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"…their opinions mean something": Care staff's attitudes to health research involving people with intellectual disabilities

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Accessible summary

- It is important for people with intellectual disabilities to be involved in research about their health care.
- Eight people working in the care sector were interviewed about their views about supporting people with intellectual disabilities to take part in research.
- Care staff were positive about research but talked about things that may make it difficult for people with intellectual disabilities to take part in research.
- We suggest some ideas that could help care staff and researchers to support people with intellectual disabilities to take part in research.

Abstract

Background: Despite experiencing health inequalities, people with intellectual disabilities are under-represented in health research. Previous research has identified barriers but has typically focused on under-recruitment to specific studies. This study aimed to explore care staff's attitudes to health research involving people with intellectual disabilities, identify barriers to conducting such research and consider solutions to those barriers.

Materials and Methods: Eight members of care sector staff took part in a focus group or telephone interview, to explore their views on health research involving people with intellectual disabilities. The transcriptions were analysed using thematic analysis; 50% were double-coded, and the emerging themes were agreed by three researchers.

Results: Three themes were identified: perceptions of research; barriers to conducting research; solutions to maximise recruitment and project success. Benefits to research were identified, but there were concerns that the time and effort required may outweigh these benefits. Barriers were identified including organisational policy and following the Mental Capacity Act 2005. There was some indication that such barriers may differ according to the severity of intellectual disabilities and the type of care setting. Solutions were proposed that involved greater collaboration between researchers and the care sector, and a more flexible approach to research.

Conclusions: Care staff are largely supportive of research that is appropriate and relevant to their service users. However, there is a need for clear communication from researchers and flexible recruitment and data collection strategies. This is likely to be facilitated by closer collaboration between researchers and the social care sector.

1 | INTRODUCTION

In 2013, it was estimated that there were 1,068,000 people living with intellectual disabilities in England, with a large proportion also experiencing health problems (Improving Health and Lives, 2014). People with intellectual disabilities are often excluded from health research studies, which may reduce our understanding of how to treat and manage health conditions in intellectual disabilities (Feldman, Bosett, Collet, & Burnham-Riosa, 2014; Lewis, 2014a). Rather than generalising findings from studies with the general population, it is crucial that treatments and interventions are evaluated with people with intellectual disabilities to maximise treatment effectiveness and to avoid potential harm (d'Abrera, Holland, Landt, Stocks-Gee, & Zaman, 2013; Feldman et al., 2014; Singh, Matson, Cooper, Dixon, & Sturmey, 2005; Tyrer et al., 2008).

However, studies that aim to recruit people with intellectual disabilities have encountered barriers. Issues that have hampered recruitment include the following: time constraints; a lack of accurate data about eligible participants; participants' anxiety; researchers' difficulties in working effectively with people with intellectual disabilities; and care staff acting as gatekeepers, restricting access to potential participants (Crook, Tomlins, Bancroft, & Ogi, 2015; Jepson, 2015; Lewis, 2014a). Willis (2016) found that in some cases, gatekeepers overruled the person with intellectual disability's decision to take part in research. Health and social care staff may act as gatekeepers for a number of reasons. These include a lack of understanding about research procedures and potential benefits of participation, a belief that some people with intellectual disabilities lack the cognitive capacity to participate in research or a lack of understanding of the Mental Capacity Act 2005 (Crook et al., 2015; Jepson, 2015; Lennox et al., 2005; Lewis, 2014b). However, gatekeepers may also play a supportive role in research, as they are often best-placed to identify potential participants and facilitate recruitment.

The Mental Capacity Act (Department of Health, 2005) states that the decision to participate in research should be made by the person with intellectual disabilities if they have capacity to consent. It must not be assumed that a person with intellectual disabilities does not have capacity. However, previous research has found that the majority of care staff would seek approval from a family member or a senior member of staff regarding a client with intellectual disabilities participating in research, even if their client was able to understand the study information and give consent (Cameron & Murphy, 2007; Lewis, 2014b) For a person with intellectual disabilities who lacks capacity to consent, the Mental Capacity Act 2005 states that a consultee, such as a family member (identified consultee) or a carer (nominated consultee) (Department of Health, 2005), may be appointed who will consider the person's best interests. Studies have found that a consultee is able to judge what is in the person's best interests and can assess the person's willingness to participate in the research using implied assent, that is through nonverbal behaviour (Boxall & Ralph, 2010; Calveley, 2012; Jepson, 2015). However, it can be difficult to obtain ethical approval for studies involving people who lack capacity to consent.

