Initial Stages of a Participatory Research Project About Risks Associated With People With Intellectual Disabilities

Clare Nicholson, PhD[1] ⬤, Marcelle Fernandes, PhD[2] ⬤, Jenna Abbott, BSc[2] ⬤, Anna Johnson, BSc[3] ⬤, Jaimie Leung, BSc[1] ⬤

[1] Psychology and Pedagogical Sciences, St Mary's University, Twickenham, [2] Psychology and Pedagogical Sciences, St Mary's University, [3] Psychology and Pedagogical Science, St Mary's University, Twickenham

Participatory research involves people who may not have formal research experience but belong to, or represent, the group being studied throughout the process. This approach is frequently used in studies involving people with intellectual disabilities. However, due to the word limits of traditional journal articles, finer details of the participatory processes are often not reported. As a result, valuable insights may be lost, and the participatory processes may receive insufficient scrutiny. To address this gap, this paper offers practical guidance about the outset of a participatory project exploring risks experienced by individuals with intellectual disabilities. Details of partnering with community members and related organisations and completing the early stages of a design phase are reported (Vaughn & Jacquez, 2020). It reports on considerations related to project planning, methodological choices, ethical issues and venue selection. Specific challenges and next steps are outlined. Some critical reflection is also provided. A conclusion emphasising the importance of enjoyment and flexibility is drawn.

Intellectual Disabilities

Intellectual disabilities are characterised by 'reduced intellectual ability and difficulty with everyday activities which affect someone for their whole life' (Mencap, 2023: para. 3). People with intellectual disabilities have a range of cognitive, sensory, communicative and physical disabilities. In the UK, the terms 'learning difficulties' and 'learning disabilities' tend to be favoured over 'intellectual disabilities'. Despite this, within this article the term 'intellectual disabilities' is used. The term 'intellectual disabilities' is used more consistently internationally (Schalock et al., 2007; Shree & Shukla, 2016) and like others (Walmsley et al., 2018) we believe the different terminology is problematic and believe use of a single term would come with benefits. For example, it could allow for easier collation of research, and systematic and meta reviews. Providing a more comprehensive evidence base could help translate research into improved practice and/or policy faster.

Adults with severe-profound intellectual disabilities require support in most, if not all, areas of life including personal care, communication and mobility. In this paper, the term severe-profound intellectual disabilities is used to encompass both people with severe intellectual disabilities and those with profound and multiple learning disabilities (PMLD). People with

severe intellectual disabilities may have limited verbal communication and require significant support with daily living, while those with PMLD have the most complex needs, often including severe physical disabilities, sensory impairments, and medical conditions such as epilepsy and dysphagia (Carpenter et al., 2015; Nind & Hewett, 2006). Because people with severe-profound intellectual disabilities often have intersecting challenges, support must be highly individualised, typically involving interdisciplinary teams across healthcare and social care (Imray & Colley, 2017). People with mild-moderate intellectual disabilities can live more independently but some support is still often required (American Psychiatric Association, 2022). For many with intellectual disabilities, there is a need for lifelong support and interventions, which are often provided by medical and social care providers (Gillberg & Soderstrom, 2003). People with intellectual disabilities are more likely to have psychiatric disorders, including both common and severe mental health difficulties (Mazza et al., 2020) and autism (Matson & Shoemaker, 2009).

Risks Experienced by People with Intellectual Disabilities

People with intellectual disabilities experience higher rates of ill-health and injuries (Dunn et al., 2024; Robertson et al., 2014; Strnadová et al., 2023), sexual assault (Hollomotz, 2011), and cyberbullying (Jenaro et al., 2018). Generally, they are more at risk of physical and sexual harm (Hughes et al., 2012) and victimisation more generally, including intimidation, property damage and destruction, and vandalism (M. H. Fisher et al., 2016). Due to the potential for these increased harms, it is crucial to understand the specific risks faced by people with intellectual disabilities. Attention should also be paid to how these risks can be minimised, the tailored actions needed to address them, and how to provide support and care that improves quality of life (Ellis et al., 2013).

Appropriate assessment and management of risks when supporting people with intellectual disabilities are vital (Department of Health, 2014) but complicated (Alaszewski & Alaszewski, 2002; Hodges & Northway, 2019). Overprotection can lead to people missing valuable experiences (Callus et al., 2019) and comes with its own risks (Bates et al., 2017), including social exclusion (Verdonschot et al., 2009). It can also leave people more vulnerable to abuse in later life (Franklin et al., 2015). Risk-taking is a part of life (Manthorpe et al., 1997) and considering additional risks does not necessarily equate to additional harms (Seale & Chadwick, 2017). Therefore, positive risk taking, which places importance on managing risk and not avoiding or ignoring it, is encouraged both in academic literature (Seale et al., 2013) and in policy (Department of Health, 2009). However, implementing positive risk taking is not straightforward (Solvoll et al., 2015). A key role for people supporting those with intellectual disabilities is to provide them with independence to make their own choices (Golding & Rose, 2015). At the same time, supporters should protect and safeguard people with intellectual

disabilities against harm (Jenkins & Middleton, 2018). Staff report that these competing demands cause them stress (Solvoll et al., 2015). The balance between safety and autonomy is nuanced and warrants further attention.

Furthermore, the views of adults with intellectual disabilities, family members, carers and other professionals about handling risks differ (Faulkner, 2012; McDonald et al., 2018). Even within these groups attitudes towards risks can be inconsistent. Faulkner (2012) found that some professionals were risk averse whereas others appeared to embrace risk in the interest of promoting a person's independence. Other examples are provided by Nicholson (2023). In one example, a man with severe intellectual disabilities who had a condition where he may stop breathing was always accompanied by two care staff at a day centre. However, when with family he moved unaccompanied using a mobility aid. Another example demonstrated that care staff were not consistent in what they considered safe weather for outings. While some risks are so serious the response is unequivocal, others allow a range of responses. These, more nuanced, everyday risks also merit attention. Given these diverse and sometimes conflicting attitudes toward risk, related research should strive to employ research methodologies that actively involve all parties. This should promote inclusive and effective research. We aim to publish research findings elsewhere. This article specifically focuses on the processes relating to completing the research activity to date.

