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What does it mean to be a 'person' with profound and multiple learning disabilities? Interviews with family members and allies

Ben Simmons and Stuart Reed

This article presents the findings of a project that explored what it means to be a person. It shares insights drawn from family members and allies of people with profound and multiple learning disabilities (PMLD), and challenges philosophical approaches to personhood that define a person primarily in terms of cognitive capacities.

Introduction

What does it mean to be a 'person'? Is a person simply a human being? Can there be non-human persons, and humans who are non-persons? When does a person begin and end? How should persons be treated, and who gets to decide?

On the surface, questions such as these seem benign and overly abstract – they are found in academic textbooks and debated on university courses by philosophers who rely on 'thought experiments', or hypothetical situations analysed through logic and debate. However, the answers to these questions and their implications are profound. They are linked to religious, medical, and legal discourse and can impact life. These kinds of questions are found in debates about abortions, animal rights, the treatment of prisoners, and a range of other major issues (Read, Simmons and Parfitt 2023).

Questions about what it means to be a person are hugely important for those with PMLD. People with PMLD are sometimes defined in the literature as non-persons. This is because a Western, individualist rational model of personhood still dominates debate. According to this model, being a person requires advanced cognitive ability, communication skills, memory and agency (DeGrazia 2005, McMahan 2010). This model has met with resistance, and some philosophers, most noticeably Eva Kittay (2005), have argued that our social relationships are far more important than our cognitive abilities, and it is these relationships that give us status as a person.

This paper contributes to debates about the meaning of personhood. However, rather than using philosophical reasoning we present the views of family members and allies of people with PMLD. It is our view that family members and allies have a wealth of insight about what it means to be a person with PMLD, but they are rarely consulted in the personhood debate. Our project begins to address this.

Methodology

We interviewed 10 people in July 2023 using an unstructured approach. We interviewed 6 parents, 1 sibling, and 3 allies with significant experience in working with people with PMLD. The interviews were unstructured and lasted between 45 minutes and 2 ½ hours. The participants included artists, academics, a doctor, communication and technology consultants, a support worker, and a charity worker. We analysed the main themes and presented these (and this paper) to interviewees for approval.

Findings: Human genes, hierarchies, and the tricky topic of animals

Family members and allies who participated in our project discussed the relationship between humans and animals. Participants debated whether human beings were a special kind of animal, and the extent to which being a person presupposed being human. The majority of participants felt that genetics played an important part in classifying somebody as a person. Participants used terms such as 'natural hierarchy' or 'evolutionary hierarchy' and stated that human beings occupied the top of the hierarchy, with all other living creatures existing beneath humans. This hierarchy was sometimes linked to moral values – only human beings can be classified as people, and because of this status, humans should be treated better than animals.

Unfortunately, some participants felt that individuals with PMLD were not always recognised as having a higher value than animals. For example, the parents we interviewed described feeling upset, frustrated and offended at people who reduced their children to animals, e.g., by comparing their cognitive abilities and actions to family pets:

So, my in-laws have a dog, and he is a lovely, lovely dog. [...] It drives me nuts that they are comparing their dog to my child. I can see that Harry is a lovely cockapoo...but that comparison really gets to me every time they do it. ... [my daughter's] behaviour sometimes gets compared to the dog.

Furthermore, some parents described their children as being treated worse than animals, such as receiving less attention than pets:

[...] when you're walking down the street, I'm with [my son] and my husband and with my other child and everyone gets a hello, but [my son] doesn't get a hello. I find it so horrible to do that, because he might not answer hello. People say hello to a dog, to a cat, and they don't do that to [my son] and he is very happy to smile back to a person that says hello.

Not everyone agreed on the special nature of being human, and some interviewees suggested moving away from the human-animal distinction towards exploring commonalities:

There is some sort of hierarchy whereby if I equate a person to a dog or, you know, a cat or something that that is monstrously offensive because I've traversed this huge gap that there is supposed to be between us. But if what we're saying is that this cat feels this person, this person feels, and they are equivalent, I don't know what that monstrous gap is made out of other than a, sort of, prejudice against the animal kingdom. I don't know how offensive it is to be equated to an animal.

Similarly, one sibling suggested there was more to being a person than genetics or human morphology, and that relationships should be foregrounded in the debate about what a person is:

[...] you're a person because you take on a human kind of form but actually your interactions may be quite similar to an animal [...] there are people where they would probably relate their relationships with their pets, with their dogs, with their cats as a very similar to a human relationship but they wouldn't say that their dog is a person but is that just because they don't inhabit a person form? If suddenly the dog was a person would that relationship be like that? What they're getting from that is a similar kind of thing isn't it?

