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A Narrative Review of Inclusive Research Practices

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ABSTRACT

Inclusive research recognises the right of people with intellectual disability to collaborate, lead and direct research projects rather than participate only as subjects. Researchers have a responsibility to make the process of research accessible and open to researchers with disability. This narrative review is a response to Walmsley et al.'s article that discusses the value of inclusive research. The review aimed to provide an update on the progression of inclusive research and ascertain current practices and strategies for inclusive research whilst identifying and analysing gaps in knowledge. Thematic analysis of papers identified four areas underpinning inclusive research: (1) highlighting the voices of people with intellectual disability in research; (2) ensuring accessible research; (3) encouraging collaborative research; and (4) committing to reflexive improvement. However, the literature also indicated that there is no standard practice when it comes to inclusive research. This highlights the need for a uniform curriculum for inclusive research training that ensures the active participation of people with intellectual disability within research projects.

1 | Definitions

In this article, the authors use the term 'inclusive research' to refer to research that actively involves people with intellectual disability in the research team. The authors recognise that funding and employment constraints may make true co-design difficult, as they limit opportunities for people with intellectual disability to design a research project from conception.

The authors also use the term 'lived experience researcher', to refer to researchers with intellectual disability. This is because the authors are discussing projects regarding the lives and experiences of people with intellectual disability. In this case, researchers with intellectual disability have lived experience on the topics being researched. However, this does not make 'lived experience researcher' the most appropriate term across all research that may not be centred around the lives and experiences of people with intellectual disability.

2 | Background

The inclusion of people with disability within research has not always been considered important. The study of disability, and particularly intellectual disability, 'has roots in a time when disability epitomised deviance and incompetence' (McDonald et al. 2023, 398). As a result, people with disability were viewed as vulnerable and in need of paternalistic care, which justified their segregation in society and research. However, progressions in advocacy and autonomy such as the independent living movement and the United Nations' Convention on the Rights of Persons with Disabilities (UN CRPD) Articles 19 and 32 have indicated a recognition of the rights of people with disability, and the need to include them in research surrounding their lives and supports (O'Brien et al. 2022; Hole and Schnellert 2024).

Walmsley and Johnson's introduction of the concept of inclusive research in 2003 signalled a response to the activism of people

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with intellectual disability and disabled academics like Barnes and Oliver. It signified that people with disability must be involved in the research process rather than having research ‘performed on, to, or about disabled peoples without them’ (Hole and Schnellert 2024, 1). One aspect of the increasing acknowledgement of the pertinence of inclusive research is the responsibility of researchers to ensure that the process of research is accessible and open to researchers with disability (McDonald et al. 2023, 398). However, this is not the full complement of what inclusive research should and can be. People with intellectual disability need to be involved in the design and execution of research projects. To do so requires encouraging the development of long-term relationships in the research space, highlighting voices of researchers with intellectual disability, ensuring accessible frameworks, and committing to the improvement of inclusive research.

However, if people with intellectual disability are to become researchers, training of methodology and research processes is needed. Salmon et al. (2017, 182) emphasise that ‘a clear understanding of the research process appears to be necessary in redressing historical power imbalances.’ It has been agreed that research training for people with intellectual disability needs to be a combination of formal as well as experiential learning (Fullana et al. 2017; Salmon et al. 2017; Tuffrey-Wijne et al. 2020). However, the literature highlights that research training for people with intellectual disability often focuses on experiential learning, and therefore fails to ensure that individuals understand the purpose and processes of research (Tuffrey-Wijne et al. 2020). This poses barriers for accessibility, as lived experience researchers are then faced with limited resources beyond ‘on the job’ learning, as well as complex language, an overreliance on text-only materials, and a failure throughout the process to account for and mitigate against the power imbalances with academic researchers (Salmon et al. 2017). Tuffrey-Wijne et al. (2020) have identified a need for formal research training courses for people with intellectual disability, to assist active inclusion and participation in research.

Literature in this space is underdeveloped, with little on the need for the combination of both formal and experiential learning for people with intellectual disability. Whilst there are current practices and strategies that are contributing to the development of inclusive research, the field of inclusive research itself is not uniform in approach. As a result, each project uses different methods and lived experience researchers are reliant on the academic researchers to provide adequate training and opportunities for inclusion. There is a need for an inclusive research curriculum that provides clear outlines and outcomes for research teams to ensure inclusive research is achieved, and which builds capacity amongst people with intellectual disability across the diversity of the research design approaches so that they can lead project design from the outset.

The authors used Walmsley et al. (2018) work to frame this review. Walmsley et al. (2018) used Nind and Vinha (2012)’s framing of good inclusive social research to guide their work. Walmsley et al. conclude their paper by proposing that Walmsley and Johnson (2003)’s previous definition of inclusive research

be updated to reflect its added value. They then define inclusive research as:

1. Research that aims to contribute to social change, that helps to create a society in which excluded groups belong, and which aims to improve the quality of their lives.
2. Research based on issues important to a group, and which draws on their experience to inform the research process and outcomes.
3. Research which aims to recognise, foster, and communicate the contributions people with intellectual disabilities can make.
4. Research which provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.
5. Research in which those involved in it are ‘standing with’ those whose issues are being explored or investigated’ (Walmsley et al. 2018, 758).

