Article

Expanding Possibilities for Inclusive Research: Learning from People with Profound Intellectual and Multiple Disabilities and Decolonising Research

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Abstract: This paper pursues the argument that finding a way for people with profound intellectual and multiple disabilities to belong in inclusive research requires starting from a deep knowledge of the people in question. This paper illustrates this idea in action showing what can be possible from building research around 'being with' people with profound intellectual disabilities, creating intersubjective knowledge together. It follows the journey of fostering a relational research space that a young person with profound intellectual and multiple disabilities can occupy, their assenting to share the space and ensuing exploring together in embodied ways. Small stories show where this particular open road of inclusive research can lead. The analysis interacts with provocations from decolonising research that demand respect for wider ways of knowing, doing research and being human. The paper invites reflection on the ways in which research needs to be deconstructed to be inclusive for all.

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

1. Introduction

In our last paper (de Haas et al. 2022), we argued that it is important to find a way for people with profound intellectual and multiple disabilities to belong in research. We concluded that to do research *with* (not *on*) people with profound intellectual and multiple disabilities, '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' (de Haas et al. 2022, p. 1). In this paper, we share an illustrative example of this approach in practice. We recognise people with profound intellectual and multiple disabilities as people possessing and experiencing meaning and provoking and providing love. We acknowledge them as people leading lives in bodies complicated by profound cognitive and multiple sensory and physical impairments, having high and pervasive support needs. We remain committed to learning from this group new ways of knowing about the world. We rise to the challenge of joining with them in closing the gap between their inclusion in the research world and the inclusion of other disabled people already making important contributions. Our work is inspired by the strong tributary of ethnography set by Mietola et al. (2017), Skarsaune et al. (2021) and Simmons and Watson (2014). We also explore parallels with decolonising research in our shared desire to relinquish established ways of knowing and be open to wider forms of meaning and knowledge construction.

This paper reports on the ongoing work of Joanna Grace (hereafter Jo) and our joint methodological and conceptual work. This is informed by the existing literature and our connections to people with profound intellectual and multiple disabilities and their families.

We are conscious of 'moving forward on a road less well-travelled' (O'Brien et al. 2022, p. 483) and have taken particular insight from decolonising research. We acknowledge that people with profound intellectual and multiple disabilities are not an indigenous population and are not clamouring for fair treatment. However, we note parallels in their subjugation by power hierarchies and exclusion from the production of valued knowledge. The people are not analogous, but the issues are. Moosavi (2023) calls for researchers to make decolonising epistemology more all-encompassing. Our work maps a similar terrain in that our journey necessitates questioning how we create knowledge and challenges underlying assumptions about valid forms of knowing.

'If we are committed to anticolonial thought, our starting point must be one of disobedient relationality that always questions, and thus is not beholden to, normative academic logics' (McKittrick 2021, p. 45, cited by Rutazibwa 2023, p. 329). The normative academic logic of research inclusion is to enable inclusion within existing research processes and evaluate success on these terms (see, e.g., Bigby and Frawley 2010; Bigby and Wiesel 2019; Kellett and Nind 2001; Nind and Seale 2009; Nind 2017; Strnadová et al. 2014; Tuffrey-Wijne et al. 2008; Tuffrey-Wijne and Butler 2010; Woelders et al. 2015). Instead, by beginning from a deep knowledge of people with profound intellectual and multiple disabilities, we transform the *doing research with* of inclusive research (Walmsley and Johnson 2003; Nind 2017) into 'being with' people with profound intellectual and multiple disabilities in research (de Haas et al. 2022). In doing so, we are inspired by Go's (2023, cited by Rutazibwa 2023, p. 330) anticolonial approach to social inquiry, to 'consider a standpoint (heterogeneous though it may be) that has not yet been considered' (Rutazibwa 2023, p. 290).

Decolonising research recognises the importance of spending time getting to know populations who have been excluded from research. Smith (2021) comments on the culturally sensitive nature of the interview format, remarking that if a Māori person consents to a standard one-hour interview then the researcher has not succeeded in involving them in research. This acknowledges how Māori people share knowledge collectively in communities, meaning a researcher must spend hours or days with them, dining with them, talking and listening and being a part of the sharing of wisdom. Yunkaporta (2019, p. 168) speaks of the kinship mind of Aboriginal people, whereby knowledge sits in the relationship between people and is best accessed together. While a Western researcher might assume they bring only themselves to research, indigenous researchers speak of carrying a responsibility towards their ancestors in all they do (Lavallée 2009; Liebert 2021). Rhee (2021) describes how knowledge is 'grounded within our bodies, born out of our mother's bodies, and our body bridges the past and the future'.

Inclusive researchers similarly recognise the importance of spending time with people with profound intellectual and multiple disabilities (Mencap 2011; Watson et al. 2006), getting to know them (Chalachanová et al. 2020; Lesseliers et al. 2009), working alongside them and allowing time for expression (Steve Hollingsworth 2020; Mikulak et al. 2022; Nieuwenhuijse et al. 2020; Simmons 2018). Macpherson et al. (2016) highlight how advantageous the 12 years spent weekly together was for one partnership within their inclusive arts practice. This was crucial, they say, to their ability to be with and listen expansively to people with learning disabilities. Spending close time together is, we argue, a key resource in enabling some groups to belong in inclusive research, as in advocacy and other related work.