The majority of studies that have addressed recruitment difficulties among people with intellectual disabilities and likely solutions have been retrospective explorations of specific studies that did not meet their recruitment target (Lennox et al., 2005; Nicholson, Colyer, & Cooper, 2013). They have typically looked at the attitudes of people with intellectual disabilities and clinicians (Crook et al., 2015; McDonald, Kidney, & Patka, 2013) or outlined strategies for adapting consent materials (Kidney & McDonald, 2014). Care staff are often key in the lives of people with intellectual disabilities and are important stakeholders in the research process. They may be the primary person who assists and supports the participation of the person with intellectual disabilities (Jepson, 2015; Lutz, Fisher, & Robinson, 2016). Therefore, the aim of this study was to explore the attitudes of care staff who were not already involved in specific research projects involving people with intellectual disabilities. Our objectives were as follows: (i) to identify barriers to the recruitment and participation of people with intellectual disabilities to health research studies, and (ii) to explore potential solutions to such barriers that could be implemented in future studies.

2 | METHOD

This study was approved by the University of Hertfordshire Health and Human Sciences Ethics Committee (LMS/SF/UH/00107) and has been reported following the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist (Tong, Sainsbury, & Craig, 2007).

2.1 | Participants

Employees of local care companies, who were currently or had previously worked with people with intellectual disabilities, were invited to participate in this study. Eight individuals aged 20–59, with varying amounts of experience in the care sector, from six care companies, providing domiciliary care ($n = 4$) and residential care ($n = 4$) in Hertfordshire, were recruited (Table 1).

2.2 | Procedure and data collection

Twenty care settings in Hertfordshire offering domiciliary and residential care to people with intellectual disabilities were identified from the website www.carehome.co.uk. The manager of each setting was contacted by telephone to introduce the study. If the managers expressed interest in the study, they were then sent postal information and contacted by phone approximately 1 week later to discuss further. Interested care companies then identified potential participants. Focus groups and telephone interviews, according to participant preference, were arranged through the care companies. Managers of ten companies expressed an interest in participating and care staff from six companies took part in the study (Figure 1).

At the start of the focus groups and telephone interviews, the aim of the study was explained to participants, and individual written consent was taken. Demographic information was then collected from a questionnaire. Participants taking part in a telephone interview returned the consent form and the questionnaire to the research team via email. A topic guide with questions such as "What are the positive aspects of health research for people with learning disabilities?" (Learning disability is a term for intellectual disability that is commonly used in the UK) and "What do you think are the barriers which make it difficult for carers to assist their clients/residents to participate in health research?", along with prompts, based on previous research, were used to facilitate discussions. Participants were asked to consider positive and negative aspects of people with intellectual disabilities taking part in research, barriers to participation and solutions to these barriers.

TABLE 1 Participant characteristics

	Number of participants
Gender	
Male	2
Female	6
Age	
20–29	3
30–39	1
40–49	2
50–59	1
Length of time working in the care sector	
<1 year	1
1–10 years	3
11–20 years	1
21–30 years	2
>30 years	1

Note: 1 participant did not disclose their age.

The focus groups and telephone interviews followed the natural progression of dialogue with appropriate prompts to facilitate conversation. The focus groups lasted for approximately 1 hr and the telephone interviews lasted for approximately 30 min. Two focus groups and one telephone interview were moderated by NH and SM, and one telephone interview was moderated by NH only. NH is a female psychology undergraduate research assistant with experience in residential care and SM is a female post-doctoral psychology research fellow with experience in qualitative research with people with intellectual disabilities.

2.3 | Data analysis

The focus groups and telephone interviews were audio-recorded, transcribed verbatim by NH, and the data were managed using NVivo (QSR International, 2015). The analysis followed Braun and Clarke's (2006) six phases framework for thematic analysis (see Table 2). Key themes and subthemes were identified through inductive coding. All four transcripts were coded by NH, focus group 1 was also independently coded by SM and interview 1 was also independently coded by M-AD. Therefore, 50% of the data was dual-coded. Codes were compared and discussed to result in final codes, and the key themes and subthemes were derived through discussion between all authors. Differences regarding the wording of a code or theme led to the refinement and clarification of the wording. Due to time constraints and limited funds, transcripts were not returned to participants for comment.

