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INCLUSIVE RESEARCH WITH PEOPLE WITH INTELLECTUAL DISABILITIES. CURRENT RESEARCH STATUS ANALYSIS

Abstract: The widespread interest in inclusive research justifies the need to establish its added value and scientific merit. We analysed recent studies following the analyses by Walmsley, Strnadová, and Johnson aiming to assess the relevance of such projects from the perspective of the involved people and to assess their scientific value. We conducted a systematic analysis of studies produced between 2016 and 2021. We designed our own tools for assessing added and scientific value based on available research and commonly used criteria. The significance of inclusive research for persons with intellectual disability was confirmed. The analysed studies met the criteria for scientific validity to a varying degree. Adhering to the principles applied in the scientific community is key, considering first ethics, careful choice of the method, and activating people involved in the research.

Keywords: inclusive research, intellectual disability, co-researchers, added value.

Introduction

Nind et al. (2017, p. 387) offered a broad definition of inclusive research, defining it as, "an inherently eclectic and epistemologically diverse umbrella term for a ‚whole family of approaches, all of which reflect a particular turn toward democratization of the research process". Walmsley and Johnson (2003), on the other hand, described it as an approach to research assuming people with intellectual disabilities are involved as active participants.

According to Nind (2016b) the way of presenting inclusive research, when researchers demonstrated its usefulness, described the implementation process, and noted the challenges they faced, is currently insufficient. What is important, it is not so much the analysis of the process itself – much less an unreflective

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description – but the assessment of its relevance from a scientific perspective, and especially of the knowledge it provides. A relatively complex question arises if good science and the practice of inclusive research go hand in hand (Nind 2016b).

The second phase of inclusive research provides an opportunity for meta-analyses to establish the added value of such research (Armstrong et al. 2019; Di Lorito et al. 2018; Rix et al. 2020). The added value is the voice of people with intellectual disabilities, their experiences, thoughts, and feelings, plus the cultural knowledge they represent (Nind 2016b). In 2018, Walmsley, Strnadová, and Johnson published a review paper analyzing the added value of inclusive research realized up to 2015. They defined added value as the contribution of inclusive research to the quality of the research process and its outcomes, and the impact of the research on those involved. In making their assessment, the researchers considered the criteria proposed by Nind and Vinha (2012, p. 43) that can be used to confirm that "good science meets good inclusive practice": (1) The research answers questions we could not otherwise answer, that are important; (2) The research reaches participants, communities, and knowledge, in ways that we could not otherwise access; (3) The research involves, using and reflecting on the insider, cultural knowledge of people with learning disabilities; (4) The research is authentic (recognised by the people involved); (5) The research makes an impact on the lives of people with learning disabilities. The authors added their own criterion, "finding the shared spaces" meaning that "the process of inclusive research, an extensively documented task, if finding ways to collaborate fruitfully, is perhaps its most important added value if these lessons are widely shared and implemented" (Walmsley, Strnadová, Johnson 2018, p. 757).

The purpose of the presented review analyses, inspired by the work of Walmsley, Strnadová, and Johnson (2018), is to evaluate available inclusive research based on an understanding of their added value from the perspective of (1) actively participating people including the ones with intellectual disabilities (co-researchers); (2) good science.

Methods

Inclusion criteria and search strategy

The search included scientific articles in English written between 2016 and 2021. The indicated period is a continuation of the review study conducted by Walmsley, Strnadová, and Johnson (2018) covering papers written between 2003 and January 2016.

The review included searches in: (a) academic databases; (b) journals: British Journal of Learning Disabilities, Disability and Society, Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual and Developmental Disability; (c) a grey literature search and (d) references in articles found in the databases.

Resources in PsycArticles, Academic Search Ultimate, ERIC, Medline, and Scopus databases were searched. Additionally, the Google Scholar database was checked. The same search terms were used as the ones used by Walmsley, Strnadová, and Johnson (2018): inclusive research OR emancipatory research OR participatory research AND intellectual disability OR learning disability OR mental retardation OR developmental disabilities. These terms were also used when searching for articles in Google. The literature references in the reviewed articles found in the databases were also reviewed. The search results are shown in Figure 1 (page 386).

Analysis

The material was analyzed in two stages: (1) selection of studies in which people with intellectual disabilities played active roles in the research process; (2) detailed evaluation of the studies in terms of the adopted criteria.

