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Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice?

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Background: Inclusive research is increasingly common in intellectual disabilities research, but ways in which voice of co-researchers with intellectual disabilities is presented remain underexplored in the literature.

Materials and Method: The authors conducted a literature review and analysis of peer-reviewed journal articles reporting on inclusive research. The aim was to explore the ways the voices of co-researchers with intellectual disabilities are represented in published peer-reviewed journal articles.

Results: The findings indicate that there are a wide range of ways in which inclusive research projects are reported in peer-reviewed journals. However, the experiences, views and opinions of co-researchers are often either absent or very selectively reported.

Conclusions: The article concludes that although inclusive research has proliferated in the 21st century, more attention needs to be paid to the ways in which the voices of co-researchers with intellectual disabilities are heard in formal academic contexts. Guidelines for future practice are offered.

KEYWORDS
authorship, inclusive research, intellectual disabilities, voice

1 | INTRODUCTION

This paper explores how the voice of co-researchers with learning disabilities is conveyed in academic research which describes itself as 'inclusive', 'participatory' or 'emancipatory'. The paper takes up a theme highlighted by Goethals, van Hove, Van Breda, and De Schauwer (2016) who wrote 'While it is important to conduct research that aims to give voice, it is essential to simultaneously problematize the premise of giving voice' (p.213). Inclusive research claims to 'give voice' to people with intellectual disabilities (Walmsley & Johnson, 2003). Nind comments that 'Authorship … is an important way of people being credentialised through research … and without it they can feel used or made to feel inferior' (2014, p.28).

Here, the present authors explore how voices of co-researchers with intellectual disabilities are heard in academic publishing. The paper critically analyses the peer-reviewed literature on inclusive, participatory or emancipatory research with people with intellectual disabilities. Inevitably this excludes many other media through which inclusive research is disseminated. However, the authors argue that in the academic context it is peer-reviewed journals which carry most weight. Hence, the paper seeks to answer this question: How is the voice of co-researchers with intellectual disabilities represented in peer-reviewed journal articles reporting on inclusive research?

2 | NOTE ON TERMINOLOGY

Terminology is contested in this area of work. In this paper, whilst recognizing that there are international and intranational differences in labelling, the term 'intellectual disabilities' is used to refer to people who have been variously labelled as having learning difficulties or disabilities, being learning or intellectually disabled, or, in the past, retarded or mentally handicapped.

To refer to the area of endeavour which is research where people with intellectual disabilities work as researchers, the term 'inclusive research' is used. This incorporates participatory and emancipatory (see Walmsley & Johnson, 2003; Nind, 2014, for a discussion of terminological nuances).

To refer to the people with intellectual disabilities working as researchers, the term 'co-researchers' is used. Other terms such as 'research partners' (Nierse & Abma, 2011) and 'self-advocates' (Williams & Simons, 2005) are also used. It is recognized that singling people with intellectual disabilities out by giving them a specific label is discriminatory, as noted by Seale, Nind, Tilley, and Chapman (2015). The term co-researcher is the most widely used term, but in a seminar dedicated to identifying common ground between participatory research with people with learning disabilities and participatory research conducted with other groups, Toby Brandon and Caroline Kemp argued against the term preferring to use "researcher" for all partners in that, "you are either a researcher or you are not." Seale et al. (2015, p. 488). However, without identifying people with intellectual disabilities in research teams, this paper would be impossible to write, so, with some reservations, the term co-researcher is used.

3 | BACKGROUND

Inclusive research is a term used to describe research undertaken with people with intellectual disabilities, in ways which include them as actors, rather than subjects of research. 'Inclusive research' was a term coined by Walmsley (2001) to encapsulate both participatory research, where people with disabilities work in partnership with academic researchers, and emancipatory research, where the aspiration is for people with disabilities to lead and control the research, changing the relationships of research production (Oliver, 1992). In this paper, the term 'inclusive research' is used. It is here defined as research in which people with intellectual disabilities are involved as: '...instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users' (Walmsley & Johnson, 2003, p. 10).

Inclusive research encompasses a spectrum of approaches ranging from work akin to community development (Johnson, 2009) to major projects, such as the English National Survey undertaken in 2005 (Emerson, Malam, Davies, & Spencer, 2005). Bigby, Frawley, and Ramcharan (2014) describe a spectrum from people with intellectual disabilities in advisory roles, through to collaborative (or participatory), and user-led (emancipatory). It has also been described as fulfilling 'an important symbolic role as emblematic of inclusivity and empowerment for people with intellectual disabilities' (Fyson & Fox, 2014, p. 252).

