

Co-production and public involvement in research: Lessons from Engage to Change by

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How I Engaged to Change by Gerraint Jones-Griffiths, Project Lead Ambassador

I was a participant in a project called Engage to Change. I then became employed by Learning Disability Wales as the Lead Ambassador for the project.

Engage to Change was a seven-year partnership project led by Learning Disability Wales, funded by The National Lottery Community Fund and supported by the Welsh Government. The project was evaluated by the National Centre for Mental Health at Cardiff University.

Engage to Change worked across the whole of Wales and aimed to support young people who have learning difficulties, learning disabilities and autistic young people to raise their employment skills and enter paid employment. I am now Lead Ambassador for Influencing and Informing – Engage to Change. This is a partnership between Learning Disability Wales and the National Centre for Mental Health at Cardiff University. My job is to share information and talk about learning from the Engage to Change project. This includes what works and what is needed to help people with learning disabilities get paid work.

I have been working with Andrea Meek and Dr. Elisa Vigna from the National Centre for Mental Health as a co-researcher to make sure the research and project legacy reflects the stories of people with lived experience on the project. This is an important project that has had a big impact on my life as a person with lived experience.

To me co-production is a way of working together but being equal. It means coming up with a plan to make sure that whatever we produce people with



Co-production with the public must include people with learning disabilities. Without co-production you would be in the same team with the same ideas. This is fine, but there wouldn't be any diverse way of thinking.

Accessible and easy read research is important for people with learning disabilities and for someone like me who has no background of research, no PhD! Although I can read and write. If you have someone with profound learning disabilities and for example, you ask them to look at a journal, how would you expect that person to read it and understand the language!? This is why we need to work with people with learning disabilities. They are the experts and without their valid input all of our papers, articles, and journals would be only for professionals. That just simply should not happen.

I've always been fascinated with figures, such as X out of how many are in full paid supported employment for example. Working with researchers has helped me discover why some people do not understand writing accessible information. It is a skill. There has been a lot I did not know about research for example the submission of abstracts etc. I did not think I could be a researcher because I have not got the IQ. However it has helped me discover some skills that I did not know I had!! I have always loved presenting. Now when giving presentations which include figures I am in heaven!

I would not say I have found anything particularly difficult. This is because I work with a research team who understand my needs and they support me well. If I ever have a query, I know that I can always come to them for advice. They have clearly shown what good supportive researchers look like. They are never on my case they just let me get on with it.

One thing I will say is though I do need support with my confidence, if that is such a thing! In the public eye I look confident and I never need support. However, when it comes to research I am really out of my comfort zone. I often know the answers, but do not have the confidence to put the answers I know into practice or even to paper. I know getting the confidence to do this will take time. I lack confidence in writing and putting my name as author. We are working on this as a team. I am doing some writing for academic journals as lead author. This is out of my comfort zone but putting my name first is right.

We had 7 years to work together on Engage to Change. The three of us know our own strengths and what each person is good at. We bounce ideas off each other. When we deliver presentations we make it conversational rather than just talking from PowerPoint on a screen. We know we can always ask each other for advice.

We are lucky to have time to work with groups. We work with young people with learning disabilities, parents, employers, local authorities and even Welsh Government and Members of the Senedd! Because co-production has made the research accessible for me, I have the skills to make it accessible for other people. I have been able to work with the research team to help tell people about supported employment and supported internships for young people with learning disabilities across Wales.

Talk to people with learning disabilities. As I have mentioned they are the experts. If they do not like what you have said they will tell you. You need to engage with them. Cardiff University has shown a good example of this with Engage to Change. I would like to see more work like this. I would like to see universities employing more people with learning disabilities as researchers so that co-production can be led by them. We have shown this can be done. Here are some of our top tips and lessons on co-production and public involvement in research from Engage to Change.

We would like to thank members of the All Wales People First evaluation forum who have engaged with the project, contributed to the research and have made sure that we listened to the voice of the experts.

You can find out more about the work of All Wales People First here: [Welcome to All Wales People First - All Wales People First \(allwalespeople1st.co.uk\)](https://www.allwalespeople1st.co.uk)



Top Tips for Co-production and Public Involvement

1. The importance of Easy-Read/ Accessibility



Do not underestimate the importance of making everything accessible. Accessible and easy read are not the same thing. When writing proposals or content avoid:

- Long sentences and paragraphs
- Jargon
- Acronyms
- Making assumptions that people outside of academia will understand what you mean.

Also think about:

- Font type
- Font size
- Can it be read by text to speech/ screen reader
- Using numbers (for example is 5 out of 10 better than using 50%)
- Colours
- Using complicated charts
- Using unsuitable graphics

Forms associated with public involvement are generally not accessible. Signing up to websites, creating accounts and navigating tick or selection boxes can be difficult.

