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# A call to action for conducting research with people with profound and multiple learning disabilities

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People with profound and multiple learning disabilities (PMLD) are marginalised in society. This marginalisation extends to research, and people with PMLD are often the 'subjects' of university studies. This means that research is often done 'on' people with PMLD rather than 'with' them and with those involved in their care. In this article we describe our vision for a new research agenda. We are developing a research network run by disabled people, for disabled people. We want to explore how people with PMLD and their families/carers/allies can be involved in conducting research that matters to them.

## **Current climate: People with PMLD participating in society and research**

**R**esearch can play an important role in identifying the experiences and potential challenges that people with PMLD and their families/carers/allies face. Research is a tool that can help people document their lives, legitimise their experience, and 'evidence' the reality of their day-to-day living. It can be used to challenge 'expert opinion', influence policy makers, and shape services for people with PMLD and those who support them.

Unfortunately, whilst there is a plethora of research 'on' people with PMLD, it often fails to have a positive impact. By this we mean that it rarely leads to large-scale, beneficial change. Researchers are good at identifying some of the problems that people with PMLD face. For example, through research we know that disabled people experience significant health inequalities compared to non-disabled people (Emerson & Hatton, 2014). We also know that people with PMLD have a higher mortality rate than the rest of the population (Mansell, 2010), and the more profound a person's learning impairment, the more likely they are to die from a premature or avoidable death (Heslop et al., 2014). Researchers have highlighted that the Coronavirus pandemic has led to increased social isolation for people with learning disabilities, and families have reported that people with PMLD have lost confidence, communication skills and life skills, and there is a fear that this loss could be permanent or require extensive additional support to rectify (Maguire & Gillooly, 2021). These studies show that researchers can identify major problems. However, it is not always clear what the solutions could be, or how these solutions should be put into action. The authors of the PMLD Standards have (quite rightly) been vocal about this and criticised policy makers for failing to identify and act upon the specific support needs of people with PMLD (Doukas et al., 2017).

Whilst we agree that policy makers must recognise the

unique needs of people with PMLD, our contention is that the meaning and practice of 'research', and the identification of who can be counted as a 'researcher', has historically marginalised people with PMLD and those who support them. Those who have the most to benefit from research are not typically involved in the identification of problems and solutions. They are not involved in designing and running the research, nor in suggesting or influencing social change. In other words, whilst people with PMLD are the 'subjects' (and sometimes 'objects') of research, they are not equal partners and it is possible, perhaps probable, that researchers are not always serving the best interests of participants. In fact, even in radical fields such as Disability Studies, people with PMLD are largely excluded from the research process and their voices are rarely acknowledged, as Vehmas and Miettola (2021:7) note: individuals with PMLD 'are virtually missing from key theoretical and methodological discussions, as well as from empirical studies in the field'. Certain impairment groups are privileged in disability research, such as those who are linguistically strong. This leads to people with PMLD remaining on the margins of disability research and activism.

The problem being identified here is not new. In fact, some readers are likely to recognise the issues we describe in this paper. There have been on-going calls for 'emancipatory', 'participatory', and 'inclusive' research for nearly thirty years (Nind, 2014; Oliver, 1992; Warwick-Booth et al., 2021). However, to date, these calls have not succeeded in developing equitable ways of working with people with PMLD, and it is this that we want to address. If genuine change for people with PMLD is to occur, universities must find ways of working together with people with PMLD as well as their families/carers/allies. We must take research out of the ivory towers of academia and ground it in the communities who have an urgent need for change. This requires us to reimagine what research is, and who can be researchers, and we

hope to explore this in the near future through our new research programme.

### Wellcome Trust-funded research programme

**W**e at Bath Spa University have recently begun a five-year research programme funded by the Wellcome Trust, worth over £1 million. For this research programme, we aim to create a disability activist-led research network and community for South West England. Our rationale for this programme is that our research network will allow local disabled people and disability allies to co-produce and run research projects on topics that matter to them. By 'co-produce', we mean that disabled people (including people with PMLD and their allies) will work in partnership with academic researchers at every stage of our research programme. For example, people with PMLD and their allies will help develop important research questions that matter to them, create new and inclusive research methodologies, analyse data, and develop outputs to present their work. We hope that by creating the research network for South West England, four main benefits will emerge:

1. People with PMLD and their families/carers/allies will be able to share their activist voices and experiences in ways that matter to them.
2. Policy makers, and local and national organisations, will become aware of the issues that matter to people with PMLD in South West England.
3. We want to show how research with people with PMLD and their allies can be conducted inclusively and collaboratively between organisations and universities.
4. We want to foster a culture of sharing between different disability and non-disability groups, so that finite resources, such as finance and knowledge can be used to benefit the entire region.

### How you can help us

**F**or the first phase of our research programme, we are interested in networking with as many organisations and allies specialising in PMLD as possible. Later on in the programme, we will be creating local research hubs in the South West, so that disabled people and their allies can discuss topics that affect their specific town, city or region. We will also create an advisory panel of disabled people and allies to help us oversee the research hubs, and to decide the direction of the programme. There will also be opportunities for disabled people to complete their own research, and demonstrate their work at public events, such as art exhibitions. Finally, we hope to create an inclusive training programme designed and led by disabled people on topics that are important to them. There are numerous ways that you can help us in our programme, and you can choose to participate in whichever ways are accessible for you. If you are interested in being involved and sharing your stories, please feel free to contact us, and we can discuss your

ideas with you. For instance, if you are based within South West England, you are welcome to join one of our regional research hubs as they develop over the forthcoming months. We will also have research equipment, such as video cameras, which you will be able to request from us.

### Concluding comments

**T**hrough this research programme, we are trying to fundamentally change how universities and other organisations engage with people with PMLD. We hope that our research programme will become an exemplar of how to work inclusively with all disabled people and allies. The programme we are proposing is radical, both in purpose and in scope, but we hope that colleagues reading our paper can appreciate our vision and support us going forward.

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