The authors drew on Walmsley et al. (2018)’s update, to identify articles discussing inclusive research, as defined in the list above. This review aimed to provide an update on the progression of inclusive research and ascertain current practices and strategies for inclusive research whilst identifying and analysing gaps in knowledge.

3 | Methods/Design

The authors work for the National Centre for Excellence in Intellectual Disability Health (‘the Centre’) at the Centre for Disability Studies (CDS) and University of New South Wales. CDS runs the Inclusive Research Network (IRN), an inclusive research group with people with intellectual disability that designs and leads its own research projects, as well as consulting on existing projects. CDS staff members have provided ad hoc research training to the IRN over the years, but the authors recognized the need for a more structured approach.

This need aligned with the establishment of the Centre and CDS’ role in the provision of inclusive research training to consortium members as well as the development of an inclusive research unit of study to be taught in universities. Therefore, the purpose of this review was to inform the broader project and CDS’ development of the inclusive research training. This posed time constraints around the review, as the time limits imposed on the delivery of the team’s training dictated the time spent on the review. Acknowledging the need for a consistent training outline, the authors focused on reviewing existing strategies and practical applications of inclusive research to establish current practices.

The review was conducted in conjunction with consultations with the IRN, forming an inclusive and collaborative design process. Whilst the IRN was consulted, no lived experience researchers co-authored the review due to lack of capacity with other projects at the time. However, the co-delivery of inclusive research training to consortium members was completed in March 2025 and represents a process which promoted inclusive

design and delivery, which was in part driven by the teams and projects discussed in this review.

A narrative review was selected to scope the literature. This method was suited to our research aim given the growing, yet comparably limited, literature on inclusive research practices and training. The purpose for using a narrative review was so that the authors could identify the available evidence in inclusive research literature and thus analyse gaps in practice.

Included papers needed to meet all five of Walmsley et al. criteria to be defined as inclusive research and included in this review. The papers also needed to be published in peer-reviewed journals between January 2017 and March 2024 and provide an overview on the development of inclusive research. This includes ascertaining current practices and strategies for inclusive research whilst identifying and analysing gaps in knowledge. The databases PROQUEST, INFORMIT and CINAHL were searched to find relevant articles. The inclusion criteria for this review included:

1. The articles were peer-reviewed articles.
2. The articles were published in or after 2017, when Walmsley et al. update was accepted to be published, and before or in March 2024, when the search was conducted.
3. The full text of the article was available.
4. Articles were published in English.
5. Articles reported on the practical strategies involved within their own inclusive research projects/training.
6. The articles were discussing inclusive research, as outlined in Walmsley et al.'s definition for inclusive research, done by and with people with intellectual disability.

The keywords used for the searches were as follows:

“inclusive research” OR “accessible research”

AND

“intellectual disability”

AND/OR

“curriculum” OR “training”

The initial search returned 4012 results. Duplicates and papers that did not feature inclusive research either in training or practice were removed, and 43 articles were determined to be potentially relevant. These articles were then screened by two authors. A further 19 articles were excluded at this stage because they were not relevant (e.g., not related to inclusive research in training or practice). Any conflicts were resolved through discussion. This left 24 articles to be included in the final review. The first and fifth authors reviewed all 24 articles to extract the practices utilised in each study. Using this data, the first author established initial codes, such as accessibility and reflexivity. These codes were discussed with the fifth author and agreed to. Following this, the broad original codes were further refined to four categories based on the practices used in the project.

4 | Results

These practices were drawn from 24 articles, across 13 countries. All articles included qualitative practices and are summarised in Appendix A. This table summary demonstrates that whilst there are strong inclusive research strategies occurring in training and in practice, they are not uniform. Additionally, this table summary highlights that whilst the literature on inclusive research is growing, less literature has been released focusing on how to use an inclusive research approach.

This is also not to say that the strategies themselves need to be the same in each project, but rather that inclusion is not standard across all stages of research. Different projects employed different practices such as Plain English materials (Fullana et al. 2017; Schwartz and Durkin 2020; Hughes and Schwartz 2024; Pfeiffer et al. 2024; Wanjagua et al. 2024; Belperio et al. 2024) or social events outside of the project for researchers to develop stronger relationships (Puyaltó et al. 2022; Zaagsma et al. 2022). We highlighted four categories that indicated inclusive research. We discuss these categories as ways to measure inclusion. These categories are (1) highlighting the voices of people with intellectual disability in research; (2) ensuring accessible research; (3) encouraging collaborative research; and (4) committing to reflexive improvement.

4.1 | Highlighting Voices of People With Intellectual Disability in Research

The literature maintained that the voices of people with intellectual disability must be actively highlighted in research for the research to be determined inclusive. Fullana et al. (2017) emphasised that not only should people with intellectual disability be involved in research, but that their lives and experiences should also help shape research. Westermann et al. (2022, 7) outlined how, through their project, their lived experience researchers ‘recognised it as an opportunity to have their voices heard and influence decision making’.