The inclusive research agenda also similarly recognises the necessity of being open to listening in different ways (Bos and Abma 2022; Goodwin 2013; McCormack 2017; Olsman et al. 2021; Skarsaune et al. 2021) and appreciates embodied knowing. We answer 'now' to Manning's (2016, p. 4) challenge: 'When do we honor significantly different bodies and ask what they can do, instead of jumping to the conclusion that they are simply deficient?' In our work, we, as Van Goidsenhoven and De Schauwer (2020, p. 332) advocate, 'explicitly honor complex forms of interdependence in thinking about voice and create modes of encounter for that difference'. We conceive knowledge not as located awaiting extraction by a researcher but as an experience of meaning shared between people, even between

bodies. In going about sharing meaning, we are strongly influenced by our experiences of using Intensive Interaction (Nind and Hewett 2005), which provides a framework for connecting without leading, sharing joint focus, and mutually attuning.

The work described in this paper took the goal of inclusion, or rather belonging, in research. Here, we mean belonging in the sense of being 'related to and part of something' (Block 2018, p. xvii) and the 'familiarity, comfort and security and emotional attachment' (Antonsich 2010, p. 645) that comes with it. In a move of 'disobedient relationality that always questions' (McKittrick 2021, p. 45), Jo placed belonging as the foundation stone in her research, seeking to establish the 'being with' people with profound intellectual and multiple disabilities before anything else. This belonging is the 'being with' that opens the possibility of a research encounter. In the research, Jo establishes 'being with' and then invites questions about their subject of joint study (embodied identity) into the research space. In this paper, we describe the process of locating a space of 'being with' in which to do research with people with profound intellectual and multiple disabilities.

2. Locating a Space of 'Being with'

Jo utilised participant observation (Glaser and Strauss 1967; Patton 2015) informed by sensory and autistic ethnography (Greco 2022; O'Reilly 2012; Pink 2015) and phenomenology (Merleau-Ponty 1945) in her processes of finding a way to research identity inclusively. She focused particularly on Merleau-Ponty's (1945) idea of intention as the movement of an embodied consciousness towards the world, of 'being in and toward the world'—rather than consciousness understood solely as thought. She visited three people with profound intellectual and multiple disabilities, Becky, Felicity and Senen, spending 3–5 h with them weekly at their school. Ethics approval for this work was obtained from University of Southampton Faculty of Social Sciences Research Ethics Committee (73404) with informed consent given by the young people's parents and school. Becky, Felicity and Senen's real names are being used in line with the consent given and the argument made by Grace (2022) that protection is not always found in anonymity and that by showing their faces and speaking their names, we ensure that these people are not hidden but are recognised for their part in the research (see also Tilley and Woodthorpe (2011) for arguments against the prevailing orthodoxy of anonymity). Inclusive research commonly names, as authors or in acknowledgements, the people with intellectual disabilities involved as contributors. By naming Becky, Felicity and Senen, we are acknowledging their role as collaborators in Jo's work.

Process assent (Dewing 2007) was sought continually when working with Becky, Felicity and Senen to ensure, as far as possible, that their agency and autonomy within the process were respected. We illustrate this with a small story (a concept adapted from Bamberg and Georgakopoulou 2008) of process assent in action with Becky (see Figure 1).

Small Story 1

Becky is vibrant and curious, alert to sounds around her. She delights in textures and vibrations. She is very expressive, using her own lexicon of sounds to convey meaning and amplifying these with gestures and bodily movements, for example, waving her arms and jumping if she is happy. Hoping to collaborate with Becky to explore embodied identity, we began with exploring leaf litter. Becky's understanding of this is better than mine; today, I noticed how the leaves and sticks ping gently against the fence; it's a very pretty sound. Ordinarily, she plays with the resources in the sand pit or crouches by the fence. Today, we did both of these things; I also pulled aside a chair to sit out of the way. She chose to come over to me, and to spend a good deal of time near me, looking at me, leaning towards me, a couple of times she hugged me, and at one point, she climbed onto my lap to explore my hair more closely. I did not prompt or request her to be with me at all; she came across entirely of her own volition. To me, this indicates her assent to be with me. I will look for indicators of her assent at every juncture of our work together. Today, I felt like I got the thumbs up.

Figure 1. Gaining assent to do research together.

