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What Does It Mean to Be a 'Person' With Profound and Multiple Learning Disabilities? Presenting the Views of Family Members and Allies

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ABSTRACT

Background: Individuals with profound and multiple learning disabilities are at the centre of debates about what it means to be a person. These debates sometimes start from the position that a person is somebody who possesses mature cognitive abilities, such as intentional communication skills and self-reflection (which individuals with profound and multiple learning disabilities are sometimes said to lack). However, those closest to people with profound and multiple learning disabilities are rarely consulted. This paper presents research that addresses this gap.

Methods: Ten unstructured interviews were conducted with family members, friends and allies of the profound and multiple learning disabilities communities. Participants were asked to discuss what being a person meant to them, using their knowledge of supporting individuals with profound and multiple learning disabilities.

Findings: Interviewees suggested that a person was fundamentally a relational being, but this relationality was described in a myriad of ways (e.g., as mutual dependence, social role, social gradient, interactionist and storied).

Conclusions: A richer understanding of the personhood of individuals with profound and multiple learning disabilities can be developed by listening to more family members and allies, and this can provide a counter-narrative to the current dominant rational view of personhood.

1 | Introduction

1.1 | Defining Personhood

The answer to the question 'what is a person?' seems trivial and obvious. You (the person reading this paper) are a person and we (the authors who wrote the paper) are also people. This is uncontroversial, perhaps even mundane. When we go about our daily routines we rarely (if ever) question whether somebody (or something) qualifies as a person. We simply know what a person is and can identify them with ease if asked. However, there are ongoing debates in philosophy and bioethics about what a person is, where a person begins and ends, and how people should be treated, and a lot appears to hang on the answer to this question. In this section we briefly introduce two competing perspectives in the personhood debate—a rational model and a relational model—before examining the implications of these models for individuals with profound and multiple learning disabilities[1].

The rational model of personhood is the dominant model found in Western philosophy. This model equates being a person with

Summary

- Some philosophers say that individuals with profound and multiple learning disabilities are 'too disabled' to count as 'people'.
- We are worried that this way of thinking is harmful to individuals with profound and multiple learning disabilities and can upset the people who love them.
- We asked family members and allies of individuals with profound and multiple learning disabilities what they think a person is.
- They told us that a person is somebody who needs help and support, is somebody who is related to others, and is somebody we can get to know by being with them.
- Our research is important because it challenges philosophers who say that individuals with profound and multiple learning disabilities are not proper people.

the possession of mature cognitive abilities such as the capacity for abstract reflection and the use of symbolic language:

> *The modern concept defines persons as* beings with the capacity for certain complex forms of consciousness, *such as rationality or self-awareness over time. [...] The term refers paradigmatically—that is, without controversy—to normal human beings who have advanced beyond the infant and toddler years. Such human beings [...] are psychologically complex, highly social, linguistically competent, and richly self-aware*
>
> (DeGrazia 2005: 3).

This definition is often traced back to John Locke (1632–1704) who famously stated that a person is 'a thinking intelligent being, that has reason and reflection, and can consider itself, as itself, the same thinking thing, in different times and places' (1975: 335). According to Goodey (2011), the idea of a 'birth-to-death self' (337) that underpins the modern concept of personhood was absent in pre-Lockean thought. Medieval doctrine held that everything—including who we are as people— was subject to modification by divine intervention and therefore the very idea of a permanent and unique intellectual identity was considered blasphemous. Locke radically challenged this logic by suggesting that our identities were permanently ours, and that the divine would judge us based on the extent to which we acted morally over our lives:

> *[...] the new ways of conceiving personhood that Locke typifies were new ways of assessing moral responsibility: the submission to divine authority of an audited account of actions undertaken over one's entire life... what makes the person is his consciousness, which is etymologically related to conscience of the rendering of accounts with God*
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> (Goodey 2011: 339).

Whilst the spiritual dimension of personhood is no longer foregrounded in Western philosophy, the Lockean idea of a rational being that possesses a sense of self over time continues to be pervasive (Carlson and Kittay 2010). Philosophers might debate exactly which rational qualities are needed to qualify as a person (e.g., abstract reflection, autonomy, grasp of moral principles) (Cantor 2009; DeGrazia 2005) but the premise that being a person requires the ability to reason is at the centre of modern definitions.