In the first stage of selecting inclusive research, we adopted relatively narrow and rigorous requirements, closely following Walmsley and Johnson's definition that in such research people with intellectual disabilities are involved as "instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users" (Strnadová, Walmsley 2018, p. 133). Given this framing of the role, the authors found it appropriate to use the term "co-researchers" in their analyses (Strnadová, Walmsley 2018).

In second stage we conducted the analysis using our own criteria based on relevant literature (Table 1). They include the essential characteristics of inclusive research described above and some key aspects that determine methodological validity. In the latter case, a tool for evaluating scientific papers was used: Critical Appraisal Skills Programme. CASP Qualitative Studies Checklist, 2018. Following Williamson, van Heumen and Schwartz (2020) we made sure that the selection from the pool of criteria for evaluating traditional (non-inclusive) projects is consistent with the essence of inclusive research. In the evaluation, using the developed criteria, we paid attention to the content of information, following a scale: 0 points for no or insufficient information; 1 point for moderate information; 2 points for full information (Table 2) (Lam et al. 2019).

Results

General characteristics of the study

In the first stage of the analysis, 21 articles (Table 3) describing studies with the active participation of people with intellectual disabilities were selected from 36 articles. Most of the studies (18) originated in Europe, including the UK (9), the Netherlands (5), Spain (2), Ireland (1), and Greece (1). Two originated in the US and one in Australia. Most of these participatory studies used qualitative methods

(Georgiadou, Vlachou, Stavroussi 2020; Gratton 2019; Power, Bartlett, Hall 2016; Puyalto et al. 2016; Watchman 2020).

A detailed evaluation of the research

The extent of information on inclusive projects varied (Table 1): almost all papers provided data about the research tasks performed by people with intellectual disabilities and their contribution to the research. Relatively less information was provided about activities that optimized inclusion, perhaps because such activities (for example coaching) were not always needed. While the problem/objective was concretized in each paper, not all researchers provided information that could be used to assess the relevance of their research. This was especially true about theoretical and practical implications, plus dissemination of results. Not all authors justified their choice of method, which would also make it easier to assess its adequacy in relation to the selected topic. When justified, there was no information about the accessibility of the method for co-researchers or respondents with intellectual disabilities. Few authors reflected on the participation of co-researchers or the importance of inclusive projects for non-disabled researchers, especially from the perspective of working with people with intellectual disabilities. The papers that problematize this issue are specific here (Beihton et al. 2019; Embregts et al. 2018; Frankena et al. 2019b, 2019c; Nind 2016a; Riches, O'Brien & The CDS Inclusive Research Network 2017; St. John et al. 2018). Most reviewed papers reported that the collaboration was based on respect and partnership but fewer made any note about the time taken for reflection. Several papers lacked information about the approval of the research by the relevant ethical body. In most studies, there was no data on the consent given by co-researchers or on the efforts to support them and the respondents with intellectual disabilities in their decision to participate in the research. Summarizing this aspect of the articles, considering primarily the information available to the reader, we identified four studies that included the most exhaustive data to consider the projects as inclusive: Amstrong et al. (2019), Gratton (2019); Salmon et al. (2019) and Rojas-Pernia et al. (2020).

Acting as co-researchers, people with intellectual disabilities undertook different tasks in the research process. In several cases (Amstrong et al. 2019; Beihton et al. 2019; Owen et al. 2016; Power, Bartlett, Hall 2016; Puyalto et al. 2016; Rojas-Pernia et al. 2020; Seale, Choksi, Spencer, 2019), they collaborated in concretizing the research project or developing a draft grant proposal (Watchman et al. 2020). They collaborated with researchers in determining the research problem and the methods to address it. Most often, on their own or with support, they collected material using qualitative methods (group or individual interviews, photovoice). Their respondents were other people with intellectual disabilities some of whom were earlier co-recruited by the co-researchers (Amstrong et al. 2019; Cluley 2017; Gratton 2019; Power, Bartlett, Hall 2016; Rojas-Pernia et al. 2020; Salmon et al. 2019;