3. 'Being with' as a Space for Feeling

Rhee (2021) talks of starting her work from 'a feeling place'. Similarly, Jo's collaborative work starts from the presence of a space of 'being with' in which a research encounter is made possible via feeling. Two moments can look alike in movement and in expression, but one offers the opportunity of 'being with' while the other does not. Jo's detailed reflection and analysis have led us to appreciate the movements made to create a space in which 'being with' is possible and its subtle distinction from *not* 'being with' as captured in these examples of field notes:

> Even though I had not managed to 'be with' Senen, the effort of trying left me feeling like I wanted to disconnect rather than connect. The class moved into an activity dedicated to the birthday of a class member. Various articles were passed around, to be looked at, smelled, etc. I took an active role in passing these around, in wafting, moving, putting things against their hands; it is easy to feel like you are doing something without having to move towards the children with your emotional self. (Jo field notes)

> I looked at the maths resources and considered trying to get back into a state of being with Becky and couldn't imagine doing the emotional work to get around these things. . . . I decided to back off and to perform the teaching assistant role. I counted to 3 and threw a brick into the sandpit every time I reached three. Becky enjoyed this and bounced to show her enthusiasm. (Jo field notes)

By contrast, 'being with' is a felt space of belonging, apprehended via affect. Here, Jo describes her process to create the possibility of 'being with':

> I first locate my embodied self, attempting through focus on the here and now to occupy the time and space I find myself within, rather than the many landscapes available to me intellectually. I then seek to locate the other person, I attempt to go deeper than simply looking and listening, I pay attention across sensory systems and attempt to attune myself to their being. To create the potential for being with I lean heavily on Merleau-Ponty's (1945) descriptions of our experience of consciousness as a directed movement towards the world in which our intention is placed in things towards which we then move. These movements can be physical, they can be utterances, or they can simply be the movement of consciousness. Once I have a rough grasp on where I am and where they are, I try to work out where their intention might lie, I then try to move my intention to that place, and if I can get a match, I experience the sensation of being with them and the potential for a research encounter is created.

The following small story from one of Jo's first meetings with Senen exemplifies this process and reveals the multisensory nature of their communication (see Figure 2). By narrating this micro-interaction, we aim to provide the reader with a tangible example to illustrate the argument of this paper.

Small Story 2

Senen arrived at school asleep and was positioned on an adjustable bed for the morning routine. Partway through the morning she woke up in pain and moaned; staff all expressed their sympathy, they fitted a tube to her stomach to try and wind her and then took her out of the room to adjust her position. When she returned, she was lying on her side on the bed and seemed awake. I took the chance to go and meet her (see Figure 2). I sat alongside the head of her bed, saying Hello and saying her name. Her eyes seemed bright. I was unsure of her vision and if her alertness was to me, or to something happening in her body.

With her arms bent and one fist near her mouth, she extended a finger and put it in her mouth, chewing on it and exploring it with her tongue. I copied her facial movements and angled my head to lie as if on her pillow close to hers. I extended my tongue as she extended hers.

Her eyes continued to be bright, giving the impression that wherever she was it was a happy place, and I was keen to be invited in or to try and wheedle my way in. Outside of what seemed to be our shared gaze, the class continued with a sensory story. The longer I spent with my head angled to the pillow, the more I felt where Senen's meaning was. All of her doing was around her mouth and her extended finger. I put my own fist to my mouth and reflected back Senen's expressions on my own face. It didn't feel like enough. I wanted into her world of meaning, so I moved so that my fist rested against hers, and she seemed to notice. Her tongue protruded in a triangular point, the pointiness of it gave it a sense of purpose. I touched the end of her tongue with my finger, and so began a conversation where I told her I could see what she was doing, I told her I could hear her. I discovered the finger in her mouth was hooked around so that its tip pressed back through the skin of her gum, I pressed it with my own finger from the outside of her face. "I see your finger there, I see where you are hiding it, I see what you are doing." She appeared to smile, and encouraged I repeated the action more playfully. She extended her smile and made a faint sound, which I repeated turning my sound into a laughing rhythm; again, her smile responded, and the rhythm of the slight noise matched my own.

Her tongue came out and I felt more confident so bounced my finger against the tip of it. She grinned and her hands lifted slightly and then she shook her head from side to side (the biggest movement I had observed her making). We continued that game until after a couple of headshakes, Senen seemed to calm, and I was mindful that I wanted to be with her, so I calmed with her and did not try to provoke further responding.

There was a pause and I repositioned myself so that my hand matched against my face where hers was against her face, she seemed to look at me, but I couldn't be sure her gaze was directed. I moved closer so that our fists touched each other, as my hand touched hers, she withdrew her hand from her mouth and the fingers uncurled. I had thought they were held in the fist shapes from spasticity, so it was unexpected when she opened her fingers to a splayed high five a little way from her face. I copied and matched my fingers to hers like praying hands. She seemed pleased and I was delighted, then she dropped her hand and shook her head again. Her vocalisations this time were more audible, and I matched them back to her.

Reflection: As I have continued to work with Senen, I have found that by locating her intention and placing mine with it I can create a connection, a 'being with' that then extends to experiences outside of that place of engagement. I make sure, when doing this, to focus on my being and on Senen's being. I might notice her doing, as I did with her sticking out her tongue in the small story above. When her being and her doing seem to be in the same space I allow myself to bring a small amount of my own doing into that space, as with the tongue tap. When I do this, I focus on ensuring that my doing does not overwhelm my being. If I feel that I am doing more than being I stop my action to refocus on being. I am also mindful to ensure that my doing does not overwhelm Senen's doing. It is easy for me to join in with her activity, and to do it more than her, bigger, faster, more dramatically, etc. I aim for my doing to be second to her doing and second to my being always.
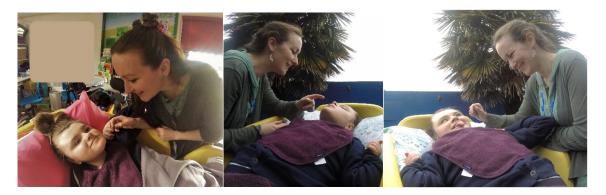
Figure 2. Senen and Jo starting out and later finding a feeling space of 'being with'.