Despite its dominance, the rational view of personhood is not without opposition, and some have argued for a 'relational' view of personhood. The relational view holds that a person is inseparable from social networks and human relationships. For example, Splitter (2015: x) argues that '[...] personhood is social and communal, wherein each individual becomes aware of her/himself as 'one among others', not any others, but specific others with whom our lives are 'in some sense interwoven'. Reinder (2008) offers a theological interpretation of the relational, and suggests that everyone counts 'one of us' as we are each a gift from God. Relational understandings of personhood are also found outside of Western traditions. For example, Gunkel and Wales (2021: 474) note that:

> *In a number of African traditions, like Ubuntu, person is not the natural condition of an individual human being, it is an achieved social condition. Instead of operationalizing the individuated "cogito ergo sum" [I think therefore I am] of Descartes, this way of thinking proceeds from the adage: "I am because we are, and since we are, therefore I am"'*
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> (Mbiti 1990, pp. 108–109)

1.2 | The Personhood of Individuals With Profound and Multiple Learning Disabilities

Individuals with profound and multiple learning disabilities are sometimes implicated in debates about what it means to be a person, particularly when debate revolves around the extent to which cognitive ability is prerequisite to being a person. The label 'profound and multiple learning disabilities' is used in the UK to refer to individuals who experience significant cognitive impairments. These impairments are sometimes framed in terms of global developmental delay, and individuals with profound and multiple learning disabilities are described as failing to reach developmental milestones associated with later infancy (e.g., cause-effect awareness, intentional communication, and intersubjective awareness) (Simmons and Watson 2014).

If being a person is defined in terms of the possession of mature intelligence, and being an individual with profound and multiple learning disabilities is defined in terms of profound cognitive impairments, then individuals with profound and multiple learning disabilities are at risk of being defined as 'non-persons', as Cantor (2009: 18) suggests:

> *Any position viewing high intellectual capacity of the human mind as the key to personhood [...] would exclude some profoundly disabled beings. Some profoundly*

> *disabled people are so severely neurologically damaged that they cannot reason or communicate, although they can experience pleasure and pain.*

The link between rationality and personhood has led to claims that individuals with profound and multiple learning disabilities are, in some sense, closer to farm animals than people. Singer (2010) claims 'that pigs are animals who compare quite well in terms of cognitive abilities with human beings who are profoundly mentally retarded' (343)[2]. McMahan (2002: 221–222) states:

> *When one compares the relatively small number of severely retarded human beings who benefit from our solicitude with the vast number of animals who suffer at our hands, it is impossible to avoid the conclusion that the good effects of our species-based partiality are greatly outweighed by the bad.*

The reduction of people with profound and multiple learning disabilities to non-humans is not new. Locke himself labelled individuals who lacked rational minds as 'changelings' (Goodey 2011: 316)—creatures who had human form but lacked a human mind or soul and were considered to be closer to monkeys than human beings.

The view that individuals with profound and multiple learning disabilities lack sufficient cognitive ability to be accorded personhood and, as a consequence, are deemed to have a lower status than nondisabled people, is known as moral individualism (Vehmas and Curtis 2021). We worry that the reduced status of individuals with profound and multiple learning disabilities will have a tangible effect on how they are treated. This is a view also shared by some philosophers such as Cantor (2009: 14) who states that 'if profoundly disabled beings are not persons, then decisions to terminate […] life-sustained medical intervention (and thereby precipitate death) are facilitated'.

Some researchers working closely with individuals with profound and multiple learning disabilities have challenged moral individualism by calling into question taken-for-granted ideas about the nature of the mind or decoupling the value of a person from the possession of mature cognitive abilities (Skarsaune 2023). For example, Vorhaus (2020) differentiates between pre-reflective awareness and reflective self-awareness and suggests that whilst some individuals with profound and multiple learning disabilities may not have capacity to reflect about their experiences, they still have experiences that are uniquely theirs and therefore a first-person perspective. This study resonates with neuroscience literature that describes how people diagnosed with hydranencephaly and lacking a cortex are still capable of affective experience (Solms 2021). Vorhaus (2020) and Vehmas and Curtis (2021) suggest that we avoid grounding respect for people based on some kind of intrinsic (rational) capacity and instead embrace an ethical orientation that begins with the view that individuals with profound and multiple learning disabilities warrant respect simply by existing. It is the duty of rational moral agents to give greater care and concern to those who cannot care for themselves.