Project Background and University Research Team

The research activity detailed within this paper took place in London, UK as part of a funded project. Funding was obtained from UKRI Participatory Research Fund via a UK university. The first author is a psychology lecturer who has specific learning disabilities and considers herself an advocate for those whose needs and preferences may get overlooked, especially people with severe-profound intellectual disabilities. The co-authors of this paper are another psychology academic and two psychology graduates and one psychology MSc student who were employed as research assistants. We are all female and have varied upbringings, social economic statuses, ethnicities and nationalities. United by our interest in people and commitment to issues relating to equality within research, academia and beyond, we strive to be both kind and pragmatic. This collective standpoint informs the approach taken in this paper, which emphasises practical details and is guided by inclusive practices.

The broad research topic of risks experienced by people with intellectual disabilities emerged from the first author's PhD research, an exploratory observational and ethnographic study examining interactions involving people with severe-profound intellectual disabilities. Through this research, it became apparent that carers' perception and management of risks could heavily influence the lives of people with severe-profound intellectual disabilities (Nicholson, 2023). Some suggest that ethnographic approaches and close observation can contribute to participatory research by enabling

the inclusion of the interests and needs of people with severe-profound intellectual disabilities, particularly when direct verbal participation may be limited (de Haas et al.Mieta, 2022; Simmons & Watson, 2015). Carrying out fieldwork in group homes and day centres and 'Being with'—as described by Forster (2020), has enabled the exploration of the lives of adults with profound intellectual and multiple disabilities and identified acknowledged key areas of further inclusive research (Mietola et al., 2017; Skarsaune et al., 2021). Since the topic of this research emerged from direct observation of people with severe-profound intellectual disabilities and support staff using ethnographic methods, it could be seen as having roots in participatory research, even though it initially began without formal stakeholder involvement, developing in a genuine and organic way. While we acknowledge that the absence of stakeholder involvement in defining the initial research topic means that the participatory element of this project is partial, engagement with stakeholders has been central to shaping more specific research questions - particularly regarding holidays for people with intellectual disabilities and the development of a new risk assessment tool for professionals. Additional funding has since been secured (UKRI Enhancing Research Culture Fund via a UK university), and we are currently working to establish the extent to which various community members wish to be involved in these projects and, more broadly, in university activities beyond this research. However, the research activity and considerations discussed in this paper relate to activity possible thanks to the initial funding.

Foundations of Participatory and Inclusive Research

Participatory Research: Aims, Benefits and Challenges

Having a broad idea for a research topic, namely, to explore different approaches towards the assessment and management of risks for people with intellectual disabilities, but without a set of specific research questions, the authors decided to use a participatory research approach. Participatory research entails a collaborative approach to research that involves the active participation of stakeholders, particularly those who are directly affected by the issues being studied (Bergold & Thomas, 2012). It is an umbrella term for any research using such an approach. As Vaughn and Jacquez (2020) explain, participatory research involves individuals who may not have formal research experience but belong to, or represent the interests of, the group being studied. These individuals are treated as knowledgeable co-researchers rather than simply objects of the study (Van Eerd & Saunders, 2017). Participatory research shifts from completing research on community members, to research being completed *with, or by,* community members (Fransman & Newman, 2019; Reason & Torbert, 2001).

There are several different participatory research approaches and even within specific approaches the extent to which stakeholders are involved varies. Some participatory research projects may largely be academic-led whereas others are community-driven (Key et al., 2019; Vaughn & Jacquez,

2020). Most participatory research projects will include several phases (e.g. design, implementation, analysis, dissemination; Scher et al., 2023) and community involvement may vary vastly between various stages of an individual project. In Vaughn and Jacquez' (2020) seminal paper, they set out key choice points throughout a research project where academics need to decide upon the level of participation from community members. They break the research cycle down into partnering, designing, collecting, analysing, disseminating, acting and note that: "choices might lead to highly participatory strategies for some steps in the research process, and more researcher-driven strategies at others" (Vaughn & Jacquez, 2020, p. 5).

As Scher et al. (2023) note, all participatory research should be grounded in respect, accessibility, inclusivity and ethics. These human-centred philosophies feed directly into further benefits. For example, involving people directly affected by the proposed research can ensure that research is relevant (Vaughn et al., 2018), improve the reach of the research (Balazs & Morello-Frosch, 2013) and mean that it is likely to be more readily accepted by, and implemented in, relevant communities (Fletcher-Watson et al., 2019; Lasker & Weiss, 2003). This allows for more uptake and a quicker translation of knowledge (Van Eerd & Saunders, 2017). Enabling people to have ownership of the research (Areljung et al., 2021) facilitates this. Whereas those involved have traditionally been viewed as objects of research, a participatory approach can empower those participating in it, instead of the research only benefiting researchers (Richardson, 2000). Participatory research is also a way to elaborate and enhance the understanding of the findings and a means to bridge the gap between practice and research (Areljung et al., 2021). Incorporating community members in research can also lead to higher levels of rigour and validity (Balazs & Morello-Frosch, 2013; Lasker & Weiss, 2003) and academics can benefit from real-world knowledge of community members (Warren et al., 2018) including appropriate terminology (Israel et al., 2010; Shalowitz et al., 2009). Moreover, participatory research can be a genuine vehicle for societal change (Calderón, 2004).

Cargo and Mercer (2008) provide a comprehensive general summary of numerous challenges that are particularly associated with participatory research. Some examples include establishing and maintaining trust with partnerships, overcoming partnership tensions and power imbalances, finding the infrastructure to complete research outside of a research institution and sustaining funding. Furthermore, as Southby (2017) argues, participatory research is often expected to achieve much more than traditional research projects. Such expectations can include being able to address research questions which non-participatory research cannot, to provide training and develop new skills, to empower others, change people's lives for the better and make a genuine positive difference to society. This is a significant task. He suggests that rather than being strict and precious about what does and does not constitute participatory research, instead we should acknowledge the value that different types of research can bring.

Inclusive Research: Participatory Research Involving People with Intellectual Disabilities

Inclusive research is an umbrella term, first introduced by Walmsley (2001), and soon after formalised by Walmsley and Johnson (2003). It encompasses approaches such as participatory, emancipatory and co-produced research which all seek to challenge traditional power dynamics in knowledge production and ensure meaningful involvement of people with intellectual disabilities (Nind & Vinha, 2014; Walmsley & Johnson, 2003). While these approaches have distinct emphases, they share a common commitment to shifting power dynamics and fostering genuine collaboration in research. Although the term has been in use for nearly 25 years, research that would be considered inclusive pre-dates that (Garratt et al., 2022). However, inclusive research has gained popularity internationally in recent years (Chalachanová et al., 2020; Di Lorito et al., 2018; Jones et al., 2019; O'Brien et al., 2022).

