ORIGINAL ARTICLE



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Inclusive peer review: Reflections on an adapted citizens' jury with people with learning disabilities

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Abstract

Background: Inclusive research is widely accepted as an essential part of the process to democratise knowledge creation and dissemination. However, while peer review is an important part of academic publishing, the potential to include people with learning disabilities in this element of the research process has not previously been explored using a deliberative approach.

Methods: Accessibility adaptations were made to the citizens' jury approach enabling people with learning disabilities to participate. Sixteen adults with mild to moderate learning disabilities were recruited to participate in the adapted citizens' jury. Jury members took part in capacity-building workshops to develop their knowledge of research and research processes. Six expert witnesses presented evidence to the citizens' jury and were questioned on aspects of inclusive research, representation, peer review and academic publishing processes. Facilitators supported citizens' jury members to reflect on the evidence presented and to develop recommendations for inclusive peer review.

Findings: The citizens' jury was an effective inclusive research approach in this case. Jurors made recommendations related to the question of inclusive peer review: inclusive reviews should be done by groups rather than individuals; the research under review must be in accessible formats and on relevant topics; reviewers need sufficient time to conduct reviews; and diverse groups of people with learning disabilities should be involved.

Conclusions: People with learning disabilities appreciate the importance of peer review but do not necessarily want to participate in it. This jury suggested creative approaches to disseminating, reviewing and engaging with research, including building more opportunities for dialogue between researchers and selfadvocates. The adapted citizens' jury was a novel and effective method of supporting deliberation on this topic but other approaches to including the views and experiences of those with more severe learning disabilities should be explored.

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KEYWORDS

citizens' jury, deliberative democracy, inclusive research, intellectual disabilities, learning disabilities, peer review

Accessible Summaries

- Peer review is an important part of making sure that research is done properly.
- The project was set up to make recommendations about how research reviews could be more inclusive of people with learning disabilities.
- We used an accessible citizens' jury to talk about research reviews with a group of people with learning disabilities.
- People with learning disabilities understand that reviewing research is important.
 The group suggested different ways that people with learning disabilities could be involved in publishing and sharing research.
- We found out that an accessible citizens' jury is a good way to talk about complicated issues with people with mild to moderate learning disabilities.

1 | INTRODUCTION

The objective of this paper is to critically evaluate the adapted citizens' jury method that we adopted in a novel project concerned with developing recommendations for the largely unchartered territory of including people with learning disabilities in the peer review process for the British Journal of Learning Disabilities (BJLD). In evaluating this innovative approach, we discuss the jury's priorities in engaging with research that concerns them and discuss the outcome. We begin by outlining the key ideas in the paper.

BJLD is committed to supporting the rights of people with learning disabilities and working to improve their lives (Nind, 2020). Inclusive research is a core part of democratising the research process and opening it up to people with learning disabilities. It enables people with learning disabilities to take active roles in the research process and not just be the object of the academic research gaze. However, as we show in our literature review below, the peer review process has tended to remain the purview of academics and the involvement of people with learning disabilities and other researchers outside the academy happens rarely.

Peer review is an essential part of the research cycle and involves other researchers (peers) commenting on the quality of a paper. Most authors seek feedback from their peers even before submitting a paper for consideration by a journal for publication. After submission, the peer review process becomes a formal part of the process of deciding whether to accept or reject the paper and giving feedback on how it might be improved. As Wiley (2023), the publishers of this journal, clarify, peer review is designed 'to assess the validity, quality and often the originality of articles for publication' maintaining academic integrity by 'filtering out invalid or poor-quality articles'; it has to establish that the research was done responsibly, with respect, and following agreed rules. The nature of peer review is that the feedback comments are made by experts in the same field as the author/s.

We created a citizens' jury of people with learning disabilities to deliberate on what the inclusion of people with learning disabilities might add to the research process (the wisdom of doing this) and what kind of model of inclusive peer review might work (the feasibility). We wanted to explore these wisdom and viability dimensions of inclusive peer review for a journal that values dialogue with people with learning disabilities and the usefulness of citizen jury as a method for doing this. We describe citizens' juries in more detail in the methods section.

2 | LITERATURE REVIEW

Inclusive research, which has become gradually more established in learning disabilities research since the 1980s, asserts that disabled people can be active participants in research rather than mere objects of research. It has been named, characterised, advocated for and experimented with as a phenomenon of importance to people with learning disabilities and their allies. Walmsley and Johnson (2003) originally characterised inclusive research as beyond participation; it was research in which disabled people owned the research problem, collaborated in the research process and exerted some control over it, such that the research represented their views and experiences, and became for their benefit and improved lives, and was respectful and accessible. Writing recently with Strnadová, they have expanded their defining characteristics to stress that the research must be aimed at social change and be research 'in which those involved in it are "standing with" those whose issues are being explored or investigated' (Walmsley et al., 2017, p. 758). Inclusive research, therefore, is unashamedly political (Woelders et al., 2015), becoming more so if anything. Exploring the rise of inclusive research across fields and disciplines, Nind (2014) argues for its position within a wider movement to democratise research.

