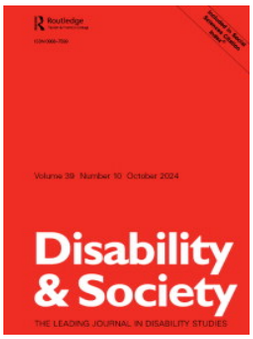

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RESEARCH ARTICLE

The emotional wellbeing of students with profound intellectual disabilities and those who work with them: a relational reading

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ABSTRACT

Interest in the mental health landscape of young people is widespread. This paper focuses in on the emotional wellbeing of students with profound intellectual disabilities and those who work with them in special schools. A relational reading of the situation illustrates some relationships between the two and vulnerabilities of both. The authors engage with theory: the double (and triple) empathy problem and empathy more widely, and with the concepts of affect attunement, holding and ethics of care. They interweave brief reflections on their own experiences working and researching in special schools and argue that these relationally constituted spaces present challenges for the emotional wellbeing of students and staff. The paper concludes by calling for recognition of the emotional labour involved in interacting across different ways of being and of knowing the world and for greater attention to empathising in embodied, perceptual ways to aid mutual understanding and support wellbeing.

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Wellbeing; mental health; special schools; profound intellectual and multiple disabilities; empathy; emotional labour

Points of interest

- Emotional wellbeing means feeling good more than feeling bad. Having good emotional wellbeing is important for staying healthy and coping. This makes it a public health priority.
- Young people with intellectual and multiple disabilities have worse wellbeing and mental health than others their age. There has been little research or talk about the emotional wellbeing of people with profound intellectual disabilities.
- Students with profound intellectual and multiple disabilities and their special school staff experience challenges understanding each other. This can be emotionally draining on both sides.

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- Pressures on school staff make it harder from them to support these students in the best ways. The paper shows why it is important to address the wellbeing of students and staff together as they are interconnected.

Introduction: our approach and positionality

In this paper we make the case for addressing the emotional wellbeing of students with profound intellectual disabilities *and* those who work with them. A positive sense of wellbeing is a component of mental health (Fergusson, Howley, and Rose 2008; Huppert and So 2013) and emotional wellbeing is important to health (Stewart-Brown 1998), human functioning and flourishing such that it is a 'significant public health priority' (Park et al. 2023, 18). However, for people with multiple disabilities, support for emotional wellbeing often comes second to attention to physical health and support for medical needs and basic functioning. We argue that the emotional wellbeing of students matters, and the emotional wellbeing of staff matters, and that they matter equally not least because of their equal personhood. Like Goodley (2023), we recognise that the lives, aspirations and contributions of people with intellectual disabilities (known as learning disabilities in the UK) are often deemed unworthy and that 'unworthy lives often become non-theorisable lives; excluded from theory and absent in the curricula of disciplines across the human, social and natural sciences' (180). Staff at the frontline of education and care are implicated in this devaluing too by virtue of parallel stigma (Brett 2002; Mitchell 2000). We use theorisation as a tool at our disposal as academics to value students and teachers, who are worthy of our attention, and in our effort to do what Davy (2019, 103) describes as 'rendering the invisible visible' - showing how wellbeing matters concern not just students and staff but the interactions between them and between them and their contexts.

Working in dialogue with theory, this paper represents a shift in the discourse about the emotional wellbeing of the people it is about. Fundamentally this works on a fairness level: to include previously neglected people in relation to important ideas. This in turn enhances the ideas: by engaging with insight and wisdom often and otherwise lost to everyone. Moreover, the paper looks at emotional wellbeing in a less simplistic and less cognitive-oriented way than is common in the literature, recognising different and reciprocal influences interacting with it. In discussing emotional wellbeing it is a paper that shows emotion and empathy as well as being about emotion and empathy. It arises out of the dialogue between us as authors about how, while times we have spent with people with profound intellectual disabilities have often nourished us, times spent with them in schools (in our UK context) has sometimes done the opposite. Our

experiences have led us to experience strong emotional responses, including feelings of belonging or not belonging, adequacy and inadequacy, justice and injustice. Theorising is helping us to make sense of these complexities, reminding us of bell hooks (1994, 59) reflection on theory when she was hurting:.

> I came to theory desperate, wanting to comprehend—to grasp what was happening around and within me. Most importantly, I wanted to make the hurt go away. I saw in theory then a location for healing.

Melanie first wrote about the emotional wellbeing of people with profound intellectual disabilities twenty years ago (Sheehy and Nind 2005), noting the lack of insight on the topic and arguing that, 'To attend to the emotional well-being of people with profound and multiple learning disabilities is to assert their very humanness and their right to quality of life', and observing the positive role played by meaningful, quality interactions. With the growth in uptake in schools and other settings worldwide of nurturing, humane approaches like Intensive Interaction (Nind 2008; Nind and Hewett 2005), there is more research and resource now to support such interactions. However, other normalising pressures associated with independence, autonomy and academic achievement remain live, and school staff interacting with young people with profound intellectual disabilities are faced with conflicts in what they prioritise (Imray, Kossyvaki, and Sissons 2023). Joanna has been discussing emotional wellbeing with professional special school audiences for more than a decade, with the training that she provides for schools on this topic shifting from garnering no interest, to now being her most booked event, indicating that wellbeing is on practitioners' minds. Her art project (www.TheSensoryProjects.co.uk/projects/the-structured-sensory-art-project) was designed so that people with profound intellectual disabilities would realise the universal wellbeing benefits of being involved in creative practice, and her sensory being project (Grace 2018) sought to facilitate their access to mindfulness type experiences. Here we join forces in addressing challenges that are not new, but that can benefit from being looked at afresh.

The paper is the result of dialogue between us and between thoughts and feelings. The first part presents the problem. The second part is our dialogue with theory. We draw on the work of Damian Milton (2012) on the 'double empathy problem' and autistic people, which we use to help us think about wellbeing in relation to mutual understanding across difference beyond autism. We also dialogue with work on the relational turn and feminist ethics of care (Davy 2019) to support our exploration of how the emotional wellbeing of staff and students need to be looked at together. Davy (2019) highlights how people are not self-contained, independent of one another; we are all vulnerable and we all need the support of others. Throughout the paper, a major tool for our thinking about emotional wellbeing is theory on

empathy as we deploy the work of Synne Skarsaune (Skarsaune 2024; Skarsaune, Hanisch, and Gjermestad 2021; Skarsaune and Hanisch 2023) addressing empathy and people with profound intellectual disabilities.

Schools should be nurturing places, and in some respects they are micro-environments in which everyone's mental health grows and flourishes or withers and dies (McCallum and Price 2010). We see staff and students as in this together: 'there are no independent selves; we are each constituted by others (who are themselves similarly constituted)' (McNamee and Gergen 1999, 11–12, cited by Hibbin 2023, 4). As former teachers ourselves we speak from long-term engagement with students with profound intellectual disabilities and their school staff. Resonating with the position of Walmsley, Strnadová, and Johnson (2018) in discussing inclusive research, we *stand with* those students and teachers in a desire to create positive experiences and spaces that cherish those within them. When we describe school practices in the course of the paper we are presenting an amalgam of practices we have seen and been involved in as teachers and researchers across multiple settings. Rather than using data from any particular project, we are using insights drawn over years of reflection. As we have no desire to hurt anyone by calling out particular incidents or practices as we build our argument, we use techniques of fictionalisation (Campbell, McNamara, and Gilroy 2004; Gibson 2021) to merge characters and voices, incidents and contexts, while retaining the essence of our experiences (Wade, Vaughn, and Long 2009).

