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Comment

Comment on Grace et al. (2024). Expanding Possibilities for Inclusive Research: Learning from People with Profound Intellectual and Multiple Disabilities and Decolonising Research. *Social Sciences* 13: 37

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Abstract: This article is a response to a paper, published last year in this journal, by Grace, Nind, de Haas and Hope. The authors sought to "question how we create knowledge and challenge underlying assumptions about valid forms of knowing" (p. 3). Their focus is on inclusive research with people who have profound intellectual and multiple disabilities (PIMDs). They describe their approach as "being with", aligned with the experience of meaning, as opposed to doing research with people, which they locate in knowledge extraction. Recognising the authors' commitment to foregrounding the personhood of people with PIMDs, a critique is developed in order to open a debate around issues of ethical research practices, decolonisation and conceptualisation of 'deep knowledge'.

Keywords: inclusive research; participatory research; profound intellectual and multiple disabilities; decolonising research; ethics; vulnerability; epistemology; positionality; reflexivity

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1. Introduction

A paper by Grace et al. (2024) was met with great interest from colleagues working in the field of intellectual disabilities. We know that researchers and practitioners new to the field of profound and multiple intellectual disabilities (PIMDs) will look to these well-regarded authors to provide a lead in what to research and how to conduct it. This confers a huge responsibility. In 2012, McDonald and Kidney suggested that ethical research practices need to be developed through the systematic scrutiny of published studies and comparison of perspectives. They address the value-based tensions between the need to include and to respect self-determination on one hand and the need to safeguard vulnerable participants on the other. The critical question they pose is "whose values prevail?" (p. 36). It is in the hope of furthering open debate to advance the field of study that this response is proffered. The issues addressed include:- working with vulnerable populations; informed consent and participation; positionality and reflexivity; decolonisation theories and practices; and the concepts of "being with" and of "deep knowledge", which are described as fundamental to the methodology.

2. Vulnerable Populations

Carrying out research with people with PIMDs is not straightforward (Maes et al. 2021). Grace and her colleagues should be applauded for championing the inclusion of, and belonging for, people with PIMDs in research, and for their use of fine-grained ethology to describe behaviours that are so easily ignored. However, this kind of research involves epistemological and ethical risks. A crucial aspect of conducting research with vulnerable populations is rigorous adherence to ethical standards, particularly concerning informed consent and ongoing engagement. There is, of course, a sense in which all participants are vulnerable to the objective and subjective pressures exerted in research (Moriña 2021) and are also subject to compound disadvantages (see Cooms et al. 2022). There is increasing awareness of, and sensitivity to, the power dynamics intrinsic to working with marginalised and excluded groups (Shaw et al. 2020), of whom people with PIMDs are clearly members. The term is used to describe a heterogeneous population of children and adults with high support needs (Maes et al. 2021), characterised by (a) a profound level of intellectual disability - in traditional psychometric parlance, an IQ below 20, or 4 or more standard deviations below the mean (WHO 2018) and (b) complex and multiple health problems, sensory and physical impairments. They typically function at the earliest, preverbal stage of development (Iacono et al. 2009; Maes et al. 2007), show fleeting attention for people and objects around them (Hostyn et al. 2010) and face severe challenges in communication (Petry et al. 2005). Their social repertoires may include body movements and posture, eye gaze, gesture, facial expression, vocalisation and signs of emotional responsivity, usually highly individualised. Subtle changes in their behaviours carry different meanings, which may not always be recognised by the people around them (Griffiths and Smith 2016; Grove et al. 1999; Martin et al. 2022; Nakken and Vlaskamp 2007; Neerinckx and Maes 2016). However, it is apparent that prior experiences influence their behaviour and their affective and mental states (Wigham et al. 2011). Typically, interactions are led by the communication partner, with a focus on instructions, information giving and social pleasantries (Antaki and Kent 2012). Significant others (e.g., parents, carers and teachers) are constrained to interpret their behaviours in the moment because, by definition, people with PIMDs do not have the symbolic or linguistic skills to make themselves understood outside the immediate context. It is difficult for us to know how anyone with PIMDs understands and experiences the world around them (Grove et al. 1999; Mietola et al. 2017). That said, it is recognised that the quality of the relationship is critical to meaningful interaction. This is underpinned by attunement, familiarity with and understanding of the individual, their personalised social repertoires and expression of affective states (Griffiths and Smith 2016; Forster and Iacono 2014; Hostyn and Maes 2013; Martin et al. 2022; Penninga et al. 2022). It is evident that we ourselves have much to learn from persons with PIMDs when we view them as communication partners (Clapton 2010; Forster and Iacono 2014; Grove et al. 2022; Nind 2014; Skarsaune 2024).

