

# Adaptive interviewing for the inclusion of people with intellectual disability in qualitative research

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## Abstract

**Background:** Historically the voices of people with intellectual disability have been occluded by barriers imposed by research practice. More recently, adaptive research approaches have been proposed to enhance the inclusion of people with intellectual disability in qualitative research.

**Method:** This article presents an adaptive interviewing approach employed with five people ageing with intellectual disabilities in rural South Australia. The interviews were conducted within a broader participatory action research project in which tools and resources were co-designed for post-parental care planning.

**Results:** We describe our adaptive interviewing approach incorporating multiple methods: (i) responsive communication techniques; (ii) the inclusion and support of family carers; (iii) visual tools; (iv) walking interviews.

**Conclusion:** Findings contribute knowledge about how an adaptive interview approach supports the participation of people with an intellectual disability in qualitative research.

## KEYWORDS

adaptive interviewing, inclusive research, intellectual disability, qualitative research, visual tools

## 1 | INTRODUCTION

Historically, barriers to participation in research for people with an intellectual disability emanated from a problematisation of the ‘intellectually disabled person’. This problematisation largely takes form through issues relating to impaired cognitive process and communication impacting comprehension, consent and expressive capacity. Together these perceived impairments have troubled research praxis in the realms of validity, reliability and ethics (Finlay & Lyons, 2001; Hartley & MacLean, 2006; Heal & Sigelman, 1995; Sigelman et al., 1981; Sigstad, 2014). In addition, further barriers arise from disabling social conditions connected to paternalistic power such as the operation of ‘gatekeepers’ and proxy

decision-makers or communicators (Bains & Turnbull, 2022; Hollomotz, 2018).

Adaptive approaches orient to a problematisation of research methods, with the intention of tailoring the research approach to afford people with intellectual disability inclusive participation (Hollomotz, 2018). Such approaches recognise the value of addressing power imbalances, reducing disparity and improving quality of life for people living with an intellectual disability (Schwartz et al., 2020). A growing body of evidence documents a wide range of adaptive methods including accessible language (Schwartz et al., 2020), participatory and creative methods such as photovoice, photography, film, drama, and storytelling (Gjermestad et al., 2023), visual and metaphorical devices (Nind & Vinha, 2016), as well as flexible approaches for

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improving the quality of participation (Nind & Vinha, 2014; Schwartz et al., 2020).

This article draws from a participatory action research project in which a post-parental care planning approach and tools were co-designed to support people ageing with an intellectual disability in rural South Australia. The research was undertaken as a response to a post-parental care crisis in the service sector. At the centre of the crisis are people ageing with an intellectual disability in the family home who, upon the death or incapacity of family caregivers, experience unplanned transitions to disability-supported accommodation and services (Garnham et al., 2019; Wark et al., 2023). In rural communities, planning for the provision of future care is complicated by substantial unmet need for residential disability support (Eley et al., 2009; Wark et al., 2015), scarcity of disability services and discontinuity of disability support workers (Judd et al., 2017) and an urban-centric service model (Bryant & Garnham, 2017; Garnham et al., 2019). The unplanned crisis transition portends negative outcomes for people with intellectual disabilities resulting from abrupt dislocation without transition support or the opportunity to develop adequate skills in independent living (Bibby, 2013; Bigby, 2000). These issues may be compounded further by inappropriate or unstable residential placements, significant geographical dislocation from social supports and familiar environments, and the failure of care systems to attend to issues of grief and bereavement, in addition to ensuring residential security and primary care arrangements (Bigby, 2000). Our research, therefore sought to provision older parental caregivers, people ageing with an intellectual disability and disability service providers with resources that would enable planned transitions to post-parental care.

Within the overarching participatory research approach, our project included qualitative interviews with people ageing with an intellectual disability in rural areas. These interviews sought subjective experiences, preferences and perspectives concerning current and future residential and disability support. This article explores the adaptive interviewing approach that was adopted in which multiple methods were flexibly incorporated including: (i) responsive communication techniques; (ii) the inclusion and support of family carers; (iii) visual tools; (iv) walking interviews. The approach is illustrated through excerpts from the five interviews to demonstrate how the tailored and flexible approach enabled inclusive participation. We conclude by discussing the methodological implications derived from our findings.