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For this paper, what matters most is what people with learning disabilities say about inclusive research and why it-and aspects of it-matter to people. García Iriarte et al. (2023) show a level of maturity emerging in which established inclusive research teams can evolve and become self-critical. Nind and Vinha (2014) and Armstrong et al. (2022), using dialogue to take stock of progress in inclusive research note that we ask it to do a lot, including producing important, impactful findings via egalitarian processes that are empowering for self-advocates and self-advocacy. Hence, as Woelders et al. (2015) argue, idealisation can take root, expecting inclusive research to be some kind of panacea. In 'a world where people with learning disabilities are routinely excluded' (Armstrong et al., 2022, p. 314), inclusive research has become a symbol of change as well as a route to change; it represents the rights of people with learning disabilities to 'interpret their own lives' (p. 317).

The political and ethical arguments for the democratisation of research urge us all to be inclusive and to support the building of capacity for undertaking research among people with learning disabilities interested in generating their own knowledge. One of the conclusions of Armstrong et al. (2022, p. 326) is that such investment in building capacity 'is not a matter of teaching them research skills but supporting them to understand the academic world so that they can contribute'. Through being involved in all stages of research, various groups of people with learning disabilities have come to understand research bidding, ethics applications, data generation, data analysis and dissemination, including in academic journals (O'Brien et al., 2022; Tilley et al., 2021). Much of this learning has been through researching alongside academic researchers, doing research collaboratively, asking questions, posing challenges, and solving problems (Bigby & Frawley, 2010; Nind, 2016). BJLD has supported inclusive research (see O'Brien et al., 2022) and fostered the involvement of people with learning disabilities in academic roles as collaborating authors (e.g., Mikulak et al., 2022; Townson et al., 2004), guest editors (e.g., Blunt et al., 2012; Chadwick et al., 2023) incorporating an element of reviewing, and since 2020 with the In Response initiative, as partners in academic dialogue (see e.g., Lewis et al., 2020).

In this paper we focus on the largely unexplored role of people with learning disabilities as peer reviewers. Reflecting on managing a whole special issue of BJLD, Blunt et al. (2012, p. 83) comment:

it is time that people with learning disabilities became involved in *more than just* co-writing and research. We wanted to see a partnership approach to the whole process of peer review and publishing research.

They add:

The process of peer reviewing and making decisions about the articles submitted was not an easy one, and we think we have learnt some important lessons that we would like to share with you.

These lessons include how to make difficult decisions on which papers to accept and reject, how to deal with the emotional impact of papers addressing distressing issues, how to handle difficult and inaccessible language, and how to respond when authors write as if people with learning disabilities are all the same. Most recently, Cameron Richards, self-advocate, co-guest editor of the special issue on digital inclusion, echoed the accessibility challenge point and reflected: 'I got a lot of new knowledge and work experience out of being an editor' (Chadwick et al., 2023, p. 122). Similarly, Lewis et al. (2020, p. 271) ended their inaugural *In Response* paper with, 'Thank you for giving us the opportunity to respond. It is rare to be asked what we think about academic research'.

There is a nascent sense then, that inclusion in the world of academic publishing of research is appreciated by people with learning disabilities who have taken up opportunities to participate. Giving people recognition and a 'bridge' into new worlds constitute some of what we ask of inclusive research (Nind & Vinha, 2014). There is richness and purpose in having diverse perspectives informing research outputs, and epistemic justice in hearing from people with learning disabilities when it comes to research about their lives (Armstrong et al., 2022). However, there are strong warnings in the literature about bringing difference into dialogue rather than eradicating it in 'striving for normalisation', which 'can be paralysing' (Woelders et al., 2015, p. 528): Inclusive researchers may need to resist pressures for people with learning disabilities to do research roles in the same way as academic researchers, while still achieving the same levels of value for their distinctive part in the research process as well as their empowerment.

In the next section, we report on the methods we adopted to further explore, alongside people with learning disabilities, their role in the peer review process using the specific approach of an (adapted) citizens' jury. Citizens' juries have developed as an approach to public engagement that is underpinned by deliberative democratic theories (Street et al., 2014). In common with other methods of deliberative democracy, the citizens' jury approach is based on the principles of informed deliberation between a group of citizens on a specific topic. Citizens' juries have been widely used internationally to enhance public engagement with public policy-making processes, particularly around complex and contested issues of concern to communities (Roberts & Escobar, 2015; Tully et al., 2019). Wakeford and Walcon (2015) describe the process as bringing together:

Twelve or more members of the general public (the "jurors") [to] participate in a process of dialogue under the guidance of a chair or "facilitator". They interrogate specialist commentators (sometimes called witnesses) chosen because of their knowledge of a particular subject ... Jurors then draw up and publish their conclusions.

A key part of the process, which was developed by the Jefferson Center (now the Center for New Democratic Processes) in the United States, is the deliberation, usually over 2–7 days (Involve, n.d.). As the



popularity of this method of deliberative and active citizenship has increased so has the development of adaptations to the original model. Street et al. (2014, p. 8) argue for the importance of these adaptations in furthering our understanding of 'how various methodological decisions can shape jury processes and outcomes'.