Introducing the people and the problem

Most students with profound intellectual disabilities experience additional multiple physical and sensory disabilities, hence we use the internationally recognised term students with profound intellectual and multiple disabilities (a shorthand which is synonymous with profound and multiple learning disabilities in the UK) though following the trend to defining levels and types of support (Schalock, Luckasson, and Tasse 2021**)** we also often refer to the relational element of support needs. These are students who have 'high and pervasive support needs and multiple disabilities (and often life-limiting conditions), including intellectual impairment such that communications will be idiosyncratic, not symbolic' (de Haas et al. 2022, 1–2). Importantly, countering the tendency to focus on the challenges associated with such profound impairment, we also define this group as 'possessing and experiencing meaning and provoking and providing love' (Grace et al. 2024, 1). As a subset of an already marginalised group though, they are a group that research and wellbeing interventions have often failed to serve or include. In the UK where we work, as in comparator countries internationally, their school lives are spent in special schools and even special classrooms within them (Jones and Riley 2017; Nind and Strnadová 2020).

Data on the emotional wellbeing or mental health of people with intellectual disabilities are both hard to ascertain and troubling (Vos et al. 2010). The reported prevalence of mental ill-health among adults with intellectual disabilities ranges from 7 to 97%, owing to methodological limitations' (Cooper et al. 2007, 27). Nonetheless, the consensus is that 'mental ill-health is over-represented among people with an intellectual disability compared with the rest of the population' (Whittle et al. 2018, 69). In the UK, a Foundation for People with Learning Disabilities (2002) inquiry into the mental health needs of young people aged 13–25 years found that those with learning disabilities were four times more likely than their age peers to develop mental health problems. As Davies and Hogg (2004) note, this *Count Us In* report asserted the right of all young people with learning disabilities to positive mental health and emotional wellbeing. Yet, soon after, Emerson and Hatton (2007) calculated that children with learning disabilities were seven times more likely to be diagnosed with mental health difficulties than children without learning disabilities. Clarity about the wider emotional wellbeing of people with profound intellectual disabilities is not helped by some definitions of emotional wellbeing having a cognitive element that serves to exclude them. For example, 'Emotional well-being (EWB) includes a positive balance of pleasant to unpleasant affect and a *cognitive* [our emphasis] appraisal of satisfaction with life in general (Keyes 2003)' (Langeland 2022, 1). What happens when such cognitive appraisal is out of scope is rarely asked.

Despite some interest in addressing poor emotional wellbeing and the recommendation that 'schools and colleges should aim to promote and sustain positive mental health in young people with learning disabilities', work on the emotional wellbeing needs of young people with severe or profound and multiple learning disabilities has been limited (Davies and Hogg 2004, 6) and the topic is under-discussed (Devlin 2024). One follow-on project with this group found that parents were seeking their own solutions, and that their children's wellbeing was impacting their own wellbeing (Philip et al. 2005). It reasonable to assume that children's wellbeing impacts their close school staff too, and the additional emotional pressures of working with students with profound intellectual and multiple disabilities have been noted by professionals in the field (Aird 2001; Black and Halstead 2021; Halcrow 2014; Jones 2019). There has certainly been a lack of support from external agencies, which is stressful for ill-prepared staff (Rose et al. 2009; Jones 2019).

Mental health whole school initiatives, such as SEAL - *Social and Emotional Aspects of Learning* (Banerjee, Weare, and Farr 2014) and Thrive (Thrive, n.d), are popular with schools. However, they often neglect young people with intellectual disabilities (Weare and Nind 2011) or lack systematic evaluation (Gibby-Leversuch, Field, and Cooke 2019). Links are made between the emotions of students and staff and Jones (2019) found school staff able to find their own reasons to be positive and resilient, celebrating the 'small things' in

their working lives and their students' progress. More generally, positive actions, such as the NHS (2020) *5 steps to mental wellbeing* (i.e. Connect with other people; Be physically active; Learn new skills; Give to others; Pay attention to the present moment) can present challenges in their application to people with profound intellectual and multiple disabilities. As Calveley (2020) discusses, this leaves a gap in understanding about what constitutes evidence-based emotionally nurturing experiences in this context.

It is not just the emotional wellbeing of young people with profound intellectual disabilities that has been poorly served by academic research to date; this group has barely been included in research on people's experiences (Mietola, Miettinen, and Vehmas 2017; Vos et al. 2010). Mietola, Miettinen, and Vehmas (2017, 264) echo Tuffrey-Wijne, Bernal, and Hollins (2008) in highlighting that it is 'unethical to exclude such persons from research that could provide insights about their subjective experiences, and about how to promote their well-being'. Cognitive ableism is at work positioning some people as outside the realm of social research (Bach 2017; Chalachanová, Jaeger Fjetland, and Gjermestad 2023) or so-called universal interventions.

The ongoing neglect of people with profound intellectual disabilities in research (and theory/practice) arises in part from their neglect as people worthy of interest (Booth and Booth 1996; Mansell 2010) and in part from the challenges presented to researchers (Milner and Frawley 2019; Veck and Hall 2020). As Simmons and Watson (2015, 50) contend, 'either children with PMLD [profound and multiple learning disabilities] are positioned as incompetent and lacking voice; or researchers are positioned as lacking the appropriate tools to gain access to such voice'. Their answer to this, as is ours, is to approach 'voice not as singular and literal, but as something that is enacted or comes into being through relationships'. In this way research is beginning to acknowledge that we can, and should, access their subjective experiences (de Haas et al. 2022; Grace et al. 2024).

Given the challenges outlined in this section, it is not surprising that there has been a lack of analysis of how the emotional wellbeing of students with profound intellectual disabilities and staff are interconnected. When attention has been paid to this in schools (see e.g. Aird 2001; Black and Halstead 2021; Colley and Tilbury 2021; Landers 2018), this has tended to be practical/instrumental with a professional or psychological emphasis. The challenges of 'diagnostic overshadowing' (Fergusson, Howley, and Rose 2008; Javaid, Nakata, and Michael 2019), in which problems of pain (physical or emotional) are seen merely as features of intellectual impairment, have been highlighted including where poor wellbeing can become the norm and so not treated as an indicator of something being wrong. To counter misreading of internal states, mood is starting to be assessed to better understand symptoms of depression as opposed to framing behaviours as challenging and dealt with accordingly (Tsiouris 2001; Ross and Oliver 2003, cited by Forster et al. 2011).

Such assessment may be more common in adult services than in schools with all their focus on doing rather than being (Goodwin 2020).

We end this section on the nature of the problem by turning our attention to the wellbeing of school staff. Usefully, there is a literature (mostly psychological) on teacher wellbeing that recognises its importance and the contextual links between this, the culture of schools and student wellbeing (e.g. Harding et al. 2019; Turner and Thielking 2019; Fox et al. 2020). Feeling a sense of belonging to the school and wider community is known to be important to wellbeing, with connectedness and communication seen as essential to establishing supportive and productive communities (McCallum and Price 2010). Black and Halstead (2021) and Frenzel, Daniels, and Burić (2021) discuss how the emotional states of teachers can be transferred to the students and vice versa, giving some insight into the interconnectedness of the emotional landscape. The work on this though rarely extends to special school contexts where teachers do a different kind of work leaving them distanced from the research, cultures and identities of the mainstream (Brett 2002; Jones 2004) and where there are many low status support staff, made vulnerable to poor wellbeing from engaging intimately with students' pain and discomfort and with family accounts of their struggles. Black and Halstead (2021) summarise the small literature on teacher and teacher assistant emotional wellbeing in the context of working with students with severe and profound intellectual disabilities, and stress both increased risks to mental health and the role of resilience.