Rooted in disability rights (Charlton, 1998) and often drawing upon the social model of disability (Oliver, 1997) much inclusive research has adopted the 'nothing about us, without us' philosophy, accepting that people with intellectual disabilities can be involved in all stages of research. Challenging the traditional boundaries of academic research, such as objectivity, distance from participants and the focus on purely objective outcomes, much of inclusive research has focused on the quality of the research process within research rather than solely exploring the findings. However, as noted by Nind (2017) and Nind and Vinha (2014), it is still important to consider the quality of inclusive research

Key concepts within this movement include conducting research that addresses issues which matter to people with intellectual disabilities, integrating meaningful involvement rather than superficial representation, and holistically giving adults with intellectual disabilities the respect they deserve within the research community. The transformative nature of this research relies heavily on the notion that everyone involved is a learner and encourages collaborative thinking through both formalised and improvised approaches (Nind & Vinha, 2012).

While integration and participation are encouraged, current research processes often hinder this goal. Funding allocation models frequently rely on predetermined topics (Giannelos et al., 2024). As a result, without changes to funding procedures—such as providing grants without requiring a fixed research topic—participants can only engage once topics have already been decided, thus undermining meaningful participation from the outset. One alternative model, used in health research, involves traditional stakeholders proposing research foci and funding bids, which are then refined and contextualised by participants (Den Oudendammer et al., 2019).

Additionally, despite the growth of inclusive research, peer review processes have typically included only academic reviewers. Involving people with intellectual disabilities in reviewing research remains rare. However, the

British Journal of Learning Disabilities (BJLD) has begun fostering inclusion by encouraging collaborative authorship (Mikulak et al., 2023) and involving people with intellectual disabilities in reviewing work—such as the paper by Bates et al. (2020) on the role of social care staff (Lewis et al., 2020). The BJLD also provides a platform for people with intellectual disabilities to comment on published articles by publishing *In Response* papers (Nind, 2020).

It has been cautioned that integrating people with intellectual disabilities into academic processes may inadvertently require them to assimilate into dominant academic norms (Henderson et al., 2024), rather than shape research on their own terms. This concern highlights the need for continued open discussion if inclusive research is to evolve in meaningful and responsive ways. Positive research experiences have been noted by co-researchers with intellectual disabilities, in all parts of research, from conceptualising the research outputs to writing journal articles (Crowther et al., 2024). The lived experience of adults with intellectual disabilities co-researching increases feelings of self-determination and autonomy. Therefore, in addition to gaining greater collective voice in research, it is beneficial on an individual level (Gilmartin & Slevin, 2010).

It is important to recognise that there are also challenges associated with inclusive research. Active inclusion of vulnerable groups, such as adults with intellectual disabilities, in participatory research can lead to additional ethical scrutiny compared to other forms of research (Northway et al., 2015). This in turn may well be time, morale and finance intensive (Benz et al., 2024). It is likely that people will have different availability and varying other commitments (Bonaccio et al., 2013) which as S.L. Fisher et al (2023) point out may be heightened when working with people with disabilities, not least because of fluctuating health.

People with intellectual disabilities are reported to have different concerns about risks that may affect them in comparison to professionals who provide support (Faulkner, 2012). This is particularly relevant here. For marginalised groups, taking a participatory approach may allow people to fully engage and clarify their struggles, whilst shifting the imbalance of power within research (Scally et al., 2021). This is particularly important for people with intellectual disabilities as many express feelings of powerlessness and fear of losing their independence and opportunity to assert their rights (Faulkner, 2012).

Rationale For This Article

The rise in popularity of participatory research has led to many journal articles detailing the findings of such research. However, as Vaughn and Jacquez (2020) note, such articles often do not provide detail about how the collaborative nature of the research was conducted. For example, Lapierre et al. (2018) outline that how partnerships are formed is rarely shared – leaving inexperienced researchers embarking on similar research without the insights of their predecessors. This can be detrimental to early career researchers who may, in any event, find conducting participatory research particularly

challenging. Competitive research cultures may contribute to this (Kramer et al., 2021). It may also be daunting for early researchers to have to navigate unequal power balances between university academics and community members. Pressure to ensure mutual benefit for all may be particularly intimidating for those at the start of their research journey (Renick & Turchi, 2024). Therefore, this paper aims to elaborate on the decisions and lived experiences of university researchers during the initial stages of a participatory research project involving adults with intellectual disabilities and important people in their lives, such as family, friends and professionals. The goal is to share insights that may benefit other university researchers.

This article focuses on the early-stage design work of the project — a phase often overlooked in participatory research literature but rich with methodological and ethical complexity. By sharing details of this stage, we aim to set out how decisions, delays, adaptations and relational challenges were navigated in real time. These experiences are central to the ethos and practice of participatory research.

It is acknowledged that the omission of detailed accounts of methods does not necessarily reflect minimal participatory activity (Rix et al., 2020). Sparse detail about participatory methodologies may well be due to lack of space in traditional methods sections and it is uncommon for authors to publish separate reports on how research partnerships between academics and the community are established and maintained (Le Cunff et al., 2023).

Rix et al. (2020) also acknowledge that it may not be possible to capture and represent all activity in a single academic paper. This could potentially mean that large parts of the research process avoid scrutiny and, perhaps more importantly, as Le Cunff et al. (2023) note, mean that valuable knowledge is lost. They argue that by sharing collaborative research practices by publishing detailed accounts including the nature, benefits and challenges of their processes, authors could positively contribute to "the critical appraisal of participatory methods" (p.4) and not to do so is problematic. Stack and McDonald (2014) also specifically acknowledge this need for participatory research involving people with intellectual disabilities. In their review, 25% of related studies referred to using a community advisory group but, as Rix et al. (2020) note, "there was virtually nothing in the literature discussing how best to set these up and work with them" (p.16).

To address this gap and in the spirit of transparency, we present a brief overview and discussion about our research to date. Practical planning considerations relating to ethical issues and venue choice, the process of partnering with community members and methodological choices are elaborated on. We critically reflect upon the early stages of the design phase. Specific challenges and next steps are also outlined. The aim of the research activities reported here was to establish relationships and to gather information which in time should enable identification of critical areas for research relating to risks associated with people with intellectual disabilities

and to allow for research questions and methods to be established. The findings from analysis of this data will be submitted for publication when completed.