Henderson et al. (2022) developed and evaluated an adapted citizens' jury model to enable a group of people (aged over 16 years) with mild to moderate learning disabilities to deliberate on the broad area of inclusive health research. The jurors on this project made 10 recommendations for inclusive health research and their work informed the development of the peer review citizens' jury project we report on here. The adapted citizens' jury model developed by Henderson et al. (2022) prioritised four components of citizens' juries: recruitment of a demographically representative group of people with learning disabilities, who were then informed through the provision of high-quality accessible information relevant to the project; witness testimonies were impartial, and the process was facilitated to enable a deliberative approach. In their review of public engagement in a research priority exercise, Gooberman-Hill et al. (2008) concluded that the structured processes of a citizens' jury (evidence sessions, facilitation and deliberation) facilitated informed and deep engagement with the topic. The adaptations to the Citizens' jury model described in detail by Henderson et al. (2022) had previously demonstrated that people with learning disabilities, when effectively supported, can deliberate and form consensus recommendations on complex issues. This provided an empirically validated methodological foundation for an approach well-suited to the aims of this study on inclusive peer review.

3 | METHODS

The current study investigated:

- What can a citizens' jury tell us about the viability and wisdom of inclusive peer review in the quest to democratise the research process and include dialogue with people with learning disabilities?
- To what extent is the adapted citizens' jury approach an effective method for delivering rapid research evidence in keeping with the ethos of doing research inclusively?

Ethics approval was given by University of Southampton Faculty of Social Science Research Ethics Committee [no. 70302]. Participants, who were people with mild to moderate learning disabilities, were given accessible information sheets and consent forms and the opportunity to discuss the research with people who support them and the research team before giving informed consent.

The citizens' jury had to adapt to the constraints of a short project timescale and the COVID-19 pandemic which impacted on demographic representativeness of the jury and mitigated against inperson meetings. Therefore, one major adaptation made to the method for this project was in the selection of participants. In essence, these were a convenience sample of self-advocates known

to the researchers. Some of the participants attended as independent individuals who had collaborated with the researchers in previous projects and others as members of self-advocacy organisations. In keeping with wider uses of citizens' juries, however, the findings were to be fed back to policymakers (in this case the editorial board and publishers) to inform policy decision-making.

There were 16 individual participants (9 male, 7 female), including five organisations and three countries—England, Scotland, and Wales. They had previous experience of inclusive research and in most cases of self-advocacy. Four additional people from the participating advocacy organisations were present in the meetings to provide practical support for participation to the self-advocates (the jury members). The role and remit of the jurors was to hear evidence from expert witnesses on inclusive peer review, to deliberate as a group on the evidence presented and to develop a set of evidence informed recommendations on which all jurors agreed. The language of juror comes from the original citizen jury method. Expert witnesses were recruited to present their perspectives on issues relevant to deliberation on inclusive peer review.

The jury process, adapted from the Center for New Democratic Processes (Figure 1) took the jurors through the stages of capacitybuilding, considering evidence, and finally collaborating on guidelines and recommendations for inclusive peer review. Two preparatory 2-hour workshops, using the Zoom platform were delivered to introduce the jurors to each other, develop their knowledge of research and research processes including the role of peer review, and to agree ground rules. These workshops were followed by four online sessions where the jury members heard evidence from six expert witnesses on separate topics. The topics were selected to enable jurors to hear and deliberate on evidence relating to inclusive research and peer review processes. Expert witnesses were drawn from diverse backgrounds and were selected on the basis of their knowledge and experience of self-advocacy in research, academic authorship, as experts by experience and in academic publishing. All had knowledge of peer and academic review processes, with the exception of the expert by experience. These evidence sessions addressed the topics of: (i) inclusive research, focusing specifically on defining this concept and reflecting on inclusive research practice; (ii) speaking for others (e.g., people with profound and multiple learning disabilities), which considered issues of representativeness within self-advocacy groups; (iii) giving and receiving a research review, examining the concept and practice of academic peer review; and (iv) the editor's and publisher's perspectives on the role of peer review in the editorial and publishing process. Jurors heard from each expert witness who explained relevant concepts or issues in a 20-minute presentation. Following each presentation, the jurors prepared questions in discussion in small groups. Each group was facilitated by a member of the research team who supported jurors to reflect on the presentation, and using prompts to ensure key issues were discussed. However, it was the jury members who agreed the final questions for the expert witnesses. Expert witnesses were given guidance on accessible presenting and asked to share their presentation with researchers in advance to support this aim. In a

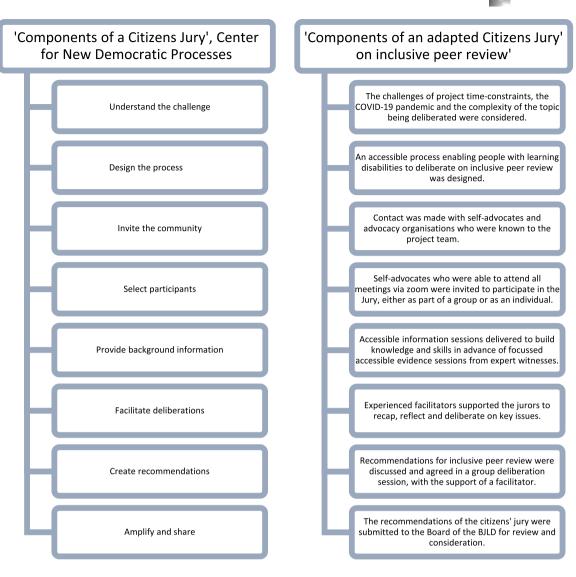


FIGURE 1 Components of an adapted Citizens' Jury. [Color figure can be viewed at wileyonlinelibrary.com]