To ensure that all research team members are equally valued and listened to, teams must be clear in setting expectations for the project (Ćwirynkało et al. 2024). This was evident throughout the literature, as the articles illustrated that highlighting the voices of lived experience researchers required meaningful planning. This meant ensuring open conversation during the data collection process (Schwartz and Durkin 2020). It was often made clear that equal membership was not fixed across projects, but rather something to continually discuss throughout the project to ensure transparency and agreement (Zaagsma et al. 2022). The literature (Sergeant et al. 2022; van den Bogaard et al. 2024) concluded that regardless of role, it was important that each member felt their contributions were important and that their knowledge was valuable to the team. Not every member will be involved in the writing process or the analysing of data, yet no member should be excluded from the opportunity to do so.

Fostering an equal research space and thus highlighting voices of people with intellectual disability within research also came from recognising the different roles individuals can hold within a project. Fullana et al. (2017) highlighted three approaches that

people with intellectual disability may take within research: advisory, leading, or collaborative. There is no correct approach to take, and all three have their individual strengths and weaknesses. Knevel et al. (2022) used an advisory approach, where advisory groups made up of people with intellectual disability and support workers were able to advise the research team on the research questions and the direction of the project. This approach allows people with intellectual disability to influence the direction of projects; however, it does not allow opportunities to decide research topics and lead them. Hopkins et al. (2022) adopted a leading approach, where the inclusive research group decided that relationships were their research priority and so created and led projects about relationships that reflected their experiences whilst advocating for greater structural change in the lives of people with intellectual disability. This approach ensures people with intellectual disability can conduct research on topics that are important to them; however, it relies on funding and support to include lived-experience researchers from the beginning of a project. Alternatively, Zaagsma et al. (2022, 10) mentioned that their study took on a collaborative approach, which has people with and without intellectual disability working on a project together. This approach allows people with intellectual disability to influence projects and share their experiences; but as Zaagsma et al. noted, their lived experience researcher never led the study so ‘questions such as whether this would have produced more results, or given more scope for experimenting with different research methods, remain unanswered’.

Highlighting voices of people with intellectual disability within research was also argued to have impacts beyond developing inclusive research (Puyaltó et al. 2022). The literature outlined that lived experience researchers spoke of skill progression and meaningful contributions because of their involvement in research, which indicated a development of self-determination in all aspects of their lives (St John et al. 2018; van den Bogaard et al. 2024; Wanjagua et al. 2024). By emphasising the experiences and topics important to researchers with intellectual disability, researchers have an opportunity to increase representation and improve institutional structures and practices. In developing accommodations, such as planning and open communication, to make the research process accessible and ensuring adequate support within a project, there was an active effort to ensure that the voices of people with intellectual disability were highlighted which contributed to improvements in confidence, sense of self and capacity for self-advocacy.

4.2 | Ensuring Accessible Research

Shown in the review, there is no singular inclusive and accessible research/study design. There is potential to make all research accessible and inclusive. Below are strategies identified in the literature to support making each step of the research process accessible.

4.2.1 | Preparing for Research

4.2.1.1 | Research Training. The literature outlined the importance of providing research training to lived experience researchers before commencing a project (Salmon et al. 2017;

St John et al. 2018; Kirova et al. 2023; Pfeiffer et al. 2024). The desired outcomes of research training were two-fold: that people with intellectual disability would have a better understanding of what research was and could thus decide if they wanted to continue with it, and that it would make it easier for academic researchers to recruit lived experience researchers as they had an entire cohort to choose from Tuffrey-Wijne et al. (2020).

Several projects implemented training courses that focused on the development of basic research skills through experiential learning, which refers to training that focuses on practicing and enacting skills, and had lived experience researchers developing research questions, collecting data and presenting their findings (Tuffrey-Wijne et al. 2020; Webb et al. 2022; Kirova et al. 2023; Pfeiffer et al. 2024). Despite a focus on developing research skills, it is also noted that people with intellectual disability are more than capable of working with core research concepts such as ethics; however, it is integral that this information is presented in accessible formats (Salmon et al. 2017).

Other training delivered aimed to also develop social and self-advocacy skills, so lived experience researchers could have a greater understanding of research and how to share their life experiences (Ćwirynkało et al. 2024). Wanjagua et al. (2024) spoke about the need to provide research training in the appropriate cultural context to allow lived experience researchers the opportunity to practice inclusive research that they could relate to. It was clear in these examples that training for research involved a myriad of components that went beyond the development of basic research skills and that sought to develop an understanding of research that allowed lived experience researchers to participate actively in the research process.

4.2.1.2 | Recruitment and Application Process. As well as research training, a crucial aspect of preparing for a research project is ensuring that the recruitment and application process is accessible to people with intellectual disability. Bonello et al. (2022) included their existing lived experience researchers in the recruitment of additional lived experience researchers. The literature (Schwartz and Durkin 2020; Zaagsma et al. 2022) highlighted that this process should involve accessible language and materials, as well as support with onboarding documents. There was also a focus on ensuring that lived experience researchers were paid and reimbursed for transportation, two benefits that are often not discussed for people with intellectual disability (Schwartz and Durkin 2020; Wanjagua et al. 2024). However, to make this consistently possible in future research projects, inclusive approaches and practices would then need to extend beyond the research team and be adopted by Human Resources departments and employment departments at universities and research institutes, which was not discussed in the literature.