## 2 | THE SHIFTING PROBLEMATISATION OF PEOPLE WITH INTELLECTUAL DISABILITY IN QUALITATIVE RESEARCH

Corresponding with their level of cognitive and communicative impairment, people with intellectual disabilities have varying capacity in language comprehension, memory, abstraction, processing speed, formulating responses and expression (Corby et al., 2015; Sigstad & Garrels, 2018). Limited response to questioning is common and people with intellectual disabilities are

considered to acquiesce, whereby a positive or agreeable response is offered that does not necessarily correspond with how the person feels (Corby et al., 2015; Hollomotz, 2018). Such cognitive limitations and communicative challenges may trouble the quality and depth of qualitative research interviews.

Inclusive research refers to a paradigm committed to research praxis for the active participation of people with an intellectual disability in ways that move beyond being subject to research (Walmsley & Johnson, 2003). According to Walmsley and Johnson (2003, p. 16), inclusive research:

...must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them...it must access and represent their views and experiences [and]...people with learning disabilities need to be treated with respect by the research community.

There are a broad range of potential modes of engagement for people with intellectual disabilities within inclusive research, many of which are shaped by participatory, action or emancipatory research designs and methods (Walmsley & Johnson, 2003). Whilst inclusive research is diverse in its application (O'Brien et al., 2022), this paradigm consolidates around emancipatory values and an ethos in which it is the responsibility of those undertaking research to create methodologies, project designs and methods that afford people with intellectual disabilities dignity, the right to be heard on topics that matter to them and have influence regarding the nature, undertaking, dissemination and implementation of research (Nind & Vinha, 2014). One area in which this agenda has been advanced in the research literature, includes understanding traditional barriers to research participation through a focus on methods.

A systematic review by Corby et al. (2015) examined phenomenological studies using interviews with people with intellectual disability. The review concludes that the quality of the research is concomitant with the relationship between researcher and participants, the nature of recruitment, adaptive, innovative and flexible methods of data collection and rigour of analysis. The studies reviewed document a variety of techniques aimed at enhancing interviews, including extended rapport building to establish trust and learn about participants' communication skills and preferences, keeping interviews relaxed and conversational and conducting interviews in a familiar venue. Communication techniques include ensuring vocabulary is clear, avoiding complex language and using visual methods to support comprehension.

Informed by Critical Disability Studies, Caldwell (2014) proposes dyadic interviewing as a method that attends to and welcomes the interdependent relationship people with intellectual disability have with a support person. This perspective offers an alternative perspective to the problematisation of 'proxy' respondents by acknowledging and welcoming the role of support in the self-determination of people with intellectual disability. Dyadic interviewing involves a series of three interviews and was developed for people with mild to moderate

levels of intellectual disability. The first interview is conducted with the person with intellectual disability to build rapport and trust, to gather background information, and to identify the participant's experience and supports. Participants are asked to nominate a key support person whom they would like interviewed. The second interview, conducted with the support person, aims to triangulate data gained through the first interview. In the third interview, the researcher meets with the participant with intellectual disability for a second time. Informed by the second interview, the researcher aims to further deepen understanding. In addition to the sequential method of dyadic interviews, dual interviews with both the person with an intellectual disability and their support person can be facilitated when the unit of analysis is not the individual but the dyad itself (Caldwell, 2014).

Many authors concede that not all people with intellectual disability have the requisite capacity to provide accurate descriptive accounts of their subjective experiences, thoughts and sentiments in interviews (Sigstad & Garrels, 2018). However, the boundaries of inclusive participation are being subject to increasing challenge through theoretical advancement and methodological innovation. Gjermestad, Skarsaune and Bartlett (2023, p. 40) for example, argue that a sensory-dialogical approach would enable meaning creation from the 'non-verbal, emotional, sensory and bodily utterances of people with profound intellectual disabilities'.

### 3 | RESEARCH DESIGN

Our participatory action research project was conducted in South Australia between 2019 and 2022 to develop best practice in post-parental care planning for uptake by the social service sector. The project was funded through an Australian Research Council Linkage grant with a disability support organisation as a funding partner. Ethical approval for the project was granted by the Human Research Ethics Committee at the University of South Australia (Application ID: 203471). The project incorporated a co-design methodology that drew on principles of user-centred design to develop a people-centred approach to care planning (Farr, 2018). Through purposive sampling, 'experts by experience' in post-parental care planning (post-parental carers, older parental carers, persons with intellectual disability and disability service workers) were brought together with experts in co-design (the research team). The research occurred in three progressive stages. Stage One was focused on building an evidence-base for the co-design that occurred in Stages Two and Three. Stage One included face-to-face semi-structured interviews with post-parental carers ( $n = 9$ ), three online focus groups with disability service workers ( $n = 4$ ), ( $n = 3$ ), ( $n = 2$ ) and face-to-face interviews with participants with intellectual disability ( $n = 5$ ). This article specifically focuses on the adaptive interview approach that was employed with people who have an intellectual disability.