Conceptually, inclusive research is described as research that is important to people with disabilities and involves them in some meaningful way. Participatory research goes further, in that the people involved in the research take active roles in constructing and interrogating knowledge (Nind 2014). There is general recognition that people with PIMDs have been excluded from participatory research for too long, and that to change this situation requires a critical re-imagining of existing frameworks and strategies. There is emerging agreement that approaches developed within qualitative paradigms show promise in counteracting the objectifying of this population, including the following:

- Recognition of the asymmetric reciprocity inherent in the researcher–participant relationship, thus acknowledging inevitable power dynamics that otherwise remain implicit (McDonald and Kidney 2012; Mietola et al. 2017).

- Adopting relational concepts of autonomy and consent, so that intellectual capacity is no longer privileged as an absolute requirement for participation (Jackson 2023; McDonald and Kidney 2012; Moriña 2021; Van Goidsenhoven and De Schauwer 2022).
- Treating "consent" as a dynamic, emergent, responsive process rather than as the product or outcome (Haines 2017; Moriña 2021; McDonald and Kidney 2012; Van Goidsenhoven and De Schauwer 2022).
- Viewing "voice" as embodied interaction, including nonverbal behaviours, thus broadening definitions of communication (de Haas et al. 2022; Skarsaune 2024).
- Valuing and respecting the views and interpretations of those who know a person well, rather than excluding those with insight from the research (de Haas et al. 2022; Haines 2017; Jackson 2023).
- Using strategies developed within ethnography—taking time to get to know individuals, thick description of interactions—that allow researchers to become familiar with an individual's unique style and presentation (Haines 2017; Maes et al. 2021; Mietola et al. 2017; Birt and Poland 2021).

Both de Haas et al. (2022) and Grace et al. (2024) explicitly reference ethnography as a formative discipline in the development of their ideas and processes. It is therefore worth citing the questions posed by Shaw et al. (2020, p. 3):

> *. . .who benefits from the production of knowledge about people from vulnerable and marginal groups? And, how do our own perspectives and lived experience shape what counts as knowledge?*

According to Luna (2009), cited in Van den Breemer et al. (2024), potential "layers of vulnerability" need to be acknowledged in a research population. For people with PIMDs, there is first the issue of participation on an informed and voluntary basis when the person lacks capacity for autonomous decision-making. Second, in order to adapt appropriately to their highly individual profiles as participants, we need to consider methodologies for data collection that do not rely on the use of conventional communication skills (e.g., speech or text) or standardised testing. Third, the data consist of repertoires of nonverbal behaviours and signals which require interpretation in order to discern form–meaning correspondences. Fourth, there is the interpretation of qualitative evidence collected from individuals who are not in a position to verify such interpretations, even if invited to do so. The vulnerabilities connected to non-conventional, individualised behaviours are addressed directly by Grace et al. and form the basis of their methodology. The vulnerabilities that are perhaps less convincingly managed are those relating to consent, interpretation and verification. We turn first to the issue of consent.

3. Informed and Voluntary Participation: Ethical Issues

Simmons et al. (2022, p. 39) describe three approaches to the design and implementation of ethical procedures: *universal* (one approach for all, such as the current view of informed consent); *consequential*, where the emphasis is on benefits to the participants; and *relational*, where ethical procedures emerge from deep interpersonal engagement with participants. All aspects are deemed relevant in working with people with PIMDs.