With students and staff highly vulnerable to poor emotional wellbeing and bound together intimately in the closed context of special schools (which in our experience can feel nurturing or suffocating), education/disability research has a responsibility to offer something useful to understanding the dynamic at work. We therefore turn our focus to an exploration of theory and the potential of understanding a kind of double empathy problem scenario at work in schools supporting students with profound intellectual disabilities. We go on to link this with other issues with empathy and emotional attunement.

Using theory: empathy and the ethics of care

A double empathy problem

Milton (2012; Milton, Gurbuz, and Lopez 2022) has made an important difference to our understanding of what happens in interactions surrounding autism with his delineation of the 'double empathy problem'. He describes the gap in natural understanding that occurs between people of 'different dispositional outlooks' seeking to communicate meaning (Milton 2012, 884). Historically, problems with empathy have been positioned as located in the brains of autistic people, but Milton argued that there was in reality a 'double

problem', experienced by autistic and non-autistic people as 'differently disposed social actors' (Milton 2012, 884). This work has importance for us authors working together across the different dispositions (Joanna is autistic, Melanie is not) and it has apparent application to understanding the emotional labour that goes on in special schools, perhaps especially for staff working across a neuro-divide. We argue that understanding each other when staff are cognitively and linguistically able and students have profound intellectual disabilities (and are sometimes also autistic) similarly brings challenges of social insight for both. Conceptually, it is now widely accepted that with the potential for 'breakdown in mutual understanding' for autistic people and non-autistic people interacting comes the 'reciprocal challenge of each having to work hard to understand the other' (Milton, Gurbuz, and Lopez 2022, 1901). We postulate that for students with profound intellectual disabilities and staff interacting something similar is happening. We recall the challenges evoked when a student with profound intellectual and multiple disabilities expressed pain and joy through crying. Also familiar is the situation in which staff disagree on what a behaviour means in a student, the importance of this for everyone involved and the emotional impact of knowing one or both had to be wrong. This hard work of mutual understanding is emotionally draining and there may be implications for mental health (Mitchell, Sheppard, and Cassidy 2021). The toil may even begin with the desire to be noticed, acknowledged, the kind of recognition that Bos (Bos and Abma, 2022) describes as 'a *rush* of shared understanding and comradery, or better yet: a shared pursuit of mutual understanding', the lack of which can feel deeply unsettling.

The struggle to interact across difference is complicated by context. Shaw et al. (2023), for example, suggest that the double empathy problem becomes a triple empathy problem in medical/health contexts, as the cross-neurological empathy challenges interact with the doctor-patient empathy challenges. In some situations we read each other better: beyond institutional constraints where children of different dispositions get to mix, young children may readily move into a mode of being that is accessible for children with profound intellectual disabilities, making reciprocal interaction easy (Grace and Nind 2024; Simmons 2020). In family contexts, parents and siblings form bonds, easy routines and ways of being together (Luijkx, van der Putten, and Vlaskamp 2016), not least because as one parent commented, 'I *feel* things through her eyes' (Jackson 2023, 80). This is the mingled voices and bodies that McGregor (2022) describes experiencing with her profoundly disabled son, also highlighting how medics devalued the mingled understanding they had and failed in establishing mutual understanding of their own.

As Jackson (2023, 79) discusses, 'Daly's [2016] concept of primary empathy is useful for thinking about how parents caring for children with severe cognitive disabilities becomes more attuned to their emotional and practical

needs over time', turning the 'I' into a 'We'. Emotion and affect open and configure intersubjective space. School classrooms constitute differently configured spaces. Schools can be uncomfortable spaces for empathetic working (Stothard 1998) and being out of the classroom can free support staff to be playful (Simmons 2021). It is layers of cultural expectations around what we should be doing and how we should be behaving in school that can make staff not just inaccessible to students but unknowable to themselves, thereby impacting their wellbeing. A stream of experiences entangle themselves in our engagement with theory: *What am I doing here baking in the hope that you can see and smell as you sit there? The baking gives us a product to hold up in assembly and contribute to the cake sale, but is it also a distraction from our lack of connection? How are we supposed to be together in this sensory room? Can I lie here and recuperate while you watch the lights? I want to play with you but I am worn down from the effort to teach you things. Why am I looking for recordable progress rather than enjoying our time together?* From a student perspective, we imagine a bombardment of sensory experiences and recognise a desire to avoid them, or to enjoy the flickering of light without being interrupted by a phonics lesson! As the student's hands are manipulated such that they 'paint' a mother's day card, there is less a mingling of voices and bodies (McGregor 2022) and more a taking over of another's body (a denial of personhood).

The result of failed empathy/mutual understanding can be that staff and student each take refuge by not seeking to engage the other, each busy with their separate agendas. Joanna recalls difficult days during which she consciously decided to give up attempting to reach someone, switching instead to busying herself creating resources for them. As well as bringing her the satisfaction of small accomplishments, her actions were more easily understood by those around her, meaning that she felt safer in *her* social world. This is another kind of a triple empathy situation, requiring balancing reaching the students with performing social norms correctly. Being busy is not just easier in giving an escape from the difficult nature of being, it is easier in the prevailing social landscape of the school.

An attunement issue

The mutual breakdown of understanding and wellbeing in school classrooms can also be understood in terms of failures of affect attunement. Attuning, as Forster and Iacono (2014) drawing on Stern (1985) and Stern et al. (1985) explain, involves 'recasting of one person's affect by another with emphasis' (1105), making it a point of connection. This can be natural to some people and in some contexts, but not when the internal states of students or staff are not expressly valued and when there are the felt pressures that we have seen and known to counter passivity and low mood with forced jollity. The

result of not attuning can be a failure to 'respond and commune' (Forster and Iacono 2014, 1106), which we argue negatively impacts the emotional wellbeing of everyone involved. We have known rest times to be mandated as care practices in schools, when staff leave students without demands placed on them, and the practice of leaving profoundly disabled students indoors during outdoor play times. These practices inhibit staff from attuning and engaging at times when students may be most receptive, away from the demands and sensory onslaught of busy classrooms. When staff and students experience challenges in understanding the other and attuning, poor emotional wellbeing can be socially upheld. The challenges that occur are exacerbated by curricula that overlook them and school cultures can encourage emotional distance thereby reducing empathy and emotional availability (Goodwin 2020).

Holding on to self and humanising the school

Lindemann (2010, 2014) has argued that while all humans need to be 'held', that is, supported to be understood and respected, often by narratives that are true to them, this is particularly so for people with high support needs. 'Holding is a matter of understanding who someone is and treating the person accordingly' (Skarsaune and Hanisch 2023, 26). Lindemann was concerned with people with dementia, but Skarsaune and Hanisch (2023) apply this thinking to people with profound intellectual disabilities. It is important to appreciate that failures in empathy, attunement, holding or respect across differences in how we understand, are both highly contextual and harmful for students and staff.

Schools rarely do the narrative work that families do to hold on to the identity of someone with profound intellectual disabilities when they are unable to tell their own stories. When urged to write things down about students, it is behaviours and attainments that are recorded, not stories. And big stories are reduced to small ones: the journey to a city 40 miles away for lifesaving emergency treatment becomes a comment to a parent, 'oh has he been playing you up again?', leaving so much unseen and unsaid in the shortcutting of narratives like these. This reduces the narrator as well as the narrated, stripping them of the opportunity to nurture and hold identity and wellbeing. Failing to empathise or to hold can mean 'a sense of losing the other' (Skarsaune and Hanisch 2023, 34). School staff can feel like the love, empathic concern, and loyalty that Kittay (2019) highlights as important for acting on behalf of another are mismatched to their roles. Perceptions of what is expected of them may interfere with their openness to respond intuitively. This adds to the emotional labour of juggling how to *be* and again this is mutually harmful.

