Autism/Takiwātanga in Aotearoa New Zealand: medication prescribing, educational outcomes, and criminal justice system interactions

Investigations using linked whole-of-population administrative data

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Abstract

Background

Autism/Takiwātanga is a lifelong neurodevelopmental condition that is currently estimated to impact 2.3% of children. It is characterised by persistent social and communication differences, sensory issues, and restricted repetitive patterns of behaviour or interests. While associated with strengths such as visual thinking, logic, and memory, the effects of autism on adaptive functioning can result in a need for a range of supports in order for autistic people to live their daily lives. Common co-occurring conditions include intellectual disability, mental health conditions such as anxiety, depression, and attention-deficit/hyperactivity disorder (ADHD), and physical health conditions such as asthma, epilepsy, and gastrointestinal problems.

Autistic young people are at risk of health, academic, social, and behavioural difficulties that can result in long-term deleterious effects on social inclusion, employment, adaptive functioning, and overall quality of life. In particular, they are more likely to experience inequities in health, education, and the criminal justice system (CJS).

There is lack of quantitative data on autism in Aotearoa/New Zealand and an absence of population-level lifecourse research. Notably, there is no registry for autism, and no recognised method for identifying cohorts of autistic people using administrative data. Therefore, autism research in Aotearoa/New Zealand is typically restricted to small clinical samples or is based on survey information.

The Integrated Data Infrastructure (IDI) is a large research database, curated by Statistics New Zealand, and contains a wide range of data about people and households from national

administrative collections and surveys. The breadth of data in the IDI represents one of its key strengths as it links data across multiple life domains, including, but not limited to, health, education, and the CJS. Moreover, these are population-level data, making the IDI a world-leading source of information for research. Use of the IDI presents a unique opportunity for research in Aotearoa/New Zealand, one that has yet to be explored with respect to autism and which has the potential to make important contributions to international literature. Effective use of existing administrative data offers opportunities to better understand autism and meet Aotearoa/New Zealand's obligations under the United Nations Convention on the Rights of Persons with Disabilities including collecting disability data and conducting research in domains such as health, education, and the CJS.

Aims

The overall aim of this thesis is to understand the impacts of autism across the lifecourse using linked administrative data contained within the IDI. There are four specific aims:

1) Explore ways in which the IDI can be used to identify autism among children and young people aged 0–24 years, describe differences in subsequent rates of autism by sociodemographic characteristics, and examine rates of co-occurring mental health and related conditions in this group.
2) Examine medication dispensing for autistic children and young people and compare dispensing and polypharmacy rates among those with autism, ADHD, and the general population.
3) Quantify differences in suspension rates from school for autistic compared to non-autistic students and assess whether high need education-based funding is associated with differential suspension rates for autistic students.

4) Explore CJS interactions, including with police, courts, and corrections for young autistic adults compared to non-autistic people and assess whether offence types differ.

Methods

The studies in this thesis are quantitative and used linked population-level health and non-health administrative data from the IDI. Participant populations were established using IDI-based methods for establishing Aotearoa/New Zealand estimated resident populations or, in the case of the birth cohort study design (Chapter 6), using birth registration data.

Autistic cases were identified using an IDI-based case identification method developed as part of this thesis (Chapter 3). This method uses diagnostic information captured within three health data sets; publicly funded hospital admissions, publicly funded secondary specialist mental health service use, and disability support services needs assessment information. An individual was indicated as autistic if they had an autism diagnosis in one or more of these data sets.

The primary outcomes explored included autism and co-occurring mental health and related conditions (Chapter 3), medication dispensing and polypharmacy (Chapter 4), stand-downs and suspensions (Chapter 5), and interactions with police, courts, and prisons (Chapter 6).

Sociodemographic information was captured in the IDI personal details table. This includes sex, age, and ethnicity determined using the major ethnic groups defined by the New Zealand Standard Classification: European, Māori, Pasifika, Asian, Middle Eastern/Latin American/ African (MELAA) and Other. Socioeconomic status, using the New Zealand Deprivation Index, and urban/rural profile of residence were derived using historical residential address information from the IDI address notification table.

This study was reviewed by the University of Otago Human Research Ethics Committee as a 'Minimal Risk Health Research – Audit and Audit related studies' proposal and received ethical approval (Reference: HD17/004). Access to the IDI and approval for the study was provided by Statistics New Zealand.

Results

The autism case identification method yielded a cohort of 9,555 children and young people (0.57% of the Aotearoa/New Zealand estimated resident population of 0-24 year olds). Among eight-year-olds (the rate that aligns with CDC annual autism prevalence estimates) the corresponding rate was 0.98% (or 1:102). Rates of autism were highest among males (0.88%), those aged 5-9 (0.90%) and 10-14 years (0.86%), and Europeans (0.68%), and lowest amongst Māori (0.49%), Pasifika (0.39%), and Asians (0.45%), as well as those living in high deprivation (0.53%) and rural areas (0.46%). Autistic young people were found to have high rates of co-occurring mental health and related conditions with 68% affected by at least one condition, including intellectual disability (30%), emotional conditions (anxiety and/or depression) (28%), and ADHD (27%).

Analysis of medication dispensing revealed that autistic young people faced a high medication burden. In a one-year period, autistic young people were dispensed four unique medications on average, including relatively high rates of psychotropic, asthma, and gastrointestinal medications. They also experienced high rates of polypharmacy with 57% experiencing polypharmacy of three or more medications (36% higher than non-autistic people), and 11% experiencing extreme polypharmacy of 10 of more medications (over twice that of non-autistic people).

Rates of school suspension were found to be nearly three times higher among autistic students compared to non-autistic students (adjusted odds ratio 2.81; 95% confidence interval [CI] 2.55-3.11). However, high need education-based funding support in the form of the Ongoing Resourcing Scheme (ORS) was associated with significantly reduced suspension rates among autistic students (adjusted odds ratio 0.29; 95% CI 0.21-0.40). This meant that autistic students with ORS funding experienced suspension at approximately the same rate as their non-autistic peers.

Analysis of CJS data revealed that young autistic adults were significantly less likely than their non-autistic peers to be proceeded against by police (adjusted hazard ratio 0.62; 95% CI 0.56-0.70), charged in court (adjusted hazard ratio 0.61; 95% CI 0.53-0.70), and convicted in court (adjusted hazard ratio 0.57; 95% CI 0.48-0.67). However, there was no significant difference in the risk of being imprisoned (adjusted hazard ratio 1.01; 95% CI 0.67-0.1.51). Moreover, among those charged with a crime, autistic people were at greater risk of being charged with serious offences deemed punishable by two or more years in prison (adjusted hazard ratio 1.73; 95% CI 1.44-2.14).

Conclusions

This collection of studies demonstrates the value of employing linked population-level administrative data to conduct lifecourse research into the experiences of autistic children and young people as they interact with health, education, and criminal justice systems. The findings describe challenges and inequities experienced by autistic people in Aotearoa/New Zealand including disproportionately high rates of co-occurring physical and mental health problems, higher risk of suspension from school, and evidence of differential treatment within the

criminal justice system. The study also highlights the value of effective support policies and advocacy in improving these outcomes. It changes the landscape of autism research in Aotearoa/New Zealand by demonstrating ways in which the IDI can be utilised to improve understanding of autistic people and their experiences. It also identifies further opportunities for cost-effective research such as examination of labour market outcomes for autistic people and research to understand the experiences of parents and siblings of autistic children.

A note on terminology

This thesis recognises that, when referring to autistic people, there is no one term that is preferred by all people. A variety of terms are used interchangeably. However, in partnership with co-authors of the studies contained in this thesis and in recognition of the growing desire among Autistics to use terminology that reflects the belief that being autistic is something intrinsic to them and is therefore an important part of their identity they can be proud of, the terms ‘autistic person’ and ‘autistic’ have been prioritised (Bury, Jellett, Spoor, & Hedley, 2020; Monk, 2022). Autism spectrum disorder (ASD) is diagnostic terminology and typically used in the context of a person being diagnosed with autism spectrum disorder. The evolution of the way language is used throughout the thesis reflects my growing understanding of importance of language in shaping our ideas about disability.