final 2-hour session dedicated to review, deliberation and consensus forming, jurors worked together in groups, with facilitation from the research team or support staff, to find consensus and make recommendations. This session drew on analysis of recordings and summaries from all jury sessions (including data from Facebook summaries of questions and responses). A total of seven online sessions were held across the project, each session was videorecorded via Zoom. The jurors also had a group Facebook page that hosted a video of the presentations to jurors and accessible summaries of questions and discussions that followed expert witness sessions. These were available for reference and for communication and community-building between sessions. The preparatory, evidence and deliberation sessions were delivered and facilitated by academic researchers Abigail Croydon, Rhiann McLean, Angela Henderson and Angeliki Katramadou.

In addressing the wisdom of inclusive peer review, we sought to investigate the extent to which the inclusion of people with learning disabilities in peer review could add value to this part of the research process. If worth doing we needed to investigate how feasible it was and what the challenges were that we would have to negotiate. Findings in relation to these questions were drawn from the recommendations reached through the jury process. In the final meeting, jurors reviewed expert witness presentations and points made during deliberations to develop guidelines for inclusive peer review. Their conclusions were summarised in accessible language with visual supports by the research team and returned to jurors for comment and amendment. In this sense, the findings emerged from a thorough participatory process of analysis, accessible presentation, and review/amendment by jury members. For the present paper, Abigail Croydon reviewed the workshop recordings to identify potential omissions regarding coverage of the issues and to select quotations that aligned with findings. The findings with respect to the usefulness of the jury method are presented thematically and we drew these from the juror's and moderators' comments on the jury experience captured in the session recordings, field notes and reflections from the academic team.



A member of the citizens' jury, John Cassidy, agreed to collaborate in the development of this manuscript and was supported by Angela Henderson to reflect on the initial objectives of the project and the extent to which these were achieved. Through six meetings, John and Angela met (via a combination of virtual and in-person meetings) to discuss, agree and amend sections of the manuscript and to reflect on specific themes from the perspective of a jury member. All contributing authors met via Zoom at different stages in the development of the manuscript to support this collaboration.

4 | FINDINGS

The findings address first the jurors' conclusions about the viability and wisdom of inclusive peer review before addressing the effectiveness of the citizen's jury method. We summarise the recommendations made by the Jury to BJLD, which were reached following the final review session where jury members were supported to reflect on all previous jury sessions, undergo further deliberation and reach a group consensus.

4.1 | Inclusive peer review

Jurors were confident in their understanding of the logic of inclusive research. Some referred to extensive experience within research teams. Three themes emerged early and recurred regularly in later sessions. First was the perennial issue of accessibility of information about research ('a journal needs to be easy read and accessible and photo symbols' said one juror). The second was the frustrating slowness of academic research processes, especially in terms of delivering social change. This was a particular concern for jurors engaged in activism. Third, and most positively, jurors talked about the value of learning collectively about research, summed up by one juror as 'the more we get together and talk, the smarter we get, and knowledge is power'.

Bearing in mind the priority for diverse perspectives to inform research outputs, and our recruitment of people involved in self-advocacy and with prior research experience, we explored with jurors their role in 'representing others', especially those experiencing more severe disability. The expert witness for this session presented on the challenge of participation and 'voice' for people with profound and multiple learning disabilities. She introduced the example of her daughter and highlighted the challenge—'we want to give them their voice and not give them our voice'. This session was effective in extending thinking about the means of inclusion and representation at the intersection of learning disability and academic research. A juror reflected on the difference between his aspirations for himself and what the witness's daughter's preferences might have been:

My voice is like trying to find the right sort of questions to ask, to try not to say something which might feel like the wrong thing to say ... I want to be

independent, but she couldn't be ... not everyone can or even wants to do this...

His reflection gave rise to discussion of whether the witness and her daughter together might be able to take part in peer review and question to the witness, 'is there a way in which teams can get involved rather than individuals?' The idea of joint peer review developed through subsequent sessions as jurors thought about the 'know-how' challenges involved in peer reviewing and the social, well-being and learning priorities of people with learning disabilities. Working on reviewing in teams might reduce the investment of time and effort involved in addressing peer review, while providing meaningful social and learning opportunities important for the wellbeing and agency of people with learning disabilities.

Jurors considered who might be invited to do peer review. A juror with experience of Patient and Public Involvement in research made the case to widen recruitment beyond self-advocacy groups as 'more people with disabilities are not in self-advocacy'. In their recommendations, jurors emphasised the importance of diverse representation of groups of people with learning disabilities in inclusive reviews.

The BJLD *In Response* initiative provided the expert witnesses for the issues of receiving and giving feedback on a journal paper. Jurors heard from the lead researcher of a project on fathers with learning disabilities (Symonds et al., 2021) and from members of the group that had read and responded to the paper (Williams et al., 2021). This session produced intense discussion, with focus on questions about recruitment and the findings of the research as well as the reviewing process. Jurors with experience of parenting saw this as an outstanding example of research with personal relevance. The associated video featuring reconstruction of vignettes and debates from the research contributed significantly to communicating the aims and findings and this feature was a focus of deliberation.

