

## **Inclusive research: where does it leave people with PMLD?**

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*With the support of my colleague, Hilra Vinha, and about 60 other researchers who participated, I recently completed study that shows what happens when research communities become inclusive of people with learning disabilities. This research was funded by the Economic and Social Research Council and it was essentially about research designs and research methods. In this paper I reflect on the implications of developments in inclusive research for people with learning disabilities - particularly those with more profound and complex impairment.*

### **Why research matters**

Research concerning people with learning disabilities has been undergoing considerable change in the last two decades. It used to be the case that research was done with a professional or medical gaze and many people with learning disabilities and their families and allies have found this uncomfortable or unhelpful. Valuing People (DoH 2001), with its emphasis on people with learning disabilities as active citizens enjoying rights, independence, choice and inclusion, marked a change; in research terms it suggested that there were alternatives to people with learning disabilities being the passive objects of other people's research. This reflected, as much as directed, changes becoming apparent at the grassroots.

Research produces knowledge, but it also tells us what is worth knowing and who is worthy of doing the prestigious work of doing the finding out. Ultimately research is about whose knowledge counts. So, when the research community becomes inclusive of people with learning disabilities things begin to shift. New roles open with people with learning disabilities becoming researchers, advisors, writers, and even reviewers, editors and commissioners of research. Any reader of British Journal of Learning Disabilities would see evidence of this shift in the accessible abstracts and balance of topics and authors. (Readers of other journals might not have any indication that the world of research production was any different from the 1960s or 70s!) It takes time for the ripples of change to spread outwards and while there is certainly plenty to celebrate, there are also questions to ask, including how much the inclusion of some people with learning disabilities in research communities changes things for all people with learning disabilities and what this means for people with PMLD.

### **Taking stock of where we are**

I have been researching in the field of learning disability for three decades and the majority of this research has been about how we might communicate and relate better with people whose disability

circumstance mean they seem most remote to us. This research has involved a lot of imaginative listening to, and observing and attuning to, young people without verbal or formal communication and those who are part of their social worlds. It has only been more recently that I have been reading papers (co-)authored by people with learning disabilities, enjoying their presentations at conferences, and seeking to work with them on projects in new ways. All this has helped to alert me to the way that policy supporting inclusive research has run ahead of our ability to evaluate it. There is a celebratory narrative and a new orthodoxy emerging, but there are also people (such as Walmsley and Johnson, 2003) calling for pause for thought so that we do not gloss over the real challenges.

The aim of my recently completed research, *'Doing Research Inclusively, Doing Research Well?'* (Nind and Vinha, 2012), was to better understand inclusive research and to build capacity for it among individuals and systems. It involved a range of us, each knowers and learners, in dialogue together. We used focus groups to pool knowledge leading to guidance on working through the issues and challenges faced by people, with and without learning disabilities researching together and separately.

### **So what does all this mean for people with profound and multiple learning disabilities**

This was a hugely productive process in which many of the people leading the way in grappling with breaking new ground in learning disability research were candid in openly sharing their perspectives and struggles. They reflected on things like how theory is made accessible, how people with learning disabilities engage in data analysis, and how people with profound impairments are enabled. For this anniversary issue of PMLD Link it is the later issue that matters most.

The nature of the study was that the people with learning disabilities who were invited to take part were competent researchers or able to contribute to research with support. This did not mean that they were all literate, or eloquent, or without additional impairments. It did mean though, that the population was skewed towards those who have already found their voice and a way to use it in research/, and away from those with profound intellectual impairment. This is the reality of the population of inclusive researchers in the learning disability field. The decision to include a group of academic researchers who do research in which they seek to maximise the participation of people with learning disabilities was in part about anticipating this and ensuring that research with people with profound impairment was represented. In the focus groups I asked:

- Can everyone be a researcher?
- Can everyone give research data?
- What do you need to be a researcher?
- Has anyone done research involving people with profound and multiple disabilities?
- What were you trying to find out?
- How did you go about it?

