

A Comprehensive Study on Life Course Outcomes for Autistic Children and Young people and their Families in Aotearoa | New Zealand using Population-Level Linked Data

Authors

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Disclaimer

These results are not official statistics. They have been created for research purposes from the Integrated Data Infrastructure (IDI). The IDI is a research database which is managed by Statistics New Zealand. For more information about the Integrated Data Infrastructure, please visit <https://www.stats.govt.nz/integrated-data/>.

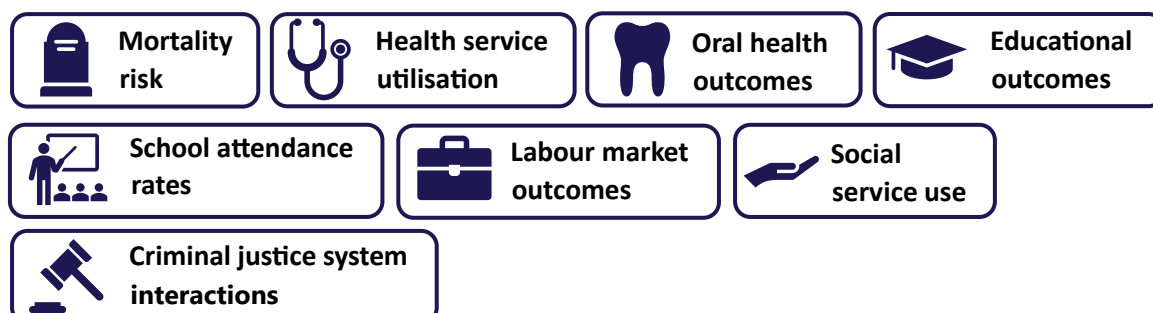
Summary

This report, commissioned by the Laura Fergusson Trust and Joyce Fisher Endowment Fund Trust, investigates life course outcomes for Autistic children, young people, and their families in Aotearoa, New Zealand.

Utilising population-level linked data from the integrated data infrastructure (IDI), the study aims to provide insights into the challenges and disparities faced by Autistic individuals and their families.

This research is crucial for informing policies and practices that support the well-being of Autistic people and their families, aligning with the obligations under the United Nations Convention on the Rights of Persons with Disabilities.

The report consists of 10 studies. Studies one to eight focussed on Autistic youth (aged 0-24 years). These explored:



Two studies focussed on parents of Autistic children and explored:



Autistic youth

Participants

For most of the studies included in this report, the participant population was the IDI estimated resident population of all children and young people (0-24 years) in New Zealand for the 2019 calendar year. Some studies varied in their design and therefore had different participants.

Number of youth included

Total: 1,580,757

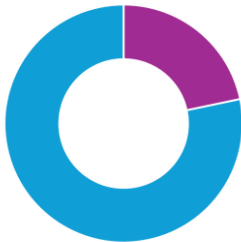
Non-autistic: 1,561,278

Autistic without intellectual disability: 13,821

Autistic with intellectual disability: 5,658

Sex

Autistic



Female: 4,227 youth (21.7%)

Male: 15,252 youth (78.3%)

Non-autistic



Female: 763,959 youth (48.9%)

Male: 797,319 youth (51.1%)

Ethnicity

Autistic



Non-autistic



Results

Mortality

This 15-year birth cohort study is one of the first to examine mortality risk among Autistic children and young people at a population level, before and during the period of the COVID-19 pandemic.