This is one of the ways I work to ensure Senen's agency, as well as my own, is able to direct our work. I work to find my way to a space of 'being with', but I recognise that at times the people I am working with make movements towards me, we each find our own way into that space, and are each free to withdraw from that space. My ability to be, rather than to do, is key here, when an activity is taking place, it is all too easy for me to slip into just doing, the way one might ride a bike without considering one's movements or truly taking in one's surroundings. Being requires a presentness of self: thought and affect, and is necessary for connecting with someone in this context. Once a space of being with has been established—meaning that a research encounter is possible—I invite questions relating to embodied identity, I also respond to invitations that stem from them, in this way we both influence the research we conduct together.

We are conscious that the interaction described here is an intimate one that might cause some readers discomfort (Melanie recalls that such responses were common in the early days of Intensive Interaction). Yet the embodied nature of 'being with' is integral to the belonging of people with intellectual disabilities in research. For Senen, connecting via her tongue was what made the connection meaningful; for others, it would be different and personal to them. Senen was assenting and engaging with apparent comfort.

4. Different Ways of 'Being with'

By working through rapport building, communicating using Intensive Interaction techniques (Nind and Hewett 2005) and seeking to meet in an embodied fashion via the co-location of intention, Jo attempts to create a space in which a research encounter can happen. Once that space is created, research questions can be introduced and discovered. Jois focused on the substantive topic of embodied identity, and she brings objects into the research encounter to explore this, remaining alert to the location of her collaborators' curiosity and joining with them in their exploration of what holds meaning for them.

Catherine is keenly aware of the deep connection between families and their child with profound intellectual and multiple disabilities from personal experience (de Haas et al. 2022). In her research, because parent and child experience so much of the world together, hearing from people with profound intellectual and multiple disabilities means hearing from parents, too. This goes beyond proxy reporting of experience; it is about exploring experiences of community as merged identities. (Such intercorporeality is also evident in Jo's work.) Like Jo, Catherine will build upon some of the techniques and mindset of Intensive Interaction (Nind and Hewett 2005), using sensory and affective awareness, together with an openness to experience the world from the perspective of the person with profound intellectual disabilities, describing how physically close bodies connect, with one body becoming an extension of the other. This draws on the work of Lindemann (2010, 2014) and Skarsaune and Hanisch (2023), recognising that people with high support needs are held, both physically and in terms of having their identities held, and narrated in relation to places, time and rituals. Her research begins with conversations with families and other allies of people with profound intellectual disabilities to gain deep knowledge of a small group of people with profound intellectual disabilities. These

conversations will bring together elements of the focus group method (Kreuger and Casey 2015; Krueger and King 1998; Nind et al. 2021), the coffee shop conversations of Collis (2021), the work of Critical Communicative Methodology (CCM: Puigvert et al. 2012) and the collaborative conversations of Sandra Hollingsworth (1992). Then, she will deepen her knowledge by working directly with one or two of these people with profound disabilities and their families to access their knowledge of how they experience their communities (the substantive topic). She will also be following Skarsaune (2023), who suggests that empathy is used to grasp the perspective of a person with profound intellectual disabilities.

Catherine will use small stories employing photographs and text to attempt to translate the nonverbal experience of people with profound intellectual disabilities into a narrative format. This is more acceptable to Western culture, which valorises the written word (Smith 2021). However, in creating small stories, Catherine and her collaborators aim to respectfully borrow (rather than raid) research tools from indigenous and folk cultures in the form of yarning (Byrne et al. 2021), carving and other art forms such as weaving and knitting (Gudjonsson 2022; Smith 2021; Vidal de Milla 2000; Yunkaporta 2019). Which artifacts they produce will depend on the interests, knowledge, and skills of those collaborating in the research and on what helps them to be simultaneously doing and providing information. This approach is about encompassing knowledge from the heart and the mind (Atkinson et al. 2021; Rieger et al. 2023) and sharing meaning and emotion in mutually beneficial ways, as in oral traditions (Byrne et al. 2021). The aim is that participants/collaborators will deepen their connections by having fun and supporting each other and that they will maintain and extend their communities by putting respectful, genuine and reciprocal relationships at their heart (Smith 2021).