Inclusive research is essentially value-driven. It sets out to change society with people with intellectual disabilities as active partners and contributors. It is akin to participatory research, but with an acknowledgment that there are unique challenges in working in a participatory way with people with intellectual disabilities, given the cognitive nature of their impairment.

In 2007, Grant and Ramcharan observed that researchers have gained considerable knowledge about process (i.e., how to do inclusive research), but less about (a) what forms of relationships between academic researchers and co-researchers with intellectual disabilities, (b) making these relationships inclusive, and (c) whether good science and good inclusive research practice can be brought together. These comments, published more than a decade ago, remain pertinent, and particularly so when considering how co-researchers with intellectual disabilities are involved in the publishing and dissemination end of the research pathway. It has always been a challenge to resolve the tension that exists between research which is academically rigorous, acceptable to funding organizations and publishable, and research which is of use to the people who are subject to it, which is relevant to their needs and can inform and promote needed social change (Walmsley & Johnson, 2003, p. 9).

The fact that many co-researchers with intellectual disabilities cannot read well, and have not had the benefit of higher education, makes their inclusion in academic publishing particularly problematic (McClimens, 2004). However, since the beginning of the 21st century, inclusive research has made increasing inroads into the academic research lexicon. A Special Issue of the *British Journal of Learning Disabilities* was co-produced by people with intellectual disabilities and academics in 2012, under the leadership of the University of Manchester, UK. A further special Issue of the *Journal of Applied Research in Intellectual Disabilities* was published in 2014. Inclusive research has had an increasing impact internationally, particularly in Australia (Bigby et al., 2014), New Zealand (associated with the Donald Beasley Institute http://www.donaldbeasley.org.nz), Nordic (Hreinsdóttir, Stefánsdóttir, Lewthwaite, Ledger, & Shufflebotham, 2006), the Republic of Ireland (Bane et al., 2012; García Iriarte, O'Brien, & Chadwick, 2014; García Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty, 2014; Johnson, Minogue, & Hopklins, 2014), and more recently in other West European countries (Buchner, Koenig, & Schuppener, 2016; Goethals et al., 2016; Koenig, 2012; Woelders, Abma, Visser, & Schipper, 2015).

Whether the research is emancipatory or participatory, the tenets of inclusive research demand a shift in power from academic researchers without disability to co-researchers with intellectual disabilities. The degree to which this happens varies with the particular study; and, arguably, with the stage of the research (Seale et al., 2015).

Conducting research with people who are not trained researchers and who have intellectual disabilities raises particular challenges when writing up and disseminating the research, particularly when academically rigorous outlets are sought. It is highly unlikely that co-researchers will be able to sole author journal papers; therefore, this task usually falls to academics (McClimens, 2004). Yet, if it is important that people with intellectual disabilities are full partners in inclusive research, then the authors of this paper agree with Nind (2014) that it is important that they are involved in the writing up stage, and that the contribution they make is recognized. This aspect has been less debated in the literature than issues such as training co-researchers (Cook & Inglis, 2009; Nind, Chapman, Seale, & Tilley,

2015; Perry & Felce, 2004; Strnadová, Cumming, Knox, & Parmenter, 2014), co-design of research methods (Bigby et al., 2014; Walmsley & Johnson, 2003), or, more recently, participatory data analysis (Nind, 2011; Seale et al., 2015; Stevenson, 2014). Nevertheless, the involvement of co-researchers with intellectual disabilities in the writing up process has surfaced from time to time. McClimens (2004) asked of academic publications 'What difference does it make who is speaking?', and the same scholar, in 2008, wrote a sole authored paper inspired by an inclusive research project in which he had participated. He delineated the challenges of reconciling academic convention with co-authoring. He made the broad point, with which this paper wrestles, that an academic paper is structured by a researcher, for his or her own purpose, registered in his or her own voice (McClimens, 2008, p. 275). He noted the danger of academic researchers being accused of ventriloquism if they include reported speech or selected quotations from co-researchers in what is essentially their article. He also raises some procedural questions, for example, 'How does alphabetical listing work if contributions vary wildly? What of the people who dropped out before the writing stage?' (p. 275). Goethals et al. (2016) also problematize voice and draw on the work of Lawrence-Lightfoot and Davis (1997) to critically analyse their own work as researchers with self-advocates in Flanders. It is the way inclusive research teams have met such challenges since 2003 that is the focus of this paper.