3 | RESULTS

Two focus groups and two telephone interviews were conducted. Focus group one consisted of three participants (one male and two female) from a domiciliary care company providing support in a client's home. Focus group two consisted of three participants (one male and two female) who were from different care settings, including
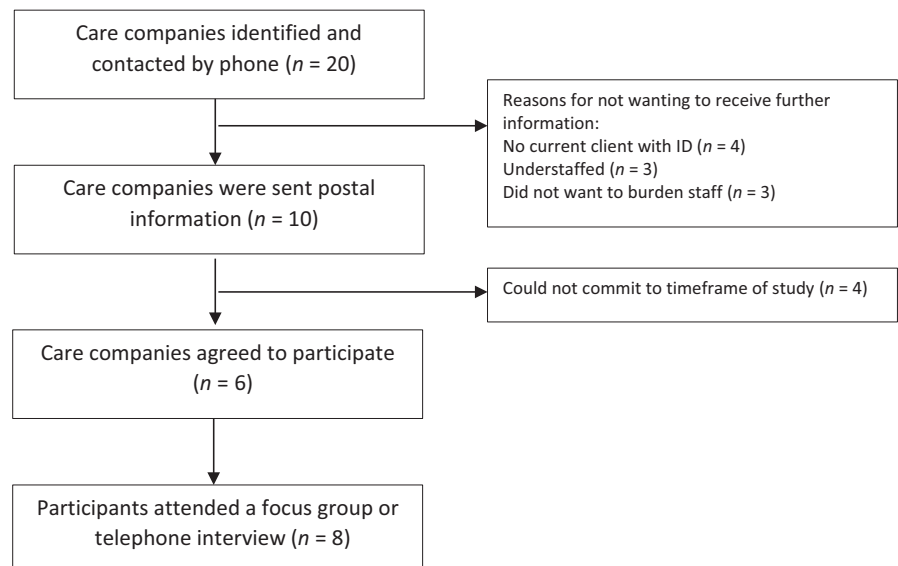

FIGURE 1 Recruitment flow chart

domiciliary and residential settings. Two participants took part in separate telephone interviews: both were female and worked in different residential care homes. Five of the participants were managers or assistant managers. No participant had assisted someone with intellectual disabilities to participate in research. Three key themes and thirteen subthemes were identified from thematic analysis (Table 3), which are discussed below with participant quotes to illustrate the findings.

TABLE 2 Phases of thematic analysis from Braun and Clarke (2006)

Phase		Description
1	Data familiarisation	Transcribing data, reading and re-reading the data, keeping a record of initial ideas.
2	Generating initial codes	Coding interesting features of the data across the whole data set in a systematic fashion, gathering data relevant to each code.
3	Searching for themes	Organising codes into possible subthemes and themes, gathering data relevant to each subtheme and theme
4	Reviewing themes	Level 1. Checking themes work in relation to the subthemes and coded extracts.
		Level 2. Checking themes work in relation to the whole data set.
5	Defining and naming the themes	Ongoing analysis to refine each of the themes, generating clear names and definitions for each of the themes
6	Producing the report	Selection of quotes, final analysis and relating the analysis to the research question, producing a scholarly report.

3.1 | Theme 1: Perceptions of research

Participants felt that the aim of research was to increase scientific knowledge and in context of intellectual disabilities research, studies would tend to involve questionnaires. Participants expressed that it was important to understand the outcomes and applications of research, but they felt that research findings may not always be shared and translated into changes in policy and practice.

> *It's just nice to know what the outcomes of the research are, because research seems to be going on all the time, and there doesn't seem to be an end,*
> *(Participant 5, 2nd focus group)*

Five participants spoke about how research has the potential to empower people with intellectual disabilities and have a direct benefit on their lives. Research was seen as an opportunity for people with intellectual disabilities to express their views, learn about themselves and exercise control over their lives. Four of the participants spoke about how people with intellectual disabilities have a right to be involved in decisions and activities that may affect them, including research.

> *The very people that you're delivering the service to, if you want to improve that service, if you want to get a real and true picture, they're the people you talk to,*
> *(Participant 7, 1st telephone interview)*

Three participants believed that participating in research had the potential to directly benefit people with intellectual disabilities. They viewed this as a reason why people with intellectual disabilities may choose to take part in research projects.