In the following section, we provide a chronological, descriptive account of the research activity carried out to date. This is deliberately kept separate from the sections that follow, which explore the reasoning behind key decisions, discuss emerging tensions, and consider how these relate to broader methodological debates.

Overview of Research Activity

Research networking events were organised for people with mild-moderate intellectual disabilities, family members, friends and related professionals. Four events were held between May and July 2024. All attendees were adults. Two of these events included people with intellectual disabilities and two events were for family, friends and professionals. One networking event for the attendees with intellectual disabilities was held at a building which is managed by the university. The other was held at a community centre during a local charity's weekly evening social group. In total 12 adults with intellectual disabilities were involved, two of whom were also employed as peer advocates. Seven supporters attended, including those who usually ran the social group. One of the two events for family, friends and professionals also took place in a community arts venue managed by the university. Another was held online. Two family members, five professionals and two people who were both family members and professionals attended. No-one who primarily identified as a friend was recruited. In total there were three audio-recorded focus groups with people with intellectual disabilities and three with family and professionals. Food and drink were provided, travel expenses were offered and each attendee was provided with a £20 voucher as a token of gratitude for their time.

At the in-person networking events, the first half of the session was kept relatively casual. Easy-listening music was played and drinks and snacks were provided as attendees arrived. This was done to present a relaxed environment and encourage authentic engagement. Topic-related questions were asked verbally for people with intellectual disabilities and written on large pieces of paper for attendees to consider and discuss with each other. Attendees could also capture their opinions on these immediately if desired. Introductions, a quick health and safety briefing, icebreakers, and discussions relating to expectations and the purpose of the event took place before pizza and salad were provided for lunch. Then, focus groups were led by a member of the university research team in break out rooms, for one hour. All focus groups were audio recorded. Once the focus groups were completed, everyone came back together, concluding thoughts were captured and feedback about the networking event was gathered.

The networking event for people with intellectual disabilities was also held at the community centre during the local charity's weekly evening social group. It also started in a relaxed fashion with introductions and non-

pressurised chatty conversations. However, following the preferences of the attendees and the advice of management, after the initial activities (which were streamlined as all attendees already knew the building), recorded focus groups took place. Afterwards, pizza was provided, and feedback was sought. The online networking event for family and professionals was attended by three people so although similar introductory activities took place, potentially because of the nature of online meetings (Tammaru, 2024) and the small number of attendees, the focus was more on the recorded discussion. An online event was incorporated into the research project, to increase accessibility for those who could not attend in-person.

The audio recording of the focus groups was transcribed and coded by various members of the university research team, including interns and research assistants as well as by the academics involved, with a view to enable thematic analysis. Themes have begun to be established; analysis is ongoing. From these themes, potential research questions will be created. At this point, consultation with community advisory groups will occur. These community advisory groups will consist of attendees from all groups who have indicated that they would be happy to be involved further with the project. This is to ensure that community member voices are genuinely represented, and that analysis of the focus groups has not missed key concerns of the community. After this, additional funding will be sought.

Having described the setup and implementation of the networking events, the following sections reflect on tensions, trade-offs, and methodological learning points that emerged. We consider how these experiences relate to broader conversations in participatory and inclusive research.

Practicalities of Planning Networking Events Involving People with Intellectual Disabilities

Ethical approval was granted by a University Faculty Ethics Committee, and the British Psychological Society's ethical guidelines (Oates et al., 2021) were considered and followed throughout. Ethical considerations are a vital part of any research project but are especially important here as following ethical procedures during research increases trust, accountability, equity and inclusion allowing for collaborative and participatory research (Jamshidi et al., 2014). It should be noted that ethical approval was only obtained for the initial stages of this project as it was only these stages which had yet secured funding (from the Participatory Research Fund, UKRI).

Special consideration was given to specific ethical issues that relate to including people with intellectual disabilities in research. For example, easy read versions of information about the research and consent forms were made using simple language and images to ensure that all materials were suitably accessible (S. L. Fisher et al., 2023; Newman et al., 2022). These were provided to those with intellectual disabilities weeks before each event. If a person was happy to consent, this was obtained in a variety of ways, depending on the person's capabilities. There was an option to submit their

consent online – through a survey tool, to scan or take a photograph of a physical copy and send it via email – sometimes with the support of a member of care staff or family member. Alternatively, verbal consent could be provided. By offering multiple methods for obtaining consent, both online and through physical copies, the process ensured accessibility and flexibility for all participants. This was audio recorded with support from a member of the university research team. All participants were considered to have the mental capacity to be able to consent (Mental Capacity Act, 2005) and could answer questions such as what we were doing and why, whether they had to take part, whether they wanted to take part and why, and what to do if they wanted to stop. These questions served as a Mental Capacity Assessment, since being able to respond reasonably to those questions requires understanding and retention of related information, weighing up decisions and communicating their choice.

Several additional health and safety considerations were necessary as some people with intellectual disabilities may be considered as vulnerable adults (Lord Chancellor's Department, 1997). First, someone with an enhanced Disclosure Barring Service check (Gov.uk, 2024) was present at all times. It was also arranged that a First Aider would be in the building for each event, which is particularly important given the health complications that some people with intellectual disabilities face (American Psychiatric Association, 2022). To account for potential memory impairments (Vicari et al., 2016) clear signage was displayed directing people to the toilets and the research rooms which should reduce the cognitive load for attendees and the risk of anyone getting lost in the building. Each of the attendees with intellectual disabilities was provided with their own personal visual timetable for the day (Koyama & Wang, 2011) which they could mark off themselves. This was intended to help with planning and transitioning which rely heavily on executive functioning which may be difficult for people with intellectual disabilities (Spaniol & Danielsson, 2022). Use of visual timetables has been shown to reduce anxiety and frustration and to promote involvement for both adults and children with intellectual disabilities (Foster-Cohen & Mirfin-Veitch, 2015; Spriggs et al., 2017). As people with intellectual disabilities may struggle with abstract concepts (American Psychiatric Association, 2022), the health and safety briefings were provided in a concrete manner. For example, rather than simply describing the route to take in case of a fire, we walked down the stairs and showed the attendees the fire escape and assembly point. Efforts were made to keep language and all communication simple throughout the events.