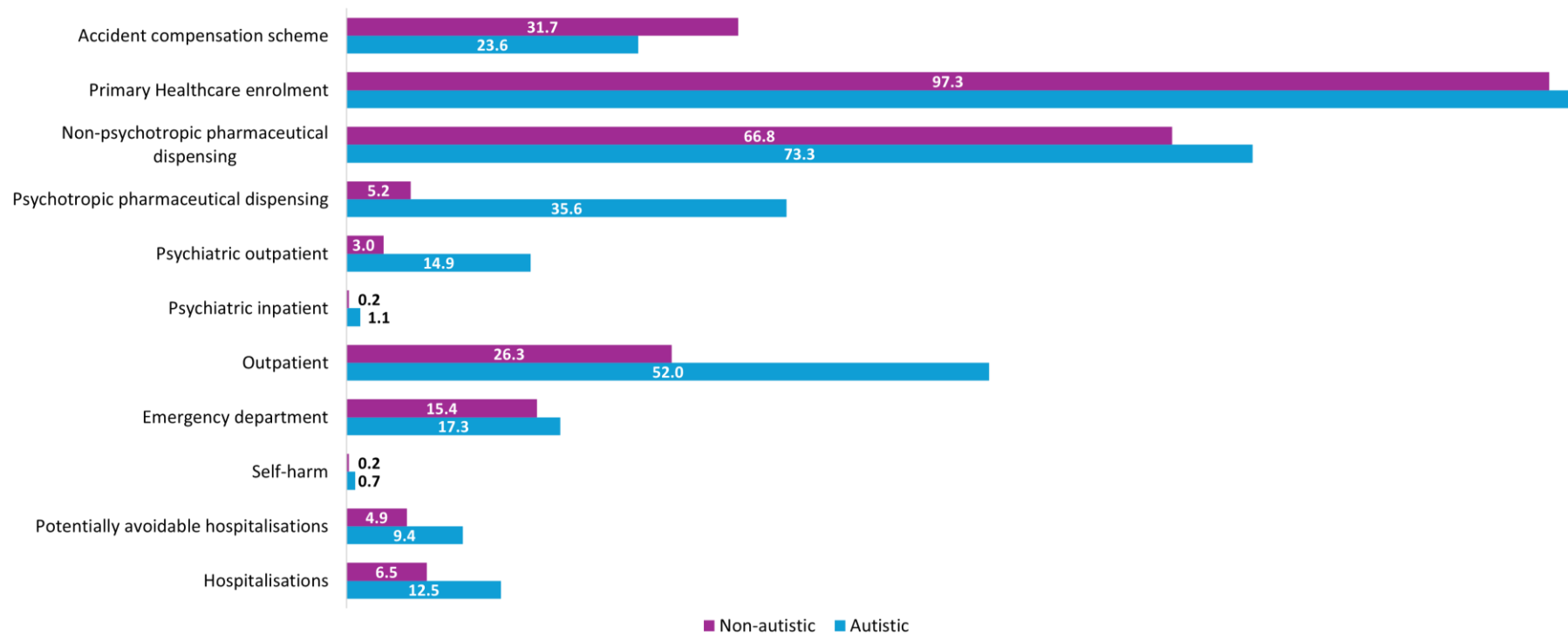
The estimated mortality risk for Autistic individuals was 2.35 times that of non-Autistic individuals and substantially higher among females than males.

Moreover, among Autistic children and young people, co-occurring intellectual disability was associated with almost twice the risk of mortality compared with Autistic individuals without ID.

Health service use

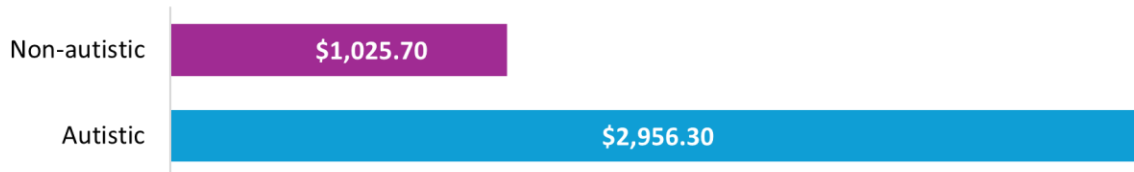
Autistic youth showed significantly higher rates of health service utilisation compared to their non-Autistic peers.

Percentage of youth accessing health services in 2019



The total annual healthcare costs were significantly higher for Autistic individuals.

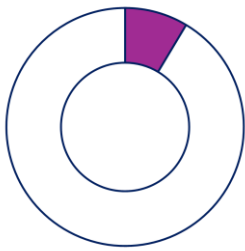
Average annual cost of health service utilisation for 2019



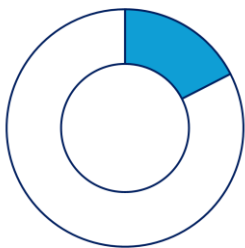
Oral health

Autistic youth faced poorer oral health outcomes compared to their non-Autistic peers. Autistic children had an increased risk of dental hospitalisations and children with a neurodevelopmental condition (autism, attention-deficit/hyperactivity disorder [ADHD], or ID) also had a significantly higher rate of visible dental carries at age four.

Percentage of participants who had at least one hospitalisation

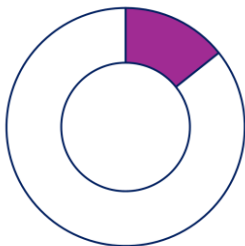


8.6% of participants without identified neurodevelopmental disability had at least one dental hospitalisation.

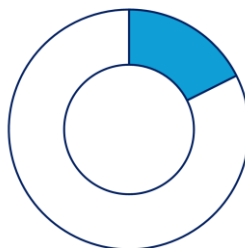


17.5% of Participants with an identified neurodevelopmental disability had at least one dental hospitalisation.

Percentage of participants who had dental carries at age 4 years



14.3% of participants without identified neurodevelopmental disability had visible carries.