Environments impact wellbeing (Aird 2001; Carpenter 2002; Falecki and Mann 2021). One example is autistic burnout, a concept used to describe the 'exhaustion and interpersonal withdrawal' that can arise for autistic people 'from the stress of living in an unaccommodating neurotypical world' (Arnold et al. 2023). While parallels for people with profound intellectual disabilities have not previously been drawn, we postulate that school classrooms may be similarly unaccommodating for the people with limited agency to act within and on them. We recall Nicholas, who in one classroom was constantly in an agitated state, presumed at the time to be caused by his neurodivergence, while in another classroom with different tempo and sensory demands he was calm and able to engage.

Goodwin (2020), a disaffected special school teacher and artist, created her 'golden tent' as 'an immersive and sensorial installation that symbolised a space of refuge away from the reductive practices' (59) of school life that she rejected. She explains:

> To offer an aesthetic space for simply 'being' together within a school setting is to subvert the current educational imperative for pre-specified learning outcomes and to challenge hierarchical understandings of education in which the competent educator facilitates the progressive development of an incompetent learner. … With our current approach, the value of complex, meaningful and potentially mutually rewarding relationships between staff and pupils is diminished because they cannot be measured in objective ways. (Goodwin 2020, 59–60)

Her work underlines the potential of teachers to use art and agency to create more inclusive spaces of belonging for people with different cognitive abilities to share and be together. It also says much about pace as well as space in showing the need to slow things down to be together attentively to keep recreating 'moments of mutual connection' (61). Such attuning in her classroom was created by timetabled group sessions without language when staff offered 'attentive but relaxed presence' (63). Goodwin's research on how staff responded to time inside Golden Tent captured some of the nurturing impact on them of time when, '*you're with the child, the student, you're with them … And you're completely in-the-moment here*' (Michelle, in Goodwin 2020, 68).

Efforts to humanise education and put wellbeing, empathy, compassion, dignity, kindness and recognition at its core (for comparison see the iHuman project on humanising healthcare (https://www.sheffield.ac.uk/ihuman/our-work/marginalised-humans/critical-disability-studies/humanising-healthcare) have been dispersed, left to individual schools and staff who are stressed by lack of resources for identifying and responding to mental health difficulties (Rose et al. 2009). Even in special schools humanising efforts to empathise and attune compete with discourses favouring normalising, achieving and measuring progress (Smith, Critten, and Vardill 2020). Research has shown the importance of quality interactions, which with people with profound intellectual disabilities encompass 'sensitive

responsiveness, joint attention, co-regulation and an emotional component' (Hostyn and Maes 2009, cited by Forster and Iacono 2014, 1106). But in schools quality interaction has to fight for attention with 'keeping a professional distance' which works against it and thereby against support for wellbeing.

Empathy – a relational issue

In this paper, by putting the emphasis on the interconnectedness of student and staff wellbeing, we address the importance of each understanding the other, and creating school environments in which this can happen. We feel for the students and staff caught up in environments in which they feel the need to seek refuge, or opt out altogether. As former teachers this is part of our stories too. This brings us to further explore how important recent work on empathy provides tools to think with and to heal with. Going beyond double (triple) empathy problems, new work on empathy and people with profound intellectual disabilities offers hope. Jackson (2023, 77) argues that 'empathy is dynamic and dialogic, it is predicated on an openness to the experiences of others'. He and Synne Skarsaune and colleagues (Skarsaune 2024; Skarsaune and Hanisch 2023; Skarsaune, Hanisch, and Gjermestad 2021) show the relevance of various schools of thought on empathy for the lives of people with profound intellectual disabilities.

It is the concept of primary empathy (Daly 2016) that Jackson (2023) uses to understand 'how parents caring for children with severe cognitive disabilities become more attuned to their emotional and practical needs over time, and how the individuals with cognitive disabilities that they care for are able to act upon their parents in ethically significant ways' (79). This is about the primal openness inherent to sociality and the power of others 'to transform our sense of the world by offering another perspective on it' (Jackson 2023, 79, discussing Daly 2016). Jackson links this to developing intersubjective understanding, responsiveness and receptivity. Skarsaune (2024, 102) observes that empathy is understood as either 'primarily a cognitive or emotional act'. A cognitive view on empathy implies a requirement to infer from what you know and understand. In contrast, applying a perceptual view sees empathy as based on perception: 'with a directedness and immediacy … We can perceive someone else's joy or sadness in their movements and gestures (Gallagher and Zahavi 2021)' (Skarsaune, 2024, 102). In interactions between students with profound intellectual and multiple disabilities and their staff, perceptual empathy requires less cognitive work. It may be one way in which staff gain a lift from their interactions with students who sometimes seem to 'get' how they are feeling. We have experienced this ourselves, with Joanna recalling when, as an out-of-her-depth new teacher, one child known within her school for behaviours that staff found challenging would always follow Joanna's directions. At the time this felt as if the child

understood she needed support as a teacher. In a different class, at a time when Joanna was dealing with sadness in her personal life, a student considered to be 'in his own little world' would seek Jo out as she was doing her paperwork and lay his head companionably on her shoulder. Students with profound intellectual disabilities do not need to be able to infer using cognition to be able to empathise.

With empathy comes affective matching (Coplan 2011, cited by Skarsaune 2024). This is relevant for wellbeing in that, as Skarsaune (2024, 103) argues, it is not about 'feeling the same, but instead involves 'feeling into', that is, 'grasping another's feelings'. There is emotional connection when we engage using this kind of empathy - an affective response because we are 'emotionally available and relatable' (Skarsaune 2024, 106). Inevitably, responsible staff will want to add inferential empathy to their perceptual empathy and affective matching if they move into wanting to understand the cause of perceived/felt distress. As Skarsaune (2024) explains, this relies on not just knowing the unique person but drawing inferences based on context. Being unable to 'grasp the object of the experience' (106) (cause of distress) can in turn be distressing for the empathetic teacher/carer.

Skarsaune (2024) notes the limits of different views on empathy with it being 'more common to focus on empathy as the individual's abilities (van Dijke et al. 2020)', thereby the 'relational dimension of empathy has received little attention in both theoretical and empirical research' (106). This resonates strongly with what we are arguing about wellbeing, where the relational dimension and the relevance of theory for practice can be overlooked. Importantly, Skarsaune (2024, 106) draws on the argument of Magrì (2015) that empathy goes beyond 'direct access' to another to involve motivation to respond, in that 'One is being led or 'pulled' by the state of the other, underlining both the emotional and relational aspects of empathy'. As Bos and Abma (2022) argue, when we put down our 'verbal and cognitive weaponry' (1718) we allow ourselves to be receptive (and vulnerable), and as we have found in our own work, this means keeping more of ourself engaged. We see direct relevance for wellbeing here: If staff allow themselves to be empathetic, and are able to engage in embodied, affective communicating and relating, what do they do with their inability to follow through? How do they process 'situations of uncertainty [when] the empathic act is triggered' (Skarsaune 2024, 107) but when they lack the skills, knowledge and time for the inferential work or for supportively being together. Empathy offers a mix of hope and despair in special school classrooms, it offers frustration as well as the motivation to stay in the work and do it well (Halcrow 2014); moreover it may explain some of the emotional fatigue we have seen and felt. As Spelman (1988, cited by Skarsaune 2024, 107) has argued, 'in imagination, one can escape from the demands of the other, while, when engaging directly through perceiving, one must deal with the reality of the other'. No

wonder then that – as we have done as teachers and researchers – staff and students sometimes opt out of perceiving.

