

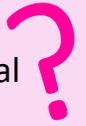
IMAGINE ID RESEARCH STUDY FINDINGS

IMAGINE recruited over 2,000 people with a rare genetic condition that was associated with **intellectual disability** to take part in a research study. We asked parents of IMAGINE children to complete surveys about their child's development, behaviour and mental health.

Who took part?

- Children were aged between **4** and **19**
- **56%** were male and **44%** were female
- We found a very wide range of genetic conditions cause intellectual disability, each one of which affected just a few children:
- In total, IMAGINE children had changes affecting **1166** different areas of their genetic make-up. Most were so rare that very little is known about the way in which those changes affect their development.

What is intellectual disability?



Intellectual disability, learning disability or developmental delay are terms used to describe people who struggle with some everyday activities and learning. This often means it will be more difficult for them to understand complex information, develop new skills, and cope with unfamiliar situations.

What did we find?

1. IMAGINE children are **complex**

IMAGINE children were **4 times more likely** to have a mental health or developmental condition (such as an autism spectrum condition or attention deficit hyperactivity disorder) than typical children in the UK:



1 in 3 met criteria for an Autism Spectrum Condition (ASC)



1 in 10 met criteria for an anxiety condition



1 in 5 met criteria for Attention Deficit Hyperactivity Disorder (ADHD)



1 in 10 met criteria for an Oppositional Defiant Disorder (ODD)

42%

had one or more mental health or neurodevelopmental conditions

90%

Reported one or more physical health difficulties

2. Need for **early support**

- IMAGINE children living in more deprived areas had greater behavioural difficulties, and less educational and social support than those living in more advantaged circumstances.
- Providing earlier social and behaviour support for families may help improve children's outcomes.

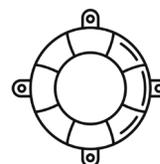
What next?

Children with rare genetic condition and intellectual disability have a **high chance of neurodevelopmental, behavioural and mental health difficulties**, irrespective of their specific genetic condition.



We can't change a person's DNA, but we can **improve the support we offer them**. The IMAGINE study's findings should be used to **plan targeted assessments and behavioural interventions** to support families at the earliest opportunity.

The IMAGINE 2 study aims to describe how IMAGINE children's needs change as they grow up. We hope that looking at how **things change over time** will help us to understand how best to **offer support**.



Resources for parents

Many parents told us that they found it difficult to access support for their child's difficulties. Here are some guides that might help:



Unique practical guides for families:

<https://rarechromo.org/practical-guides-for-families/>



Practical support, advice and events for families:

<https://contact.org.uk/>



Parent-centred online information, news and resources:

<https://www.specialneedsjungle.com/>



GP Information pack:

<https://www.learningdisabilities.org.uk/learning-disabilities/our-work/health-well-being/improving-access-mental-health>



Support for parents:

<https://cerebra.org.uk/download/factsheet-emotional-well-being/>