



## Article

# Doing Research Inclusively: Understanding What It Means to Do Research with and Alongside People with Profound Intellectual Disabilities

Catherine de Haas <sup>1</sup>, Joanna Grace <sup>1</sup>, Joanna Hope <sup>2,3</sup> and Melanie Nind <sup>1,\*</sup>

<sup>1</sup> School of Education, University of Southampton, Southampton SO17 1BJ, UK; c.j.de-haas@soton.ac.uk (C.d.H.); j.m.grace@soton.ac.uk (J.G.)

<sup>2</sup> School of Health Sciences, University of Southampton, Southampton SO17 1BJ, UK; j.l.hope@soton.ac.uk

<sup>3</sup> National Institute for Health Research (NIHR), Applied Research Collaboration (ARC), Wessex, Southampton SO16 7NP, UK

\* Correspondence: m.a.nind@soton.ac.uk

**Abstract:** Positive developments in inclusion in line with ‘Nothing about us without us’ have rarely extended to people with profound intellectual disabilities. Advances in inclusive research are in danger of leaving this group (and their families and allies) on the outside, with researchers relying on proxies at best, or more often omitting this group as ‘too difficult’ to include in the research process at all. This paper argues that finding a way for people with profound intellectual disabilities to belong in inclusive research is important. Using examples, small stories and photographs, it explores and illustrates potential ways to research with and alongside those with profound intellectual disabilities that celebrate different kinds of agency and personhood and that support relational autonomy. The paper concludes that rather than starting from how inclusive research is currently conceived, the starting point should be a deep knowledge of people with profound intellectual and multiple disabilities. The way forward is likely to be an inclusive research culture that can accommodate ‘being with’ as core to its research approach. This will enable the voices of people with profound intellectual disabilities to inform the research in creating intersubjective knowledge together.

**Keywords:** inclusive research; participatory research; profound intellectual and multiple disabilities; belonging; intersubjectivity



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## 1. Introduction

Developments in inclusive research have done much to include the views and experiences of people with intellectual disabilities. In line with the call for ‘Nothing about us without us’ (Charlton 1998), many people with intellectual disabilities are now involved in research about them, not just as participants, but as instigators of ideas, researchers and authors (Walmsley and Johnson 2003). (See Bigby et al. 2014 for a history of the movement). The added value of research of this kind is well rehearsed (Nind and Vinha 2014; O’Brien et al. 2014; Walmsley et al. 2018).

These developments in inclusive research, however, have not embraced the call that ‘All Means All’ (Australian Alliance for Inclusive Education n.d.; UNESCO 2020) that is usually applied to inclusive education. People with profound intellectual and multiple disabilities are yet to belong in any meaningful way to the inclusive research movement(s) (Jones et al. 2020; Mietola et al. 2017; Ward et al. 2016) and are often excluded from research altogether (Kellest and Nind 2001). This means not just exclusion for individuals with profound intellectual disabilities, but the loss of the insights that could be gained from their involvement. When referring to people with profound intellectual and multiple disabilities, we mean people with high and pervasive support needs and multiple disabilities (and often life-limiting conditions), including intellectual impairment such that communications

will be idiosyncratic, not symbolic. However we stress (i) that people with profound intellectual and multiple disabilities have assets too and (ii) that they are also disabled by poor resources and care (see the discussion in [Nind and Strnadová 2020](#) and [Vehmas and Mietola 2021](#)).

In this paper, we reflect on the important steps taken by researchers who have begun to include people with profound intellectual and multiple disabilities in research in ways that make them more than just the object of the researchers' gaze ([Nind 2014](#)). This is a reflective piece, reviewing the state of the art. We raise fundamental questions about the impact of the exclusion and inclusion of people with profound intellectual disabilities in research, arguing for a paradigm shift. We illustrate some of our points using 'small stories' ([Bamberg and Georgakopoulou 2008](#)), that is, brief stories that ground the self and identity in interactive engagement with people. 'Small stories' put forth arguments and confirm and challenge views. Ours combine pictures and words to animate the perspective of someone with profound intellectual disabilities, often enabling the reader to read body posture and facial expression. The small stories add something about what is going on as we take on the role of animator (while limiting how much we interpret). They deliberately communicate in very few words, reflecting that including people with profound intellectual disabilities challenges us in terms of modes of communication.