Co-authorship form

Details of publications included in and/or appended to this thesis

Chapter/ Append.	Paper title	Authors	Contribution of candidate and co-authors – please detail the nature and extent (%)	Journal	Status (e.g. under review, forthcoming, published)
3	Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand	Nicholas Bowden, Hiran Thabrew, Jesse Kokaua, Richard Audas, Barry Milne, Kirsten Smiler, Hilary Stace, Barry Taylor, and Sheree Gibb	Bowden (70%) Conception and design, acquisition, analysis and interpretation of data, drafting the manuscript. Thabrew (6%) Interpretation of data, critical review of manuscript. Kokaua (4%) Conception and design, interpretation of data, critical review of manuscript. Audas (4%) Conception and design, interpretation of data, critical review of manuscript. Milne (4%) Conception and design, interpretation of data, critical review of manuscript. Smiler (2%) Interpretation of data, critical review of manuscript. Stace (2%) Interpretation of data, critical review of manuscript. Taylor (2%) Interpretation of data, critical review of manuscript. Gibb (6%) Conception and design, interpretation of data, critical review of manuscript.	*Autism*	Published

4	National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder	Nicholas Bowden, Hiran Thabrew, Jesse Kokaua, Rhiannon Braund	Bowden (75%) Conception and design, acquisition, analysis and interpretation of data, drafting the manuscript. Thabrew (10%) Conception and design, interpretation of data, critical review of manuscript. Kokaua (5%) Design, interpretation of data, critical review of manuscript. Braund (10%) Conception and design, interpretation of data, critical review of manuscript.	*Research in Autism Spectrum Disorders*	Published
5	Association between high need education-based funding support and school suspension for autistic students	Nicholas Bowden, Sheree Gibb, Richard Audas, Sally Clendon, Joanne Dacombe, Jesse Kokaua, Barry Milne, Himang Mujoo, Samuel Murray, Kirsten Smiler, Hilary Stace, Larah van der Meer, and Barry Taylor	Bowden (70%) Conception and design, acquisition, analysis and interpretation of data, drafting the manuscript. Gibb (5%) Conception and design, interpretation of data, critical review of manuscript. Audas (3%) Conception and design, interpretation of data, critical review of manuscript. Clendon (2%) Interpretation of data, critical review of manuscript. Dacombe (3%) Conception, interpretation of data, critical review of the manuscript. Kokaua (2%) Conception and design, interpretation of data, critical review of manuscript. Milne (4%) Conception and design, interpretation of data, critical review of manuscript. Mujoo (1%) Interpretation of data, critical review of manuscript. Murray (1%) Conception, interpretation of data, critical review of the manuscript. Smiler (1%) Interpretation of data, critical review of manuscript.	*JAMA Pediatrics*	Published

			Stace (3%) Conception, interpretation of data, critical review of the manuscript. van der Meer (1%) Conception, interpretation of data, critical review of the manuscript. Taylor (4%) Conception and design, interpretation of data, critical review of manuscript.		
6	Criminal justice system interactions among young adults with and without autism: a national birth cohort study in New Zealand	Nicholas Bowden, Barry Milne, Richard Audas, Betony Clasby, Joanne Dacombe, Warren Forster, Jesse Kokaua, Sheree Gibb, Nathan Hughes, Conrad MacCormick, Kirsten Smiler, Barry Taylor, and Brigit Mirfin-Veitch	Bowden (72%) Conception and design, acquisition, analysis and interpretation of data, drafting the manuscript. Milne (4%) Conception and design, interpretation of data, critical review of manuscript. Audas (2%) Conception and design, interpretation of data, critical review of manuscript. Clasby (2%) Conception and design, interpretation of data, critical review of manuscript. Dacombe (1%) Interpretation of data, critical review of manuscript. Forster (2%) Conception and design, interpretation of data, critical review of manuscript. Kokaua (1%) Interpretation of data, critical review of manuscript. Gibb (3%) Conception and design, interpretation of data, critical review of manuscript. Hughes (1%) Conception, interpretation of data, critical review of the manuscript. MacCormick (2%) Analysis of data, critical review of manuscript. Smiler (1%) Interpretation of data, critical review of manuscript.	*Autism*	Published

			Taylor (2%) Interpretation of data, critical review of manuscript. Mirfin-Veitch (7%) Conception and design, interpretation of data, drafting and critical review of the manuscript.		

Certification by Primary Supervisor:

The undersigned certifies that the above table correctly reflects the nature and extent of the candidate's contribution to this co-authored work

Name: *Professor Barry Taylor* Signature:  Date: *7th July, 2022*

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I could not have asked for better support and guidance throughout this thesis. I have been blessed with the people around me and I would like to take this opportunity to express my thanks.

My supervision team, Professor Barry Taylor, Professor Rick Audas, Dr. Sheree Gibb, and Associate Professor Barry Milne have been incredible. They were instrumental in encouraging me to attempt a PhD at a time when I needed a bit of convincing. They mentored and guided me well beyond the scope of this thesis and have been available whenever I have needed them. Their support, guidance, and encouragement have made the completion of this thesis always seem manageable. I will be forever grateful to each of them and look forward to many more years of working together.

I have also had a wonderful and eclectic group of advisors, co-authors, and mentors. In total, 20 different people were involved in co-authoring the four papers presented in this thesis. I would like to thank them all for their contributions, support, and direction. In particular, I would like to acknowledge Joanne Dacombe, Dr. Hilary Stace, Dr. Kirsten Smiler, and Dr. Jesse Kokaua who have all been key advisors and mentors during the programme of work and have helped elevate it to a level I am very proud of.

I would also like to make special mention to the staff and students at Sara Cohen School in Dunedin. My time with these wonderful people was cut short by Covid, but in the formative stages of my thesis I was fortunate to spend an hour each week at the school. I am thankful to the principal, Matt Tofia, for enabling this and I benefited greatly from discussions with Matt and staff at Sara Cohen. However, the students were the stars and it was a privilege to get to

know them. They have had a significant influence on this work, and on me. Autism New Zealand has also supported this research, and in particular I would like to thank Dane Dougan and Larah van der Meer.

Importantly, my research would not have been possible without the funders of this work, A Better Start National Science Challenge. I am grateful for their commitment to fund big data research on autism in Aotearoa/New Zealand.

Lastly, words cannot describe how fortunate I am to have had the support of my beautiful family. To my brothers, nephews, nieces, and brother and sisters in law, from near and far, you have all supported me in this process and I am very thankful. To my parents, I am incredibly lucky to have such supportive, loving, hard-working, and wise parents. It is thanks to you that I found myself in the privileged position of being able to undertake a PhD. You have both been fantastic sounding boards for ideas and thoughts related to the thesis, as well as emotional support when things have been a bit tough. And my work is markedly improved for having the best editor in the world as well – thanks Mum ☺.

To my beautiful wife Hien, and amazing three children Maia (6), Liem (4), and Ellie (2). It is difficult to put it into words how much I love and appreciate you all. You have made sacrifices so that I could do this research and that will never be lost on me. Hien, you have been the cornerstone of our family, ensuring we all thrive, while at the same time being oceans away from your own family. It has been hard at times, but it is your love and strength that has made this manageable. I can't thank you enough and I count my lucky stars we are together. Maia, Liem, and Ellie, my love for you and the energy you bring to every day, the smiles, the hugs,

and the tears have been my biggest motivation throughout this thesis. You have taught me what is important in life and every day with you is a blessing – I'm the luckiest Dad in the world!

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Approach to the thesis

At the conception stage of this thesis, my hope was to establish a programme of research that was meaningful and had the potential to improve the lives of autistic people and their whānau. With this in mind I engaged in the process based on some core principles that I felt would help enable a purely quantitative research project to connect and engage with the autistic and autism communities, meaningfully contribute to existing literature, and ultimately improve autistic people's well-being.

This section describes my approach to research developed throughout the thesis. It has seven key components:

- Initial consultation, engagement, and personal development
- Co-production of knowledge
- Volunteer work
- Cultural engagement
- Multidisciplinary research
- Alignment with emerging literature
- Giving back

Initial consultation, engagement, and personal development

When I began the journey I was very aware that I had no personal connection to autism. For this reason I wanted to engage with as many people as I could: autistic people, people who had autistic family members, as well as organisations and groups who work with autistic people. I wanted to be able to understand autism and, importantly, I hoped to get community feedback and input into the programme of research I was proposing. While the priority was community

and sector engagement, this phase also involved consultation with academics and clinicians as well as attendance at related workshops and conferences.

I was fortunate to meet and discuss my proposed research with a number of autistic adults and parents of autistic children and these were the most significant conversations I had at any stage of my study. It was particularly important to have these in the conception stage to ensure my proposed programme of work was meaningful. The conversations led to further discussions with other people and organisations, widening the scope and coverage of engagement, and the content of the thesis was developed and changed as a result of these discussions.

Next, I met with representatives from a number of organisations that engage with autistic people, and several health service providers. This helped me to better understand the health and disability landscape, the strengths and limitations of my proposed programme of research, and to establish a degree of credibility within the sector. I was grateful for the input from representatives of Autism New Zealand, Altogether Autism, and CCS Disability Action. I met with AccessAbility, a Needs Assessment and Service Coordination agency, and the Southern District Health Board ASD Coordinator. I also met with a range of academics and clinicians including autism researchers, Māori and Pacific health and disability researchers, IDI researchers, international autism researchers, and clinicians (paediatricians, psychiatrists, and clinical psychologists). I obtained useful feedback into the development of the thesis and a number of these people would eventually contribute as co-authors to the research papers.

Lastly, I attended several workshops and conferences to broaden my understanding of autism. ‘Way-to-Play’ and ‘Framework for Autism in New Zealand’, two workshops run by Autism New Zealand, helped me learn more and afforded me the opportunity to meet and talk with

parents of autistic children and people working with autistic children. Insights into the lives of parents who had recently received an autism diagnosis for their child or were in the process of receiving one were particularly enlightening, and it was a privilege to hear their stories, experiences, and thoughts.

A key contribution to the formative stages of this thesis came from Dr. Hilary Stace, a researcher at Victoria University, disability advocate, and mother of an autistic son. I valued her contribution in the development stage and her ongoing involvement as a key mentor. Hilary has played a significant role in the direction of the work and has been an important link to key people and organisations. It was a special moment for me when she accepted my request for her to be a co-author on the first paper of the thesis (Chapter 3) and it was tangible recognition that the research programme was meaningful. Hilary's ongoing involvement has been important to me and has strengthened the relevance of the research.