4.2.1.3 | Research Meetings. Accessible preparation for research also required research teams to decide on strategies and practices they would implement in research meetings to ensure they were made accessible for lived experience researchers (Kramer et al. 2024; Hole and Schnellert 2024; Belperio et al. 2024). This aspect of project design was critical to ensuring the active inclusion of lived experience researchers in the development stage of the project and would then continue

throughout the remainder of the project. Several projects held weekly meetings at a time that suited everyone, and individual catch ups were scheduled if someone could not make a meeting (Kramer et al. 2024; Hole and Schnellert 2024). Around the time of the initial meetings, there was a focus on discussing the needs of research team members to ensure that they were being listened and responded to by the team (Kramer et al. 2024). The literature emphasised the importance of taking time to ensure everyone was aware of each member's strengths, needs and goals within the research project so that the design of the project remained accessible to lived experience researchers (Krueger et al. 2024).

4.2.1.4 | Accessible Information. Another aspect of making research accessible whilst preparing for a project was ensuring that all information regarding the project was easy to understand. This was particularly important for the project design as it ensured all team members were able to actively participate, a practice which continued throughout the project. The literature outlined strategies like accessible agendas, clear instructions for pre-meeting work, sending reminders for upcoming meetings, and visual reports for meeting summaries (Knevel et al. 2022; Kirova et al. 2023; Kramer et al. 2024). The literature also discussed the length and number of meetings (Kramer et al. 2024). In doing so, research teams made use of accessible practices to support the research process and ensure active engagement. However, to achieve this consistently, all staff require training and skills in inclusive resource development.

4.2.2 | Collecting Data

Data collection can involve methods like interviews, focus groups, literature reviews, and secondary data analysis. In the literature, data collection commonly referred to interviews (Puyaltó et al. 2022; Webb et al. 2022; Ćwirynkało et al. 2024; Belperio et al. 2024) and focus groups (St John et al. 2018; Westermann et al. 2022). Inclusive research often gathers qualitative data. The literature did not discuss strategies to include researchers with intellectual disabilities in the collection and analysis of quantitative data, which is noted as a gap in the literature. As a result, the remainder of this section discusses the strategies and practices used to collect data through interviews and focus groups.

The literature outlined strategies used that assisted in ensuring accessibility was practiced whilst collecting data. Unfortunately, the literature was not clear on the extent of the needs of the lived experience researchers, so it is difficult to gauge the inclusion of people with more complex needs. Researchers, however, acknowledged that accommodations varied based on the needs of each researcher, and these accommodations included working in pairs, providing an Easy-English and/or large print version of all research materials, ensuring all material was accessible via computer screen magnifier, and providing materials in advance (Schwartz and Durkin 2020; Sergeant et al. 2022; Hughes and Schwartz 2024; Kramer et al. 2024).

The literature highlighted that it was important for lived experience researchers to understand the qualities of a good researcher

when collecting data. This was/could be covered in research training, as well as in accessible materials. Zaagsma et al. (2022) said that observing methods and discussing them afterwards allowed their lived experience researcher to begin leading interviews themselves, and Wanjugua et al. (2024) emphasised the need to be able to practice the interview questions beforehand. For Schwartz and Durkin (2020), their team ensured research training for lived experience researchers included a discussion on how to interview people successfully, which led to the creation of a Plain English "tip sheet" and interview guide to refer to during data collection. This was also used by Webb et al. (2022), who created prompt sheets as a visual aid for the interview process, detailing questions and possible responses. These accommodations ensured that lived experience researchers were able to actively participate in the collection of data.

Flexibility was found to be a key part of inclusive research projects in this review. It was not always possible to establish all accommodations at the beginning of the project. It was necessary for many of these research projects to establish regular check-ins that allowed for accommodations to be introduced when needed. Ćwirynkało et al. (2024) highlighted that each lived experience researcher had their own strengths and experiences that they brought to their job, and not everyone would respond in the same way to each task. As a result, the team was required to operate flexibly so that each team member was able to contribute according to their wishes (Ćwirynkało et al. 2024). Some of these ongoing accommodations meant trying something, debriefing as a research team, and adjusting accordingly. Another method was having research team members fill out questionnaires to ascertain levels of understanding and what aspects of the project needed to be made more accessible (Fullana et al. 2017). These questionnaires established current levels of participation and the amount of support needed and aided in the establishment of a set of guidelines for the practice of accessible research.

4.2.3 | Analysing Data

Data analysis refers to the methods adopted to draw conclusions from the information collected. In the literature, data analysis was largely thematic, as the teams exclusively gathered qualitative data (Zaagsma et al. 2022; Bonello et al. 2022; Ćwirynkało et al. 2024; Belperio et al. 2024). The literature (Kramer et al. 2024; Belperio et al. 2024) highlighted that research teams must identify how best to discuss and share the task of data analysis with their lived experience researchers. This included considering the accessibility of written materials, ensuring everyone understands the research questions and methodologies and that people can work collaboratively based on their needs (Fullana et al. 2017; Sergeant et al. 2022; Webb et al. 2022; Belperio et al. 2024).