1.3 | Absence of the Profound and Multiple Learning Disability Community in Debates About What It Means to Be a Person

Debates about what it means to be a person are inflammatory—they can upset and anger people whose loved ones are described as lacking the capacity to be a proper person. The philosopher who has perhaps been most vocal against arguments that reduce loved ones to non-persons is Eva Kittay. Kittay draws on her experience of being a parent to Sesha who is 'severely to profoundly' (2005: 126) intellectually impaired and describes her revulsion to such debate:

> *For a mother of a severely cognitively impaired child, the impact of such an argument is devastating. How can I begin to tell you what it feels like to read texts in which one's child is compared, in all seriousness and with philosophical authority, to a dog, pig, rat, and most flatteringly a chimp; how corrosive these comparisons are, how they mock those relationships that affirm who we are and why we care?*
>
> (2010: 397)

Whilst Kittay's (2005, 2010) voice is strong, she is one of the very few philosophers whose views are informed by direct lived experience of being a family member of somebody with profound and multiple learning disabilities. In fact, there is a distinct lack of research about the views of individuals with profound and multiple learning disabilities, as well as their loved ones and allies, regarding what it means to be a person. Despite the mantra 'Nothing About Us Without Us' in fields such as disability studies, it appears that philosophers and researchers working in this space have overlooked the views of those closest to individuals with profound and multiple learning disabilities who (arguably) have the most wisdom to offer, and also the most to lose when loved ones are considered to be non-persons. It is our contention that the views of the profound and multiple learning disabilities community should be centred in such debates, and that by looking at the meaning of personhood through the lens of the profound and multiple learning disabilities community, we can potentially identify counter-discourses to moral individualism and begin to enrich the personhood debate from the perspective of those who are talked about, but not always listened to. It is against this backdrop that the paper is set, and we present research that explores what it means to be a person, from the perspective of family members, paid carers and allies of individuals with profound and multiple learning disabilities.

1.4 | An Alternative Take on the Meaning of Personhood: Phenomenology of Sociality

Researchers and philosophers such as Skarsaune (2023), Vorhaus (2020) and Vehmas and Curtis (2021) have followed Kittay (2005, 2010) footsteps by challenging moral individualism and its reduction of the moral status of individuals with profound and multiple learning disabilities. We also follow these footsteps but veer from the path by exploring how the personhood of individuals with profound and multiple learning disabilities emerges in lived experience rather than logical debate. Our thinking is informed by literature about the phenomenology of sociality (Szanto and Moran 2016), which examines the nature of social experience from a first-person perspective.

Phenomenologists investigating sociality are sometimes concerned with intersubjectivity. This includes the relations between subjects, (e.g., 'you' and 'me'), and the ways in which the 'we' comes into being, or how the 'us' is formed. When individuals with profound and multiple learning disabilities are described as non-persons they are positioned as separate from 'us': the privileged group accorded personhood. However, we argue that this is a conclusion made from a detached perspective, from a community of philosophers who appear to rely on reason and logic more than experience of being part of the profound and multiple learning disabilities community. For phenomenologists, the personhood of others is something experienced rather than deduced, and therefore requires certain conditions to be met—such as sustained interaction - to see 'who' (rather than 'what') individuals with profound and multiple learning disabilities are. We are particularly influenced by Sophie Loidolt's (2016, 2018) exegesis of Hannah Arendt's (1906–1975) work and outline this Loidolt-Arendtian lens below.

According to Loidolt (2016, 2018), one of Arendt's original contributions to philosophy is her account of 'plurality'. Plurality refers to a 'primary state of community' or a 'primary reality' which consists of an implicit (non-thematic) experience of other people as unique first-person perspectives (Loidolt 2018: 65–66) or a multiplicity of individual 'whos' (Ibid 2016: 44). The concept of 'plurality' refers to our predisposition to experience others as unique subjects with their own point of view, and for us to appear before others and to be experienced as subjects. However, plurality in this sense is not something that simply is, but has to be brought into being, something that Loidolt (2018) refers to as 'actualizing plurality in a space of appearances' (52, italics omitted). To appear and be experienced as a person, we must have opportunities to either act in the world in the presence of others, or directly interact with others. Our personhood is thus contingent on the gaze of others who must recognise our actions as meaningful expressions of a first-person perspective. Hence, Arendt sidesteps the issue of 'what' a person essentially is (e.g., bodies, minds, souls, relationships) to develop an account of how the 'who' appears to others through observation and interaction. The appearance of the 'who' through interactions leaves something behind: stories which are accidental by-products (Arendt 1998) told by others. Hence, the way to discover who individuals with profound and multiple learning disabilities are is to listen and learn from the stories that families, friends and allies tell about individuals with profound and multiple learning disabilities. We take this as our starting point in this paper and discuss our methodological approach below.