Co-production of knowledge

It was important that the research team was connected to the autistic community in a way that enabled meaningful relationships and that the research was to be beneficial for the community. Therefore, a priority was to involve an autistic advisor. At the end of the first year of my studies I was introduced to Joanne Dacombe and we met in person in late 2019. This was the start of a journey together that was one of the highlights of my research.

Joanne is deaf, was diagnosed late in life with autism, and has an adult autistic son. She has worked tirelessly for decades as a disability advocate with a focus on health and I feel honoured to have worked with her over the last three years. Joanne is a co-author on the third and fourth papers of the thesis (Chapter 5 and 6) and has had a significant role in their respective study

designs, interpretation of results, and critical review of the manuscripts. Her contribution to the research has ensured the work is meaningful, the interpretation of results is grounded in autistic experiences, and the language and discussion is appropriate.

Volunteer work

I was interested in meeting autistic young people and contacted Matt Tofia, principal of Sara Cohen School, to enquire about volunteering. Sara Cohen is a specialist school in Dunedin, focussing on teaching students with diverse needs (including autism). Matt was very supportive and in the early stages of my studies I was at the school an hour a week spending time with students and helping in their classrooms and during breaks.

I found I was unaware of the level of need of many of these students and this made me realise why it was so important for me to spend time with them, especially those with complex needs. I had not interacted with anyone who was non-verbal before, I was not familiar with stimming (repetitive or unusual movements of noises), and I was not aware of how physically intimidating autistic adolescents could be, both in terms of physical size and the intensity of some of their movements. I experienced some of the behaviours to be confronting but over time realised this was due my own lack of experience. Those first few times attending the school were some of the most eye-opening experiences of my life.

Over the next two years I came to know many of the students and learned to appreciate their ways of being, including non-verbal forms of communication, different conversations, unique views of the world, genuine kindness, and warm hearts. I also developed a greater understanding of the considerable and complex challenges many of these young people, their teachers, caregivers, and whānau face. I am extremely grateful for the numerous conversations

with Sara Cohen staff, particularly Matt Tofia, who helped me further understand the value of education for these young people, and the associated challenges. Some of these conversations led to conceptualisation of the third paper of the thesis (Chapter 5); the examination of school suspension and the impact of high need funding support for autistic students. This paper was not part of the original thesis proposal.

Cultural engagement

A history of colonisation and institutional racism has led to inequities in many areas of health for Māori (Waitangi Tribunal, 2019). Te Tiriti o Waitangi (The Treaty of Waitangi), Aotearoa/New Zealand's founding document, promotes Oritetanga, equality and equity, (Article 3) (Waitangi Tribunal, 2019). I spent a considerable amount of time with Dr. Kirsten Smiler, a Māori health and disability researcher from Victoria University, learning to understand the way my programme of research could honour commitments outlined in Te Tiriti o Waitangi around equity and equality. Valuable engagement with leading Māori in this area was undertaken and meaningful relationships were established. Ultimately however, Dr. Smiler and I decided (with support from the Te Ara Tika framework) that Māori specific analyses would require longer times frames, more robust relationships, and specific resourcing to be undertaken in an ethical way (tika) (Hudson, Milne, Reynolds, Russell, & Smith, 2010). Therefore, the thesis is respectfully and mindfully located as a mainstream analysis with a view that I am committed to partnering with Māori to conduct Māori analysis in the long-term.

Pacific peoples also experience significant and long-standing health inequities in Aotearoa/New Zealand (Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). Therefore, it was important to include appropriate Pacific engagement throughout the programme of research. I was fortunate that Dr. Jesse Kokaua, a Pacific health researcher and

statistician, agreed to act as an advisor for my thesis. Jesse and I communicated regularly and we incorporated elements of his Tivaivai research framework for quantitative Pacific research using big data to ensure key values and principles were upheld (Kokaua et al., 2020). In particular, pathways to positive community outcomes were considered (Te Oroma), community engagement was undertaken to obtain feedback on key findings (Mareka'anga), and the implications of the research were considered in terms of the community (Orongo'anga).

It is important to acknowledge that there are other groups whose needs are also worthy of specific consideration. For example, other ethnic groups or gender minorities. These were considered out of scope for this thesis, but will be important to consider in future work.

Multidisciplinary research

Another key aspect of my thesis was the multidisciplinary approach. I have really enjoyed bringing together multidisciplinary teams and this is a strength that has developed in my research. In addition to autistic, autism, and cultural advisors, the research team has included clinicians, disability advocates, big data researchers, social scientists, health economists, methodologists, statisticians, and health and disability researchers. For specific papers, researchers who specialised in pharmacology, CJS research, and education research were also involved. In total, 20 different researchers combined to contribute to the four published papers. It was not always an easy task to incorporate the views of such a wide-ranging group of academics but I believe this approach produced more relevant and meaningful research.

Alignment with emerging literature

The term 'nothing about us without us' is now a clear imperative in autism research. According to Poulsen et al. (2022), autism researchers are responding to this call and it is being

increasingly recognised that co-production of research enhances research quality and outcomes (Fletcher-Watson et al., 2019; Hudry, Pellicano, Uljarević, & Whitehouse, 2020; Pellicano, Dinsmore, & Charman, 2014; Poulsen, Brownlow, Lawson, & Pellicano, 2022). I am happy that some of the core principles for research that I held close from the beginning of my studies align well with preferences for the way autism research should be conducted.

The leading international autism journal, *Autism*, has now made it mandatory to include a 'community involvement' sub-section in the Methods of any submitted manuscript. I was happy to be able to include the following statement in the fourth paper of the thesis (Chapter 6):

Engagement with the autism community and co-production of knowledge is important to our research. To this end, one of the co-authors of this study is an autistic adult, a well-respected representative of the autism community, with a long history of community involvement. This co-author contributed to the study design and provided feedback on manuscript drafts to help ensure its contents, including the interpretation of results would be acceptable to the autistic community (Bowden, Milne, et al., 2022, p. 5).

It is important there is a balance in the funding of autism research in Aotearoa/New Zealand. Emerson (2021) indicates that two thirds of funding goes to research examining the biological differences associated with autism rather than the needs of autistic people and supports required (Emerson, 2021). However, autistic communities are increasingly determining priorities for autism research and translational research that can make a difference to people's everyday lives has emerged as a key priority (Gatfield, Mangan, Haar, Kinniburgh, & Rodger, 2016; Pellicano et al., 2014). The lifecourse approach of this thesis aligns with this priority.

Giving back

Meaningful engagement necessitates giving back to communities. I undertook two approaches to this. The first was a concerted effort to disseminate the research information via a range of modalities. This included through mainstream media (e.g., print and radio), social media (e.g., Twitter, LinkedIn, and Facebook), autism organisations (e.g., Autism New Zealand and Altogether Autism), and through conference presentations (e.g., the Australasian Society for Autism Research conference 2020 and the Autism New Zealand Education Day 2022). Secondly, I have a commitment to being available to communities who want to engage further in this research. I support the principal of dynamic reciprocity, defined as *an ongoing practice of exchange for mutual benefit between academic and community research partners* (Diver & Higgins, 2014, p. 2). The authors describe giving back through dynamic reciprocity as a process that is dependent on time and contextual factors, community needs, and changing circumstances. The benefits of this process may not be apparent for some time, may be short lived, and may not be tangible, but our ability to give back as researchers will extend as the community relationships deepen. In a quantitative thesis I have been pleased to be able to hold the importance of relationship and meaning at its core.

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List of abbreviations

ABA	Applied behaviour analysis
ADDM	Autism and Developmental Disabilities Monitoring
ADHD	Attention-deficit/hyperactivity disorder
ANZSOC	Australian and New Zealand Standard Offence Classification
ASD	Autism spectrum disorder
B4SC	B4 School Check
CBT	Cognitive behaviour therapy
CDC	Centers for Disease Control and Prevention
CDD	Childhood disintegrative disorder
CI	Confidence interval
CJS	Criminal justice system
DHB	District health board
DIR	Developmental, Individual Differences, Relationship-Based Model
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSS	Disability Support Services
DTT	Discrete trial training
EIBI	Early intensive behavioural intervention
EO	European and Other
ERP	Estimated resident population
HR	Hazard ratio
ICD	International Classification of Diseases
IDI	Integrated data infrastructure
IQ	Intelligence quotient

MADDSP	Metropolitan Atlanta Developmental Disabilities Surveillance Program
MELAA	Middle Eastern, Latin American, African
MHINC	Mental Health Information National Collection
NASC	Needs Assessment Service Co-ordination agency
NDBI	Naturalistic developmental behavioural intervention
NGO	Non-governmental organisations
NHI	National Health Index
NMDS	National Minimum Dataset
NPV	Negative predictive value
NZDep	New Zealand Index of Deprivation
NZHS	New Zealand Health Survey
OCD	Obsessive-compulsive disorder
ODD	Oppositional defiant disorder
ORS	Ongoing Resourcing Scheme
PDD-NOS	Pervasive developmental disorder–not otherwise specified
PPV	Positive predictive value
PRIMHD	Programme for the Integration of Mental Health Data
RECORD	Reporting of studies Conducted using Observational Routinely-collected health Data
SPA	Support package allocation
SSRI	Selective serotonin reuptake inhibitors
TEACCH	Treatment and Education of Autistic and related Communication-handicapped CHildren
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
USA	United States of America

Publications, presentations, grants, and media associated with this thesis

Publications

Bowden, N., Thabrew, H., Kokaua, J., Audas, R., Milne, B., Smiler, K., Stace, H., Taylor, B., Gibb, S. (2020). Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand. Autism, 24, 2213-2227. (Bowden, Thabrew, Kokaua, Audas, et al., 2020). Chapter 3.