Analysing data within inclusive research often involved collaborative processes, where teams compared and discussed emerging patterns. The literature referred to hands-on processes, such as using flip charts and coloured markers to highlight and interlink concepts, writing findings on sticky notes, highlighting sections of interviews, and creating collages of findings from the project (Westermann et al. 2022; Zaagsma et al. 2022). Kramer

et al. (2024) found that by establishing data analysis as a collaborative process, they were able to adjust the research process when needed. When coding family member responses, a lived experience researcher found some focus groups had implicit biases regarding people with intellectual disability. The researcher found this difficult to engage with and shared the experience at a team meeting. Another team member swapped roles so that the lived experience researcher was able to continue analysing data without experiencing material that was upsetting (Kramer et al. 2024).

4.3 | Encouraging Collaborative Research

A frequently repeated theme throughout the literature was the concept of collaborative research. The idea of building and sustaining long-term and mutual relationships within research was identified as crucial to the development of inclusive research, thus collaboration within research projects was important to building inclusivity (Chalachanová et al. 2020). An emphasis on collaboration within the research projects acknowledged the life experiences of people with intellectual disability and the contributions they can bring to research (van den Bogaard et al. 2024). There are a multitude of factors required to achieve this; staff must have security of employment to ensure continuity, the team must invest in collaboration as a contributor to successful inclusive research, and opportunities for skill development and training must be made available for members of research teams.

Research teams acknowledged that support for people with intellectual disability should not just be for research training, but also for developing collaboration and cohesion (Chalachanová et al. 2020; Knevel et al. 2022; Kirova et al. 2023). As Fullana et al. (2017) suggested, collaborative research is a process that results in the formation of a group that can work together and support one another when completing a research project. Strategies to encourage collaborative practices included icebreaker activities in meetings and social activities outside of the project (Puyaltó et al. 2022; Zaagsma et al. 2022; Kramer et al. 2024). These strategies were important, as Fullana et al. (2017) emphasised that lived-experience researchers considered the facilitation of a wider social network as integral to the process of inclusive research, as it allowed for future partnerships and ensured they were able to seek support when needed. Additionally, collaborative practices ensured that lived experience researchers were able to gain confidence in their research skills, eventually leading interviews on their own (St John et al. 2018). It was found that when a research team had created meaningful connections, it ensured a non-judgemental environment that facilitated the inclusion of people with intellectual disability (Kramer et al. 2024; Pfeiffer et al. 2024).

The need for collaborative research to further develop inclusive practices was frequently emphasised. This is largely due to the inherent power imbalances that researchers must wrestle with, as many may not have worked with lived-experience researchers before (Knevel et al. 2022). To contend with these power imbalances, it was necessary for the research teams to develop trust with one another. The literature (Chalachanová et al. 2020; Knevel et al. 2022; Hughes and Schwartz 2024; Ćwirynkało et al. 2024; van den Bogaard et al. 2024) highlighted that it was

important for teams to share goals, follow through on actioning feedback, and be transparent with communication and the research process to develop trust and maintain relationships. The development of trust meant that teams felt comfortable to communicate with each other and express concerns, which led to positive experiences within research and encouraged further participation in the future (Fullana et al. 2017; Chalachanová et al. 2020).

Collaborative research practices are necessary to ensure that lived experience researchers are actively included in the writing stage of research. Inclusive practices involved group discussions on findings and the team's reflections, support in extending ideas into full text, and prioritising the ideas of lived experience researchers in the initial writing stages (Westermann et al. 2022; Hopkins et al. 2022; Krueger et al. 2024). This ensured that the research team actively created space for a lived experience researcher to provide their perspective within the writing process. It was clear that successful collaboration in the writing together process was intentional, as it required planning and commitment.

The literature also emphasised that reciprocal relationships within collaborative research were important to understand the benefits of inclusive research for all team members. When research teams emphasised collaborative research, it was found that members benefitted from the trust and respect that was developed (Schwartz and Durkin 2020; Chalachanová et al. 2020; Ćwirynkało et al. 2024). Building the confidence of researchers with intellectual disability contributed to increased self-esteem and a sense of autonomy through participation. In addition, researchers without a disability were able to further see the potential in inclusive research and the roles of people with intellectual disability, which was beneficial for ensuring future inclusive research (Fullana et al. 2017).

4.4 | Committing to Reflexive Improvement

Inclusive research improved the accessibility and relevance of research and required reflexivity from researchers. As people with intellectual disability have often been excluded from the research process, the articles stated that research teams must be continually reflexive to ensure that the process remains accessible (O'Brien et al. 2022; Kramer et al. 2024). The literature discussed strategies such as employing an external group to assess the participation of lived experience researchers and provide feedback and recommendations, having research team members keep logbooks to record their experiences throughout the project, or having the team write reflections once the project finished (Schwartz and Durkin 2020; Zaagsma et al. 2022; Webb et al. 2022).

Part of ensuring constant and reflexive improvement was both reflecting on past efforts and planning for future projects. It was suggested that purposeful planning for future projects, combined with effective collaboration, could help facilitate reflexive action and ensure that inclusive research practices remained a priority within research projects (Hughes and Schwartz 2024). Puyaltó et al. (2022) indicated that writing articles about the process of inclusive research allowed the team the opportunity to

discuss their project's successes and limitations in greater depth. This was also evident in Westermann et al. (2022) and Hopkins et al. (2022) work, that involved the research team actively reflecting on their processes. The literature emphasised that successful inclusive research involved reflection on successful strategies and the identification of areas that require improvement (Hole and Schnellert 2024; Hughes and Schwartz 2024; Kramer et al. 2024).