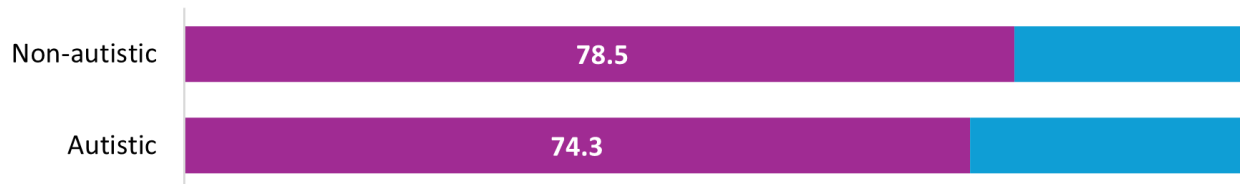
17.6% of Participants with an identified neurodevelopmental disability had visible carries.

Educational outcomes

Autistic students had lower rates of enrolment in early childhood education, primary school, high school, and tertiary education. Autistic students were less likely to attend school with significantly higher chronic absence rates. Suspension rates were also significantly higher. In addition, Autistic students were significantly less likely to attain National Certificate of Educational Achievement (NCEA) qualifications.

Children aged 0-4 years

Percentage of participants enrolled in ECE

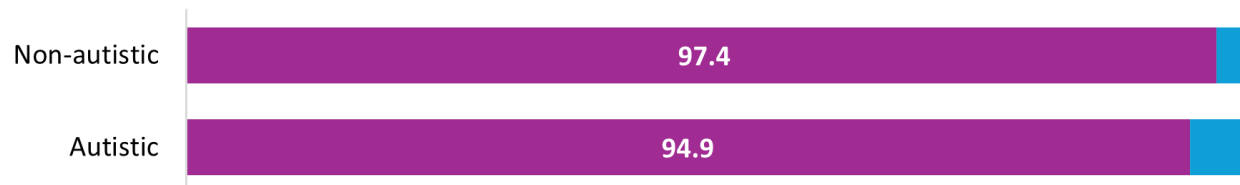


Percentage of participants receiving early intervention services

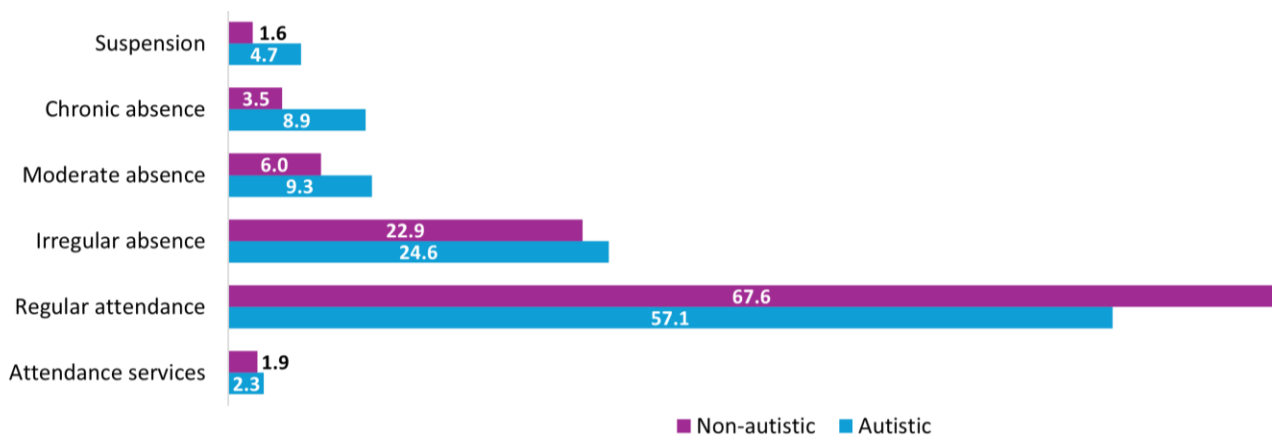


Children aged 5-12 years

Percentage of participants aged 5-12 enrolled in school

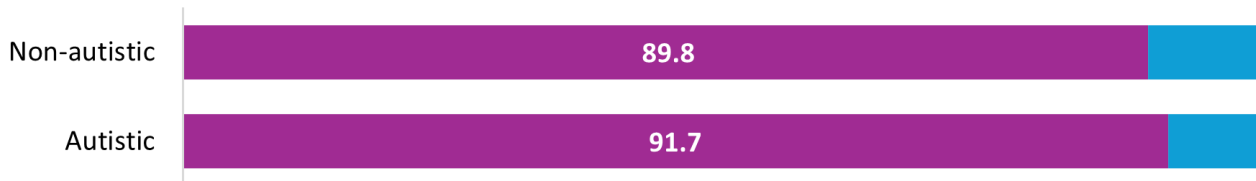


