REVIEW

A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences?

Olivia Hewitt[1,2] | Peter E. Langdon[1,3] | Katherine Tapp[1] | Michael Larkin[4]

[1]Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick, Coventry CV4 7AL, UK

[2]Learning Disability Services, Berkshire Healthcare NHS Foundation Trust, 3 Floor, Fitzwilliam House, Skimped Hill Lane, Bracknell RG12 1BQ, UK

[3]Coventry and Warwickshire Partnership NHS Trust, Rainbow Unit, Brooklands Hospital, Marston Green, Birmingham B37 5RY, UK

[4]School of Psychology, Aston University, Birmingham, UK

Correspondence
Olivia Hewitt, Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick, Coventry, CV4 7AL, UK.
Email: olivia.hewitt@warwick.ac.uk

Funding information
National Institute for Health Research, Grant/Award Number: NIHR300501

Abstract

Background: Using inclusive research methods with people with intellectual disabilities is increasingly common. A recent consensus statement identified key elements when conducting and reporting inclusive research with people with intellectual disabilities. This review identifies the range of health and social care research topics using inclusive research methodologies, systematically appraises the involvement of researchers with intellectual disabilities, and identifies facilitators and barriers to inclusive research. Researchers' experiences of engaging with inclusive research are synthesised.

Method: Seventeen empirical studies focused upon inclusive health and social care research were identified. The associated inclusive research methodologies employed, and the stages in which researchers with intellectual disabilities were involved, along with the experiences of researchers with and without intellectual disabilities were synthesised.

Results: Papers focused on a broad range of health and social care topics and largely employed qualitative or mixed-methods designs. Researchers with intellectual disabilities were frequently involved with data collection, analysis and dissemination. Facilitators of inclusive research comprised sharing power, team working, having sufficient resources and making research methodologies accessible.

Conclusions: Researchers with intellectual disabilities are involved in a wide range of methodologies and research tasks. How the added value of inclusive research is measured and its impact on outcomes, require consideration.

KEYWORDS
research, inclusive, health and social care research, co-production, inclusive, intellectual disability, systematic review

1 | INTRODUCTION

Within health and social care settings, collaborative or participatory research has become increasingly commonplace (Chinn & Pelletier, 2020; Strnadová & Cumming, 2014), with the National Institute for Health Research developing specific guidance around co-production in 2018. A number of terms are used to describe various participatory or inclusive methodologies including 'engagement',

'involvement' and 'inclusion' (Williams et al., 2020). This creates difficulties understanding the amount, level and type of involvement of those who are not academic researchers.

A broad distinction has been made within the literature between people being passively involved with research as informants or participants, and the active involvement of people within various stages of the production process, which includes holding power and making decisions (Abma et al., 2009). Despite this, there remains confusion over the range of terminology and methodologies used within this literature, and the extent to which people with intellectual disabilities are involved in both tasks and processes across the research cycle.

The term 'inclusive research' has been described as any research involving people with intellectual disabilities as 'more than just subjects or respondents' (Johnson & Walmsley, 2003, p. 10). As such, it encompasses various research approaches traditionally termed 'participatory', 'action' or 'emancipatory'. It includes various forms of involvement by people with intellectual disabilities and refers to collaborations in which people with and without disabilities work together and make equally valued contributions. Inclusive research is driven by values and it aims to change society through conducting research with people with intellectual disabilities as active partners (Strnadová & Walmsley, 2018).

The increase in inclusive research is due to a convergence of social, political and cultural change in the active inclusion of people with lived experiences in designing the services they use (Williams et al., 2020). Inclusive research emerged from the struggle for equality embodied in the disabled people's movement (Walmsley et al., 2018), and has been strongly influenced by Social Role Valorisation (Wolfensberger, 1980). The focus on inclusive research has also been driven by the role of funders within some countries more recently, including the United Kingdom (e.g., NIHR), who have expanded their requirements for public and patient involvement (PPI) in research, to promote deeper involvement including co-production methodologies.

As inclusive research has become more widely adopted, researchers have sought to define and identify the added value this methodology provides. Added value has been defined in terms of the contribution inclusive research makes to the quality of the research (both in terms of process and outcomes). In addition, added value can occur at different levels, for example including the effect of being involved in the researcher for the individual, and potentially using the research to affect positive social change (Walmsley et al., 2018). Whilst inclusive research is generally stated to empower researchers with intellectual disabilities and increase the relevance of study results, a range of other outcomes including improving the quality of data and developing services and policies to better meet the healthcare needs of people with intellectual disabilities (Frankena et al., 2019).

Researchers are increasingly aware of the ethical aspects of conducting research with people with intellectual disabilities (Frankena et al., 2019). Conducting inclusive research with people with intellectual disabilities is ethically, methodologically and practically complex (Bigby et al., 2014). Challenges commonly include the additional resources needed to develop relation-based collaborations and

understanding how co-researchers with intellectual disabilities are represented in relation to the wider intellectual disability population (both by themselves and by other research team members; Chinn & Pelletier, 2020). Other challenges include the nature of support provided to co-researchers with intellectual disabilities, and how transparently this is reported, and considering the nature of knowledge developed from inclusive research (Bigby et al., 2014).

In this review, Johnson and Walmsley (2003) 'inclusive' research definition was used, which incorporates various active approaches from people with intellectual disabilities providing advice, expertise of lived experiences and steering a project, through conducting a whole project with support from allies (Bigby et al., 2014). People with intellectual disabilities were not merely participants but part of the wider project and held decision making power. Inclusive research is not conceptualised as recruiting people with intellectual disabilities into research projects, or augmenting research methodologies to promote accrual. Within this definition of inclusive research, various models or ways of conducting the research can be used, with researchers employing several alternative or additional terms within papers, including co-production, participatory action research and co-design (Bigby et al., 2014). All of these terms fall within Johnson and Walmsley's (2003) definition of 'inclusive' research. However, terms such as participatory or emancipatory research were not included. The term 'co-researcher' has been used to indicate the equal but different contributions of researchers with intellectual disabilities, although the limitations of this term are acknowledged (see Walmsley et al., 2018).

People with intellectual disabilities experience more health inequalities than the general population (van Schrojenstein Lantman-de & Walsh, 2008). Reducing health inequities is a key focus of the NHS long-term plan (NHS, 2019). Despite this, they are a historically marginalised group and routinely excluded from health research (Feldman et al., 2014), especially large-scale research projects and population studies. Whilst people with disabilities have been included in some specific research, this has tended to be as the 'objects' of study (Nind, 2013). However, there is growing interest in inclusive health research with people with intellectual disabilities. People with intellectual disabilities also experience higher levels of social deprivation (Emerson, 2013), which in turn compounds an inability to access preventative healthcare (Pownall et al., 2020). This interaction between social exclusion and health inequalities means both health and social care topics have been included in this review. A broad definition of health research which includes all research that addresses the physical, mental and social health for all populations across the life course (Alliance for Health Policy and Systems Research, 2022, p. 4) has been adopted. Social care topics are defined as those relating to social well-being, social cohesion, the quality of social support, or the capacity to live and manage a social life (Cho et al., 2020).

A recent consensus statement (Frankena et al., 2019) provides researchers with guidelines, agreed upon by experts in the field, regarding attributes of inclusive research with people with intellectual disabilities. It details 10 key elements for reporting and publishing good quality inclusive research with this population. This review uses these two aspects of the consensus statement to understand the

extent to which researchers with intellectual disabilities are involved with inclusive research, and to appraise the quality of the inclusive research reviewed. To the authors' knowledge, this is the first systematic review using this particular framework.

This review aims to identify the international range of health and social care inclusive research topics and the various methodologies employed, to systematically appraise the involvement of researchers with intellectual disabilities across different stages and processes of inclusive research, and the facilitators and barriers to inclusive research. The experiences of researchers with and without intellectual disabilities of engaging with inclusive research were synthesised.

1.1 | Review questions

1. What are the topics, models and methodologies employed in inclusive research into health and social care topics with researchers with intellectual disabilities?
2. How are people with intellectual disabilities involved in inclusive research in health and social care topics? What are the research tasks and processes they are involved with?
3. What are the experiences of researchers with and without intellectual disabilities of being involved with inclusive research methodologies around health and social care topics?

2 | METHODS

The systematic review is reported in line with current PRISMA-S guidelines (Page et al., 2021; Rethlefsen et al., 2021).

2.1 | Eligibility criteria

Studies were included if they: (a) reported a completed, empirical research study focused on a health or social care topic, using an inclusive research methodology (i.e., people with intellectual disabilities undertook research alongside academic researchers and held some power and decision making authority); (b) were conducted with adults (18 years or older) with intellectual disabilities and (c) were published after 2000 (following Walmsley, 2001 seminal paper). No exclusion was made on the basis of language, with papers published in all languages considered for inclusion.