5. Making Sense of the Direction of Travel

We (the authors) began our collaborative work on doing research *with* people with profound and intellectual learning disabilities by focusing on belonging, identity and community. Our starting point has always been that we work from the position that this group belongs in the inclusive research movement, and from here, we seek to discover what this means in practice. Our research conversations as a group of scholars have included appreciating the ways in which our direction of travel has strong parallels with decolonising research. The decolonising research turn (e.g., Smith 2012; Chilisa 2017) has highlighted the injustices of relying on one way of knowing at the expense of other equally valid but subjugated ways of knowing. Inherent to challenging the status quo has been bringing into action and legitimising such ways of knowing (Chilisa 2017). This, Chilisa (2017, p. 813) argues, means seeing indigenous people as 'Authors of what they know and how it can be known'.

Research with people with profound intellectual and multiple disabilities is still at the stage of raising awareness about the validity of the ways in which people can know. It can be discomforting for Western researchers to consider unfamiliar ways of knowing, such as knowing with one's ancestors alongside (Lavallée 2009; Liebert 2021) or in ways deeply connected with one's relationship with the land (Smith 2012). Similarly, it can be disturbing to think about the embodied ways of knowing that we are exploring as a form of knowing that is felt first and thought afterwards can leave those confident in their command of intellectual knowledge feeling out of their depth in this less certain landscape. Decolonising work has questioned 'methodological hegemony' and its 'tendency to perpetuate the dominance of one race over the 'other' by building a collection of theories, concepts, methods, techniques, and rules designed to promote only the knowledge that promoted and profited Eurocentrism' (Chilisa 2017, p. 814, drawing on Chilisa 2012). As we have shown, understanding this dynamic has resonance for profoundly disabled people and for those of us who are allies seeking theories, concepts, methods and techniques that not just include them but that honour them and work against their oppression.

We appreciate that we can take the connections with decolonising research too far, but there is liberation in freeing ourselves from the anchor points of inclusive research

that are most familiar to enable us to think afresh. Equally, going outside Western frames of reference has taken our journey towards different ontologies such as Ubuntu, a more inclusive, communal, social justice way of understanding the nature of being human (Chataika and McKenzie 2013; Chilisa 2017; Ifejika 2006; Yunkaporta 2019). We use the African philosophy of Ubuntu because we consider all people to be connected relationally to other people, and we challenge dominant Western notions of individualism (Baggini 2019; Chataika and McKenzie 2013) because they encompass an unhelpful ontology for profoundly disabled people. Yunkaporta (2019) also highlights the Aboriginal concept of Ngal, capturing how knowledge develops inter-relationally. All this helps us to feel comfortable in the non-individualistic 'we-ness' (Nyasini 2016, cited by Chilisa 2017, p. 820) or intersubjectivity necessarily inherent in doing research with people with profound intellectual disabilities.

Kittay (2019), in discussing disability yet in common with indigenous scholars, reminds us that independence is an illusion because everyone relies on interdependence to communicate competently. Skarsaune (2023, p. 8) suggests that by 'heightening the status of embodied communication and the reliance on feelings as an epistemic resource' we can enable people with profound intellectual disabilities to be the 'subjects' of research rather than the 'objects' of research. Our argument is that in this way, they can be part of inclusive research as knowledge producers, too. We are, in effect, seeking to decolonise research for people with profound intellectual disabilities. A key concern of this paper is our process of moving away from the 'I/You relationship' (Chilisa et al. 2017) and finding connected ways of researching and knowing that is put into a historical and global context.

6. Conclusions

We have attempted to deconstruct research with people with profound intellectual and multiple disabilities such that it begins with a deep connection with the people about whom and with whom it is created and proceeds from there, respecting multiple ways of knowing and being. In this paper, in the spirit of show not tell, we have demonstrated the possibility that we introduced in our first paper (de Haas et al. 2022, p. 8) that 'being with' (Forster 2020; Goodwin and Griffiths 2022; Macpherson et al. 2016), 'could be key to doing research inclusively'. By taking seriously the possibility of people with profound intellectual and multiple disabilities being active agents within research, we reject the commonly accepted assumption that research is an inherently intellectual pursuit and therefore only accessible to people in proportion to their presumed intellectual capacity. In working with people with profound intellectual and multiple disabilities, we are attempting to hear from people previously excluded from knowledge-making and considering knowledge outside pre-determined acceptable sources. This incorporates using all our senses, our bodies and our capacity to hold and narrate stories for and with people who communicate without words. It echoes the widening of ways of doing research that come from indigenous and decolonising research.

We embrace the uncertainty of not/knowing and lean into felt embodied forms of meaning, finding these disorientating as anyone accustomed to the certainty of traditional forms of knowledge production would. However, we recognise any tremulousness as a part of the process, not a reason to turn back. Treading this path is difficult, but it is essential that researchers engage with researching with and alongside populations whose meaning has historically not been valued by dominant groups. This is not only to reduce vulnerability via inclusion but also because an account of human experience is incomplete until all humans belong within it.

References

Antonsich, Marco. 2010. Searching for belonging—An analytical framework. *Geography Compass* 4: 644–59. [CrossRef]

Atkinson, Petah, Marilyn Baird, and Karen Adams. 2021. Are you really using yarning research? Mapping social and family yarning to strengthen yarning research quality. *AlterNative: An International Journal of Indigenous Peoples* 17: 191–201. [CrossRef]

Baggini, Julian. 2019. *How the World Thinks*. Croydon: Granta.

