

What should researchers know about how to approach families to engage in research?

Robyn:

The challenge you have is how to connect with families from all backgrounds, not just those who are easily accessible. I think one of the best ways you could do this is through community outreach, by which I mean actually going to families where they are in their communities (rather than expecting them to find you for example on a website or in a pamphlet). This would be especially true in lower income areas or countries where access to the internet, to transport, or even to health services is limited.

To me, families are also at something of a disadvantage in family engagement in research because they don't really have a group that represents them, there's no organisation to represent their interests. But the one thing that does exist are parent networks, and these could be one way through which to connect and build relationships with parents and potential parent research partners. For example, in Hong Kong, I'm on the operating committee of a parents' network that has over 650 members and has broad reach throughout the territory, and we aim to connect and support parents of children who have disabilities. We have a very active community, we have an active social media engagement and we arrange talks and events quite regularly. And I think this could be a really great starting to build relationships for family engagement in research.