The paper is not what [Davy \(2019, p. 111, after Kittay 1999\)](#) would call a 'view from nowhere', but is situated in our joint positionalities. We are researchers spanning novice to experienced; we have been practitioners (teachers, a speech and language therapist, and an assistant clinical psychologist), and our understandings of people with profound intellectual disabilities come from decades of involvement as variously: professional, advocate, voluntary sector worker, ally, friend and, most deeply, mother.

## 2. Why People with Profound Intellectual Disabilities Are Left Behind

Inclusive research was not developed with people with profound intellectual disabilities in mind. It has at its heart exploring, celebrating and utilizing the resources that people with intellectual disabilities have that can make research more meaningful, credible and valuable to them ([Walmsley and Johnson 2003](#)). Advocates of inclusive research have asserted the need for research 'with', 'for' and 'by' the people the research is about and have rejected research merely 'on' them ([Nind 2014](#)). However, over time, the elements of 'with' and 'by' have tended to take precedence over research 'for' people with intellectual disabilities and assumed a new taken-for-granted status as how inclusive research should be. These features of recent history have culminated in a model of inclusive research in which the people for whom the research is 'for' or is conducted 'alongside' are required to be able to express their views about needed research and fulfill roles that academic researchers have traditionally occupied—colleague, interviewer, observer, seeker of patterns in the data, writer, disseminator and creator of impact. This means that they need to match what a conventional researcher knows and does. As [Bigby and Frawley \(2010\)](#) note, when reflecting on work with a co-researcher who resists such molding, this is neither fair nor reasonable. It is no wonder, then, that inclusive research has not been able to stretch its parameters sufficiently to enable people with profound intellectual disabilities to belong.

[Walmsley and Johnson \(2003, p. 10\)](#) see research 'as a microcosm of the wider community'. This makes the restriction of inclusive research to those whose intellectual disabilities are at the mild/moderate end of the spectrum unsurprising; it is typical of wider failures to include those at the other end of the spectrum. The exclusion of people with profound intellectual and multiple disabilities from inclusive research is part of wider marginalization; it reflects what [Davy \(2019, p. 101\)](#) refers to as, 'The modern Western notion of the self as an autonomous, self-contained centre of thought and agency [which] informs cultural understandings of "the good life"'. This reflects the predominance of a narrow conceptualization of citizenship as involving 'communicative competence' ([Anderson 1999, cited in Vorhaus 2014, p. 618](#)). [Vorhaus \(2014, p. 618\)](#) argues that this focus on communicative competence means that 'profoundly disabled people are ... set up to fail the tests' of

full citizenship. This conceptualization of citizenship has underpinned policy imperatives around the increased involvement of people with learning disabilities in everyday life, particularly the ethos of normalization and social role valorization, which has been reproduced in inclusive research approaches, particularly in the UK (where people with intellectual disabilities employed by universities may be viewed as the pinnacle of inclusion). These high bars are evident in inclusive research, where people with profound intellectual and multiple disabilities are often excluded because their forms of communication lie beyond the technologies and practices of traditional, verbally based research roles, meaning that they ‘have had little or no chance to self-author their place within our historical record, nor to contest the many “unauthorized” representations’ (Milner and Frawley 2018, p. 386) in research accounts. They have been the ‘lost voices’ (Atkinson and Walmsley 1999, cited by Milner and Frawley 2018, p. 386) of qualitative research and may be the ‘most silenced’ (Mietola et al. 2017). We follow Vorhaus (2014) here in arguing that, just as this narrow form of citizenship needs redefining to include people with profound intellectual disabilities, so too must inclusive research be reconceptualized to be inclusive of people with profound disabilities.

We acknowledge that this is a challenge. There are structural (practical, methodological and ethical) (Tilley et al. 2020) and conceptual barriers to the inclusion of people with profound disabilities, even as research participants; the ethics procedures designed to protect vulnerable people are increasingly regulatory, often resulting in the exclusion of people with profound disabilities (Kellett and Nind 2001). Moving beyond inclusion as participants, as people have sought to firm up the structures that govern inclusive research to make it fundable, it has become less flexible; this systematically excludes people who cannot meet its requirements (Jones et al. 2020). This was a concern for Nind and Vinha (2014) when they advocated for keeping the phenomenon of inclusive research fluid, and this is why we use their more flexible term ‘doing research inclusively’ in the title of this paper. Without intending to do so, moves to pull some people inside inclusive research expose how people with profound intellectual disabilities are largely left sitting on the outside. As Seale et al. (2015) found, some definitions of inclusive/participatory research would not accommodate projects involving people with profound intellectual disabilities, but such projects ‘serve an important purpose in calling these boundaries into question’ (p. 491).

