

Working together on research: Experiences of the 'renting your own place' advisory group



This easy-read article tells the story of working together on a research project about people with learning disabilities who rent their own homes.



This group included self-advocacy experts with learning disabilities, research collaborators and academic researchers.

The group is introduced below.



Eppie is a researcher at the University of York.



David is a researcher at the University of Bristol.



Debs is also a researcher at the University of York.



Andy is a self-advocacy expert at York People First.



Becca is a self-advocacy expert at York People First.



Paul is a self-advocacy expert at My Life My Choice.



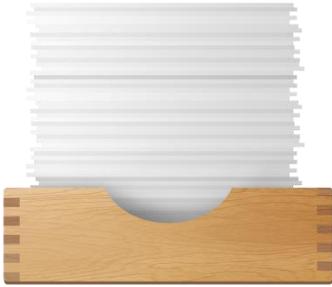
Sam is a research collaborator who works for Learning Disability England.



Stephen is an independent researcher, doodler and supporter of York People First.



We worked together to design the interview questions, information sheets, consent forms and the creative parts of the project.



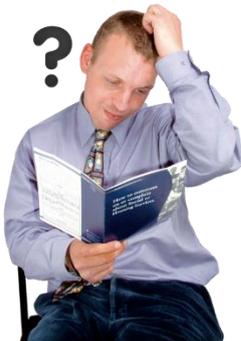
These forms went through checks by the University of York and were turned into very long forms with lots of extra legal information.



This was not very accessible.



We had to get approval from the Health Research Authority (HRA) to make sure our research was ethical to take part in.



This process was not very accessible and finding ways to include people with learning disabilities in getting ethical approval was hard.



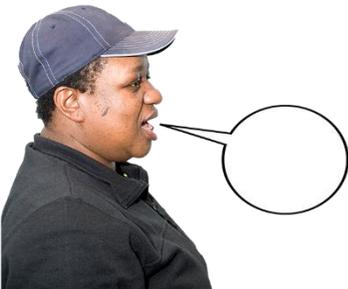
One of the things we talked about at our meetings was who was included in our project about renting and support and who was left out.



For example, people living in Shared Lives schemes or who don't have access to the internet.



Self-advocates felt very strongly that as many people as possible should be involved in the research.



One self-advocacy expert said...

"I think everybody should be included...and I think it should be everyone buying their own house or renting their own house."



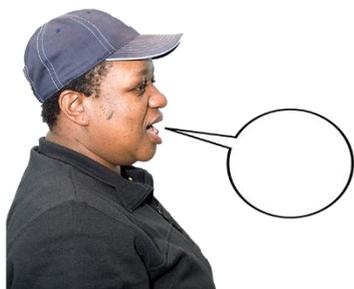
Self-advocates also asked why they were not doing the research interviews as well as the university researchers.



It quickly became clear that self-advocates wanted more involvement, more respect, and more power.

Stop Hello Eat
Words
Person Day Open

The language the academics and self-advocates used was sometimes different.



The academics referred to people with 'learning disabilities'.

Some of the self-advocates preferred the used term 'learning difficulties.' It was an example of everyone not always agreeing.



One self-advocacy expert said...

"It was quite debilitating. Me and [other team member] say learning difficulties but [other team member] says learning disabilities. We can kick up a debate but then go with the percentage. I think me and [other team member] couldn't sort of say anything so we just went along with it".



The academics chose to continue using learning disabilities as this was what their colleagues and social care staff also used.



This showed that even in doing research together academics hold quite a lot of the decision-making and power.



Sometimes in research projects people with learning disabilities get left out of the part called - data analysis.

This is the part when we try to understand what all the information we have collected means.



We wanted to make sure that didn't happen on our project so had online and in-person meetings to decide together what we had found.



To do this, we listened to anonymised clips and talked about what stories we were hearing based on what renters had shared with us.



This was really helpful, and we wished we had more time together particularly in person to do more of this.

If we had, we think we could have learned even more from the research.



Having the advisory group made the research better as the people making decisions about the project were not just academics but also people with learning disabilities who were experts on renting and support.



The academics felt they could have been better at working together and being more inclusive.



There were some mistakes like leaving the photographs of the self-advocacy experts off drafts of our information sheet.

We changed this in the end.



There were lots of good things about working together like silly glasses at Christmas and meeting each other's pets.



There were also harder things about working together.

Like working out how to write about what we did.

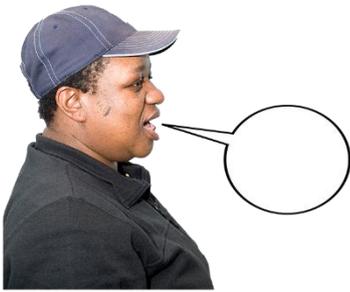


If we didn't have the advisory group, the research would not have been as useful.



Coming to the end of the project was difficult.

At the time of writing, we are still telling people about what we found out during our research.



The self-advocacy experts said:



“We should go further out; we should take it to other places. I think if we go wider out then people might say, ‘this is a problem we’ll get our heads together’ and go to the MP’s or House of Lords and say this is what we found, and they could do a proposal on it.”



“Very sad... it’s a shame we can’t extend it further.”



“Worried that by ending the project the things we have learned will be lost - people will forget what we’ve done.”



The self-advocacy experts thought about what it had been like working together and had some suggestions for the university researchers on the project:



“You think about it and get the ideas and then come to us. It would be nice to actually ask me where to go to and what to talk about, come up with an idea together. We could plan it together and all be treated as one.”



“Instead of you doing the work, get some of us involved in the work with you. Work as a team altogether instead of you three doing it all together or working one to one with each other to do things like the phone calls (interviews). Because you don’t have a lot of time to do things and we could help. I know you’ve done very brilliant work with us.”



“You’ve done a good job – a fantastic job including us. I’m glad we’ve had the opportunity to say these things. It’s given us a voice to say how we feel about things. Sometimes we don’t have that opportunity. Professionals talk to you and look down at you all the time, but you don’t.”



Finally, we want to say a huge thank you to everyone who took part in our project.

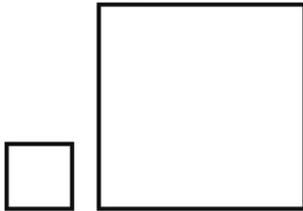


More Information



A longer version of this article can be found at:

<https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-023-00494-7>



More information about the study can be found here:

<https://www.york.ac.uk/chp/housing-health-wellbeing/learning-disabilities/>





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The views in this document are those of the authors and not always the views of the NIHR School for Social Care Research or the Department of Health and Social Care, NIHR or NHS.



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