Bowden, N., Thabrew, H., Kokaua, J., & Braund, R. (2020). National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder. Research in Autism Spectrum Disorders, 78, 101642. (Bowden, Thabrew, Kokaua, & Braund, 2020). Chapter 4.

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Presentations

Bowden, N., Gibb, S., Thabrew, H., Milne, B., Kokaua, J., Smiler, K., Stace, H., Taylor, B., Audas, R. (2020). Autism/Takiwātanga: An integrated data infrastructure-based approach to autism research in New Zealand. *Australasian Society for Autism Research 2020 Conference.*

Thabrew, H., Bowden, N., Kokaua, J., Braund., R. (2020) National Prescribing Rates and Polypharmacy for Children and Young People in New Zealand with and without Autism Spectrum Disorder. *Australasian Society for Autism Research 2020 Conference.*

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Grants

MacGibbon Travel Fellowship $13,670

This funding aims to support PhD students to spend time working in a research group in the USA and assist in the learning of new techniques and methodologies, with access to datasets and technology not available in Aotearoa/New Zealand and to the building of collaborations.

Laura Ferguson Trust $883,903 (Named investigator)

Stream 1 $268,178 (Co-investigator)

Stream 2 $268,565 (Principal investigator)

This is a two-year project, starting in May 2022, that aims to establish an evidence base to:

1) examine the benefits of the *Early Steps* programme for early intervention (stream 1);
2) quantify variation in life outcomes for autistic children as well as for their caregivers, compared to non-autistic children and their caregivers (stream 2);
3) estimate associated government costs of autism (stream 2).

Media

6/7/22 JAMA Pediatrics Editors Podcast

Association Between Funding and School Suspension Rates for Autistic Students in New Zealand; Developmental Outcomes for Children After Elective Birth at 39 Weeks' Gestation

17/5/22 New Zealand Herald

Autistic students in NZ three times more likely to be stood down, suspended - new research

17/5/22 Newstalk ZB Mike Hosking Breakfast

Kids with autism almost three times as likely to be stood down compared to those without autism

17/5/22 Newstalk ZB Early Edition

Principals' Federation President: When autistic children have the right levels of support, they're more likely to succeed

17/5/22 Newshub

Autistic students more likely to face suspension that non-autistic students - study

17/5/22 New Zealand Herald

School suspensions can help get support for autistic kids – Principals' Federation Present

19/5/22 95bFM The Wire

ORS and Addressing Suspension w/ Nick Bowden

8/2/22 Radio New Zealand Nine to Noon

Study raises questions over autism and the criminal justice system

5/2/22 Otago Daily Times

Researchers debunk myths about autism and crime

4/2/22 95bFM The Wire

Misconceptions of Autism in the Criminal Justice System with Nick Bowden & Dane Dougan

27/1/22 Stuff

Autistic young adults are less likely to be charged with crimes, but those charged face tougher penalties - NZ study

5/12/20 Otago Daily Times

Different Ways of Thinking

23/7/2020 Education Central

Novel approach enables improved capabilities for autism research in New Zealand

29/8/2019 Otago Daily Times

Fellowship offers chance to study autism

1 Literature review

1.1 What is autism?

Autism/Takiwātanga[1] refers to a lifelong neurodevelopmental condition characterised by persistent social and communication differences, sensory issues, and restricted repetitive patterns of behaviour or interests (American Psychiatric Association, 2013a). While associated with strengths such as visual thinking, logic, and memory (Altogether Autism, 2019; Meilleur, Jelenic, & Mottron, 2015), the effects of autism on adaptive functioning can range from low to high levels of support required for autistic people to live their daily lives.

Autism is currently estimated to impact 2.27% (or 1 in 44) of children (Maenner et al., 2021). This represents a more than three-fold increase in prevalence since 2000 and is thought to be due to improved identification methods, changing definitions, increased awareness, and potentially overdiagnosis (Amaral, 2017; Merten, Cwik, Margraf, & Schneider, 2017; Skellern, Schluter, & McDowell, 2005). Changes in environments and genetic/environment interactions have also been postulated to play a lesser role in the increase in prevalence over time (Amaral, 2017; Panisi et al., 2021). Autism is estimated to be approximately four times more common in males than in females (Maenner et al., 2020; Maenner et al., 2021), although contemporary research has challenged the magnitude of this disparity citing missed and delayed diagnoses among females (Gesi et al., 2021).

Symptoms of autism are typically recognised during the second year of life but may be seen earlier than 12 months in high need cases, or after 24 months if symptoms are subtle (American Psychiatric Association, 2013a). First symptoms typically involve delayed language

development accompanied by lack of social interest, and unusual play or communication patterns. In year two, unusual and repetitive behaviours develop as well as the absence of typical play. The pattern of onset can include regression of social or language skills, and since this is uncommon in other conditions, can often be a strong indication of autism. It is estimated that intellectual disability affects about one third of autistic individuals and approximately 70% have at least one co-occurring mental health condition such as anxiety, depression, and attention-deficit/hyperactivity disorder (ADHD) (American Psychiatric Association, 2013a; Baio et al., 2018; Maenner et al., 2021; Matson & Shoemaker, 2009; Simonoff et al., 2008).

1.1.1 History

The first mention of autism was in an 1828 report by Itard (Carrey, 1995). In 1911, the term autism was used to describe social withdrawal in adults with schizophrenia by the Swiss psychiatrist, Eugen Bleuler, and subsequently by American psychiatrist, Leo Kanner, in 1943 to define a syndrome observed in children. This syndrome was characterised by early onset, social withdrawal, language impairment, intellectual disability, and repetitive behaviours (Bleuler, 1950; Kanner, 1943). In 1943, Austrian psychiatrist Hans Asperger differentiated autism from Kanner's definition by describing 'personalities with autistic tendencies' as having specific and exceptional talents as well as conserved language skills (Asperger, 1944).

Autism was distinguished as a clinical diagnosis for the first time in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-3) (American Psychiatric Association, 1980). It then became recognised as a spectrum of separate behavioural disorders in the DSM-4 that included five subtypes of autism: autistic disorder, Asperger's disorder, pervasive developmental disorder–not otherwise specified (PDD-NOS), childhood disintegrative disorder (CDD), and Rett's disorder (American Psychiatric Association, 1994).

DSM-5 redefined autism as a single condition comprised of the first four subtypes (American Psychiatric Association, 2013a). Given these changes over time, the terms autism, autistic disorder, childhood autism, and autism spectrum disorder (ASD) are used in the literature with differing definitions depending on the date, type, and context of publication.

1.1.2 Diagnostic criteria

Autism, as defined in the DSM-5, consists of five diagnostic criteria. Criterion A describes deficits in social communication and interaction as captured by three dimensions:

1. Deficits in social and emotional reciprocity such as not responding when spoken to, not initiating conversations, and an inability to share excitement and joy.
2. Deficits in non-verbal communicative behaviours used for social interaction. For example, not making eye contact, and the inability to understand and use gestures such as headshaking, nodding, and pointing.
3. Deficits in developing and maintaining developmentally appropriate relationships including difficulties adjusting behaviour to suit social situations, difficulties making friends, while some may have no interest in others at all.

Criterion B, restricted repetitive patterns of behaviour or interests, requires at least two of the following to be expressed: stereotyped or repetitive movements, use of objects, or speech such as rocking, hand flapping, lining up of objects, or repetitive or idiosyncratic speech; the need for sameness which might include extreme distress at small changes, insistence on the same food choices, and rituals associated with greetings; abnormal fixations and interests, for example, attachments to unusual objects like rubber bands and preoccupations with historical events and timetables; and abnormally high or low sensitivity to stimuli such as indifference to pain or temperature, excessive touching or smelling of objects, or fascination with lights or the movement of objects.

Criterion C states that symptoms need to be present in early childhood, however, these may not manifest fully until later in life when social demands exceed capabilities.

Criterion D states that these symptoms must cause clinically significant impairments.

Criterion E demands that these symptoms are not better explained by intellectual disability or global developmental delay.

1.1.3 Diagnosis in Aotearoa/New Zealand

An overview of the process of diagnosing autism in Aotearoa/New Zealand is contained in *How is ASD diagnosed? A resource to help identify autism spectrum disorder* (New Zealand Guidelines Group, 2010). Publicly funded specialist autism diagnostic services, free for children, adolescents, and adults with an intellectual disability, and private services are the main entities that conduct autism assessments in Aotearoa/New Zealand. Publicly funded specialist services generally only accept referrals from general practitioners. However, on occasion, referrals are accepted from other professions such as teachers, psychologists, public health nurses, Plunket nurses and speech-language therapists. Private services accept self-referrals and referrals from other agencies or professionals.