Studies were excluded if: (a) participants were not diagnosed with, or self-identified as having an intellectual disability. For papers in which only some co-researchers had an intellectual disability, the paper was excluded unless the results from co-researchers with intellectual disability were presented separately. Papers were also excluded if (b) the paper did not report a completed empirical research study (including papers focusing on facilitating inclusive research methodologies). Only empirical papers were included for several reasons. Papers reporting solely the process or methodology of inclusive research (rather than a specific, inclusive research project) tended to report the generic

research process. This review sought to understand the specific details and practicalities of how inclusive research was conducted during a research project, rather than the underlying principles of using inclusive research within a research group or team. This review aimed to understand the areas of health and social care in which inclusive research was being conducted, and without having a specific research project as the focus of each paper, this was not possible to achieve. However, if an empirical paper met our inclusion criteria and the authors had published a separate paper focusing on the methodology of conducting that research project, we included this paper in our review, in order to answer the research questions more fully. This was the case for two methodologically focused papers (Butler et al., 2012) which reported on the methodology of Tuffrey-Wijne (2013) empirical paper, and Turk et al. (2012) methodological paper which reported on the process of conducting Turk et al. (2010) empirical paper.

Electronic databases (AMED, BNI, CINAHL, EMBASE, MedLine, PsychINFO) were searched through Healthcare Databases Advanced Search and Education Research Complete (through EBSCO), and Web of Science on 11 October 2021 and re-run on 14 March 2022 with no new relevant results identified. No search filters were used.

2.2 | Grey literature and registries

The grey literature was initially searched on 18 November 2021, with searches re-run on 14 March 2022, and no new results identified.

Google scholar (https://scholar.google.com/) was searched using the terms (intellectual disability OR learning disability) AND inclusive research. The first 100 results were screened, and no new relevant articles identified.

The British Library EThOS database of dissertations was searched using the terms ('learning disability' OR 'intellectual disability') AND 'inclusive research'. This returned 8 results, none of which met inclusion criteria.

2.3 | Citation searching

Backward and forward citation searching was undertaken on 20 December 2021 (forward citation searching was re-run on 15 March 2022), with no additional studies identified. Reference lists of all included articles were manually screened to identify additional studies. Forward citation searching involved checking each included article on Google Scholar and manually screening all articles citing that paper. Articles included in similar reviews and literature searches (Di Lorito et al., 2018; Jones et al., 2020) were checked and one additional study included (Timmons et al., 2011). For two included studies, a separate paper focusing on the inclusive methodology had been published and was included in this review.

2.4 | Full search strategy

The reproducible searches for all databases are available at [public depository—https://wrap.warwick.ac.uk/160232/] Search strategies
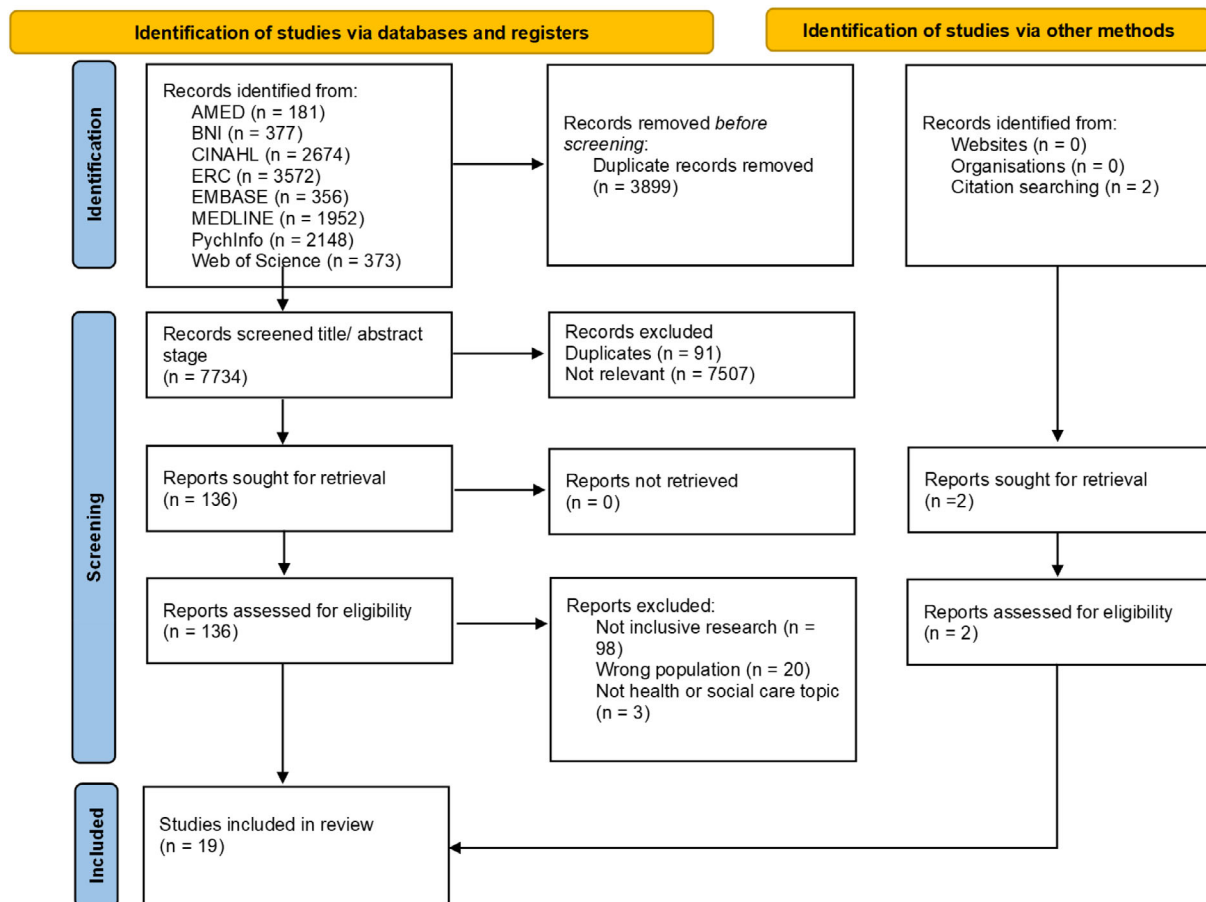
FIGURE 1 Flow chart of study selection

were comprehensive, and included a number of alternative terms and synonyms for inclusive research such as emancipatory research, participatory action research, patient participation, exp* patient participat*and action research. Search terms were peer reviewed by ML and PL, and an experienced librarian. The search is registered with PROSPERO (PROSPERO 2021 CRD42021275031).

2.5 | Selection process

A total of 7734 results were exported into EndNote, 3899 of which were duplicates that were removed using EndNote's duplicate identification strategy. Results were exported to Rayyan for screening, and an additional 91 duplicate results removed. Rayyan is a free, online tool, which can be used to screen and rate papers when conducting systematic reviews. It allows several researchers to complete blind rating of results and then for raters to compare which results they gave the same or different ratings to, thus providing inter-rater reliability scores.

The initial screening of the 7734 titles and/or abstracts of records was conducted by OH, with a random sample of 20% blindly reviewed by an independent second rater (KT) through Rayyan. There was an inter-rater reliability of 96%, $k = 0.82$, with 15 disagreements

discussed and consensus reached on all results through discussion. This included judgements regarding whether the paper focused on a health or social care topic.

Therefore, 136 articles required full text screening, completed using Rayyan. OH read and appraised 100% of texts with the second rated (KT) blindly reading and rating 50% of texts, resulting in an inter-rater agreement level of 94%, $k = 0.84$. Three conflicted decisions were resolved through discussion, and 100% agreement was reached on all studies. Therefore, 19 articles (reporting 17 studies) met the full inclusion criteria (see Figure 1). One paper (Pallisera Diaz et al., 2017) was translated from Spanish by a native Spanish speaker and academic psychologist.

2.6 | Data extraction

Data were extracted to include: (a) study reference and year, recruitment source for researchers with intellectual disability and geographical location of study; (b) health or social care topic investigated; (c) study aim; (d) information about researchers with intellectual disability (number, sex, age, population drawn from); (e) model of inclusive research and methodology; (f) main findings; (g) stages of research in which researchers with intellectual disabilities were involved; and (h) whether

TABLE 1 The 10 key elements for publishing and reporting inclusive research from Frankena et al. (2019) and the indicators used for identifying how these were completed within each paper

Key elements of reporting inclusive research from Frankena et al. (2019)	Indicators used in current review
1. Describe and explain why an inclusive research process was chosen.	1. The paper provides a clear rationale for using an inclusive methodology
2. Describe how decisions were made during the research process, including the level of engagement of team members in these decisions, regarding: recruitment, funding, ethics application, research topic and question, methodology, data collection, data analysis and data dissemination.	2. A description is provided of how decisions were made in the research process 3. Researchers with intellectual disabilities were engaged in decisions regarding recruitment 4. Researchers with intellectual disabilities were engaged in decisions regarding funding 5. Researchers with intellectual disabilities were engaged in decisions regarding ethics application 6. Researchers with intellectual disabilities were engaged in decisions regarding the research topic 7. Researchers with intellectual disabilities were engaged in decisions regarding methodology 8. Researchers with intellectual disabilities were engaged in decisions regarding data collection 9. Researchers with intellectual disabilities were engaged in decisions regarding data analysis
3. Give all team members' reflection on their experiences with inclusive health research, including barriers, benefits, added value, outcomes and lessons learned.	10. Reflections were provided within the paper from all team members including researchers with intellectual disabilities
4. Describe how data were disseminated through non-scientific publications, how the voices of all team members were represented in outputs, and how decisions were made regarding authorship.	11. Researchers with intellectual disabilities were engaged with data dissemination
5. Describe how communication and dialogue were facilitated between team members with and without intellectual disabilities.	12. A description was provided of how communication facilitated between team members
6. Describe how support was provided to all team members involved	13. A description was provided of how support provided to all members
7. Describe the research team and each team member's role.	14. A clear description was provided of the research team and the role of all the team members.
8. Describe how health researchers with intellectual disabilities were financially compensated (and, if not, why not).	15. Researchers with intellectual disability were paid, or a clear explanation of why this did not happen was provided.
9. Describe how modifications were made to the research design and process.	16. A clear description of how the research process was modified was provided.
10. Provide an accessible abstract and report to be distributed among people with intellectual disabilities and service providers	17. An accessible abstract was provided within the paper

the experiences of researchers with intellectual disabilities were included (see Table 2). The data extraction form was piloted by OH and KT on three papers. Data were extracted independently for 100% of articles by OH and 30% of articles by KT. There was an inter-rater reliability of 97%, $k = 0.94$ for data extraction.