Any forms created should be accessible and or easy read.

Learning Disability Wales have some good easy read resources here: [Our Easy Read resources - Learning Disability Wales \(ldw.org.uk\)](http://Our Easy Read resources - Learning Disability Wales (ldw.org.uk))

2. Additional time.



Researchers will need to account for extra time for:

- Writing accessible and easy read versions
- One to one or small group support to go through anything that needs to be reviewed (time for this will need to be flexible and needs led for each group member)

Support to sign up and fill in details on research websites (as above)

- Processing information - give additional time for people with learning disabilities to have space to think and respond
- Building relationships

3. Building relationships



The best and most honest feedback occurs when people are comfortable in the working group. If meetings are rushed and only focussed on “technical” parts of research, such as reviewing content, it can be difficult for people to give honest opinions. For example, we asked one young person to read a document and give us feedback. The first response was “It’s fine”. After several sessions we asked them again. Their response was: “I have looked through the form and honestly for me there is too much information on this form for me to really understand what it’s trying to tell you. This form is really not easy read at all. it’s difficult to read and understand when there is so much text on the pages”.

Have time for people to socialise and get to know each other. Do not have an “academic” and “public” split. Encourage everyone to work together.

4. Communication



- Think about the best way to communicate and keep in touch. For people with learning disabilities WhatsApp or messenger may work better than email for communication that is not confidential and for sending links.
- Any written communication should be easy read including emails or messages.
- In written communication do not put too many requests in one message or email. Start with one request per message or consider numbering points (limit to 2 per message)
- Do not send someone a whole document and ask them to “review” it. Give clear instructions on what you want people to look for. Setting out information in table form can be useful here.

5. Consider task analysis



Task analysis is breaking down a task into small pieces which are completed step by step. Think about using a tick box feedback form with text broken into small chunks. Have space for people to write any terms or wording they don't understand.

6. Payment



Offer a choice of payment by vouchers or money. Give individual choice. Consider an easy read timesheet so that payment shows any additional time contributed by people with learning disabilities who require additional time or meetings to process information.

7. Support



People might need to bring individual support. You may need to allow for additional time if the person giving the support needs to explain something. . Ensure that the supporter does not speak instead of or over the person they are supporting. Include additional costs for extra support.

8. Be flexible



Be prepared to explain things in a different way. It is best to keep checking people have understood. Give people the opportunity to ask as many questions as they need. Use visual and verbal information. Real life examples can help people put things into context.

9. Don't make assumptions



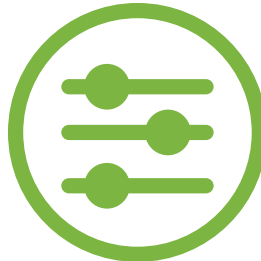
Do not make assumptions that everyone has the same experience of something or that a person may hold a particular view. Ask people for words they want you to use. For example, terms such as “service user” or “client” may not be used or liked by everyone.

10. Avoid Ableism



Ableism is discrimination in favour of non-disabled people. Do not assume that a person will adapt to the environment. Offer reasonable adjustments and consider accessibility for every person on an individual and needs led basis.

11. Offer a “menu” of reasonable adjustments



Asking a person “what do you need” can be a big question. If the activity is new it can be hard for a person to know what may help or support them in that situation. It can be useful to have a visual menu for people to see what you are able to support them with. Be flexible and understand that adjustments may need to change in or between meetings.

12. Comfort



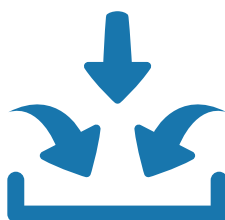
Check that any venue is comfortable. It is not too hot or cold. Is the room set up appropriate for a group meeting. Is there access to a quiet space for people to take time out. Are bathrooms easily accessible. Are chairs comfortable for long meetings. Is the decoration in the room likely to cause discomfort. Have regular breaks.

13. Set ground rules



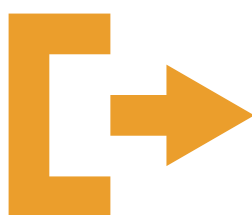
Ask the group to use the chosen terms. Have a system for speaking (so that people avoid speaking over each other). Ask the group to respect each others opinions. Tell the group about confidentiality. Check that they understand the rules.

14. Acknowledge input



Everyone who contributes to any co-production, report writing, academic paper, social media or other output should be acknowledged and referenced.

15. Don't forget about accessible outputs



Anything produced from research should be accessible. Academic journal articles are not. Film videos of key recommendations. Write short easy read reports. Use Canva to create infographics for social media. Use the voices and faces of people with lived experience. Share the research findings with the people whose lives it impacts most.



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