Consent is a multi-phased process, involving both procedural and practical decision-making (Haines 2017; Maes et al. 2021; Moriña 2021; Shaw et al. 2020). The initial (official and *universal*) step ensures that participants (or, as in this case, their proxies) are informed about the nature and purpose of the study and voluntarily agree to take part; it is a one-off action that is not subsequently repeated. However, as Moriña points out (2021, p. 1561), in the case of emergent, qualitative paradigms, the document quickly becomes obsolete (or at the very least, needs qualifying). To rectify this issue, researchers engage in practice ethics, using process or rolling assent/consent (Dewing 2007) whereby the researcher is constantly alert to signals that the individual is willing to engage with the particular moment-by-moment demands of the research. This is clearly a *relational* ethical stance. Relational ethics emphasises the dynamic, ongoing nature of consent and the importance of dialogical, trust-based relationships. This approach requires researchers to remain responsive to participants' needs and contexts, ensuring that research activities align with participants' everyday lives and preferences rather than imposing external priorities (Montgomery and Baglioni 2020). Process assent, as a relational practice, involves continuous attunement to participants' cues of assent or dissent. For individuals with PMIDs, researchers are recommended to predefine behavioural indicators in consultation with caregivers and adjust their methods based on ongoing observations (ASSENT 2022; Haines 2017; Jackson 2023; Van Goidsenhoven and De Schauwer 2022). Such engagement enables benefits of participation to be considered—*consequential* ethics. For all of these aspects, a positive communication of assent, i.e., 'engaged assent', could be regarded as an ethical prerequisite for involvement in ongoing research (ASSENT 2022). However, as Simmons et al. (2022, p. 39) point out, "the processes by which we seek assent are neither regulated nor universally acknowledged, resulting in inconsistent ethical practices".

Another dimension that is becoming vital in the context of social media as a vehicle of dissemination is consent to allow images or films, or information relating to oneself, to be widely shared. This has hardly been touched on in relation to persons with PIMDs, but is the fulcrum of the debate between inclusive practice and safeguarding. Grace (2022) makes a strong case for inclusion, as a *consequential* ethical stance (i.e., online presence viewed as conferring benefits, as analogously argued by Carlson and Frazer (2020) in the case of marginalised Indigenous communities. As regards children, parents commonly act as consent givers. However, it is surely legitimate to ask if this is enough in the case of clearly identifiable images, particularly in public online contexts, where once made available, they cannot be retracted?

Ethical approval for the study in question was granted by the University of Southampton (Social Sciences Research Ethics Committee: 73404). This phase equates to the initial seeking of consent to take part in principle. In the interests of promoting good practice, the provision of some further details regarding consent procedures would have been helpful. This is particularly relevant given the population in focus, the inherent risks to choice and control, and the close and intimate character of the proposed research relationship. Informed consent was obtained from the parents and from the school, but we do not know if the extent and nature of the researcher's contact with participants was made explicit. It is essential that the research outlines how the voices of the participants themselves were included in the consent process (Hart et al. 2020) as advised in the Mental Capacity Act (MCA) Code of Practice (UK Department of Constitutional Affairs 2007). Irrespective of chronological age, it is incumbent on the researcher to involve individuals deemed to lack capacity in decision-making about their participation in research, as much as possible (Health Research Authority 2024).

With regard to process assent, the authors clearly acknowledge the complex and individual profiles of persons with PIMDs (the second layer of vulnerability) and their distinctive repertoires of communication (the third layer of vulnerability). However, a brief account would have been useful to show how procedures were tailored to the needs of the individuals concerned. Over what period of time, and through what range and types of encounters with the three young people, did the researcher learn about their personal communication repertoire, in order to develop process assent? Were familiar people (e.g., family members, teachers and carers) involved in the design of procedures, and did they help to identify and interpret ongoing responses concerning their assent to engage or withdraw from particular events? (See Haines 2017; Jackson 2023; Krisson et al. 2022)

An illustrative example is provided by the vignette of child B. Her movement toward the researcher was used as an indication that she had indeed chosen to spend time with the researcher, supported by other behaviours such as her directed eye gaze and leaning in; this behaviour is well described, and the inference is understandable. What is omitted, however, is the critical research dimension (Breault and Zeng 2024; Haines 2017; Hart et al. 2020), which would suggest that such narratives need to be balanced with (a) other possible interpretations and (b) an account of active refusal by a participant and how this was recorded, interpreted and responded to (addressing the fourth layer of vulnerability). These procedures help to safeguard the researchers against their own powerful biases in favour of presumptions of assent (see, for comparison, the discussions in relation to similar instances by Mietola et al. 2017).

