

What do researchers need to do to support parents as partners in research?

Robyn:

Remember that families caring for children with CP may have little emotional or mental bandwidth or even time, and certainly their financial resources are likely to be stretched by the additional expenses of caring for a child with disability. So volunteering to do research probably not on most people's high list of priorities. And therefore to make even just the "idea" of being a research partner seem possible to families and parents or caregivers, you need to start by making things like compensation (so, payment) and training and flexibility of the schedule, just need to be the baseline, they need to be prerequisites.

I think you need to set the project up and fund it sufficiently to ensure that you have all the financial and human resources you need so that you really can level the playing field and make sure you are reaching families from all different types of backgrounds. Because to me if you can't do that, I'm really not sure what value there is to engaging families in research.

And then of course, you would need to build sufficient trust with families to demonstrate to them that their input would be both valued and respected. And that means thinking a bit differently, take your academic hat off and put your parent hat on (if you are one) or your aunty hat or your sister hat or your neighbourly hat. You have to connect with families as families in the first instance and try to understand what it is that they might value from working with you.

If I was asked to participate as a research partner, I would want to see that my experiential knowledge (that's the knowledge I have from experience) was being actively sought out, and that it would be used to challenge existing academic knowledge even - and be taken seriously.