Seale, Choksi, Spencer 2019; St. John et al. 2018; Watchman et al. 2020). In many projects, co-researchers were involved in analyzing the material, developing the discussion (by consulting it), and outlining specific findings and recommendations (Amstrong et al. 2019; Georgiadou, Vlachou, Stavroussi 2020; Gratton 2019; Owen et al. 2016; Power, Bartlett, Hall 2016; Puyalto et al. 2016; Riches, O'Brien, The CDS Inclusive Research Network 2017; Rojas-Pernia et al. 2020; Salmon et al. 2019; Watchman et al. 2020). They also participated in the dissemination of research results. This last aspect was important for assessing the relevance of the projects. Project results were presented at conferences, including international ones (Beihton et al. 2019; Riches, O'Brien, The CDS Inclusive Research Network 2017; Rojas-Pernia et al. 2020; Watchman et al. 2020). There were also efforts to initiate conferences or workshops (Gratton 2019; Watchman et al. 2020). Rojas-Pernia et al. (2020) created a website, prepared an exhibition at the university, and collaborated with the press. In one study, co-researchers, as subject matter experts, provided training to peers with intellectual disabilities (Watchman et al. 2020). To disseminate findings to the community of people with intellectual disabilities, reports were prepared in an easy-to-read text format (Doherty 2020; Salmon et al. 2019; St. John et al. 2018; Watchman et al. 2020). Text fragments authored by people with intellectual disabilities were in several cases marked in the article written by non-disabled researchers (Frankena et al. 2019c; Riches, O'Brien, The CDS Inclusive Research Network 2017; Rojas-Pernia et al. 2020; Seale, Choksi, Spencer 2019). Co-researchers co-commented on draft versions of the papers or participated in responding to reviewers' comments (Amstrong et al. 2019; Salmon et al. 2019). Three studies reported that co-researchers were paid for their participation (Doherty 2020; Frankena et al. 2019b; Power, Bartlett, Hall 2016). As previously noted, perhaps it was not always the case that people with intellectual disabilities needed to be prepared to participate in the research, since some of them had prior experience in collaboration and inclusive research (Amstrong et al. 2019; Beihton et al. 2019; Embregts et al. 2018; Frankena et al. 2019b; Seale, Choksi, Spencer 2019; Vlot-van Anrooij et al. 2018). Some individuals with intellectual disabilities were members of the self-advocacy movement with competencies in social activism (Amstrong et al. 2019; Doherty 2020; Embregts et al. 2018; Gratton 2019; Owen et al. 2016; Power, Bartlett, Hall 2016), and some were experienced researchers and advisors working in institutions (e.g. Inclusive Research Work, Riches, O'Brien, The CDS Inclusive Research Network 2017). However, in many studies recruitment was conducted by non-disabled people including carers or professionals, with the involvement of specific institutions or associations (Doherty 2020; Gratton 2019; Power, Bartlett, Hall 2016; Puyalto et al. 2016; Seale, Choksi, Spencer 2019; Watchman et al. 2020). In these cases, non-disabled persons including professionals and carers determined the participation of co-researchers, and information about co-researchers' consent was most often missing. Puyalto et al. (2016) write about a meeting where researchers communicated the purpose of the project taking care to adapt the information to