Percentage of participants aged 5-12 with attendance related outcomes

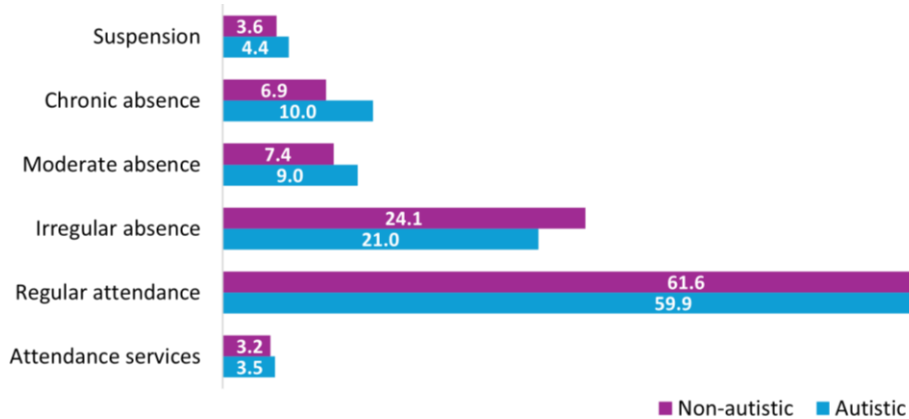


Young people aged 13-18 years

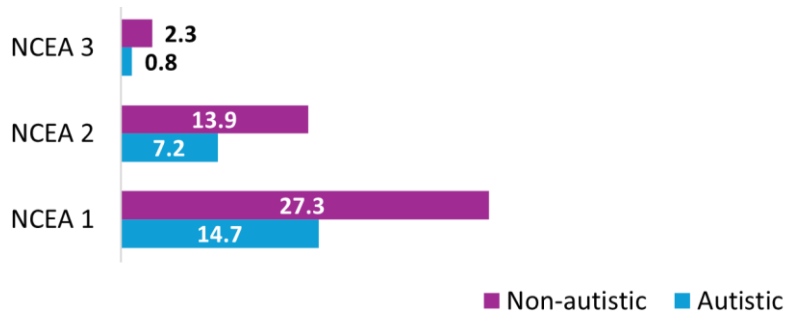
Percentage of participants aged 13-18 enrolled in school



Percentage of participants aged 13-18 with attendance related outcomes



Percentage of participants aged 13-18 years with NCEA completion



Young adults aged 19-24 years

Percentage of participants with tertiary enrolment and qualifications



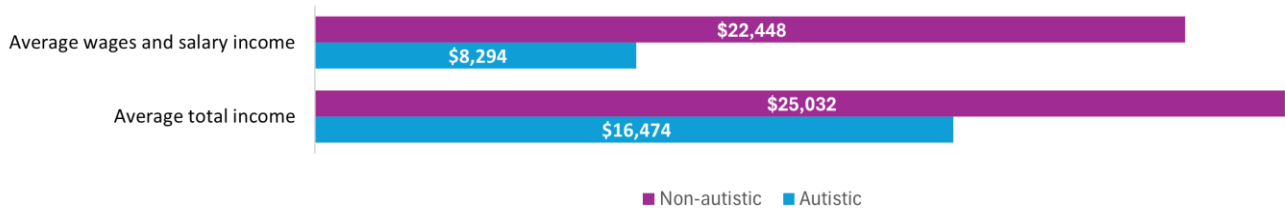
NZQF 7 or more: Bachelor's degree or higher

NZQF 4: Certificates for vocational training. First year undergraduate.

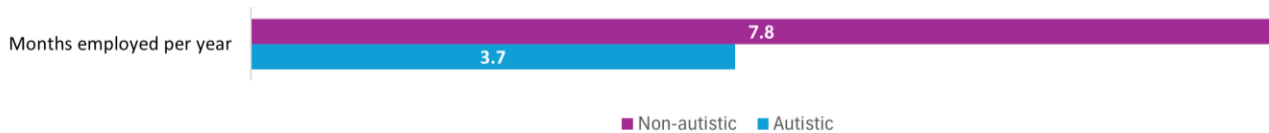
Labour market outcomes 18-24 years

Autistic young adults (18-24 years) faced significant barriers in the labour market. In 2019, they had fewer average number of months in paid employment. Autistic individuals also had significantly lower overall annual average income and income from salary and wages