Bamberg, Michael, and Alexandra Georgakopoulou. 2008. A small stories as a new perspective in narrative and identity analysis. *Text and Talk—An Interdisciplinary Journal of Language Discourse Communication Studies* 28: 377–96. [CrossRef]

Bigby, Christine, and Ilan Wiesel. 2019. Using the concept of encounter to further the social inclusion of people with intellectual disabilities: What has been learned? *Research and Practice in Intellectual and Developmental Disabilities* 6: 39–51. [CrossRef]

Bigby, Christine, and Patsie Frawley. 2010. Reflections on doing inclusive research in the "Making Life Good in the Community" study. *Journal of Intellectual & Developmental Disability* 35: 53–61.

Block, Peter. 2018. *Community: The Structure of Belonging*, 2nd ed. Oakland: Berrett-Koehler.

Bos, Gustaaf, and Tineke Abma. 2022. Putting down verbal and cognitive weaponry: The need for 'experimental-relational spaces of encounter' between people with and without severe intellectual disabilities. *Disability & Society* 37: 1703–27.

Byrne, Amy-Louise, Sandy McLellan, Eileen Willis, Vanessa Curnow, Clare Harvey, Janie Brown, and Desley Hegney. 2021. Yarning as an interview method for non-Indigenous clinicians and health researchers. *Qualitative Health Research* 31: 1345–57. [CrossRef]

Chalachanová, Anna, Melanie Nind, May Østby, Andrew Power, Liz Tilley, Jan Walmsley, Britt-Evy Westergård, Torill Heia, Alf Magne Gerhardsen, Ole Magnus Oterhals, and et al. 2020. Building relationships in inclusive research in diverse contexts. *Scandinavian Journal of Disability Research* 22: 147–57. [CrossRef]

Chataika, Tsitsi, and Judy McKenzie. 2013. Considerations of an African childhood disability studies. In *Disabled Children's Childhood Studies*. Edited by Tillie Curran and Katherine Runswick-Cole. London: Palgrave Macmillan, pp. 152–63. [CrossRef]

Chilisa, Bagele. 2012. *Indigenous Research Methodologies*. Los Angeles: Sage.

Chilisa, Bagele. 2017. Decolonising transdisciplinary research approaches: An African perspective for enhancing knowledge integration in sustainability science. *Sustainability Science* 12: 813–27. [CrossRef]

Chilisa, Bagele, Thenjiwe Major, and Kelne Khudu-Petersen. 2017. Community engagement with an African-based relational paradigm. *Qualitative Research* 17: 326–39. [CrossRef]

Collis, Anne. 2021. Not the Usual Suspects: Designing a New Method for Public Consultation. Ph.D. thesis, Bangor University, Bangor, UK.

de Haas, Catherine, Joanna Grace, Joanna Hope, and Melanie Nind. 2022. Doing research inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences* 11: 159. [CrossRef]

Dewing, Jan. 2007. Participatory research. *Dementia* 6: 11–25. [CrossRef]

Forster, Sheridan. 2020. Approaching a person with profound intellectual and multiple disabilities: What do you think, what do you do? In *Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion*. Edited by Melanie Nind and Iva Strnadová. Abingdon: Routledge, pp. 133–58.

Glaser, Barney G., and Anselm L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.

Go, Julian. 2023. Thinking against empire: Anticolonial thought as social theory. *British Journal of Sociology*. [CrossRef] [PubMed]

Goodwin, Jill, and Ellie Griffiths. 2022. "Being With" in Sensory Theatre. Available online: https://oilycart.org.uk/wp-content/uploads/2022/09/Being-With-in-Sensory-Theatre-DIGITAL-VERSION (accessed on 20 November 2023).

Goodwin, Martin. 2013. Listening and responding to children with PMLD—Towards a framework and possibilities. *The SLD Experience* 65: 21–27.

Grace, Joanna. 2022. Share their picture, say their name. Is it safe to share photos of people with profound intellectual and multiple disabilities online? The ethics of being presented to the online world. *PMLD Link* 34: 35–37.

Greco, Cinzia. 2022. Divergent Ethnography: Conducting Fieldwork as an Autistic Anthropologist. Available online: https://culanth.org/fieldsights/divergent-ethnography-conducting-fieldwork-as-an-autistic-anthropologist (accessed on 20 September 2023).

Gudjonsson, Elsa E. 2022. The origins of Icelandic Knitting. In *Knitting with Icelandic Wool*. Edited by Oddny S. Jonsdottir. Reykavik: Forlagid, pp. 9–20.

Hollingsworth, Sandra. 1992. Learning to teach through collaborative conversation: A feminist approach. *American Educational Research Journal* 29: 373–404. [CrossRef]

Hollingsworth, Steve. 2020. Inhabiting Remote Spaces: An Aesthetic of the Inter-Human. Ph.D. thesis, University of St Andrews, Scotland, UK.

Ifejika, Nkem. 2006. What Does Ubuntu Really Mean? The Guardian. Available online: https://www.theguardian.com/theguardian/2006/sep/29/features11.g2 (accessed on 14 September 2023).