The aim of this article is to report on the ways the voices of co-researchers are represented in the published peer-reviewed journal articles. This is significant, because as inclusive research becomes more widely adopted, it is timely to draw attention to this problematic issue, and to offer some guidance.

4 | METHOD

A review of peer-reviewed journal articles published between January 2003 and June 2016 was conducted to answer the question: How is the voice of co-researchers with intellectual disabilities represented in peer-reviewed journal articles reporting on inclusive research?

Databases searched for the purpose of this article were the following: ERIC, PsycINFOR and Scopus. In addition, a search of Google Scholar was undertaken to identify journal articles, which were not yielded by the specified databases. A hand search was undertaken in four peer-reviewed journals, which have consistently published in the area of inclusive research: *British Journal of Learning Disabilities*, *Disability & Society*, *Journal of Applied Research in Intellectual Disabilities*, and *Journal of Intellectual & Developmental Disability*.

The inclusion criteria for peer-reviewed journal articles were as follows: (a) published in English; (b) published in or after 2003, when the seminal work on inclusive research was published (Walmsley & Johnson, 2003); (c) reported on one or more research projects in which people with intellectual disabilities participated as co-researchers.

The keywords used for searches were the following:

"inclusive research" OR "participatory research" OR "emancipatory research"

AND

"intellectual disability" OR "learning disability" OR "mental retardation" OR "developmental disability".

The database search yielded 103 articles. The manual search of the selected journals yielded a further seven articles, which met the inclusion criteria. Both database and manual searches took place between January and June 2016. In order to apply the criterion of including only peer-reviewed articles that reported on specific research projects in which people with intellectual disabilities participated as researchers, the first author read all the abstracts. The result was an exclusion of 52 of 110 papers. The second author independently repeated the process by reading abstracts of all 110 articles, and excluded 58 articles. Inter-rater reliability counted using Cohen's kappa was high at $\kappa = .8912$ (Cohen, 1960; McHugh, 2012). The disagreements were resolved by repeated readings of the articles and discussion. This process resulted in 52 journal articles meeting the inclusion criteria.

The boundaries were not clear-cut regarding inclusion criterion (c), according to which the included articles had to report on one or more research projects in which people with intellectual disabilities participated as researchers. Some articles, which claimed in their title to be 'inclusive', did not meet the definition of inclusive research adopted for this paper, 'research in which people with learning disabilities are involved as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users' (Walmsley & Johnson, 2003, p. 62). An example is Boland, Daly, and Staines (2008). The title included the term 'inclusive intellectual disability research', but was about academic researchers accessing the perspectives of people with disabilities. There were also some articles which recounted the life stories of people with intellectual disabilities (e.g. Hamilton & Atkinson, 2009; Roberts & Hamilton, 2010), which did not meet criterion (c) because there was no description of how the accounts were obtained.

The next step was to read the selected papers in full to verify that the articles met the inclusion criteria, and to conduct the analysis in order to answer the research question: How is the voice of co-researchers with intellectual disabilities represented in peer-reviewed journal articles reporting on inclusive research?

Through further readings of the selected papers, the authors identified research subquestions to be addressed:

1. Were co-researchers with intellectual disabilities named authors?
2. Was the process of co-authoring transparent?
3. Was there space for co-researchers' reflections on research process and/or results?
4. How was the voice of co-researchers with intellectual disabilities represented (e.g. use of direct quotations, reported speech, shared authorship – 'we')?

Each author independently answered these questions for each article. The authors then compared the results of their analysis and discussed all areas where they disagreed.

As a result, the authors developed a typology of how voices of co-researchers with intellectual disabilities are presented in articles on inclusive research. [Please note that the 110 yielded articles, and thus also the 52 selected articles, do not represent an exhaustive list of the body of inclusive research articles. These are only representative of the database and manual search employed by the authors for the purpose of this article.]