Secondly, we developed a further data extraction form based on Frankena et al.'s (2019) 10 key elements for the attributes, potential outcomes and the reporting and publishing of inclusive health research with people with intellectual disabilities. Frankena's criteria were chosen as the evaluative criteria for this review as they are specifically designed for inclusive health research with people with intellectual disabilities, have been recently published (and therefore are relevant to the literature being reviewed), and were developed using a robust methodology. This allowed for the gathering of information, in a standardised manner about how people with intellectual disabilities were involved in inclusive research, including the various tasks and

processes of the research. These 10 elements were broken down into 17 items, and each study was assessed as to whether it met the item (marked 'yes', 'no', or unclear'; see Table 1). Using this framework provided a standardised means of assessing the type and amount of involvement of people with intellectual disabilities both within and across identified studies.

Each study was independently evaluated against these 18 items for 100% of articles by OH and 50% of articles by KT, resulting in an inter-rater agreement level of 94%, $k = 0.87$. All conflicted decisions were resolved through discussion, with 100% agreement reached.

2.7 | Data synthesis

To address research question 1, data was described using the PRISMA statement (Page et al., 2021).

To answer research question 2, a standardised framework specific to inclusive research with people with intellectual disabilities (Frankena et al., 2019) as described above was used to consider the range and type of involvement from people with intellectual disabilities within individual studies, and across the identified literature (see Table 3). Areas where knowledge and evidence were missing were noted, as well as new information and areas of learning.

In addressing research question 3, we employed a deductive approach to thematic synthesis (Thomas & Harden, 2008); see Table 4. Thematic synthesis consists of three stages, that of coding the text, developing descriptive themes and generating analytical themes. All findings, including descriptions and quotes regarding the experiences of researchers (relating to people with intellectual disabilities or other researchers) were coded and then extracted from each paper by OH. Strategies and tools that facilitated and hindered inclusive research were also extracted. Coded data were clustered to form descriptive themes. These themes synthesised the data and organised data into concepts marked by common characteristics across studies. To generate analytic themes, additional analysis was conducted to infer themes not explicitly identified within papers but inferred from the results presented. Both superordinate and subordinate themes were presented to two team members to discuss and refine syntheses. Issues of trustworthiness of the analysis (in terms of the credibility, transferability and dependability) were addressed through various tools including the use of a reflexive diary, a detailed audit trail, grounding themes in verbatim quotes, and iterative discussions with the research team regarding representing and displaying data meaningfully.

3 | RESULTS

The 19 papers (reporting 17 studies) were conducted in six countries, with 59% (n = 10) in the United Kingdom. Other countries included Ireland (n = 2), Spain (n = 2), the United States (n = 2) and Malta (n = 1). The number of researchers with intellectual disabilities per study ranged from 1 to 26.

Researchers with intellectual disabilities were recruited through self-advocacy organisations (n = 5), open advertisement (n = 4), previous collaborations with academic partners (n = 2), independent companies (n = 3) and support services (n = 1).

> Research Question 1: What are the topics, models and methodologies employed in inclusive research with researchers with intellectual disabilities?

Inclusive research addressed a wide range of health and social care topics including promoting physical health (n = 4), social inclusion (n = 4), housing (n = 2), mental health (n = 2), sexuality (n = 1), parenting (n = 1), promoting positive relationships (n = 1), employment (n = 1) and communicating health information (n = 1).

Studies used various terms including inclusive research (n = 10), co-production (n = 1), participatory or participatory action research (n = 2), co-design (n = 1), consumer research (n = 1) and doing research together (n = 1).

Most studies employed a qualitative or mixed methods design. Thirteen studies collected data through interviews (seven structured and six semi-structured), ten used focus groups, three administered questionnaires, one used direct observation, and one employed a randomised controlled trial design. Studies employed one or more than one method of data collection.

> Research Question 2. How are people with intellectual disabilities involved in inclusive research? What are the research tasks and processes they are involved with?

We drew upon Frankena et al.'s (2019) consensus statement for a standardised perspective on the various stages of research in which researchers with intellectual disabilities were included. This encompassed both specific research tasks as well as the processes of research running throughout a project such as working as part of a team. The specific indicators are provided in Table 1.

People with intellectual disabilities were reported to be involved with various stages of inclusive research (see Table 3) such as recruitment (n = 10), applications for funding (n = 2), ethical applications (n = 5), deciding on a research topic (n = 8), making decisions about the methodology (n = 13), data collection (n = 14), data analysis (n = 13) and disseminating findings (n = 14), which included providing an accessible abstract or summary (n = 13). Studies ranged considerably as to how many different tasks involved researchers with intellectual disabilities. Some studies (e.g., Gates et al., 2007) involved researchers with intellectual disabilities in nearly every aspect of the research process, whereas others such as Hughes et al. (2020) and Martin et al. (2021) engaged them in discrete aspects of the research.

Frankena et al.'s (2019) statement also considered the process of conducting research. Most studies (n = 14) gave a clear rationale for using inclusive research. Seven studies did not state how researchers with intellectual disabilities were included in decision making. Reflections from all team members were provided by 11 papers and facilitating communication between team members was described in 12 papers. Thirteen papers described the role of all team members, and how they were supported to engage in inclusive research. Only six papers either stated that people with intellectual disabilities were paid for their work or explained why payment did not happen. Most papers (n = 13) described adaptations to the research methodology to improve accessibility for all researchers. Detailed descriptions of how each of these tasks were specifically conducted were not generally included in these papers, as papers included in this review reported an empirical research project and therefore limitations of space may have prevented this.

> Research question 3: What are the experiences of researchers with and without intellectual disabilities of being involved with inclusive research methodologies?

A deductive approach to thematically synthesising the papers was used (Thomas & Harden, 2008), resulting in seven superordinate themes being identified (see Table 4).

TABLE 2 Data extraction for included studies

Study number	First author (year), recruitment source, geographical location	Health/social care topic	Study aim	Co-researchers with ID (number; sex; age in years; population of co-researchers)	Model of inclusive research; methodology	Main findings	Stages of research where involvement occurred	Does study report views of co-researchers
1	Azzopardi-Lane and Callus (2015); self-advocacy group; Malta	Sexuality	Explore issues related to sexuality and self-advocacy for people with ID.	$N = 7$; 4F 3M; early 20s to late 50s; people with intellectual disabilities	Inclusive research methods; semi-structured focus groups	people with ID are aware of their sexuality and how it is perceived by others. They wish to make concrete changes in how their sexuality is discussed and supported by others.	Compiling questions for the focus groups Data analysis Disseminating results	No
2	Brooks et al. (2013); open advertisement; UK	Mental health	To adapt and psychometrically test the CORE-OM outcome measure questionnaire for people with a learning disability.	$N = 5$; 3F 2M; late 20s and early 50s; people with learning disabilities	Inclusive research; administer questionnaire, make adaptations and test reliability and validity of new measure	Developed and tested 17 item questionnaire that was appropriate and accessible for people with a learning disability to evaluate their experience of receiving psychological interventions	Recruiting participants Administering questionnaire Data analysis	Yes
3	Doherty et al. (2020); self-advocacy group; UK	Promoting physical health	To explore the views and experiences of adults with ID in relation to barriers and facilitators to eating well, living well, and to managing their weight	$N = 2$; NG; NG; People with intellectual disabilities	Co-production; semi-structured focus groups	Themes arose around problems accessing routine caring support; a lack of clear and accessible healthy lifestyle information; unmet training needs for carers and support workers; personal income restrictions; and external barriers such as inaccessible services and the widespread marketing and availability of less healthy foodstuffs.	Co-produce recruitment materials Facilitate focus groups Disseminate results	No
4	Franklin et al. (2021); self-advocacy group; UK	Parenting	To explore the experience of stigma in the lives of parents with a learning disability	$N = 3$; NG; NG; People with learning disabilities	Inclusive research; semi-structured interviews	Thematic analysis generated four key themes; (1) positions of powerlessness; (2) assumptions of incompetence; (3) challenging assumptions and proving competence and (4) claiming power.	Designing the project, data collection, data analysis and dissemination of the research	No
5	Gates et al. (2007); open advertisement; UK	Promoting physical health	To examine the effectiveness of health action plans, and the	$N = 2$; 1F 1M; NG; People with learning disabilities	Consumer research; semi-structured interviews	People enjoyed doing their Health Action Plan (HAP). Not everyone was clear about the purpose of the HAP. Most HAP meetings were good	Deciding on research topic Data collection Data analysis	Yes

(Continues)

TABLE 2 (Continued)