TABLE 3 Key themes and subthemes from the focus groups and interviews

Perceptions of research	Barriers to conducting research	Solutions to maximise recruitment and project success
Research gathers information and increases understanding.	People with intellectual disabilities and carers may not take part due to lack of time and perceived benefits	Appropriate planning and adaptations for people with intellectual disabilities
Research listens to the voices of people with intellectual disabilities and is empowering	People with intellectual disabilities may find it difficult to understand research demands	Flexibility when initially approaching care settings
Research can have direct benefits for people with intellectual disabilities	The consent process may be difficult and time-consuming.	Support of management is crucial for recruitment
Participating in research can have negative consequences	Organisational policies can compromise research participation	Recognition of key role of care staff
Care staff support people to live their lives how they want to.		

If they know it will benefit them in the future they will take part in research

(Participant 7, 1st telephone interview)

When discussing the possibility of their clients taking part in research, participants generally saw this as a positive thing, which they would be willing to support. This was related to how they perceived their role. Three of the participants described their role as supporting people with intellectual disabilities and facilitating them to live as independently as possible, rather than just taking care of health conditions and physical wellbeing.

We don't have that much control, nor should we; it's helping people to live in their own homes ... the way they want, to live their lives and live in their own home.

(Participant 3, 1st focus group)

Some concerns were expressed about participation in research. Three participants felt that it may be difficult for people with intellectual disabilities to understand why they had been invited to participate and what was involved. This could make them feel under pressure, with the potential to be intrusive and distressing. Two participants expressed that research may be seen as a burden by some care staff as it could be time-consuming and may not result in immediate or tangible results.

Say for example someone got a letter through the door for research purposes, you'd see that and think, do I have the time to process this, to take it on to this person, who needs to go through this person etc.

(Participant 1, 1st focus group)

3.2 | Theme 2: Barriers to conducting research

Research projects were generally seen as time-consuming for people with intellectual disabilities. Therefore, without clear incentives or benefits, people may lack the motivation to take part. One participant noted that in everyday life, people with intellectual disabilities often had to answer questions about themselves to visitors without knowing what happened to that information, and research may be viewed similarly.

If you come along and say, right we're going to do this research, and they participate, and they don't know what has happened to that, and what benefits might come out of it, it's nothing done, just another bit of paperwork.

(Participant 4, 2nd focus group)

A perceived lack of benefits and the time commitment required for research could potentially discourage care staff from promoting research opportunities with their clients. The turnover of staff could make it difficult to carry out research if a care worker was replaced during the study with another care worker who did not wish to support participation. Those

in focus group 1 (participants in a domiciliary care company) highlighted that care staff are often allocated a set amount of time per client and that it would be difficult to include additional activities in this limited time. Participants felt that managers may be unlikely to authorise the extra time that research would require and that the nature of their contract would not allow them to provide support, outside of their allocated time.

You know if you only have a certain amount of allocated time with that person, and the care plan says you have to do this, this and this, there would not necessarily be any extra time,

(Participant 3, 1st focus group)

With the care industry, if you're not being paid to be in a customer's home, you're not insured to be there, in the sense of, basically you shouldn't be there,

(Participant 2, 1st focus group)

There was some concern that people with intellectual disabilities may not be able to understand study information or questions asked as part of the research. Proxy questionnaires were also stated to be potentially difficult. Participants in the domiciliary care company who primarily worked with people with mild intellectual disabilities felt that it would not be appropriate for them to complete proxy questionnaires as it could undermine their client's independence. Some participants felt that their clients with moderate to severe intellectual disabilities may look to them to help provide the "right" answer if they were answering questions. This group of care staff had no issues with the principle of proxy questionnaires but were concerned that they may not be able to give a true, reliable answer on behalf of their client.

Because they do look upon us sometimes for the answer, you know they will typically look at you, what do I say,

(Participant 6, 2nd focus group)

I suppose it's whether we're giving the information across rightly, on behalf of those guys, I mean are we actually giving you accurately what they might think,

(Participant 5, 2nd focus group)

The process of obtaining consent for participation in research was viewed as potentially difficult and time-consuming. The issue of capacity and the impact on consent was viewed differently by those who worked primarily with people with mild intellectual disabilities and those whose clients had moderate-severe intellectual disabilities. The latter group expressed that they would be able to interpret the responses of their clients and would be able to advise whether their client would want to participate or not. However, participants who worked primarily with people with mild intellectual disabilities stated that due to organisational policies, they would be unable to advise about their client's participation in research even if their client lacked capacity.