#### 3.1 | Recruitment and sample

At the end of each of the carer interviews, the researcher provided an information sheet explaining the process for interviewing people with

intellectual disability and inviting them to consider the participation of their son/daughter/sibling. One parental carer was enthusiastic about us approaching her daughter and felt that it would be a beneficial experience for her. One of the carer interviews was conducted with both carer and the person with intellectual disability at their supported accommodation. Notably, six of the nine carers initially expressed ambivalence about their son/daughter/sibling being able to contribute to the study in any useful or meaningful way. The reasoning expressed by these carers was that their son/daughter/sibling would not understand the interview questions.

Discussion amongst the research team about this recruitment challenge resulted in the development of a follow-up letter that was disseminated to these parental and sibling carers. In this letter, carers were first thanked for their time and contribution to the study and reminded that the study also crucially sought to hear from people with intellectual disability about their care transitions. We acknowledged the concerns that were raised about their son/daughter/sibling being able to fully understand our interview questions. To alleviate these concerns, we introduced the researcher interviewer—a social worker who had worked in the disability field for 15 years prior to commencing his PhD on choice and control for people with intellectual disability under the National Disability Insurance Scheme (NDIS). We described how his professional role had provided him with skills and experience in interviewing, conducting assessments and case managing adults with intellectual disability—including post-parental care transitions. We shared the following personal insight that had emerged from his PhD research:

During interviewing for my PhD on NDIS choice and control, very few of the adults with intellectual disabilities showed an understanding of choice and control. But their answers still revealed what was important to them (e.g., talking about helping in the community) or difficulties that are important to understand such as not knowing what a Plan is, or the name of their NDIS provider and reveals their ability to exercise choice and control over their funds. Even where people cannot say anything at all, that is important information. None of my participants could use the NDIS MyPlace Portal, for example, which says a lot about what it means when the NDIS *places emphasis on using that portal*. It is our job to interpret the data and silence can be as loud as words in this respect.

Three of the remaining carers responded positively to this follow-up communication, stating that they were now happy for the researcher to approach their son/daughter/sibling, acknowledging the researcher's prior experience, and expressing a renewed confidence that he would be able to obtain useful information during an interview.

Hollomotz (2018) emphasises the importance of taking the time to get to know respondents prior to the interview, as this enables researchers to identify in advance which adaptations might be most

effective. However, due to geographical distance of research participants, available budget and Covid-related constraints on face-to-face research, longer-term rapport building with participants could not be pre-established. This also impacted the ability of the research team to pre-establish relationships with service managers and support staff during the recruitment phase.

The five face-to-face interviews with people ageing with intellectual disabilities (refer to Table 1) were conducted in a variety of rural locations. Participants were three males and two females aged between 39 and 57. Four of the participants were born and lived for the majority of their lives in (or near) the rural town or regional centre where they were currently residing (three resided in a rural town and two resided in a regional centre). The other participant had relocated with their family 19 years prior from a capital city to the rural town where they were currently residing. The interview questioning framework is included in Appendix A.

## 4 | ADAPTIVE INTERVIEWING

Adaptive interviewing offers a tailored approach to the inclusive participation of people with an intellectual disability that is attuned to significant variation in understanding and engagement with the interview process (Bains & Turnbull, 2022). Through this attunement, the interviewer is able to accommodate a person-centred approach to the interview, drawing flexibly on a range of methods and techniques to enhance participation and expression of the person with an intellectual disability. Such an approach eschews rigid adherence to an interview schedule and a regimented approach to conducting interviews.

In our research on post-parental care planning, the interviewer adopted a multi-method approach that was flexibly tailored to the respondent during the interview process. The approach incorporated four methods: adaptive communication techniques, including family carers to support self-determination and communication of participants, use of visual tools as prompts and adjuncts to verbal communication and a walking interview method that allowed the physical space and place of the interview to be incorporated. Each method is described and illustrated through research data in the sections to follow.