Kellett, Mary, and Melanie Nind. 2001. Ethics in quasi-experimental research on people with severe learning disabilities: Dilemmas and compromises. *British Journal of Learning Disabilities* 29: 51–55. [CrossRef]

Kittay, Eva Feder. 2019. *Learning From My Daughter: The Value and Care of Disabled Minds*. New York: Oxford University Press.

Kreuger, Richard A., and Mary Anne Casey. 2015. *Focus Groups: A Practical Guide for Applied Research*, 5th ed. London: Sage.

Krueger, Richard A., and Jean A. King. 1998. *Involving Community Members in Focus Groups. Focus Group Kit 5.* London: Sage.

Lavallée, Lynn F. 2009. Practical application of an indigenous research framework and two qualitative indigenous research methods: Sharing circles and Anishnaabe symbol-based reflection. *International Journal of Qualitative Methods* 8: 21–40. [CrossRef]

Lesseliers, Joan, Geert van Hove, and Stijn Vandevelde. 2009. Regranting identity to the outgraced—Narratives of persons with learning disabilities: Methodological considerations. *Disability & Society* 24: 411–23.

Liebert, Rachel. 2021. What could the white body do for decolonising psychology? 31 questions. *AWRY: Journal of Critical Psychology* 2: 99–123.

Lindemann, Hilde. 2010. Holding one another (well, wrongly, clumsily) in a time of dementia. In *Cognitive Disability and its Challenge to Moral Philosophy*. Edited by Eva Feder Kittay and Licia Carlson. Hoboken: Wiley-Blackwell, pp. 161–70.

Lindemann, Hilde. 2014. *Holding and Letting Go: The Social Practice of Personal Identities*. Oxford: Oxford University Press.

Macpherson, Hannah, Alice Fox, Susan Street, John Cull, Tina Jenner, Des Lake, Martyn Lake, and Shirley Hart. 2016. Listening space: Lessons from artists with and without learning disabilities. *Environment and Planning D: Society and Space* 34: 371–89. [CrossRef]

Manning, Erin. 2016. *The Minor Gesture*. Durham and London: Duke University Press.

McCormack, Noelle. 2017. Making Memory Sites: Extending Opportunities for People with Profound and Multiple Learning Disabilities to Participate in Life Story Work. Ph.D. thesis, University of East London, London, UK.

McKittrick, Katherine. 2021. *Dear Science and Other Stories*. London: Duke University Press.

Mencap. 2011. Involve Me: Practical Guide. Available online: https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmld/pmld-involve-me (accessed on 20 September 2023).

Merleau-Ponty, Maurice. 1945. *Phenomenology of Perception*. London: Routledge.

Mietola, Reetta, Sonia Miettinen, and Simo Vehmas. 2017. Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology* 20: 263–74. [CrossRef]

Mikulak, Magdalena, Sara Ryan, Pam Bebbington, Samantha Bennett, Jenny Carter, Lisa Davidson, Kathy Liddell, Angeli Vaid, and Charlotte Albury. 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: 52–60. [CrossRef]

Moosavi, Leon. 2023. Turning the decolonial gaze towards ourselves: Decolonising the curriculum and 'Decolonial Reflexivity' in Sociology and Social theory. *Sociology* 57: 137–56. [CrossRef]

Nieuwenhuijse, Appolonia M., Dick L. Willems, and Erik Olsman. 2020. Physicians' perceptions on quality of life of persons with profound intellectual and multiple disabilities: A qualitative study. *Journal of Intellectual and Developmental Disability* 45: 176–83. [CrossRef]

Nind, Melanie. 2017. The practical wisdom of inclusive research. *Qualitative Research* 17: 278–88. [CrossRef]

Nind, Melanie, Alex Kaley, and Edward Hall. 2021. Focus group method: Doing research inclusively and supporting social inclusion. In *Handbook of Social Inclusion*. Edited by Prannee Liamputtong. Cham: Springer Nature.

Nind, Melanie, and Dave Hewett. 2005. *Access to Communication: Developing the Basics of Communication with People with Severe Learning Difficulties through Intensive Interaction*, 2nd ed. London: David Fulton.

Nind, Melanie, and Jane Seale. 2009. Concepts of access for people with learning difficulties: Towards a shared understanding. *Disability & Society* 24: 273–87.

Nyasini, Joseph. 2016. The Ontological Significance of "I" and "We" in African Philosophy. Available online: http://www.galerie-inter.de/kimmerle/frameText8.htm (accessed on 10 July 2023).

O'Brien, Patricia, Edurne Garcia Iriarte, Roy Mc Conkey, Sarah Butler, and Bruce O'Brien. 2022. Inclusive research and intellectual disabilities: Moving forward on a road less well-travelled. *Social Sciences* 11: 483. [CrossRef]

Olsman, Erik, Appolonia M. Nieuwenhuijse, and Dick L. Willems. 2021. Witnessing quality of life of persons with profound intellectual and multiple disabilities. A practical-philosophical approach. *Health Care Analysis* 29: 144–53. [CrossRef]

O'Reilly, Karen. 2012. *Ethnographic Methods*. London: Routledge.