Ethics of care

Through the lens of empathy we can appreciate the vulnerability of students and staff, how this and their emotional wellbeing are relational requiring an relational response. In the everyday lives of schools we experience together, not as separate entities but as a 'we'. In this way, the philosophical theory of the ethics of care illuminates the importance of interpersonal caring and dependence on each other for wellbeing (Jacobs 2020; Mietola, Miettinen, and Vehmas 2017; Tronto 1993). Seeing vulnerability as a feature of being human rather than of being disabled not only underlines all of our humanness and personhood (Jacobs 2020; Kittay, 2001; Mietola, Miettinen, and Vehmas 2017), but makes the project of emotional wellbeing in schools an inclusive one, relevant to all. Adherents of an ethics of care philosophy argue that it is our capacity to love and be loved, rather than cognitive capacity, that makes us human. Moreover, the care that goes on – emotional and practical – is vital (Rogers 2016). This leads us to argue the need to place more value on the qualities of attending, attuning and being responsive. For teaching assistants particularly, who do a lot of the care-giving in schools, this relational reading means there needs to be equal valuing of caring about (attentiveness), caring for (responsibility), care-receiving (responsiveness), and caring with (solidarity) (see Brannelly 2016; Tronto 2013). With all of these human dimensions recognised as part of everyday life in schools, the emotional wellbeing of everyone involved would be better supported.

The relational turn in the geographies of disability literature highlights 'the active inter-relationality of embodied and emotional actions, intentions and desires' (Hall and Wilton 2017, 728) at work in making home, for example, what it is. Hall and Wilton (2017) explain how, in relational terms, making the social, and making sense of the social, is a relational practice, forever in relational transformation. They draw on the work of Holt (2010) to describe (special) schools as 'relationally constituted spaces' in which how people view themselves interacts with how they are viewed by others. While painfully uncomfortable sometimes for us when immersed in such spaces as a neurodivergent or neurotypical teacher, it becomes evident that we can alter the relational space. Creating 'a relational space of 'being with' between care recipient and provider – an unrushed moment of meaningful encounter (Cranford and Miller, 2013)' (Hall and Wilton 2017, 734) becomes possible. This relational reading maps well onto other work on the importance, not just of meaningful moments in interactions between people with profound intellectual disabilities and their staff, but of the embodied and social spaces these depend on (Penninga et al. 2022). It resonates with research findings

about how the mood and wellbeing of people in families affect each other (Luijkx, van der Putten, and Vlaskamp 2016) and about how schools can work in relationship-focused ways with distributed effort and benefit (Hibbin 2023). And in terms of the ethics of care, understanding that 'the self is constituted in and through relationships and that interpersonal relationships and connections to others are essential to the development and maintenance of identity and the development and exercise of agency' (Davy 2019, 102) changes how we need to think about caring for emotional wellbeing in special schools. It invites us to let go of striving for the idealised 'autonomous individual' and to see instead that 'the ebb and flow between care and autonomy is a dynamic common to all interpersonal relationships' (Davy 2019, 102). Our argument is that we can use this to understand and support relational wellbeing, making an ethic of care and responsivity to the needs of all central to what is valued in the social ecology of the (special) school.

Conclusion

In the literatures on student wellbeing and on teacher wellbeing the relationship between the two are sometimes recognised and occasionally students with profound intellectual disability and their staff are included and made visible. There have been calls to do more to support the emotional wellbeing and mental health of students with (profound) intellectual disabilities. In this paper, through our relational (and experiential) lens, we have connected various literatures together and interjected theories that can enrich understanding and practice. We have woven empathy and theories about empathy into a portrayal of what might make a difference to people's emotional wellbeing in everyday school lives. The paper is personal in that while writing it we have been reflecting on our own wellbeing and how it is interwoven with those around us and the schools we have worked in. We have found real value in the work of crossing the neuro-divide and of empathising with and accepting different ways of being. It frees us a little, and gives more options or permissions of what we can be with each other.

We conclude with a call to value wellbeing as relational and personhood as universal. This is a call to recognise the emotional labour of interacting across different dispositions in difficult circumstances and of empathising in embodied, perceptual, relational ways. Most importantly, we want to kickstart a conversation that needs to be going on, not just between theory and practice, but about universal human vulnerability and the roles schools can and could play in supporting emotional wellbeing.

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References

Aird, R. 2001. *The Education and Care of Children with Severe, Profound and Multiple Learning Difficulties*. London: David Fulton.

Arnold, S. R., J. M. Higgins, J. Weise, A. Desai, E. Pellicano, and J. N. Trollor. 2023. "Confirming the Nature of Autistic Burnout." *Autism: The International Journal of Research and Practice* 27 (7): 1906–1918. https://doi.org/10.1177/13623613221147410.

Bach, M. 2017. "Inclusive Citizenship: Refusing the Construction of "Cognitive Foreigners" in Neo-Liberal Times." *Research and Practice in Intellectual and Developmental Disabilities* 4 (1): 4–25. https://doi.org/10.1080/23297018.2017.1306794.

Banerjee, R., K. Weare, and W. Farr. 2014. "Working with 'Social and Emotional Aspects of Learning' (SEAL): Associations with School Ethos, Pupil Social Experiences, Attendance, and Attainment." *British Educational Research Journal* 40 (4): 718–742. https://doi.org/10.1002/berj.3114.

Black, N., and E. Halstead. 2021. "Mental Health and Subjective Well-Being of Staff in a Secondary School for Adolescents with Severe and Profound Multiple Learning Difficulties." *British Journal of Special Education* 48 (4): 477–496. https://doi.org/10.1111/1467-8578.12389.

Booth, T., and W. Booth. 1996. "Sounds of Silence: Narrative Research with Inarticulate Subjects." *Disability & Society* 11 (1): 55–70. https://doi.org/10.1080/09687599650023326.

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 (10): 1703–1727. https://doi.org/10.1080/09687599.2021.1899896.

Brannelly, T. 2016. "Citizenship and People Living with Dementia: A Case for the Ethics of Care." *Dementia (London, England)* 15 (3): 304–314. https://doi.org/10.1177/1471301216639463.

Brett, J. 2002. "The Experience of Disability from the Perspective of Parents of Children with Profound Impairment: Is It Time for an Alternative Model of Disability?" *Disability & Society* 17 (7): 825–843. https://doi.org/10.1080/0968759022000039109.

Calveley, J. 2020. "Emotional and Mental Wellbeing – the Launch of a New Resource." *PMLD Link* 32 (3): 41–42.

Campbell, A., O. McNamara, and P. Gilroy. 2004. *Practitioner Research and Professional Development in Education*. London: Sage.

Carpenter, B. 2002. *Count us in. The Report of The Committee of Inquiry into Meeting the Mental Health Needs of Young People with Learning Disabilities*. Foundation for People with Learning Disabilities. London: Mental Health Foundation.

Chalachanová, A., K. Jaeger Fjetland, and A. Gjermestad. 2023. "Citizenship in Everyday Life: Stories of People with Intellectual Disabilities in Norway." *Nordic Social Work Research* 13 (1): 148–162. https://doi.org/10.1080/2156857X.2021.1981985.

Clough, P. 2002. *Narratives and Fictions in Educational Research*. 1st ed. Buckingham: Open University Press.

Colley, A., and J. Tilbury. 2021. *Enhancing Wellbeing and Independence for Young People with Profound and Multiple Learning Difficulties*. London: Routledge.

