# **Communicating better with people with learning difficulties**

# **Reflections on the research process**

## **Challenges of coproduction: what is coproduction, and are we really ‘doing’ it?**

A key theme that emerged from this work was to what extent we were actively engaging in coproduced research. We as academic researchers want our research to be led by/collaborative with our partner groups, and this is an ethos we try to embed in all of our work. However, to engage in coproduction, there needs to be a mutual understanding regarding what research and coproduction actually is, and this is something we as researchers are wrestling with. Is co-production a methodology, which holds a distinct philosophy and assumptions about the nature of knowledge, and which therefore creates a potential rulebook to follow, and a framework for what methods could be used? Or is coproduction something which is more abstract? For instance, is coproduction a philosophical stance or an ethical stance insofar as it is what we as researchers are striving for, but is it something that can actually be measured in practice?

The reason why we as researchers have been wrestling with the idea of what ‘is’ coproduction is because of the potential inaccessibility of this culture of research for our partner groups. For instance, researchers might find a question such as ‘what would your group like to research?’, as open and exciting due to the possibility of researching something that interests them. But for people who have not been involved in research before, this question may be very difficult to answer. Without prior knowledge of what research is and means in practice, being asked to share ideas and/or design a research project could potentially be incredibly anxiety-provoking. In other words, some disabled people may be keen to tell stories about the challenges that they have experienced, but they may not want to co-produce a project for various reasons, such as confidence, skills, time, money, interest, energy levels etc, and so this means that disabled people’s desire for co-produced research may not always be there. There is a risk that if we as researchers are privileging coproduced research, then there are questions about the extent to which we are behaving ethically in terms of coercing groups to work in a manner that suits our interests rather than theirs. For instance, does coproduced research actually make sense for our partner groups, and is there a risk that certain groups are ignored if they do not want to engage in coproduction? We wonder whether part of the problem is that coproduction is an academic term and therefore presupposes certain academic skills and understandings that researchers may take for granted (e.g., the ability to reflect about past experiences, speak about them, and anticipate what a better future could entail for the person reflecting).

To ‘do’ coproduction or any form of research well, we as researchers have wondered if certain partner groups need to be given time and support to think about what their ideas are for problems that need addressing, and perhaps the possible solutions and approaches, before they can be ‘ready’ to engage in coproduced research. In other words, we have wondered if there *needs to be* a power imbalance in the research setup in order to allow for any project to flourish. In advance of projects starting, it is perhaps beneficial to agree what the terms of coproduction are for the project, including how researchers and partners work together, such as what support is needed. Individuals who are knowledgeable about research may be needed to educate and provide support for individuals who are new to research, such as in regards to designing research questions, demonstrating how to use different research methodologies, and educating on the importance of research ethics. Moreover, one or more individuals need to take the responsibility for project managing the work so that the work is completed on time, which may likely end up being the researchers themselves.

For people who fill roles that provide them with additional power, the challenge is ensuring that they do not use this power to artificially shape the narrative or interests of the partner group(s) they are working with. For instance, for researchers that have a particular interest or expertise in social science or qualitative research, it is important that they provide education for their partners they are working with on what this type of research could look like, but also not to push this type of research if this does not make sense for their group(s).

From a coproduction standpoint, there is a delicate balance for powerful researchers to navigate in terms of their partners being active coproducers of research versus their partners simply providing their thoughts and ideas for research. The latter option is potentially indicative of a more traditional research setup of researcher and participant. Nevertheless, it is important that we acknowledge that for certain partner groups, this latter option may be what is wanted: they may want an external person to organise the research for them so that they can comment on things that are tangible (i.e., as discussed above, given that for people new to research, coming up with an idea for a research project can seem quite abstract). However, the autonomy for making this decision has to come from the partner groups themselves. This means that they are actively making an informed decision for this approach, rather than being coerced into this approach via the powerful researcher.

