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University Researchers and Researchers With Learning Disabilities Co-Interviewing as Part of an Inclusive Research Team

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ABSTRACT

Background: Co-production in research entails researchers, practitioners and the public working together on a project, sharing decision making, responsibility and ownership of a project and its outcomes. This paper reflects on the process of university researchers and researchers with learning disabilities working together on an inclusive research project about supporting people with learning disabilities to make decisions about mental health medication.

Method: This paper explores the inclusive approach taken to design and conduct interviews.

Findings: Researchers with learning disabilities brought a unique perspective to the project due to their lived experience, which resulted in benefits for the whole research team as well as research participants. Interview materials were relevant and accessible and there was often common ground, increased trust and a strong rapport with interview participants with learning disabilities. The co-interviewing approach with health professionals appeared to increase reflection on working practices.

Conclusions: Co-interviewing can be a more inclusive, equitable interview approach, leading to more relevant, meaningful and impactful research outcomes.

1 | Background

Historically, across the global North, people with learning disabilities have been excluded from research due to assumptions about their capacity and overprotective attitudes which deem them vulnerable to exploitation and harm (Carlson 2013; Hart et al. 2020). In the United Kingdom, during the 1990s, the disability movement introduced the slogan 'Nothing about us without us' to challenge the idea that nondisabled people should produce research about disabled people without involving disabled people (Charlton 1998). For people with learning disabilities, while this increased opportunities for getting involved in studies through inclusive research, UK academic research has been slow to apply the Social Model of Disability to the experiences of people with learning disabilities (Chappell et al. 2001). The Social Model of Disability originated from the experiences of people with physical and sensory impairments (Oliver 1996). It states that people are disabled by societal barriers (physical, attitudinal, institutional, communication) rather than their impairment. Chappell et al. (2001) advocated for research methodologies that actively involve people with learning disabilities, moving beyond traditional researcher–participant

Summary

- Co-production is when researchers with and without learning disabilities work together on a project.
- This project was about supporting people with learning disabilities when making decisions about mental health medication. This paper looks at what it was like when researchers with and without learning disabilities carried out interviews.
- Interviewers with learning disabilities helped participants with learning disabilities to feel at ease. Interviewers with learning disabilities made sure that interview materials could be understood by everyone.
- Interviewers with learning disabilities helped health professionals to think about how they shared mental health medication information with people with learning disabilities.
- Involving people with learning disabilities as interviewers values people with learning disabilities and helps improve the research.

divides, to help address social oppression and disabling barriers for this group. Over time, the methodology has moved towards co-production, with research increasingly used as a tool for advocacy (Garratt et al. 2022). There has also been an increased acknowledgement that people with learning disabilities are the best experts on their own experiences (Garratt et al. 2022). Despite continued efforts to develop accessible methodologies, challenges remain in fully including people with profound and multiple learning disabilities (Gjermestad et al. 2023).

Inclusive research involves the participation of people from outside the academic research community and includes a wide variety of involvement (Webb et al. 2022; Tuffrey-Wijne et al. 2020). Involvement in research for people with learning disabilities can take various forms from consultation to advisory roles, active involvement in the design and conduct of the study, research analysis and dissemination (Webb et al. 2022; Tuffrey-Wijne et al. 2020). These roles may differ depending on the strengths and preferences of the individual (Webb et al. 2022). Co-production is a form of inclusive research, an approach that requires researchers and members of the public to share power and responsibility from the start to the end of the project to achieve a joint understanding (NIHR 2024). With co-production, everyone's skills and knowledge are viewed as having equal importance (NIHR 2024).

Co-production of inclusive research entails providing necessary support for participants (e.g., digital skills) and training for the research team on co-production values; ensuring all information and processes are easy to understand and use; involving people from the start and throughout (design, development, outputs, dissemination and evaluation); and paying people for their expertise (Achieve Together 2025; Mencap 2025). There is a growing body of co-produced research with people with learning disabilities, covering a wide range of topics. Examples of co-produced research include addressing health and social care inequalities faced by people with learning disabilities (e.g., Bateson et al. 2024; Gray and Kerridge 2023); issues related to leisure participation (e.g., Maenhout et al. 2023), human rights self-advocacy (Roberts et al. 2012) and a need for better services for people with learning disabilities who have been sexually assaulted (Olsen and Carter 2016).