2 | Methodology

2.1 | Study Aim and Design

The aim of the study was to explore how family members, carers, and allies of individuals with profound and multiple learning disabilities understand what it means to be a 'person' with profound and multiple learning disabilities. The study design drew influence from traditional constructivist paradigms of research (Denzin and Lincoln 2017) which recognise that knowledge can be subjective, relative, and reflect the personal beliefs of an individual or group (in this case, the research participants' individual and collective views of what it means to be a person).

2.2 | Participants

Ten participants in England were interviewed. All participants were women and included six parents, a former foster parent, a sibling, a paid carer, and a charity worker. The participants had a range of professional and educational experiences.

The participants were recruited via a combination of non-probability convenience, purposive and snowball sampling methods (Cohen et al. 2017). Participants known to the researchers were invited to interview. After the interview participants invited people from their own networks to get in touch about the research. Calls for participants were published on social media platforms, through an article in a family and practitioner journal (Read et al. 2023), and during a conference presentation (Simmons 2024).

2.3 | Data Collection

Data was collected via unstructured interviews. The term 'unstructured interview' is used interchangeably in the literature with other terms such as 'informal interview', 'in-depth interview' and 'informal conversational interview'. What each of these terms have in common is the view that research is a generative and inductive process, and the researcher largely avoids pre-determined interview questions, and instead has conversations with participants and aims to generate questions in response to the participants' given narrative (Punch 1998). Our process was facilitated by an aide memoire (or broad topic guide) (McCann and Clark 2005) consisting of three broad questions: 'What is profound and multiple learning disabilities?', 'What is a person?' and 'What does it mean to be a person with profound and multiple learning disabilities?'.

Interviews took place during June and July 2023 via Google Meet video conferencing software, except for one interview that took place on the phone at the participant's request. The interviews lasted between 45 min and 2 ½ hours. Each interview was audio recorded and transcribed. Each participant received a copy of their own interview transcript to read and confirm that they were happy for the researchers to use the data in its current form. Some participants supplemented their interview data with additional materials during the interviews. This included photographs, video clips, a eulogy book, and literature that was read out by the interviewees.

2.4 | Data Analysis

Inductive thematic analysis was performed over several stages (Braun and Clarke 2021). Data familiarisation took place by listening to the recorded audio and rereading the interview transcripts before coding. Initial descriptive codes were generated based on the topic of conversation. These descriptive codes were then analysed in terms of the nature of the data within those code. After categorising and generating finite codes, a list of potential themes was generated, reviewed, refined and named. Six eventual themes emerged: (i) an overarching theme of how being human means being a person; (ii) how personhood requires mutual dependence; (iii) how personhood is shaped by sociocultural gradients; (iv) how personhood means having a social value; (v) how personhood appears through actions; and (vi) how personhood can be discussed through storytelling. These themes are discussed below.

2.5 | Research Ethics

Ethical clearance was granted by the School of Education Research Ethics Committee, Bath Spa University, before data collection took place.

3 | Findings

3.1 | From Species Membership to Relational Accounts of Personhood

Interviewees typically said that being human was pre-requisite to being a person. This view appeared to emerge out of the offence family members felt when their children were compared to pets: 'I can't stand it when my daughter is compared to dogs. Yes, your dog may be cute and enjoys being with you, but my daughter is more than a pet!'. Interviewees sometimes felt that pets received more attention than children: 'It's horrible when we all go out together—our dog gets more attention than [our son]. They'll talk to our dog, but they don't even look at [our son!]'. One parent described the link between being human and personhood as 'evolutionary' and suggested that there is a 'hierarchy in the animal kingdom', with human beings on top and therefore having a special 'status' owing to their capacity as a species for language and advanced skills.

