



Read, S., Simmons, B. and Parfitt, A. (2023) 'Creating authentic and positive stories about personhood for people with profound and multiple learning disabilities: a call for reader expressions of interest', *PMLD Link*, 35.1 (104), pp. 37-38.

This is a copy of the final version of an article published in *PMLD Link* (ISSN 2042-5619) in May 2023 reproduced with permission from the publisher. For more information about this publication please go to <https://www.pmlmlink.org.uk/>.

ResearchSPAce

<https://researchspace.bathspa.ac.uk/>

This published version is made available in accordance with publisher policies.

Please cite only the published version using the reference above.

Your access and use of this document is based on your acceptance of the ResearchSPAce Metadata and Data Policies, as well as applicable law:-

<https://researchspace.bathspa.ac.uk/policies.html>

Unless you accept the terms of these Policies in full, you do not have permission to download this document.

This cover sheet may not be removed from the document.

Please scroll down to view the document.

Creating authentic and positive stories about personhood for people with profound and multiple learning disabilities: a call for reader expressions of interest

Stuart Read, Ben Simmons and Anne Parfitt

This paper introduces the controversial concept of ‘personhood’ as it relates to people with profound and multiple learning disabilities (PMLD). Traditional narratives of ‘PMLD’, combined with dominant accounts of what it means to be a person, can lead to people with PMLD being identified as ‘non-persons’. We are concerned that framing people with PMLD as non-persons contributes to the perpetuation of existing inequalities that this group experiences. We are interested in changing this narrative in ways that allow authentic and positive stories of personhood for people with PMLD to be generated and shared. In closing this paper, we introduce our new research in this field, and welcome readers to contact us if they are interested in getting involved.

What is personhood?

The terms ‘person’ and ‘human’ are sometimes used synonymously in everyday discourse. However, in legal, medical, theological, and philosophical texts, the terms can have different meanings. For example, the term ‘human’ is sometimes used as a biological designation and refers to those who belong to the species ‘Homo sapiens’ (University of Missouri, School of Medicine, 2023). By contrast, the term ‘person’ is sometimes used to refer to individuals who are deemed to meet certain measures of conscious awareness and cognition (e.g. being a person presupposes an individual’s ability to move with intent, communicate and make moral decisions) (DeGrazia 2005). In fields as diverse as artificial intelligence and zoology there are debates about whether personhood is something that is solely the preserve of living, conscious and cognitively-competent human beings, or whether other mammals such as primates, or non-biological machines, such as sophisticated computers, can also be considered ‘people’. Similarly, there are ongoing debates about when personhood begins and ends. For example, people who are professionally medically trained are likely to have different answers than religious leaders about what happens before birth and after death.

How does the personhood debate relate to individuals with PMLD?

Debates about personhood sometimes focus on individuals with neurological impairments, particularly if those impairments are persistent and severe. These debates can upset people as they involve questioning the status of loved ones. Such debates

extend to a consideration of who should be protected in our society, and how and when such protection should be introduced or taken away. High profile examples of personhood debates include campaigns around abortion laws, and court cases about when children should be taken off life support machines.

In our review of the personhood literature, we have identified problems with narrow definitions of both ‘personhood’ and ‘PMLD’, which leads to a difficult suggestion that individuals with PMLD may lack personhood (Simmons and Watson 2014a). To be specific, dominant accounts of personhood in Western philosophy require individuals to display a set of cognitive competencies in order to be classed as fully-fledged people (e.g. Kittay, 2009). Whilst the exact mix of competencies is contested, philosophers have suggested that personhood requires rationality, agency, linguistic communication skills, and a sense of self over time (DeGrazia 2005). However, children with PMLD are described in psychological and educational literature as experiencing congenital neurodevelopmental impairments and are said to ‘function’ at the earliest, preverbal stages of development. For example, children with PMLD are described as being pre-agentive, pre-linguistic and pre-intersubjective (Simmons and Watson 2014b). The dominant individualistic, competence-based view of personhood, combined with developmental descriptors of ‘PMLD’, precludes children with PMLD from being classed as ‘people’ (Kittay, 2009). It is this tension that we want to examine and challenge through our work.