In recent years a small number of studies have co-produced research with people with learning disabilities as peer interviewers (Caton 2020; Montgomery et al. 2022; Schwartz and Durkin 2020; St John et al. 2018; Webb et al. 2022). Peer interviewers are people who are generally understood to carry out interviews with people with similar characteristics or experiences (INVOLVE 2017). Interviews are a much used, valuable research method and these studies have shown how working in collaboration with people with learning disabilities as peer interviewers can help to make participants feel more comfortable sharing their experiences (Schwartz and Durkin 2020; Webb et al. 2022). This can potentially lead to more open and honest responses and high-quality data (Bigby et al. 2014; Schwartz and Durkin 2020). This, in turn, can help to challenge assumptions about the ability of people with learning disabilities to participate proactively in research. Peer interviewers have reported improved research skills and increased confidence (Caton 2020; Webb et al. 2022), as well as appreciating how their lived experience of having a learning disability was valued (Montgomery et al. 2022). For university researchers, adopting a peer interviewer approach entails researchers acknowledging that their knowledge and understanding of learning disabilities will always be partial (Fischbein et al. 2024). However, this can be enriched—but never fully completed—by the lived experiences of insider peer researchers (Fischbein et al. 2024).

This co-authored paper offers a new perspective on co-interviewing with people with learning disabilities on an inclusive research project. Unlike the studies above, co-researchers' interviewing role was broad, both in terms of level of involvement in the interviewing process and the range of people being interviewed. Co-researchers carried out interviews with peers, family members, paid carers and health professionals (i.e., prescribers of mental health medication). This paper adds to the existing body of knowledge by showing that involving people with learning disabilities to co-interview individuals other than their peers (such as professionals) offers unique opportunities for individual empowerment, reciprocal learning and systems change. However, it can also introduce power imbalances and communication and skill gaps (e.g., co-researchers may need specific interviewing training when a participant is not a peer).

For consistency, and due to the broad nature of the role that research team members with learning disabilities had, we will be using the term 'co-researcher' to describe the people with learning disabilities who worked on this project. Some of the co-researchers working on this project had previous research experience and were familiar and comfortable with the term. We are aware that the term 'co-researcher' may appear 'tokenistic' with arguments that a person is either a 'researcher' or not, regardless of disability. 'Co', however, can also emphasise working in partnership, where everyone's input is valued and respected.

The aim of this paper is to reflect on the benefits, challenges and learning arising from collaborative interviewing between university researchers and co-researchers with learning disabilities.

1.1 | Background to the Project

Our experiences of co-interviewing are taken from a co-produced project on supported decision-making around mental health medications. The project developed through discussions between university researchers and self-advocacy organisations. In the United Kingdom, a self-advocacy organisation is a group that supports individuals, often people with disabilities, in speaking up for themselves and their rights and making their own choices and decisions about their lives (People First 2025). Given the focus of this project was about decision-making for mental health medication, a co-production approach was considered crucial.

To recruit co-researchers into the project, each collaborating self-advocacy organisation was sent a co-researcher role description, the role was then discussed with the groups and people said whether they wanted to be part of the project. This meant that people with learning disabilities were working on the project without being in formal employment, with money from the project being transferred to self-advocacy organisations to renumerate co-researchers for their contribution and time.

The project benefitted from the contributions of seven people with learning disabilities. Co-researchers took part in tasks across all aspects of the research project, including deciding what questions to include in interviews and the survey, interviewing participants alongside university researchers, recording videos of themselves asking the questions for the online survey, data analysis, co-hosting workshops, producing outputs and presenting at conferences. As well as appointing co-researchers, self-advocacy organisations also collaborated throughout the project by sharing information about the project to potential participants and hosting workshops to analyse the research data and co-design the information toolkit format and content. Co-researchers were not required to attend any interview pre-meetings.

This project involved four participant groups with different interview schedules for each. This meant that there was considerable breadth to the interviewer role for co-researchers. Interviews took place with the co-researcher asking the questions and the university researchers any follow-up questions. Forty interviews were completed over video call, with just over half conducted by a pair of researchers—the university researcher and a co-researcher (see Section 2.3.1 for why co-researchers did not carry out all the interviews). In total, the university researcher and co-researchers carried out 11 interviews with people with learning disabilities, 2 interviews with family members of someone with learning disabilities, 1 interview with a paid carer and 7 interviews with health professions whose role includes prescribing. Interviews lasted between 30 min to 1 h.

1.2 | Working With Co-Researchers to Write This Article

Our project produced a number of accessible outputs including Easy Read reports and accessible videos (using clear language, slow pacing and Easy Read symbols). Writing academic outputs is less straightforward in terms of co-producing an output. We debated the best way to do this, looking at how other university researchers had co-written papers with people with learning disabilities (e.g., Mikulak et al. 2022; Tuffrey-Wijne et al. 2020) and spoke with the co-researchers about how they would like their 'voice' to appear in the paper. It was agreed that university researchers would write the main text, with contributions from the co-researchers from conversations with the first author represented as quotations to ensure their contributions were clear in a paper otherwise written in an academic style.