### 3. Why People with Profound Intellectual Disabilities Need to Belong

In this paper, we argue that current definitions of inclusive research have pushed the field forward, but are, in some ways, problematic because, in including some people, we have somehow excluded others. If inclusive research, like inclusive education, is a simultaneous process of increasing inclusion and decreasing exclusion (Booth 1999), we need an ‘inclusion/exclusion’ project ‘to encourage the keeping of both processes in mind’ (Booth 1999, p. 164). As Vorhaus (2014, p. 616) argues with regard to citizenship more broadly, ‘a profoundly disabled person may be unable to speak or contribute to a process of rational argument, but even when these capacities are absent, she remains a conscious agent, whose acts reveal human intentions and purposes’. This resonates with Carlson and Kittay (2010), who argued that we have moral obligations to people with profound learning disabilities. Only by engaging with these can we explore the nature and limits of concepts such as justice, rights, respect, care and responsibility to inform relevant policy, provision and practice. We add inclusive research to this list. Inclusive research is poorer if we fail to incorporate the experiences, intentions and purposes of people with profound intellectual and multiple disabilities. Society is poorer if we keep some people with intellectual disabilities and their families invisible (an invisibility lamented by Ryan 2021). We need research that explores how different forms of agency can contribute to and enrich inclusive research processes and findings.

Our desire to find ways to do research inclusively of/with people with profound intellectual disabilities is partly a recognition of their marginalization in society (Ockenden

2006)—they and their families are the excluded of the excluded (Lyle 2019). This has meant that research agendas have been underpinned by gross, negative and erroneous assumptions of impoverished lives (Ryan 2021). Assuming the quality of people's lives to be low results in discrimination with real-world consequences. This includes having a learning disability being used as a justification for placing DNACPR orders (Do Not Attempt Cardiopulmonary Resuscitation) on people's records without consultation with families or individuals (NHS England and NHS Improvement 2019). Instead, we follow Reinders (2008, p. 14) in arguing that people with profound disabilities can be understood 'as the rule of what it means to be human instead of the exception'. Without this, we lose the knowledge base held within these differently experienced lives.

Enabling people with profound intellectual and multiple disabilities to belong in inclusive research involves accepting that, while including them is hard, this is not a valid reason for exclusion. We illustrate this with the first of our 'small stories', showing that if something is hard in the lives of people with profound intellectual and multiple disabilities, then our work is to find a way around the barriers.

#### *Small Story 1*

Just once, Johanna (Catherine's daughter) went to an international conference. In this photograph (Figure 1), she was checking in the eleven bags that were all just for her. Clare Barnett came as an informal carer. Johanna was frisked soon after this just in case she had illegal substances hidden in her wheelchair.



**Figure 1.** Checking in at the airport ahead of an international conference.

If all means all, then we must address both micro and macro exclusions. As Grant et al. (2010, p. 160) have argued, this is 'one of the most vulnerable groups in society; and if society is to be judged by how it cares for its more vulnerable members, there is clearly much yet to be accomplished'. If the research community heard more from people with profound intellectual disabilities and their families, the benefits could be transformative. We might think differently about the costs in money, time, space and effort of including them (Brusch 2017) and appreciate the value of their lives. Community is not a problem to solve; instead, we need to build a community around our most vulnerable members (Block 2018). In this paper, we adopt Davy's (2019) feminist ethics of care approach, as this draws attention to the problematic, normative aspect of notions of vulnerability, dependency and responsibility.



#### 4. Advances in Doing Research Inclusively with People with Profound Intellectual Disabilities

In this part of the paper, we argue that doing research inclusively with people with profound intellectual and multiple disabilities is possible. If we can work out their involvement as participants who are able to share their experiences, then we can work out how they can accomplish further research roles. Moreover, meeting the challenge of meaningfully including people with profound intellectual and multiple disabilities in research can be a catalyst for developing approaches that are capable of hearing meaning in new ways, which, if clearly documented, will benefit the whole inclusive research community (Jones et al. 2020, p. 114).