Cooper, S. A., E. Smiley, J. Morrison, A. Williamson, and L. Allan. 2007. "Mental Ill-Health in Adults with Intellectual Disabilities: Prevalence and Associated Factors." *The British Journal of Psychiatry: The Journal of Mental Science* 190 (1): 27–35. https://doi.org/10.1192/bjp.bp.106.022483.

Coplan, A. 2011. "Understanding Empathy: Its Features and Effects." In *Empathy: Philosophical and Psychological Perspectives*, edited by A. Coplan and P. Goldie, 3–18. Oxford: Oxford University Press.

Cranford, Cynthia J, and Diana Miller. 2013. "Emotion Management from the Client's Perspective: The Case of Personal Home Care." *Work, Employment and Society* 27 (5): 785–801. https://doi.org/10.1177/0950017013477901.

Daly, A. 2016. *Merleau-Ponty and the Ethics of Intersubjectivity*. London: Palgrave MacMillan.

Davies, J., and J. Hogg. 2004. "Count Us In." *PMLD Link* 16 (1): 9–12.

Davy, L. 2019. "Between an Ethic of Care and an Ethic of Autonomy: Negotiating Relational Autonomy, Disability, and Dependency." *Angelaki* 24 (3): 101–114. https://doi.org/10.1080/0969725X.2019.1620461.

de Haas, C., J. Grace, J. Hope, and M. Nind. 2022. "Doing Research Inclusively: Understanding What It Means to Do Research With and Alongside People with Profound Intellectual Disabilities." *Social Sciences* 11 (4): 159. https://doi.org/10.3390/socsci11040159.

Devlin, E. 2024. "Exploring Teachers' Confidence in Addressing Mental Health Issues in Learners with Profound and Multiple Learning Difficulties (PMLD) Pre and Post Training." *Cylchgrawn Addysg Cymru / Wales Journal of Education*. 1–10. https://doi.org/10.16922/wje.p5.

Emerson, E., and C. Hatton. 2007. The Mental Health of Children and Adolescents with Learning Disabilities in Britain. Retrieved from https://www.mentalhealth.org.uk/sites/default/files/mh_children_adolescents.pdf

Falecki, D., and E. Mann. 2021. "Practical Applications for Building Teacher WellBeing in Education." In *Cultivating Teacher Resilience*, edited by C.F. Mansfield, 175–191. Singapore: Springer.

Fergusson, A., M. Howley, and R. Rose. 2008. "Responding to the Mental Health Needs of Young People with Profound and Multiple Learning Disabilities and Autistic Spectrum Disorders: Issues and Challenges." *Mental Health and Learning Disabilities Research and Practice* 5 (2): 240–251. https://doi.org/10.5920/mhldrp.2008.52240.

Forster, S., K. M. Gray, J. Taffe, S. L. Einfeld, and B. J. Tonge. 2011. "Behavioural and Emotional Problems in People with Severe and Profound Intellectual Disability." *Journal of Intellectual Disability Research: JIDR* 55 (2): 190–198. https://doi.org/10.1111/j.1365-2788.2010.01373.x.

Forster, S., and T. Iacono. 2014. "The Nature of Affect Attunement Used by Disability Support Workers Interacting with Adults With Profound Intellectual and Multiple Disabilities." *Journal of Intellectual Disability Research: JIDR* 58 (12): 1105–1120. https://doi.org/10.1111/jir.12103.

Fox, H., E. Tuckwiller, E. Kutscher, and H. Walter. 2020. "What Makes Teachers Well? A Mixed-Methods Study of Special Education Teacher Well-Being." *Journal of Interdisciplinary Studies in Education* 9 (2): 223–228.

Frenzel, A. C., L. Daniels, and I. Burić. 2021. "Teacher Emotions in the Classroom and Their Implications for Students." *Educational Psychologist* 56 (4): 250–264. https://doi.org/10.1080/00461520.2021.1985501.

Gallagher, S., and D. Zahavi. 2021. *The Phenomenological Mind*. 3rd ed. Abingdon: Routledge.

Gibby-Leversuch, R., J. Field, and T. Cooke. 2019. "To What Extent is the Thrive Intervention Grounded in Research and Theory?" *Educational Psychology Research and Practice* 5 (2): 1–8.

Gibson, W. 2021. "Aesthetics, Verisimilitude and User Engagement: Reporting Findings through Fictional Accounts in Qualitative Inquiry." *Qualitative Research* 21 (5): 650–666. https://doi.org/10.1177/1468794120925769.

Goodley, D. 2023. "Being Human as Praxis: For People with Learning Disabilities." *Subjectivity* 30 (2): 1–18. https://doi.org/10.1057/s41286-023-00159-6.

Goodwin, J. 2020. "On 'Being' Together as Belonging: Inside Golden Tent." In *Belonging For People with Profound Intellectual and Multiple Disabilities*, edited by M. Nind and I. Strnadová, 59–74. Abingdon: Routledge.

Grace, J. 2018. *Sensory-Being for Sensory Beings: Creating Entrancing Sensory Experiences*. Abingdon: Routledge.

Grace, J., and M. Nind. 2024. "Creating Insight about Inclusion Together with Young People with Profound Intellectual and Multiple Disabilities." In *Including Voices: Respecting the Experiences of Individuals from Marginalised Communities*, edited by R. Rose, and M. Shevlin. London: Emerald.

Grace, J., M. Nind, C. de Haas, and J. Hope. 2024. "Expanding Possibilities for Inclusive Research: Learning from People with Profound Intellectual and Multiple Disabilities and Decolonising Research." *Social Sciences* 13 (1): 37. https://doi.org/10.3390/socsci13010037.

Halcrow, P. J. 2014. "Some Children, You Know, Physically so Deformed, That It's Scary": an Interpretative Approach to Exploring the Experiences of Teaching Assistants Working in a Special School with Severe, Profound and Multiple Learning Difficulties." Thesis for Doctorate in Child, Community and Educational Psychology, University of Essex.

Hall, E., and R. Wilton. 2017. "Towards a Relational Geography of Disability." *Progress in Human Geography* 41 (6): 727–744. https://doi.org/10.1177/0309132516659705.

Harding, S., R. Morris, D. Gunnell, T. Ford, W. Hollingworth, K. Tilling, S. Bell, et al. 2019. "Is Teachers' Mental Health and Wellbeing Associated with Students' Mental Health and Wellbeing?" *Journal of Affective Disorders* 242: 180–187. https://doi.org/10.1016/j.jad.2018.08.080.

Hibbin, R. 2023. "Relational Responsibility, Social Discipline and Behaviour in School: Re-Orienting Discipline and Authority Through a Distributed Network of Relational Accountability." *Pastoral Care in Education:* 1–21. https://doi.org/10.1080/02643944.2023.2263453.

Holt, L. 2010. "Young People with Socio-Emotional Differences: Theorizing Disability and Destabilizing Socioemotional Norms." In *Towards Enabling Geographies: 'Disabled' Bodies and Minds in Society and Space*, edited by V. Chouinard, E. Hall, and R. Wilton, 145–164. Farnham: Ashgate.

hooks, b. 1994. *Teaching to Transgress: Education at the Practice of Freedom*. London: Routledge.

Hostyn, I., and B. Maes. 2009. "Interaction between Persons with Profound Intellectual and Multiple Disabilities and Their Partners: A Literature Review." *Journal of Intellectual & Developmental Disability* 34 (4): 296–312. https://doi.org/10.3109/13668250903285648.

