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Challenging the developmental reductionism of 'profound and multiple learning disabilities' through academic innovation

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Abstract

In this paper we show how developmental definitions of 'PMLD' in the academic literature can reduce children with PMLD to the status of 'non-persons'. We highlight some of the innovative dimensions of our work which challenge this status quo. These include the application of new theory and research methodology, and our studies of the social interaction of children with PMLD. We argue that these aspects of our research help reinstate the value of children with PMLD in the academic literature and arguably have important practice implications. However, we conclude that much more work is needed in our fight against the exclusion and degradation that some children with PMLD face.

Part 1: Developmental definitions of 'PMLD' and the classification of non-persons

- **Developmental definitions of PMLD**

Within the research literature, children with PMLD are typically understood as experiencing global developmental delay. The abilities of such children are often compared to those of the infant insofar as children with PMLD are described as being at the preverbal stage of development (i.e. the earliest stage of development which ends about a year after birth). A range of descriptors are used in the PMLD literature to indicate that some children fail to reach developmental milestones associated with later infancy. For example, children with PMLD have been described as being pre-volitional (they lack the ability to move) (Farrell, 2004); pre-contingency aware (they do not show awareness of cause-effect relationships) (Ware, 2003); and pre-symbolic (they do not intentionally communicate meaning to others) (Coupe O'Kane and Goldbart, 1998).

In our view, describing children with PMLD primarily in terms of developmental deficits dehumanises them and potentially leads to their exclusion and degradation. Whilst this may sound dramatic and controversial to some readers, we wish to give context to our view by drawing on two contemporary areas of research: debates in bioethics about what it means to be a person, and the findings of the *Confidential Inquiry* (Heslop et al., 2013) into the premature deaths of people with learning disabilities.

- **Personhood, non-persons, and the right to life**

The current developmental definitions of children with PMLD lead to questions about the extent to which these children demonstrate ‘personhood’. In the field of bioethics, personhood is used as a measure to determine who counts as a person (and who - or rather, *what* - counts as a ‘non-person’). According to the philosopher, David DeGrazia (2005), the term ‘person’ refers to “*beings with the capacity for certain complex forms of consciousness*” (p. 3, *original italics*). He continues:

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 certainly beings with the capacity for complex forms of consciousness, for they are psychologically complex, highly social, linguistically competent, and richly self-aware (ibid.).

Do children with PMLD enjoy the ‘complex forms of consciousness’ that DeGrazia refers to? If the developmental definitions of ‘PMLD’ are to be believed, then no. Children with PMLD have not progressed beyond the pre-verbal stage of development hence they are not ‘linguistically competent’ (they cannot speak to tell us their stories). They are not ‘highly social’ in the sense that they are described as lacking the capacity to communicate with intent. Nor are they ‘richly self-aware’ since this involves learning how other people perceive us (they are without intersubjectivity).

- **The importance of personhood**

The debate about the definition of personhood is important because it relates to the value of life, and impacts upon the distribution of rights and entitlements. For example, recent high-profile reports have documented the health inequalities that people with learning disabilities face in NHS care which undermine the right to life. It is estimated that 1,238 children and adults with learning disabilities die preventable deaths each year in NHS care (Glover & Emerson, 2013). Furthermore, the more severe an individual’s learning disabilities, the more likely they are to die a preventable death because of a lack of appropriate healthcare (Heslop et al., 2013). Given the situation, it is not unreasonable to suggest that the prejudice children and adults with PMLD face stems from the view that some are not identified as being people at all.

Part 2: Innovation - addressing dimensions of personhood in our work

In this section we outline three aspects of our work (Simmons and Watson, 2014) which contribute to understandings of the ‘personhood’ of children with PMLD. This includes the application of philosophy to develop insights about ‘self-awareness’, the development of research methodology which shows ‘voice’ is not the same as ‘linguistic competence’, and on-going research about the sociability of children with PMLD.

- **Phenomenology: towards a theory of ‘self-awareness’**

Following dissatisfaction with developmental definitions of children with PMLD, we began to enrich our understandings of personhood by reading the phenomenology of Maurice Merleau-Ponty. Phenomenology is the study of the structure of experience, and Merleau-Ponty’s (2002) work explores the role of the body in that experience. An important concept for Merleau-Ponty is the idea of the “corporeal schema” (p. 164) or ‘body schema’. The body schema is our experience of the body that emerges through interaction with the world. When we normally think about our bodily experiences we tend to think of our body image (i.e. what our body looks like to us and other people). In contrast, the body schema is more of an intuitive feel that we get from our bodies. The philosopher Evan Thompson (2007) gives an example:

...not only do we feel the things we touch, but we feel ourselves touching them and touched by them. When I pick up a cup of hot tea, I feel the hot, smooth surface of the porcelain and the heat penetrating my fingers, and these sensations linger for a time after I have put the cup back down on the table (p. 250).