Average income



Average number of months employed per year

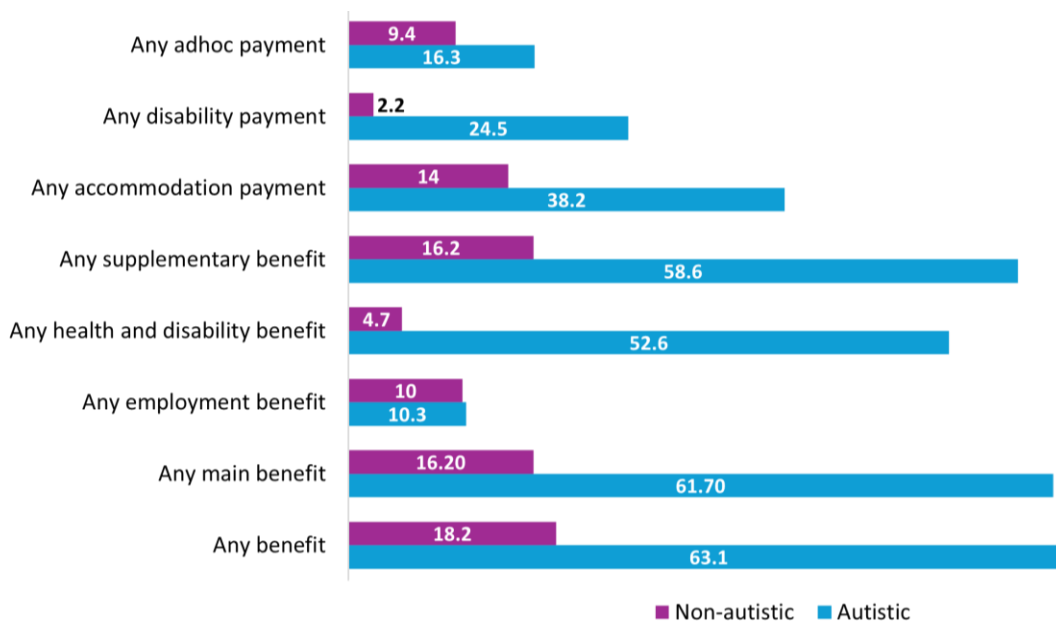


Social service use

Benefit use among Autistic young adults was significantly higher compared to their non-Autistic counterparts.

Main benefits are payments for working-age individuals who are not employed and cannot work full time due to various circumstances. Main benefits include unemployment benefits for those seeking full-time work, carer benefits, health and disability benefits for those unable to work due to illness, youth benefits, and emergency benefits for individuals who do not qualify for other payments.

Percentage of participants receiving benefits from Ministry of Social Development



Disability support service use

11.3% of autistic participants received DSS payments.

0.2% of non-autistic participants received DSS payments.

Average DSS payment amount

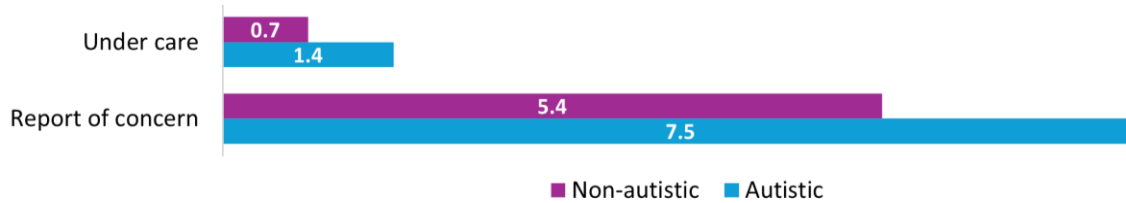
Autistic: \$6,665

Non-autistic: \$106

Oranga Tamariki

Autistic young people (0-17 years) were more likely to have interactions with Oranga Tamariki (OT) with reports of concern rates and rates of being under state care both significantly higher.

Percentage of participants with contact with Oranga Tamariki

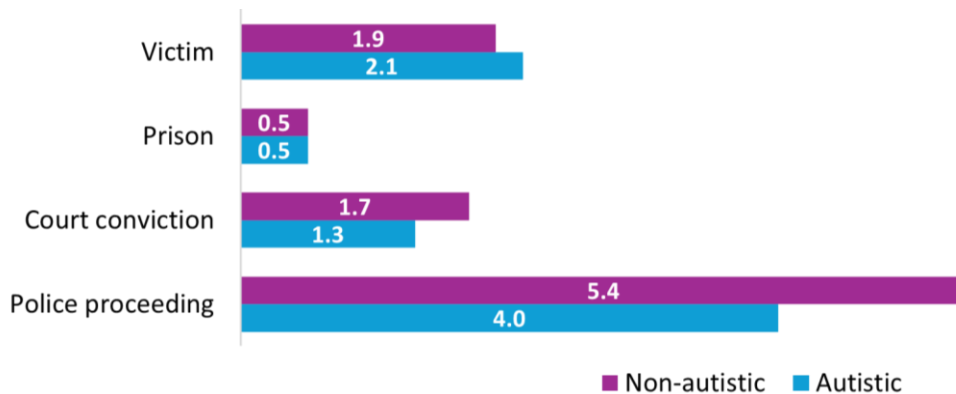


Criminal justice system outcomes

Autistic individuals (17-24 years) had significantly lower interaction rates with the criminal justice system. This included lower rates of police proceedings, and court convictions, but similar rates of incarceration.

Autistic youth were slightly more likely to be victims of crime.