The expert witnesses who had given feedback on the journal paper made powerful points regarding the process of choosing what to engage with. The 'accessible' summaries they selected included some that they regarded as wholly inaccessible, meaning that 'people aren't going to want to engage with that research'. Following this session, in particular, jurors discussed the limitations of easy read formats ('I'm no bothered about easy read') and moved towards seeking video and audio research summaries.

Jurors developed the theme of investing time and effort in producing inclusive peer reviews. There was some scepticism about the balance between effort and reward, in terms of pay, intrinsic reward and achieving social change. Developing reviews in in-person meetings and in dialogue with academic authors (the process followed in the *In response* initiative) appeared to improve the balance. The witnesses on giving and receiving feedback gave positive accounts of the benefits of the experience, with the reviewers saying, 'we all felt - what's the word - boosted by being part of this conversation'. This contrasted with the academic witness' account of anonymous peer review processes as sometimes 'nerve-wracking'.

The research topic of the session (fathers with learning disabilities) prompted discussion about the purposes of learning about research for jury members. One juror was 'spellbound' by the topic, 'it's so close to my heart, I got a lump in my throat thinking about this'. He returned to the theme raised earlier of the benefits of meeting and talking in groups about research, 'what I think is missing is the encouragement to show people with disabilities that you can help improve your life or somebody else's life because you learn something ... researchers don't make enough of that right, they're just "let's get your answer". This was a key reason for seeking group debate about research-its function in terms of learning and wellbeing: 'if a guy finds out that it's no just peer review, but it could help their mental health-that would encourage a man [otherwise it's] "can't be bothered mate". This juror argued for structured and supported debate among peers with learning disabilities about personally relevant research, whether producing a peer review or another form of engagement with research. Others endorsed this emphasis on learning, though there was also contrast with activists who saw research more in terms of serving the purposes of activism. This debate arose in response to some jurors' doubts about the benefits of peer review to people with pressing practical difficulties: 'people might ask themselves: What's the point in joining the peer review groups?'

The discussion highlighted that jurors' interest in reviewing research was selective, even conditional. One juror argued that if research 'said something about your life', it might be worth the time and effort involved in getting to grips with it. This became a key point in the guidance for inclusive peer review. Jurors who saw themselves as primarily activists sought better focus by researchers on orienting research towards support for self-advocacy campaigns. Other aspects of research, setting research priorities and taking part in dissemination/impact activities, in particular, might have a higher priority for people with learning disabilities. An advocacy group leader felt that people might need a clear understanding that contributing to peer review might deliver change in academia rather than wider social change. Implicit in these strands of thought was a resistance to the exclusive nature of academic writing and publishing, its priorities, timescales, and accessibility ('you can't buy [journals] in WH Smiths or on Amazon or anything'). Ultimately, the set of consensus recommendations on inclusive peer review were that:

- Reviewing should be done by groups not individuals, in dialogue with authors, not anonymously.
- Research for review must be genuinely accessible and engaging, for example, using video and audio formats.
- We would like to review research concerning topics that we know about and are relevant to our lives.
- We need time for processing information and engaging in debate about the research reviewed, which means proper funding.
- We want to include as many different people as possible, including people with more severe disabilities, people who are not members of self-advocacy groups and people from black and minority ethnic groups.

The jurors also had concerns and practical suggestions for improving research outputs:

- We need an accessible research journal for all people not just people in universities.
- We need forums for learning and discussion about research besides peer review.
- We would like to be paid, but some of us think that taking part is more important than being paid.

4.2 | The citizen's jury method

Street et al. (2014) recommend that in evaluating citizens' juries, special attention should be paid to recruitment, moderation, and jury duration. In the case of people with learning disabilities, there are intrinsic difficulties in attempting to represent the population concerned. In our research, short timescales and limited funding also ruled out seeking to represent the demographic profile of the population with learning disabilities. Knowledge of inclusive research was determined to be a requirement to progress efficiently to deliberating the case for peer review. This meant that juror recruitment focused on people with stronger verbal skills and milder learning disabilities. However, we sought to address the question of representation as part of the jury process itself. Citizens' juries though lend themselves to populations who can converse with ease.

With respect to moderation, the research team, who all work in learning disabilities research, selected and briefed witnesses, moderated all sessions and summarised group questions and discussions in accessible formats for jurors' reference between sessions. Two team members provided support to breakout groups of jurors to facilitate discussion and develop questions for witnesses. We balanced the priority to make progress on the topic with the wider remit of enabling participation and deliberation. Facilitators experienced some limitations in providing remote support to jury members, including technical support. This was particularly the case where members attended as a group sharing one screen, preventing them from joining breakout rooms as individuals. This meant that the research team could not always distinguish individual voices, including the voice of group support staff from that of jurors.

The duration of our jury was 14 hours, over a 7-week period, a comparatively long participation compared with others reviewed by Street et al. (2014). Nevertheless, some participants felt there was not enough time to process information and to deliberate. This may have reflected, in part, the conceptual difficulty of the topic of peer review, but also jurors' interests in debating issues of inclusion, accessibility, and research dissemination beyond peer review.