Ideally, an autism diagnosis is made by a multidisciplinary team, comprising two or more professionals with expertise in autism and related conditions: a paediatrician, psychiatrist, psychologist, speech-language therapist, and/or occupational therapist. However, in Aotearoa/New Zealand, access to assessment and diagnosis is inequitable and inconsistent (Ministries of Health and Education, 2016). In parts of Aotearoa/New Zealand where

multidisciplinary teams do not exist, a paediatrician, psychiatrist, or clinical psychologist alone may conduct the diagnostic assessment.

The guidelines state the assessment process should consist of five core components:

1. Interviews with the individual discussing information about their development and family history.
2. Observations in different settings such as in the home, and at school where communication, social, and play/leisure skills are observed.
3. Medical evaluation including medical history, undertaking medical tests, and a comprehensive medical record review.
4. Assessments of intellectual functioning, communication skills, mental health and behaviour problems, and family resources and needs.
5. Interviews with others, including early childhood educators or teachers who have observed behaviours of the child in the classroom and playground.

Additional components may also be assessed, such as social and emotional abilities, adaptive functioning, cognitive abilities, neurological abilities, vision and hearing, sensory and motor abilities, occupational therapy and physiotherapy needs, and personal interests and activities. Once all this information has been gathered a report is written outlining the results of assessments as well as information regarding diagnosis, recommendations, intervention strategies, medications, support needs, and sources of further information.

There are several touch points in the Aotearoa/New Zealand health system to facilitate early identification of autism. The Well Child/Tamariki Ora programme, a series of health assessments and support services for children and whānau up until five years of age, provides monitoring of developmental milestones (Ministry of Health, 2021b). Best practice requires all

health care (and education) professionals to elicit any concerns about developmental milestones and behaviour from the parent of caregiver. The B4 School Check (B4SC), a nationwide health screening programme for four-year-old children, also provides an opportunity to identify behavioural and developmental issues (Ministry of Health, 2016). Despite these early touchpoints, assessment wait times can be long, assessment pathways can incur long delays, and access to culturally appropriate care can be limited (Eggleston, Thabrew, Frampton, Eggleston, & Hennig, 2019; Tupou, Curtis, Taare-Smith, Glasgow, & Waddington, 2021).

Upon receiving an autism diagnosis, post-diagnosis services and supports become available to the individual and their family/whānau. These have changed considerably over time and can vary by District Health Board (DHB: publicly funded organisations that plan and fund health services for their populations) (Thabrew & Eggleston, 2018). From 1993, under the Ministry of Health, disability support services (DSS) have been available to autistic people who meet certain eligibility criteria (Ministry of Health, 2002). Eligible individuals will be referred for a needs assessment undertaken by a needs assessment service co-ordination (NASC) agency who will determine the needs of the individual and the services required to support them to be as independent as possible. Prior to 2014, only those with a dual intellectual disability diagnosis met these criteria. While some DHBs were more flexible, most were not, meaning that many autistic individuals did not receive disability support. This changed in 2014 when an autism diagnosis alone became an approved diagnosis for support (Ministry of Health, 2014). Another major change in post-diagnostic support came in 2011 when ASD coordinators within each DHB were established. ASD coordinators' core roles were to ensure autism assessment and diagnostic processes were well coordinated and post-diagnostic support services were effectively made available. Moreover, the health care of autistic children is typically monitored

by a paediatrician in addition to a general practitioner. This specialist paediatric support usually ends when the individual reaches adulthood (Ministries of Health and Education, 2016).

On 1 July, 2022, Aotearoa/New Zealand moved to a reformed national health system. This included the abolishment of the 20 DHBs and establishment of two new centralised bodies: Te Whatu Ora (Health New Zealand) that will replace the DHBs and be responsible for the planning and commissioning of health services, and Te Aka Whai Ora (Māori Health Authority) that will work with Te Whatu Ora to focus on improving services and achieving health equity for Māori. At the same time, Whaikaha (Ministry for Disabled People) was launched. Whaikaha was established to provide cross-government coordination and leadership on issues affecting disabled people. It is unclear at this point how the health reforms and the establishment of Whaikaha will affect diagnostic services for autistic people and their whānau.

1.1.4 Epidemiology of autism

1.1.4.1 International prevalence of autism

In the 1960s, the estimated prevalence of autism was between 0.04% to 0.05%, equating to roughly 1 in 2,000 to 2,500 individuals (Gillberg & Wing, 1999). Since then, various organisations have reported considerable increases in prevalence of autism using administrative data, national surveys, and active public health surveillance (Cavagnaro, 2007; Croen, Grether, Hoogstrate, & Selvin, 2002; Newschaffer, Falb, & Gurney, 2005). Specifically, the Centers for Disease Control and Prevention (CDC), Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and the Autism and Developmental Disabilities Monitoring (ADDM) Network have largely contributed to this changing landscape (Blumberg et al., 2013; Boyle et al., 2011; Kogan et al., 2009; Schieve et al., 2012). In 1996, the MADDSP first estimated autism prevalence to be 0.34% of children aged 3–10 years (or 1 in 294)

(Yeargin-Allsopp et al., 2003). Later, the larger ADDM Network estimated autism prevalence among children aged eight years biennially from 2000 and have reported steady increases over that time. In 2000 they estimated prevalence at 0.67% (or 1 in 150) while their most recent estimate in 2018 was 2.27% (or 1 in 44) (Maenner et al., 2021).

Autism prevalence estimates have been consistently higher among males compared to females with a recent approximated ratio of 4.2:1 (Maenner et al., 2021). However, contemporary research has challenged the magnitude of the gender difference suggesting that missed and delayed diagnoses among females may account for some of this gap (Gesi et al., 2021). Autism prevalence estimates in the United States of America (USA) have historically varied by ethnicity, although the most recent estimates show no statistically significant differences across ethnic groups (Baio et al., 2018; Maenner et al., 2020; Maenner et al., 2021).

1.1.4.2 Reasons for increased prevalence

There is debate about whether increases in reported autism prevalence are attributable to real-world increases in underlying aetiologic factors or if there are alternative explanations such as changes in reporting practices, referral patterns, public awareness, diagnostic processes, and lower age of diagnosis. Factors that influence autism prevalence may be categorised into three groups (Rice et al., 2012):

1. Intrinsic identification: Relating to the study methods or measurement factors involved in generating autism prevalence estimates.
2. Extrinsic identification: Including changes in diagnostic criteria, public awareness, access to diagnostic services, age of diagnosis, and reporting practices.
3. Risk: Reflecting possible true aetiologic change in autism symptoms due to genetic, biologic, or environmental factors (or combinations thereof).

Overall, the consensus is that identification factors account for a large proportion of the increased prevalence but no single factor explains the increasing trend and more research needs to be undertaken to understand the contribution of the various factors involved, including aetiologic factors (Amaral, 2017; Rice et al., 2012).

1.1.4.3 Prevalence of autism in Aotearoa/New Zealand

In Aotearoa/New Zealand, the Ministry of Health does not collect data on the prevalence or incidence of autism (Ministries of Health and Education, 2016). Instead, autism prevalence is based on older research from the United Kingdom which results in a conservative estimate of the prevalence of autism in Aotearoa/New Zealand at about one percent of the population, equating to approximately 40,000 individuals (Baird et al., 2006; Ministries of Health and Education, 2016; New Zealand Guidelines Group, 2010). More recently the New Zealand Health Survey (NZHS) has estimated autism prevalence based on parents' and caregivers' self-reports on receiving an autism diagnosis for their child (Ministry of Health, 2019a). In 2006/07 the estimated rate was 0.5 percent, while the most recent estimate from the 2020/21 survey is 2.5% percent (or 1:40). The most recent NZHS estimate for the male female ratio is 4.4:1 and rates vary by ethnicity, with European/Other estimated at 2.5 percent, compared to 3.1 for Māori, 1.9 for Asian, and 3.2 for Pacific (Ministry of Health, 2021a).

1.1.4.4 Co-occurring psychiatric conditions

Co-occurring psychiatric conditions are common among autistic people. It is estimated that approximately 70% have at least one co-occurring mental health condition such as anxiety, depression, and ADHD (American Psychiatric Association, 2013a; Matson & Shoemaker, 2009; Simonoff et al., 2008). A more recent meta-analysis found that the pooled prevalence of

any psychiatric condition across 18 studies was 55% (95% confidence interval [CI] 47-63) (Lugo-Marin et al., 2019).

Among specific conditions, a recent meta-analysis estimated ADHD to be the most common 26% (95% CI 19–34). Other common co-occurring conditions as estimated by recent meta analyses include: mood disorders, 19% (95% CI 11–31); anxiety, 18% (95% CI 12–25); sleep problems 13% (95% CI 9–17); disruptive, impulse control, and conduct disorders, 12% (95% CI 10–15); schizophrenia spectrum disorders, 12% (95% CI 8–18); personality disorders, 13% (95% CI 5–29); substance abuse, 8% (95% CI 4–16); and eating disorders 4% (95% CI 2–6) (Lai et al., 2019; Lugo-Marin et al., 2019).

Intellectual disability is also disproportionately experienced by autistic people. Estimates of the prevalence of intellectual disability (intelligence quotient [IQ]<=70) vary significantly and have tended to reduce over time (Postorino et al., 2016). The CDC has reported declining rates of intellectual disability among autistic children from approximately 50% in 2000, to 35% in 2018 (Maenner et al., 2021). Given the increasing prevalence of autism, this suggests that lower need cases of autism are increasingly being diagnosed.