Now that the workshops with people with learning difficulties have finished, an important point of reflection is regarding whether we engaged in coproduction as much as we would have liked to, and whether our research is an actual example of ‘coproduction’, or whether we are simply using this as a buzzword. The point regarding our partner groups being new to research is a valid one, and we as researchers would be concerned about the ethics of expecting individuals new to research to engage in such tasks without prior experience. But, we also wonder whether our project could have done more to enable the coproduced element of the research to come through more strongly. For instance, actively working with our partner groups for a more extensive period than we did, so that we really understood their views and interests. As valuable as the workshops were, there is only so much that could be said in one session, and so the coproduction element and relationships we have with our partners, could have blossomed if we worked together more intensively. There were of course additional challenges outside of our control that prevented this more intensive working in terms of the availability of us as researchers and of the partner groups; and the length of the funding, and managing expectations about what was going to be achievable in the timeframe. Nevertheless, we hope that as our Wellcome project continues, we can build on these initial relationships, and develop something overtime that more truly reflects the ethos and spirit of coproduction, if this is what is wanted by our partner groups.

## **The inaccessibility of accessibility**

Given the nature of our research project, accessibility was of key importance throughout our discussions as researchers, but also with our partner groups as part of the workshops. While we have tried to be as accessible as we can be, there were instances in the project where we have not been as accessible as we would have liked. For instance, there were examples raised in our workshops about how the consent form was difficult to complete, and how the term ‘accessible’ was itself inaccessible. There were also examples of where we provided ‘accessible’ versions of our materials for participants which were unfortunately inaccessible for others. It was for this reason, and no doubt others, that a key theme from our research was the importance of providing information in different formats, such as easy read, video, and having people explain things verbally.

A key challenge to presenting information in multiple formats is that we cannot assume that what we make and say is accessible. We can only know whether what we have produced or said is accessible once people have something tangible to offer improvements on. For instance, it is only when a researcher writes or says a word or phrase that a person with a learning difficulty can say ‘*I don’t know what that word or phrase means*’. In this sense, true accessibility and inclusion comes from learning after being critiqued when things are not accessible. Any critique can be seen as a threat or cause anxiety, which is a potential reason why people may feel reluctant about engaging with accessibility and inclusion, for fear of being judged or getting things wrong. But the only way we can be truly accessible and inclusive is being willing to having our ‘accessible’ practices critiqued, and to have the opportunity to critique accessibility in a space that ironically, is accessible. For instance, we have commonly encountered situations in academic research whereby researchers feel they are being accessible and inclusive, but in actuality, no one has yet critiqued their practice – and this may be because the people who would typically critique such practice have been excluded from the space.

An example of this is in relation to making information accessible for people with learning difficulties. Ideally, we would want people with learning difficulties to support us in the coproduction of project materials, such as making consent forms in easy read formats. However, for people with learning difficulties to do this, they may be put in an inaccessible position of having to understand both standard print and easy read information, in order to allow for information to be presented in an accessible way. It is common for people without learning difficulties to design easy read materials for people with learning difficulties to interpret, which was the approach taken for our research. The challenge here, however, is that when materials are produced by people without learning difficulties for people with learning difficulties, biases and assumptions are being used in the design process.

A further example is when interacting with people who ‘fall outside’ the traditional expected means of communication, which in society, is typically vocalisation or via commonly understood gesturing. People with profound and multiple learning difficulties, for instance, may lack the ability to vocalise and use gestures that are readily understood by non-disabled people. In such cases, we as researchers are left unsure if we are being accessible or not, since the method of communication for people with profound and multiple learning difficulties may not be accessible for us. For instance, we as researchers may not necessarily understand subtle eye movements or noises that may indicate understanding or pleasure of the people we are working with. A common provocation question was asked across the research which was ‘*how can we know we are being accessible if disabled people are not in a position to tell us*?’ Even with people who understand disability well (e.g., parents of children with profound and multiple learning difficulties) are going to be making a degree of assumptions and interpretations about the people they interact with.

So, the central point of reflection we would want to stress through doing research on accessible communication is that to try to be truly ‘accessible’ also requires an ability to recognise the inherent inaccessibility and of that ethos. In other words, to be accessible is to show the greatest commitment to accessibility, while also recognising that true accessibility for all is unrealistic. It is important for us all to be optimistic and committed to what we can achieve with regards to accessible practice, which means doing the best that we can through finding and learning about accessible approaches that allow as many people as possible to feel included and equal.