5 | RESULTS

The authors found four types of articles in relation to how the voice of co-researchers with intellectual disabilities was presented (see Table 1). These types were the following:

(a) Articles co-authored by co-researchers with intellectual disabilities, which included an account of how the research team cooperated to write the article with distinctive co-researcher contributions;

(b) Articles, which were co-authored by co-researchers with intellectual disabilities and included their reflections; however, the authorship process was not explained;

(c) Articles, which are academic researchers' reflections on inclusive research including some quotations or reported speech from co-researchers with intellectual disabilities;

(d) Articles purely written as academic researchers' reflections on inclusive research.

The detailed description of these types of articles is further discussed, including strength and challenges encountered in each of the types.

5.1 | Type (a) articles: Articles co-authored by co-researchers with intellectual disabilities, which included an account of how the research team cooperated to write the article

There were nine articles in type (a) that is co-authored by co-researchers with intellectual disabilities, which include an account of how the research team cooperated to write the article, with distinctive co-researcher contributions. Different approaches included:

1. shared authorship using 'we' throughout the article
2. first person account in the voice of the co-researcher
3. article divided into sections written by academic researchers and sections written by co-researchers with intellectual disabilities.

Abell et al. (2007) is an exemplar of shared authorship, using 'we'. The inclusive research team co-authored the manuscript and provided a clear description of authorship process (e.g. the whole team discussed the article content; the names of people who made notes are mentioned, as well as the names of people who turned these notes into an article). The article includes boxes with thoughts and reflections of individual group members. The idea of giving people with intellectual disabilities a voice is

also addressed: 'The main reason is to do research but the group is also about giving people with learning disabilities a voice in the research community.' (p. 121) Similar approaches were used by Bentley et al. (2011), Björnsdóttir and Svensdóttir (2008), and Butler, Cresswell, Nikoletta, and Tuffrey-Wijne (2012).

There was one article written in the 'first person', with an academic researcher seemingly in the role of ghost writer (Atkinson & Walmsley, 1999, p. 210). White and Morgan's (2012) article, though co-authored, is written in the first person (i.e. 'I') by Emma (White), a co-researcher with intellectual disabilities. The process of co-authoring the article is described in great detail.

The authors of those articles in which the voice of co-researchers with intellectual disabilities is distinct from the voice of academic researchers approached this in different ways. Walmsley (2014) used different fonts to distinguish the words of the academic researcher from those of the co-researchers and used 'we' for shared ideas. Tuffrey-Wijne and Butler (2010) included a vignette written by the co-researcher, as well as a section with the co-researcher's reflections. In Williams and Simons's (2005) article, the academic researchers wrote most of the article. The summary version of the article was read and commented on by the co-researchers, and their comments are included in bold. The article by Williams et al. (2003) was written by the academic researcher, who reflects on the process and way this article was co-authored:

> However, partly because of lack of time and resources, the team made a joint decision that the research supporter should be the main author of the current paper. She took the text back to the whole team who went through it, read it out and revised the wording, content and style many times. This final version is thus a group effort, as is all academic writing.
>
> (p. 220)

There are advantages to both shared authorship and distinctive contributions approaches. The shared authorship approach is more in tune with a standard academic approach to co-authoring articles, as typically co-authors of an article do not have distinctive voices (a point made by Williams & Simons, 2005, quoted above). On the other hand, explaining which parts of an article were written by a co-researcher provides greater transparency of inclusive research processes, which has been long called for (Walmsley, 2004).

5.2 | Type (b) articles: Articles, which were co-authored by co-researchers with intellectual disabilities and included their reflections; however, the authorship process was not explained

There were thirteen articles, which were co-authored by co-researchers with intellectual disabilities and included their reflections, but where the authorship process was not explained. For example, while Burke et al.'s (2003) article is co-authored, it is unclear from the text, in what way the process of co-authoring this article was