The principle of maintaining anonymity in ethical research has been challenged on grounds of both practicality (with small case studies, it is difficult to avoid recognition at some level: Moriña 2021) and community presence and acknowledgement (Grace 2022; Shaw et al. 2020). As persuasively argued by Grace and colleagues, excluding images and profiles online reinforces the ghettoisation of people with PIMDs, a statement with which we concur. The authors and the families collectively decided to share images of the children in order to promote inclusion and to acknowledge their personhood. What is not discussed, however, is the involvement of the young people themselves in this decision. Although challenging, such participation is not impossible, at least in a graduated way. The ethical principle of promoting understanding comes into play here (McDonald and Kidney 2012). For their groundbreaking project *Meet the People* (2011)[1], Mencap engaged with individuals and their families over time, involving them in events where they shared their films with audiences of varying sizes, and it was apparent that the people concerned were aware that they were indeed revealing aspects of their lives to others. In the ongoing project *What Matters to Me*, run by the Challenging Behaviour Foundation (2025)[2], a similar procedure operates to determine the level of awareness and enjoyment of sharing personal details with others. It is clear that many individuals described as having PIMDs are becoming increasingly familiar with, and engaged in, digital interactions (Caton et al. 2023), and the question of online presence urgently needs to be a focus of critical debate.

4. Positionality and Reflexivity

The nature of voluntary participation of people with PIMDs in research activity in the context of conducting their everyday lives is relevant here, as is the discipline of ethnography, closely allied to the “being with” paradigm advocated in the paper. Of course, ethnography as a discipline has its roots in colonial and imperialist forms of knowledge; contemporary application stresses the adoption of principles and values that align with decolonising paradigms (Abo-Zena et al. 2022; Ram 2018). As Abo-Zena et al. (2022) point out, researchers are liable to bias because they are inevitably entangled with their participants and the stories they hold and tell about them. Transparent statements of positionality enable informed critiques of the findings and their limitations. Researchers must be continuously alert to the risk of intrusion, where activities may be conducted by researchers for their own purposes, rather than initiated and chosen by participants in the continuation of their everyday lives (Shaw et al. 2020).

Inclusive research (including ethnographic research) has problematised the use of unquestioned one-sided accounts of research processes and interpretations, what they represent, what can be demonstrated from such accounts and who has the right to represent what is being done and why (Breault and Zeng 2024; Hammersley 2006). Here, the appearance and voice of people with PIMDs seem to be represented unproblematically by the researchers, without any interrogation of what this means for the nature of research experience and research interpretation.

This is an issue of researcher positionality, defined as the position a researcher chooses to adopt, and requiring conscious reflection on self-identity and perspectives adopted (Breault and Zeng 2024). It is clear that the researcher in the paper by Grace et al. does not share the same group identity as the participants described in the paper, although she aligns herself with them. Indeed, most researchers possess multiple 'insider' and 'outsider' characteristics (Le Gallais 2008). However, the 'being with' account of the research and the way meanings are ascribed to participant behaviours fail to critically review the 'outsider' role of the researcher in producing knowledge. The data reported are based on a single perspective record and interpretation of a participant's behaviours during encounters with the researcher. The participant is unable to question or refute what is recorded and interpreted—and readers can only speculate as to alternative interpretations. As Skarsaune (2024) points out in one of the cited studies, "*Being open for corrections is of the utmost importance because persons with profound and multiple learning disabilities cannot object to misunderstandings in verbal ways. To include the perspective of persons with PIMDs in research comes with several challenges regarding, for example, how much others should rely on the researcher's reporting of an alleged perspective of the person with profound and multiple learning disabilities*" (p. 108). The fact that researchers do not have lived experience of PMIDs (as distinct from family experiences) can inadvertently reinforce hierarchies, even within inclusive frameworks.

Skarsaune's analysis of empathetic interactions emphasises the importance of *critical reflexivity*, of recognising that an interpretation of ambiguous communication is just that, and likely to be one amongst many. Reflexivity has been defined as "a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes" (Olmos-Vega et al. 2023, p. 242). The application of critical reflexivity in these situations would mean considering alternative interpretations. Failure to do so introduces bias into the research and runs counter to efforts towards inclusivity. This potential for researcher bias is a critical concern, particularly given the subjective nature of interpreting behaviours in individuals with PIMDs. The original study does not seem to address how the researchers' perspectives and potential biases were managed throughout the research process. Implementing reflexive practices, such as maintaining a detailed research diary with engaging in peer debriefing sessions, involving personal consultees and asking for their comments on observations, can help mitigate this issue (Haines 2017; Morris 2010).

