Parental Attitudes and Experiences in Pursuing Genetic Testing for Their Child's Motor Speech Disorder

Key terms

Childhood Apraxia of Speech, dysarthria, speech motor disorder, genomic testing

What this research is about

Approximately 30% of children who undergo genomic testing for motor speech disorder (such as Childhood Apraxia of Speech and dysarthria) have an explanatory genetic finding.

Understanding how parents views and experience genetic testing for their child is critical in providing holistic genetics healthcare to families.

What the researchers did

- 20 parents whose child underwent genetic testing for motor speech disorder were interviewed
- Of the 20 parents interviewed, 8 received a genetic finding, 12 did not

What the researchers found

- Parents were **highly motivated** to pursue genetic testing for their child's speech condition

Some common motivating factors were:

Finding an explanation

Parents wanted to determine the cause of the speech condition in their child and other family members.

Having a label

Parents felt that a genetic label adds weight to their child's speech diagnosis and improves access to NDIS funding.

Building a bigger picture

Parents wanted information about their child's prognosis and other medical issues that may arise.

Providing information for others

Genetic testing was thought to be informative for other relatives as well as other families affected by speech conditions.

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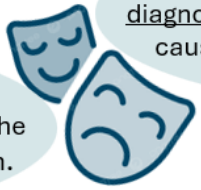
- Regardless of the test outcome received, most parents experienced mixed emotions and felt that it was **"bittersweet"** to learn about their child's genetic test results.

While there was **relief** in ruling out a genetic diagnosis, there was still **uncertainty** around the cause for the child's motor speech disorder.



While there was **relief** in obtaining a genetic diagnosis, there was still **uncertainty** around the implications of having a rare genetic condition.

- Parents who received a genetic finding for their child were able to better **access funding and clinical care**; however they also **hoped for ongoing support** in navigating the uncertainty surrounding their child's rare diagnosis

A desire for **peer support**, particularly in connecting with other families with similar lived experiences.

Hope to be **notified when new information becomes available**, especially if relevant to the child's clinical care.

- Parents who did not receive a genetic finding for their child used both **practical and emotional ways of coping** with the lack of a genetic diagnosis

Shifting their focus to **managing the child's symptoms**, which often does not rely on a genetic diagnosis.

Recognising the **unconditional love** for their child, regardless of genetic testing outcome.

What this means for parents pursuing genetic testing for motor speech disorder

This research helps improve the support that we provide to families affected by childhood motor speech disorder.

Learn more here: Atkinson, C., Lee, Y.Q., Lauretta, M.L. *et al.* Parental attitudes and experiences in pursuing genetic testing for their child's motor speech disorder. *Eur J Hum Genet* (2024). https://doi.org/10.1038/s41431-024-01755-z

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