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## **Creating a resource that captures the social histories and lived experiences of the PMLD community: which stories should be collected and shared, and how?**

**Ben Simmons, Becky Churchill and Katie Crouch**

In this short article we introduce a new project that aims to develop a resource that shares the stories of the PMLD community. By 'PMLD community' we mean people with profound and multiple learning disabilities (PMLD), their loved ones such as family and friends, and those who regularly support people with PMLD, including day centre staff and paid carers. Our project involves working with the PMLD community to identify what stories they would like to share, with whom, and how. We will then work with the community to co-create a resource and share this with readers of PMLD Link in a future issue.

### **Background**

Our project began with an exploratory phase that investigated the research priorities of the PMLD community (i.e. the topics that the PMLD community wants more research on). We put out calls in PMLD Link asking for reader's suggestions (e.g. Read, Simmons and Parfitt, 2023; Simmons, Read, Parfitt and Bush, 2022; Read, Simmons, Levinson and Bush, 2021), presented our work at conferences and asked people to feedback, and also contacted families and services in South West England asking for their suggestions. The exploratory phase generated a range of potential projects such as research to improve the public's awareness of people with PMLD, research to improve social workers and doctors' knowledge of the communication needs of people with PMLD, and research that can improve the accessibility of cultural spaces such as museums.

Instead of choosing one topic ourselves, we shared our findings with an advisory group (or what we call a 'working group') consisting of family members and day centre staff. Whilst all the themes resonated with members of the working group, the group felt that a cross-cutting issue was a need for more publicly accessible resources written by the PMLD community itself. In other words, whilst each of the research topics were important, the group felt that the topics were a product of society's misunderstanding of people with PMLD and those involved in their day-to-day lives.

The working group suggested developing a project that can shed light on the everyday lives of people with PMLD, a project that can lead to a resource that can inform both trainee practitioners (e.g., social work students) and the public more generally about what life is like for the PMLD community. We are about to begin this project and seek reader suggestions for what the resource could look like.

## Next steps

Over the next 10 months (September 2024-July 2025) we will be co-creating a resource with our working group. We are in the early stages of imagining what this resource could look like and are open to suggestions from readers of PMLD Link regarding the resource's form and content. For example, which stories should a resource include? How can we best collect and share the stories of the PMLD community? Which formats of story-sharing are most impactful? If you have any suggestions, please feel free to get in touch with our team.

The research is funded by the Wellcome Trust and forms part of the 'We Are The People Project'. More details online at: <https://www.bathspa.ac.uk/projects/we-are-the-people>

## References

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