1.1.4.5 Co-occurring physical health conditions

Autistic young people are also significantly more likely to experience co-occurring physical health conditions. For example, they are more likely to experience eczema or skin allergies, asthma, ear infections, headaches, epilepsy, and gastrointestinal problems compared to those without autism (Al-Beltagi, 2021; Isaksen et al., 2013).

Gastrointestinal problems are one of the most common medical conditions experienced, affecting between 46% to 84% of autistic children (Al-Beltagi, 2021). A meta-analysis found

that autistic children experience gastrointestinal problems at significantly higher rates compared to non-autistic children (pooled odds ratio 4.4; 95% CI 1.9-10.3) (McElhanon, McCracken, Karpen, & Sharp, 2014). This included higher odds of diarrhoea, constipation, and abdominal pain. Likewise, asthma is experienced at higher rates among autistic children compared to their non-autistic peers (Miyazaki et al., 2015; Zheng et al., 2016). Zheng et al. (2016) found the prevalence of asthma among autistic children was 20% (pooled odds ratio 1.3; 95% CI 1.0-1.6). Epilepsy is also experienced disproportionally by autistic children, with an estimated prevalence of 10% (Liu et al., 2021).

1.1.4.6 Premature mortality

Autism has been regularly associated with shorter life expectancy compared with the general population (Bilder et al., 2013; Gillberg, Billstedt, Sundh, & Gillberg, 2010; Isager, Mouridsen, & Rich, 1999; Mouridsen, Brønnum-Hansen, Rich, & Isager, 2008; Pickett, Paculdo, Shavelle, & Strauss, 2006; Shavelle, Strauss, & Pickett, 2001). In a population-based study using Utah State data, significantly elevated risk of mortality was observed among autistic people (hazard rate ratio 9.9; 95% CI 5.7-17.2). More recently, in a large Swedish population-based study, increased mortality was observed in autistic individuals (odds ratio 2.6; 95% CI 2.4–2.8) and was elevated across all International Classification of Diseases (ICD) categories except infectious diseases (Hirvikoski et al., 2016). Mortality risk was higher for females and more complex cases of autism (Hirvikoski et al., 2016). The study also reported a suicide rate of 0.31% among autistic people, significantly higher than among the general population (0.04%) (odds ratio 7.6; 95% CI 6.0-9.4). This risk was significantly higher for autistic people without co-occurring intellectual disability (odds ratio 9.4; 95% CI 7.4-11.9). Lastly, in a recent systematic review of 12 studies, all-cause mortality among autistic people was estimated to be higher than the general population (risk ratio 2.1; 95% CI 1.1-4.0) (Catalá-López et al., 2022)

1.1.5 Aetiology

There is complexity in understanding the full aetiology of autism though there is an interplay between genetic and environmental factors (Amaral, 2017; Y. Kim & Leventhal, 2015; Trottier, Srivastava, & Walker, 1999).

1.1.5.1 Genetic

It is widely understood that autism has a strong genetic component as gene defects and chromosomal anomalies are found in 10-20% of autistic individuals (Herman et al., 2007; Miles, 2011). Over 100 genes are known to influence risk of autism and it is speculated more genetic risk factors will be identified in the future (De Rubeis & Buxbaum, 2015; De Rubeis et al., 2014; Geschwind & State, 2015; Iossifov et al., 2014). Furthermore, variable penetrance and expressivity of these genetic factors provides the variety of phenotypes that are characteristic of the autism spectrum and associated comorbidities (e.g., epilepsy).

Heritability of autism is estimated to be 83% (Sandin et al., 2017), with a 50 times increased likelihood of autism among children with an autistic sibling (Szatmari, Jones, Zwaigenbaum, & MacLean, 1998). Twin studies provide valuable information supporting the heritability of autism given the significant differences in concordance rates between monozygotic (identical) and dizygotic (fraternal) twins (Folstein & Rutter, 1977; Steffenburg et al., 1989). Although subsequent studies have questioned the magnitude of genetic causes among siblings, given the confounding effect of a shared environment (Hallmayer et al., 2011), recent larger scale studies have attributed genetic background as the major contributor (Colvert et al., 2015).

1.1.5.2 Environmental

Potential environmental causes of autism have been categorised into five major groups by Amaral (2017):

1. Maternal infection
2. Maternal antibodies
3. Drugs
4. Environmental toxicants
5. Postnatal factors.

Maternal Infection

The effect of rubella on development during the pre-natal period provides the most compelling evidence supporting the role of environmental pathogens underlying autism. In a study of 243 children exposed to rubella during pregnancy, the observed rate of 741 per 10,000 children diagnosed with autism was several hundred times published prevalence rates at the time (Chess, 1971). Other viral or bacterial infections associated with autism have been found, including members of the herpes virus family and influenza, but these associations are much weaker than those with rubella (Libbey, Sweeten, McMahon, & Fujinami, 2005). More recently however these findings have been challenged (Zerbo et al., 2017). In a series of studies, they concluded neither maternal influenza, nor viral infections during pregnancy, nor the influenza vaccine, was associated with increased autism risk. Amaral (2017) concludes autism is not substantially increased by today's commonly occurring infectious illnesses and therefore gene/environment effects may provide more answers.

Maternal Antibodies

In 2008, the first study of its kind reported that 12 percent of mothers with autistic children had unusual antibodies to foetal brain proteins, promoting the idea that circulating antibodies may

cause some forms of autism (Braunschweig et al., 2008). More recently it has been proposed that up to 22 percent of cases of autism could be associated with Maternal Antibody-Related causes (Fox-Edmiston & Van de Water, 2015).

Drugs

Several studies have demonstrated associations between the ingestion of certain drugs and increased likelihood of autism. The first such evidence came from a study of 100 adults whose mothers had taken thalidomide during pregnancy where four were found to have autistic characteristics (Strömland, Nordin, Miller, Akerström, & Gillberg, 1994). Subsequently, a large epidemiological study concluded that 7.5 percent of children born to mothers taking valproic acid during pregnancy (primarily used to treat epilepsy) had some form of neurodevelopmental disorder (typically autism) compared to 1.9 percent in the non–epileptic group (Bromley et al., 2013). More recently, concerns have been raised over selective serotonin reuptake inhibitors (SSRIs), a class of antidepressants. A recent meta-analysis found that SSRI use during pregnancy was significantly associated with autism (Kaplan, Keskin-Arslan, Acar, & Sozmen, 2016). However, these results are often caveated by the confounding role of underlying mental health issues of the mother during pregnancy. One study that did control for underlying mental health issues concluded that, particularly in the case of autism without intellectual disability, while confounding alone cannot explain these associations, the increased likelihood of autism is small (Rai et al., 2018). A recent cohort study of over 400,000 mother-child dyads found that prenatal use of antipsychotics was not associated with an increased likelihood of autism (Wang et al., 2021).

Environmental Toxicants

Environmental toxicants such as air pollution, pesticides, heavy metals, and cigarette smoke have been another focus of research into autism (Mandy & Lai, 2016; Ornoy, Weinstein-Fudim, & Ergaz, 2015). However, this field of research is still relatively new and techniques to establish environmental factors during the prenatal period are still under development. With this in mind, Amaral (2017) suggests that, given autism is not likely explained fully by genetic factors, understanding environmental causes, and therefore potentially avoiding or minimising certain factors, could have a significant impact.

Maternal smoking has been explored in relation to autism. However, despite contradictory results from individual studies (Jung, Lee, McKee, & Picciotto, 2017), several recent meta-analyses have all concluded there is no evidence to suggest autism is significantly increased by maternal smoking (Jung et al., 2017; Rosen, Lee, Lee, Yang, & Burstyn, 2015).

Postnatal factors

Amaral (2017) largely dismisses the idea that postnatal factors could be a cause of autism. Historically, measles, mumps, and rubella vaccines have been linked to autism. However, a number of large-scale epidemiologic studies have since proven this untrue (Committee to Review Adverse Effects of Vaccines, 2012; Demicheli, Rivetti, Debalini, & Di Pietrantonj, 2013; Nordahl et al., 2011).

One study associated autism with the profound social isolation experienced by those in the Romanian orphanage system (Dozier, 2014). However, another argued that while almost 10 percent of children raised in Romanian orphanages showed autistic features at age four, the substantial improvements, including the degree of social interest observed by age six, is evidence of autism-like traits but not true autism (Rutter, 1999).

Given the exponential growth in children's use of screens over recent years, the association between 'screen time' and autism has become a focus of emerging literature. In a recent literature review of 16 studies, a consensus view was reported that young autistic people were exposed to higher amounts of screen time during childhood than their typically developing peers (Slobodin, Heffler, & Davidovitch, 2019). More recently, a large Japanese birth cohort study found that among boys (but not girls), higher levels of screen time at one year of age was associated with significantly higher odds of an autism diagnosis (Kushima et al., 2022). One explanation is reverse causation, whereby, autistic children might be more likely to seek screen time, or parents with autistic children may be more likely to use screen time as a form of respite.