Study number	First author (year), recruitment source, geographical location	Health/social care topic	Study aim	Co-researchers with ID (number; sex; age in years; population of co-researchers)	Model of inclusive research; methodology	Main findings	Stages of research where involvement occurred	Does study report views of co-researchers
						quality with people with learning disabilities being listened to and given time to respond and ask questions.	Disseminating results	
6	Haigh et al. (2013); various services supporting people with learning disabilities; UK	Mental health	To explore what makes people with a learning disability happy and satisfied with their lives ('subjective well-being')	Unclear; NG; NG; People with learning disabilities	Inclusive research; semi structured interviews	Lots of things are important for people with learning disabilities to be happy and satisfied with their lives. We put these things into three themes: 'environmental factors', 'enabling and disabling' and 'personal characteristics'	Deciding research topic, collecting data, data analysis and dissemination	Yes
7	Hughes et al. (2020); people active in disability rights activities; USA	Promoting positive relationships	To develop and test the feasibility of an accessible Interpersonal Violence prevention programme for people with intellectual disability.	N = 6; 4F 2M; NG; People who self-identify as having an intellectual disability	Participatory research; adapting an intervention for people with intellectual disabilities through iterative consultation with co-researchers	Adapted a safety awareness programme to meet the needs of people of all genders with intellectual disability. Conducted a feasibility test to assess the practicality of implementing the programme	Ensure the accessibility of the course content and materials Dissemination of results	No
8	Martin et al. (2021); NG; Ireland	Promoting physical health	To design an education intervention to equip people with intellectual disabilities with information and knowledge to make informed decisions regarding diet and food choices	N = 3; NG; NG; people with intellectual disabilities	Co-design; focus groups and individual interviews including Talking Mats	The development of a teaching module which aligns with inclusion, self-determination and the promotion of healthy behaviours in relation to diet for people with mild or moderate intellectual disability.	Deciding on research topic, adapting educational materials, disseminating results	No
9	Mooney et al. (2019); Building Bridges Training; UK	Social inclusion	To find out more about the barriers that stop people with a learning	N = 8; NG; NG; People who self-identify as having	Inclusive research; focus groups	Themes that limited community access included transport, fear and anxiety, limits on choice	Deciding on research topic, data collection,	Yes

TABLE 2 (Continued)

Study number	First author (year), recruitment source, geographical location	Health/social care topic	Study aim	Co-researchers with ID (number; sex; age in years; population of co-researchers)	Model of inclusive research; methodology	Main findings	Stages of research where involvement occurred	Does study report views of co-researchers
			disability being more involved in the community	a learning disability		and control, risks and personal safety.	data analysis and writing up results	
10	Pallisera Diaz et al. (2017); previous collaboration with academic partners; Spain	Housing	To understand where people with ID want to live and who they want to live with.	NG; NG; NG; people with intellectual disabilities	Inclusive research; focus groups, photovoice activity	Identified the barriers and supports to people with ID living independently. Also identified a number of proposals for improving the independent living situation for people with ID	Data collection Data analysis dissemination	Yes
11	Rojas-Pernia et al. (2020); self-advocacy service; Spain	Social inclusion	To investigate the experiences of loneliness and social isolation in people with and without intellectual disabilities.	N = 8; NG; 19–26; people with intellectual disabilities	inclusive research; semi-structured interviews	Social relationships are important for young people both with and without learning disabilities. A person may want or need to be alone, but nobody wants to feel lonely	Deciding on research topic, conducting interviews, data analysis, dissemination	Yes
12	Salmon et al. (2019); Inclusive Research Network; Ireland	Housing	To explore the experiences of people with intellectual disabilities in Ireland when moving home using an inclusive research approach	N = 26; NG; NG; people with intellectual disabilities	inclusive research, collaboratively designed; structured interviews	Thematic analysis yielded four themes: 'expressing choice' in the moving process; 'feeling connected or isolated when moving'; 'accessing supports during and after the move'; and finally, participants' reflections on 'experiencing vulnerability and feeling safe' while resetting.	identify research, plan and conduct interviews, data analysis, writing results	No
13	Tilly (2012); Building Bridges Training; UK	Social inclusion	To identify the barriers in the lives of people with a learning disability that make life difficult for us and people like us	N = 11; NG; NG; People who self-identify as having a learning disability	inclusive research using action research approach; focus groups, interviews	Main findings were around coping day to day and support, poverty, friends and social networks and losing our children	Deciding research topic, being research participants, disseminating results	Yes
14	Timmons et al. (2011); open	Employment	To identify factors that shape the employment-	N = 1; NG; NG; people who self-identify as	participatory action research; semi-	Factors influencing employment-related decision-making include: The family in the	Ensuring accessibility of research	No

(Continues)

TABLE 2 (Continued)

Study number	First author (year), recruitment source, geographical location	Health/social care topic	Study aim	Co-researchers with ID (number; sex; age in years; population of co-researchers)	Model of inclusive research; methodology	Main findings	Stages of research where involvement occurred	Does study report views of co-researchers
	advertisement; USA		related decisions of individuals with Intellectual and/or Developmental Disabilities (ID/DD).	someone with ID/DD	structured interviews	formative years, school-based staff and early employment experiences, the culture of the Community Rehabilitation Providers, the job developer, and personal preferences	materials, co-conducting interviews, data analysis	
15	Tuffrey-Wijne (2013) (empirical paper); Butler et al. (2012) (methodological paper); recruited through previous contact with university researchers; UK	Communicating health information	To explore how to break bad news to people with intellectual disabilities	N = 2; 1F 1M; NG; people with intellectual disability	Doing research together; focus groups, interviews	Ten guiding questions developed to help people think about how best to break bad news of a significant diagnosis to someone with ID	Conducted focus groups, data analysis, writing results	Yes
16	Turk et al. (2010) (empirical paper); Turk et al. (2012) (methodological paper); open advert; UK	Promoting physical health	To evaluate the implementation of a personal health record for people with ID	N = 4; NG; NG; people with intellectual disability	Inclusive design; Randomised Controlled Trial, interviews, checklists	The intervention did not increase attendance at GPs or other health care services.	Devising, piloting and administering the research interview, administer research instruments, data coding	Yes
17	Watchman et al. (2021); NG; UK	Social inclusion	To identify effectiveness of psychosocial interventions in social care settings for people with ID and dementia	N = 5; NG; NG; People with an intellectual disability	inclusive research (participatory action research); mixed methods design; semi-structured interviews, longitudinal and cross-sectional surveys and structured observations	Seventy-four percent of individual goals met or exceeded expectations with reduction in some 'as required' medication. Qualitative findings include themes of enabling care and interventions as tools for practice. Photovoice provided insight into previously unreported fears about dementia	Grant application Data collection Data analysis Disseminating findings	No

TABLE 3 How different studies met standards in inclusive research

Study number	Author (date)	Rationale for inclusive method	Describe how decisions made	Engaged in recruitment	Engaged in funding	Engaged with ethics application	Engaged with research topic	Engaged with methodology	Engaged with data collection	Engaged with data analysis	Engaged with data dissemination	Reflections form all members	Communication facilitated between team members	Support provided to all members	Describe members role	People with ID paid	Amendments to research process	Accessible abstract
1	Azzopardi-Lane and Callus (2015)	Unclear	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	No	No	No	Unclear	No	Yes	Yes
2	Brooks et al. (2013)	Yes	Unclear	Yes	No	No	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Unclear	No	Yes	Yes
3	Doherty et al. (2020)	Yes	Unclear	Yes	No	Yes	Unclear	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes
4	Franklin et al. (2021)	Yes	No	No	No	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	No
5	Gates et al. (2007)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6	Haigh et al. (2013)	Unclear	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
7	Hughes et al. (2020)	Yes	Yes	No	No	No	No	Yes	No	No	No	No	No	No	Yes	No	No	No
8	Martin et al. (2021)	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	No	No	No	Yes	No	Yes	Yes
9	Mooney et al. (2019)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
10	Pallisera Diaz et al. (2017)	Yes	No	Unclear	No	No	No	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes
11	Rojas-Pernia et al. (2020)	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
12	Salmon et al. (2019)	Unclear	Yes	Yes	No	Unclear	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
13	Tilley (2020)	Yes	No	Yes	Unclear	Unclear	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
14	Timmons et al. (2011)	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Unclear	No	No	No	Yes	Yes	No	No	No
15	Tuffrey-Wijne (2013) (empirical paper); Butler et al. (2012) (methodological paper)	Yes	Yes	No	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
16	Turk et al. (2010) (empirical paper); Turk et al. (2012) (methodological paper)	Yes	Yes	No	No	Unclear	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No

(Continues)

TABLE 3 (Continued)

Study number	Author (date)	Rationale for inclusive method	Describe how decisions made	Engaged in recruitment	Engaged in funding	Engaged with ethics application	Engaged with research topic	Engaged with methodology	Engaged with data collection	Engaged with data analysis	Engaged with data dissemination	Reflections form all members	Communication facilitated between team members	Support provided to all members	Describe members role	People with ID paid	Amendments to research process	Accessible abstract
17	Watchman et al. (2021)	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	No	No	No	No	No	No	Yes
	Total number of studies meeting this criterion	14	12	9	2	5	8	13	14	13	14	11	12	12	13	6	13	13

Experiences of both researchers with intellectual disabilities and other research team members regarding conducting inclusive research were reported. Facilitators and barriers to the methodology were identified. Themes related to the ethical justification for inclusive research, the additional resources required to undertake inclusive research, practical aspects of making such research accessible, and wider, indirect effects of undertaking inclusive research.