**TABLE 1** Adaptive interview participants with intellectual disability.

| Pseudonym | Age (years) | Diagnosis  | Living arrangement                   | Interview type                     |
|-----------|-------------|--|--------------------------------------|------------------------------------|
| Naomi     | 39          | Intellectual disability  | Supported accommodation              | 1-1 interview                      |
| Wayne     | 56          | Down Syndrome<br>Early dementia<br>Mild epilepsy<br>Sleep apnoea | Supported accommodation (<12 months) | Dual interview with brother        |
| Richard   | 54          | Down Syndrome  | Independent accommodation            | Dual interview with sister         |
| Eric      | 47          | Down Syndrome  | Independent accommodation            | Dual interview with parents        |
| Fiona     | 47          | Asperger's syndrome  | Supported accommodation              | Dual interview with support worker |

### i. Adaptive communication techniques

Describing the barriers to participation in qualitative health research, Bains and Turnbull (2022) argue that adults with intellectual disabilities may experience 'cognitive overload' if presented with detailed information and resources prematurely, using complex, abstract language. Hollomotz (2018) describes how posing direct and specific questions in plain language can support successful dialogue. However, the phrasing of questions should be adapted in terms of depth, according to the respondent's capacity, to avoid patronising respondents with overly simple questions or missing opportunities for greater elaboration. Hollomotz (2018) also examines ways in which the interviewer may contribute to the unresponsiveness, acquiescence and recency effects attributed to people with an intellectual disability through their communication. This includes ambiguity, negatively worded questions, lengthy questions and misattunement to discomfort indicating reluctance to respond. To enhance the interviewer's 'communicative competence', Sigstad and Garrels (2018), suggest adopting techniques from counselling practice including silence and encouraging prompts, rephrasing questions, repeating, paraphrasing and summarising responses.

The following extract, taken from the interview with Naomi, illustrates how a combination of direct and specific questions with the repetition of key words are used by the interviewer.

Interviewer: Can I ask why you moved from the house to here, to the [supported accommodation]?

Naomi: That was actually my family's reasons, I think.

Interviewer: Your family's reasons?

Naomi: Yes. That's - well that was my first thought.

Interviewer: Your first thought.

Naomi: Yeah.

Interviewer: So your family had some reasons as to why you should move from the family house to here, in the [supported accommodation]?

Naomi: Yes.

Interviewer: But it sounds, from what you're saying, that you've been very happy living here in the [supported accommodation]?

Naomi: Yes.

Interviewer: How was the move for you? Were you happy to come here?

Naomi: Yeah. I was fine.

Interviewer: When that was happening, when you lived in the family house, did you want to move here then?

Naomi: Sometimes it was really hard.

Interviewer: Sometimes it was really hard in the family house?

Naomi: But sometimes I just got used to it. I just got used to it now.

Interviewer: Sometimes it was really hard when you first moved here?

Naomi: Yes, that's what I was saying.

Interviewer: But after a while you got used to it?

Naomi: Yes, that's right.

Through the direct and specific questions posed by the interviewer, along with encouragement and check-ins using repetition of key words, Naomi was supported to engage with the topic of the inquiry and meaning was clarified when ambiguity arose.

On the topic of where he lives, Eric introduces the idea of 'good people' and his 'favourite friend' followed by the names of some of the friends he has made.

Interviewer: So it sounds like your friends are really the best thing about where you're living now?

Eric: That's right, yes.

Interviewer: So did you not, are those friends people you, you made those friends after moving to your house?

Eric: Yeah.

Interviewer: So you didn't have those friends before?

Eric: Yeah.

Interviewer: Okay.

Eric: New.

This extract demonstrates how the interviewer pulls the topic together by providing a summary sentence stem 'So it sounds like your friends are really the best thing about where you're living now' to clarify the significance of what Eric is communicating and then clarify that these are new friends following his transition to his current accommodation.

Phrasing questions using information already provided by Eric increased specificity of the information sought and thus enhanced

conceptual clarity by reducing abstraction. This included using the names of carers when questioning Eric about the support that he receives, or mentioning people he had already talked about when asking about activities he likes.

Interviewer: So thinking about your carers, like David, Felicity, Roger and Rosemary.

Eric: Correct.

Interviewer: What help do they come and give you?

Eric: A hug.

Interviewer: They give you a hug?

Eric: Yes.