The question of who can do research led to answers that were grounded more in politics than experience. People with learning disabilities involved in collaborative research partnerships spoke a little of the ways in which they reached out to people with high support needs (for example, someone who was losing their abilities to dementia). Academics spoke of methods they used to

enhance engagement, such as working responsively in the co-design of bespoke musical instruments and using (life) story methods and mobile interviews. There was a real reluctance, though, for people to speak about the boundaries to what was possible. This may relate to the 'stifling of debate' that Walmsley and Johnson (2003) have highlighted, or to a genuine desire not to close down possibilities. There was a touching faith in what might be achieved given the right training or support. For example one researcher with learning disabilities reflected:

The way I see it, because you can't verbally communicate, there is always a way that you can find [to] communicate with people. I think there is an assumption we often make that just because the person can't verbally communicate like talk that they don't understand and that is so [...] I mean they can. Just because they can't [talk] doesn't mean they can't understand.

This fails to confront the realities about over-interpreting voice and opinion among people with PMLD that Ware (2004) alerts us to. It does, however, reflect the commitment to recognising the humanity – and human rights – of those with PMLD.

There were explicit references to working to extend the understanding of steering committees and ethics committees so that they might have greater confidence in seeing people with PMLD as more than just vulnerable. One academic argued 'good research is also research that is not frightened to go near people with high support needs'. She describes,

trying to involve people with very high support need alongside people who were more articulate and documenting that experience. I was thinking I can't say that I involved everyone in the analysis. But now, towards the end I can see my ideas of analysis completely changed ... the idea of analysis being quite complex can inhibit us and it can work against people with high support needs.

In this context, by prompting reflection, people with PMLD were contributing to knowledge.

When it came to the skills or qualities needed to do research participants avoided the things that they saw could be aided by better accessibility and focused instead on curiosity: 'Perhaps what we do require to be a researcher is agency or to be able to demonstrate a willingness to want to find something out and to ask questions'. This for some raised the question of how we know whether someone is expressing agency in terms of research. They looked for ways round this, including life story work; one participant asserted: 'we have to have their inclusion in research. There are ways of doing it'. Such ways included dynamic, flexible and respectful approaches to consent issues, and tackling people's fears of getting the ethics wrong.

The research exposed the continuing attitudinal, social and material barriers that make inclusive research challenging; it offered less clarity on the intellectual barriers that may also be relevant. Here I think we may need to look not just to the advocates of inclusive research, but to the advocates of new ways of thinking about impairment and disability. I see real promise in the way Goodley (2001) describes distributed competence – the real importance being in increasing what we can do together rather than alone. Similarly, Simmons (2011) challenges us to re-think our current conceptual frameworks surrounding people with PMLD as 'pre-' many of the developmental stages of infancy. Using a case study of one child, involving interviews with his significant others and extended observation, Simmons was able to engage in deep data analysis and show different

readings of that child's social interactions and abilities. If I were to argue that this research was inclusive I may need to stretch the concept, but in identifying it as research in the interests of people with PMLD I feel that I am on safer ground.

## **Conclusion**

There was, and is, a great deal of talk about research *done with* people with learning disabilities when collaborations and partnership are involved, and more radically about research *done by* them. These are the completely welcome alternatives to research *done to* them. Occasionally our focus group talk turned to research *for* people with learning disabilities. It is this, I think, that is in danger of being lost in the clamour for, and celebration of, research *with* and *by*. Research *for* can reflect all the very best of citizen advocacy and of people working as allies of people who face the biggest obstacles in speaking for themselves.

Some self-advocate researchers will remember those with PMLD and assert their rights; they may capture the attention of users of research in ways that academic researchers cannot. Whether or not they are more able than other allies/carers to speak for the experiences of people with profound impairment, though, is debatable. In this respect creating a new breed of experts – so-called experts by experience - brings with it new problems as people with learning disabilities are diverse and their life experiences equally so. My own view is that we are all learners rather than experts. We have travelled massively important territory when it comes to both advances in inclusive research and advances in recognising the humanity of people with the most profound impairments. We are, however, only at the very beginnings of bringing the two together.

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## **Further information**

Information about the Doing Research Inclusively, Doing Research Well? Study is available at [www.doingresearchinclusively.org](http://www.doingresearchinclusively.org)