As the above quote suggests, the body schema is the experience of our embodiment, and this can emerge in action (e.g. picking up a cup of tea). We are aware of being hot or cold, but we are also aware of our body’s position and movement, and whether and which parts of the body are being touched. This awareness is instant – if we stump our toe we know that we are in pain, and we know where it hurts without having to think about it.

What does this mean for children with PMLD? It means that children with PMLD may have an embodied sense of self that is yet to be explored through research. There is little published work about how children with PMLD experience themselves in relation to the world, and what experiences they find meaningful in relation to their body and the actions they perform. It also leads to an important (and unanswered) question: If children with PMLD experience themselves through their interactions with the environment, then to what extent do opportunities to interact with *different* environments lead children to learn more about themselves?

- **Richly interpretivist methodology: having a ‘voice’ without being ‘linguistically competent’**

Another area of our work focuses on the development of research methodology which illuminates the meaning of children’s actions. Our approach relies on researchers working with children with PMLD in real-world contexts, utilising the knowledge and expertise of others who know the child well. This demands time and resources as well as a great deal of skill and capability to ‘see’ the child from the perspectives of others. We strongly believe ‘voice’ does not simply mean ‘speaking’ (‘linguistic competence’). Instead, voice can mean children’s preferences, opinions, and agency expressed over time and across contexts. This is at the core of our approach described below.

Our approach is comprised of three methods. First, the researcher runs focus groups with family members and professionals in order to determine how a child acts and the meaning people ascribe to those actions. This provides an initial ‘lens’ which guides the researcher’s interpretations of the child. Second, the researcher engages in a period of ‘participatory observation’. This involves the

researcher learning about the child by supporting him/her during their daily routines (perhaps by acting as a teaching assistant or support worker). During this time, the researcher engages in reflective conversations with other members of staff about his/her interpretations of the child. Finally, the researcher engages in 'non-participatory observation' in order to write 'vignettes'. Vignettes are the main source of data. They have a narrative, story-like structure that preserves chronological flow and offer a vivid portrayal of the events in everyday life. The aim is to write vignettes 'live and in the moment', making detailed descriptions of children's interactions. These vignettes are shared with others (parents and professionals close to the child) and the interpretation of the vignettes negotiated.

- **Exploring the sociability of children with PMLD**

Finally, we are involved in research which explores the social engagement of children with PMLD using the above methodology. We are investigating how different educational environments (mainstream and special) afford children with PMLD opportunities for social interaction, and how children with PMLD respond to these opportunities to interact. This research began with the first author's PhD work (Ben Simmons). During the research, Ben observed an eight year old boy with PMLD called 'Sam' one day a week in a mainstream school and one a day a week in a special school over an academic year. The research found that Sam eagerly engaged with his mainstream school peers, experienced opportunities to express his social awareness, and both acquired and rehearsed his communication skills. For example, in his mainstream school Sam participated in affective playful exchanges with others which were characterised by mimicking and turn-taking. He learned to initiate social interaction by stroking or tapping children's arms, and near the end of the project he used this strategy to initiate interaction with his special school peers. We consider Sam to be 'highly social' given the findings. Whilst the research involved only one boy, it does raise questions about whether it is appropriate to automatically assume all children with PMLD lack social awareness and intentional forms of communication. It also suggests the need to provide children with PMLD with diverse contexts so they can demonstrate and express their abilities.

We are currently extending our research with funding from the British Academy to explore how children of different ages (pre-school to post-16) engage with different school environments and will report the findings in due course.

Conclusion

In this paper we have argued that developmental definitions of 'PMLD' can reduce children with PMLD to the status of 'non-persons' We have highlighted how aspects of our academic work address the situation in relation to the concepts of 'self-awareness', 'linguistic competence', and 'sociability'. Whilst we feel that our work is innovative, we recognise that there is a long way to go before children with PMLD will be fully accepted as 'people' in their own right. We call on readers to take up the debate about what it means to be a person, and to continue to challenge the developmental reductionism of the label 'PMLD'.

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