3.2 | Personhood and Mutual Dependency

However, despite interviewees saying that being human was essential to being a person, descriptions of personhood extended beyond an individual's anatomy and contained a fundamental 'relational' component. The relational was described in a myriad of ways, but these descriptions often revolved around a continuum of dependency that connected individuals with profound and multiple learning disabilities to others. One participant described how 'if someone has needs, they are a person [...] we all have basic needs. We need love, we need care, we need attention, we need help with things, just some people need more or less of all of that'. The organisation of society was said to reflect our dependency on others to meet basic needs. One participant described: 'I think we are all dependent on others and that's why we live as we do. I know some people live on their own, but we tend to live in families, don't we? Or groups of humans'. A similar view was expressed by one parent who defined personhood not simply in terms of 'having' needs, but 'meeting' needs: 'personhood means for her [child] having all those things working around her to mean that she can be the best that she is'.

A common 'need' described by interviewees related to advocacy. Interviewees were acutely aware of their role in interpreting the behaviours of, and advocating for, individuals with profound and multiple learning disabilities, and challenged the view that self-advocacy was a key to personhood. At the same time, parents also expressed epistemological modesty about their children and suggested that whilst they were best placed to understand their children's thoughts and feelings, they were not always absolutely certain. Hence, being a person with profound and multiple learning disabilities was less about self-advocacy, and more about being recognised as having a voice, participating in a space where that voice matters, and having people interpret and 'speak up' for the child:

> *[...] does personhood mean that you can self-advocate? I've had people argue with me [that] everyone can self-advocate. I would argue you'd have to have a very keen understanding of someone's behaviours to know what they were trying to self-advocate about. Even then, you're still only making a guess. People say what does she [my child] mean? I don't know. How do I know? I've got no idea. However, because I've known her for so long, I can make a pretty good guess. That's the whole idea of best interest, isn't it? You make an educated guess about what's going on, but you can't ever really know.*

3.3 | Sociocultural Gradients of Personhood: Being and Becoming a Person

Another aspect of relational personhood concerns how individuals with profound and multiple learning disabilities relate to society. Some interviewees suggested that being a person meant participating in cultural norms, sharing values and perspectives, and being part of a common experience and history:

> *A person to me is a being who is part of a community, whether that's a community based on your identity, your locality, even part of a family. A person is [...] part of a collective where you have shared beliefs, values, understandings, traditions [and] norms.*

In fact, having relationships and participating in culture and community were not just important aspects of being a person, but also *becoming* a person. Who we are as people was said to be shaped by our opportunities to interact with others and engage in society. Personhood was said by one participant to be 'completely dependent on who you interactive with, where you interact' and also 'develops throughout your life': being 'part of a collective, part of a community' is 'what makes you a person'. This view may be dubbed a relational-gradient view: the being and becoming of a person emerges through social participation and develops across the lifespan. However, some interviewees also reflected about the consequences of this view for people who experience limited social interaction—if personhood depends on others, then a reduction in social interaction could limit personhood:

> *[...] no man is an island [...] you are a product of your relationships. If I say that and you try to generalise out, where does that put someone who has lived and has always lived in an institution and who has PMLD?*

Parents described a range of challenging situations which involved their children being treated as 'lesser than they are' and their personhood being ignored or 'denied'. These situations included children being abused by members of the public (e.g., people staring or filming children on their phones and laughing at them), being treated with neglect by clinicians (e.g., inserting cannulas into children without offering numbing cream), and paid carers ignoring best practice guidelines. These kinds of interactions were described by one parent as a 'wilful diminishing of someone's personhood' and sometimes led to parents limiting how often they left their home to avoid being seen by the general public.

3.4 | Social Roles and Value

One interviewee considered whether being a person was the same as being a citizen. Being a citizen was said to involve individuals fulfilling some kind of role that contributes to the functioning of society, such as gaining employment and raising children. The interviewee suggested that these kinds of roles were out of reach for her daughter, and instead suggested that personhood was contingent on social identity, such as being somebody's child, sibling, friend, neighbour or classmate. However, this idea of 'social identity', of personhood being defined in terms of how you stand in relation to others, was not something shared by all interviewees, and sometimes the boundaries between self and other were blurred. For example, one parent described how she and her daughter were intertwined in life, and this relationship continued in some sense after death:

> *I can't separate [my daughter] from me. [...] She is there. [My daughter] is no longer alive, she is in my heart and in my mind, and on my lips, isn't she? She is not a physical presence anymore. [...] There were often times when we were still one person even though she was an adult, because I would walk into a room and think, "Is she going to be comfortable here?" Because if she is not comfortable, I am not going to be comfortable, and none of us are staying.*

In life, and in death, personhood was said to extend beyond the boundaries of the individual—being a person meant shaping the personhood of others, and even existing through and with others.