We find the example of child S., in 'small story 2' (p. 5), particularly concerning. Observing the participant lying in her bed, the researcher states how she is '*keen to be invited in or to try and wheedle my way in*'. Angling her head toward the participant's pillow and imitating some of S's fist-to-mouth behaviours, the researcher declares, '*it didn't feel enough*'. The intentions of the researcher are clear, but those of the participant are not. Neither is it clear from this ambiguous statement whether the action was felt to be insufficient to the needs of S, or of the researcher. Nevertheless, the encounter moved to a stage when the researcher touched the protruding tongue of the participant. There is nothing in this narrative description to suggest that S had invited the researcher to share her space as she lay on the bed or indeed wanted to have her tongue touched repeatedly. The singular purpose of the researcher is what is conveyed in the description, with all of S's behaviours seen as positive responses to the researcher's actions.

The power differential here renders the participant extremely vulnerable in this situation. Importantly, there is no critical reflection on the nature of the research relationship being constructed in this way and no attempt to judge how this might fit with the participant's frames of reference. The authors comment that "*the interaction described here is an intimate one that might cause some readers discomfort*" (p. 6). There is an implication here that since the researcher did not experience this discomfort, the reader is somehow lacking in judgment. But whether or not the reader is uncomfortable is irrelevant to the methodological and ethical integrity which we regard as the central issue, namely whether this intimacy was something under the control of the individual concerned, whether and how she could have objected or refused the touch and whether it was necessary in any sense for the researcher's purposes. In addition to the questionable nature of the research relationship in this encounter, it is important to consider potential health risks. Individuals with PIMDs are particularly and continuously at risk of infection; minor illnesses can escalate quickly and lead to complications (Zijlstra and Vlaskamp 2005). Such intimate contact around the oral cavity would normally require the adoption of practices to minimise risks of infection and contamination, such as the use of surgical gloves. However, there does not appear to have been any consideration of this issue, at least in the account provided in the paper. The ethical imperative to "do no harm" (Gorman et al. 2023) seems compromised in this instance.

5. "Doing Research with" vs. "Being with"

The authors make a distinction between two positions in inclusive research: "being with" and "doing research with". The former is said to focus on capturing the "experience of meaning", and the latter is located in "knowledge extraction". It is not entirely clear what we are meant to understand by this, but the authors seem to imply some kind of exploitation of a passive subject in order to accumulate information. We might ask what type of knowledge is extracted and how it is situated. However, to do so already challenges the authors' framing that the pursuit of knowledge through "doing research with" will be conducted independently of its meaning for participants, which is not necessarily the case. For example, several researchers who might be said to have "done research with" colleagues who have intellectual disabilities have adopted collaborative principles and designs (e.g., Chalachanová et al. 2020; Ellis 2018; Watson 2023).

The concept of "being with" persons with PIMDs has featured in models of attunement in communication processes (Forster and Iacono 2014; Griffiths and Smith 2016); the study of belonging (Goodwin 2020; Guerin and McMenamin 2018); relationships (Johnson et al. 2012; Reinders 2008); respectful interaction for its own sake (Forster and Iacono 2014; Forster 2020); and ethnographic research (Haines 2017; Krisson et al. 2022). Pertinent to the paper under discussion is the work of Simmons (2021) with a child with PIMDs, which also focuses on processes of "being with". Simmons uses different approaches (participatory observation and focus group discussions) to explore the world of his young participant and two contrasting lenses (phenomenological and physical) to capture distinctions in the way that staff and mainstream peers construct partnerships and interact with him. Different aspects of "being with" are interrogated in ways that help us to see the child's life through new eyes.