Finally, a commitment to reflexive improvement required the research team to consider how they shared their research findings. The literature (Webb et al. 2022) discussed the importance of providing credit for the role lived experience researchers played in the project, as lived experience researchers detailed instances that they were not acknowledged for the outputs of a project. Additionally, the literature noted that barriers to accessible research included time and funding constraints, such as a lack of compensation for lived experience researchers during the writing stage of a project, which reduces opportunity for co-writing, and temporary research positions that meant lived experience researchers must risk their pension or existing employment to participate (Hughes and Schwartz 2024; Zaagsma et al. 2022). Engaging in reflective practices allowed research teams to identify these accessibility barriers and work to instil practices that made conducting and publishing research more inclusive; however, there was noticeably little discussion in the literature regarding sharing results in accessible formats.

5 | Discussion

In searching the available evidence in inclusive research literature, current strategies and gaps in practice were identified and analysed. Forber-Pratt (2024, 33) emphasises that 'there is no singular inclusive method', and that each research team must take time to understand each members' interests, skills and support needs. The review highlighted a variety of practical applications of inclusive research strategies, and inclusive practices relating to every step of the research process were discussed and thematically organised. It was apparent that inclusive research did not just randomly occur, projects prioritised collaboration and actively committed to inclusion by ensuring that the voices of people with intellectual disability were highlighted. This 'genuine openness to learning and changing' by emphasising the experiences and topics important to lived experience researchers also created opportunities for research teams to promote inclusion and improve institutional structures and practices (McDonald et al. 2023, 407).

The literature also highlighted that there are several challenges and barriers to access for inclusive research. A critical challenge that was acknowledged in the literature was funding. Not all articles highlighted this, but the ones that did discussed impacts on inclusivity surrounding data analysis, as well as ensuring accessible publications (O'Brien et al. 2022; Kirova et al. 2023; Hughes and Schwartz 2024). Additionally, Bonello et al. (2022) highlighted that funding challenges dictated the design of the research, as their team had to readjust their research aims to better fit an available grant and attain funding. Despite ongoing discussions around inclusion,

funding structures and publication have not shifted enough to reflect them. For example, collaborative research and relationship building are vital, and encouraged, but not included in grant timeframes. During a review of funding within Australian disability research, Smith-Merry et al. (2024) discovered that only 16 out of 1241 funded papers were done inclusively, despite current frameworks and policies seeking to increase the inclusion of people with disability as lived experience researchers in funded studies. This highlights issues around the inclusion of lived experience researchers in publication writing, as well as the lack of opportunities for employment in universities and research institutes beyond a funded project (O'Brien et al. 2022; Smith-Merry et al. 2024). Ultimately, funding issues are part of a much-needed system change, which needs to be considered to advance inclusive research.

Other recurring barriers for inclusive research included organisational, and communication challenges. Organisational challenges for research teams included recruitment, scheduling times for meetings, as well as data collection and analysis, that suited everyone (St John et al. 2018; Ćwirynkało et al. 2024). Communication challenges referred to issues surrounding effective communication and collaboration between researchers, as well as a lack of accessible material (Ćwirynkało et al. 2024; Wanjagua et al. 2024).

Interestingly, whilst almost all the articles referenced the importance of accessible materials, most did not provide examples. Additionally, the target groups involved in each project were not clarified. Several articles indicated that they provided information in Plain English to lived experience researchers (Fullana et al. 2017; Schwartz and Durkin 2020; Hughes and Schwartz 2024; Pfeiffer et al. 2024; Wanjagua et al. 2024; Belperio et al. 2024), however only two articles articulated that they provided Easy Read documents to lived experience researchers (St John et al. 2018; Kramer et al. 2024). In fact, often the only time Easy Read was mentioned in relation to lived experience researchers was when they assisted with the development of the materials for participants or publication (Chalachanová et al. 2020; Hopkins et al. 2022; Webb et al. 2022; Bonello et al. 2022; Belperio et al. 2024; Ćwirynkało et al. 2024). It was not made clear whether researchers with more complex needs were accommodated within projects. This is a significant gap in the literature as it suggested that inclusive research practices and critique focuses on the most able. If accommodations are not made for those with more complex needs, inclusion in research is only possible for those with mild intellectual disability.

The literature did not discuss strategies to include lived experience researchers in the collection and analysis of quantitative data, which is a significant gap in inclusive research practices. It would be beneficial to have future projects produce evidence of accessible practices during quantitative analysis.

Finally, there were projects that included people with intellectual disability but did not report on how they were included or what practices were used (St. John et al. 2022; Steele et al. 2023; Strnadová et al. 2023; Callus et al. 2024). Publishing co-authored papers, particularly methodological papers, requires extra time and can be viewed as less of a priority for reporting purposes.

Why this might happen includes a lack of resources and funding available to pay and support lived experience authors beyond the term of the research grant. However, this also indicates a lesser discussed problem in inclusive research: that projects are being conducted inclusively but they are not publishing methodology pieces on the process. A lack of transparency surrounding inclusive practices amongst researchers makes it difficult to learn from the practices of other teams. Whilst these were excluded from the review, it is still useful to see that these inclusive projects are happening.