3.5 | Revealing Personhood Through Actions

A key theme in the interview data concerns the ways in which people come to know the personhood of individuals with profound and multiple learning disabilities. For some, personhood was immediately perceptible—interviewees felt that personhood could be directly experienced, without the need to calculate the extent to which somebody meets predetermined criteria.

Some interviewees described the perception of personhood as requiring context, meaning that the personhood of others is revealed when the actions of individuals with profound and multiple learning disabilities are experienced as meaningful responses to observed situations. A common example of a meaningful response was behaviour that elicits an action from others. The smallest of gestures performed by individuals with profound and multiple learning disabilities can affect those around them, and the effect itself was described as something that conferred personhood:

> *[...] the children that go to the hospice, they are all different and sometimes you see them that they are like asleep, or maybe they don't do much or things, but you can see that everyone is having joy with them and they still have a little bit of smile. They maybe smile different, they maybe interact different [...] but the parents know, and the people that know them know [...] that is a person. He is a child and he is an important person in society.*

Whilst some interviewees described the immediateness of personhood when observing individuals with profound and multiple learning disabilities interact with family and friends, other interviewees suggested that experiencing somebody's personhood required us to enter the space of individuals with profound and multiple learning disabilities and engage with them on their own terms. Rather than talking about what personhood is, interviewees sometimes discussed strategies that helped reveal 'who' individuals with profound and multiple learning disabilities are. These included 'two-way interaction' with individuals with profound and multiple learning disabilities which can sometimes lead to an 'instant connection', allowing oneself to be affected by others. Interviewees talked about interaction strategies, such as being close, being seen, allowing individuals with profound and multiple learning disabilities time to respond to initiations, being willing to lay on the floor or sit on a chair facing the person, and by being willing to be ignored. Some interviewees said that getting to know who somebody is takes time and can be aided by observation across contexts. For example, some young individuals with profound and multiple learning disabilities were described as more social and talkative during family gatherings or evening meals, whilst attending after-school clubs, and when adults were out of sight. Children needed to feel comfortable and confident to 'open up'. Family members emphasised that 'being well' was essential for personhood to appear and 'catching' individuals on the right day will allow insights into how responsive individual children can be and the enjoyment that they experience and give to others.

What is important here is that personhood was not typically described by interviewees as something that is consistent, static, fixed, and located in an individual. Instead, its appearance is something that emerges in space and time, and is contingent upon the nature of the spaces that individuals find themselves in. Revealing 'who one is' as a person is shaped by opportunities provided by others, and individuals needed to be afforded opportunities to be comfortable enough to express themselves, and for other actors to be familiar enough with the expressions to be affected by them.

3.6 | Storying Personhood: Narratives That Come From Knowing Others and the Need for Authenticity

Rather than dwelling on personal definitions of personhood, interviewees often described individuals with profound and multiple learning disabilities using anecdotes and stories that revealed their personhood. They described the impact their children had on others, such as the kinds of stories others would share:

> *I would say the thing that you ask anybody about who knows [my daughter] well, they'd say she likes people. She loves being around people. She engages so powerfully as well with people. It is really lovely to see. So, she wants to be social, she wants to be out and seeing people [...]. Ultimately everything for [her] revolves around her interactions with people. It is what she thrives on.*

These stories painted a vivid picture of who children with profound and multiple learning disabilities are, their personalities, what they enjoy, how much they are loved by and enrich the lives of family and friends. Some parents came to interviews prepared with material to show and discuss such as photographs, video clips, poems, a book of condolences, and clips from newspapers. Interviewees shared personal moving moments, including the birth and death of their children. Recalling interactions with children with profound and multiple learning disabilities led family members to laughter, and also anger when describing how their children had been treated, and sometimes tears when discussing the loss of loved ones. Personhood was essentially 'storied'—it was demonstrated through the rich narratives told by those close to individuals with profound and multiple learning disabilities. As one interviewee shared, 'Thank you for keeping my daughter alive'.

