Commentary on Williams (2019) "It all sounds very interesting, but we're just too busy!":
Exploring why 'gatekeepers' decline access to potential research participants with learning disabilities"

Andy Coverdale & Melanie Nind, University of Southampton, UK

Peter Williams provides a useful paper that brings much needed attention to the power of gatekeepers in facilitating or preventing the involvement of people with learning disabilities in research. He has utilised his own data resources and the literature to stimulate a conversation that researchers in the field of learning disabilities (in particular but not exclusively) need to have. As researchers negotiating this terrain ourselves we offer some observations on the paper and reflections on our own experience.

The primary useful thing this paper does is to ask why gatekeepers might decline access to potential research participants with learning disabilities. The subtext is that this is to decline involvement in something that has potential to help the people involved. There can be no guarantees about benefits that might accrue from involvement in research, but the paper moves swiftly into the terrain of problems and risk that gatekeepers feel need to be weighed. The implication is that risk avoidance comes first. While Williams mentions positive risk-taking, it may be that using this concept – of weighing possible benefits ahead of possible harms – is more useful for researchers' negotiations with gatekeepers than it is given credit for in the paper. Williams' advice, to ensure 'the research itself aims to improve the lives of participants, their peers, and the wider community – and that this is clearly outlined in any approach to gatekeepers', is good though it may not be enough. It raises the wider question of how research is perceived by gatekeepers. There is much written about how researchers have poorly treated people with learning disabilities, but it is not clear from this paper the extent to which this critique of research labelling, rejecting, medicalising, pathologising, even de-humanising, people with learning disabilities has reached gatekeepers. Mistrust of research may not be irrational and the history of past research should never be forgotten when we are seeking access to research relationships.

In seeing the paper as the start of a conversation, one direction the paper might lead us is better understanding the nature of gatekeepers. We get some sense from Williams' analysis of their various motivations, but the discussion stops at analysis of their relationship to power. There are gatekeepers in powerful roles and there are people with little power in their working lives

supporting people with learning disabilities who, in this instance of gatekeeping, exercise some power. It is important for us as researchers to understand the nuances of this and to respect the fluidity of power in the Foucauldian sense of something that is exercised or mobilised rather than possessed.

If we contribute to the conversation lessons learned from our working with gatekeepers this takes us further into the realm of research relationships. While working directly with people with learning disabilities rather than proxies necessitates relationship-building with then, we still need to build relationships with the people around them. For example, we recognise the scenario in which people who provide support or services have their own ideas about ideal candidates for participants. It is only in investing time in dialogue that we can engage properly with these ideas, following their direction or seeking alternatives. Our current work, on how adults with learning disabilities in the UK are self-building the pattern of their daily lives in the changing landscape of care (https://selfbuildsocialcare.wordpress.com/), has necessitated seeking participants with learning disabilities. In one of the rural case study areas, we needed to recruit focus group participants and we did so through two organisations: an advocacy group and a day opportunities provider. Our experiences of seeking access benefitted from existing relationships between the advocacy group and senior researchers on the project, from Advisory Groups linked to them, and from a recommended local practitioner with a key role in the social care sector acting as an initial gatekeeper in providing an area overview making introductions.

Similar to some of Williams' experience, in our initial approaches to the organisations it was useful to share a briefing paper (and a summarised 'easy-read' version) outlining the project. We witnessed busy practitioners who were stretched and under-resourced, and understood that gatekeepers typically wanted to know about the purpose, methods and intended outcomes of the research and its potential impact on their organisations and their region. Our initial fieldwork involved conducting interviews with the gatekeepers themselves, typically managers. This helped us assess potential case study sites, develop relationships with organisations, show gatekeepers our capacity to listen and care about their perspectives, and ultimately access people with learning disabilities as participants. While projects may not always require data from gatekeepers, and while interviewing them may place an additional burden on their time, we think there is something important in this ethic of valuing their perspectives too.

With the advocacy group, we were able to spend time with potential participants in a process of mutual weighing up. It was important to recognise their capacity and agency as individual self-advocates by communicating with them directly and we provided accessible information sheets and consent forms for them to share with family members or support workers. We also continually consulted with staff and volunteers, drawing on their experience and supporting a good working relationship. Maintaining the balance between promoting the advocacy of individuals and respecting the safeguarding role of organisations was an ongoing methodological and ethical consideration. In making final arrangements for the focus groups it felt appropriate, both ethically and practically, to do this through a key member of staff. Ultimately we worked, not with an initial gatekeeper, or the senior manager, but with the person we considered best placed to communicate with other staff and potential participants. We suggest that identifying such a person may be a helpful step for other researchers.

The circumstances of accessing the other organization dictated that the manager be the gatekeeper with responsibility to negotiate recruitment with potential participants. We emphasised the focus of the research and made reassurances over the anonymity of the organisation to help them to avoid favouring those who might represent the organisation in the best light. Even so, we may, like other researchers working with and through gatekeepers, be complicit in relying on the usual suspects rather than participants with other valuable experiences to share. None of us it seems, are able to access the hidden majority of people with learning disabilities who do not use services and for whom gatekeepers cannot be readily identified. This, we suggest, may be an even bigger problem than the one Williams brings to researchers' attention.