the cognitive abilities of people with intellectual disabilities. St. John et al. (2018a), on the other hand, reported that consent was given by co-researchers. Various, albeit few, measures were taken to optimize the inclusion of people with intellectual disabilities as co-researchers or respondents. Supportive or specially designated individuals (such as a student) were present to assist with, for example, conducting interviews or completing questionnaires (Doherty 2020; Nind 2016a, Owen et al. 2016; Power, Bartlett, Hall 2016; St. John et al. 2018). Some studies offered training sessions or induction (Amstrong et al. 2019; Gratton 2019; Rojas-Pernia et al. 2020; St. John et al. 2018). In one study such supportive activity was removed upon receiving feedback from a self-advocacy organization that positively evaluated the co-researchers' competencies (Power, Bartlett, Hall 2016). Interestingly, the co-researchers' needs were not verified. In several projects, the material was adapted to the potential of people with intellectual disabilities (Beihton et al. 2019; Frankena et al. 2019b; Puyalto et al. 2016), considering, among other things, their communication skills. If researchers justified their choice of research method, they focused on allowing people with intellectual disabilities to share their views and removing the limitations imposed by traditional methods that prioritize the verbal channel. Methods such as photovoice were used to include individuals with greater limitations (Cluley 2017; Watchman et al. 2020). Inclusive research, in which the tasks performed by people with intellectual disabilities affirm the importance of their active role, immanently involves partnership and respect for the knowledge and experience of all those involved. People with intellectual disabilities are treated as experts whose experience can have educational value for others (Doherty 2020; Puyalto et al. 2016; Riches, O'Brien, The CDS Inclusive Research Network 2017). All the involved individuals have the opportunity to express themselves freely (Amstrong et al. 2019; Beihton et al. 2019; Puyalto et al. 2016; Riches, O'Brien, The CDS Inclusive Research Network 2017), and feel safe (Beihton et al. 2019), plus the distribution of tasks is determined not only by competence but also by comfort — especially of the co-researchers (Frankena et al. 2019b). Efforts are made to integrate the team against the exclusion of team members (Riches, O'Brien, The CDS Inclusive Research Network 2017). Respect reflected in actively seeking collaboration, accepting choices, and acknowledging opinions was also an integral aspect of research involving people with more significant limitations (Cluley 2017). This was manifested in providing opportunities to communicate in ways that are accessible to people with different needs, e.g. those with sensory disabilities (Riches, O'Brien,The CDS Inclusive Research Network 2017). To implement the aforementioned aspects, efforts by non-disabled researchers to reduce potential inequality stemming from professional status or educational attainment are essential (Beihton et al. 2019).

Discussion and conclusion

Answering Nind's (2016b) question which inspired our research intent, good science and inclusive research practice can go hand in hand. Some studies support this by providing indicators of positive scientific value/scientific rigor and by demonstrating the tangible benefits of conducting such projects. Strnadová et al. (2016) posed several questions about the status of inclusive research. The obtained material allows us to address them.

1. The definition of inclusive research should encompass different levels of co--researchers' involvement: from advisory roles to active researcher roles. The former was reflected, for example, in studies aimed at developing instruments designed for people with intellectual disabilities (e.g., Frankena et al. 2018; Vlot-van Anrooij et al. 2018). The latter included participation in all stages of the research process (e.g. Amstrong et al. 2019; Power, Bartlett, Hall 2016). The co-researchers' level of involvement is determined by their capabilities and the resulting ranges of support, but most importantly by their motivation to undertake certain activities.
2. We cannot conclude that certain perspectives and methods are excluded from inclusive research. If we acknowledge the usefulness of advisory roles, then quantitative-qualitative approaches can also be pursued, noting that qualitative methods lie primarily within the capacity of people with intellectual disabilities as co-researchers. According to the non-disabled health researchers whose opinions were probed, qualitative projects offer more opportunities, but quantitative projects may also give space for co-researchers' tasks in the form of being a board member, advocate, or partner. Quantitative approaches may require more effort from non-disabled researchers (Frankena et al. 2016).
3. After analysing the available inclusive studies we cannot conclude if there is a need for research training. Training and other forms of preparation were implemented in a few cases (e.g. Gratton 2019; Rojas-Pernia et al. 2020; St. John et al. 2018). Co-researchers' experience gained from previous projects may justify this. Still, the question applies to individuals who participate in a research project for the first time. There is a danger of recruiting unprepared people with intellectual disabilities, selected, for instance, based on their formal carers' feedback (cf. Bigby, Frawley, Ramcharan 2014). The evaluated papers lacked thorough information about the recruitment of co-researchers and their consent. The motivation of people with intellectual disabilities is crucial here and will be important for them to feel safe and at ease (Di Lorito et al. 2018). If non-disabled people make the decision to select co-researchers based on some self-assessment of ‚their suitability', a pattern specific to many traditional studies is replicated. In this context, we should consider the status of the co-researcher. This status seems to be fully validated when a person with an intellectual disability is included in some structured community, such as

an advisory committee (e.g. Riches, O'Brien, The CDS Inclusive Research Network 2017). This provides greater opportunities for long-term rather than haphazard action, a formal confirmation of status (e.g., with appropriate contracts, compensation), and perhaps greater opportunities for disseminating results through conferences or papers. In this context, it is useful to develop general research competencies and not only those related to a specific project (cf. Strnadová et al. 2016).