> Theme 1: Negotiating who's responsible for the research and how we share power

3.1 | Understanding who directs and holds power in the research

Projects that involved researchers with intellectual disabilities in decision-making from the design stage (e.g., Mooney et al., 2019) enabled them to hold power. Responding to the input from researchers with intellectual disabilities encouraged them to lead in decision making. Researchers with intellectual disabilities needed to be empowered to negotiate with and challenge colleagues, which was facilitated through involving self-advocacy organisations.

3.2 | The ethical argument for people with intellectual disabilities holding control and power in the research

Most papers identified that people with intellectual disabilities should hold more power because of 'how important it is to have people with learning disabilities involved in studies right from the start, because it means that the studies really matter to them' (Researcher without intellectual disability; Butler et al., 2012). Such research can directly impact their lives in a way that was different from academics.

3.3 | Agreeing that research is jointly owned

Stakeholders viewed the research as a joint endeavour, with 'the active and collaborative participation of everyone involved' (Researcher without intellectual disability; Pallisera Diaz et al., 2017). Most papers endorsed joint ownership, and saw this as a separate from research expertise: 'We think it is important for people to research together. We believe that everybody has different skills that they bring to research whether or not they have a learning disability. These skills are different, but all are important'. (Haigh et al., 2013).

At times researchers without intellectual disabilities struggled not to take over the research and understand how much guidance and support they should be providing. Awareness of the power imbalance between researchers with and without intellectual disabilities was important.

> Theme 2: Conducting research is a meaningful experience, even when it's boring

TABLE 4 Thematic synthesis of studies

Superordinate theme	Subordinate themes	Example of supportive quote and reference	Number of studies endorsing theme
1. Negotiating who's responsible for the research and how we share power	Understanding who directs and holds power in the research	'It is important to have someone who knows about research to keep things on track, but it is also important to remember the research belongs to everyone'. (Haigh et al., 2013)	13
	The ethical argument for people with intellectual disabilities holding control and power in the research	'We are proud of our reports—and we are proud that we got awarded a lottery grant! This made us feel what we had to say was important'. (Tilly, 2012)	11
	Agreeing that research is jointly owned	'We have enjoyed doing the research together'. (Butler et al., 2012)	14
2. Conducting research is a meaningful experience, even when it's boring	Engaging in research is enjoyable	'It was very exciting to be part of such an innovative research process'. (Turk et al., 2012)	14
	Aspects of research can be challenging	'Research can be boring and hard work sometimes'. (Haigh et al., 2013)	16
	Acknowledging the added value of inclusive research	'The study entailed collaboration between the lead researcher and adults with intellectual disabilities to generate new knowledge that neither could produce alone'. (Doherty et al., 2020)	16
3. It helps to be able to work as a team	Good collaborative working is essential	'We really enjoyed working as part of a team and we think it is really important for people with and without a learning disability to work together in research'. (Haigh et al., 2013)	16
	Being clear about everyone's roles is helpful	'The combination of expertise and respectful partnership between people with intellectual disability, service providers and academia resulted in an educational initiative that met student's needs'. (Martin et al., 2021)	16
	Understanding how we work with the wider project team	'For example, instead of having to completely rewrite an evaluation question that [we] had agreed upon, a NAB member [with intellectual disability] offered a slight change in wording'. (Hughes et al., 2020)	13
	Everyone is equal	'We think it is important to remember that people have different skills but equal value'. (Haigh et al., 2013)	13
4. Inclusive research requires additional resources	Developing and practicing new research skills	'As academic researchers we have acquired new skills related to listening to collaborators with disabilities, to the organization and presentation of the information in an accessible way and to the continuous adaptation of research activities to a dynamic that favors the active and collaborative participation of everyone involved'. (Pallisera Diaz et al., 2017) 'Our researchers with learning disabilities have been trained "on the job." We are learning by trial and error. This has worked alright so far, but it would be wonderful to be able to offer formal research training and a qualification to people with learning disabilities interested in becoming researchers'. (Butler et al., 2012)	17
	Additional practical support is essential	'All researchers were employed for short research days to facilitate access to off peak transport, help researchers with ID and carer researchers overcome the problem of salaries resulting in benefits being lost, and reduce tiredness and overload'. (Turk et al., 2012)	16
	Additional emotional support is needed	'Before we started, we thought about what might happen if people told us about things that were sad or difficult to hear, but it is not always easy to prepare for how you are going to feel when this happens'. (Haigh et al., 2013)	14
	Inclusive research requires time	'Getting groups together was much more difficult than we thought... One of them took a whole year to negotiate and set up'. (Butler et al., 2012)	16

TABLE 4 (Continued)

Superordinate theme	Subordinate themes	Example of supportive quote and reference	Number of studies endorsing theme
	Inclusive research requires additional finances	'The funding provided inbuilt flexibility to facilitate the creative solutions sometimes needed to overcome hurdles that occurred during the research period'. (Turk et al., 2012)	16
5. How can inclusive research be made accessible?	We need to use multiple strategies to improve the accessibility of the research process for everyone	'The main challenge that had to be addressed in a design including adults with ID as researchers, was to ensure all elements were ethical and non-exploitative, e.g. the potential researchers had to be able to understand the research, and the tasks had to be reasonable and realistic for someone with ID to complete'. (Turk et al., 2012)	17
	There must be flexibility in our research methodologies to improve accessibility	'Flexible. Each group had different needs and wishes. One group wanted Irene to explain facts about cancer, so she prepared a slide show for this. One group wanted more pictures and stories to think about. One group wanted more time to talk about their experiences. We also included some role-play'. (Butler et al., 2012)	16
6. Where does inclusive research fit into wider project timeframes?	Thinking about endings from the beginning	'Help was built in from the beginning to prepare the researchers for the eventual end of the project, e.g., personal development plans, writing curriculum vitae'. (Turk et al., 2012)	9
	Inclusive research should be built in from the beginning of the project	'We developed a research project with the group and asked our local NHS research network for money for this. They agreed but first we had to get ethical approval from the local ethics committee (LREC). This took quite a while to do, as we had to fill in a long form, much of which was not relevant to this kind of research'. (Gates et al., 2007)	8
	The need for longer term collaborations	'Policy shift is required to provide resources on an ongoing basis to support meaningful longer-term engagement with wider reach'. (Watchman et al., 2021)	9
7. Through involvement in inclusive research, people experience additional benefits.	We made new relationships	'Opportunities to connect with peers in a supportive environment, can contribute to the ongoing social development and inclusion of people with intellectual disability'. (Hughes et al., 2020)	12
	We feel more confident	'[Researchers with intellectual disabilities] found participation in the research useful for them to learn more about society, to have greater confidence in a group setting, to learn important things about the future and to improve their self-esteem as their opinions are valued…We (as academics) have learned to design and implement accessible information, facilitating strategies that we can extrapolate to teaching and other research activities'. (Pallisera Diaz et al., 2017)	11
	Becoming agents of change	'Some members raised concerns impacting the intellectual disability community, ranging from perceptions about their intellectual capacities, and discriminatory language, gestures, and other behaviors'. (Hughes et al., 2020) '[The research] allowed the project to progress its broader aims to reduce societal stigma and increase progressive attitudes towards the parenting rights of people with learning disabilities'. (Franklin et al., 2021)	14

3.4 | Engaging in research is enjoyable

Most studies described inclusive research as enjoyable and meaningful. Those with intellectual disabilities liked their role in disseminating results: 'People were really interested in our ideas. It showed on their faces how interested they were… I felt valued for what I did… Its'

good to tell people what I've been part of and what I've been doing (because) we are doing a good job and it's important to help people' (Researcher with intellectual disability; Brooks et al., 2013). Academic partners found it 'very exciting to be part of such an innovative research process' (Researcher without intellectual disability; Turk et al., 2012).

3.5 | Aspects of research can be challenging

The difficulties with inclusive research were acknowledged in nearly every study, with researchers stating: 'All found some parts of the research process hard' (Researcher without intellectual disability; Turk et al., 2012). Including researchers with intellectual disabilities was difficult regarding applying for funding (only two papers described this), ethical approval (six studies) and paying researchers (eight studies). Having lots of researchers with intellectual disabilities led to issues with consistency around data collection (Salmon et al., 2019).

3.6 | Acknowledging the added value of inclusive research

Researchers with intellectual disability and other stakeholders both described the additional benefit of using inclusive methodologies in all studies. The lived experiences of people with intellectual disabilities was perceived to improve research: We can contribute many things from our own experience… If they are talking about disability, what better teachers than ourselves? (Researcher with intellectual disability; Pallisera Diaz et al., 2017). Academics described inclusive research as 'generat[ing] new knowledge that neither could produce alone' (Researcher with intellectual disability; Doherty et al., 2020). However, as only 12 studies included direct reflections from all team members, the voice of researchers with intellectual disabilities was not always present.

