply reflexive and instructive project. We were made to think about not only how we work but also *why*. Over-reliance on communication shortcuts, acronyms and jargon all make academic research inaccessible, not just for people with learning disabilities and carers, but also for newcomers, or researchers with different disciplinary backgrounds. How we communicate is not just practical, it is also a tool for inclusion, or, if not attended to, exclusion. Therefore, and importantly, we learnt that we do not just need guidance for co-researchers, we need them for academic researchers too (see Appendices S3 and S4). This is especially needed with regard to clarity in communication and processes, which would demystify research and help co-researchers

overcome the confidence gap that might exist in the face of overly complicated language, procedures and practices.

Academic processes and academia are rife with ableism making them inaccessible for many (Brown & Leigh, 2018; Dolmage, 2017). Whilst participatory research and co-research have the potential to challenge traditional hierarchies by chipping away at the boundaries of whose voices matter in the research process (Williams et al., 2020), it is not enough *of itself* to address the systemic inequalities and ableism. Whilst on the job- and project-specific training for co-researchers is important, we echo Tuffrey's et al's point (2020, p. 303) that people with learning disabilities should be given more opportunities to participate in more formal research training and education. Indeed, Fullana et al. (2017) argue that access to professional training is a right and increases opportunities to influence political and social change and yet there are few resources available to do this.

We believe that to further democratise research and improve its overall quality, people with learning disabilities and carers should be actively engaged in co-designing and co-delivering such training. Research training and research developed in partnership with people with learning disabilities and carers have potential to open academic practice up for questioning and probing from nonacademic collaborators, which in turn might expose its dead angles and limitations. It can also challenge and motivate academic researchers to make research processes more transparent and accessible, in effect demystifying research, making room for more democratic practices of knowledge production and sharing. Whilst co-research is an important step towards more democratic research practices, it does not undo the power imbalance. It is therefore the academic researchers' responsibility to *proactively* make research processes more accessible to share some of that power.

CONFLICT OF INTEREST
No conflict of interest was reported.

DATA AVAILABILITY STATEMENT
Data sharing is not applicable to this article as no new data were created or analysed in this study.

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REFERENCES
Albert, S., Albury, C., Alexander, M., Harris, M. T., Hofstetter, E., Holmes, E. J. B., & Stokoe, E. (2018). The conversational rollercoaster: Conversation analysis and the public science of talk. *Discourse Studies*, *20*(3), 397–424. https://doi.org/10.1177/1461445618754571

Bates, K., Goodley, D., & Runswick-Cole, K. (2017). Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity. *Disability & Society*, *32*(2), 160–175. https://doi.org/10.1080/09687599.2017.1281105

Bourke, L. (2009). Reflections on doing participatory research in health: participation, method and power. *International Journal of Social Research Methodology*, *12*(5), 457–474. https://doi.org/10.1080/13645570802373676

Brown, N., & Leigh, J. (2018). Ableism in academia: where are the disabled and ill academics? *Disability & Society*, *33*(6), 985–989. https://doi.org/10.1080/09687599.2018.1455627

Burke, A., McMillan, J., Cummins, L., Thompson, A., Forsyth, W., McLellan, J., Snow, L., Fraser, A., Fraser, M., Fulton, C., McCrindle, E., Gillies, L., LeFort, S., Miller, G., Whitehall, J., Wilson, J., Smith, J., & Wright, D. (2003). Setting up participatory research: a discussion of the initial stages. *British Journal of Learning Disabilities*, *31*(2), 65–69. https://doi.org/10.1046/j.1468-3156.2003.00183.x

Butler, G., Cresswell, A., Giatras, N., & Tuffrey-Wijne, I. (2012). Doing it together (DM special issue). *British Journal of Learning Disabilities*, *40*(2), 134–142. https://doi.org/10.1111/j.1468-3156.2012.00744.x

Department of Health (2001). *Valuing People: a strategy for learning disability services in the 21st century (No. Cm 5086)*. Retrieved from London: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Di Lorito, C., Bosco, A., Birt, L., & Hassiotis, A. (2018). Co-research with adults with intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disability*, *31*(5), 669–686. https://doi.org/10.1111/jar.12435

Dolmage, J. (2017). *Academic ableism: disability and higher education*. University of Michigan Press.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Flood, S., Bennett, D., Melsome, M., & Northway, R. (2013). Becoming a researcher. *British Journal of Learning Disabilities*, *41*(4), 288–295. https://doi.org/10.1111/j.1468-3156.2012.00756.x

Forrester-Jones, R., Gore, N. J., & Melling, K. (2010). How many people with intellectual disability are employed in the UK? *Tizard Learning Disability Review*, *15*(1), 56–58. https://doi.org/10.5042/tldr.2010.0031

Fullana, J., Pallisera, M., Català, E., & Puyalto, C. (2017). Evaluating a research training programme for people with intellectual disabilities participating in inclusive research: the views of participants. *Journal of Applied Research in Intellectual Disability*, *30*(4), 684–695. https://doi.org/10.1111/jar.12262

Fulton, L., Kinnear, D., & Jahoda, A. (2021). Belonging and reciprocity amongst people with intellectual disabilities: A systematic methodological review. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 1008–1025. https://doi.org/10.1111/jar.12881

Garcia Iriarte, E. (2014). What have researchers learned from involving people with intellectual disabilities in research? Reflection of three studies conducted in Ireland. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(2), 149.

