

# Experts call for more support for parents of children with genetic learning disabilities

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Parents of children with genetic conditions that cause learning disabilities are at risk of mental health problems, suggests new research published today in the *British Journal of Psychiatry*. The teams behind the study have called for greater support for parents whose child receives a genetic diagnosis for their learning disability.

As many as one in 20 families worldwide is thought to include a child with a learning disability, but little is known about how this affects the [parents' mental health](#) and wellbeing. Although some parents experience depression and anxiety, it is not clear why some are at greater risk than others.

Professor Claire Hughes from the University of Cambridge Centre for Family Research, said: "It's important that we understand why some parents are at greater risk of mental [health](#) problems than others. If a parent experiences long-term mental health problems, this could have a knock-on effect on the whole family, affecting partner relationships, the wellbeing of their child with disability, and the experiences of siblings. That's why interventions are often more successful when they are designed to help parents in order to help children."

To address this question, Professor Hughes assembled an interdisciplinary team of researchers from the Universities of Cambridge and Birmingham to analyse information from 888 families taking part in the IMAGINE-ID study—a UK-wide project examining the links between genetic diagnoses, learning disabilities and mental health.

Parents were asked to rate their everyday feelings and the nature and impact of their child's difficulties, as well as to provide information about their family's [social circumstances](#).

One parent who participated in IMAGINE-ID said that professionals tended to focus on the child's needs and did not consider the wider needs of families: "It's very much about getting support for your child. At no point were we ever offered any mental health support, even though we have such a massive role to play in bringing up our children. We need support as well."

The study data shows that rates of negative symptoms such as worry, anxiety and stress were much higher in the IMAGINE-ID group of parents than in the general population of parents. Mothers in the IMAGINE-ID study—who were more likely to be the main caregiver—were particularly affected. Contrary to evidence from previous studies, social factors did not predict a parent's risk of low mood and stress: more important were the type of genetic disorder that affected their child, their child's physical and medical needs, and their child's behaviour.

For the first time, the researchers were able to demonstrate that the cause of a child's disabilities is one factor that predicts the emotional wellbeing of parents. A subgroup of genetic disorders is caused by short missing or duplicated sections of DNA (known as 'copy number variants'). Parents within this subgroup reported that their child's difficulties had a high level of impact on family life as well as restricting their child's activities and friendships, and these impacts were the source of their own distress.

The researchers say there could be a number of explanations for these findings, varying from the complex effects of chromosomal differences on children's development through to the availability of support for these

families. They have called for more multi-disciplinary, family-focused research to determine how genetic diagnoses are linked to parents' mental health, so that support for families can be improved in future.

Dr. Kate Baker, lead author of the research paper, based at the MRC Cognition and Brain Sciences Unit, University of Cambridge, said: "These results suggest that we need to start looking at genetic diagnoses as useful not just for predicting a child's needs and informing the support that they might receive, but also for predicting the broader impact that the diagnosis will have on their [family](#)."

Francesca Wicks, former research coordinator for IMAGINE-ID and now Family Support and Information Officer for Unique, the rare chromosome and single gene disorder support charity, said: "It's clear that not enough care and support is being offered to parents before, during and after their child's diagnosis. The help and support offered by organisations such as Unique is incredibly valuable, but much more needs to be done within health and statutory services. Many of the families I have met have expressed feelings of anxiety and depression over the years, which is why we have produced our Carers Wellbeing guide."

**More information:** Baker, K et al. Childhood intellectual disability and parents' mental health: integrating social, psychological and genetic influences. *BJPsych*; 11 March 2020; [DOI: 10.1192/bjp.2020.38](https://doi.org/10.1192/bjp.2020.38)

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