The first step in doing research inclusively with people with profound intellectual disabilities might be to accept that the absence of verbal, symbolic language does not preclude meeting the criteria for inclusive research of Walmsley et al. (2018, p. 758)—research that stands with them, ‘that aims to contribute to social change’ and ‘create a society, in which excluded groups belong’, improving the quality of their lives, drawing ‘on their experience to inform the research process and outcomes’, recognizing, fostering and communicating their contributions, which ‘can be used by people with intellectual disabilities to campaign for change on behalf of others’. The recognized sticking point is about accessing their experiences and perspectives, but for this, we do not need to rely on words.

One key advance is the use of ethnography in an inclusive way with people with profound learning disabilities. As authors Catherine de Haas and Joanna Grace embark on doctoral research concerning belonging for people with profound intellectual disabilities and look to people and approaches leading the way, it is ethnography and, particularly, the work of Gleason (1989), Simmons and Watson (2015), Mietola et al. (2017) and Skarsaune et al. (2021) that provide a strong tributary. Ethnographers are interested in the different ways that people experience the world. The impairments of people with profound intellectual and multiple disabilities mean that they experience their world in a very different way from others. Working ‘alongside’ them in research is one approach to seeing the world from their perspective (Vorhaus 2016).

Altering our lens to look through the multisensory prism offered by sensory ethnography (Pink 2015) offers a good match for the possibility of ‘being with’ people with profound intellectual and multiple disabilities, moving beyond a focus on vision, taking into account the interrelated nature of the senses to improve data quality and depth (Pink 2015). This is innovative and reflexive, and it moves beyond traditional verbally based research methods. In applying this to research with people with profound disabilities, Simmons and Watson (2015) emphasize using ethnographic methods informed by phenomenology to develop a deeper understanding of the lived experiences and agency of school children experiencing profound intellectual and multiple disabilities. Simmons (2020, p. 32) created ethnographic ‘vignettes’—‘rich and prosaic renderings of fieldnotes about social interactions . . . [with a] story-like structure’. By investing prolonged time in understanding his participants through being with them and talking with those who knew them intimately, Simmons achieved research ‘on’ them that was also ‘for’ and ‘alongside’ them. (NB: This is our claim and pre-occupation, not his.) This meets the new criteria for inclusive research proposed by Walmsley et al. (2018, p. 758) of “‘standing with” those whose issues are being explored or investigated’. This approach is also present in Vehmas and Mietola’s (2021) ethnography of Finnish group homes for people with profound intellectual and multiple disabilities and Skarsaune et al.’s (2021) ethnography exploring the relationship between people and professionals and the phenomenon of self-determination. Somewhat bravely given the barriers, Skarsaune et al. (2021) include what might be the perspectives of two participants with profound intellectual and multiple disabilities, acknowledging the epistemic risk of doing so in balance with the obligation to try to represent such “voices” (following Vehmas and Mietola 2021).

### Small Story 2

Our second small story is told with a photograph. It shows that, just like any other aunts, Johanna, the daughter of one of the authors (Catherine), enjoyed playing with her nephew. We can see this in Figure 2. This shows that people with profound intellectual disabilities are 'people first' too.



**Figure 2.** Johanna, the daughter of one of the authors (Catherine), enjoyed playing with her nephew.

Bigby et al. (2012, p. 453) argue that including the 'direct voices' of individuals with severe to profound intellectual and developmental disabilities is difficult given that 'their thoughts, feelings, and inner mental states cannot be directly accessed'. They cite Kellett and Nind (2001), who, two decades ago, observed that 'we do not yet have models for involving people with profound learning disabilities as real partners in research' (p. 52). However, we have come to understand that such direct access is a myth, as all communication is co-constructed, and inference is an ordinary part of the communication process and is not

peculiar to communications with people who are nonverbal (Grove et al. 1999). Moreover, in research, voices in any mode are constructed by the researcher for research purposes (see, e.g., Jackson and Mazzei 2009). We argue instead for constructions of voice becoming a transparent and considered part of the research. Regardless of whether we agree, the communications of people with profound intellectual disabilities are pre-intentional (see the discussion in Simmons and Watson 2015), and their communications can be systematically interpreted by a parent (Forster 2020) or another person who knows them well. This is in contrast to viewing parents as too close to the situation (Ware 2004), effectively silencing both (Kittay 2010). Kittay (2010, p. 401) argues that ‘the intimacy of a parent and child and the parent’s caring labor gives us not a lesser grasp of moral truth but a greater one’.