From another perspective, Mietola et al. (2017), in a paper with many resonances with the research under discussion, consistently offer examples where they critique their own stance and where decisions and interpretations were problematic.

de Haas et al. (2022) define "Being with" as follows:

> "'Being with' people with profound intellectual disabilities is based on the attachment between people who share meaning, interest in each other and myriad emotions. It is dialogical and rich, with multiple turns over time, not single commands, and questions. If paid care staff in the *Hanging Out Program* (Forster

> 2020) could learn this way of being alongside a person with profound intellectual and multiple disabilities, so can researchers". (p. 7)

Arguments for spending time with people and focusing on them as individuals who are valued, whether you are a friend, a carer or a researcher, have been ably demonstrated. However, what the authors do here is transmute this social purpose into a research purpose from their own perspective. Collaborative, co-productive research is surely a step beyond the creation of a responsive and sensitive sharing space. The question is, whose research is it? This brings us to the decolonisation paradigm invoked as an analogy to the authors' approach.

6. Decolonising Paradigms

The authors draw parallels between their approach and decolonising research. As defined by Thambinathan and Kinsella (2021), decolonisation "*means centering concerns and world views of non-Western individuals, and respectfully understanding theory and research from previously "Other(ed)" perspectives*" (pp. 1–2). We note that the terms "decolonising" and "anti-colonial" seem to be used interchangeably, although the concepts are distinct. Decolonisation involves dismantling colonial structures and reclaiming Indigenous sovereignty and cultural practices. In contrast, anti-colonialism emphasises resistance to colonial rule and political liberation. While the two frameworks intersect (Hiraide 2021; Ram 2018), conflating them risks oversimplifying their unique contributions to crucial academic debates. Mignolo (2017) speaks of actively unlearning and dismantling dominant Euro-American centric ways of thinking and understanding the world, but also rebuilding and re-worlding forms of knowledge-making that exist outside these dominant epistemic norms. Grace and her colleagues are making a genuine push to do exactly what these authors suggest, with a different population. However, it would be helpful to specify which boundaries are being challenged and what possibilities are being imagined. The case studies may not be entirely indicative of an anti-colonial approach for the following reasons.

The inherent power imbalance between researcher and participant in the field of intellectual disabilities may resonate with experiences of, for example, asylum seekers (Blommaert 2006) or disadvantaged Indigenous peoples, not least because of potential intersection between disabled and Indigenous identities (Puszka et al. 2022). As Thambinathan and Kinsella (2021) point out, this means a continuing alertness to the likelihood that researchers, coming from positions of power, may inadvertently act as colonisers of the space. So, what is needful is not just introspection, but *critical* introspection, presenting both interpretations and counter interpretations of the nature and effects of interactions between researcher and participant. It is vital that decolonisation parallels emerge from a deep level of engagement with the experience of colonisation. Brief references to "*using the African philosophy of Ubuntu*" (p. 8) and to borrowing practices like "*yarning and carving*" (p. 7) risk reducing these activities to technical exercises, devoid of a deeper epistemological understanding. This may be put down to the constraints of word limits, but unfortunately may come across as tokenistic, as warned by Moosavi (2020).

Tuhiwai Smith's's (2021) work seems to have been interpreted somewhat partially. Her work is cited in the context of spending time with people. Smith certainly suggests taking an Indigenous perspective on time, rather than the standard "in and out" interview, being with experts in a community to learn how knowledges are perceived, applied and transmitted, but this research has to be owned and produced by Indigenous people themselves, rather than by outsiders moving in on the space. The corollary in this context is that research participants need to own and produce the research.

The desire to engage the young people in a co-productive reciprocal enterprise is clearly in evidence, but their role and their awareness are under-specified and vague.The authors convey the important message that shared respectful space is a productive context for finding out about people, but authentic collaboration in a research process is not achieved simply by naming it so. The strong focus on relational interactions is likely to have some meaning for people with PIMDs, whilst the meaning to them of *research*, whether conceptualised as “being with” or “doing research with”, is far more problematic. It is not immediately evident that these young people knew that they were engaged in research. From their perspective, it may not matter. It matters a great deal from the research perspective when a new paradigm is in the process of development. The author’s exploration of the ‘being with’ concept holds promise, but their approach to agency and co-construction remains highly reliant on their own subjectivities for interpretation. This dynamic risks a ‘hand over hand’ communication ideology, where an outsider guides the sense-making process (Webster 2021). Future research will hopefully build on these explorations, but with a focus on developing methodologies that allow a wider range of participant inputs, possibly through the use of augmented or digital communication tools (Krisson et al. 2022; Warwick 2020); the inclusion of caregivers as interpretive collaborators in the research process (Haines 2017; Walker et al. 2023); the development over time of a community of practice within which individuals with PIMDs can become aware of their place and their role (Tilley et al. 2020), as seems likely from De Haas’s description in the paper of her unfolding group activities.