TABLE 1 Types of articles about inclusive research

Type of article	Articles about inclusive research
Type (a) – 9 articles Articles co-authored by co-researchers with intellectual disabilities, which include account of how the research team cooperated to write the article with distinctive co-researcher contributions	Abell et al. (2007)
	Bentley et al. (2011)
	Björnsdóttir and Svensdóttir (2008)
	Butler et al. (2012)
	Tuffrey-Wijne and Butler (2010)
	Walmsley (2014)
	White and Morgan (2012)
	Williams et al. (2003)
	Williams, Simons and Swindon People First Research Team (2005)
Type (b) – 13 articles Articles co-authored by co-researchers with intellectual disabilities, which include their reflections, however the authorship process not explained	Bane et al. (2012)
	Burke et al. (2003)
	Dias et al. (2012)
	García Iriarte, O'Brien, McConkey et al. (2014)
	Garbutt et al. (2010)
	Johnson et al. (2014)
	Michell (2012)
	Strnadová et al. (2014)
	Tilly and 'Money, Friends and Making Ends Meet' Research Group (2015)
	Townson et al. (2004)
	Turk et al. (2012)
	Williams et al. (2015)
	Williams et al. (2010)
Type (c) – 20 articles Articles which are academic researchers' reflections on inclusive research including some quotations or reported speech from co-researchers with intellectual disabilities	Bigby and Frawley (2010)
	Bigby et al. (2014)
	Brooks and Davies (2008)
	Cook and Inglis (2009, 2012)
	Chapman and McNulty (2004)
	Cumming et al. (2014)
	Inglis and Cook (2011)
	García Iriarte, O'Brien, & Chadwick (2014)
	Koenig (2012)
	Kramer et al. (2011)
	Manning (2010)
	McVilly et al. (2006)
	Nierse and Abma (2011)
	Nind and Vinha (2014)
	Ollerton and Horsfall (2013)
	Povee et al. (2014)
	Puyalto et al. (2016)
	Stevenson (2014)
	Walmsley (2011)

(Continues)

TABLE 1 (Continued)

Type of article	Articles about inclusive research
Type (d) – 10 articles Articles written as academic researchers' reflections on inclusive research	Chapman (2014)
	Herron et al. (2015)
	Johnson (2009)
	O'Brien et al. (2014)
	Perry and Felce (2004)
	Power et al. (2016)
	Strnadová et al. (2015)
	Strnadová et al. (2016)
	Woelders et al. (2015)
	Young and Chesson (2008)

approached. The co-researchers do not have a distinctive voice. While Garbutt, Tattersall, Dunn, and Boycott-Garnett (2010) did not specifically address the way they co-authored the article, it is written in the form of shared authorship (using 'we'), and in an accessible way (using large print, with each paragraph accompanied with a picture). It seems that the parts of the article written by an academic researcher are in footnotes, as the footnotes are written in an academic style, using references to support an argument. Michell's (2012) was another accessible article, where the process of co-authoring is unclear. It seems that the only named author, Bryan Michell, is a support worker with My Life My Choice, yet the article is written using a shared authorship approach (i.e., 'we'). The voice of co-researchers with intellectual disabilities is distinctive, as a number of their direct quotations, individual reports and research notes are used. While Williams, Ponting, and Ford (2015) did not address the process of co-authoring the article, it is clear which parts of the paper were written by the two co-researchers, and which part was written by the academic researcher, given the use of headings (e.g., 'Main Article (Williams)' on p. 107). The article by Tilly (2015) is co-authored by seven co-researchers with intellectual disabilities. It seems that parts of the article are written by Liz Tilly, and parts are co-authored by co-researchers (these parts are written using the pronoun 'we').

Johnson et al. (2014) reflect on two inclusive research studies conducted in Australia, and the Republic of Ireland. The paper is authored by two researchers and one co-researcher with intellectual disabilities, without any explanation of the authorship process. Similarly, articles by Strnadová et al. (2014), Townson et al. (2004), Turk et al. (2012), Williams, Ponting, Ford, and Rudge (2010), Bane et al. (2012), Dias et al. (2012), García Iriarte, O'Brien, and Chadwick (2014) and García Iriarte, O'Brien, McConkey et al. (2014) are co-authored by academic researchers and co-researchers with intellectual disabilities, without any clarification about the process of co-authoring the article. As a result, such co-authored articles may be perceived as tokenistic.

Three articles were not co-authored, but explained the process of developing the article and distinguish co-researchers' reflections from those of the academic authors. Bigby and Frawley (2010) described in their article, how a co-researcher with intellectual disabilities (Alan) was supported in an inclusive research team. Alan's

contribution to this article was based either on his 'conversations with the mentor or incorporated into the mentor's field notes.' (p. 55). Bigby and Frawley provided reasons why Alan was not included as a co-author (he did not meet university criteria). Similarly, Chapman and McNulty (2004) wrote an article reflecting on their experience of being research support members of the Carlisle Research 'Co-op', a research group of eight people (six with intellectual disabilities). Walmsley (2011) reported on an inclusive research study conducted in partnership with a local self-advocacy group My Life, My Choice. The author provides a clear account of her role, as well as of the role of co-researchers.