Interviewer: Do they help you in at home at all?

Eric: Like cleaning?

Interviewer: They do some cleaning?

Eric: Yeah and washing clothes.

Interviewer: Helping wash clothes?

Eric: Yeah and make beds.

Interviewer: Making beds as well?

Eric: Yeah.

Eric's speech was quite unclear and challenging to understand. Typically, most of his responses were both short and rapid, making meaning easy to miss. Pacing the interview, paraphrasing, repeating and rephrasing questions were therefore used extensively to check understanding and prompt elaboration during the interview.

## ii. Including family carers in the interview

The method of obtaining proxy responses from someone familiar with the person who has an intellectual disability (e.g., professional support staff or family member) has traditionally been used to overcome challenges to interviewing people with intellectual disability. However, the potential for proxies to suppress or erase the voice of people with an intellectual disability is subject to ongoing ethical and methodological critique and cautionary advice (Gjermestad et al., 2023).

Recent work points to the benefits of mediated participation for the inclusion of people with an intellectual disability in research (Cluley, 2017). This work points to the value of proxies for supporting communication by interpreting responses and sharing their meanings and understanding of behaviour, utterances and expression (Cluley, 2017; Gjermestad et al., 2023). In addition, the inclusion of a proxy allows for triangulation and contextualisation that can provide greater substance to unclear, incomplete or fragmented responses (Caldwell, 2014; Hollomotz, 2018).

Richard participated in a dual interview supported by his sister. Throughout the interview Richard's sister provided communication support that drew on her knowledge of Richard but allowed him to contribute to the conversation. The following extract occurred in response to the interviewer asking Richard about the places he can access from where he currently lives.

Sister: Okay. You don't go to [supported employment] anymore, no because you're retired.

Richard: Yeah.

Sister: Right. So you go to the bank.

Richard: Go to bank.

Sister: You go to the dentist.

Richard: Dentist and the shop.

Sister: And then you go shopping.

Richard: I get haircut too.

Sister: And you do get a haircut on Tuesdays.

Richard: Yeah.

Sister: And you go-

Richard: 3-0 feet.

Sister: 30th you've got feet, you've got podiatrist so-

At the beginning of the extract Richard's sister offers substantive prompts in a way that provides information for the interviewer, but also invites Richard into the conversation. After affirming the information, Richard begins to offer novel information independently and the dynamic shifts such that his sister then affirms his contributions in a way that invites him to continue. Then finally Richard's sister clarifies the meaning of '3-0 feet' for the benefit of the interviewer.

In our dual interviews we found that the presence of family carers supported the participation of people with an intellectual disability in the research interviews by helping to create a sense of safety and trust in the interview situation. Eric was accompanied by his parents to the interview and mostly engaged directly with questions to provide relevant information with little intervention from his parents. However, he was challenged by questions relating to the past or future, imagining his circumstances being different, clarifying what he may be unhappy about or giving an accurate depiction of relationships. Consequently, questions relating to elapsed time were answered by Eric's parents. As the following extract illustrates, when Eric was unsure how to respond, he was able to turn to his parents for support.

Interviewer: So you used to live with your parents?

Eric: Yep.

Interviewer: Do you have different people that you see now you live on your own?

Eric: Yep, correct.

Interviewer: Okay so what, what's changed? What's different?

Eric: What's different mum? What's different?

Eric's mum: Well you come home once, once a week.

Eric: Once a week.

Eric's mum: You go down the street by yourself.

Eric: Yeah by myself.

Eric's mum: You do all, a lot of things by yourself now.

Eric: For myself.

Eric's mum: Where you didn't before.

Eric: That's right mum.

Similar to Richard's sister, Eric's mum provides the interviewer with responses that provide relevant data but in a manner that maintains the inclusion of Eric in the interview conversation. This also enables the interviewer to readily pick up the thread of conversation and continue addressing the person with intellectual disability directly because the carer has not become the focus of questions.

### iii. Use of visual tools

Visual images such as personal or self-produced photographs and printed images sourced from media have been utilised within creative methods approaches to qualitative research with people who have an intellectual disability. In the field of ageing with an intellectual disability and futures planning, Ottmann et al. (2013), supported people with a disability to use photographs to express their hopes and dreams for the future. The aim was to incorporate the images in a person-centred planning process, so that planners have a better understanding of the person's likes, preferences, goals and aspirations. Similarly, Trip et al. (2020) sought to explore perceptions of ageing and future aspirations of people with intellectual disability living with someone they identify as family. This study used photo-elicitation in conjunction with interviews as a visual stimulus tool. The researchers found that photographs provided meaningful conceptual support for expression of associations and perspectives about ageing and the future.