4. Presumably, many co-researchers will not be able to co-author articles, either due to individual constraints or journal requirements. However, these individuals will play a key role in disseminating results through other ways available to them, as noted in the reviewed projects (e.g., Doherty 2020; Rojas-Pernia et al. 2020; Watchman et al. 2020). This is a measurable effort they should be recognized for.
5. Inclusive studies fit into the academic discipline to a varying degree. The question is how to assess their scientific value. There are some universal criteria of scientific merit that can be implemented in inclusive research, as the analyzed projects show to varying extents. This is primarily methodological consistency, here understood as a reasonable choice of the method adapted to the problem, the capabilities of co-researchers, and the respondents. This is important in traditional research as well, where problems arising from method selection also occur (Finlay, Lyons 2001; Nind 2008). The second layer of evaluation is ethics where we consider informed and voluntary participation of co-researchers. Next, the knowledge that inclusive research can provide should be relevant from the perspective of people with intellectual disabilities. This is the aspect that gives meaning to the participation of people with disabilities as co-researchers. In this context, it is possible to analyze the productivity or the impact of inclusive projects, as a way of exploring issues that are important to people with intellectual disabilities (Walmsley, Strnadová, Johnson 2018).

Evaluation of inclusive research projects depends largely on the availability of information included in the articles. Walmsley, Strnadová, Johnson (2018) emphasize that a description of the research process is particularly important because it recognizes the contributions that people with intellectual disabilities make and the efforts to enhance these contributions. Inclusive research is a collaborative effort, so its design should include acknowledgment of the authorship and contributions in the process of writing the article or its specific sections. It is important to find room for reflection by co-researchers and non-disabled researchers alike (Strnadová, Walmsley 2018).

The evaluation criteria used in the presented analysis, although closely based on the available literature, were selected by the author. Perhaps some criteria should be included to assess the quality of other aspects of the research process, such as the method and the analysis of the collected material. The evaluation includes articles that describe reflections on the implementation of inclusive research, treating them

as an integral part of the latter. However, they are specific against the background of the works that show only the project. It may be worth standardizing the selection in future analyses.

Analysing inclusive research, it is worth looking at potential costs, understood not so much in financial terms as in personnel terms. Researchers should consider: (1) the emotional involvement of co-researchers, which may arise in relation to issues that are close to them, or touch on experiences that are important to them (Tilley et al. 2021); (2) negative sensations when collaboration finishes, related to building social relationships; (3) and situations of not meeting co-researchers' expectations related to the way the results of the project are used.

Table 1. Indices for assessing inclusive research

Criteria	Indices
Roles of people with intellectual disabilities	
I.1. Active role in the research process	People with intellectual disabilities are involved in specific tasks in the research process, undertaking them independently or with support
I.2. Clear information on the contribution of people with intellectual disabilities	Specification/description of tasks with an indication of those undertaken by researchers with intellectual disabilities and non-disabled researchers
I.3. The perspective of co-authors with intellectual disabilities	People with intellectual disabilities are the co-authors of the text and/or their authorship has been marked in specific fragments of the text
I.4. Activities optimizing inclusion	Depending on the needs, actions are taken to adapt the project to the needs of co-researchers with intellectual disabilities/ respondents with intellectual disabilities, such as training, communication tools, means of transport, places for discussion, data visualization, materials allowing them to give informed consent
The rationale for inclusive research	
II.1. Important for people with intellectual disabilities, for their population, and their living environment	Clearly specified research goal/topic, important for people with intellectual disabilities from the perspective of the individual and the population; taking care to disseminate the results in the environment of people with intellectual disabilities, using dissemination forms accessible to people with intellectual disabilities; theoretical and/or practical implications of the research
II.2. Justification of the methods used from the perspective of the quality of the process and its importance	The selected method is adequate to the research topic of the project; it is accessible to researchers with intellectual disabilities (measures are taken to increase accessibility) and respondents with intellectual disabilities
Reflection on the importance of participating in inclusive research	
III.1. Regarding co-researchers with intellectual disabilities	Authors include information on how important it was for co-researchers with intellectual disabilities to participate in the project
III.2. Regarding non-disabled researchers	Authors include information on how important it was for non-disabled researchers to participate in the project, plus how these researchers assessed the quality of this research
Implementation of the principles important for cooperation	
IV.1. Time for reflection	Time for discussions and reflections was included in the project; optimal time was provided for implementing tasks by co-researchers with intellectual disabilities (depending on the needs)