7. Deep Knowledge

It is suggested that deep knowledge of the participant with PIMDs is associated with the “experience of meaning”(p. 2). Deep knowledge is not defined in the paper, so it is unclear what is meant beyond something more profound than a casual social connection. The authors associate deep knowledge with the approach of “being with”, as opposed to “doing research with”, because two processes are involved: being “open to listening” and appreciation for “embodied knowing”. While the researchers may conduct close and sensitive, embodiment-aware relationships with potential participants, a decolonising paradigm would suggest that participants similarly need to derive or reframe elements from those relationships. However, given the complex presentation of the young people with PIMDs who take part in this research, the routes whereby they might do this are not obvious. This highlights the necessity of having objective recording systems and deliberate approaches to researcher reflexivity. Furthermore, the extent to which and the process whereby interpretations of the research are mutually constructed are not established.

It may fairly be argued that the mapping of these aspects to the “being with” approach is not exclusive (Mertens 2018). Observational methods used in “doing research with” may also achieve goals of new insights and increased knowledge of a person and how to interact with them, through video-recordings that capture the individual’s behaviour, responses and interactions with familiar/unfamiliar people, objects and events in the environment (Haines 2017). Since the 1990s, established methods of careful observation and painstaking coding have enabled researchers to recognise behaviours that may carry unconventional meanings or intent (e.g., Iacono et al. 1998). Methods include transcription and analysis of interaction and discourse (verbal and non-verbal; vocal and non-vocal), instantaneous coding of engagement behaviours, narrative recording of the interaction process through close listening, watching and regard for the individual’s embodied knowledge of the world around them. Reactivity is clearly an issue, and observational protocols allow the researcher to stand back and consider the influences of their own presence and behaviours and the dynamics introduced by the research process itself. Another approach to recognising other ways of knowing is by utilising cultural insiders, or cultural brokers acting as consultees, to promote understanding of alternative perspectives (e.g., parents, carers, self-advocates with intellectual disabilities); this has become increasingly common among researchers working across cultures (Thambinathan and Kinsella 2021) and in the field of research with individuals with PIMDs (Haines 2017; Simmons 2021; Tilley et al. 2020).

A problematic encounter, which seems to exemplify the question of deep knowledge, is that between the researcher and the context in which the research takes place, in this instance, the classroom. As described, the one-to-one interaction with child S ceased because the class moved into an activity dedicated to the birthday of a class member. An account follows of objects being handed around, and the researcher reflects in her field notes that it is easy in this context to do things "to" children, rather than being "with" them: "*it is easy to feel like you are doing something without having to move towards the children with your emotional self*" (p. 4). However, it is not obvious why it should be so impossible to make yourself emotionally available to an individual whilst sharing in games and activities. The fieldnotes continue with the decision "*to back off and to perform the teaching assistant role*", into which she switches. There is an implicit hierarchy of valued interactions here, with classroom activities apparently considered less meaningful (to the researcher at least). Moreover, it is easy to overlook that, in fact, the activity is the celebration of a friend's birthday. Surely, the opportunity to celebrate and reach out to a peer could be just as important to the participant as the privileged (and isolated) interaction with the researcher? Again, this comment serves to emphasise what appears to be viewed as "deep knowledge": gained through one-to-one interactions where individuals are separated from their everyday context. An alternative perspective is that these ordinary small events, enabling individuals to come together, can be highly meaningful community experiences that can be recalled and shared with others (Grove et al. 2022; Mietola et al. 2017). There is evidence that children with PIMDs are aware of, and enjoy interacting with their peers, with and without disabilities (Nijs et al. 2016; Simmons 2021; Walker et al. 2023), and that they are happiest in relaxed social activities (Yu et al. 2002).

Other questions spring to mind. What does "deep knowledge" consist of beyond embodied knowing and listening? Who allocates the term to what they do, and by what means? Who judges the depth of knowledge? The study would have benefited from consideration of these issues. The relevance of the chosen approach to the reported example of inclusive research is not established. Without testing their assumptions or exploring alternative explanations, researchers risk colonising the lives of the people they claim to know. There is a burden of proof to be provided that the approach is not intrusive, carried out in the service of what is essentially auto-ethnography, foregrounding the researcher's interests. Viewed as such, the perspective can offer interesting insights into the research process. But as they stand, some of the actions described seem potentially disruptive of the children's own agendas.