The three co-researchers who carried out the largest number of interviews from the project (and therefore had the most experience to draw on) are authors of this paper: M.O.'F., N.R. and M.P. The first author met with the co-researchers to discuss questions about their experiences of interviewing as this would be easier than thinking about the experience more broadly. Co-researchers were asked questions based on the training, design and carrying out of interviews. For example, co-researchers were asked about their motivations for wanting to be an interviewer, how they found listening to people's stories and whether they found anything challenging about the interviewing process. The process of answering the questions was adapted to accommodate the needs and preferences of the co-researchers. One co-researcher preferred to have the questions presented in Easy Read format, which they could think about and answer in their own time. The other two co-researchers answered some questions produced in Easy Read format and answered questions during open discussion with the researcher. After co-researchers' responses had been written up by the first author, they were shared with the co-researchers to ensure accuracy of their views.

2 | Interview Research Process

The co-researchers contributed to many aspects of the project, but for the purposes of this paper, we are focusing on carrying out interviews. The interview research process for the research team entailed three key stages: motivations, training and preparing for interviews, designing interview schedules and the interviews. The approaches to these three stages are presented and discussed below in Sections 2.1–2.3.

2.1 | Motivations, Training and Preparing for Interviews

The research team was committed to an inclusive, equal approach to interviewing that moved people with learning disabilities beyond 'passive participants' to 'active contributors', who can bring personal insights that academics might miss. As an opener to conversations with the co-researchers writing this paper, we talked about motivations for wanting to partake in interviewing. While enjoyable, for the university researchers, undertaking the interviews was a key expectation of the job. For the co-researchers, motivations were more nuanced and included to enable people with learning disabilities to have a voice; to challenge assumptions about the capabilities of people with learning disabilities; to help make interviewees with learning disabilities feel more relaxed and comfortable; and to have 'university' experience:

I wanted to be an interviewer because I wanted to prove to professionals that people with learning disabilities have a voice and they have the capacity to be interviewers. Also, for participants with a learning disability, they may not be used to being interviewed by a person with a learning disability. It may give them the confidence to speak up.

(M.P.)

It is a good idea for a person with a learning disability to be part of an interview team, especially when interviewing other people who also have a learning disability as I can relate to them better than a non-disabled person.

(M.O.'F.)

I wanted to become an interviewer because I wanted to get as close as possible to knowing what it is like to go to university without paying student loans. It is difficult to go to university as a young person today, but even harder if you have a learning disability.

(N.R.)

Prior to arranging any interviews, the research team considered needs around training to carry out interviews. The university researchers had prior experience of interviewing, and the co-researchers had varying levels of prior experience; however, none of the team had prior experience of carrying our interviews in pairs, so this needed some consideration. Providing training on interview techniques for people with learning disabilities such as how to ask questions, listen actively and build rapport can help to build confidence and skills (Tuffrey-Wijne et al. 2020). Teaching interview skills via role playing in a safe and supportive environment has also been found to be effective in preparing people with learning disabilities to conduct interviews (Tuffrey-Wijne et al. 2020). However, a less formal approach with a focus on accessibility, respecting people's individual needs and valuing different approaches can help to avoid 'over-training' and demanding conformity to 'like us' standards as this can undermine genuine inclusion (Nicholson et al. 2024). Our approach was for co-researchers to 'bring and be themselves.' By this we meant that we did not want co-researchers to feel that they had to hide their disability to appear neurotypical or traditionally academic. We wanted co-researchers to feel safe to say, 'I have a learning disability' without fear of judgement. Creating a safe and supportive environment where interviewers with learning disabilities feel comfortable to share their experiences and ask questions is also important (Petropoulou et al. 2025). As well as considering training needs, support for co-researchers can be facilitated by ensuring that research processes and materials are accessible (e.g., using clear and simple language and offering information in formats that are easy to understand (Petropoulou et al. 2025).

University researchers needed specific knowledge and training in the following areas: on accessible communication and plain English; co-production and power dynamics. The process of learning, however, was ongoing. For example, during an interview with a prescriber, a co-researcher asked the first author if they could ask the interviewee a question outside of the co-produced interview schedule. The first author had not considered asking co-researchers if they had other questions before. The first author reflected on this and from that point on asked all co-researchers if there was anything else they would like to ask interviewees. She saw this as learning how to facilitate rather than direct.

To ensure all interviewers were well prepared we held an interview skills workshop. The research team developed an 'Easy Read interview guide' with information about preparing for the interview, what the interview will involve and what happens after the interview. The research team discussed the guide at the Interview Skills workshop and answered any questions that the co-researchers had about the interviewing process (see Figure 1). An inclusive approach was important to show that everyone's experiences and contributions were valuable, with the workshop beginning with an open discussion about what makes a good interview. We found this to be a useful starting point as we did not want to make any assumptions about the team's prior experiences of interviewing. The discussion revealed that several co-researchers had taken part in research projects with university-based researchers in the past, and had brought their skills, knowledge and experience to the project:

I thought the training was useful...I have done research before...People with learning disabilities have lived experience and researchers have different skills. We complement each other.

(M.P.)