Criteria	Indices
IV.2. Respect and partnership	People with intellectual disabilities take their rightful place: they can share their experiences in the research process, their voice is respected
IV.3. Compliance with ethical criteria	Actions are taken to ensure the ethical practices are followed during the research, such as obtaining the consent of the relevant institution; informed consent of the respondents; article contains information on the voluntary participation of co-researchers with intellectual disabilities and on their recruitment / on previous experiences related to conducting projects

Table 2. Evaluation of inclusive studies

Criteria	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
I.1.	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
I.2.	0	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
I.3.	0	0	0	0	0	2	0	0	0	0	2	0	2	2	0	2	2	0	0	2	0
I.4.	0	1	1	2	0	0	0	0	2	1	2	1	2	0	2	2	1	1	0	2	1
II.1.	2	1	1	2	2	2	1	1	2	1	2	1	2	2	2	2	2	1	1	2	2
II.2.	2	2	1	1	2	0	0	1	0	2	1	1	2	1	2	2	2	1	1	2	2
III.1.	2	1	0	2	1	1	0	0	2	1	2	2	0	1	2	1	0	0	1	1	1
III.2.	2	0	0	2	0	0	0	0	2	1	2	0	0	0	1	1	0	0	0	0	0
IV.1.	2	0	0	0	1	0	1	0	0	0	2	2	1	0	1	1	0	0	0	2	2
IV.2.	2	1	0	1	2	0	1	0	1	2	2	2	2	0	2	2	2	1	0	2	1
IV.3.	1	1	1	2	2	0	2	1	2	2	1	1	0	1	1	2	2	2	1	2	2

0 points for no or insufficient information; 1 point for moderate information; 2 points for full information

Table 3. Summary of the reviewed studies

Author(s)	Aim	Methods	Participation of people with ID in the research
1. Nind (2016a), UK	Assessment of participation in inclusive research from the perspective of how people with intellectual disabilities learn	Focus group discussion	People with intellectual disabilities as respondents sharing their experiences related to participating in inclusive research during discussions in focus groups
2. Owen et al. (2016), US	Exploration of how people with intellectual disability define sexual self-advocacy	Nominal Group Technique	People with intellectual disabilities, members of the self-advocacy movement, as co-researchers undertaking tasks: developing conceptual frameworks, participating in a research forum People with intellectual disabilities as respondents sharing opinions and co-creating the final version of the sexual self-advocacy
3. Power, Bartlett & Hall (2016), UK	Examining the experiences of some people's involvement in peer-advocacy groups within the broader context of personalization and declining formal services	Participatory research Interviews	People with intellectual disabilities as co-researchers undertaking the following tasks: participation in research design, including the development of questionnaires; conducting interviews; participating in the analysing results and developing recommendations
4. Puyalto et al. (2016), Spain	Learning the views of counsellors with intellectual disabilities and non-disabled researchers on the participation in inclusive research on the transition into adulthood	Participatory research Questionnaire Focus group interviews	People with intellectual disabilities, members of the advisory board for research into the transition into adulthood People with intellectual disabilities as respondents
5. Cluley (2017), UK	To explore how learning disability is understood by both people with and without learning disabilities	Photovoice	People with intellectual disabilities as co-researchers collecting material using photography (sometimes with help of a supporting person)
6. Riches, O'Brien, The CDS Inlcusive Research Network (2017), Australia	Presentation of the experiences of the participants of the CDS Inclusive Research Network	Focus group	People with intellectual disabilities, members of the Inclusive Research Network, as respondents sharing experiences related to inclusive projects

