

## Information seeking is part of parents' emotional journey: an exploratory study on the experiences of parents of children with learning difficulties

### What we found

Parents described receiving information but feeling lost, isolated and alone. Although parents talking about needing information or advice, often they expressed this with a need for support around the complexity and difficulty of their child's and their own lives. They wanted to know what to do – but also wanted someone to talk to about their experiences.

"You're given the leaflets [...] and then you're on your own" (Parent)

"They are not forthcoming with the information that will make your life easier" (Parent)

Parents described their access to information as luck or chance. When they asked professionals for services or types of support then they were able to secure these. But parents needed to know enough to make the request. Information was sometimes only accessed through another parent.

Information that parents did receive was not always in a form that they could use; for example a long list of resources that might help their child, but without contact details or information on how to access these forms of support.

Parents were extremely grateful for what they described as the 'human touches' from professionals. These included a professional who chased up a letter and one who sent a text to say an action had been followed up.

"Her communication is excellent [...] it's very respectful, it's very responsive. She emails, she texts." (Parent)

"You shouldn't have to be there fighting these people that should be put in place to support you. But they're not. They make it even more difficult." (Parent)

Respectful communication from professionals was not a universal experience. Parents talked about not being listened to and how difficult they found it to always have to chase professionals for information. Parents described feeling like they were forced into a position of having to fight.

### Recommendations for future research

Research should consider how current information provision (including ongoing communication by professionals) affects parents' emotional experiences, such as how secure or respected they feel. This would help identify what role information can and cannot play in supporting parents' whole experiences as well as the ways to most usefully provide information to parents.

## **How we carried out the research**

Two groups of parents were asked to talk about their information needs, including the information they wanted or received from professionals, and the types and sources of information they found useful.

10 parents took part in total, all women with primary school aged or younger children. The parents identified as parents of children with learning difficulties; the children had a range of diagnoses including autism spectrum disorder, Attention Deficit Hyperactivity Disorder (ADHD), global development delay, Developmental Coordination Disorder (DCD) and no formal diagnosis.

## **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 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 focused on parents’ information needs. There is a relatively large body of existing research which recommends improvements to information provision for parents or which identifies a gap between the information parents are seeking and what they have access to. Nevertheless, this continues to be an area of insecurity and concern for parents. This scoping study was an initial exploration of what may be happening behind parents’ information needs, in order to identify how to fulfil those needs more effectively.

## **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.

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This briefing focuses on the second 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](http://www.mindroom.org/index.php/help_and_support/research)

The briefing was drafted by Dr Ruth Friskney, Childhood and Youth Studies Research Group, University of Edinburgh, on behalf of Salvesen Mindroom Centre.

[www.ed.ac.uk/education/childhood-and-youth-studies](http://www.ed.ac.uk/education/childhood-and-youth-studies)