Huppert, F. A., and T. T. C. So. 2013. "Flourishing across Europe: Application of a New Conceptual Framework for Defining Well-Being." *Social Indicators Research* 110 (3): 837–861. https://doi.org/10.1007/s11205-011-9966-7.

Imray, P., L. Kossyvaki, and M. Sissons. 2023. *A Different View of Curriculum and Assessment for Severe, Complex and Profound Learning Disabilities*. Abingdon: Routledge.

Jackson, A. J. 2023. "Attuned Fathering and the Moral Dimensions of Caregiving." *Anthropological Quarterly* 96 (1): 65–90. https://doi.org/10.1353/anq.2023.0010.

Jacobs, P. 2020. "Transitions in the Lives of Adults with Severe Intellectual Disability: An Ecological Life Course Perspective." PhD thesis. University of Edinburgh.

Javaid, A., V. Nakata, and D. Michael. 2019. "Diagnostic Overshadowing in Learning Disability: Think Beyond the Disability." *Progress in Neurology and Psychiatry* 23 (2): 8–10. https://doi.org/10.1002/pnp.531.

Jones, P. 2004. "They Are Not Like Us and Neither Should They Be': Issues of Teacher Identity for Teachers of Pupils with Profound and Multiple Learning Difficulties." *Disability and Society* 19 (2): 159–169.

Jones, P., and M. W. Riley. 2017. "Trying, Failing, Succeeding, and Trying Again and Again": Perspectives of Teachers of Pupils with Severe Profound Multiple Learning Difficulties." *European Journal of Teacher Education* 40 (2): 271–285. https://doi.org/10.1080/02619768.2017.1284196.

Jones, C. 2019. "All the Small Things": Research Exploring the Positive Experiences of Teachers Working with Pupils with Profound and Multiple Learning Difficulties." Thesis. Cardiff University.

Keyes, C. L. M. 2003. "Complete Mental Health: An Agenda for the 21th Century." In *Flourishing: Positive Psychology and the Life Well-Lived*, edited by C.L.M. Keyes and J. Haidt, 293–312. Washington, DC: American Psychological Association.

Kittay, E. F. 2019. *Learning from My Daughter The Value and Care of Disabled Minds*. Oxford: Oxford University Press.

Kittay, Eva Feder. 2001. "When Caring is Just and Justice is Caring: Justice and Mental Retardation." *Public Culture* 13 (3): 557–580. https://doi.org/10.1215/08992363-13-3-557.

Landers, A. J. 2018. Teachers' Educational Beliefs about Students with Learning Disabilities. PhD Diss., Fordham University.

Langeland, E. 2022. "Emotional Well-Being." In *Encyclopedia of Quality of Life and Well-Being Research*, edited by F. Maggino. Springer, Cham. https://doi.org/10.1007/978-3-319-69909-7_859-2.

Lindemann, H. 2010. "Holding One Another (Well, Wrongly, Clumsily) in a Time of Dementia." In *Cognitive Disability and Its Challenge to Moral Philosophy*, edited by E.F. Kittay, and L. Carlson, 161–170. Oxford: Wiley-Blackwell.

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

Luijkx, J., A. A. J. van der Putten, and C. Vlaskamp. 2016. "I Love My Sister, but Sometimes I Don't": A Qualitative Study into the Experiences of Siblings of a Child with Profound Intellectual and Multiple Disabilities." *Journal of Intellectual & Developmental Disability* 41 (4): 279–288. https://doi.org/10.3109/13668250.2016.1224333.

MacGregor, L. 2022. "Mingled Bodies and Voices: Maternal Reflections on Caregiver Expertise and Intellectual Disability." *Journal of Intellectual Disabilities: JOID* 26 (3): 594–602. https://doi.org/10.1177/17446295211009339.

Magrì, E. 2015. "Subjectivity and Empathy: A Steinian Approach." *Discipline Filosofiche* XXV (2): 129–147.

Mansell, J. 2010. "Raising Our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities." *Tizard Learning Disability Review* 15 (3): 5–12. https://doi.org/10.5042/tldr.2010.0399.

McCallum, F., and D. Price. 2010. "Well Teachers, Well Students." *The Journal of Student Wellbeing* 4 (1): 19–34. https://doi.org/10.21913/JSW.v4i1.599.

McNamee, S., and K. J. Gergen. 1999. *Relational Responsibility: Resources for Sustainable Dialogue*. Thousand Oaks, CA: Sage.

Mietola, R., S. Miettinen, and S. Vehmas. 2017. "Voiceless Subjects? Research Ethics and Persons with Profound Intellectual Disabilities." *International Journal of Social Research Methodology* 20 (3): 263–274. https://doi.org/10.1080/13645579.2017.1287872.

Milner, P., and P. Frawley. 2019. "From 'On' to 'With' to 'by:' People with a Learning Disability Creating a Space for the Third Wave of Inclusive Research." *Qualitative Research* 19 (4): 382–398. https://doi.org/10.1177/1468794118781385.

Milton, D. 2012. "On the Ontological Status of Autism: The 'Double Empathy Problem." *Disability & Society* 27 (6): 883–887. https://doi.org/10.1080/09687599.2012.710008.

Milton, Damian, Emine Gurbuz, and Betriz Lopez. 2022. "The 'Double Empathy Problem': Ten Years On." *Autism: The International Journal of Research and Practice* 26 (8): 1901–1903. https://doi.org/10.1177/13623613221129123.

Mitchell, D. 2000. "Parallel Stigma? Nurses and People with Learning Disabilities." *British Journal of Learning Disabilities* 28 (2): 78–81. https://doi.org/10.1046/j.1468-3156.2000.00044.x.

Mitchell, P., E. Sheppard, and S. Cassidy. 2021. "Autism and the Double Empathy Problem: Implications for Development and Mental Health." *The British Journal of Developmental Psychology* 39 (1): 1–18. https://doi.org/10.1111/bjdp.12350.

NHS. 2020. The NHS 5 Steps to Mental Wellbeing. https://www.nhs.uk/conditions/stress-anxiety-depression/improve-mental-wellbeing/

Nind, M. 2008. "Promoting the Emotional Well-Being of People with Profound and Multiple Learning Difficulties: A Holistic Approach through Intensive Interaction." In *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*, edited by J. Pawlyn, and S. Carnaby, 62–77. Oxford: Wiley-Blackwell.

Nind, M., and D. Hewett. 2005. *Access to Communication: Developing the Basics of Communication with People with Severe Learning Difficulties through Intensive Interaction*. 2nd ed. London: Routledge.

Nind, M., and I. Strnadová. 2020. "Changes in the Lives of People with Profound Intellectual and Multiple Disabilities." In *Belonging For People with Profound Intellectual and Multiple Disabilities*, edited by M. Nind, and I. Strnadová, 1–21. Abingdon: Routledge.

Park, Crystal L., Laura D. Kubzansky, Sandra M. Chafouleas, Richard J. Davidson, Dacher Keltner, Parisa Parsafar, Yeates Conwell, et al. 2023. "Emotional Well-Being: What It is and Why It Matters." *Affective Science* 4 (1): 10–20. https://doi.org/10.1007/s42761-022-00163-0.

Penninga, W., S. L. P. Nijs, H. J. A. van Bakel, and P. J. C. M. Embregts. 2022. "Meaningful Moments of Interaction with People with Profound Intellectual Disabilities: Reflections from Direct Support Staff." *Journal of Applied Research in Intellectual Disabilities: JARID* 35 (6): 1307–1316. https://doi.org/10.1111/jar.13019.