Patton, Michael Quinn. 2015. *Qualitative Research & Evaluation Methods*, 4th ed. London: Sage.

Pink, Sarah. 2015. *Doing Sensory Ethnography*, 2nd ed. London: Sage.

Puigvert, Lidia, Miranda Christou, and John Holford. 2012. Critical communicative methodology: Including vulnerable voices in research through dialogue. *Cambridge Journal of Education* 42: 513–26. [CrossRef]

Rhee, Jeong-Eun. 2021. Decolonial Feminist Research: Haunting, Rememory, and Mothers. National Centre For Research Methods. Available online: https://www.youtube.com/watch?v=5d-h_-Hrph8&list=PLzv58M2GAfm43IeW5iiDrjNUK3BrXWXC0&index=6 (accessed on 14 September 2023).

Rieger, Kendra L., Mabel Horton, Sherry Copenace, Marlyn Bennett, Mandy Buss, Anna M. Chudyk, Lillian Cook, Bobbie Hornan, Tara Horrill, Janice Linton, and et al. 2023. Elevating the uses of storytelling methods within indigenous health research: A critical, participatory scoping review. *International Journal of Qualitative Methods* 22: 16094069231174764. [CrossRef]

Rutazibwa, Olivia U. 2023. After inclusion. Thinking with Julian Go's 'Thinking against empire: Anticolonial thought as social theory'. *British Journal of Sociology* 74: 324–35. [CrossRef] [PubMed]

Simmons, Ben. 2018. The phenomenology of intersubjectivity and research with profoundly disabled children: Developing an experiential framework for analysing lived social experiences. In *Seen and Heard: Exploring Participation, Engagement and Voice for Children with Disabilities*. Edited by Miriam Twomey and Clare Carroll. Oxford: Peter Lang, pp. 125–44.

Simmons, Ben, and Debbie Watson. 2014. *The PMLD Ambiguity—Articulating the Life-Worlds of Children with Profound and Multiple Learning Disabilities*. London: Karnac.

Skarsaune, Synne Nese. 2023. Persons with profound and multiple learning disabilities as individuals of knowledge: Exploring the possibilities of empathy. *British Journal of Learning Disabilities*. [CrossRef]

Skarsaune, Synne Nese, and Halvor Melbye Hanisch. 2023. Holding and professional care: On self-determination for persons with profound intellectual and multiple disabilities. *Research and Practice for Persons with Severe Disabilities* 48: 25–40. [CrossRef]

Skarsaune, Synne Nese, Halvor Hanisch, and Anita Gjermestad. 2021. Self-determination: What can we learn from persons with profound intellectual and multiple disabilities? *Scandinavian Journal of Disability Research* 23: 317–27. [CrossRef]

Smith, Linda Tuhawi. 2012. *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books.

Smith, Linda Tuhawi. 2021. Resisting Coloniality in Academic Knowledge Production. Webinar 2. National Centre For Research Methods. Available online: https://www.youtube.com/watch?v=EFQ09rPQFyA&list=PLzv58M2GAfm43IeW5iiDrjNUK3BrXWXC0&index=2 (accessed on 14 September 2023).

Strnadová, Iva, Therese M Cumming, Marie Knox, and Trevor Parmenter. 2014. Building an inclusive research team: The importance of team building and skills training. *Journal of Applied Research in Intellectual Disabilities* 27: 13–22. [CrossRef] [PubMed]

Tilley, Liz, and Kate Woodthorpe. 2011. Is it the end for anonymity as we know it? A critical examination of the ethical principle of anonymity in the context of 21st century demands on the qualitative researcher. *Qualitative Research* 11: 197–212. [CrossRef]

Tuffrey-Wijne, Irene, and Gary Butler. 2010. Co-researching with people with learning disabilities: An experience of involvement in qualitative data analysis. *Health Expectations* 13: 174–84. [CrossRef]

Tuffrey-Wijne, Irene, Jane Bernal, and Sheila Hollins. 2008. Doing research on people with learning disabilities, cancer and dying: Ethics, possibilities and pitfalls. *British Journal of Learning Disabilities* 36: 185–90. [CrossRef]

Van Goidsenhoven, Leni, and Elisabeth De Schauwer. 2020. Listening beyond words: Swinging together. *Scandinavian Journal of Disability Research* 22: 330–39. [CrossRef]

Vidal de Milla, Delia. 2000. *Arte Textil: Simbolismo de Los Motivos Decorativos [Textile Art: Symbolism of Decorative Motifs]*. Cusco: Convenio Munipalidad del Cusco.

Walmsley, Jan, and Kelley Johnson. 2003. *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley.

Watson, Debbie, David Abbott, and Ruth Townsley. 2006. Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services. *Child: Care, Health and Development* 33: 90–95. [CrossRef] [PubMed]

Woelders, Susan, Tineke Abma, Tamara Visser, and Karen Schipper. 2015. The power of difference in inclusive research. *Disability & Society* 30: 528–42.

Yunkaporta, Tyson. 2019. *Sand Talk: How Indigenous Thinking Can Save the World*. New York: HarperOne.