The Facebook group was designed to extend the possibilities for participation, by giving jurors access to presentations and questions, and the facility to engage in debate between sessions. There was little active participation in this, though participants referred to the resources. A greater sense of community and participation might have been achieved through attendance in person, though this would have reduced geographical spread. Jurors' concerns at the outset

(e.g., regarding the accessibility of language) developed as they deliberated. The idea of group peer review, a key recommendation, gained traction across the sessions as jurors became confident that the academic format could be reformulated.

Jurors reported that the jury process had provided an enriching, collaborative experience, which was valuable in terms of learning, opportunities to collaborate with others with learning disabilities and to be heard in a supportive environment. The jury process successfully established the jurors' views on academic review and provided a strong foundation for developing a more inclusive approach to academic publishing. In summary, the citizen's jury method adapted successfully to provide guidance on inclusive peer review from a particular learning disability perspective at short notice. It was experienced as democratic and deliberative in line with the wider principles the citizens' jury concept.

5 | DISCUSSION

This novel and inclusive approach to exploring the potential role of people with learning disabilities in the specific area of peer review makes a significant contribution to the conceptualisation and practice of inclusive research. In this project we investigated the viability and wisdom of inclusive peer review through a structured dialogue with people with learning disabilities, using an adapted citizens' jury method. A key driver was to provide recommendations to the editor and publishers of BJLD, on how to further democratise the academic publishing process, and specifically on how to further include the perspectives of people with learning disabilities. Thus, following a process of deliberation and consensus forming this citizens' jury produced a series of clear recommendations on the question of the viability and wisdom of inclusive peer review.

The jurors welcomed the inclusive potential of peer review by people with learning disabilities. Their consensus recommendations, however, did not suggest methods of replicating the peer review system that is already an established part of the academic process. In exploring the potential for people with learning disabilities to become meaningfully engaged in peer review we were reminded of the argument of a researcher with learning disabilities that 'it was not important to do exactly the same thing as an academic researcher did, but to do what was within her capacity' (Woelders et al., 2015, p. 538) and of the 'taken-for-granted academic frameworks and demands' (p. 539). Instead, the jury recommendations prioritised the need to foster dialogue between authors and reviewers, community representation, participation in reviewing research of direct relevance to their experiences and interests and improving accessibility of research outputs. The citizens' jury on inclusive peer review thus reinforces the conclusions made by Armstrong et al. (2022, p. 326) that self-advocates want support to contribute to the research process in ways that are defined by them and designed to further benefit their community.

Instead of suggesting ways to engage in the academic peer review system, the citizens' jury recommended establishing a

platform for dialogue between people with learning disabilities and authors as a prerequisite for democratising research. If, like Jones et al. (2020) and Milner et al. (2020) who cite them, we draw on the lens of relational equity, we also need to appreciate that many of the ontologies and epistemologies at work are contestable. It may be that in seeking to admit people with learning disabilities to another academic process, there are dangers of assimilation too, in requiring them 'to approximate ourselves' (Milner & Frawley, 2019, cited by Milner et al. (2020, p. 128). These points are further reinforced by the jurors' recommendation that reviewers should be able to choose topics of personal interest, otherwise, as one member said, 'people might ask themselves what's the point?'

We see a real resonance in our findings from this project with the liberating effect found by Milner and colleagues of people with learning disabilities refusing traditional methods or roles, preferring to steer things according to their motivations. The power of the *In Response* initiative is that people with learning disabilities can 'speak back to' academic research about their lives, rather than following an academic agenda about the quality of papers which matters more to people who have not taken on an academic researcher identity. In reflecting on his own experiences while we were writing this paper John Cassidy said that some research topics would be too troubling for him to be a part of.

Jurors also agreed that representation of diverse voices within the learning disabilities community was important. They expressed their concerns on representativeness in two ways. First, concern that people with more severe learning disabilities might not have the chance to contribute to inclusive research and second that inclusive research groups often tend be drawn from established self-advocacy groups, which they argued could lead to exclusion of more diverse voices and experiences. This is resonant with the systematic review of inclusive health and social care research in which Hewitt et al. (2023, p. 698) reflect on representativeness and highlight the potential risk of creating a 'subsection of researchers with [learning disabilities], who no longer hold the position of "outsider" and are therefore less likely to challenge the established research paradigm. The jury's concern that people with more severe learning disabilities were generally excluded from inclusive research and their assertion that efforts should be made to ensure their voices are heard echoes the argument of de Haas et al. (2022, p. 2) that 'inclusive research has not been able to stretch its parameters sufficiently to enable people with profound [learning disabilities] to belong' and that simple modification of existing methods of inclusive research will not achieve 'epistemic justice' for people with more profound learning disabilities. McCoy et al. (2020) also identify harms in partial representation. They acknowledge the challenge in achieving comprehensive representation and suggest that claims of representation should reflect the specific subgroup engaged with (e.g., selfadvocates with learning disabilities). Alternatively, they suggest that comprehensive representation might be attempted using deliberative and consultative methods to understand the interests of all subgroups.

Throughout the deliberative process, jury members raised practical barriers to engagement in inclusive peer review. These included challenges related to the accessibility of research processes and outputs, dissemination methods, timescales and funding of research. Jury members reflected on their positive experiences of self-advocacy in research, where they felt rewarded by making a difference to the lives of other people with learning disabilities while experiencing personal growth and extending knowledge and skills. For John, as a coauthor on this paper and member of the citizens' jury these aspects made him feel empowered ('it has improved the quality of my life in all aspects').