Ultimately, there is a need for significant structural change to ensure that inclusive research is possible. Inclusive research practices must be fully supported and embraced by mainstream research communities and funders for inclusive research to be widely practiced.

6 | Limitations

The rapid scoping review identified practical methods used within inclusive research, as well as current gaps in the literature. However, whilst 16 of the 24 included articles were co-authored by people with intellectual disability, there were still eight articles that were not. It is important to consider that there is potential for a biased perspective in some of these papers. Additionally, the quality grey literature on the topic in question must also be acknowledged despite not being included in this review. The Disability Innovation Institute at the University of New South Wales (Strnadová et al. 2022) and NSW Regional Health Partners (2024) are amongst a variety of organisations that have produced material aimed at informing inclusive research. However, as the authors wished to review practical applications of inclusive strategies in research, grey literature was not included in this review.

It being a desktop narrative review limited by time constraints surrounding the delivery of the authors' own training meant that the authors were not able to implement a comprehensive search strategy with inclusive scope, as the primary aim was to investigate the practical work of published inclusive research. Additionally, the authors were not able to employ a quality assessment aside from the need to meet the definition of inclusive research as per Walmsley et al.'s (2018) specified criteria. It is possible that some articles were missed in the selection process, despite every effort to ensure that search terms captured all relevant discussions in relation to inclusive research practices. Efforts were made to minimise this risk by ensuring that the search strategy was hand searched and reviewed independently by the second author; however, a replication of the review would confirm that the mentioned methods and strategies are indeed the most current and effective practices.

7 | Implications

The authors set out to respond to Walmsley et al.'s (2018) article by identifying articles that fall within their definition of inclusive research and establishing current practices used to encourage inclusive research, as well as challenges and gaps in

the literature. Walmsley et al. (2018) identified that inclusive research indeed adds value to projects, and the practice of inclusive research carries benefits beyond research. The role of people with intellectual disability in wider society can benefit from the increased participation in research design and processes. These inclusive methods and strategies can be implemented in policy development and advocacy beyond research. However, they raised concerns around the current practice and distribution of inclusive research.

Based on this review, the authors conclude that inclusive research empowers individuals with intellectual disability to collaborate on projects, rather than participate only as subjects. However, to do so requires joint effort from all research team members, as well as staff beyond the research team such as Human Resources and employment departments at universities and research institutes to ensure that appropriate accommodations are made to facilitate participation.

However, Walmsley et al. (2018) did not address the issue of funding. For inclusive research to be successful, it needs to be funded appropriately; acknowledging the time it takes to build relationships, undertake training, do research, and write collaboratively. Current funding structures do not support this, and mechanisms of accessing funding are not accessible or inclusive (Smith-Merry et al. 2024). This is a significant gap in current inclusive research and requires collaboration between researchers and funding bodies to develop opportunities that allow for lived experience researchers to fully engage in the research process, from project design to data dissemination.

The literature identified that successful inclusive research highlights the voices of people with intellectual disability, ensures accessibility through all stages of research, encourages collaboration and commits to reflexive improvement. All phases of research require commitment and consideration to ensure that adjustments are made when needed and that inclusion is made possible. It was highlighted that there are currently many strategies being employed to facilitate inclusive research; however, these practices are not uniform across research projects. The literature argued for formal research training that developed a basic understanding of the research process and encouraged active participation (Tuffrey-Wijne et al. 2020). Further to this, the summary table in Appendix A highlights that most resources referenced in existing literature are not provided, in particular training material. Whilst some material has been published, a lot is not shared publicly, which makes it difficult for an evidence-based training system to be developed.

Whilst current practices and implementation challenges were identified in this narrative review, there is need for established and widely shared training tools and modules to ensure sustainable and continuing inclusive research that prioritises the inclusion of and leadership by people with lived experience. These findings sought to determine the direction of the authors' own inclusive research training, as well as its availability for broader use. The authors have decided to make their own inclusive training accessible for public use following internal delivery so as to contribute to the growing literature on inclusive research practices and strategies. There is also need for increased focus on how to include people with more severe/profound intellectual

disability in research design and implementation, which could be investigated further in future research.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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Appendix A

Summary of Included Literature

Citation	Country	Co-authored	Study design	Data collection	Practices described	Resources used	Availability of resources
Belperio et al. 2024	Australia	Yes	Qualitative	Semi-structured interviews	Planning ahead, inclusive data analysis, collaboration, understanding each researcher's skills and needs, regular check-ins	Lived experience researcher helped develop a plain English version of the document used for framing analysis	Available in paper
Bonello et al. 2022	Malta	Yes	Qualitative	Case study	Inclusion in research planning and funding acquisition, understanding each researcher's skills and needs, regular check-ins	No resources mentioned, however lived experience researchers helped develop video CVs format for people with intellectual disability	Available on YouTube
Chalachanová et al. 2020	England, Norway	Yes	Qualitative	Narrative account	Co-writing/authorship, accessible materials, regular check-ins	Guide of analytic process	Available in paper
Ćwirynkało et al. 2024	Poland	No	Qualitative	Interviews, focus groups	Rapport among researchers, training on the research process before commencing project, understanding each researcher's skills and needs, regular check-ins	Training was given to lived experience researchers	Training materials not provided
Fullana et al. 2017	Spain	No	Qualitative	Case study	Training for lived experience researchers—included introduction to research, data collection and data analysis	Training was given to lived experience researchers	Training materials not provided
Hole and Schnellert 2024	Canada	No	Qualitative	Focus groups	Inclusion in research planning, collaboration in data collection and analysis, open discussions about the roles of each researcher, self-advocacy work	Project used a list of recommendations to guide their inclusive work	Recommendations provided in paper