Philip, M., L. Lambe, and J. Hogg., edited by The Foundation for People with Learning Disabilities. 2005. "The Well-Being Project: Identifying and Meeting the Needs of Young People with Profound and Multiple Learning Disabilities and Their Carers." In *Making us Count: Identifying and Improving Mental Health Support for Young People with Learning Disabilities. A Research Report* 111–130. London: The Mental Health Foundation.

Rogers, C. 2016. *Intellectual Disability and Being Human: A Care Ethics Model*. London: Routledge.

Rose, R., M. Howley, A. Fergusson, and J. Jament. 2009. "Mental Health and Special Educational Needs: Exploring a Complex Relationship." *British Journal of Special Education* 36 (1): 3–8. https://doi.org/10.1111/j.1467-8578.2008.00409.x.

Ross, E., and C. Oliver. 2003. "The Assessment of Mood in Adults Who Have Severe or Profound Mental Retardation." *Clinical Psychology Review* 23 (2): 225–245. https://doi.org/10.1016/s0272-7358(02)00202-7.

Schalock, R. L., R. Luckasson, and M. J. Tasse. 2021. *Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports*.12th ed. USA: American Association on Intellectual and Developmental Disabilities.

Shaw, Sebastian Ck., Laura Carravallah, Mona Johnson, Jane O'Sullivan, Nicholas Chown, Stuart Neilson, and Mary Doherty. 2023. "Barriers to Healthcare and a 'Triple Empathy Problem' May Lead to Adverse Outcomes for Autistic Adults: A Qualitative Study." *Autism:*

The International Journal of Research and Practice 28 (7): 1746–1757. https://doi.org/10.1177/13623613231205629.

Sheehy, K., and M. Nind. 2005. "Emotional Well-Being For All: Mental Health and People with Profound and Multiple Learning Disabilities." *British Journal of Learning Disabilities* 33 (1): 34–38. https://doi.org/10.1111/j.1468-3156.2004.00290.x.

Simmons, B. 2020. "Exploring the Situated Social Being of Children with Profound and Multiple Learning Difficulties across Educational Contexts: A Study of Belonging." In *Belonging For People with Profound Intellectual and Multiple Disabilities*, edited by M. Nind, and I. Strnadová, 27–40. Abingdon: Routledge.

Simmons, B. 2021. "The Production of Social Spaces for Children with Profound and Multiple Learning Difficulties: A Lefebvrian Analysis." *British Journal of Sociology of Education* 42 (5–6): 828–844. https://doi.org/10.1080/01425692.2021.1922269.

Simmons, B., and D. Watson. 2015. "From Individualism to Co-Construction and Back Again: Rethinking Research Methodology for Children with Profound and Multiple Learning Disabilities." *Child Care in Practice* 21 (1): 50–66. https://doi.org/10.1080/13575279.2014.976179.

Skarsaune, S. N. 2024. "Persons with Profound and Multiple Learning Disabilities as Subjects of Knowledge: Exploring the Possibilities of Empathy." *British Journal of Learning Disabilities* 52 (1): 101–109. https://doi.org/10.1111/bld.12550.

Skarsaune, S. N., and H. 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 (1): 25–40. https://doi.org/10.1177/15407969231153579.

Skarsaune, S. N., H. M. Hanisch, and A. Gjermestad. 2021. "Self-Determination: What Can We Learn from Persons with Profound Intellectual and Multiple Disabilities?" *Scandinavian Journal of Disability Research* 23 (1): 317–327. https://doi.org/10.16993/sjdr.830.

Smith, E., V. Critten, and R. Vardill. 2020. "Assessing Progress in Children with Severe/Profound Intellectual Disabilities: What Are the Issues?" *Disability & Society* 35 (10): 1688–1692. https://doi.org/10.1080/09687599.2020.1719042.

Spelman, E. V. 1988. *Inessential Woman: Problems of Exclusion in Feminist Thought*. Boston, USA: Beacon Press.

Stern, D. 1985. *The Interpersonal World of the Infant: A View from Psychoanalysis and Developmental Psychology*. New York, NY: Basic Books.

Stern, D. N., L. Hofer, W. Haft, and J. Dore. 1985. "Affect Attunement: The sharing of feeling States Between Mother and Infant by Means of Inter-Modal Fluency." In *Social Perceptions in Infants*, edited by T.M. Field, and N.A. Fox, 249–268. Norwood, NJ: Ablex.

Stewart-Brown, S. 1998. "Emotional Wellbeing and Its Relation to Health." *Bmj* 317 (7173): 1608–1609. https://doi.org/10.1136/bmj.317.7173.1608.

Stothard, V. 1998. "The Gradual Development of Intensive Interaction in a School Setting." In *Interaction in Action*, edited by D. Hewett, and M. Nind, 149–164. London: David Fulton.

Thrive. https://www.thriveapproach.com/

Tronto, J. C. 1993. *Moral Boundaries: A Political Argument for an Ethic of Care*. New York, NY: Routledge.

Tronto, J. C. 2013. *Caring Democracy. Markets, Equality and Justice*. New York, NY: University Press.

Tsiouris, J. A. 2001. "Diagnosis of Depression in People with Severe/Profound Intellectual Disability." *Journal of Intellectual Disability Research: JIDR* 45 (Pt 2): 115–120. https://doi.org/10.1046/j.1365-2788.2001.00333.x.

Tuffrey-Wijne, I., J. Bernal, and S. Hollins. 2008. "Doing Research on People with Learning Disabilities, Cancer and Dying: Ethics, Possibilities and Pitfalls." *British Journal of Learning Disabilities* 36 (3): 185–190. https://doi.org/10.1111/j.1468-3156.2008.00519.x.

Turner, K., and M. Thielking. 2019. "Teacher Wellbeing: Its Effects on Teaching Practice and Student Learning." *Issues in Educational Research* 29 (3): 938–960.

van Dijke, J., I. van Nistelrooij, P. Bos, and J. Duyndam. 2020. "Towards a Relational Conceptualization of Empathy." *Nursing Philosophy* 21 (3): 12297. https://doi.org/10.1111/nup.12297.

Veck, W., and M. Hall. 2020. "Inclusive Research in Education: Dialogue, Relations and Methods." *International Journal of Inclusive Education* 24 (10): 1081–1096. https://doi.org/10.1080/13603116.2018.1512659.

Vos, P., P. De Cock, K. Petry, W. Van Den Noortgate, and B. Maes. 2010. "What Makes Them Feel Like They Do? Investigating the Subjective Well-Being in People with Severe and Profound Disabilities." *Research in Developmental Disabilities* 31 (6): 1623–1632. https://doi.org/10.1016/j.ridd.2010.04.021.

Wade, Danny, Courtney Vaughn, and Wesley Long. 2009. "The Power of Fiction: A Novel Approach to Presenting Research Findings." *Journal of Thought* 44 (1–2): 37–58. https://doi.org/10.2307/jthought.44.1-2.37.

Walmsley, J., I. Strnadová, and K. Johnson. 2018. "The Added Value of Inclusive Research." *Journal of Applied Research in Intellectual Disabilities: JARID* 31 (5): 751–759. https://doi.org/10.1111/jar.12431.

Weare, K., and M. Nind. 2011. "Mental Health Promotion and Problem Prevention in Schools: What Does the Evidence Say?" *Health Promotion International* 26 (suppl 1): i29–69. https://doi.org/10.1093/heapro/dar075.

Whittle, E. L., K. R. Fisher, S. Reppermund, R. Lenroot, and J. Trollor. 2018. "Barriers and Enablers to Accessing Mental Health Services for People with Intellectual Disability: A Scoping Review." *Journal of Mental Health Research in Intellectual Disabilities* 11 (1): 69–102. https://doi.org/10.1080/19315864.2017.1408724.