Concerns about inferring the perspectives of people with profound intellectual disabilities are rooted in ideas about the ‘self-representing subject’, ‘seen as autonomous, articulating their authentic self and interests . . . , whereas speaking for the other is automatically deemed suspicious because this form of representation is mediated by the positioning of the speaker, their biases, privilege, and context’ (Davy 2019, p. 109). Davy’s concept of relational autonomy supports a view that the role of engaged others in helping the individual to live in and make sense of the world, including translating, interpreting and communicating their perspectives, is part of someone’s authentic autonomy, rather than something to be feared as undermining it. Kittay (2019) similarly reminds us that independence is an illusion, and this applies to communicative competence, too; we all rely on others to interpret, and through the reciprocity of close interactions, we can achieve ‘intersubjectivity’ (Stern 2005), which is understood as ‘the ability to share in another’s lived experience’ (Skarsaune et al. 2021, p. 318).

Advancing the inclusion of people with profound intellectual and multiple disabilities in research requires an inclusive stance on humanity, research and communication. In her co-constructed storytelling, Grove (2016) uses any expressive ability a person has, such as a movement or a sound, to enable a group of people tell a story together. Switches, objects of reference and symbols (Goldbart and Ware 2015) are resources for communication, but a stronger resource is the attitudinal shift from thinking in an individualistic way about people to thinking about how we relate to each other (Vorhaus 2021). Whenever Catherine spends time with groups of friends who have children with profound intellectual and multiple disabilities, she is filled with wonder by the capacity of humans to be interactive and find means of communication.

‘Being with’—as described by Forster (2020), partly based on Intensive Interaction (Nind and Hewett 2005)—could be key to doing research inclusively. ‘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. While people with a purpose, such as teachers and teaching assistants, struggle with being still and ‘being with’ (Goodwin 2020), as a parent, Catherine feels that is exactly how she and Johanna (her daughter) were together, relaxed and enjoying each other’s company, even during tasks. Catherine would go as far as saying that Johanna taught her how to just be. ‘Being with’ is not another task, but a mode of being. In a study of quality in inclusive research, Nind and Vinha (2014) found that some of the most established inclusive research teams had established a way of being; they could just be people together alongside doing research together. A research culture that can accommodate ‘being with’ as a core element will hear the voices of people with profound intellectual disabilities by enjoying their presence and letting this inform the research in creating intersubjective knowledge together.

### *Small Story 3*

Kate knew immediately when she met Johanna how to be alongside her and have fun, together. Their immediate connection and engagement with each other were evident (see Figure 3) and meaningful. Kate could adapt herself as a communication partner to



Johanna's communication with a little guidance from Catherine, her parent. Johanna was stretching out on the floor having a break from her wheelchair during a coffee break of Jo Grace's Sensory Stories Training weekend. Jo and Kate came over to say hello; Catherine said that if you lie down next her, she will love it, especially if you clap hands with her. Kate felt comfortable doing this even though she had not spent time with anyone with disabilities since she was a child.



**Figure 3.** Johanna and Kate ‘being with’ each other.

In their book on belonging for people with profound intellectual and multiple disabilities, [Nind and Strnadová \(2020\)](#) bring together accounts from researchers with a readiness to push the boundaries on inclusion. [McCormack \(2020\)](#) used a life story approach, which, working with families and technology, she was able to do inclusively and accessibly. [Tilley et al. \(2020\)](#) enabled a profoundly disabled participant to deposit her life story material in an archive of the lives of people with intellectual disabilities by working with this individual alongside her family, practitioners, academics, archivists and solicitors. [Goodwin \(2020\)](#), while making no claims to doing research inclusively, used a creative art installation—‘golden tent’—to provide an immersive environment for staff and pupils to ‘be’ together, while [Warwick \(2020\)](#) supported a person with profound intellectual and multiple disabilities to use a wearable camera to shift the gaze of the research to her gaze and to see



the meaning in her activity from her (literal) perspective. This is an eclectic assortment of examples that show inclusivity at different levels of granularity—from design issues to micro methods. What they have in common is the researchers' determination that the life experiences of people with profound intellectual disabilities merit our efforts to seek to understand and share them. Their research was 'on' persons in this group but always seeking to be alongside them, appreciating that they can contribute significantly to research outcomes.