Citation	Country	Co-authored	Study design	Data collection	Practices described	Resources used	Availability of resources
Hopkins et al. 2022	Ireland	Yes	Qualitative	Narrative account	Co-writing/authorship, inclusion in research planning, self-advocacy work	Accessible material mentioned	No resources provided
Hughes and Schwartz 2024	United States	No	Qualitative	Case study	Understanding each researcher's skills and needs, inclusion in research planning, payment for lived experience researchers, collaboration between researchers, data analysis training for lived-experience researchers	Training given to lived experience researchers	Training materials not provided
Kirova et al. 2023	United States	Yes	Qualitative	Case study	Experiential training for lived experience research, self-advocacy work, printed materials as well as PowerPoint	Resources were given online and in hard copy, surveys were given to lived-experience researchers post training	Training resources not provided, survey provided at https://doi.org/10.1186/s40900-023-00450-5
Knevel et al. 2022	Netherlands	No	Qualitative	Method configuration (dialogues, unstructured interviewing, focus groups, participatory observations, design thinking, double diamond principles)	Consultation with lived experience researchers, highlighting voices of lived-experience researchers and awareness of power imbalances	Paper ball showers, musical chairs, prompting questions, scaling questions, brainstorm techniques, empathy mapping, collective analysis, planning ahead, evaluation of process, visualisations of meetings	Provided in paper
Kramer et al. 2024	United States	Yes	Qualitative	Retrospective evaluation	Accessible materials, regular check-ins, understanding each researcher's skills and needs, training for researchers, collaborative processes	Easy Read agenda, one-page plain language descriptions with embedded visual supports were created for each meeting, plain language PowerPoint slides, research training	No resources provided
Krueger et al. 2024	United States	Yes	Qualitative	Narrative account	Co-writing/authorship, understanding each researcher's skills and needs, accessible information, highlighting the voices of lived experience researchers	No resources mentioned	No resources provided
O'Brien et al. 2022	Australia	Yes	Qualitative	Narrative account	Co-writing/authorship, collaborative practices, highlighting the voices of lived experience researchers	No resources mentioned	No resources provided
Pfeiffer et al. 2024	United States	Yes	Qualitative	Scoping review and development of peer support toolkit	Co-writing/authorship, inclusive data analysis practices, regular check-ins, development of role play videos for training lived experience researchers	Videos with a lived experience researcher roleplaying three roles of research for training future researchers	Outline of toolkit units and material was provided in paper, full version not provided
Puyaltó et al. 2022	Spain	Yes	Qualitative	Interviews and focus groups	Regular check-ins, inclusive research planning, collaborative design of data collection, bar graphs used for thematic data analysis	No resources mentioned	No resources provided

Citation	Country	Co-authored	Study design	Data collection	Practices described	Resources used	Availability of resources
Schwartz and Durkin 2020	United States	Yes	Qualitative	Interviews	Regular check-ins, assistance with hiring process, research and ethics training, collaboration between researchers, inclusive data collection and analysis processes	Plain language materials (job application, interview guide, tool for follow up interview questions)	Provided in paper
Sergeant et al. 2022	Netherlands	Yes	Qualitative	Narrative account	Regular check-ins, inclusive data analysis practices, accessible materials, addressing power imbalances, collaboration between researchers	No resources mentioned	No resources provided
St John et al. 2018	United States	No	Qualitative	Case study	Experiential training for lived experience researchers, accessible material, reflexive activities	Primary questions for reflection interview with lived experience researchers	Primary questions for reflection interview provided in paper, training material not provided
Tuffrey-Wijne et al. 2020	United Kingdom	Yes	Qualitative	Case study	Experiential training for lived experience researchers, co-writing/authorship	Training curriculum and content	Training curriculum, examples of recruitment flyer, and homework provided in paper, full training material not provided
van den Bogaard et al. 2024	Netherlands	No	Qualitative	Narrative account	Understanding each researcher's skills and needs, collaborative processes, regular check-ins	No resources mentioned	No resources provided
Wanjagua et al. 2024	Kenya	No	Qualitative	Interviews, focus groups	Experiential research and ethics training for lived experience researchers, accessible and culturally relevant materials, inclusive data collection practices	Training given to lived experience researchers	No resources provided
Webb et al. 2022	Northern Ireland	Yes	Qualitative	Interviews	Inclusive research planning, collaborative practices, regular check-ins, inclusive data collection and analysis practices	Prompt sheets as visual aids during interviews, training given to lived experience researchers	No resources provided
Westermann et al. 2022	Australia	Yes	Qualitative	Focus groups	Co-writing/authorship, inclusive data collection and analysis practices, reflections by research team	No resources mentioned	No resources provided
Zaagsma et al. 2022	Netherlands	Yes	Qualitative	Interviews	Reflections by research team, co-writing/authorship, collaboration between researchers, inclusive data collection and analysis practices	Guideline for writing reflections	No resources provided