If you work with someone with LD [learning disability], you tend to have a very close relationship with them, that you have built up over a matter of time, and you would know if they could take part or not, but when you are bound by policies and procedures, it's not necessarily, it still isn't your choice

(Participant 3, 1st focus group)

Organisational policies and practices could put constraints on care staff and pose logistical issues for research involvement. Three participants spoke about how not all care staff may be familiar with their organisation's policies, which could in turn delay the research process. In addition to obtaining consent from the client, some participants discussed how they would need to seek permission from other stakeholders, such as their managers, and families, which could be time-consuming.

3.3 | Theme 3: Solutions to maximise recruitment and research

Seven participants highlighted that the research process could be improved by being accessible and appealing for people with intellectual disabilities, such as using simple study information to explain the research, planning participation in advance and adapting the research sessions according to individual needs. Participants expressed the need for all information to be worded and presented in a manner that carers and people with intellectual disabilities would be able to understand, which might involve individually tailoring the information to participants, or having different formats available.

If you just go to someone and say, we're going to do research on this and do you agree, they don't have a comprehension of what you mean by research, you need to break it down and make it as simplistic as possible.

(Participant 4, 2nd focus group)

The participants were confident that people with intellectual disabilities would cope with the disruption to their routine, if this was planned in advance, fully explained and scheduled into their daily routine.

If you explain from the beginning, you know, we're going to be here for three weeks, basically on a Tuesday, for three weeks, then that's fine,

(Participant 4, 2nd focus group)

Participants also highlighted that the study information would need to be introduced sufficiently in advance to allow the person with intellectual disabilities, their care worker and their family, as appropriate, time to consider the research project. It would also be helpful for the researcher and person with intellectual disabilities to meet on an informal basis before the start of the study. This would foster trust and would allow the staff to be less involved in data collection, which could also address the concern that people with intellectual disabilities may rely on care staff to provide the "right" answer to questionnaires.

Whoever's going to be doing the research, I would just say it would be nice to meet them first, informally before the research is done, because it just gets you a little bit more trust, and gets them a bit more relaxed in whoever's company it is ... and they'd probably be more likely to give you honest answers if they trust you,

(Participant 7, 1st telephone interview)

There were suggestions for how to adapt research sessions for people with intellectual disabilities, including asking questions in an informal manner, keeping the sessions as short as possible and having different options for how to record people's answers rather than having proxy questions. This included the use of picture supports, forced-response answers and social stories, adapted to the ability of the person with intellectual disabilities.

I am thinking along the lines of the ones who are not that verbal, I would use, umm, something more of a sense of a, social stories, or just pictures, or just, you know, two options, you know, as to how are you feeling today, happy or sad, and then the person can say,

(Participant 8, 2nd telephone interview)

The method of initial contact between researchers and care settings was discussed. There was a consensus that care companies would welcome contact from researchers, but flexible contact methods would be needed. Technology was discussed as an alternative to traditional letter writing or phone calls through emails and publicity on social media. Various recruitment avenues such as charities, families, support groups and multisite organisations were also suggested. Forming stronger relationships between care companies and universities was suggested as mutually beneficial to disseminate research findings and foster opportunities for participation in upcoming studies.

I mean a lot of care companies and organisations have twitter accounts, and Facebook accounts and what have you, so you're going to reach a lot of the demographic of that company, just by doing that, then you would probably be able to say we are doing this and we are looking for this, you would probably get a lot of response, cos a lot of people are interested in that.

(Participant 4, 2nd focus group)

A key factor to successful recruitment was stated to be supportive managers. Five participants suggested that people with management or coordination responsibilities would be the key contacts for researchers. Managers would be in the best position to identify eligible clients and authorise care staff to support their clients to take part in research.

The care coordinators for the area will know how many clients they've got with LD [learning disability], and whatever else, and they will know who to approach, and they will know which carers are in their area and which clients ...

I would be ringing up the companies and asking to speak to the care coordinators for such and such an area. That is the person I would approach, or can I have the email for.