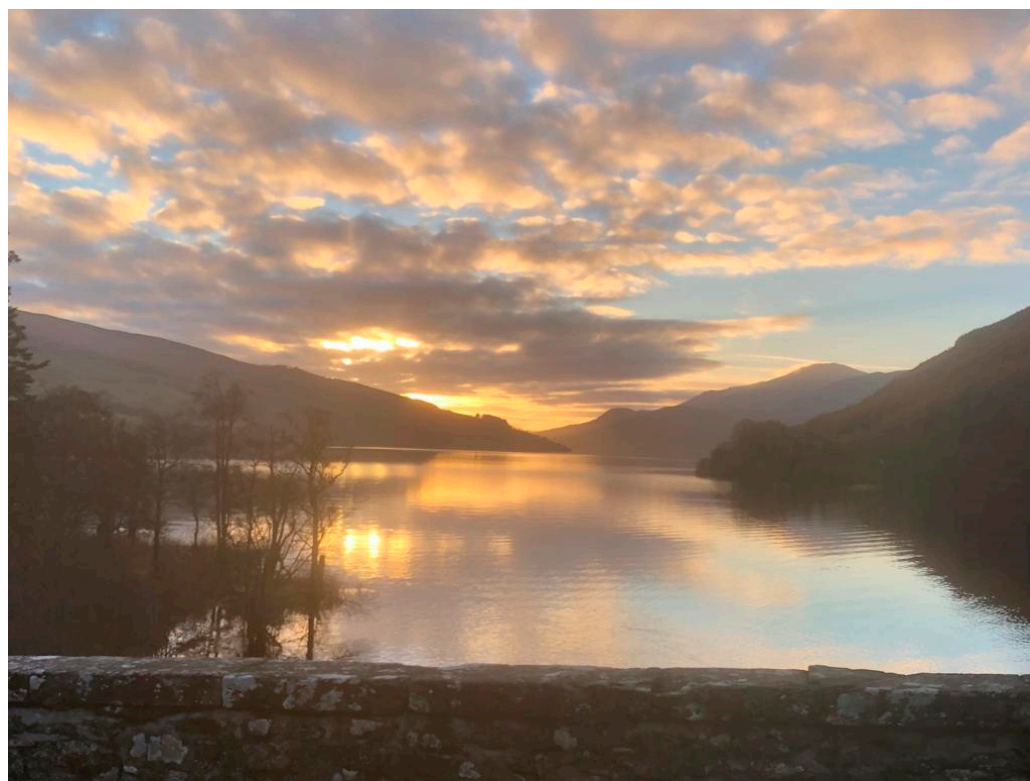
For some researchers, including people with profound intellectual and multiple disabilities is a creative endeavor of opening ourselves up to be surprised by things that we would otherwise have missed (Goodwin 2020) and being willing to use mediated approaches (Cluley 2016). People's capabilities in research have been revealed through their laughter (Brigg et al. 2016; Johnson et al. 2012) and their responses to music and other art forms (Macpherson et al. 2016; Vorhaus 2016; Warwick 2020). Ethnographers working with people with profound intellectual disabilities use careful observations to allow the person to 'speak' for themselves (Watson 2020). Interpretation is handled so that the reader can see what the researcher saw when they were with the person with profound disabilities. Researchers check their interpretations of communications, situations and cultures with people who know the person well (see also Ware 2004). Lyle (2019) argues that knowing someone with profound disabilities well requires being with them for two to five years. As with any inclusive research, there are strong indications that long-term immersion is beneficial or even necessary.

This is a prompt to recognize the many practical and ethical risks in doing research inclusively with people with profound intellectual and multiple disabilities. Inevitably, we warn against attempts from under-skilled researchers or researchers working in time-pressured conditions. We advise critical pauses to pose the difficult questions about whether this really is the way to proceed, whether the process is really 'being with' and 'standing with' and whether an interpretation stands up to scrutiny. However, we must not let risk aversion paralyze us and prevent positive risk taking and possibility thinking (see Seale et al. 2013).