Visual activity schedules (VAS) include line drawings, photographs or pictures, expressed in hard copy or electronic formats, that are used by people with disabilities to perform tasks with greater independence or exercise choice and control (van Dijk & Gage, 2019). The research literature focuses on the application and benefits of VAS in a range of applied areas such as education (Cohen & Demchak, 2018; Spriggs et al., 2017) and life skills (Burckley et al., 2015; Watson, 2017) rather than as a research tool.

When the opportunity arose in our research interviews, we drew on VAS and other visual tools to support communication and participation of people with intellectual disability. These tools offered a communication device that was meaningful and familiar to the person with an intellectual disability and that could prompt specific information. The following extract illustrates how a VAS was incorporated into the interview with Richard.

Interviewer: [indicating the VAS] Is that Richard's writing?

Richard's sister: [the interviewer] was just asking about your writing?

Richard: Yeah.

Interviewer: Can you tell me about this?



Richard's sister: This is all Richard's writing on the board, yes.

Interviewer: This is yours?

Richard: Yeah.

Interviewer: Can you tell me who are these people?

Richard: Yeah.

Interviewer: Are these the people that come here?

Richard's sister: Yes the [disability support] team isn't it?

Following this dialogue, Richard was supported by the VAS and his sister's help to identify people, activities and places that he engages with. Using the visual tool allowed conceptually complex questions to be formulated sequentially through concrete cues in a way that was adaptive to Richard's communication style and invited his contribution and participation.

#### iv. Walking interviews

Walking interviews, or more broadly walking research methods, allow exploration of social or spatial phenomena through movement afforded by walking practice (Kowalewski & Bartłomiejski, 2020). They are often incorporated in research that prioritises participation and place-based approaches to understanding socio-spatial phenomenon (Bartlett et al., 2023). The walking interview combines the qualities of an in-depth qualitative interview and movement allowing spatial cues and multi-sensory stimuli to inform the discussion and prompt subjective experience relating to the space (Evans & Jones, 2011; Kowalewski & Bartłomiejski, 2020). Such an approach provides greater access to participants experience of place and connection to physical and social dimensions of their world (Evans & Jones, 2011; Kinney, 2021). In addition, walking interviews can ease social tension and redefine power relations between interviewer and interviewee, as they have the potential to be more informal and take place side-by-side in locations that are typically familiar to the participant (Evans & Jones, 2011; Kinney, 2021).

A multitude of walking research methods have been used in a range of applied areas and with a range of participant populations, including those whose experience is shaped by social vulnerability to exclusion such as older people, people with mental health difficulties and people with disabilities (Bartlett et al., 2023; Kinney, 2021). There are walking method research studies that include people who are experiencing dementia, but we were unable to locate studies utilising this method with people who have an intellectual disability.

In our adaptive research interviews, walking was flexibly utilised as a means for using the physical space and place of the participant's home environment as a resource for visual cues and prompts to elicit meaningful responses. Supported by his brother, Wayne was asked to provide a 'tour' of his home.

Interviewer: Wayne, could you take us on a bit of a tour?

Wayne's brother: Yeah, come on-

Interviewer: Can you take me on a tour, please? Show me the-

Wayne's brother: Come and show us your room.

Interviewer: Show me your room. That'd be great.

Wayne: Okay.

By leading a 'tour', Wayne was able to direct the focus of the interview and show the interviewer possessions and photos that provided insight into his hobbies and interests, family members and other things that are important to him.

Similarly, Richard was invited to provide a 'tour' of his home, supported by his sister, that allowed him to show the interviewer things that were meaningful to him and provide insight into his interests. VAS in many of the rooms provided a focal point to the discussion and a cue for questioning. The following excerpt captures one such example.

Interviewer: And then what's this one? [indicating a VAS]

Richard's sister: You missed the important one.

Interviewer: Sorry that one. What's that one?

Richard's sister: That's 9:00 till 3:00 that's Dream to Create.

Interviewer: Okay can you tell me about Dream to Create? What do you do at Dream to Create?

Richard: Go there paint.

Interviewer: Painting.