As Fisher et al. (2023) note, it is important to consider the accessibility of any building where meetings take place when involving people with disabilities in the research process. The networking events took place in a community arts building which, though managed by the university, is not on the main campus. This building has excellent public transport connections, disabled access and suitable toilets. The rooms that were used were large,

simple but modern and had easy to control temperature technology, plenty of natural light and easy to move furniture. This venue had the benefit of not feeling like an academic space. In stark contrast, the room that was originally booked (but which became unavailable) was a formal room on the main university campus. Although accessible, that room is exceptionally grand with crystal chandeliers and large portraits of aristocrats. We had also planned for served catering. The changed plans were due to potentially noisy and definitely inconvenient nearby toilet renovations. In retrospect, the grand room, with served catering, may not have been the best setting to promote equality and inclusion for all. Many people (including authors of this paper, working on the same campus but in considerably more humble rooms) may feel intimidated by its grandeur. The pleasant space we acquired with take-out pizzas, salad, fruit and juice was probably more suitable. It is a shame we cannot take credit for considering this beforehand. We acknowledge that there may be research events that would benefit from the gravitas a grand elegant room can provide but argue that it was not necessary for initial relaxed networking events for the intellectual disability community. Others also note the need for appropriate spaces to promote authentic engagement (Cook, 2012; Shukie, 2018). The adopted approach, incorporating lunch and icebreakers, was encouraged in previous research such as The Money, Friends and Making Ends Meet Research Group (2012) study. These elements help build rapport, increase concentration and enjoyment and facilitate the initial informal interactions necessary to set a positive tone for focus groups.

Practicalities of Forming Partnerships

One of the goals of this research was to improve relationships between the host university and local organisations that support people with intellectual disabilities. While forming relationships with such organisations is integral to the participatory research about risk, it is hoped that longer-lasting, mutually beneficial relationships will be established. To support the development of this collaborative dynamic, these in-person events were specifically advertised to local communities. Such relationships could promote future research projects but may also be further reaching. For example, having such relationships could mean that community members could help inform the curriculum and case-studies set as assessments thereby ensuring that teaching and assessment are meaningful which is beneficial for all (Belita et al., 2020). There may also be opportunities to incorporate service-learning within taught courses at the university, allowing students to engage in projects within these organisations as part of their coursework, or to involve some organisations in the university's workplace learning modules. However, despite several of the authors either currently or previously working with and for organisations that serve people with intellectual disabilities, prior to the inception of this research project, relationships with local organisations needed to be developed.

Forming research-based relationships is complex (S. L. Fisher et al., 2023), needs to be carefully considered and takes a lot of effort (Lapierre et al., 2018). How this was achieved in this project is set out below.

As funding for this project was limited, as is often a barrier for participatory research projects (Calyx, 2022), a research assistant was hired only for a month to work on this project. Two other research assistants were working on a different project with the same core academic team exploring the social lives of people with severe-profound intellectual disabilities. They kindly helped with the recruitment for the introductory networking events for this project. The simultaneous recruitment of both projects provided several benefits.

First, initial contact with senior members of each organisation was made 'cold' (Lapierre et al., 2018), meaning that there was no prior contact, or any pre-existing relationships between the academic team and the target organisations. This was necessary to begin the process of engagement. However, if an organisation was already interested in one of the projects, it was easier to follow up with further information about the other. As Lapierre et al. (2018) note, 'warm calling', involves contacting organisations through an existing connection, referral, or after building some form of rapport and is considerably easier, and more successful, than 'cold calling'. In hindsight, this participatory project benefitted from the team having two intellectual disabilities research projects operating simultaneously. It may have demonstrated to the organisations our full commitment to the lives of people with intellectual disabilities and that we have interests beyond risk perception, assessment and management. This may be important for any project but is likely to be particularly important when including people from vulnerable groups (Gallegos et al., 2023).

Initial emails were politely followed up with another approximately a week later, and a few days after that telephone calls were made. Once interest in the project was established, if possible, a Zoom, telephone or face to face meeting was arranged and a member of the university research team attended to promote positive engagement and build rapport. To demonstrate the research team's understanding and appreciation of the necessary actions to be taken to accommodate people with intellectual disabilities, the lead researcher always attended these meetings with organisations who might help recruit people with intellectual disabilities. Any questions they had could be addressed directly to the lead researcher and addressed immediately if possible. It may also be that the seniority of the lead researcher emphasised the significance of the project and reassured organisations of our commitment. This approach may have fostered greater engagement and collaboration.

The authors also embraced the advice offered by Chao et al. (1994) and tried to adopt the vocabulary used by the organisations. As demonstrated in this paper, for academic audiences the authors favour the term 'intellectual disabilities'. This is despite the favoured term in the UK being 'learning disabilities' (Cluley, 2017). However, because people in the UK are much

more familiar and at ease with the term 'learning disabilities' (Cluley, 2017), this term was used in all materials and discussions. Similarly, efforts were also made to use organisation specific terms. For example, some organisations referred to the people with intellectual disabilities accessing their services as residents, service-users or members. This language was mirrored. Using the same terminology as others (even if this does not align with one's own) should help with smoother communication, signal shared interests more easily and help establish closer relationships (Chao et al., 1994). Avoiding unfamiliar jargon should also reduce 'ivory tower' perceptions of academics (Lapierre et al., 2018), where scholars are seen as working in privileged, isolated environments focused solely on theoretical concepts with little connection to the practicalities of everyday life.

In addition to contacting senior members of organisations directly, several other recruitment strategies were used. For example, snowballing was encouraged. If a senior member of an organisation forwarded our email to another member of their organisation, or to people in other organisations, our contact was already 'warm', helping relationships to be established (Lapierre et al., 2018). Information about the events was also shared on social media (originally through professional X and LinkedIn accounts) which has been shown as a useful way to engage communities in research (e.g. Flood-Grady et al., 2021). To provide a wider reach and fairer representation, printed posters and information sheets were posted to all interested organisations. As noted by S.L. Fisher et al. (2023), attending both conferences and established community groups can also help form relationships with community members. The lead researcher of this project did both. Although she did neither with the primary intention of promoting this project, these opportunities provided a space to discuss this work with various stakeholders. Two conference attendees, unprompted, recognised her name from community recruitment email correspondence, demonstrating the effectiveness of attending such events for reaching potential community members. Attending community groups related to other research interests (namely the digital lives of people with intellectual disabilities) allowed for further integration in the local intellectual disability community.