(Participant 3, 1st focus group)

Participants considered that care staff would be able to assist during the recruitment process by liaising with families and offering advice regarding participation based on their knowledge of their client. The possibility of rewarding care staff for the time spent supporting a client participating in research was discussed. Participants felt that recognition of their role would be important, but there were different perspectives about what form this should take. Payment for their time, vouchers for training or resources and prize draws were mentioned and all were viewed positively. Although this was not viewed to be necessary, rewards may encourage care staff to support a research project. The participants expressed that it would not be the monetary value, but the recognition that they would find most valuable.

You wouldn't have to, but if you did it would be a very nice gesture.

(Participant 5, 2nd focus group, discussing researchers offering rewards to care staff).

Some people love getting recognition for something, so for example, if someone does a good job, you get, you, if you're not paid for it, at the end of it, it's like thank you very much … Sometimes that is payment enough.

(Participant 1, 1st focus group)

Table 4 presents practical solutions to potential barriers, as suggested by the participants in this study.

4 | DISCUSSION

Overall, the care staff in this study felt that assisting their clients to participate in research could be a positive experience for both themselves and people with intellectual disabilities, if it was conducted in a way that was adapted and relevant for their clients. Barriers to research were identified, and there was some indication that these may differ according to the severity of intellectual disabilities and the type of care setting. Solutions were also proposed (see Table 4), many of which involved a greater willingness of researchers to work with care staff and people with intellectual disabilities, in order to adapt the research design and process. However, due to differences in ethics committee requirements, local procedures and the focus of research, researchers should consider carefully whether these potential solutions are appropriate for their circumstances, and if so how best to implement them.

Previous studies have suggested that there may be a culture of care staff acting as gatekeepers regarding the participation of people with intellectual disabilities in research (Crook et al., 2015; Jepson,

2015; Lennox et al., 2005; Lewis, 2014a). The present study found that care staff were aware of the potential benefits of participating in research for people with intellectual disabilities and were open to the idea of supporting their clients. However, there was an overall feeling that the cost to both the care staff and the clients may sometimes exceed the benefit their client would receive in practice. There was a general impression of a lack of practical applications emerging from research projects, which could be addressed by giving the care staff and their clients more information about how the research would be used, how it may be relevant to them, and how the findings will be disseminated and applied. There is a need to monitor the impact of health research on practice, to ensure that research findings are utilised, for example through influencing clinical care guidelines (Kryl, Allen, Dolby, Sherbon, & Viney, 2012). Recognition of the role of care staff and the support they provide to their client during a research project may also be beneficial.

This study found that the care staff believed that many of their clients had the cognitive capacity to participate in research, provided the study was presented in a way that was accessible and relevant to them. The care staff in this study suggested that it would be helpful to tailor information to the differing needs of potential participants. Although researchers, aiming to recruit people with intellectual disabilities, often develop and use accessible materials and approaches (Durand et al., 2014; Goodwin, Mason, Williams, & Townsley, 2015; Kidney & McDonald, 2014; Lewis, 2014a,b), the present study emphasises the importance of considering the needs of the individual and using the most appropriate format of information, rather than using the same study materials with all potential participants. This may require discussing the project with people from the proposed patient/carer population, prior to the ethics submission, to plan appropriate research material and recruitment of potential participants. However, this may be difficult to achieve in research studies, which have to comply with ethical regulations and may have complicated recruitment processes.

The care staff emphasised their role in supporting people with intellectual disabilities to make their own decisions whenever possible, including regarding participation in research. However, there was some evidence of a lack of understanding or a conflict with the employee's organisational policy regarding the Mental Capacity Act 2005 and the right of people with intellectual disabilities to have the opportunity to participate in research. For example, some care staff stated that they would always get consent from family members even if the person had capacity to consent, and some care staff stated that they would be unable to act as a nominated consultee for people who lack capacity. Previous research has found similar issues (Cameron & Murphy, 2007; Crook et al., 2015; Lewis, 2014b), which indicates that it may be helpful to discuss procedures around informed consent, how these comply with statutory requirements, and how this fits in with organisational policy with care staff at the outset of recruitment.