One aspect of interviewing that was considered important by the workshop attendees was ethics. One issue for the research team related to disclosing experiences to participants. For example, since there is always the potential for interviewers to talk about their own experience at the interview, a useful discussion was had around when it might be appropriate to do so. The research team was advised to disclose only what they were comfortable to disclose and in situations where they felt that disclosure would be helpful to the person being interviewed. Other ethical guidelines covered during the workshop included the importance of protecting the information provided by participants (confidentiality).

Another ethical issue related to disclosing experiences to co-researchers. For university-based researchers, working with co-researchers added another dimension to self-reflexivity, meaning that the researcher reflected on their interaction not only with participants, but also with the co-researchers. For the first author this meant reflecting on her position as the mother of an adult son with learning disabilities and whether to disclose her lived experience. The first author disclosed that she was the mother of an adult with learning disabilities to co-researchers at the start of the project as there was the possibility that they could learn this information from elsewhere. It also felt right to do this so that co-researchers could understand her positionality when it came to interviewing and how this might influence her interpretations of what participants say (Berger 2013). This helped to establish trust.

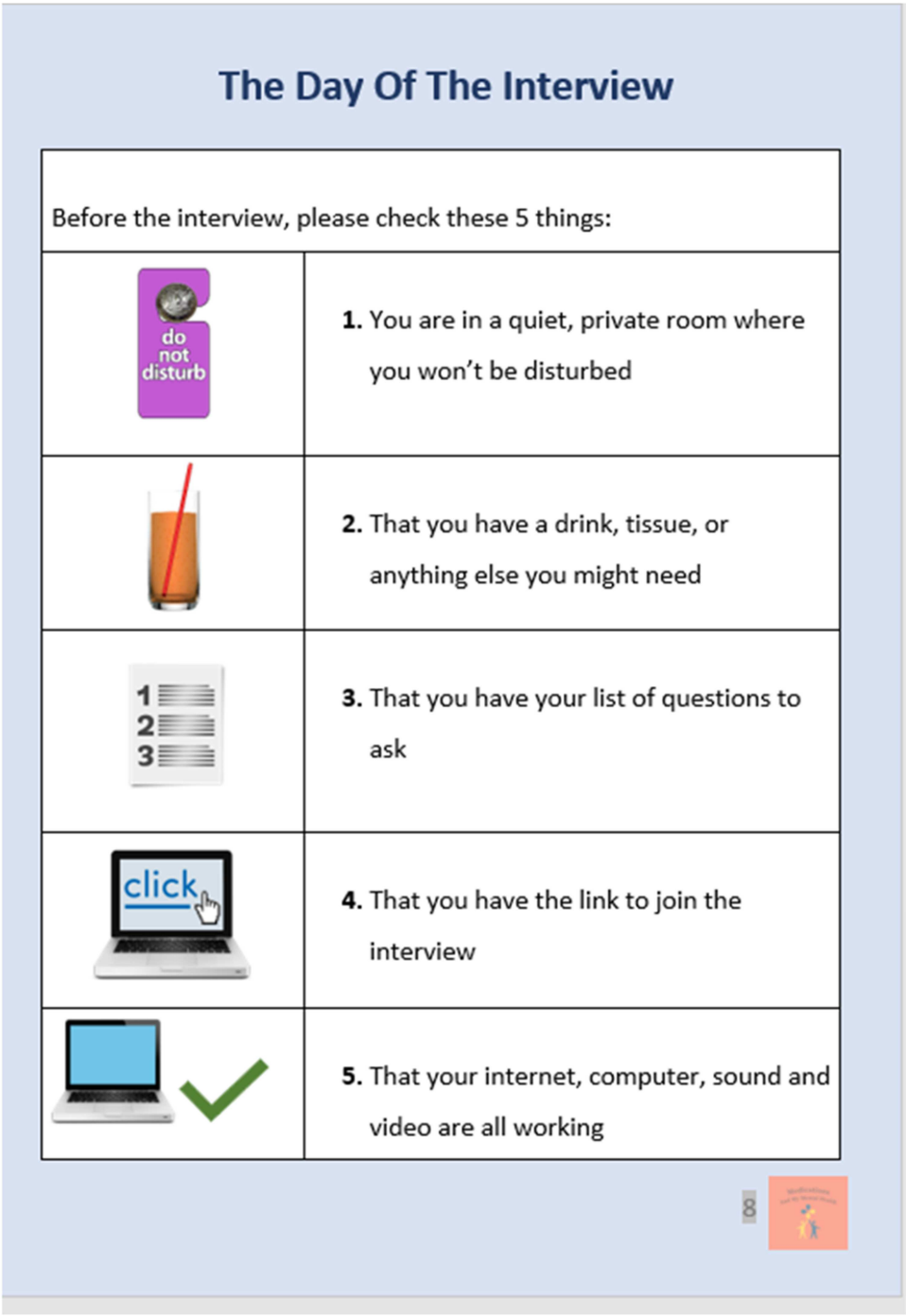

FIGURE 1 | A sample of the Easy Read interview guide. [Color figure can be viewed at wileyonlinelibrary.com]