Relational Personhood

All participants felt that definitions of personhood should extend beyond the cognitive abilities of an individual to include a social or 'relational' component. Being a person meant being in a relationship with somebody, such as being somebody's parent or sibling, being a student or a teacher, and being a friend. Being a person also meant being part of community such as church community or school community, and it also included being part of a culture:

A person to me is a being who's part of a

community, whether that's a community based on your identity, your locality, even part of a family [...] being part of a collective where you have shared beliefs, values, understandings, traditions, norms [...].

Belonging to a community was seen as transformative – personhood was said to develop and grow in relation to other people, as one parent said: "I like more the idea that no man is an island, that thing that you are a product of your relationships". An individual's personhood is therefore not fixed but dynamic, it is something that grows and develops throughout life:

It's completely dependent on who you interact with, where you interact, what your experiences are, and that develops you throughout your life and that means your personhood, I guess, can change throughout your life. So yeah, it's part of a collective, part of a community and that's what makes you a person and a human being.

Whilst relationships and communities were described as being central to the formation of a person, they were also seen as the means by which personhood could be taken away. Parents recalled a range of negative life events (e.g., their children being mocked in public, not being treated with dignity in hospital, and facing barriers accessing everyday services such as parks, schools and shops). Such events were sometimes described as stripping back the personhood of an individual, or what one parent described as a "willful diminishing of someone's personhood". Conversations around denying personhood included reflections about individuals who are hidden from sight, with limited opportunities to experience the world: "Where does that put someone who has lived and has always lived in an institution and who has PMLD?"

A different way of understanding relational personhood was through discussion of shared needs:

[...] if someone has needs, they are a person. 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. Different people need different amounts of love to be able to survive, different people need different amounts of help with eating, we all need to eat, we all need to wash, we all need to dress, we all need to communicate, we all need to survive [...]

[...] personhood means for her having all of those things working around her to mean that she can be the best that she is. If she's got good care, good support, good understanding, good guidelines, good structure, good stuff in her life, she's going to have the best life.

Relational personhood was described in terms of ‘impact’ – how one person can transform the lives of others. Participants discussed the myriad of ways that people with PMLD enriched other’s lives, such as spreading happiness and joy, teaching others to “how best to be in the moment and value simple things”, helping others focus on sensory experiences, such as appreciating the light and warmth of the sun, “to see the world differently” and “to laugh at things that I wouldn’t normally laugh at”, to learn about “very individual forms of communication” and ‘learn [...] to care more about other people’.

Finally, social interaction was seen as an important way of discovering the depths of personhood of people with PMLD. Parents were critical of university academics who wrote about personhood without ever meeting people with PMLD. Personhood was said to be revealed through ‘two-way interaction’, through ‘a physical relationship’ that leads to ‘a connection’ and discovery of the depths of an individual’s personhood. Armchair philosophers who write about people with PMLD without meeting people with PMLD were said to write from an uninformed perspective, and questions were raised about the purpose of such philosophy.

“Who” not “What”

As discussed above, philosophers who debate the meaning of ‘personhood’ have attempted to develop criteria which can be used to judge whether somebody can be classified as a ‘person’. In a nutshell, these academic debates are essentially about ‘what’ a person is. The findings presented above describe parents’ views about what constitutes a person, and these views challenge the dominant narrative that reduce personhood to an individual’s cognitive capacity. Being a person means being part of a community, having an impact on others, being treated as a person, and recognising the importance of affect and emotions. These all point toward an affective and relational account of personhood. However, a central theme that emerged during interviews was not about ‘what’ people are, but ‘who’ they are, and this switch in focus raises questions about the value of debating criteria.

The researchers were given a personhood masterclass by participants. Participants created conditions for discussing the lives of people with PMLD, which included sending photographs, video clips, poems, short stories, published literature, interacting with children with PMLD live on camera, and telling evocative stories that resulted in a range of emotions, including laughter and tears. This richness of the lives of people with PMLD is overlooked by the cold logic of philosophy where criteria is developed through detached thought experiments.

Concluding comments

This article presents a rich view of what it means to be a person with PMLD. It suggests that researchers and philosophers must work more closely with people with PMLD, families and allies to co-produce a counter narrative to the dominant cognitivist view, a narrative that is anchored in the lived realities of people with PMLD to ensure that debates are more inclusive of those who are talked about, but rarely consulted.

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