There are complex ethical considerations regarding rewards for research participation to patients and caregivers in research (Polacsek, Boardman, & McCann, 2016). There is the possibility that a carer who will be rewarded may offer more encouragement or persuasion

Subthemes	Practical Solutions
Appropriate planning and adaptations for people with intellectual disabilities	Planning research participation in advance with carer and participant
	Meeting with the participant in advance of data collection on an informal basis
	Keeping research sessions as short as possible
	Having different formats of materials available
	Tailoring materials to the individual needs of each participant
	Using flexible methods to record participants experiences and their answers to questions
Flexibility when initially approaching care settings	Using digital avenues to contact care companies, for example social media and email
	Contacting multiple organisations during recruitment
	Developing relationships between care companies and universities
	Providing information about the planned outcomes of the research study
Support of management is crucial for recruitment	Identifying who is best to contact in a company about recruitment
	Utilising the knowledge of the managers during the recruitment of participants
	Liaising with managers to ensure that care staff have the time to support participants
Recognition of key role of care staff	Ensuring that care staff are acknowledged and thanked for their part in facilitating research
	Considering a reward for care staff who support research participation

TABLE 4 Practical solutions suggested by participants for the theme "Solutions to maximise recruitment and project success"

towards their client to participate in the research. Typically, perceived ethical concerns are reduced when the reward is a "token" monetary value or is nonmonetary, so such rewards could be considered for care staff who facilitate research participation (Largent, Grady, Miller, & Wertheimer, 2012). However, in the present study, some care staff reported that they would not have time to discuss research or assist with research participation in the time currently allocated to their clients and are not permitted to be in a client's house when not being paid. A possible solution would be for the researchers to work with the managers to fund additional time. However, this would need to be added to research funding and procedures and may not always be possible. This also leads to the possibility that clients of some organisations would never be offered the opportunity to take part in research if staff did not receive the additional time allocation to spend with their client.

There were some differences in opinions between care staff who primarily worked with people with mild intellectual disabilities who lived in their own homes, compared to those who worked with people with moderate-severe intellectual disabilities living in residential care, regarding the consent process, data collection and ease of allocating time to support their clients with research. It was care staff who worked with people with mild intellectual disabilities who felt that these processes would be more difficult. This may be because they are less experienced with supporting people who lack capacity to consent. Therefore, the research team may need to spend additional time discussing the research with these care staff and their managers to support them through the process and help them to understand how the research adheres to existing organisational policies and procedures. The participants working with people with severe intellectual disabilities were more experienced in observing and assessing their client's nonverbal behaviour to

understand their wishes. These participants did not express any concerns over the use of a consultee in the consent process or the monitoring of implied assent during the research. Previous research has found that people with severe intellectual disabilities are particularly excluded from research (Boxall & Ralph, 2009, 2010; Crook et al., 2015; Feldman et al., 2014; Iacono, 2006), and ethics committees may be overly conservative in their protection of people with intellectual disabilities, resulting in a more onerous ethics process, particularly regarding consent (Calveley, 2012; Dye, Hendy, Hare, & Burton, 2004; Jepson, 2015). This study suggests that in research, there should be a more widespread emphasis on working in partnership with care staff and people who lack capacity to explain and conduct research, with the aim of ensuring ethical procedures and increasing recruitment rates.

This study aimed to explore the views of care staff who had not previously taken part in research, as the majority of care staff approached by researchers are likely to be unfamiliar with research procedures. However, it is important to note that our participants were therefore unfamiliar with typical research procedures and materials, and therefore, their views may not always be applicable to current research practice. However, this does highlight the assumptions and perspectives that care staff may have about the research process, which could be considered by researchers when designing studies, particularly recruitment procedures.

A limitation of this study is the small sample size. Although a number of care companies contacted during the recruitment phase of the study expressed interest in participating, it was difficult to arrange a mutually convenient time within the timeframe of the research. This mirrors some of the findings from the study, as although people may have positive intentions regarding research participation, the logistics and demands of research can be difficult for care staff to balance against the demands of their role. It is also possible that people with more negative views of research were not represented in this study as they chose not to take part. Further research is needed to examine whether the data collected with a small sample of care staff are generalisable. It would also be informative to conduct similar research with family carers, to identify whether they also perceive similar barriers and solutions to research involving people with intellectual disabilities.

5 | CONCLUSION

This study has provided a valuable insight into the inclusion of people with intellectual disability in research studies from the perspectives of care staff. The care staff in this study understood the potential value of research, both for empowering and benefitting participants and for the longer-term benefits for health and social care. Barriers to research participation were identified, and some practical solutions to help address these were discussed. Some of the solutions discussed could improve the inclusivity of research in the future, but further research is also needed to explore, if the views expressed are shared by others in the sector, and how the approach of researchers may have to change when working with different groups of people with intellectual disabilities and their carers.

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