> Theme 3: It helps to be able to work as a team

3.7 | Good collaborative working is essential

Developing and maintaining collaborative relationships was key for researchers with intellectual disabilities 'The most important thing is to build good relationships with the people you are researching with' (Haigh et al., 2013) and for stakeholders without intellectual disabilities in almost every study. Build trusting, respectful relationships, required time together both informally (e.g., shared lunches) and in research meetings, and a team ethos that included humour and camaraderie. Enthusiasm from all team members around using an inclusive methodology was essential. Participants reported that setting ground rules facilitated open and honest discussions, with 14 studies addressing communication between all team members. Some researchers felt that building on existing working relationships with researchers with intellectual disabilities facilitated this process, as team members already knew each other well.

Barriers to team working included interpersonal difficulties between team members, and a need for awareness and reflection around interpersonal dynamics.

3.8 | Being clear about everyone's roles is helpful

The importance of clearly defined roles within the research team was stated in nearly every study, for researchers with intellectual disabilities '[We] have collectively built a new role as researchers' (Pallisera Diaz et al., 2017), academics without intellectual disabilities 'There is a need for clarity and a division of roles' (Brooks et al., 2013), and participants with intellectual disabilities 'Everyone had their specific role in the focus groups, and that was really good. It was clear to each of us what we were there for, and I think it was clear to the participants as well. That really helped' (Butler et al., 2012).

3.9 | Understanding how we work with the wider project team

Having a wider project advisory or reference group which also contained people with intellectual disabilities could be helpful. It provided overview or steering in case of disagreements or uncertainty and was especially useful for larger projects recruiting across multiple sites. For example, Hughes et al. (2020) worked with six researchers with intellectual disabilities at a local level, and in addition convened a National Advisory Board (NAB). The NAB included three researchers with intellectual disability and was responsible for overall guidance and monitoring of the project.

3.10 | Everyone is equal

The idea that all researchers should be seen as equally valued team members was strongly endorsed by both researchers with intellectual disabilities and stakeholders without intellectual disabilities in three quarters of studies. Whilst genuine collaboration can improve the quality of academic research, disagreements needed to be discussed with everyone having an equal voice 'there were times when we [academics without intellectual disabilities] struggled not to take over' (Brooks et al., 2013). Recognising researchers with intellectual disabilities as colleagues of equal value involved 'listening, knowing, negotiating, arguing, addressing and finding new ways to be together' (Researcher without intellectual disability; Rojas-Pernia et al., 2020). Academic researchers sharing their vulnerabilities and listening to and being willing to learn from colleagues with intellectual disabilities was important.

> Theme 4: Inclusive research requires additional resources

The additional resources required for inclusive research was acknowledged by all research teams.

3.11 | Developing and practicing new research skills

The resources needed for people with intellectual disabilities to develop their research skills was identified as an issue by almost all papers. These included appropriate research training, and support to practice skills with colleagues. Eight papers described providing

training in the specific research skills and methodologies required for the research project being undertaken, whilst five discussed providing more generic research skills to co-researchers with intellectual disabilities. Engagement with research training was enhanced through practical tasks, workshops and exercises. Working together on research tasks helped all researchers develop skills. Researchers with intellectual disabilities focused on practical aspects of research: 'We also learned some practical things about research. Some of us felt nervous before we interviewed people, so it was helpful to have some water to drink' (Haigh et al., 2013). Academic partners developed new skills: 'We (as academics without intellectual disabilities) have learned to design and implement accessible information, facilitating strategies that we can extrapolate to teaching and other research activities' (Pallisera Diaz et al., 2017).

3.12 | Additional practical support is essential

Researchers with intellectual disabilities required additional support: 'The consumer researchers need support from the main researcher and steering group with liaising with key workers and support staff at home and at the day centre, travel training, accompanying the consumer researchers to various locations, sorting out travel arrangements, help with the management of their diaries and support with benefit issues' (Researcher without intellectual disability; Gates et al., 2007). Teams used support workers, personal assistants, research and writing mentors to support researchers with intellectual disabilities with various tasks, including travelling to research meetings and collecting data. Working flexible hours helped reduce fatigue for all researchers. Several papers mentioned that payments could impact on researcher's benefits and negotiating contracts with universities could be complex.

3.13 | Additional emotional support is needed

Three quarters of teams considered managing the emotional toll of conducting research into difficult topics, through talking about difficult feelings, agreeing ground rules and getting additional support (e.g., Mooney et al., 2019). Protecting researchers with intellectual disabilities by excluding them from emotionally sensitive topics was discouraged: 'No subject is too difficult for people with learning disabilities to think and talk about' (Butler et al., 2012). Instead, acknowledging difficult feelings and accepting the complexity of research was valued.

Even with careful consideration of extra support, challenges arose: 'There is...an understanding that this process requires a lot of time, a lot of commitment and a lot of care. And even with all of this, inclusiveness can slip!' (Brooks et al., 2013).

3.14 | Inclusive research requires time

This subtheme was acknowledged almost universally by academic partners concerned about how long processes took: 'It would have

been cheaper and easier to employ paid professional researchers to carry out the research'. (Researcher without intellectual disability; Turk et al., 2012). Additional time was needed across projects, as well as during specific stages (e.g., training, data analysis). Time spent initially forming cohesive teams was well invested, as was ensuring researchers with intellectual disabilities understood the research.

Stakeholders acknowledged the additional benefits of inclusive methodologies 'All those involved believe the benefits outweighed the costs in terms of the richness of the experience and the outcomes obtained' (Researcher without intellectual disability; Turk et al., 2012).

3.15 | Inclusive research requires additional finances

Almost all studies noted that additional finances are required: 'This costs money! You need to have enough money in your budget to pay for extra time and for support workers to assist the researchers if necessary' (Butler et al., 2012).

Accessing appropriate funding for inclusive research could be challenging, both in terms of having input from researchers with intellectual disabilities at the beginning of a project (before funding is secured) and accessing funding for specific tasks (e.g., writing papers and disseminating results).

> Theme 5: How can inclusive research be made accessible?

3.16 | We need to use multiple strategies to improve the accessibility of the research process for everyone

This was identified as an important theme by all researchers, both in making the methodology accessible for team members and presenting findings appropriately: 'Sometimes it is hard to write research in a way that makes sense and is useful to everybody' (Haigh et al., 2013). Stakeholders described how, working closely with researchers with intellectual disabilities, they: 'Acquired new skills around the organization and presentation of the information in an accessible way' (Researcher without intellectual disability; Pallisera Diaz et al., 2017). Fifteen papers provided an accessible abstract.

Presenting data in multiple formats (e.g., combining picture cards, with information being read out and simultaneously presented in large type) was helpful. Using diagrams, photographs and sticky notes allowed data to be manipulated more easily. Shifting from predominantly verbal discussions to activity-based exercises was helpful. The pace of meetings needed to be suitable for everyone, although working at a slower pace could be frustrating. Meetings could require additional preparation to ensure accessibility. Using existing meetings and groups ensured accessibility of locations. Having academic researchers experienced in working with people with intellectual disabilities was helpful. Obtaining meaningful feedback from researchers

with intellectual disabilities required skilled colleagues. Several teams wanted to present their research using plain English, but found this hard, especially in academic papers. Ensuring all aspects of the project were conducted to the highest ethical standards, meant that researchers with intellectual disabilities understood all tasks and such tasks were reasonable. Four papers would have liked to include people with moderate or severe intellectual disabilities but were unsure how to do this. Two papers identified that researchers with intellectual disabilities felt uncomfortable asking intimate questions of participants.

3.17 | There must be flexibility in our research methodologies to improve accessibility

Most studies engaged researchers with intellectual disabilities in the methodology, and 13 described amendments to the project. Allowing individuals to focus on their skills, rather than expecting all researchers to undertake all tasks, was helpful for some teams, whilst others initially planned for team member to undertake specific roles, but later found collaborative working a more effective strategy. Some studies found data collection strategies were less successful than anticipated and needed amending. Being adaptable was seen as key inclusive research, as endorsed by almost all studies. It generated new thinking and ideas and made the research accessible to all.

> Theme 6: Where does inclusive research fit into wider project timeframes?

3.18 | Thinking about endings from the beginning

Over half of studies planned for the ending of the project when commencing the research, which managed the team's expectations. Visually representing tasks and progress helped the team to prioritise. Researchers with intellectual disabilities were meaningfully involved disseminating results through training, conference presentations, making films and writing papers. Thinking about how researchers may wish to continue and develop their research skills, and other transferable skills were included in this theme.

3.19 | Inclusive research should be built in from the beginning of the project

Early involvement by researchers with intellectual disabilities ensured they found projects meaningful, important and interesting, and was considered in half of papers. However, obtaining funding often required a developed project plan, leaving researchers with intellectual disabilities unpaid during early stages of the research. This inability to pay researchers with intellectual disabilities during the planning stages of the project could be seen as unethical. Similarly, ethical

approval requires significant work and planning which could hinder the involvement of researchers with intellectual disabilities in the early stages.

3.20 | The need for longer term collaborations

The need for more, longer-term inclusive research was noted by over half of studies. 'We think we need to do more research with other people with a learning disability to see whether they agree with the barriers that we have identified' (Mooney et al., 2019). Researchers with and without intellectual disabilities working together over several projects develop closer working relationships. The difficulty in a project team critiquing their own work was noted and was circumvented by liaising with other inclusive research teams.