Methods Used to Capture People's Opinions and Experiences During the Design Stage

Focus groups are often used in the partnering and design stages of participatory projects (Vaughn & Jacquez, 2020). This is likely because they allow for much complex information to be gathered in a low-cost, time-efficient way (Fontana & Frey, 1994). Although there are challenges in all research, and with focus groups in particular (Krueger & Casey, 2000), Kaehne and O'Connell (2010) rightly outline that there are specific difficulties associated with including people with intellectual disabilities in focus groups. Yet, they conclude that "a careful balancing of methodological rigour and a keen awareness of the limitations of focus group research

with the learning disabilities population can result in gathering valid data on a wide range of issues relevant to people with intellectual impairment" (pp.142–143). It may take longer for people with intellectual disabilities to process questions and responses, and adequate time is needed to ensure everyone is able to express their thoughts (Kroll et al., 2007). This must be balanced against the increased potential for fatigue, particularly for individuals with varying levels of stamina and concentration (Barrett & Kirk, 2000). Even so, utilising focus groups that employ a range of communication methods has been suggested as a way to support and develop collaborative discussion and reflection (Fraser & Fraser, 2001).

This research method is noted to draw out common attitudes, beliefs and feelings (Chapman et al., 2012) and can help foster a sense of belonging for adults with intellectual disabilities by providing a setting in which they feel part of a socially valued group. This collaborative nature can further contribute to a positive self-image, enhancing social skills and overall mental health (Nind et al., 2021; Puyalto et al., 2016). Therefore, focus groups may have a transformative impact on participants. For a community that can sometimes be socially isolated, focus group research created to facilitate social connectedness can serve a dual purpose (Callus, 2017; The Money, Friends & Making Ends Meet Research Group, 2012). In summary, focus groups serve as a valuable tool for engaging individuals with intellectual disabilities, providing them with opportunities for learning, personal growth, and social connection while also amplifying their voices in research and advocacy efforts.

Despite these benefits, focus groups are not without challenges. Recording a focus group does not necessarily mean that everyone's contributions are treated equally. It is possible that during the focus groups, attention was paid to some people more than others, and university researchers could prioritise certain voices. This could be for several reasons, including disproportionately listening to authority figures or those with perceived higher social status (Sidanius & Pratto, 2012), or ideas that seem to align with common sense understandings (Neuman, 2006). It is also easy to attend most to particularly expressive individuals (Bagnoli & Clark, 2010) and those who dominate conversations (Anderson & Kilduff, 2009).

Kroll et al. (2007) outline how to ensure focus group facilities are accessible by considering entrances, toilets, focus group rooms, temperature and omission of unnecessary physical barriers. It is generally accepted that focus groups with people with intellectual disabilities should be smaller than those including their neurotypical peers (Barrett & Kirk, 2000), with Kitzinger (1994) suggesting 4–8 people. During the design stage of a participatory research project, conversations with community members are not always audio-recorded and generally not formally analysed (Vaughn & Jacquez, 2020). This approach may help build rapport (Mayan & Daum, 2016) and create a less overtly academic atmosphere. The use of recording devices can influence interactions (Rapley, 2004). Recording voices may also make people

nervous and less inclined to share certain information, particularly if it is sensitive. In some cases, detailed note-taking and subsequent write-ups may be more appropriate (Rutakumwa et al., 2020).

That said, relying solely on notes may result in a loss of valuable insight (Willig, 2001), leading to tokenistic involvement or simply meeting the expectations of funders (S. L. Fisher et al., 2023).

Accurate, meaningful notetaking is difficult (Piolat et al., 2005) and requires extensive experience and training (Rutakumwa et al., 2020). Due to the cognitive demands involved, notes will inevitably provide only a partial record. Facilitating a group while simultaneously taking notes further increases this cognitive load and can compromise both the data and the interaction. While recording devices may influence interactions, a silent observer taking notes might be even more intrusive and less conducive to a relaxed atmosphere.

This is a trade-off. Acknowledging that no method is perfect, it was decided not to record the introductory portion of the networking event, allowing for a more natural interaction. However, the focus groups were audio-recorded and formally analysed to ensure an accurate account of each attendee's input (Tessier, 2012). These recordings were transcribed and coded by a team of university researchers, including the core academic team, research assistants, and psychology and coaching students participating in a summer research internship. While it may seem counter to the participatory approach for university researchers to formally record and analyse community conversations during the design stage, it is recognised that certain aspects of participatory research can be led by university researchers (Brown, 2022; Vaughn & Jacquez, 2020).

Although participatory research often strives to involve community members at every stage, their involvement during the analysis phase—particularly for those with intellectual disabilities—has often been infrequent and partial (Stack & McDonald, 2014). Full involvement at this stage is challenging due to constraints such as the university researchers' priorities and resources, as well as the preferences, skills, and available time of community members (Rix et al., 2020). Given these challenges and considering that the research discussed here focused only on the initial design stage, the approach adopted was considered appropriate. It was hoped that this would help ensure that everyone's opinions were attended to without requiring a much larger contribution from the community members at this stage.

Further efforts were also made to try to ensure that everyone's opinions were captured. As Scher et al. (2023) note, when working with community groups, flexible and various avenues for participation should be encouraged. Attendees were given opportunities to record opinions that were important to them outside of the focus groups. Family members and professionals were able to do this by writing on large pieces of paper put around the room with relevant questions on them. As adults with intellectual disabilities

often have difficulties with reading and writing, simple Talking Products recorders (Talking Products, n.d.) were used for these attendees. The easy-to-use recorders allowed people to record their views themselves, unassisted, in a private corner of a large room. They were also able to listen back to their input to ensure they were happy with it. Finally, we addressed the extent to which each attendee felt heard in our feedback sheets, which were simplified to be visual for people with intellectual disabilities (and support was offered from either support workers or university researchers if required). Amongst other questions, we explicitly asked to what extent people felt their voices had been heard and what, if anything, could be done to improve this. Everyone who provided feedback reported that they felt their voice had been entirely heard.

Including supporters in focus groups can enhance accessibility and participation for people with intellectual disabilities (Llewellyn, 2009). Supporters may help interpret questions, encourage participation, or assist with communication. However, their presence may also alter group dynamics or inadvertently influence responses. For example, in one study, a supporter challenged a person with intellectual disabilities during the session, shaping the discussion in unintended ways (Llewellyn, 2009). Carey (1994) notes that such presence can "contaminate" the data. As such, while supporters were welcome to attend, we asked them to refrain from contributing to the group discussions unless absolutely necessary, and to sit at a distance from the group. This approach attempted to balance autonomy with support. We also remain mindful that even with these precautions, the influence of supporters cannot be entirely eliminated and must be acknowledged as a limitation (J. Fisher et al., 2024; Rix et al., 2020). Without careful reflection on these methodological complexities, participatory research risks becoming tokenistic.