However, whilst telling stories about the lives of individuals with profound and multiple learning disabilities can be a powerful way of illuminating their personhood, interviewees were clear that these stories had to be authentic. For example, some parents felt frustrated when the severity of their children's impairments were not taken seriously by others (e.g., education and care professionals) who told stories about their children and exaggerated their abilities. Overestimating the abilities of children with profound and multiple learning disabilities was said to deny personhood by creating a false representation that is not anchored in reality, as one parent said:

> *It's about going back to notions of the authentic. Don't lie [...] when you're representing her [...] because all of that denies her personhood. [It] create[s] a narrative about your idealised whoever it is, but it's not this person. Be honest, be totally authentic, and be [...] brutally honest about someone. I would much rather be seen as being brutally honest about telling you my daughter, what she understands and what she doesn't in order for her to get better care.*

4 | Discussion

The paper so far has introduced the personhood debate, described how children with profound and multiple learning disabilities do not 'fit' rationalist definitions of what counts as a person, and discussed an alternative position based on concepts found in the relational phenomenology of sociality. The paper also presented research findings about the meaning of personhood from the perspectives of family members and allies of individuals with profound and multiple learning disabilities. In this section, we bring together these different strands, and demonstrate how accounts of personhood held by family members and allies' complement and extend relational phenomenological theory, and offer new resources for challenging dominant narratives about who (or what) a person is.

4.1 | Pluralities of Dependencies

Dominant approaches to thinking about personhood fundamentally define a person as an individual that possesses certain attributes (typically, cognitive capacities such as memory, a sense of self over time, and the ability to demonstrate this) (DeGrazia 2005). Debate about what a person is revolves around determining the nature and combination of such attributes, before running thought experiments to 'test' the extent to which something can be classed a person (e.g., a pig, a foetus, a child with profound and multiple learning disabilities) (McMahan 2002; Singer 2010).

Drawing on Loidolt's (2016, 2018) exegesis of Arendt's work, we discovered an alternative way of thinking about personhood. Rather than debating individual cognitive capacity, Arendt side-steps this issue by focusing on 'plurality', which is the non-thematic or implicit experience of other people and their unique first-person perspectives. Arendt starts from this intersubjective predisposition and explores not what we are (our essential qualities) but the conditions that shape how we appear before others and how we can be experienced as a person. In other words, Arendt decentres the individual and examines the social event which leads to the appearance of self and others.

The accounts given by interviewees resonate with Arendt's philosophy, as participants typically described personhood in relational terms and drew attention to how we are all co-dependent beings who rely on others in varying degrees to ensure that needs are met. Who we are as people was said to be heavily shaped by others, by the people we interact with, the relationships we enter in to, and the opportunities for growth and development that social life affords us. This was seen as a two-way process, and individuals with profound and multiple learning disabilities were described as enriching and positively contributing to the lives of others. Being a person was also described in terms of being part of a community more broadly and being afforded opportunities to take part in cultural traditions. These perspectives are missing from traditional accounts of personhood as they relate to individuals with profound and multiple learning disabilities.

Interviewees' descriptions of what it means to be a person complement the work of Loidolt (2016, 2018) and Arendt insofar as they challenge accounts of personhood which equate being a person with an individual's rationality. Interviewees found this definition of personhood incredulous, but rather than debating what constituted individual capacity, they side-stepped the issue and focused on what existed *between* individuals. In other words, interviewees described an ontology of personhood that highlighted connections, with the focus of discussion being the plural in both a numerical sense (personhood is not $n = 1$, it cannot exist without a community) and in the experiential sense (the personhood of individuals with profound and multiple learning disabilities appeared to others, non-inferentially, it appeared because individuals with profound and multiple learning disabilities affected those around them and mattered to family members, friends and allies). These accounts provide support to the eclectic literature on relational accounts of personhood discussed earlier in the paper (e.g., Gunkel and Wales 2021; Reinder 2008; Splitter 2015) by suggesting that being a person involved more than an individual's capacity for rational thought, but was something enacted with and through culture and community.