Percentage of participants with criminal justice system interactions

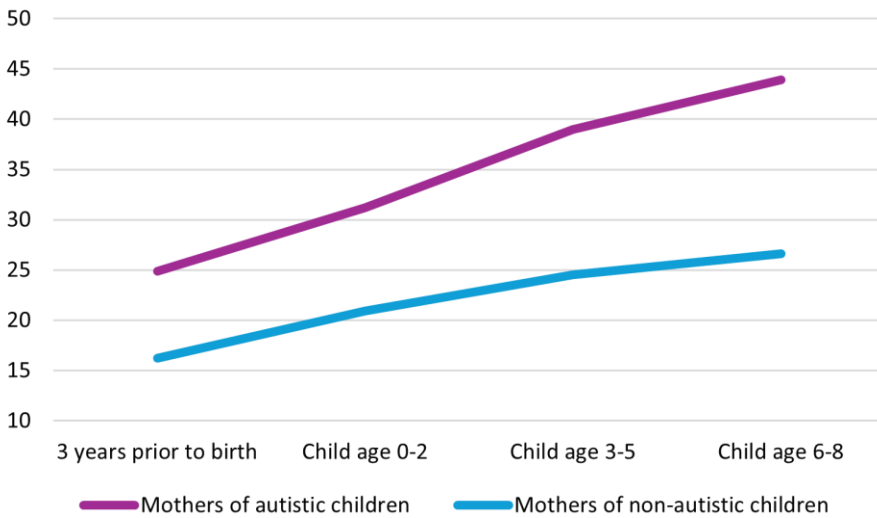


Parents of autistic children

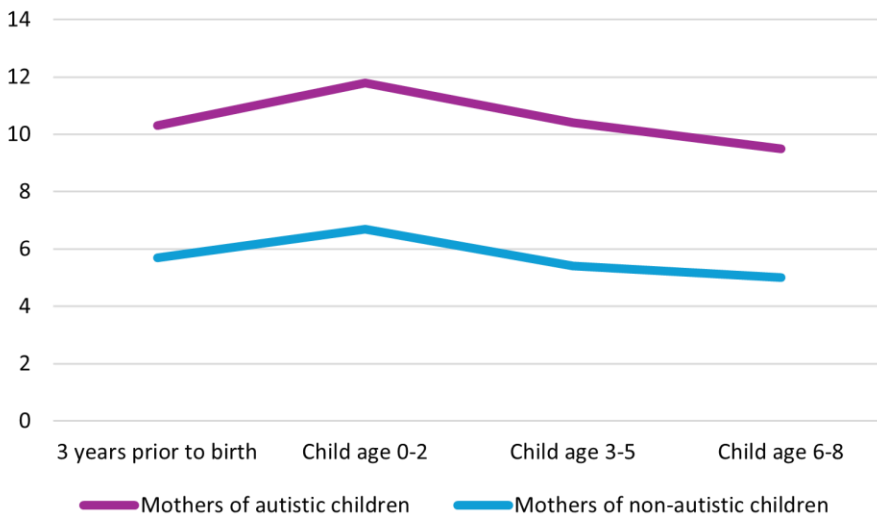
Mothers' mental health outcomes

Mothers of Autistic children experienced significantly higher rates of mental health service use compared to mothers of non-Autistic children. Mothers of Autistic children were significantly more likely to have mental health pharmaceuticals dispensed, mental health outpatient contact, mental health crisis contact, an inpatient mental health stay, and be hospitalised for self-harm.

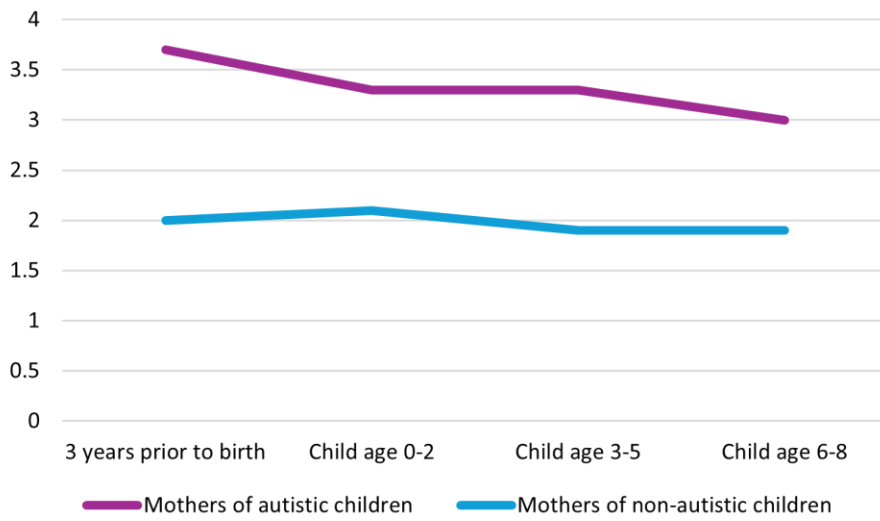
Percentage of participants who received mental health pharmaceutical dispensing