Our next steps in the research involve developing and refining themes and extracting potential research questions from the findings. These will be presented to the community advisory groups for comment.

Additional Challenges to Note

Recruiting attendees

Recruiting attendees with intellectual disabilities proved to be less challenging than anticipated. This success may be attributed to their limited social opportunities (Louw et al., 2020) and fewer avenues for earning remuneration (Verdonschot et al., 2009). Establishing strong relationships with supporting organisations facilitated the dissemination of information and introductions to potential participants.

By contrast, recruiting family members and friends proved to be notably more challenging. Family members and friends often exhibited lower engagement levels. Similarly, recruiting more senior professionals was generally easier, while less senior staff tended to attend after encouragement

from, and the support of, management. These findings align with existing literature, which highlights the emotional and time demands that can impede engagement from care providers in research (Beattie et al., 2018).

Offering genuine incentives is crucial to increasing participation among care providers facing time constraints and motivational challenges (Cyhlarova et al., 2020; Joshi et al., 2023). Although we offered travel reimbursement, food and drink, and a token of gratitude, these incentives might not have been sufficient. Educating potential contributors about the benefits of research could enhance involvement (Cyhlarova et al., 2020; Malm et al., 2021), though this approach has its own barriers. Building trust is another effective strategy for recruitment (Beattie et al., 2018), but it requires access to the target population. As friends and family may not be members of related institutions in the same way as professionals, reach and research-related support are both limited.

Efforts were made to contact relevant institutions, but we acknowledge that our online information may not have reached everyone, particularly older individuals from lower socio-economic backgrounds who may lack reliable internet access (Joshi et al., 2023). As Cyhlarova et al. (2020) suggest, employing varied recruitment strategies—including emails to organizations, social media posts, online forums, hard-copy posters, and snowball sampling—proved to be necessary. Despite these efforts, the recruitment of family members remained low, and no friends of individuals with intellectual disabilities were recruited. This could reflect the typically smaller social circles of adults with intellectual disabilities (Emerson & McVilly, 2004; Harrison et al., 2021), but time, motivation, and reach also probably played significant roles.

Future research should explore more effective strategies for engaging family members, friends, and independent carers. Researchers should carefully consider their recruitment approaches, appropriate messaging about research benefits and the provision of incentives.

Multiple roles

It is also noteworthy that some attendees had more than one role. Some had intellectual disabilities themselves and were also employed as peer advocates. Others were both family members and professionals. People with multiple roles may have unique qualities and/or insights due to their varied relationships with people with intellectual disabilities. This multifaceted perspective may enhance their contributions to research. However, it may also pose challenges when asked to choose a single identity in research projects. Future researchers should try to avoid this.

Multiple events

Holding separate events for the same project has its benefits. Providing a space just for adults with intellectual disabilities (and any supporters they chose to invite) can allow an appropriate forum that is not dominated by neurotypical communicators (McConkey et al., 1999). Likewise, separating

events for family members and friends and professionals may provide safer spaces to discuss role-specific experiences and any tensions that exist between these groups. Providing multiple events, to include a variety of different community members, may also demonstrate the commitment of the university researchers to the community as a whole and to understanding a holistic view of experiences and difficulties. However, challenges arose associated with this approach. As noted, it was difficult to recruit friends and family members to hold a meaningful networking event. To address this, family members and professionals attended the same events. Having different focus groups for family members and professionals was considered but attendees expressed that they felt mixed focus groups would enable more varied discussion, so this strategy was used.

Having different events for different groups of people also caused some confusion. One man with intellectual disabilities signed up for the event held at the university for people with intellectual disabilities. However, he was unable to attend because of ill-health. Instead, with his support worker, he arrived at the networking event for professionals which took place in the same week. A flexible approach is promoted when conducting qualitative research, (McArdle, 2022) and specifically for participatory research (Arnold & Fernandez-Gimenez, 2010). This has particular relevance when working with adults with intellectual disabilities. University researchers should adopt a flexible approach to allow for both planned and unplanned research activities (Rix et al., 2020) and allow for a "messy space" (p.1050). To reflect this, in the example quoted, an individual interview was conducted (based on the focus group prompts) with a university research assistant. This data was included in the analysis.

Finally, we considered it vital to include a networking event for people with intellectual disabilities that was accessible for those who may not have wanted or been able to come to the event at the university owned building. However, because the off-site event was held at a popular social group for adults with intellectual disabilities, two people attended both events. As they were both excited to see the university researchers and to be further involved, they both took part in two focus groups which followed the same format. It was felt this was the most flexible inclusive approach. It was also possible that they would offer new insights the second time around. It is, however, something that is worth considering when using varying recruitment methods.

Using non-university spaces

As Kitzinger and Barbour (1999) acknowledge, one of the challenges of completing participatory research is using and navigating spaces that are not necessarily set up or designed for research activities. As outlined, two networking events for people with intellectual disabilities were held. It was decided that one of these events needed to take place in a familiar setting for those who may not be able or inclined to travel to unfamiliar places. One of

these events took place at a community centre during a weekly social group organised by an intellectual disability charity. This also allowed for a more inclusive recruitment strategy (Kitzinger & Barbour, 1999).

Several visits to the social group would have been ideal but sadly two arranged visits had to be cancelled because of a death within the charity and the subsequent funeral. Rearranging was difficult because of conflicting timetables and commitments, which is a known challenge for participatory research (Del Gaudio et al., 2017). There was also some time pressure to complete the initial stage of this research. First, the staff at the local charity had already explained the purposes of the event to the service users with intellectual disabilities. The easy read materials provided had already been looked at during charity-led meetings so that those with intellectual disabilities knew what to expect and had the opportunity to process the information and ask any questions. As well as respecting the time and expectations of the community members, there were other motivating factors to complete this section of the research. These included a funder-set deadline by which to have spent the associated budget. Rigid funder set deadlines have long been understood to create a major challenge for participatory research projects (Maclure, 1990) and such difficulties are still well-documented today. However, recently attention has been paid to proposing solutions for such problems (Marschalek et al., 2023). We are hopeful that this marks the beginning of a shift towards greater understanding of, and flexibility for, participatory research projects.

