

Listening to Parents to Understand their Priorities for Autism Research

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For which topic were research priorities identified?

autism

In which location was the research priority setting conducted?

Australia - Australia

Why was it conducted at all?

Parents are often the greatest advocates for their child and thus, are especially important stakeholders when prioritising the needs of research for school-aged children. However, the research priorities of parents of school-aged children are largely understudied and consequently, the understanding of what the research priorities should be for school-aged children on the autism spectrum is currently limited. Such knowledge will help to guide the allocation of research funding and ensure that research is being done where it is needed, and thus, is most likely to have a real impact across all aspects (home, school, community) of the lives of individuals on the autism spectrum, and their families.

What was the objective?

to determine what parents identify as priorities for autism research to support their school-aged children

What was the outcome?

a ranking list of 15 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

group discussion; survey

How were the priorities for research identified exactly?

Step 1: survey: parents were asked: "In your opinion what three areas should research focus on to support your child on the autism spectrum in each of the following settings: home, school and community?". Step 2: data processing: content analysis: the top 15 categories of priorities for home and school and all 13 research priority categories for the community were derived. Step 3: group discussion: group discussion with Q-sort methodology: each priority was individually printed onto cards for parents to arrange from most important (+4) to least important (-4) using the Q-sort grid, after all participants had completed their sort they were then asked to discuss and explore the reasons behind their choices and rankings within their groups

Which stakeholders took part?

Parents of school-aged autistic children. Survey: 134 participants. Workshop: 9 participants.

How were stakeholders recruited?

Participants were recruited via PoCoG. Eligible Australian experts in FCR research were identified through the PoCoG FCR Interest Group and via snowballing).

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.