

Self-advocacy for people with profound and multiple learning disabilities

Blog by Jan Walmsley



Jan Walmsley is an academic who does a lot of research in partnership with people with learning disabilities.



Jan has been thinking about self-advocacy and people with profound and multiple learning disabilities.

She has been thinking about what self-advocates have said to her and the work she has done over many years.



Jan worked with Jackie Downer, who is a Learning Disability England lifetime member.

They wrote chapter together of a book, it said:

“I think it can work but it will take time. And we people with learning difficulties, we got no time.”



Jan spoke about how Learning Disability England got a grant from the RTR Foundation to run events to share good practice in self advocacy.

At the first event people thought the next one could be about how self-advocacy could include people with severe and profound learning disabilities.



She said self-advocacy groups had been doing this very well.

This made her think of Campaign for Change (C4C) and if they could run a workshop.

C4C had run a workshop at Learning Disability England's 2020 Conference.

It was about including people with severe and profound learning disabilities.



Two parents, Stephen Unwin and Virginia Bovell, spoke about what it would take for their sons to be part of a self-advocacy movement.

Their young adult sons, Joey and Danny have complex health needs.

She said they felt a bit nervous about this as family members have not always been welcome in self-advocacy.

Joey's dad spoke about how self-advocacy might be different for Joey.



He doesn't know what a self-advocacy group is and doesn't understand much about rights.

He thinks we should look at self-advocacy in a different way.

For Joey, just being at the meetings is how he speaks up.



Virginia spoke about her son Danny.

She said she has to campaign on things for him sometimes.

Danny had been to self-advocacy group meetings before and he didn't enjoy them at all.

Jan said that Virginia had learnt to step back and not be too overprotective.



She said she understands families can stop people feeling able to speak out sometimes.



Samir, Brad and Frankie also came to the session.

They spoke about how it was very difficult for them to get to Manchester because they had to think a lot about accessibility.

They had to really plan their journey around things like accessible bathrooms.



Jan said the big message that came from the session was that just being there is really important to disabled people.

She also said there are lots of things that make it difficult for inclusion to happen.



She ended her blog by saying we need to look at how people with profound and multiple learning disabilities can be involved along with everyone else.

Some people might want to be a part of self-advocacy and some might not.

We need to be more inclusive and that must include people with profound and multiple learning disabilities.

We must also work with parents to get there.