## **Building relationships with actual and potential partners**

In research, researchers may fall into a trap of assuming that contacting partner groups/participants, and collecting data, will be a smooth and stress-free process. However, as should be expected with coproduction, our initial networking phase to reach out to potential partners and interested individuals took considerable time for a variety of reasons. For instance, we approached a few organisations who were interested in being part of the research, but who could not commit time or resources due to previous agreements with other organisations, or because of the difficulty in organising a workshop in the timeframe allocated to the grant. Other organisations wanted to participate but are currently experiencing considerable hardship in light of ongoing austerity and the COVID pandemic, and so were unable to commit to the research due to uncertainty within their organisation. Indeed, one organisation unfortunately has ceased operating, which reiterates the challenging environment disability organisations/the charity sector are facing at present.

Alongside these contemporary challenges, there are also laws that can impact upon our ability to engage with people who may be interested in research, such as the Mental Capacity Act, and the subsequent need for national-level ethics, which can take considerable time to complete. Further, there may have been local organisations who have tried working with universities in the past, but who perhaps have had unpleasant or difficult experiences, and so may be reluctant to come forward again.

Given the complexities we encountered in confirming involvement from partners, we decided to expand our remit to people not attached to particular organisations, but who were interested in themes of accessible communication, which included allies of disabled people, and parents/carers of children with profound and multiple learning difficulties. We did have considerable interest from these individuals initially, but those who actually committed to take part in the research was much smaller. For instance, people were unable to participate due to us not finding an appropriate time for their participation, or due to health/other reasons. A learning point and reminder for all researchers is recognising the need to be careful about endorsing ableist assumptions that people will take part in research, and that they do not have any prior commitments that may impact on their ability to participate.

Alongside the time taken for networking, organising the research itself in ways that were accessible for all has been a difficult task for us. Care was taken when working with people with learning difficulties to ensure that they understood the purpose of the workshop, but given the previous ‘inaccessibility of accessibility’ theme, it was difficult for us to accurately establish to what extent our project information and workshops were actually ‘accessible’. During each workshop, we asked people in attendance to share their thoughts on what they found accessible or inaccessible about the session, and we did note some important areas for improvement, for instance, having the project material as video files, and making the consent form more accessible to complete.

Besides the accessibility of the workshops and materials, we wanted the relationship with our partners to be as equitable as possible, whereby both the researchers and partners get something out of the collaboration. As far as possible, partner groups should not be participating in the work for ‘free’, as there is typically a lot of time invested behind the scenes in getting a group ready for engaging in research. In our case, facilitators in our partner organisations spent time doing things such as: advertising and promoting the research; contacting family members of people with learning difficulties who used their services; going through the information sheets and consent forms with people with learning difficulties who were potentially interested in being part of the research; and helping to facilitate and guide the workshops themselves. The ongoing challenge of engaging in coproduced research with disabled people and other underrepresented groups is around how their time is renumerated. Many of the people with learning difficulties who were involved in the project may be in receipt of benefits, and so we and they may be concerned about what participating in research may do to their benefit entitlements. The challenge here is ensuring that partners are compensated for their time in ways that do not cause unintended hardship, such as benefit sanctions. We looked into purchasing vouchers for each partner organisation that we worked with, who can then disseminate the vouchers as they see fit (e.g., purchasing things for their members).

When we reflect about the entire project now that it is completed, we would argue that building relationships with actual and potential partners is the most important step of any coproduced project. In building relationships with these partners, researchers can see what ‘works’ for each, be that in terms of their availability, what interests them as potential projects, and how they would like to receive renumeration. The challenge is ensuring that protocols and restrictions of funding applications/actual grants do not inhibit these relationships from forming. When interested organisations feel unable to commit due to the perceived short timeframe of the grant, or due to any other reason, the onus is on the researcher(s) and the funder(s) to redesign the process so that these individuals feel enabled to engage.