Our reflections on the effectiveness of the adapted citizens' jury method of delivering rapid research evidence in keeping with the ethos of doing research inclusively were generally positive. In their systematic review of the application of the citizens' jury method in health policy decision-making, Street et al. (2014) argue that pragmatic adaptations to the 'ideal' Jefferson Centre [now the Center for New Democratic Processes] citizens' jury method are necessary to the development and application of effective, influential, and inclusive community engagement. However, they also assert that it is important to reflect on and record the impact of 'methodological decisions' on the essential component of providing an 'unbiased inclusive deliberative process'.

At an early stage in this project, we opted for pragmatic recruitment at the expense of demographic representativeness, which was a significant adaptation. This adaptation, Wise (2017) would argue, risks introducing bias to the project. However, for John and others, their prior experiences of inclusive research were important to the deliberative process.

In my first experience of inclusive research, I was shy and didn't have as much confidence and I wasn't as outgoing. I think if I didn't have that experience, I might not have been able to participate in this remote group so well. Having the opportunity to be involved in the remote group during COVID really helped me to get through that time - being involved [has] been so important to my mental health.

In thinking about the limitations of our method in relation to inclusion of a broader spectrum of people with learning disabilities, we are reminded by de Haas et al. (2022) that a more radical rethinking of inclusive research practices is necessary to include those with profound learning disabilities.

A further limitation of our adapted method relates to the role of support staff who facilitated access to online meetings. Teasing apart people's voices can be important for understanding power dynamics (Chapman, 2014; Woelders et al., 2015) and this was sometimes difficult in our sessions. A clearer set of guidelines on the role of advocacy support workers, and whether their own views were to be included in the project or not would have been useful and could be incorporated in future citizens' jury work of this kind.

6 | CONCLUSIONS

The citizens' jury was tasked with considering the viability and wisdom of inclusive peer review in the quest to democratise the research process and presented five well-considered and practical recommendations on this. The recommendations indicate that people with learning disabilities perceive inclusive peer review as more than an opportunity to replicate traditional academic roles. Instead, they seek to challenge and contribute to changing the established system, which has historically positioned them only as research subjects. The jury's recommendations are aligned with the BJLD's *In Response* approach and provide a route-map to furthering inclusive approaches to research generation, communication, and impact.

The adapted citizens' jury model was an effective method for investigating a complex conceptual aspect of the inclusive research paradigm. However, further adaptations would be needed to facilitate the representation of a wider range of people with learning disabilities

The aim of this citizens' jury was to focus on the guestion of inclusive peer review. However, the group demonstrated that their involvement was driven by a commitment to addressing the routine exclusion that people learning disabilities experience in all domains of life. They advocated for more accessible information on the outcomes of research, particularly research perceived to be of relevance to them. They sought opportunities to collaborate for the benefit of other people with learning disabilities, including those whose voices were not represented in the jury. The resulting recommendations do not align neatly with academic journals' definition of peer review but offer an approach to inclusion in research publishing that could complement the existing peer review process. Their guidelines could facilitate the dissemination of research knowledge, promote dialogue between researchers and people with learning disabilities, and bring new perspectives to the validity and quality of research. The attention of the editorial board of BJLD is now on progressing this agenda.

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CONFLICTS OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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REFERENCES

- Armstrong, A., Collis, A., & Walmsley, J. (2022). The messy realities of inclusive research. In P. Liamputtong, *Handbook of social inclusion:* Research and practices in health and social sciences (pp. 311–328). Springer.
- Bigby, C., & Frawley, P. (2010). Reflections on doing inclusive research in the "Making Life Good in the Community" study. *Journal of Intellectual & Developmental Disability*, 35(2), 53–61.
- Blunt, C., Blyth, C., Chapman, R., Frost, L., Hayward, D., Hughes, R., Perry, B., & Townson, L. (2012). Editorial. *British Journal of Learning Disabilities*, 40(2), 83–84.
- Chadwick, D., Richards, C., Molin, M., & Strnadová, I. (2023). Digital inclusion and people with learning disabilities. British Journal of Learning Disabilities, 51(2), 119–124.
- Chapman, R. (2014). An Exploration of the self-advocacy support role through collaborative research: 'There should never be a them and us'. *Journal of Applied Research in Intellectual Disabilities*, 27, 44–53.
- García Iriarte, E., Díaz Garolera, G., Salmon, N., Donohoe, B., Singleton, G., Murray, L., Dillon, M., Burke, C., Leddin, N., Sullivan, M., & Spelman, M. (2023). How we work: Reflecting on ten years of inclusive research. *Disability & Society*, 38(2), 205–227.
- Gooberman-Hill, R., Horwood, J., & Calnan, M. (2008). Citizens' juries in planning research priorities: Process, engagement and outcome. Health Expectations, 11, 272–281.
- de Haas, C., Grace, J., Hope, J., & Nind, M. (2022). Doing research inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences*, 11(4), 159–172.
- Henderson, A., McLean, R., & Kinnear, D. (2022). Including the voices of people with learning disabilities in health research. In A. Volkmer, & K. Broomfield (Eds.), Seldom heard voices in service user involvement: The how and why of meaningful collaboration (pp. 87–104). J&R Press.
- Hewitt, O., Langdon, P. E., Tapp, K., & Larkin, M. (2023). A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are coresearchers involved and what are their experiences? *Journal of Applied Research in Intellectual Disabilities*, 36(4), 681–701.
- Involve (n.d). Citizens' jury. Accessed May 23, 2023. https://involve.org.uk/resources/methods/citizens-jury
- 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.
- Lewis, B., Richards, S., Rice, S., & Collis, A. (2020). A response to Bates, C et al (2020) "Always trying to walk a bit of a tightrope": The role of social care staff in supporting adults with intellectual and developmental disabilities to develop and maintain loving relationships. British Journal of Learning Disabilities. British Journal of Learning Disabilities, 48(4), 269–271.
- McCoy, M. S., Liu, E. Y., Lutz, A. S. F., & Sisti, D. (2020). Ethical advocacy across the autism spectrum: Beyond partial representation. *The American Journal of Bioethics*, 20(4), 13–24.
- Mikulak, M., Ryan, S., Bebbington, P., Bennett, S., Carter, J., Davidson, L., Liddell, K., Vaid, A., & Albury, C. (2022). "Ethno...graphy?!? I can't even say it": Co-designing training for ethnographic research for people with learning disabilities and carers. *British Journal of Learning Disabilities*, 50(1), 52–60.
- Milner, P., Conder, J., & Mirfin-Veitch, B. (2020). The aims and complexities of conducting inclusive research. Commentary on "Are individuals with intellectual and developmental disabilities included in research? A review of the literature" (Jones, Ben-David, & Hole, 2020). Research and Practice in Intellectual and Developmental Disabilities, 7(2), 126–131.
- Milner, P., & Frawley, P. (2019). From "on" to "with" to "by": People with a learning disability creating a space for the third wave of inclusive