Goodley, D. (2018). The dis/ability complex. *DiGeSt. Journal of Diversity and Gender Studies*, *5*(1), 2593–02735.

Goodley, D. (2021). *Disability and other human questions*. Emerald Publishing.

Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, *34*(6), 972–997. https://doi.org/10.1080/09687599.2019.1566889

Harrison, R. A., Bradshaw, J., Forrester-Jones, R., McCarthy, M., & Smith, S. (2021). Social networks and people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 973–992. https://doi.org/10.1111/jar.12878

Hatton, C., Glover, G., Emerson, E., & Brown, I. (2016). *People with learning disabilities in England 2015: Main report*. Retrieved from London https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

Herron, D., Priest, H. M., & Read, S. (2015). Working alongside older people with a learning disability: informing and shaping research design. *British Journal of Learning Disabilities*, *43*(4), 261–269. https://doi.org/10.1111/bld.12147

Johnson, K. (2009). No Longer Researching About Us Without Us: a researcher's reflection on rights and inclusive research in Ireland. *British Journal of Learning Disabilities*, *37*(4), 250–256. https://doi.org/10.1111/j.1468-3156.2009.00579.x

Kramer, J. M., Kramer, J. C., García-Iriarte, E., & Hammel, J. (2011). Following through to the end: The use of inclusive strategies to analyse and interpret data in participatory action research with individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*(3), 263–273. https://doi.org/10.1111/j.1468-3148.2010.00602.x

Lester, J. N., & Nusbaum, E. A. (2018). "Reclaiming" disability in critical qualitative research: introduction to the special issue. *Qualitative Inquiry*, *24*(1), 3–7. https://doi.org/10.1177/1077800417727761

Nind, M. (2014). *What is inclusive research?*. 1st ed. Bloomsbury Academic.

Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, *17*(3), 278–288. https://doi.org/10.1177/1468794117708123

Nind, M., Chapman, R., Seale, J., & Tilley, L. (2016). The conundrum of training and capacity building for people with learning disabilities doing research. *Journal of Applied Research in Intellectual Disabilities*, *29*(6), 542–551. https://doi.org/10.1111/jar.12213

Nind, M., & Vinha, H. (2014). Doing Research Inclusively, Doing Research Well? Report of the Study: Quality and Capacity in Inclusive Research With People With Learning Disabilities. Accessible Report. Economic and Social Research Council grant: RES-000-22-4423.

O'Brien, P., McConkey, R., & García-Iriarte, E. (2014). Co-researching with people who have intellectual disabilities: insights from a national survey. *Journal of Applied Research in Intellectual Disabilities*, *27*(1), 65–75. https://doi.org/10.1111/jar.12074

Ramcharan, P., Grant, G., & Flynn, M. (2004). Emancipatory and participatory research: How far have we come? In E. Emerson, C. Hatton, T. Thompson, & R. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 83–113). Wiley.

Strnadová, I., Walmsley, J., Johnson, K., & Cumming, T. M. (2016). Diverse faces of inclusive research reflecting on three research studies. *Scandinavian Journal of Disability Research*, *18*, 52–64. https://doi.org/10.1080/15017419.2014.964766

Tuffrey-Wijne, I., Lam, C. K. K., Marsden, D., Conway, B., Harris, C., Jeffrey, D., Jordan, L., Keagan-Bull, R., McDermott, M., Newton, D., & Stapelberg, D. (2020). Developing a training course to teach research skills to people with learning disabilities: "It gives us a voice. We CAN be researchers!". *British Journal of Learning Disabilities*, *48*(4), 301–314. https://doi.org/10.1111/bld.12331

Warren, L., & Boxall, K. (2009). Service users in and out of the academy: collusion in exclusion? *Social Work Education*, *28*(3), 281–297. https://doi.org/10.1080/02615470802659464

Warwick, M. (2020). Shifting the gaze: The use of wearable cameras in research. In M. Nind, & I. Strnadová (Eds.), *Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion* (pp. 113-126). Abingdon, Oxon: Routledge.

Williams, O., Sarre, S., Papoulias, S. C., Knowles, S., Robert, G., Beresford, P., Rose, D., Carr, S., Kaur, M., & Palmer, V. J. (2020). Lost in the shadows: reflections on the dark side of co-production. *Health Research Policy and Systems*, *18*(1), 43. https://doi.org/10.1186/s12961-020-00558-0

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