> Theme 7: Through involvement in inclusive research, people experience additional benefits

3.21 | We made new relationships

This was endorsed by three quarters of papers. Researchers with intellectual disabilities found developing and rediscovering relationships valuable 'It has been good to get to know some people again that we knew from the past ...we have been able to get "peer support" from each other' (Tilly, 2012). Academics and other stakeholders valued new relationships both personally and professionally 'We have made new friends and significantly enriched the reality of the people with whom we work and research' (Researcher without intellectual disability; Pallisera Diaz et al., 2017).

3.22 | We feel more confident

Fourteen papers endorsed this theme. Whilst some stakeholders felt more confident presenting information in accessible formats, this theme was widely endorsed by researchers with intellectual disabilities: 'It has made us more confident and able to stand up for ourselves more. Now, we know we do not have to put up with things as they are, but we can challenge them' (Tilly, 2012).

3.23 | Becoming agents of change

This was identified in 16 papers, as 'self-advocates sought to use this research to bring about concrete change in their lives' (Researcher without intellectual disability; Azzopardi-Lane & Callus, 2015). Stakeholders and academic partners became more active in promoting the rights of colleagues with intellectual disabilities 'one of the CAB members set up a web-based site to help secure funding to attend and co-present with the researchers at a national disability conference'

(Researcher without intellectual disability; Hughes et al., 2020), whilst researchers with intellectual disabilities described various activities including holding a 'meeting with the MP for our area' (Tilly, 2012), collaborating with other academic institutions and disseminating research in accessible and meaningful ways: 'We wanted the research to be accessible to as many people as possible and so we decided to make a film as well' (Haigh et al., 2013). Inclusive research 'allowed the project to progress its broader aims to reduce societal stigma' (Researcher without intellectual disability; Franklin et al., 2021), engendering change at a different level.

4 | DISCUSSION

This review had three aims: to understand the range of health and social care topics being researched using inclusive research methodologies internationally, and the methodologies employed to do this; to describe how researchers with intellectual disabilities are involved in inclusive research; and to synthesis the experiences of researchers with and without intellectual disabilities.

The topics being researched using inclusive research within health and social care were disparate and included addressing physical and mental health issues, and understanding social issues including social exclusion, employment and housing. This demonstrates the breadth of areas across which inclusive research can usefully be employed, specifically in relation to areas of health and social care in which people with intellectual disability continue to experience high levels of inequality.

Studies employed various methodologies, with qualitative methodologies dominating. Also included were some quantitative, larger scale and multisite studies, which provide helpful examples of how such research projects can employ inclusive methodologies.

Inclusive research is being increasingly conducted and reported, both in the United Kingdom and internationally. Of the 17 papers included in this review, eight have been published within the last 5 years. Inclusive research methods are being championed by funding bodies (e.g., NIHR), and more widely used and taught, meaning this approach has the potential to increasingly influence and improve various research methodologies within the intellectual disability field over the coming years.

The ways in which researchers with intellectual disabilities were involved in studies varied, with some studies involving researchers with intellectual disabilities throughout the research process and others focusing on discrete tasks. This review focused on understanding to what extent researchers with intellectual disabilities were involved in the different tasks as well as the process of inclusive research. Understanding the quality of inclusive research is complex, as this is intrinsically tied to the nature of the research study itself, and therefore cannot be measured simply by the number of research tasks and processes involving researchers with intellectual disabilities. Our use of a consensus statement (Frankena et al., 2019) allowed for these areas to be systematically compared between and across studies, and therefore the extent to which each study met the key

elements of inclusive research could be rated. However, the lack of detailed information provided in papers as to exactly how each key element was met (e.g., specifying in which phases of the research people with intellectual disabilities made decisions, describing exactly how communication was facilitated between team members, etc.) meant that it was not possible to provide a detailed overall image of the predominant methods and strategies involved in inclusive research.

Recruiting co-researchers from diverse backgrounds using open advertisement occurred for only four studies in this review. Academic researchers reported that working with existing collaborators with intellectual disabilities facilitated the process because good working relationships had been established. Involving self-advocacy groups was suggested as a means of empowering researchers with intellectual disabilities to challenge academic partners. However, such approaches risk involvement being confined to a subsection of researchers with intellectual disabilities, who no longer hold the position of 'outsider'. Whether this is an issue depends on whether researchers with intellectual disabilities are seen as representing the experiences of people with intellectual disabilities broadly or contributing their own individual skills (Chinn & Pelletier, 2020).

In line with this study, the range of terms falling under 'inclusive research' were highlighted by Jones et al. (2020) although with the publication of Frankena et al.'s (2019) standards this may become less heterogenous in future. Jones et al. (2020) helpfully consider to what extent studies comply with their aims of inclusive research, and found intentions were largely congruent with processes described in the articles.

Contrasting this review with Di Lorito et al. (2018) allowed for recent trends in inclusive research to be identified. Both reviews reported wide variability in the extent of involvement from researchers with intellectual disabilities. They both found that the additional costs of an inclusive research methodology acted as a barrier to the methodology. Both reviews identified appropriate research training, clarity of research roles, and the need for flexibility and planning to make methodologies accessible. The multiple benefits for researchers with intellectual disabilities, academic partners and research participants were highlighted by both reviews. However, whilst Di Lorito et al. (2018) found that data analysis was an area in which researchers with intellectual disabilities were less likely to be involved, this was clearly described in 13 of the studies in this review, including quantitative studies. Di Lorito et al. (2018) identified long-term impact and change as being missing from studies, while this review found meaningful change being reported both in terms of the impact of accessible dissemination of results, and personal change in 13 studies.

Most papers provided insights into how researchers with and without intellectual disabilities experienced conducting the research. However, the way in which some papers were written meant it was not possible to understand whether the experiences reported were those of researchers with intellectual disabilities or of the overall project team. Difficulties in hearing the voices of co-researchers with intellectual disabilities have been highlighted previously (Strnadová &

Walmsley, 2018). Guidelines for the reporting of, among other items, the distinct experiences and reflections of researchers with intellectual disabilities did not appear to have been used effectively by the papers in this review.

The complexity of conducting research was illustrated frequently in themes in which differing aspects of lived experiences arose, such as in Theme 2 whereby inclusive research was described as both enjoyable (by 14 studies) and challenging (16 studies). Experiences were not universally challenging or enjoyable, but rather experienced as both of these at different times or indeed simultaneously. Honest appraisals of the experiences of conducting research are important, allowing inclusive researchers to make informed decisions about joining research teams.

The time required to undertake good quality inclusive research was raised by 16 papers. There can be a tendency for academic researchers to see inclusive research as requiring 'additional' time to more traditional research methodologies. However, it may be more helpful to consider that inclusive research takes time, and that sufficient time must be devoted to it, rather than seeing this as a burden when compared to how long other research methodologies may take.

A strong theme of the ethical argument for people with intellectual disabilities controlling research was found in the current review. Di Lorito et al. (2018) found a change in culture was needed to ensure researchers with intellectual disabilities were involved in an ethical manner. The increased use of inclusive methodologies means ethics boards are becoming better able to understand the need for involvement from beginning of projects. Ethical practice dictates that people with intellectual disabilities should be involved throughout research, although ensuring ethical integrity requires careful consideration (McDonald & Kidney, 2012).

4.1 | Limitations of review

Inclusive methodologies have been used in studies regarding service development and implementation, and in co-producing interventions, and may be examples of good practice within services. However, the focus of this review was on empirical, inclusive research studies which are less common, and did not include methodological papers describing inclusive research. The tension between producing sufficiently detailed descriptions of the inclusive research methodology and the limitations of space when reporting an empirical study led to two studies having been described in two separate papers (one empirical and one methodological) as to exclude either would reduce our ability to answer the research questions.

In line with previous reviews (e.g., Di Lorito et al., 2018; Jones et al., 2020) studies in this review focused on people with borderline to mild intellectual disabilities. Those with severe or profound intellectual disabilities were not included as co-researchers, although they were involved as research participants (e.g., Watchman et al., 2021), and their families and professionals were also included to keep their voice in mind (e.g., Tuffrey-Wijne, 2013). How people with profound

and severe intellectual disabilities can be involved in research *for*, rather than *with*, them (Nind, 2013), and how this relates to inclusive research needs revisiting.

Di Lorito et al. (2018) identified a source of reporting bias, in that the direct experiences of researchers with intellectual disabilities were not reported separately from the wider researcher team, meaning the reader cannot be sure that the views contained within the paper represented the specific experiences of such researchers. This was also found in the current review, with 11 papers failing to report such experiences separately. Frankena et al.'s (2019) statement that reflections from all team members should be included in the write up of the study will hopefully improve this.

4.2 | Future directions

Whilst conducting inclusive research is important, it is equally important to reflect on and evaluate this work to allow greater impact of future inclusive research (Chinn & Pelletier, 2020).

Understanding exactly what has happened in inclusive research projects is essential, both in terms of the scope of inclusive researchers, and evaluating the quality of the research.

The need for appropriate research training for co-researchers with intellectual disabilities was highlighted by a number of authors, despite it not being a specific focus of this review. Having a standardised programme available (e.g., Tuffrey-Wijne et al., 2020) would reduce the burden of having to develop and deliver this through individual research teams. However, this idea requires careful consideration, due to both the variable experiences and abilities of researchers with intellectual disabilities, and the differing roles undertaken by these researchers. The appropriateness of a standardised training programme has been considered elsewhere (e.g., Walmsley et al., 2018).

