

A Conversation about Collaboration

Sophie Phillips is leading the Collaboration element of WAARC. In this conversation we delve into Sophie's work on the project and learn about her approach to disability research.

In this conversation we ask Sophie to tell us more about the Collaborative Projects - particularly the work with Sheffield Voices - to co-produce the Open Call for funding internal projects in the University of Sheffield and the reviewing process of the submitted applications.

Sophie, you've just published a book based on your PhD. What is it about?

It is called the Autistic Postgraduate Woman: Navigating the Neurotypical University. The book is based on one of the themes from my PhD exploring autistic women's experiences of university. 6 out of 11 of my participants were postgraduate students. Academic texts about Autistic undergraduate students are now relatively popular, however Autistic postgraduate students remain neglected in the literature. Throughout my book I also discuss my own experiences of navigating postgraduate study as an Autistic woman.

So, you are a disability studies researcher, what does that mean to you?

It means that I put disability and accessibility more broadly as the forefront of all my work. This includes ensuring ethical rigour and that my work is as accessible as possible.

Can you tell me about your role on the WAARC project? From the website I notice that you lead the Collaboration area but can you tell me a bit more about this?

The Wellcome Anti-Ableist Research Cultures project (WAARC) as a whole, is a two year co-produced project, between disability-focused researchers at the University of Sheffield, a university based Participatory Research Network and four Disabled People's Organisations (DPOs) running from March 2024 to March 2026. The DPOs that are part of this project are Sheffield Voices, Speak Up Self Advocacy, Pathfinders and NASDN. In addition, senior colleagues at the university who were committed to building research culture through foregrounding disability are involved. WAARC comprises three priority areas : Environment, development and collaboration, and two cross-cutting themes: 'institutional engagement: what is an anti-ableist research culture?' and 'key performance indicators of an anti-ableist research culture'. Overall, the project aims to: (1) experiment with and create new processes, concepts and practices that create an Anti-Ableist Research Culture at the University of Sheffield; (2) work in collaboration with disabled researchers and disabled people's organisations while being intellectually underpinned by critical disability studies theory and research and (3) pilot a number of activities that will be evaluated and scaled up in relation to the three priority areas.

WAARC seeks to provide an essential platform for genuinely transforming ableist research practices, both within the University and beyond. It will enable an important pathway towards the creation of a genuinely diverse and

inclusive research culture, pivotal to our understanding and achievement of research excellence in the future.

My specific role is as a Postdoctoral Research Associate on the Collaborative Priority Area. This area aims to: (1) put disabled people front and centre and in collaboration will offer funding, via an open call, to other researchers and professional services colleagues to produce their own inclusive research projects and (2) revisit the Concordat on Researcher Development to ensure inclusivity.

So, part one of the Collaboration element of WAARC related to the commissioning of a university wide funding call to apply for up to £10,000 funding for an 11 month research or innovation project. We co-produced this research call in collaboration with Sheffield Voices, a DPO that provides activities for and campaigns with adults who have learning disabilities including some who are autistic as well.

You talk about participatory research but what do you mean by that?

Co-production seeks to give communities greater control over research (Durose et al., 2012). Historically, university processes and policies can hinder the equity of control that a university based researcher exhibits (Martin, 2010: 213). Traditionally, Disability research has centred on participants as vulnerable, and as people that needed to be researched *on*, rather than *with*. This inevitably has meant that research in the field of disability studies has predominantly benefitted the researcher, rather the people being researched and can be alienating towards Disabled participants (Oliver, 1990). In 1992

Oliver coined the term 'emancipatory disability research' in reference to a radical new approach to researching disability. This move was to ensure Disabled people were included in research and thus challenged dominant research traditions and values (Barton, 2005). Ultimately, the control in research should be predominantly with the Disabled people involved, rather than the researcher. It remains debatable whether such a radical approach is actually achievable or is a utopian belief in a neoliberal world. However, that does not mean we should not continue to strive for such an approach.