Also, because of funder timelines, a research assistant's fixed term contract was coming to an end. The permanent university researchers were keen for her to be present at one of the lively, joyful events involving people with intellectual disabilities that she had helped organise. There were three reasons for this. First, a personal commitment to her. Second, a more general commitment to enhancing research culture and creating opportunities for those at the start of their careers. Finally, although the important role of research assistants is not always fully acknowledged, their identity as neither a fully-fledged member of an academic institution nor the community group, means that they offer something unique to the research (Tang & Gube, 2022). Taking a flexible approach, we agreed with the local charity that one visit would suffice.

At this community centre, there was a medium sized, narrow room including a kitchenette. It was easy to rearrange the furniture and there was plenty of natural light. There was also a large decking area immediately outside with an electric awning and outside seating. As the exact number of people who would be attending the social group could not be confirmed beforehand and the number of those who would have wanted to be involved in the focus groups on any given day could have varied, it was difficult to plan ahead. Due to the high numbers of attendees, two focus groups were conducted. It was decided to hold one inside and one outside. This was to minimise distraction and to ensure everyone's voice could be heard, both

figuratively and literally. However, despite it being a warm summer day, as the sun set, the temperature dropped, and it started to rain. Although there was an awning it was controlled on timers and regularly needed resetting – which caused some disruption within the group. The importance of completing research (and particularly participatory research) in an appropriate environment is well-documented (Kitzinger & Barbour, 1999) but researchers should consider the risks that come with completing research activities in unfamiliar environments.

Attendees who did not want to be involved

When research activity takes place at a pre-established group at their usual venue, it is vital to consider those who may choose not to participate. To address this, on a separate table, adult colouring books and iPads with various apps installed were made available during the focus groups for those choosing not to participate. There was one person who chose not to participate and another who arrived very late and so joined them. They decided to use their own mobile phones or the charity's tablets instead of engaging in the activities we provided. They were, of course, included in the pizza and drinks and sociable conversation. When it came to handing out the tokens of gratitude, it was decided in the moment that these community members should also receive them. Physically handing out vouchers to everyone else but them would have felt exclusionary and it was clear that they were still expecting them. Moving forward, if researchers are using a similar approach to recruitment and have tokens of gratitude, then it may be worth considering, and budgeting for, an appropriate strategy beforehand.

Facilitating inclusive focus groups with people with intellectual disabilities

Focus groups can be accessible for some people with intellectual disabilities and lead to important findings, particularly on topics which directly relate to their beliefs and experiences (Sandjojo et al., 2019). However, as Beail and Williams note (2014) the number of studies involving people with intellectual disabilities using focus groups is "lagging a long way behind" (p.8) other qualitative methods, particularly semi-structured interviews. They also recognise that whilst interviews place some demands on participants (such as necessary verbal abilities and the capacity to answer questions), focus groups are more complex social interactions that require further skills. Beail and Williams (2014) do not suggest that focus groups are inappropriate for people with intellectual disabilities. Instead, they make a more general call for researchers who are interested in the voices of people with intellectual disabilities to further explore the associated methodological challenges. They rightly assert that if we want to hear the voices of people with intellectual disabilities then suitable methods need to allow for that to happen.

To address this, language used at the events for people with intellectual disabilities was simplified (Finlay & Lyons, 2002); words were kept simple and sentences short. Other interactional adjustments were also considered.

For example, long pauses were provided in between conversational turns and effort was made to speak clearly and at a slow, but natural pace. On one occasion, some Makaton (simplified British Sign Language) was used for one attendee. Picture prompts were also used to help guide discussions (Sandjojo et al., 2019).

The benefits of people with intellectual disabilities having supporters present during focus groups has been acknowledged but it is also recognised that such presence can be limiting, and any benefits may depend on the supporter (Llewellyn, 2009). To address this and be as inclusive as possible, those with intellectual disabilities were invited to bring a supporter (of any kind) to the research events. Three individual supporters attended one event. However, they were not involved in any of the research-based discussions and chose to sit quietly on the other side of the room, presumably to promote the autonomy of the people they support. At the event held during a regularly scheduled social group, the support staff for that group were also present. They generally took a similar approach to the individual supporters, with a little more input but typically very minimal participation in the research-based discussions. This approach sought to balance the level of support with the need to minimise any potential influence on the group dynamics and data collection.

The most notable contribution to a focus groups from a supporter was made by a member of staff at the research event held at the regularly scheduled social group. One of the people with intellectual disabilities who was very keen to be involved in the research appeared to have pressured speech, where speech is fast, without pauses, seemingly uncontrollable and moves quickly from one topic to another (Amercian Psychological Association, 2024). Whilst pressured speech is associated with cognitive impairments, there is a shortage of literature on the topic. Also, criteria for diagnosing pressured speech and communication guidelines to accommodate it are lacking (Lallier et al., 2023).

The university researcher facilitating the focus group wanted to demonstrate empathetic listening and for this person's opinions to be heard. The person with pressured speech was detailing several rich, important stories. However, it was also important to allow everyone a fair chance to contribute and to try to ensure that other focus group members did not become frustrated or impatient (Lallier et al., 2023). Gentle attempts to redirect the discussion were made but were unsuccessful. A member of staff who knew the person with pressured speech well, came over and sat next to her and placed a hand on her arm, whispered something to her and helped break the cycle of speech. This was done in a tender, considerate way. We felt the supporters peripherally involved in this research acted in a way that was respectful and promoted both autonomy and smooth running of the project. For the event held at the university managed building, no attendees brought supporters but the focus group discussion flowed easily and all participated.

This emphasises the benefits that supporters can bring but underlines the point that they are not always necessary. Where possible, consideration of this and professional judgement of appropriate practices should be applied.

Final Thoughts

In this paper, we have outlined the planning of networking events, the process of contacting and recruiting attendees, and how some of them agreed to continue contributing to the participatory project. We have also discussed the challenges faced during this process. It is hoped that providing this level of detail and honesty will be useful to other researchers. We argue that university researchers recording and formally analysing the information provided by community members during the design stages of participatory research projects can be useful. We acknowledge that this is a nuanced approach, which may initially appear somewhat at odds with a participatory approach. However, we believe that, on balance, it was the most appropriate approach for this project. As others have noted (Vaughn & Jacquez, 2020), participatory research is not a one-size-fits-all approach.

Finally, we agree with the philosophy expressed by Rix et al. (2020) that organisational issues should be secondary to ensuring that people enjoy involvement in research projects. Enjoyment is intrinsically valuable and often signals that activities are accessible and those involved motivated. Our networking events, especially those involving people with intellectual disabilities, were well received, with lots of laughter and overwhelmingly positive feedback, both formal and informal. This, to us, is as important as any knowledge we may gain for research purposes.

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