Why are personhood debates important for people with PMLD?

Discussions regarding what constitutes personhood are important, as interpretations determine who is and is not viewed as a complete person. While discussion of personhood in relation to people with PMLD may seem contentious and extreme, we have previously argued that denial of personhood contributes to the disadvantage and discrimination that people with PMLD and their families experience (Simmons and Watson, 2014a). For instance, the Coronavirus pandemic has revealed the stark inequalities experienced in myriad ways by disabled people due to this population being perceived as 'less than human' (Read et al., 2023, p. 40). Considering people with learning disabilities, evidence has revealed how this group are much more likely to experience mortality due to COVID-19 (Williamson et al., 2021), and how people with learning disabilities have been given 'do not resuscitate' orders despite not requiring end of life care (Care Quality Commission, 2021). These findings add to the existing body of literature which documents health inequalities that people with learning disabilities may face, which may in turn impact on perceptions of personhood. For instance, Tuffrey-Wijne et al. (2013) explored the barriers that people with learning disabilities may face when accessing healthcare, such as delays in receiving treatment. Research has also demonstrated how such barriers may contribute to people with learning disabilities experiencing premature mortality (Heslop et al., 2013, 2014).

What can we do about it? Expressions of interest for our proposed project

Throughout spring and summer 2023 we will be running a project with parents/carers of people with PMLD, as well as allies/professionals who support people with PMLD. For this project, we plan on hosting a series of focus group-style workshops and/or individual interviews in which participants will be asked to discuss what personhood means for people with PMLD. Participants will also be asked to share their thoughts on how authentic narratives of personhood for people with PMLD can be shared with policy makers and professionals. We would welcome anyone who is potentially interested in being part of this research to contact us.

Contact details

The authors are at the School of Education, Bath Spa University
 Dr Stuart Read, Research Fellow.
 Email: s.read@bathspa.ac.uk
 Dr Ben Simmons, Reader in Inclusive Education and Disability Research.
 Email: b.simmons@bathspa.ac.uk
 Dr Anne Parfitt, Research Fellow.
 Email: a.parfitt@bathspa.ac.uk

References

- Care Quality Commission (2021). *Protect, respect, connect—decisions about living and dying well during COVID-19*. <https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-%E2%80%93decisions-about-living-dying-well-during-covid-19>.
- DeGrazia, D. (2005). *Human identity and bioethics*. Cambridge University Press.
- Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., and Russ, L. (2013). The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report. University of Bristol, Bristol, UK.
- Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., and Russ, L. (2014). The Confidential inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *The Lancet*, 383(9920), 889-895.
- Kittay, E. F. (2009). The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy*, 40(3-4), 606-627.
- Read, S., Parfitt, A., Bush, T., Simmons, B., and Levinson, M. (2023). Disabled people's experiences of the coronavirus pandemic: A call to action for social change. *Social Inclusion*, 11(1), 38-47.
- Simmons, B., & Watson, D. (2014a). Challenging the developmental reductionism of 'profound and multiple learning disabilities' through academic innovation. *PMLD Link*, 26(3), 25-27.
- Simmons, B. & Watson, D. (2014b). *The PMLD ambiguity: Articulating the life-worlds of children with profound and multiple learning disabilities*. Karnac.
- Tuffrey-Wijne, I., Giatras, N., Goulding, L., Abraham, E., Fenwick, L., Edwards, C., and Hollins, S. (2013). Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: A mixed-methods study. *Health Services and Delivery Research*, 1(13). <https://doi.org/10.3310/hsdr01130>.
- Williamson, E. J., et al. (2021). Risks of covid-19 hospital admission and death for people with learning disability: Population based cohort study using the OpenSAFELY platform. *British Medical Journal*, 374, n1592. <https://doi.org/10.1136/bmj.n1592>.
- University of Missouri. (2023). *Concepts of personhood*. Published online. Accessed 24.02.2023: <https://medicine.missouri.edu/centers-institutes-labs/health-ethics/faq/personhood>