Regardless of the politics of co-production particularly within emancipatory disability research, it is not something that should be ignored, but rather considered pragmatically. Huang et al. (2024) highlight that co-production with Disabled people inevitably has challenges, for example ensuring accessibility for all when access needs might compete. They also champion the idea that reflection and (re)negotiation of access and co-production are vital to ensuring meaningful mutually beneficial research.

It would however be naive to assume that the university based researcher and community based co-researchers hold the same power in the project, which is something at the forefront of our thinking. This power imbalance is amplified in the sphere of Disability, regardless of whether the researchers are Disabled or not, where societal opinions and attitudes towards Disabled people intersect with bureaucracy. In addition, within emancipatory disability research the debates of whether Disabled people should be the subject of research, or disabling society be studied instead, remain ever present: and more so who has the power to debate these issues. It is questionable the lines between leaning on the notion that the personal is political and therefore should be

championed (Barton & Oliver, 1997) or that Disabled people remain a fascination in society. Considering the debates around power, even within emancipatory disability research, and who should be involved, the necessity for co-production and open discussions around participation, fascination and power are highly important.

You mention working with Sheffield Voices - who are they and how are you collaborating?

Sheffield Voices are a Disabled People's Organisation for self-advocates with Learning Disabilities and/or Autism. They campaign on topics of injustice for Disabled people, such as producing hate crime training for Disabled people and working on a campaign to help Disabled people save money on household bills.

Disability Rights UK (2025) explains that DPOs provide platforms for the rights of disabled people to be represented, particularly when they can be marginalised from mainstream society and discussions. By working in collaboration with Sheffield Voices we wanted to ensure that the call for research applications - that we shared with academics at the University of Sheffield - reflected this organisation's understanding of research. We also wanted to share the research call in an accessible way. We know that research can be interpreted outside of the university in a difficult way. Academic language and jargon is often difficult to understand outside of academia and this has the effect of making research and scholarship inaccessible. We therefore strived to write Our Open Call for Research Proposals to be written in an accessible and understandable way. This

included writing two versions of the research call, one in plain text English and one in Easy Read.

Can you tell me a bit more about the Collaborative Project Open Call

Any member of university staff or postgraduate research student were invited to submit a proposal; as long as their job contract/term of study spanned the length of the project. Projects also had to be co-constructed with a DPO.

University staff and postgraduate researchers were given two routes to apply by: (1) submit a full research or innovation proposal with a DPO they had previous connections with, or (2) apply to be 'match-made' with a DPO, before working with them to submit a proposal. The review panel - which included university researchers and researchers from Sheffield Voices - was interested in engaging research that would be relevant to the lives of disabled people in and outside of the university.

This match-making sounds interesting! What did it entail?

The originally proposed research call process did not include a match-making process. We assumed that university based applicants would only apply if they had pre-existing connections with a DPO. However, before we released the call we spoke with Sheffield Voices and they told us that some DPOs have never had the chance to connect with university researchers. So as well as a call to university researchers we also put out a call to DPOs: to ask them if they were interested in research and connecting with a university researcher.

Co-produced research centres the community and therefore, although including a match-making element of the research call added another element to the recruitment process, we decided to include it: responding to the expert

advice of Sheffield Voices. This organisation was also able to distribute the advert to DPOs that they have had contact with to attract a wider selection of DPOs. Ensuring a call was received by as many DPOs as possible would not have been possible if Sheffield Voices were not part of designing the research call, as we do not have that many contacts.

In order to participate in the match-making process, DPOs and university based applicants had to complete a short questionnaire documenting their research interests. DPOs were asked to describe the aims, values and objectives of their organisation and to state any research and innovation ideas they had. University based applicants were asked to write up to 500 words about their specific interests in research and innovation, and to state how being involved in a project with a DPO would help their current job or future career.

All prospective applicants were also offered a video call with me to allow them to discuss their research interests in more detail and to increase accessibility of the research call. Eight researchers took part in these calls, of which five then requested to be match-made. Dan and I match-made researchers and DPOs based on our own judgement. All five of these match made projects submitted full proposals, of which 3 were funded. In addition, one proposal where the researcher and the DPO already had a relationship with each other.