4.2 | Conditions for the Appearance of Personhood

Interviewees conferred personhood on individuals with profound and multiple learning disabilities non-inferentially and without question by virtue of the relationships they had to such individuals, and the impact that these individuals had on the lives of those around them. Furthermore, some interviewees differentiated between 'knowing that' somebody is a person and 'knowing who' a person is, and these findings lend support to Arendt's philosophy (Loidolt 2016, 2018). According to Arendt, knowledge about who somebody is must be 'actualised' or brought into being by creating a 'space of appearance' which allows the 'who' to be seen (Loidolt 2018, p. 52). The 'who' cannot be discovered through analysis of traditional personhood criteria, and it cannot appear via abstract reflection or 'armchair philosophy', since who we are is not limited to rationality. Interviewees described how the 'who' requires that we enter the personal space of individuals with profound and multiple learning disabilities and engage with them on their own terms. It requires a 'direct connection' through a 'two-way interaction', spending time with individuals with profound and multiple learning disabilities during their day-to-day routines, learning to listen by discovering their language (their individualised communication abilities), and developing insights from family members, carers and friends.

4.3 | Creating New Narratives About Personhood

One of the most striking features of the interviews was not a new definition of personhood, but a new strategy for engaging with the personhood debate. Interviewees provided a masterclass in creating narratives about individuals with profound and multiple learning disabilities in a way that helped reveal something about who, rather than what, individuals with profound and multiple learning disabilities are. Interviewees told stories, showed photographs, sent videos, read poems, described deeply personal life events, and shared innermost thoughts and feelings. What emerged from this was a multimodal collection of biographies that deeply affected the researchers. Far from being objective, the researchers laughed with parents when they told stories, shed a tear during conversations of dying, and felt frustrated when the interviewees recalled the challenges individuals with profound and multiple learning disabilities face. Arendt (1998) notes that social interaction creates stories, it produces a narrative about an individual, though the individual is never the author. These stories are told by others who encounter the individual, they are like a biproduct of appearance, a 'surplus', a 'worldly intersubjective event' (Loidolt 2016, p. 49), they are what is left behind when an encounter is over.

Literature about individuals with profound and multiple learning disabilities can appear overwhelmingly negative. It positions individuals with profound and multiple learning disabilities as lacking in rudimentary cognitive abilities and this creates problems when personhood literature defines being a person in terms of such abilities. Furthermore, the personhood literature such as narrative identity theory places the onus on the individual with profound and multiple learning disabilities to tell their own stories (DeGrazia 2005) as a precondition to be considered a person. Arendt's philosophy combined with the insights offered by interviewees offers a reconfiguration of the personhood debate. It provides us with potential tools for thinking about how we can generate new, positive, stories about individuals with profound and multiple learning disabilities, whereby their moral status can be reinstated, not as pre-persons or non-persons, but as people who matter to loved ones.

5 | Conclusion

This paper presents the views of family members and allies of individuals with profound and multiple learning disabilities on the personhood debate. Whilst individuals with profound and multiple learning disabilities are sometimes at the centre of such debate, those closest to them are rarely invited to contribute their expertise on the topic. Given what is at stake here, it is reprehensible that the people who have the greatest knowledge about individuals with profound and multiple learning disabilities have been overlooked, which in turn leads to questions about whose best interests are being served during debate. This paper gives a platform to people who had something important to say about the debate—that the individuals they love, and support are, in fact, people, and that personhood for individuals with profound and multiple learning disabilities should be thought of more in terms of relational complexity than rational capacity. This involves focusing on 'who' rather than 'what' individuals with profound and multiple learning disabilities are. We also discovered methodological insights in terms of interviewees' preferred mode for talking about personhood was through personal stories which were supplemented with text, photographs, videos and other materials. However, despite the passionate stories being told, following

Kittay (2005, 2010) and the interviewees in our study, we must also practice epistemological modesty. We have not asked individuals with profound and multiple learning disabilities what their views on the topic are, or even begun to identify how we can best include this group in research about personhood. Furthermore, our interviewees are small in number and our findings are not generalisable. However, they do provide a counter-narrative to traditional philosophical literature regarding moral individualism. We hope that other researchers provide space for more members of the profound and multiple learning disabilities community to come forward and speak out about this issue.

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Ethics Statement

The research ethics approval was granted by the School of Education Research Ethics Committee at Bath Spa University, UK.

Consent

There are no patients in our study. All participants gave informed consent.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The authors have nothing to report.

Endnotes

[1] Our firmly held position is that individuals with profound and multiple learning disabilities are people. However, in this paper we use the term ‘individuals’ with profound and multiple learning disabilities for clarity of expression.

[2] While we do not support such hostile terminology or negative comparisons associated with profound and multiple learning disabilities, we include these examples as a means of drawing attention to problematic societal discourse.

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