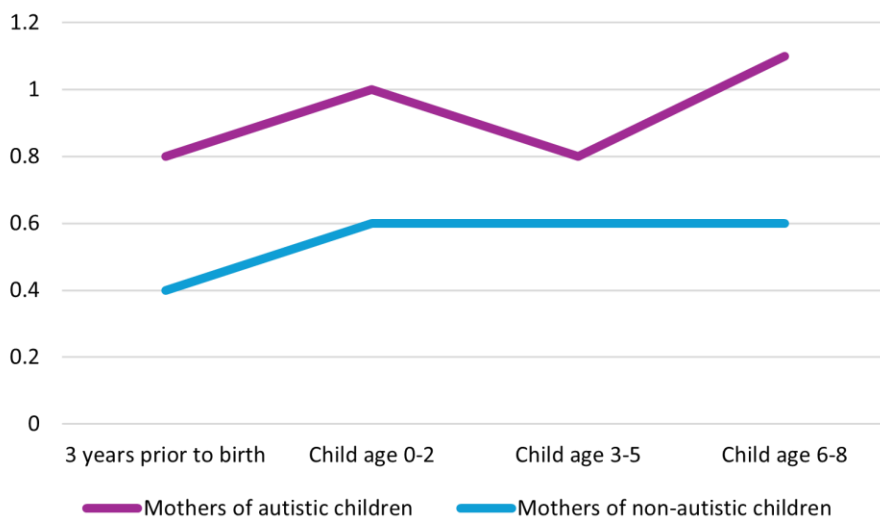
Percentage of participants who had mental health outpatient contact



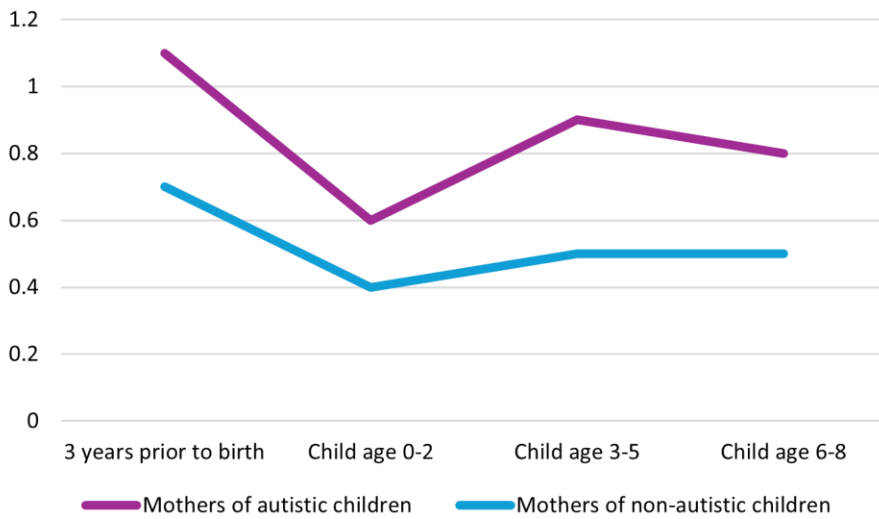
Percentage of participants who had mental health crisis contact



Percentage of participants who had inpatient mental health bed-nights



Percentage of participants who had hospitalisations for self-harm



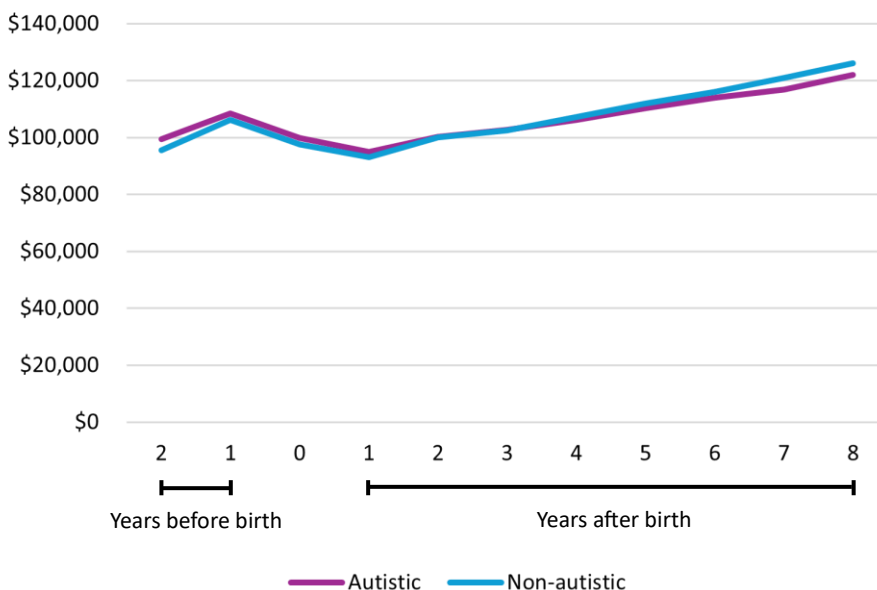
Parents' labour market outcomes

Parents of Autistic children experienced greater negative impacts on household income compared with parents of non-Autistic children.

