**“Swept under the carpet!” Let’s talk about sex, periods and having babies**

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This project is being funded by the NIHR as part of one of their program development grant calls, specifically focusing on developing inclusive approaches to research and grant development.

The idea for this grant was to work in inclusive ways to develop a program of research or an agenda of research that address community needs and interests, with the aim of the project to create a research partnership between people with learning disabilities, researchers and those in policy and practice roles on the topic of reproductive health.

The research team felt reproductive health is often an overlooked topic and people with learning disabilities don't often get to talk about these issues and what they think is important to research, - hence why they felt it was important to do this work and start from the ground up, really working with communities to get an understanding from them on what they think is important to know more about.

The final aim of this piece of work (which is running for 18 months) is to come up with a research ideas/research proposals that address the issues that people have said matter to them and to take that for further funding. This is what research priority setting is and explaining how that is done in more inclusive ways. While there is a lot of information about doing coproduced research and inclusive research, there is a lot less out there about how to do this first bit of setting research priorities in an inclusive way.

**Lived Experience and the Coresearcher perspective**

The project had two community partner advocacy organisations run by and for people with learning disabilities, which were Ace Anglia and Inclusion North.

An important part of this work was employing people with lived experience to act as co-researchers on this project and Kirsty from Inclusion North was a member of the team working in that in that role.

Kirtsy introduced herself and the title of “Swept under the carpet” which was a title from when Kirsty took part in a workshop in Lancaster about the lived experience of herself, Denise, and their colleague Gary which helped shape their thinking about this project and how various issues are swept under the carpet.

Kirsty spoke about what she liked about being a co-researcher which included liking to work with other researchers in a team so that they can share their skills and knowledge, being listened to and having a vote, and being paid for her work which made her feel valued.

The topics the team are researching are often ignored by health and social care professionals and sometimes families. They are using a survey to find out what is important to people with a learning disability and will be holding some focus groups later in the autumn. They are hoping to look at topics such as abortion, pregnancy, sexual relationships, menopause, conception and being parents in more depth.

**Discussion and Learnings from the project**

It is important to be flexible and open to doing things differently and building in time and resources is essential, along with building capacity through formal training as well as hands on learning to see what approaches work best.

New ways of working with people in their communities to come up with research ideas is needed, and the importance of being creative and practical to make the research process easier and accessible for everyone was discussed.

As the team have been doing this research and reading about how to do research priority setting and formulate research ideas the methods for setting research priorities and deciding what is important to research have not seemed very inclusive. The James Lind Alliance (JLA) method was referenced which uses a number of surveys, consensus setting, voting, ranking and various workshops, which did not look as being very inclusive.

The research team have been trying to work out how to do this as they go along noting that reproductive health covers a lot of different issues and where to start has been challenging. They wanted to start broadly and not narrow it down too early because then they felt they would be already deciding what's important to research. It was thought it would be good to begin with some focus groups and talking to people to narrow it down, but it was recognised that with not everyone knowing everything about all of these topics, and so to them to decide what's important would be overwhelming, so Kirsty came up with the idea of kind of a voting poll or short survey to get people to start thinking about the topics they think are the most important.

An easy read information pack was provided listing all those topics with a little information about each so people could pick the top three things they wanted to talk about together.

They are now collating all the information to plan for the next phase which is focus groups to explore topics in more in more detail.

Funders such as Universities can be a barrier to doing this kind of work. When working with different partners, institutions and charities there can also be issues and barriers, such asdifferent policies and procedures within organisations e.g. procurement, or delays in contracting staff. That may not be an issue for university researchers who are maybe already getting paid, but when working with other external organisations/individuals it can all make this inclusive work more difficult. In a discussion on creative methods in projects it was noted how often they can take a while to set up, and building up the partnerships and it is shame that once research ends there is sometimes a gap when trying to source funding to continue working with groups and build upon projects and the work done.

Part of this explorative work within this grant will be about going back to the funder and identifying ways of being more inclusive.

The nice thing about this research was how it was giving people with a learning disability or autism a voice to choose what is best going forward and choosing what they need rather than what others think they need and giving them a voice. It was also recognised that there should be adequate support and structures in place for researchers with lived experience.

There was a discussion about the importance of remaining flexible to allow methods and ideas to develop during coproduction. This can be challenging and mean that the process is not fixed from the start as it responds to ongoing learning and the changing needs of research participants. The use of creative methods such as storytelling, art, music, and playful engagement - for example employing puppets or mascots, were also highlighted as ways of helping to ease difficult conversations and make research more accessible and inclusive.