The research evidence around the causes of autism is complex and incomplete. While research has demonstrated a strong genetic component to autism aetiology, this can account for only a proportion of autism cases. Furthermore, the observed increase in autism prevalence over time indicates that genetics alone cannot provide the sole explanation for autism. On the other hand, while some environmental factors, such as rubella infection and foetal exposure to valproic acid, have a high association with autism, other factors such as environmental toxicants are small. It is likely therefore that a combination of the two will provide more insights over time. Regardless of the mix, it is most likely that these factors have their effect prior to birth (Amaral, 2017).

1.1.6 Strengths/difficulties associated with autism

1.1.6.1 Strengths

The medical model of autism is characterised by problems and deficits. It is also true that autistic people have a number of strengths and abilities. Box 1 displays a strengths-based

approach to describing autism by Altogether Autism, a nationwide autism spectrum information and advisory service in Aotearoa/New Zealand (Altogether Autism, 2019).

Box 1: Strengths and abilities in autism:

Autistic people may display a range of strengths and abilities that can be directly related to their diagnosis, including:

- Learning to read at a very early age (known as hyperlexia).
- Memorising and learning information quickly.
- Thinking and learning in a visual way.
- Logical thinking ability.
- May excel (if able) in academic areas such as science, engineering and mathematics as they are technical and logical subjects that do not heavily rely on social interaction.
- Having an extraordinarily good memory (being able to remember facts for a long period of time).
- Being precise and detail orientated.
- Exceptional honesty and reliability.
- Being dependable with respect to schedules and routines.
- Having an excellent sense of direction.
- Be very punctual.
- Strong adherence to rules.
- Able to concentrate for long periods of time when motivated.
- A drive for perfection and order.
- A capability for alternate problem solving.
- A rare freshness and sense of wonderment.

Source: Altogether Autism (2019)

1.1.6.2 Difficulties

Assessment of cognitive ability and adaptive function is a routine part of diagnosis as these factors define the degree of difficulties faced by autistic children (Bölte & Poustka, 2002). Typically, autistic children have difficulties with grasping complex social skills, understanding spoken information, and/or processing sensory differences. Although deficits in behaviour are often noted within 18 months of life, the average age of diagnosis is approximately six years

of age in Aotearoa/New Zealand (Eggleston et al., 2019). If left unchecked, these deficits may risk further regress, impacting on developmental milestones and/or development of conditions (Nylander, 2015).

Personal behaviours that enable independent daily life are regarded as adaptive behaviours (Farmer, Swineford, Swedo, & Thurm, 2018). Critical domains of adaptive behaviours include communication, daily living skills, socialisation, and motor skills. As a part of routine assessment, estimating adaptive behaviours is key for planning further therapy and care and often used as an outcome measure to enable predictions on how autism may impact an individual. The Vineland Adaptive Behavior Scales (Vineland-II) have, for example, been used as a standardised assessment tool to identify disabilities in autistic individuals (Leonard, Bedford, Pickles, Hill, & Team, 2015; Volkmar et al., 1987). In practice they may be used to assess a range of developmental milestones in children and also relatively more complex behaviours in adults.

Although autism has a negative impact on adaptive behaviour at any stage of life, among the most impacted are those who also have an intellectual disability (Bölte & Poustka, 2002; Matson & Shoemaker, 2009). Individuals with an intellectual disability have marked difficulties with learning and perception (Kraijer, 2000). In addition, common co-occurring mental health conditions such as ADHD, oppositional defiant disorder (ODD), anxiety, depression, or obsessive-compulsive disorder (OCD) can add additional challenges for autistic people in terms of independent living, personal autonomy, education, and interactions with the criminal justice system (CJS) (Fuller & Kaiser, 2020; Rogers & Vismara, 2008; Whitehouse et al., 2021).

1.1.7 Treatments and supports

Whitehouse et al. (2021) summarise the large body of research that highlights the immediate and long-term benefits of early intervention and support for autistic individuals and their families. The number and types of interventions available are wide-ranging and vary in their theoretical orientation and application in response to individual symptomology. In this section, using the Whitehouse et al. (2021) categorisations, nine separate non-pharmacological interventions are summarised first, followed by pharmacological interventions.

1.1.7.1 Behavioural interventions

Behavioural interventions focus on helping children to learn and manage new behaviours and skills and are the most common type of intervention for autistic children. These have mainly arisen from Applied Behaviour Analysis (ABA) and date back to the late 1980s (Lovaas, 1987). ABA focuses on improving positive behaviours such as the child's social, communication, intellectual, and life skills, and at the same time, aims to decrease challenging behaviours. ABA uses positive reinforcement to encourage the learning of appropriate behaviours. Examples include Discrete Trial Training (DTT) and the Early Intensive Behavioural Intervention (EIBI). However, in more recent years, ABA has received considerable criticism, particularly among the autistic community (Kirkham, 2017). Many reject the ideology of ABA, characterising autism as a neurological difference that should be accepted as opposed to a pathology.

1.1.7.2 Developmental interventions

Developmental interventions focus on communication and social interactions, supporting learning that is often child-directed and involving interactions with others, often caregivers. These interventions focus on improving language and communication, taking turns, imitation, and sharing interests (Sandbank et al., 2020). A limitation of developmental interventions is

that, because they are often child-led, there is a high level of skill required on the part of the therapist, including which behaviours to respond to and how to respond. Examples include the Developmental, Individual Differences, Relationship-Based Model (DIR), sometimes referred to as the Greenspan approach and commonly known as 'Floortime' (Greenspan & Wieder, 1998) and Paediatric Autism Communication Therapy.

1.1.7.3 Naturalistic developmental behavioural interventions (NDBIs)

NDBIs emerged in 2015 as an integration of behavioural and developmental theories (Schreibman et al., 2015). The theoretical framework of NDBIs reflects behavioural principles, however they are delivered like developmental interventions (Schreibman et al., 2015). They build social, communication, motor and play skills through activities that are incorporated into daily routines and interactions. Examples include the Early Start Denver Model (Rogers & Dawsone, 2010) and Pivotal Response Treatment (Koegel & Koegel, 2006).

1.1.7.4 Sensory-based interventions

Sensory interventions are based on the belief that sensory abilities are integral to all developmental skills. Some involve developing sensory processing abilities using specialist equipment in clinical facilities, such as Ayres Sensory Integration Therapy (Parham et al., 2007). Others, such as music therapy, weighted blankets, and massage, can be administered outside of clinical facilities (Baranek, 2002; Sandbank et al., 2020).

1.1.7.5 Technology-based interventions

These interventions leverage off the fact that autistic children are often attracted to technology, and therefore use computer technology (Sandbank et al., 2020). Such interventions reduce the

social demands of the intervention and can be used to support daily activities and to help with communication.

1.1.7.6 Animal-assisted interventions

These interventions focus on interactions with animals to support skill development. Animals can be a calming influence, are non-judgemental, and are often used in this context to improve health and well-being. They can also recognise when an autistic child is becoming overwhelmed, provide pressure to reduce stress and anxiety and to keep them safe, especially those prone to running away.

1.1.7.7 Cognitive behaviour therapy (CBT)

CBT is generally used to treat anxiety and depression which are common among autistic children. It helps people to develop alternative methods to cope with upsetting thoughts and distressing situations (Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2010; Rachman, 2015).

1.1.7.8 Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH)

TEACCH focuses on adapting a child's environment and tasks to support their learning and independence (Mesibov & Shea, 2010). The intervention focusses on the strengths of autism and emphasises the adaption of others to autism rather than a focus on encouraging autistic children to change.

1.1.7.9 Other

Dietary approaches, such as the Gluten/Casein-free diet, have been developed for the treatment of autism and other developmental conditions such as ADHD, although there is limited evidence such approaches improve symptoms (Sathe, Andrews, McPheeters, & Warren, 2017). In addition, complementary and alternative medicine treatments have become popular (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). These are controversial because current evidence does not support their efficacy but up to one third of parents of autistic children have tried them.

1.1.7.10 Pharmacological treatment

Pharmacological treatments can have benefits for autistic people although international guidelines on pharmacotherapies for autistic children and young people are limited and generally only provide broad recommendations (Thabrew, Viswanathan, Eggleston, Moor, & Chinn, 2020). The Food and Drug Administration in the USA has approved only risperidone and aripiprazole for treatment of irritability in autistic people (LeClerc & Easley, 2015). Hence, prescribing for other symptoms of autism mostly occurs 'off-label'. Medications that help symptoms associated with autism, such as seizures, energy levels, focus, anxiety, and depression are often utilised and research has shown that these medications are most effective when used in combination with behavioural therapies (Aman et al., 2009). A recent USA population-based cohort study of over 26,000 autistic individuals found a wide variety of medications were prescribed to manage symptoms and comorbidities associated with autism (Feroe et al., 2021). The study also found high rates of polypharmacy and medication transiency. Feroe et al. (2021) concluded that medical professionals may be increasingly incorporating pharmacological approaches to the treatment of autism and co-occurring

conditions, but note that the extent to which these approaches are effective is not clearly established.