Table 3 – continued

Author(s)	Aim	Methods	Participation of people with ID in the research
7. Embregts et al. (2018), Netherlands	Learning the opinions of people with intellectual disabilities about competencies important for inclusive research	Focus group interviews Individual interviews Expert meetings Qualitative content analysis	People with intellectual disabilities with experience in inclusive research as respondents and experts expressing opinions on the topic People with intellectual disabilities as respondents
8. Frankena et al. (2018), Netherlands	Exploring the participation of people with intellectual disabilities in research by means of a structured interview survey amongst people with intellectual disabilities regarding: (i) frequency of participation; (ii) methods used to participate; (iii) motivations to participate; and (iv) interests regarding study results	Structured interview	People with ID as co-researchers undertaking tasks: participation in developing the scope of survey content and survey questions
9. St. John et al. (2018a), US	Exploring the perspectives of co-researchers with intellectual disability on their involvement in the research process and the feasibility of their inclusion based on perspectives of research staff	Semi-structured interview Thematic analysis	People with intellectual disabilities as respondents informing about their experiences related to participating in an inclusive project, in which: they participated in the training, conducted interviews (in cooperation) according to the protocol with the possibility of supplementing it with auxiliary questions
10. Vlot-van Anrooij et al. (2018), Netherlands	Exploring the applicability of self-reported health scales in research among people with mild intellectual disability, by adjusting, testing, and reflecting on three self-reported health scales together with co-researchers with intellectual disability	Questionnaires Group discussions	People with intellectual disabilities as co-researchers undertaking the following tasks: adjusting the scales; reflecting on the adjusted scales and the test-retest study results

Table 3 – continued

Author(s)	Aim	Methods	Participation of people with ID in the research
11. Amstrong et al. (2019), UK	Description of activities related to the development of tools for self-advocates to better implement research projects	Focus groups	People with intellectual disabilities as co-researchers participating in the training; looking for respondents for research; conducting focus interviews; taking part in the data analysis and designing the tool and its initial application; presenting the results of the project; contributing to the article
12. Beighton et al. (2019), UK	Exploring the perspectives and experiences of a group of adults with intellectual disabilities and a group of parent carers about their collaborative/participatory involvement in a study which explored the effectiveness of annual health checks for adults with intellectual disabilities	Group interview Thematic analysis	People with intellectual disability as respondents describing their perspectives and experiences related to participating in inclusive research in which they: informed the choice of process and outcome measures and/or identified alternate outcome measures to be used, developed ideas for further explanatory analysis for findings, interpreted the findings of the study, disseminated results by co-presenting with research staff, and formed recommendations for further research and policy
13. Frankena et al. (2019b), Netherlands	Description and analysis of long-term cooperation with co-researchers with intellectual disability	Semi-structured interview Group discussions Membership categorization analysis	People with intellectual disabilities as respondents sharing their experiences from cooperation in long--term inclusive projects
14. Frankena et al. (2019c), Netherlands	Gaining insight into the experiences of inclusive research teams in practice regarding (1) reasons, (2) attributes, and (3) outcomes of inclusive health research	Multiple case study	People with intellectual disabilities as co-researchers and advisory board members