2.2 | Designing Interview Schedules

In a second online workshop, the research team met together to design the interview schedules. At the start of the workshop, we discussed an Easy Read version of a review that examined the literature outlining what research had already been carried out about what people with learning disabilities, and those that support them, understand about mental health medications (see Figure 2). Sharing the Easy Read version of the literature review prompted a group discussion about the questions we might want to ask participants during the interviews based on current gaps in the literature and on the lived experiences of the co-researchers:

> *I was at the workshop when we discussed what makes a good question and what questions would be good to ask. I looked at questions and gave advice on where changes could be made.*

Following the workshop, the university-based researchers drafted separate, but related interview schedules for each of the participant groups: people with learning disabilities, family members, paid carers and prescribers. The prescriber interview schedule was longer and more complex, so a pilot interview took place:

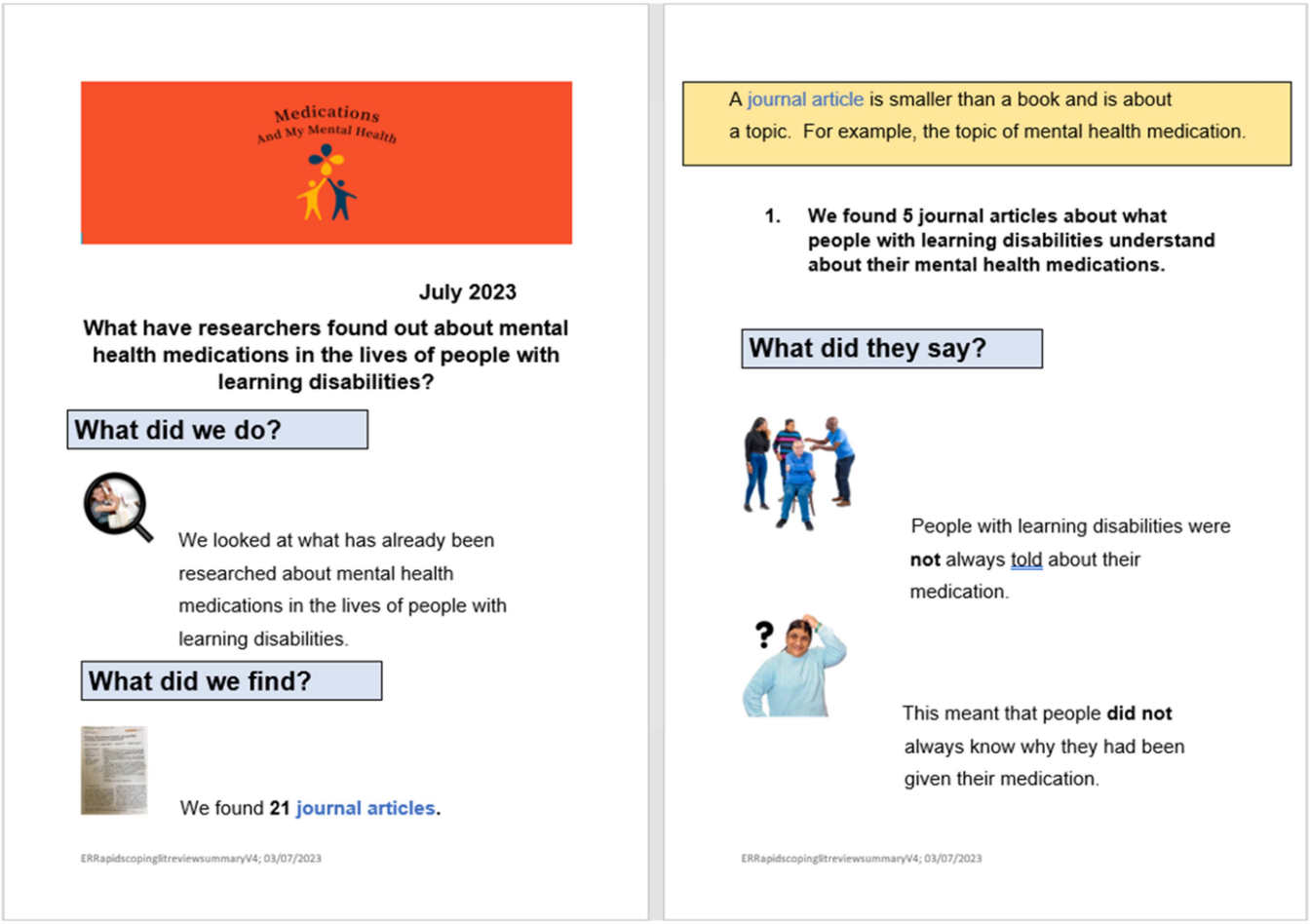

FIGURE 2 | Opening pages of the Easy Read version of the literature review. [Color figure can be viewed at wileyonlinelibrary.com]

> *I was involved in the pilot for the interview questions for the prescribers. After the pilot, changes were made to cut down the number of questions to make the interview easier. For the prescriber questions, we created an Easy Read glossary because there were some difficult words.*
>
> (N.R.)