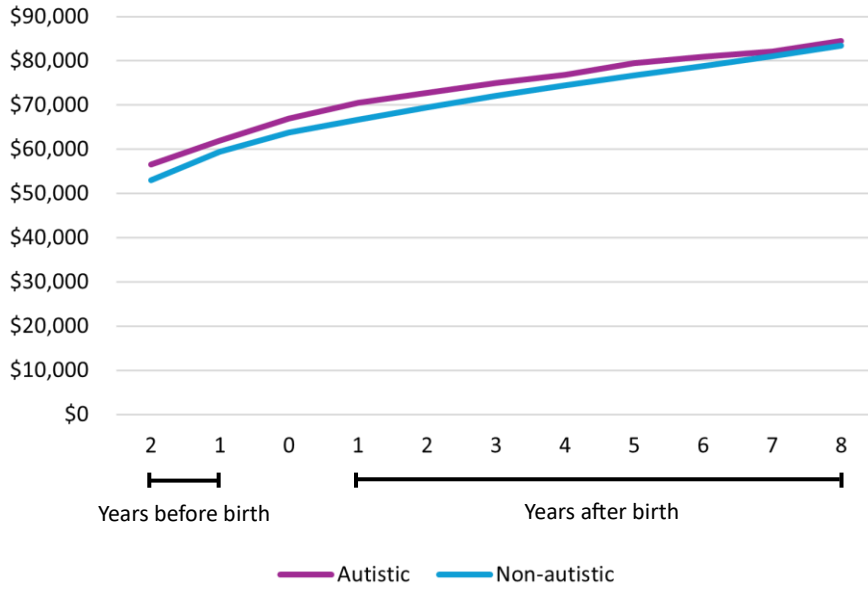
Notably, two years before birth, parents who would later have an Autistic child had higher household incomes than those who would have a non-Autistic child. However, by eight years after birth, their incomes had fallen significantly below those of comparison families. The financial impact was particularly pronounced for mothers of Autistic children.

Average income for parents based on autism status of their first-born child

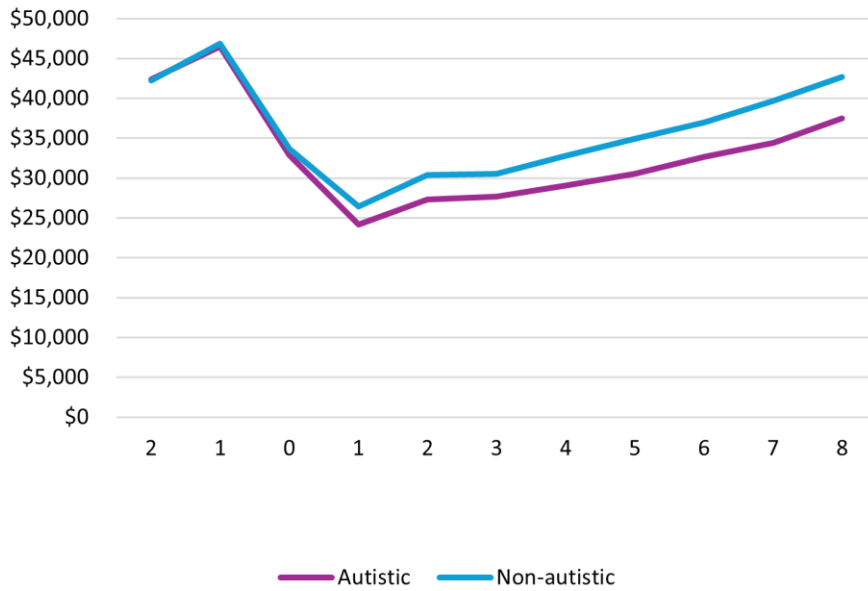
Household



Fathers



Mothers



Conclusions

This comprehensive study offers an in-depth exploration of the life course outcomes for Autistic children, youth, and their families in New Zealand, utilising population-level linked data from the IDI.

The findings reveal significant disparities across various domains for Autistic youth, including healthcare, education, the labour market, social services, and the criminal justice system.

It also highlights health and labour market impacts on parents of Autistic children. Overall, the study highlights the need for targeted interventions and policy adjustments to support this population effectively.

To read more of the published studies see the links below:

Mortality <https://journals.sagepub.com/doi/10.1177/13623613231224015>

Health Service Utilisation <https://journals.sagepub.com/doi/10.1177/13623613241298352>

Oral health outcomes <https://onlinelibrary.wiley.com/doi/10.1111/cdoe.13018>

School Attendance <https://onlinelibrary.wiley.com/doi/10.1111/jpc.16795>