That inclusive research is challenging is undisputed, but that it adds value to both the quality of research and for individuals involved in the process is also understood (Walmsley et al., 2018). The challenge is for authors to consistently capture both the impact of this added value within the literature, and the difference it makes to the lives of people with intellectual disabilities (Strnadová & Cumming, 2014).

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

700 | WILEY JARID Journal of Applied Research in Intellectual Disabilities Published for the British Institute of Learning Disabilities

HEWITT ET AL.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in Warwick Research Archive Portal at https://wrap.warwick.ac.uk/160232.

ORCID

Olivia Hewitt https://orcid.org/0000-0002-6393-2388
Peter E. Langdon https://orcid.org/0000-0002-7745-1825

REFERENCES

Abma, T. A., Nierse, C. J., & Widdershoven, G. A. (2009). Patients as partners in responsive research: Methodological notions for collaborations in mixed research teams. *Qualitative Health Research*, 19(3), 401–415.

Alliance for Health Policy and Systems Research. (2022). Systems for health: everyone has a role. https://ahpsr.who.int/publications/i/item/systems-for-health-everyone-has-a-role

Azzopardi-Lane, C., & Callus, A. M. (2015). Constructing sexual identities: People with intellectual disability talking about sexuality. *British Journal of Learning Disabilities*, 43(1), 32–37.

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3–12.

Brooks, M., Davies, S., & Twigg, E. (2013). A measure for feelings–using inclusive research to develop a tool for evaluating psychological therapy (C linical O utcomes in R outine E valuation–learning disability). *British Journal of Learning Disabilities*, 41(4), 320–329.

Butler, G., Cresswell, A., Giatras, N., & Tuffrey-Wijne, I. (2012). Doing it together (DM special issue). *British Journal of Learning Disabilities*, 40(2), 134–142.

Chinn, D., & Pelletier, C. (2020). Deconstructing the co-production ideal: Dilemmas of knowledge and representation in a co-design project with people with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, 45(4), 326–336.

Cho, S. M., Park, C. U., & Song, M. (2020). The evolution of social health research topics: A data-driven analysis. *Social Science & Medicine*, 265, 113299.

Di Lorito, C., Bosco, A., Birt, L., & Hassiotis, A. (2018). Co-research with adults with intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 669–686.

Doherty, A. J., Jones, S. P., Chauhan, U., & Gibson, J. M. E. (2020). Eating well, living well and weight management: A co-produced semi-qualitative study of barriers and facilitators experienced by adults with intellectual disabilities. *Journal of Intellectual Disabilities*, 24(2), 158–176.

Emerson, E. (2013). Commentary: Childhood exposure to environmental adversity and the well-being of people with intellectual disabilities. *Journal of Intellectual Disability Research*, 57(7), 589–600.

Feldman, M. A., Bosett, J., Collet, C., & Burnham-Riosa, P. (2014). Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of Intellectual Disability Research*, 58(9), 800–809.

Frankena, T. K., Naaldenberg, J., Cardol, M., Iriarte, E. G., Buchner, T., Brooker, K., Embregts, P., Joosa, E., Crowther, F., Schormans, A. F., Schippers, A., Walmsley, J., O'Brien, P., Linehan, C., Northway, R., van Schrojenstein Lantman-de Valk, H., & Leusink, G. (2019). A consensus statement on how to conduct inclusive health research. *Journal of Intellectual Disability Research*, 63(1), 1–11.

Franklin, L., Theodore, K., Foulds, D., Cooper, M., Mallaghan, L., Wilshaw, P., & Lee, J. N. Y. (2021). "They don't think I can cope, because I have got a learning disability…": Experiences of stigma in the lives of parents with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 35(4), 935–947.

Gates, R., Feldner, C., Gregory, C., Ahmed, A., Clayton, C., O'Hare, S., & O'Neil, A. (2007). *People with learning disabilities as consumer researchers: A case study*. Learning Disability Today.

Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D. W., & Beail, N. (2013). What things make people with a learning disability happy and satisfied with their lives: An inclusive research project. *Journal of Applied Research in Intellectual Disabilities*, 26(1), 26–33.

Hughes, R. B., Robinson-Whelen, S., Goe, R., Schwartz, M., Cesal, L., Garner, K. B., & McDonald, K. E. (2020). "I really want people to use our work to be safe"… Using participatory research to develop a safety intervention for adults with intellectual disability. *Journal of Intellectual Disabilities*, 24(3), 309–325.

Johnson, K., & Walmsley, J. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.

Jones, K. E., Ben-David, S., & Hole, R. (2020). Are individuals with intellectual and developmental disabilities included in research? A review of the literature. *Research and Practice in Intellectual and Developmental Disabilities*, 7(2), 99–119.

Martin, A. M., Divane, S., Twomey, S., O'Neill, L., McCarthy, J., Egan, C., & Caples, M. (2021). Don't mention the diet! A health promotion initiative to support healthy diet and lifestyle decision-making by people with intellectual disability. *British Journal of Learning Disabilities*, 49(4), 475–481.

McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 27–39.

Money, Friends and Making Ends Meet Research Group c/o Liz Tilly. (2012). Having friends–they help you when you are stuck from money, friends and making ends meet research group. *British Journal of Learning Disabilities*, 40(2), 128–133.

Mooney, F., Rafique, N., & Tilly, L. (2019). Getting involved in the community—What stops us? Findings from an inclusive research project. *British Journal of Learning Disabilities*, 47(4), 241–246.

NHS. (2019). The NHS long term plan. https://www.longtermplan.nhs.uk/

Nind, M. (2013). *Inclusive research: Where does it leave people with PMLD?* PMLD Link.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., & Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *International Journal of Surgery*, 88, 105906.

Pallisera Diaz, M., Fullana Noell, J., Puyalto Rovira, C., Vila Sune, M., & Diz Garolera, G. (2017). Supporting the real participation of people with intellectual disability: An inclusive research experience about independent living. *Revista Espanola De Discapacidad-Redis*, 5(1), 7–24.

Pownall, J., Wilson, S., & Jahoda, A. (2020). Health knowledge and the impact of social exclusion on young people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33(1), 29–38.

Rethlefsen, M. L., Kirtley, S., Waffenschmidt, S., Ayala, A. P., Moher, D., Page, M. J., & Koffel, J. B. (2021). PRISMA-S: An extension to the PRISMA statement for reporting literature searches in systematic reviews. *Systematic Reviews*, 10(1), 1–19.

Rojas-Pernia, S., Haya-Salmón, I., Lastra-Cagigas, S., de Santa, Á.-S., & María, L. (2020). The importance of social relationships and loneliness: An inclusive research project in Spain. *British Journal of Learning Disabilities*, 48(4), 291–300.

Salmon, N., Garcia Iriarte, E., Donohoe, B., Murray, L., Singleton, G., Barrett, M., & Dillon, M. (2019). Our homes: An inclusive study about what moving house is like for people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, 47(1), 19–28.

Strnadová, I., & Cumming, T. M. (2014). People with intellectual disabilities conducting research: New directions for inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 1–2.

Strnadová, I., & Walmsley, J. (2018). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, *31*(1), 132–141.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 1–10.

Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A., & Winsor, J. (2011). Choosing employment: Factors that impact employment decisions for individuals with intellectual disability. *Intellectual and Developmental Disabilities*, *49*(4), 285–299.

Tuffrey-Wijne, I. (2013). A new model for breaking bad news to people with intellectual disabilities. *Palliative Medicine*, *27*(1), 5–12.

Tuffrey-Wijne, I., Lam, C. K. K., Marsden, D., Conway, B., Harris, C., Jeffrey, D., & Stapelberg, D. (2020). Developing a training course to teach research skills to people with learning disabilities: "It gives us a voice. We CAN be researchers!". *British Journal of Learning Disabilities*, *48*(4), 301–314.

Turk, V., Burchell, S., Burrha, S., Corney, R., Elliott, S., Kerry, S., & Painter, K. (2010). An evaluation of the implementation of hand held health records with adults with learning disabilities: A cluster randomized controlled trial. *Journal of Applied Research in Intellectual Disabilities*, *23*(2), 100–111.

Turk, V., Leer, G., Burchell, S., Khattram, S., Corney, R., & Rowlands, G. (2012). Adults with intellectual disabilities and their carers as researchers and participants in a RCT. *Journal of Applied Research in Intellectual Disabilities*, *25*(1), 1–10.

van Schrojenstein Lantman-de, H. M., & Walsh, P. N. (2008). Managing health problems in people with intellectual disabilities. *BMJ*, *337*, a2507.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, *16*(2), 187–205.

Walmsley, J., Strnadova, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, *31*(5), 751–759.

Watchman, K., Mattheys, K., McKernon, M., Strachan, H., Andreis, F., & Murdoch, J. (2021). A person-centred approach to implementation of psychosocial interventions with people who have an intellectual disability and dementia—A participatory action study. *Journal of Applied Research in Intellectual Disabilities*, *34*(1), 164–177.

Williams, O., Sarre, S., Papoulias, S. C., Knowles, S., Robert, G., Beresford, P., & Palmer, V. J. (2020). Lost in the shadows: Reflections on the dark side of co-production. *Health Research Policy and Systems*, *18*, 1–10.

Wolfensberger, W. (1980). The definition of normalization: Update, problems disagreements and misunderstandings. In R. Flynn & K. Bitsch (Eds.), *Normalisation, social integration and community services* (pp. 71–115). University Park Press.