5.3 | Type (c) articles: Articles which are academic researchers' reflections on inclusive research including some quotations or reported speech from co-researchers with intellectual disabilities

The majority of articles (twenty) were authored by academics and included academic researchers' reflections on inclusive research, as well as some quotations or reported speech from co-researchers with intellectual disabilities. For example, Bigby et al. (2014) reflected on inclusive research in the area of the history of self-advocacy, focusing on the processes used by the History Group to research the history of self-advocacy. The authors reported on the thoughts of the co-researchers with intellectual disabilities and also provided a few direct quotations from co-researchers. Direct quotations of co-researchers with intellectual disabilities were used in other articles authored by academic researchers (Brooks & Davies, 2008; Cook & Inglis, 2009, 2012; Cumming, Strnadová, Knox, & Parmenter, 2014; García Iriarte, O'Brien, & Chadwick, 2014; Inglis & Cook, 2011; Kramer, Kramer, García-Iriarte, & Hammel, 2011; Manning, 2010; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Nierse & Abma, 2011; Nind & Vinha, 2014; Ollerton & Horsfall, 2013; Povee, Bishop, & Roberts, 2014; Puyalto, Pallisera, Fullana, & Vilà, 2016; Stevenson, 2014). In Koenig's (2012), co-researchers with intellectual disabilities role was being a part of a reference group. Their direct quotations (translated from German) were presented.

This approach of academic researchers authoring articles and including co-researchers' thoughts and quotations still provides opportunities for co-researchers' voices to be heard. It, however, raises some important questions, such as: How were the direct quotations selected? Were those selected really the best representation of what the co-researchers wanted/would have wanted to say? To what extent were the co-researchers consulted about the use of their words to illustrate academic researchers' point? And is addressing this something that is desirable?

5.4 | Type (d) articles: Articles purely written as academic researchers' reflections on inclusive research

Finally, ten articles were purely written as academic researchers' reflections on inclusive research. Chapman (2014) reported on findings of a qualitative team research project, which focused on

the role of support workers in UK self-advocacy organizations. Herron, Priest, and Read (2015) reported on work with an advisory group. The co-researchers with intellectual disabilities were involved/consulted in the development of information sheets and consent forms and interview questions, described in detail. Johnson (2009) reflected on two inclusive research projects, while O'Brien, McConkey, and García-Iriarte (2014) reflected on the process of conducting inclusive research with people with intellectual disabilities at a national level. Perry and Felce (2004) described training for a co-researcher to learn how to conduct interviews with people with intellectual disabilities about their quality of life. The authors also made comparisons between the interviews conducted by a co-researcher and an academic researcher. Power, Bartlett, and Hall (2016) reported on using 'an inclusive 'co-produced' research methodology' to empower people with intellectual disabilities (p. 185). Strnadová, Cumming, Knox, Parmenter, and Lee (2015) presented findings of an inclusive research study focused on identifying factors influencing the well-being of older women with intellectual disabilities and their self-reported satisfaction with their life as they age. Strnadová, Walmsley, Johnson, and Cumming (2016) reflected on three inclusive research studies, and on different approaches to inclusive research they used. Woelders et al. (2015) discussed experiences of academic researchers with inclusive research, with a focus on the power dynamics and the added value in the involvement of co-researchers. Finally, Young and Chesson (2008) reported on a participatory research project, where co-researchers and their carers contributed to setting up research questions, thus setting research agenda.

These academic researchers' articles about inclusive research provide important reflections on successes and challenges experienced when using inclusive research approaches. Such articles also provide the space for academic researchers that Walmsley and Johnson called for in their seminal work (2003). This article is itself an example of this type of publication. The question of course is whether such reflections should also provide space where voices of co-researchers can be heard, or whether this is not always necessary.