All of the draft interview schedules were shared with the co-researchers, who were invited to take them back to their self-advocacy groups for feedback. Feedback received included ensuring that language was clear and jargon-free, and that the questions were organised into logical sections. Based on the feedback, all the interview schedules were created in Easy Read and colour coded so that co-researchers could easily identify which set of questions to use for each interview (e.g., pink for paid carers). Questions for each schedule were also divided into color-coded themes, such as orange for 'Starting medication' or green for 'Reviewing medication.' This helped university researchers, co-researchers and participants (who had been sent paper copies of the interview schedule prior to the interview) navigate their way more easily through the schedules (see Figure 3). Co-researchers received a laminated, colour printed version of the final interview schedules in the post. We asked co-researchers about their involvement in creating the interview schedules and how they found using them:

> *The interview guides were helpful. They were easy to understand and use. The sections were in different colours, so I knew which section I needed to focus on.*
>
> (M.P.)

> *The interview guides were very helpful and were written in Easy read which meant I could follow them and know which person was asking each question. They were colour co-ordinated. I was asked for my thoughts on the guides and knew if I wanted something changed, I would be listened to, and it would get changed.*
>
> (M.O.'F.)

> *Once we had made all the changes to the guides [based on co-researchers' suggestions], I found them easy to use.*
>
> (N.R.)

To ensure that all interviewers were prepared, assessment of mental capacity to engage in sexual relations, researchers met again before interviewing began for each participant group to practise going through the interview questions:

FIGURE 3 | A color-coded theme from the Easy Read interview guide for participants with learning disabilities. [Color figure can be viewed at wileyonlinelibrary.com]

> *I thought it was useful to practise the questions before the interview in case there were any words I didn't understand or couldn't pronounce, so I went in prepared.*
>
> (M.P.)

2.3 | The Interviews

A particular benefit of sharing interviewing responsibility with a co-researcher with learning disabilities is that participants with learning disabilities might feel that they are more approachable than a traditional university researcher (Frawley and Bigby 2014). Being able to relate to participants' personal experiences (e.g., 'I know what you mean...') helped the co-researchers to establish rapport and build trust with participants, eliciting rich responses. Part of ethics training in the preparation phase entailed discussion about how the research team might respond if participants became upset during the interviews, such as offering to pause or end the interview. The research team anticipated that some participants with learning disabilities might find discussing their mental health and experiences of mental health medication challenging. However, unanticipated topics, including sectioning, sexual abuse, suicide and bereavement, also emerged during the interviews and required highly sensitive responses. Co-researchers managed such moments with care. For example, maintaining a non-judgemental, empathic stance and occasionally sharing their own experiences. This is contrary to the view held by some academics that co-researchers may not be able to manage ethical situations that arise during fieldwork (Bigby et al. 2014).

The research team was able to identify signs of participant unease or distress, and their response was to prioritise the participant's wellbeing over data collection by offering a break and/or words of comfort. It was also important that participants shared details that only they were comfortable with. A few participants looked uncomfortable and/or said that that they did not want to elaborate any further after disclosing that they had been sectioned in the past. Participants were reminded that they did not have to discuss this and that they had a right to set their own boundaries. Learning disability advocacy organisations provided emotional support if required to co-researchers after the interview. This took time and resources to facilitate and meant that the co-researchers' emotional needs were addressed by people who knew them best:

> *The stories were amazing, very powerful. It takes a lot of courage to tell your story. I felt okay listening to the stories. I hope people learn from the stories that sometimes people with learning disabilities need support and people to relate to them.*
>
> (M.P.)

> *Listening to people's stories was interesting but at times difficult to listen to due to the huge struggles people have had with their mental health challenges and not always being listened to or getting the right support.*
>
> (M.O.'F.)

The shift to online platforms during the pandemic has led to more research being conducted online, which has implications for how people with learning disabilities engage with research (Mikulak et al. 2022). Whilst online formats offer benefits such as increased accessibility and reach, they also introduce specific digital and ethical hurdles (Mikulak et al. 2022). Co-researchers were asked for their thoughts on interviewing online. M.O.'F. remarked on how interviewing online can come at the cost of providing emotional support to participants. For example, the lack of physical presence can make it difficult to offer the comfort of shared space, such as a comforting gesture, leading to emotional detachment:

> *I wanted to help more, but was unable to doing interviews online.*

M.P. and N.R. pointed to how online research interviews offered significant efficiencies, such as the elimination of travel time and expenses for both the interviewer and interviewee, and increased access to geographically dispersed participants:

> *Doing it online works so long as the technology doesn't let you down. It helped me because I don't live near the university. Face-to-face is good, but not always practical.*
>
> (M.P.)

