

Examining the engagement of community partners in autism research within the Autism CRC

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I'm not just a guinea pig or a single data point, I am part of the machinery that helps move research forward... I have a voice.
- Community partner

Background

Participatory research is gaining increased popularity as an efficacious method for conducting health research and research with minority populations. There is also growing recognition within the research community of the need to engage with the autistic community and other stakeholders not only as research participants, but as active and equal partners in research.

In Australia, the Cooperative Research Centre for Living with Autism (Autism CRC) has been at the forefront of this movement with its commitment to investing in inclusive autism research, and has implemented strategies to encourage research co-production. Yet, it is unclear whether the Autism CRC's goal of inclusive research practice has translated into genuine engagement with community partners throughout the process of Autism CRC funded research projects.

Methods

We asked all Autism CRC Project Leaders (N=31) to nominate academic and community partners involved in their research projects. We then emailed all nominated partners (n=127) with an invitation to participate in an anonymous online survey designed to measure key elements of participatory research.

65 participants responded, including 50 (77%) academic and 15 (23%) community partners. Ten (15%) identified themselves as autistic.

Results

Participants were in favour of community engagement in research, with all participants reporting that at least some community partner engagement in research is needed, and almost 40% reporting that extensive engagement is needed.

Participants rated Autism CRC's overall community engagement as moderate; yet, community engagement in specific stages of research was rated considerably lower (Figure 1).



Figure 1. Attitudes towards community engagement and participant-reported actual engagement in Autism CRC research projects

5 key themes

- Participatory research as aspirational**
Participants valued community engagement, but perceived participation as difficult to achieve.
"This was an extremely positive experience for me... I learnt a lot about the value of seeking input from partners" - Academic partner
- Superficial understanding of participatory research**
Understanding of participatory research was varied, but some key concepts were rarely mentioned.
"(Participatory research is) research done by recruiting participants as opposed to working with a pre-existing data set?" - Academic partner
- Entrenched power dynamics**
Community partners often had limited involvement and lacked decision-making power in research.
"I have not been privy to how things have been run and only know the few things that I have been asked to participate in" - Community partner
- Lack of recognition that autistic people can have a role in research that goes beyond being passive participants**
"(The) overall aim is to improve the lives of participants involved in our research, so we listen to them..." - Academic partner
- Systemic issues are perceived to constrain researchers' ability to adopt participatory research methods**
"Sometimes research has to be very rigid for certain reasons... community partners might not understand why at first" - Academic partner

Conclusions

While Autism CRC academic and community partners endorse the organisation's commitment to inclusive autism research, there may be substantial barriers limiting genuine and meaningful community engagement.

Objectives

1. To examine the nature and extent of community partner engagement within research projects funded by the Autism CRC, by gathering perspectives from both academic and community partners
2. To determine whether community and academic partners hold similar or differing perspectives of the nature and extent of community engagement within Autism CRC research

For more information

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