6 | DISCUSSION

The authors analysed 52 peer-reviewed journal articles about inclusive research to establish in what ways is the voice of co-researchers with intellectual disabilities were presented. Four main types of articles were identified, with 30 articles being authored solely by academic researchers (and only 20 including direct quotations or reported speech of co-researchers). While 21 articles were co-authored by co-researchers with intellectual disabilities (Research subquestion 1), 13 of these articles did not provide any explanation of the authorship process (Research subquestion 2). The majority of reviewed articles (41) included co-researchers' reflections on research process and/or results (Research subquestion 3). The voice of co-researchers was mostly presented by direct quotations, reported speech and/or use of photographs made by/of

co-researchers, which is more common than co-authorship of articles (Research subquestion 4).

This article leads us to consider the importance of transparency about the co-authoring process. It has been argued that the voice of co-researchers with intellectual disabilities needs to be articulated in articles reporting on inclusive research with co-researchers with intellectual disabilities. Nevertheless, it remains a question in what way this can be best achieved. While there has been a call for transparency when referring to the process of inclusive research, including co-authoring articles (Walmsley, 2004), the authors of articles in peer-reviewed journals have not been held to these standards. While peer-reviewed journals have policies on what it means to be a (co-) author of a journal article, the authors are usually not asked to explain their exact contribution within an article. This can be partially explained by the assumption that all authors are aware of journals' authorship policies, and resolve the co-authoring process via discussion, without explicitly describing it in the manuscript itself. However, this assumption is not necessarily well founded in participatory research which, by its very nature, includes people who are not familiar with academic publishing. Furthermore, the description of the writing process may result in a lengthy section, which could be undesirable given generally limited length for publications in academic journals. Should the explanation of co-authoring process be required when it comes to inclusive research articles? If a clarity about the process of co-authoring an inclusive research article, or any article based on participatory methods, is not addressed, there is a risk of tokenism. If explicit detail on the process of co-authoring articles reporting on inclusive research is requested, then there is a fundamental question to be asked – why are not academic authors held up to the same standards?

The findings in this paper indicate that there is wide variation in the ways inclusive research teams report on their work in peer-reviewed articles. Given the symbolic and practical importance of inclusive research, the authors would propose that efforts are made to encourage authors of such papers to consider the issues discussed in this paper – attribution of authorship; description of the writing process; reporting on the contributions, views and reflections of co-researchers. In the concluding section, some guidelines are proposed, while recognizing the value of enabling academic researchers to have space to reflect upon the experience of co-researching with people with intellectual disabilities, as the authors of this paper have done.

A further question that needs to be raised is about the value of involving co-researchers and academics in writing academic articles, as well as publishing research findings in other media, which maybe more useful for advocacy. For example, publishing research results via film or theatre would be a way to allow people with intellectual disabilities to benefit from shared ownership. Furthermore, co-researchers with intellectual disabilities often describe these media as their favoured way to disseminate research findings (see, e.g., My Life My Choice's film of their own history http://mylifemychoice.org.uk/campaigns/films/). While it is important to disseminate new knowledge via academic journals to inform further research, there are admittedly some underlying existing tensions between the pressure for publication in academic journals for academics and the relevance of research for advocacy for people with intellectual disabilities, which are hard to resolve.

7 | CONCLUSION

It is possible to conclude from this that there are no common standards or expectations when it comes to attributing authorship in articles reporting on inclusive research projects. The authors would propose that it would be helpful in promoting the value of inclusive research if authors consider, further discuss and explore with teams of co-researchers the guidelines below, suggested by the way this article has been structured.

7.1 | Attribution of authorship

In reporting on inclusive research projects, authors are expected to include all members of the research team as authors, or to explain why they are not included.

7.2 | Description of the writing process

The process of co-authoring should be described when papers are co-authored by researchers and co-researchers.

7.3 | Reporting on the contributions, views and reflections of co-researchers

When writing peer-reviewed journal articles reporting on inclusive research projects, good practice dictates that the distinctive voices of co-researchers with intellectual disabilities find a place in the text.

7.4 | Finding space for reflection

There is a place for journal articles where academic researchers reflect upon the process of inclusive research. It is also appropriate to find space for the reflections of co-researchers on their experiences of inclusive research.

This article has sought to meet Walmsley's (2004) call for 'the contributions they (co-researchers) make to be named and described and recognized for what they are' (p. 69) so that others can build constructively on what has gone before. The authors would argue that this applies as much to the process of authoring as it does to other steps in the research process.

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