- research. Qualitative Research, 19(4), 382-398. https://doi.org/10.1177/1468794118781385
- Nind, M. (2014). What is inclusive research? Bloomsbury Academic.
- Nind, M. (2016). Inclusive research as a site for lifelong learning: Participation in learning communities. Studies in the Education of Adults, 48(1), 23–37.
- Nind, M. (2020). Not a journal about people with learning disabilities without people with learning disabilities. *British Journal of Learning Disabilities*, 48(2), 81–83.
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102–109.
- O'Brien, P., Garcia Iriarte, E., Mc Conkey, R., Butler, S., & O'Brien, B. (2022). Inclusive research and intellectual disabilities: Moving forward on a road less well-travelled. *Social Sciences*, 11(10), 483.
- Roberts, J., & Escobar, O. (2015). Involving communities in deliberation: A study of three citizens' juries on onshore wind farms in Scotland. ClimateXChange.
- Street, J., Duszynski, K., Krawczyk, S., & Braunack-Mayer, A. (2014). The use of citizens' juries in health policy decision-making: A systematic review. Social Science & Medicine (1982), 109, 1–9.
- Symonds, J., Abbott, D., & Dugdale, D. (2021). "Someone will come in and say I'm doing it wrong." The perspectives of fathers with learning disabilities in England. *British Journal of Learning Disabilities*, 49(1), 23–33.
- Tilley, E., Strnadová, I., Ledger, S., Walmsley, J., Loblinzk, J., Christian, P. A., & Arnold, Z. J. (2021). 'Working together is like a partnership of entangled knowledge': Exploring the sensitivities of doing participatory data analysis with people with learning disabilities. *International Journal of Social Research Methodology*, 24(5), 567–579.
- Townson, L., Macauley, S., Harkness, E., Chapman, R., Docherty, A., Dias, J., Eardley, M., & McNulty, N. (2004). We are all in the same boat: Doing 'people-led' research. *British Journal of Learning Disabilities*, 32(2), 72–76.
- Tully, M. P., Hassan, L., Oswald, M., & Ainsworth, J. (2019). Commercial use of health data—A public "trial" by citizens' jury. Learning Health Systems, 3, e10200.
- Wakeford, T., & Walcon, E. (2015). Refashioning citizens' juries: Participatory democracy in action. In H. Bradbury-Huang (Ed.), *The sage handbook of action research* (3rd ed., pp. 229–245). Sage.
- Walmsley, J., & Johnson, K. (2003). Inclusive research with people with learning disabilities: Past, present and futures. Jessica Kingsley.
- Walmsley, J., Strnadová, I., & Johnson, K. (2017). The added value of inclusive research. Journal of Applied Research in Intellectual Disabilities, 31(5), 751–759.
- Wiley. (2023). What is peer review? Accessed 25 May 2023. https://authorservices.wiley.com/Reviewers/journal-reviewers/what-is-peer-review/index.html
- Williams, J., Barr, G., Bell, S., Baynes, L., & Moon, S. (2021). Response to Symonds, Abbott and Dugdale (2020) "Someone will come in and say I'm doing it wrong." The perspectives of fathers with learning disabilities in England'. *British Journal of Learning Disabilities*, 49(1), 34–38.
- Wise, J. (2017). Citizens' juries for health policy. *British Medical Journal*, 357, j2650.
- Woelders, S., Abma, T., Visser, T., & Schipper, K. (2015). The power of difference in inclusive research. *Disability & Society*, 30(4), 528–542.

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