

When a parent asks for support: An exploratory study of professionals' perspectives on decision-making around children with learning difficulties

What we found

"You have to trust that a parent knows the best thing for the child."
(Professional)

We specifically asked professionals and autism experts about times when parents had requested a particular form of support for a child. Professionals could not easily think of examples of this. Professionals and experts thought few parents would be in a position to make such a request. Only some parents would have the knowledge, negotiation skills, time or financial resources.

Professionals viewed decision-making as a collaborative discussion with parents about ways forward. Parental expertise was valued explicitly by professionals, but they expected parents to be sources of information, and not necessarily to bring solutions.

"We have a discussion about what matters to you, what matters to your child."
(Professional)

Children's views were rarely mentioned and therefore did not seem to be a key part of the decision-making process.

Professionals saw their decisions primarily as based on what would work for the child; a key next step was to consider what services were available locally to meet that child's needs. Professionals acknowledged that pressure on budgets was part of the picture; experts suggested that resources were a more important factor than professionals were describing. Both thought that how professionals talked to parents about resources was an area of difficulty in their relationships.

"It's really about resources."
(Autism Expert)

Professionals were cautious about their relationships with one another. They raised several areas of tension, including not listening to each other, not understanding each other's roles, and dealing with resource pressures. Where there were tensions, professionals and experts were concerned that families could feel they were being passed around services.

Recommendations for future research

We need to know more about how decision-making is working for all the individuals involved. A mix of observation and gathering views from all parties could work well for this. Further research must include the perspectives of children and young people.

It would be helpful to know how professionals, parents and carers, and children and young people view the same interactions, whether all perceive decision-making to be happening collaboratively and communication to be effective.

How we carried out the research

We reviewed existing research and carried out ten one-to-one conversations for this exploratory study. Six conversations were with professionals: social workers, educational psychologists; people in frontline posts; and those with more managerial or developmental responsibilities. Four were with autism experts: people with experience in research, consultancy or voluntary sector provision around autism.

We asked people about a scenario of a parent making a request for a particular support, including whether they had experience of this occurring with Applied Behaviour Analysis (ABA). We asked them to talk about what might happen in this sort of scenario, what local policies or practices might affect the decision-making, and also how it could affect professionals' relationships with parents and with other professionals.

Why it matters – our rationale for the research

Between 2015 and 2017 Salvesen Mindroom Centre and Salvesen Mindroom Research Centre, together with the James Lind Alliance, conducted a priority setting exercise to identify the top ten research priorities for learning difficulties. Over 800 questions were received during this exercise.

Several questions were identified as being 'out of scope' for the priority setting exercise itself. Salvesen Mindroom Centre themed these questions into three areas of further interest and commissioned the Childhood and Youth Studies Research Group (University of Edinburgh) to conduct scoping studies in these three areas. The purpose of these scoping studies was to identify gaps in knowledge and key questions for future research. The quality of communication between parents, children and young people and professionals was the overwhelming theme which arose in all three scoping studies.

This study focuses on professionals' experiences where parents are seeking a particular form of support for their children. It was motivated specifically by questions in the priority setting exercise about parental requests for Applied Behaviour Analysis (ABA), as well as Salvesen Mindroom Centre's own experiences of providing support to parents. There is existing research around parents' perceptions of support or of relationships with professionals, but relatively little which considers what happens when parents are seeking a particular form of support for a child.

Thank you

This research could not have taken place without the generosity of the young people, parents and professionals who took part. Thank you for your time and your willingness to share your stories and insights.

This briefing focuses on the first of three scoping studies on the experiences of children with learning difficulties, and their families, in Scotland. Full findings for all three exploratory studies are found in the report: 'Communication matters' available at

www.mindroom.org/index.php/help_and_support/research

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www.ed.ac.uk/education/childhood-and-youth-studies