8. Epistemic Self-Doubt

The reflections on community-based participatory research (CBPR) by Van den Breemer et al. (2024) are helpful in addressing issues of positionality and subjectivity. This research team comprised academics and teachers with experience in parenting children with congenital deaf blindness. Like Grace, they used auto-ethnography as a lens through which to examine personal experiences, alongside feminist, emancipatory and epistemic injustice theoretical positions. They draw on the work of Luna (2009) to suggest that rather than categorising individuals as vulnerable, researchers should adopt "*a case-by-case basis, if and how individuals in the research are vulnerable and what they need protection from, rather than presuming vulnerability*" (p. 3). For example, the children described by Grace and her colleagues could be considered vulnerable in this context, and the implications for working with them highlighted. In the case of child S, lack of mobility likely makes it difficult for her to physically move in a way that suggests refusal or rejection; for child B, possibly an interest in novelty and novel experiences may lead her to seek physical contact with people she does not know well (the problem is that within the paper as written, it is not clear how long it took to establish relationships and become a "familiar face" in the school—see above).

Van den Breemer and colleagues also introduce a term that seems applicable to research with this population, a stance of "epistemic self-doubt", specifically, regarding one's knowledge or role in the research (p. 5). Epistemic self-doubt, an experience of sensed uncertainty, ensures that we are always prepared to live with ambiguity, and to be open to alternative readings and to question our actions. We recognise that we may indeed sometimes have to take risks in order to get to know each other in a deep way, but we need to be able to explain our reasons for doing so, and in whose interest such risks are taken.

9. Conclusions

The starting point of the study by Grace et al. (2024) is the idea that inclusive research with people with PIMDs might best be achieved by approaching data collection through "being with" as opposed to "doing research with". Grace's exploratory work demonstrates how she identifies with participants at an embodied level, but what this leads to in terms of insight and how agency is promoted remains unclear. The authors are clearly committed to opening up the debate about whether, and how, it is possible to involve persons with PIMDs as research initiators or collaborators, but there are ethical, conceptual and methodological problems that may challenge their conclusions. The conflation of the researcher–participant roles, the blurring of recruitment procedures (e.g., "assent process in action") and data collection, the singular perspective that is used for interpreting participant responses and which claims to provide experience of meaning and the drive of the researcher-led agenda all raise issues of ontology: what is actually happening? Who are the participants, and what are the practices? In addition, there are deeply concerning issues of epistemology: how the researchers present this type of activity, and the relative weight given to researchers' and participants' voices, purposes and truth judgements. The omissions may be due to space limitations in articles which preclude the inclusion of sufficient reflexive accounting throughout the paper, an issue previously acknowledged in qualitative research endeavours (Newton et al. 2012). However, reference to positionality and reflexivity should be anticipated, even in an exploratory paper. The authors are not alone here, as it appears to be a common phenomenon in published research that due weight is seldom accorded to either dimension (Breault and Zeng 2024; Olmos-Vega et al. 2023).

In conclusion, the authors claim to have deconstructed research involving people with PIMDs by starting with and proceeding from, forming deep connections. However, in such encounters, there is a constant need to check and evidence interpretations of the behaviours demonstrated by research collaborators and participants—an extension of good everyday practice in care and education. This commentary has endeavoured to identify crucial areas in need of further discussion and improvement to advance the field of research involving individuals with PIMDs.

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Positionality Statement: We are a group of white researchers from the UK, five women and one man, who are committed to developing inclusive practices with people marginalised through disability and associated stigma. Our research variously involves people with lived experience of severe and profound intellectual disabilities, and of dementia, over periods ranging from 30 to 50 years and across different global cultural settings. In order to address issues of decolonisation, we took advice from Professor Mershen Pillay.

Notes

[1] https://www.youtube.com/watch?v=3v8jfr2ztSQ (accessed on 9 April 2025).

[2] https://www.challengingbehaviour.org.uk/what-matters-to-me/ (accessed on 9 April 2025).

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