So now you have these DPOs and university researchers working together. Can you tell me how you navigate intellectual property (IP)? I imagine that both parties want to share the IP?

Negotiating Intellectual Property (IP) was a particular challenge of the research call and initial setting up of the projects. When approaching DPOs about potential research collaborations, some common themes and questions were asked. These questions may have stemmed from the traditional historic exploitation of DPOs and other organisations by researchers. Historically, in research, Disabled people and the organisations that represent them have experienced being exploited in the research process. Therefore, I did expect that DPOs may be wary of the processes, policies and procedures universities have in place to ensure equitable research but had not foreseen IP to be an issue.

Intellectual Property (IP), specifically who legally owns any outputs and the ways in which they can be used both within and after the project was also of key concern of DPOs. This again stems from universities tending to be very protective over IP or a lack of definitive guidance about it. Traditionally, universities tend to own all of the IP that arises from a research project.

One DPO who was initially interested in the research call, decided not to apply for the 'match-making' process as they wanted to own all of the IP. Whilst universities can have draconian IP processes, in co-produced research particularly where there is financial benefit to the DPO, there needs to be some benefit to both parties. Negotiating this, in line with policies and the wants of all involved in the research is therefore difficult.

In practice, in these projects IP was negotiated to mean that the university owned the physical outputs (for example, a video of a theatre performance and photographs of artwork), but that any creative ideas (for example, the theatre performance storyline) were the IP of the DPO and the individuals

within them. Any writing outputs (such as co-written journal articles) followed the traditionally academically accepted guidance of having shared IP. This complicated negotiation highlights how organisations based on creativity, including the arts may be disadvantaged in the research process with universities. It also demonstrates the university can be responsive to having a more collaborative understanding of IP.

The difficulties associated with IP and ownership of data and outputs may reduce the desire to produce creative non-text based outputs. In the context of Disability, where co-researchers may not use text as a primary means of communication, discouraging the use of creative outputs by complicated bureaucracy could be detrimental to making academia more inclusive and accessible.

Can you talk to me a little more about how you approached access and accessibility in this Collaboration Priority Area of WAARC?

As part of the research call, proposals had to be written in plain English. This meant writing in a style that was understandable to a non-academic. We requested this so it was easier for proposals to be understood by both academic reviewers who were not familiar with the subject area and for non-academic reviewers from Sheffield Voices. In order to increase accessibility further, particularly for reviewers with Learning Disabilities at Sheffield Voices, we requested plain English to be used because writing a proposal in non-academic language tends not to be common in academia. We were keen to balance familiarity and accessibility of researchers with the accessibility requirements of the reviewers. It was important to us that

researchers were not discouraged from applying due to unfamiliarity with writing in accessible ways. Throughout the timespan of the call ensuring accessible communication was key however, it was not a requirement to understand this prior to being successful in the research proposal.

However, the majority of submitted research proposals were not written in a way that equated to being in plain English. This was a big factor in the scoring. If members of Sheffield Voices or the Participatory Research Network did not understand the proposal due to their reading ability or subject specialism then the proposal overall was rated lower.

What lessons could be learnt from this project?

In conclusion, both positive and ethical challenges arose from matching researchers and DPOs together. Here recommendations for funders are provided in the hopes that future collaborative research can occur.

- Funders should consider the benefits of including DPOs in reviewing
- Consider a match making process to increase accessibility to both DPOs who may be less connected with universities and to researchers, particularly those in the early stages of their career or professional services staff.
- Consider the importance of IP and the impact it has on DPOs.

Considering the historic exclusion of people with Learning Disabilities from research as researchers, it is important to ensure meaningful inclusion in not just the actual research, but also the topics of research that are funded. It is essential that policies and procedures, particularly surrounding Intellectual

Property and ownership are transparent and easy to navigate to ensure that research is set up and in a timely manner.

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