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IMPROVING THE WELL-BEING OF YOUNG CHILDREN WITH LEARNING DISABILITIES

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About this briefing

This briefing highlights work by researchers, charities and parents to develop an information booklet to help parents of children with learning disabilities promote their child's well-being. It provides an overview of the booklet and demonstrates how research can be made more accessible if academics work collaboratively with non-academic stakeholders, such as parents and charities, and disseminate findings in creative ways.

Why is well-being important for families of children with learning disabilities?

Children with a learning disability (LD) are more likely than children without LD to experience difficulties with their physical, mental, emotional and social well-being. Some of these difficulties arise from issues associated with having a disability, but most often difficulties arise because of environmental adversities. One example of environmental adversity is families not having access to the right type of support and information at the time that it is most needed.

Key findings and recommendations

- Parents need and want guidance on supporting the well-being of children with LD.
- Parents want guidance on supporting the development of their child's positive skills, not just guidance on managing difficult behaviours.
- Partnerships between researchers, charity partners and parents can help make research accessible to the people that can benefit most from evidence.
- Supporting the development of social well-being in young children with LD can take place through regular family processes, such as having warm, close relationships, doing fun activities at home and playing with friends outside the home.

Research in LD has focused extensively on understanding the behavioural, emotional and social well-being of children with LD. However, parents of children with LD often say that the information and support they receive about their child's well-being focuses on medical and other health issues and not on more general aspects of their well-being. Most of the relevant research is not accessible to parents, and what is tends to focus most on managing behaviour problems and addressing functional limitations (e.g., feeding, self-care). Parents also want and need information on how to support their child to reach their full potential in all aspects of their lives and well-being.

Working with parents to translate research findings

Researchers are increasingly recognising the need to make research more accessible to research subjects and beneficiaries, and to break down the barriers between academic evidence and practice.

The University of Warwick has co-produced an innovative information booklet with families and partner

organisations based on findings from over 20 years of research into the well-being of families of children with LD. Families of children with LD were specifically involved with the design and content of the booklet to ensure it would be both relevant and easy to access. They also contributed their own stories to illustrate how the findings from research turn into lived experiences and actions in day-to-day life. Researchers, parents, and partner organisations were very clear that the booklet should focus on promoting child well-being, especially social well-being, such as social skills, independence and empathy.

Working with third sector partners to make research accessible

Third sector organisations are key stakeholders in the process of translating research evidence into practical knowledge and useful information. To develop the booklet, the researchers worked with three organisations that they have long-established relationships with and that came together under their shared interest in early support and intervention for families. Each has a long history advocating for and supporting individuals with LD:

- [Cerebra](#) is a charity working wonders for children with brain conditions. They listen to families, use what they say to inspire the best research and innovation, and then help them put that knowledge into practice so that they can discover a better life together.
- The [Challenging Behaviour Foundation](#) supports families of individuals with severe LD whose behaviour challenges. They provide information, resources and training for families and professionals. They have recently led on [early intervention](#) for families of children whose behaviour challenges, including mapping provision, identifying what works, and talking to families and children about their vision for early intervention.
- [Mencap Northern Ireland](#) is leading Mencap's early intervention in the UK, in terms of policy change, research and practice. They offer innovative early intervention services from their Belfast-based children's centre to families across the country.

Booklet content

The information for parents in the booklet is organised into four chapters, which they can access in any order. The chapters focus on parental well-being, spending time together (relationships in families), social relationships and family routines, and activities that parents do with their children in and out of the house. Each one provides a summary of the underpinning research, and includes examples from parents of children with LD on how to apply the research findings in everyday life. Parents felt that

there should be some space for reflection within the booklet, so at the end of each chapter there are some questions that can guide their reflection and planning for change.

What did parents who read the booklet say about it?

"The language is clear and easy to understand. It has a positive outlook. I like the focus on parents' well-being. I like that it references research in a user-friendly way".

"Lots of positive statements about having a child with a learning disability and I liked the parents' comments".

"Information is clearly presented in friendly language. Illustrations are good. Useful checklist at the end of chapters".

"It was well written, straightforward, and not condescending".

"The best part about the booklet was hearing about other people's experiences and coping mechanisms. From reading these, I know I am not alone".

Further information

This briefing is based on: Flynn, S., Totsika, V. and Hastings, R. (2018) [A Parent's Guide: Improving the well-being of young children with learning disabilities](#)

The booklet was produced as a collaboration between the University of Warwick, Cerebra, Mencap, the Challenging Behaviour Foundation, and parents of children with learning disabilities.

The views contained in this briefing do not necessarily reflect the views of the University of Warwick.

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