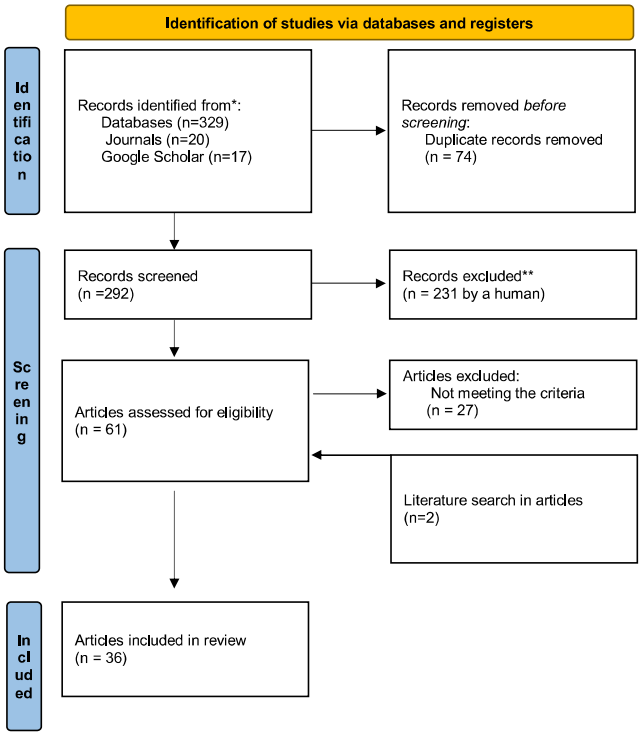
Table 3 – continued

Author(s)	Aim	Methods	Participation of people with ID in the research
15. Gratton (2019), UK	Determining the perceptions of culture for people with learning disabilities and the needs of the group in relation to accessing and engaging in mainstream arts and cultural activity	Participatory action research Semi-structured interview Focus group interviews Thematic analysis	People with intellectual disabilities as co-researchers conducted semi-structured interviews or focus groups with 82 participants, consulted research material, and conducted workshops as a continuation of the research project People with intellectual disabilities as respondents
16. Salmon et al. (2019), Ireland	Exploring the experiences of people with intellectual disabilities in Ireland when moving home focused on reasons for moving and supports provided during the transition process	Structured interview	People with intellectual disabilities as co-researchers undertaking the tasks: co-developing a structured interview guide; co-conducting interviews; co--analysing data; preparing a report in easy-to-read text format
17. Seale, Choksi & Spencer (2019), UK	Learning about the experiences of people with intellectual disabilities related to the use of technology in their lives	Life histories	People with intellectual disabilities as co-researchers cooperating in the process of establishing methods and means supporting the process of telling life's stories; collecting material; preparing the article
18. Doherty (2020), UK	Checking the views and experiences of people with intellectual disabilities in relation to barriers and factors facilitating good nutrition, good life, and coping with excessive weight	Focus groups Questionnaires	People with intellectual disabilities, self-advocates, as co-researchers involved in the development of research methods, preparation of materials in an easy-to-read format regarding consent, and recruiting respondents
19. Georgiadou, Vlachou & Stavroussi (2020), Greece	Developing an instrument for the assessment of Special Vocational Education service quality, drawing on scales in the fields of management, technical and vocational education and tertiary education for students with disability	Participatory research	People with intellectual disabilities involved in the preparation of the initial version of the tool, and undertaking activities: (1) as members of focus groups; (2) as reviewers of the pre-pilot version of the instrument; and (3) in the process of selecting a pictorial five-point Likert-type rating scale

Table 3 – continued

Author(s)	Aim	Methods	Participation of people with ID in the research
20. Rojas-Pernia et al. (2020), Spain	Exploring the experience of loneliness in other young people with and without intellectual disabilities and to know whether this was also an important issue for them	Semi-structured interview	People with intellectual disabilities as co-researchers undertaking tasks: cooperation in the conceptualization of issues and research goals, methods and participants; co-development of interviews; discussion of ethical issues; co-realization of interviews; material co-analysis
21. Watchman et al. (2020), UK	To identify the benefits and challenges of co-researchers with intellectual disability engaging with photovoice methodology and assignment how far this study contributed to the development, and sharing through social action, of new knowledge about dementia in people with intellectual disability	Participatory action research Photovoice	People with intellectual disabilities as co-investigators undertaking the tasks: preparation of the initial project grant application, co-creation of the advisory committee during the project (3 years), participation in the training, data collection, data co-analysis, dissemination of research results

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only (modified)



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

Figure 1. Flow diagram of literature search and study selection

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BADANIA WŁĄCZAJĄCE Z UDZIAŁEM OSÓB Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ. ANALIZA STATUSU BADAŃ

Streszczenie: Szerokie zainteresowanie badaniami włączającymi z udziałem osób z niepełnosprawnością intelektualną zrodziło potrzebę refleksji, której celem ma być ustalenie wartości dodanej takich projektów. Analizy własne miały na celu prześledzenie nowszych badań i stanowiły kontynuację rozważań Walmsley'a, Strnadovy i Johnson, zmierzających do oceny znaczenia badań włączających z perspektywy podmiotów w nie zaangażowanych oraz ustalenia wartości naukowej. Przeprowadzono systematyczną analizę badań z lat 2016–2021. Wykorzystano autorskie narzędzia do oceny wartości dodanej, inspirowane pracami innych autorów oraz powszechnie stosowanymi kryteriami. Potwierdzono znaczenie badań włączających z perspektywy osób z niepełnosprawnością intelektualną. Wykazano, że analizowane badania w różnym stopniu spełniają kryteria poprawności naukowej. Kluczowe jest spełnienie zasad powszechnie obowiązujących w środowisku nauki, wśród których na pierwszym miejscu sytuują się kwestie etyczne, staranny namysł nad metodą oraz możliwościami aktywizacji podmiotów biorących udział w badaniach.

Słowa kluczowe: badania włączające, niepełnosprawność intelektualna, współbadacze, wartość dodana.