#### *Small Story 4*

Each of us has a unique view of the world. If an academic researcher and a person with profound intellectual disabilities were to look at the scene in Figure 4, one person may enjoy the wide expanse of the hills, and another the light effects. By being in each other's presence, their enjoyment of the scenery can be enhanced, as each pays attention to the other's perspective. Our insights may be shared, and collaboration becomes possible. A person with profound intellectual disabilities may, with their reaction, draw our attention to something that we would otherwise miss.

Doing research inclusively of/with people with profound disabilities involves us as researchers in expanding our capacity to see and listen. We can learn from the work of Olsman et al. (2021) on families as witnesses, practical tips on listening from Goodwin (2013) and creative methods for hearing voice from Evans (2021). We can learn from co-design techniques (Neidlinger et al. 2021) and from seeing the person with profound intellectual disabilities as the teacher (Ward et al. 2016). Doing research inclusively of/with people with profound disabilities also involves reconceptualizing the research partnership (Seale et al. 2015; Tilley et al. 2020). More dialogue is needed to move the flow of ideas forward (Nind and Seale 2009; Seale et al. 2015), as schools are attempting to do (Colley et al. 2022). People with profound intellectual disabilities are capable of being responsive to their environment and of forming deep relationships with people they know well (Kittay 2010). This means that they can play a role in a research partnerships or teams where each person has a unique, interdependent role.



**Figure 4.** Different ways of seeing.

## 5. Conclusions: The Need for a Paradigm Shift

We need to move from focusing on the challenges of doing research with people with profound intellectual and multiple disabilities to considering what we gain by embracing new possibilities. We argue here that when embarking on new research on and with people with profound disabilities, researchers should not start by attempting to modify currently accepted models of inclusive research. Instead, we should begin from a deep understanding of people with profound intellectual and multiple disabilities. This allows us as researchers to tap into the meaning contained within and around people's lives while striving to realize their contributions, recognizing that all people hold valuable knowledge. This would allow us to conduct research underpinned by epistemic justice (see [Collis 2021](#); [Walker 2019](#)).

People with profound intellectual and multiple disabilities are human not because of a list of psychological or cognitive capacities, but because of how they are in the world and how they interact with others and are cared for by others ([Kittay 2010](#)). This focus on personhood directs us not to tweak often verbal inclusive research practices, but to shift our thinking fundamentally. Inclusive research in the field of intellectual disabilities in the UK has deep connections with the self-advocacy movement; both inclusive research and self-advocacy celebrate the power of people's voices and choices. However, just as the self-advocacy movement has left people with profound intellectual disabilities and their families with a sense of not belonging ([Palmer and Walmsley 2020](#)), so too has inclusive research. There is a risk that in emphasizing the capacity of self-advocates and self-advocacy, people with profound disabilities are excluded on the grounds of cognitive incompetence ([Davy 2019](#)), mirroring the exclusion of people from true citizenship described by [Vorhaus \(2014\)](#). This may be a little unfair to self-advocates and their allies who do seek to speak *with* people with profound disabilities, which we, like [Davy \(2019\)](#), recognize makes 'self-representation' collective rather than individual. Nonetheless, we may need to look elsewhere when addressing 'all means all'.

A more solid foundation for doing research inclusively of/with people with profound intellectual disabilities involves genuine engagement with the relational concepts of self described by [Davy \(2019\)](#). Here, dependency and vulnerability are the norm; they are

‘basic features of the human condition’ (Davy 2019, p. 102). This allows us to dispense with notions of the ‘autonomous individual’, instead acknowledging *all* people as ‘situated and embodied’ and as requiring care in order to engaged autonomously in the social world (Davy 2019). We concur that agency and autonomy can only emerge relationally, and propose that the place of people with profound intellectual disabilities in research is as much about care as it is about autonomy. We need to resist seeing people with profound intellectual disabilities as a deviation from what it means to be intellectually disabled and from what it means to be human. Our position is one of optimism. We believe that by freeing ourselves of the preoccupation with autonomous or verbal voice, and by making explicit the issues involved, we can begin to make use of the conceptual and methodological tools at our disposal to do research inclusively with people with profound intellectual disabilities. We are confident that people with profound intellectual disabilities have knowledge to share and that, by being open to this, we all have much to gain.

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