

# Genetic Testing

---

## **What is Autism New Zealand's understanding of genetic testing?**

In line with our Principles of Service, we understand autism is a neurological difference and that brain differences are a normal part of human variation, rather than deficient or in need of curing.

Therefore, research that aims to cure autism, or to reduce the numbers of autistic people in the population/prevent autism is not supported by Autism New Zealand as an organisation.

There can be benefits in genetic testing if it is used to support diagnosis. However, current research and best practice in Aotearoa New Zealand recommend diagnosis via psychological assessment to ensure the most accurate and reliable diagnosis. At this stage, there is no genetic test that is refined enough to accurately and reliably diagnose autism without the support of a psychological assessment. It is important to consider whether the benefits outweigh the risks.

## What are the pitfalls of genetic testing for autism?

- Given more than 100 genes are linked to autism, research to date indicates genetic testing can only be used to confirm a diagnosis in a small percentage of people. Psychological assessment is currently the recommended and most accurate and reliable method to confirm diagnosis.
- Genetic testing around autism has a tendency to lean towards looking at causes, cures and preventions, which leads into eugenics. It can hold a negative and misguided understanding of autism that hinders progression of more inclusive societies.
- Genetic testing can create unnecessary psychological ups and downs for parents who perhaps get their hopes up for certain outcomes for their children.
- There are data safety concerns around genetic testing. Subjects often contribute their genetic material to a data bank rather than a specific study, and that material can then be used for research the subjects may not necessarily agree with or want to contribute to. It is important to check how your data is being used.

## When is genetic testing for autism helpful?

- When a psychological assessment is inconclusive, or there is significant psychological trauma or other circumstances in the mix, genetic testing can be helpful in addition to psychological assessment but not as a standalone.
- There are many co-occurring physical conditions that an autistic person may experience, genetic testing may be one way to help identify some of these.
- Some autistic people or parents can find that having the scientific proof of their diagnosis is validating, but, again, this is in addition to the psychological assessment, not on its own.
- When genetic testing can confirm a diagnosis, it can also enable access to the right supports.