> *It was good having online interviews because we could reach out to more people.*
>
> (N.R.)

Co-researchers were comfortable with interviewing other participant groups, such as family members and paid carers. For example, feeling comfortable enough to call a family member or paid carer by their first name and/or to go off script: 'Okay, so this is about everyday mental health. So, yeah, there are three questions in this one...' (N.R.). However, co-researchers expressed some initial apprehension about interviewing prescribers.

> *At first, I found it daunting interviewing GPs because they have a lot of power over my health.*
>
> (N.R.)

People with learning disabilities can find healthcare professionals and environments intimidating due to communication barriers, and a lack of familiarity with, and knowledge about, people with learning disabilities, which can lead to prejudice, stereotyping and discrimination from healthcare staff (Pelleboer-Gunnink et al. 2017). The opportunity to engage with healthcare professionals outside of a clinical setting, where power imbalances stem from differences in knowledge, institutional authority, social status and patient vulnerability, helped to lessen co-researchers' anxiety. When individuals with lived experience collaboratively undertake interviews with university researchers, they can directly challenge health professionals' assumptions and hold them accountable in a way academic researchers alone cannot. This can help increase the value and authenticity of the research. For example, MP made a point that would have been missed by the first author:

> *Yeah, I was going to say. With the labels on the medication bottles and stuff, it's not very clear, is it?...and the numbers are small.*

Such a question helped to expose systemic health inequalities, supporting the transition toward more humanising mental healthcare:

> *We don't obviously put the label on the medicines, that's the pharmacy. It's a good point though.*
>
> (Prescriber 6, General Practitioner)

Being interviewed by the co-researchers via the use of Easy Read interview schedules made prescribers think about how they were conveying information to people with learning disabilities about mental health medications, with some prescribers acknowledging that they needed to provide information in a more accessible format (e.g., using simple language, providing Easy Read documents and visual supports). For example, one prescriber said that he tended to 'explain things verbally' and that he needed to make 'more use of written information... [and] pitch it at a level that... [people with learning disabilities] can understand.'

Some participants with learning disabilities were recruited from the same self-advocacy organisations of which co-researchers were members. This meant that it was possible that participants with learning disabilities could be interviewed by a co-researcher who was well known to them. The research team anticipated that this might cause role confusion because being interviewed by someone known to you can blur the lines between friendship and professionalism. Participants were therefore given the option for the interview to be carried out by a different co-researcher; however, no participants requested this. When the co-researcher was known to the interviewee, the university research team found participant responses were honest and open, especially regarding sensitive topics.

> *When I interviewed people, I did not know it felt more intense because you were dealing with a stranger and I did not know how they liked to communicate. It would have been useful to know how people liked to communicate.*
>
> (N.R.)

While university researchers had asked about the communication needs of participants with learning disabilities, this information did not always get passed on to co-researchers. Communication needs were often discussed in interview pre-meetings, which co-researchers were not required to attend. We acknowledge that this information should have been given to the co-researchers because understanding the communication needs of interview participants is general good practice.

2.3.1 | *Challenges Arising From Interviewing*

While it was our intention to carry out all of the interviews as university researcher/co-researcher pairs, this was not always possible. While co-researchers were paid members of the research team, they did not have all their time available to work on the project. This meant that sometimes they were occupied with other projects when participants were available to be interviewed. Due to time pressures associated with funded project deadlines, interviews would sometimes have to go ahead without the co-researcher present. Unfortunately, this meant that co-researchers interviewed only one paid carer and two family members of people with learning disabilities. This was in addition to the interviews carried out with people with learning disabilities and prescribers.

A further challenge was anticipating the response of participants to being interviewed by two people. While peer interviewing can help to mitigate the power imbalances inherent in traditional research relationships, helping to create a more equitable research environment (Lushey and Munro 2014), there is the risk that having two interviewers present, especially when they are of a different background to the participant, can intimidate and exacerbate the power imbalance due to outnumbering (Velardo and Elliott 2021). As a consequence, participants may feel uncomfortable or less willing to share information with two interviewers present (Monforte and Úbeda-Colomer 2021). We recruited some family members through a family carer forum and were advised by the forum that it would be best for the university researcher to interview one parent alone as they were going through a difficult time and felt nervous when talking about their situation. Parents of people with learning disabilities may encounter difficulties when discussing their children due to a combination of factors, including stress and anxiety and fear of how they and their child will be perceived, which can stem from various sources, including societal attitudes, interactions with professionals and

their own internalised feelings (Griffin 2024). For some parents fear of judgement might be compounded when talking to a person with learning disabilities, leading them to potentially withhold information. Where research participants may feel discomfort, as in the aforementioned example, interviewing alongside people with learning disabilities may require careful consideration to ensure that the safety of the participant is prioritised. It might be useful to offer participants a choice as to who conducts the interview.