Richard's sister: Yeah.

Richard: Everything I like.

Richard: Make keyring.

Richard's sister: Making keyrings.

As the extract demonstrates, walking into a room with the VAS and support from his sister allowed Richard the opportunity to share the creative activities he engages with through a disability service. In both Wayne and Richard's walking interviews, the verbal dialogue was supplemented through movement through the physical space of the home and encounters with material possessions that provided an opportunity for participants with intellectual disability to share information about themselves in the research.

## 5 | CONCLUSION

In our adaptive interviewing approach a range of person-centred strategies were flexibly used, in concert with the interview

questioning framework, to enhance inclusive participation of people with an intellectual disability and communication between researchers, participants and parental and sibling carers. Variation in participant's capacity to express themselves in an interview context was met with a corresponding adaptive response by the interviewer through the adoption of a range of verbal and non-verbal techniques including utilising visual activity schedules, photographs and walking interviews. This flexible use of methods broadened opportunities for inclusivity and provided a space for meaningful accounts of personhood and experience to unfold. Such an approach is in accord Hollo-motz (2018, p. 155), who encourages movement away from the alleged 'limitations' of the person with intellectual disability to an explicit focus on enabling and disabling aspects of the researcher's style and techniques. In this way, adaptive measures are not used to enhance the 'validity' or 'reliability' of the data collected—but rather emanate from a starting point of inclusivity.

The four methods flexibly adopted in our study represent enhancement of a traditional qualitative interview. To reduce cognitive burden, our interviewer endeavoured to ask clearly phrased, direct and specific questions. They also drew from communication skills often utilised in counselling contexts including paraphrasing, summary sentence stems, check-in's and repetition of key words to check understanding and encourage elaboration. Dual interviews with family carers acknowledge the role of interdependence for self-determination and our interviews demonstrate how participation and communication of people with an intellectual disability can be ethically supported through a chosen support person. In our interviews, family carers varied in the level of support they provided during interviews and acted to facilitate appropriately tailored communication, elaborate and explain ambiguous or unclear responses and maintain the active participation and contribution of the person with an intellectual disability. Visual tools were incorporated in the interviews when the opportunity arose and allowed conceptual clarity of questioning by reducing abstraction using devices that were meaningful and familiar to participants. To a similar degree, walking interviews allowed access to place and material possessions as cues for specific questions and discussion. In addition, inviting participants with intellectual disability to lead 'tours' of their home environment offered an opportunity for agency and non-verbal 'showing' of meaningful aspects of personhood and experience.

Owing to our overall research design, family carers were positioned in a 'gatekeeper' role with respect to their adult son/daughter/sibling participating in the study. As a consequence, family carers were initially reluctant to facilitate recruitment, family carers made the decision about whether interviews with their family member with intellectual disability would be single or dual and participants with intellectual disability did not have free choice in identifying who they wished to provide support in a dual interview. In light of these findings, we encourage consideration of ways that prioritise the agency of adults with intellectual disability in choosing modes of participation in research.

Excluding persons with intellectual disability from research based on cognitive and communicative limitations may lead to

critical aspects of their lives—including those related to post-parental care transition—being left unexamined. As a consequence, services and supports intended to improve quality of life may not be accessible or meaningful. The adaptive interviewing approach discussed in this article offers empowered participation through its research methods to enhance the potential for meaningful accounts of post-parental care transition to emerge. To improve the inclusivity of research for people with intellectual disability, future researchers are encouraged to adopt a range of flexible and creative strategies and methods in their approach tailored to the unique needs of participants.

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## CONFLICT OF INTEREST STATEMENT

No conflict of interest to declare.

## DATA AVAILABILITY STATEMENT

Data supporting the results in the paper will be archived in an appropriate public repository on completion of the study.

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## APPENDIX A

'Hi there. Thank you for giving up your time to come and talk with me today. I'm really interested to find out about your life, where you live, what you do, how you're feeling; and I'm particularly interested in where you want to live. I'm going to ask you a few questions, but I want you to feel free to talk about whatever comes up as we chat ok?'

- Can you tell me about where you live?
- Can you tell me about what you do during the day?
- Please tell me about the people in your life.
- Please tell me about the support or help you have at the moment.
- What is a good life for you? What is important to you in your life?
- Looking towards the future, what would you like your life to be like in say 5 or 10 years' time?
- [Is there] anything else you would like to tell me?