With interviews predominantly taking place online, essential criteria for the post were that co-researchers had access to video conferencing platforms such as Zoom or Microsoft Teams, and were supported to use these platforms if required. Zoom is the most commonly used platform among people with learning disabilities and the most frequently preferred (Caton et al. 2022). All co-researchers who were recruited via the self-advocacy organisations had, post-Covid, acquired digital skills, and understood the social codes and conventions of using such platforms (Chadwick et al. 2023). There are a number of barriers to digital participation for people with learning disabilities (Caton et al. 2022), such as accessibility to technology (e.g., internet connection difficulties, cost of devices, payments and lack of digital skills) and restrictions to access imposed by others. Self-advocacy organisations facilitated internet access and support. For example, M.O.'F. did not have access to a device or to the internet. This meant borrowing a device and connecting to the internet at a self-advocacy organisation:

> *It was difficult to find a suitable room at times to hold the interviews which was quiet and private. I don't own a laptop or have access to the internet at home, so I had to rely on borrowing a laptop and use a local community centre or local office space which is a 45-minute bus drive away. I had to rely on my support to make all the arrangements in finding a suitable room which was not always ideal.*
>
> (M.O.'F.)

A further challenge was that sometimes 'it was difficult to find a suitable room to hold the interviews which was quiet and private' (M.O.'F.).

If an interview was paused due to interruptions by people, it could be difficult to resume the conversation at the same depth. Background noise could also be a problem for some co-researchers and participants. However, in one instance, both the co-researcher and participant with learning disabilities said that they preferred to remain in a moderately noisy environment where there was some background noise rather than move to an unfamiliar room where they did not feel as comfortable and relaxed.

An unexpected challenge for the research team involved managing instances of imposter participants, in which potential participants misrepresented their identities and lived experiences, potentially for financial gain (Chandler and Paolacci 2017). This was a phenomenon the research team had not previously encountered. In a small number of cases, co-researchers were present during interviews before imposter participants had been identified. Although co-researchers appeared to sense that participants were being dishonest, they were unsure how to manage this in real time and therefore took their lead from the university researcher. The university researcher ultimately made the decision to end video calls once it became clear that an imposter participant was present. Co-researchers expressed concern about the possibility of people pretending to have learning disabilities or be a family member or carer of someone with a learning disabilities:

> *I did not like it when people pretended to have a learning disability. I was angry.*
>
> (N.R.)

As a response to this situation, the research team developed a protocol to manage suspected imposter participants. This included identifying potential red flags such as large volumes of email responses, similarities in email addresses and writing styles and non-visual participation during interviews. Additionally, an initial screening meeting with potential participants prior to the interview was introduced. This meeting took place without the co-researchers being present. These strategies appeared to be effective in addressing the issue.

3 | Conclusion

In inclusive research projects, co-interviewing is a valuable, inclusive interview approach. Co-interviewing helped to ensure that the research was more meaningful, relevant and accessible to people with learning disabilities. Co-researchers brought a unique perspective based on their lived experience, which helped them to build a strong rapport with participants with learning disabilities. This appeared to create a more relaxed and comfortable atmosphere for sharing, ensuring that findings were rich and impactful.

While peer-to-peer interviewing is highly valuable for building rapport and a sense of safety, to understand the challenges faced by people with learning disabilities, researchers must investigate the systems around them. For the purposes of this project, people with learning disabilities interviewed not *only* their peers, but also family members, paid carers and healthcare professionals. Co-researchers' interviews with prescribers helped these professionals to think about how they were conveying information to people with learning disabilities about mental health medication. However, we do not know whether this actually changed prescribers' medical practice and it would be useful to follow this up with prescribers. Co-researchers reported that interviewing people other than peers helped 'their confidence to blossom' (N.R.).

As this is the first study that we know of where people with learning disabilities interviewed general populations and/or professionals, there is a need for more inclusive research where people with learning disabilities and university academics co-interview a broader demographic. Interviewing people in power such as healthcare professionals and clinicians, social workers and services providers, and policy makers and government officials shift the power dynamic. This may help to hold people to account, leading to more honest and open answers.

Author Contributions

Dawn Cavanagh: collected interview data, co-wrote the paper. **Sue Caton:** conceptualisation, funding acquisition, review and editing of paper. **Umesh Chauhan:** conceptualisation, funding acquisition, review and editing of paper. **Chris Hatton:** conceptualisation, funding acquisition, review and editing of paper. **Christine Hutchinson:** conceptualisation, funding acquisition, review and editing of paper. **Mark O'Farrell, Matty Prothero, Nathan Rawcliffe:** design of interview questions, interviewed participants alongside university researchers and co-wrote the paper. **Francesca Ribenfors:** collected interview data, review and editing of paper. **Katherine Runswick-Cole:** conceptualisation, funding acquisition, review and editing of paper.

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Conflicts of Interest

The authors declare no conflicts of interest

Data Availability Statement

Due to ethical restrictions, the data are not publicly available.

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