1.2 Long term sequelae for autistic young people

Autistic children are at risk of academic, social, and behavioural difficulties (Lang, Regester, Rispoli, Pimentel, & Camargo, 2010; Lang et al., 2013; Watkins et al., 2015), resulting in long-term deleterious effects on their social inclusion, employment, adaptive functioning, and overall quality of life (Fuller & Kaiser, 2020; Rogers & Vismara, 2008; Whitehouse et al., 2021). A recent systematic review and meta-analysis identifying 15 studies from around the world found that outcomes for approximately 50% of autistic adolescents and adults were 'poor' (defined as "severely impaired but with some potential for social progress") or 'very poor' (defined as "unable to lead any kind of independent existence") (Steinhausen, Mohr Jensen, & Lauritsen, 2016). In contrast, only 20% of individuals were found to have good outcomes (defined as "normal or near-normal social like and satisfactory functioning at school or work"). The results highlight the myriad of challenges faced by autistic young people.

1.2.1 Educational outcomes

Behavioural, cognitive, and social challenges in conjunction with unrecognised and unmet need can make it difficult for autistic students to cope in schooling environments (Montes & Halterman, 2006). Consequently, autistic students often have poorer educational outcomes such as lower attendance, higher rates of suspension, and lower academic achievement (Krezmien, Travers, & Camacho, 2017; Montes & Halterman, 2006; Munkhaugen, Gjevik, Pripp, Sponheim, & Diseth, 2017). This places additional stresses on the student, parents, and education providers and is a reason why addressing the needs of autistic individuals is a public welfare issue. In addition, the known link between poor educational outcomes and other

deleterious consequences in later life underscores the importance of adequate and targeted support for autistic students within the school setting (Wald & Losen, 2003; Wilson, Malcolm, Edward, & Davidson, 2008).

1.2.1.1 Attendance

School attendance problems are a recognised concern for many autistic children and their parents (National Autistic Society, 2019). Research on school absenteeism has mostly focused on truancy which is associated with behavioural problems such as defiance and a lack of interest in school (Cardwell, Mazerolle, & Piquero, 2019; Ripamonti, 2018; Sutphen, Ford, & Flaherty, 2010). In comparison, less research is available on school refusal where emotional problems such as school phobias or anxiety are the cause of absenteeism. Irrespective of the nature of school absenteeism, it is concerning due to its associated outcomes which include school dropout, increased crime, and worsening of socioeconomic condition (Wilson et al., 2008). Given that autism is independently associated with several negative long-term outcomes, absenteeism among autistic children may compound the risk for poor outcomes later in life.

Depending on the presence of comorbidities, school refusal (the reluctance or outright refusal to go to school) is more likely than truancy among autistic children. There is a paucity of research into school refusal among autistic students, however, those that do exist indicate it is a far greater problem among autistic students compared to the general population (Munkhaugen et al., 2019). A recent study reported that autistic children were six times more likely to refuse school than typically developing children (Munkhaugen et al., 2017). Risk of absenteeism is particularly an issue for autistic students during transition from primary to secondary school,

where there is illness in other family members, when the child has received an additional diagnosis, or in the presence of cognitive problems (Munkhaugen et al., 2019).

1.2.1.2 Academic achievement

Academic achievement among young autistic people varies with symptomology (Keen, Webster, & Ridley, 2016; S. H. Kim, Bal, & Lord, 2018) and comorbidities (Keen et al., 2016; Montes & Halterman, 2006). For autistic people, this is important as research has shown that higher levels of educational attainment are associated with better labour market outcomes (Hedley et al., 2017).

Epidemiological evidence suggests that autistic individuals are less likely to obtain educational qualifications and secure employment (Brugha et al., 2011). An overview of the literature found considerable variation in academic achievement among autistic young people (Keen et al., 2016). Notably, the review found that sensory sensitivities, behavioural issues, social and communication challenges, and lower IQ were all associated with poorer academic success. A more recent population-level Danish registry study of academic achievement among young people with mental health conditions found that autistic children had a lower rate of taking their final grade nine examination compared to children without mental health conditions (Dalsgaard et al., 2020). In another study using Danish registry data, completion of ninth grade was found to be only marginally lower for autistic students, compared to non-autistic students (Toft et al., 2021). However, rates of upper secondary school completion were significantly lower for autistic students (adjusted prevalence ratio 0.46; 95% CI 0.42-0.50).

Particularly concerning is that young autistic people are at increased risk of not participating in further education following high school (Brugha et al., 2011; Shattuck et al., 2012) and of

lower tertiary completion (Toft et al., 2021). Shattuck et al. (2012) found that among young autistic people, only one in three had attended post-secondary education within six years of high school (Shattuck et al., 2012). Likewise, Toft et al. (2021) reported a significantly lower rate of tertiary completion for young autistic people, compared to non-autistic people (adjusted prevalence ratio 0.33; 95% CI 0.26-0.41). Disparities in outcomes related to post-secondary school education for autistic young people have been associated with lower rates of employment, lower earnings, and under-employment (Whittenburg, Cimera, & Thoma, 2019).

1.2.1.3 Bullying

Autistic students have higher risk of being victims of bullying compared to their typically developing peers (Ashburner et al., 2019; Hwang, Kim, Koh, & Leventhal, 2018; Maiano, Normand, Salvas, Moullec, & Aimé, 2016; Twyman et al., 2010). A meta-analysis found that the pooled lifetime incidence of bullying victimisation for autistic students was 44% and a significant increased odds of being bullied (odds ratio 3.0; 95% CI 1.9-4.9) (Maiano et al., 2016). Bullying is also likely to be a factor around school refusal for autistic students.

1.2.1.4 Disciplinary actions

Disciplinary actions at school include exclusionary action which removes students from their schooling environment (e.g., suspensions and expulsions) or inclusionary actions which provide corrective services within schooling environments (e.g., detentions) (Petrosino, Fronius, Goold, Losen, & Turner, 2017). While evidence demonstrates the negative effects of disciplinary actions on future academic achievement (Yaluma, Little, & Leonard, 2021) contemporary research examining the prevalence of disciplinary actions taken against autistic students is limited and inconclusive. The most recent literature has demonstrated that autistic students are more likely than their non-autistic peers to be suspended (Ambler, Eidels, &

Gregory, 2015; Krezmien et al., 2017), however this is in contrast to earlier studies which found no difference (Krezmien, Leone, & Achilles, 2006; Losen, Hodson, Ee, & Martinez, 2014).

1.2.1.5 Impact of co-occurring conditions on educational outcomes for autistic students

Autism impacts on a range of educational outcomes, however co-occurring conditions common among autistic students likely independently impact on these outcomes as well. Therefore, it is important to recognise the complex needs associated with autism and the role that co-occurring conditions play. There is a strong correlation between the presence of intellectual disability and educational achievement for autistic students (S. D. Mayes & Calhoun, 2008). More generally, a nationwide cohort study showed that students with mental health conditions had significantly lower attainment levels compared to those without mental health conditions. In particular, conditions that commonly co-occur with autism such as intellectual disability, ADHD, ODD, anxiety, and substance use disorders were all associated with poorer academic performance (Dalsgaard et al., 2020). Likewise, risk of exclusion from school is particularly elevated among young people with ADHD (Ford et al., 2018).

1.2.2 Criminal justice system interactions

Research on the interactions of autistic people and the CJS focusses on either criminal actions or victimisation. Contemporary literature is conflicted with regards to criminal actions and there is debate about whether autistic people are over- or under-represented in the CJS (Cashin & Newman, 2009; Howlin, Goode, Hutton, & Rutter, 2004; King & Murphy, 2014; Mouridsen, 2012; O'Brien, 2002). On the other hand, victimisation of autistic individuals, such as interpersonal violence and sexual assault has been consistently documented at rates higher than the general population (Brown-Lavoie, Viecili, & Weiss, 2014; Edelson, 2010; Mandell,

Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005; Sevlever, Roth, & Gillis, 2013; Weiss & Fardella, 2018).

1.2.2.1 Criminal actions

Highly publicised criminal cases have led many in the public to assume autistic people are more likely to commit criminal offences (Allen et al., 2008; Howlin, 1997; Howlin et al., 2004). In contrast, recent literature presents an unresolved debate (Howlin et al., 2004; King & Murphy, 2014). The debate on whether autistic individuals are likely to commit criminal actions hinges on ways that behavioural traits associated with autism might impact offending behaviour, legal culpability and sentencing. On one hand, since autistic people may find rules and routines helpful for social navigating, it is hypothesised that they are less likely to offend (Cashin & Newman, 2009; King & Murphy, 2014; Mouridsen, 2012; O'Brien, 2002). Others suggest, since autistic individuals are often socially naïve, they may be more susceptible to manipulation and consequently may be coerced into committing crimes (Howlin et al., 2004). It has also been suggested since some autistic individuals develop maladaptive or challenging behaviours (e.g., aggression), they may be predisposed to act out violently (Rivera, Gerow, & Kirkpatrick, 2019).

Research on autism and the CJS can be grouped into two main types of studies: prevalence of autism in the CJS; and prevalence of CJS interactions among autistic populations (King & Murphy, 2014; Railey, Love, & Campbell, 2020). Existing prevalence studies on autism in the CJS have tended to indicate autistic young people are over-represented (Ali, 2018; King & Murphy, 2014). However, these studies are characterised by methodological shortcomings; highly specialised (biased) samples, poor methods for the diagnosis or case identification of autism, and absence of controls for confounding factors (Ali, 2018; King & Murphy, 2014).

As stated by King and Murphy (2014), this makes direct comparisons among these studies difficult, but more importantly brings into question the robustness of findings. That said, the conclusions drawn, that autistic people are over represented in CJS populations, has shaped some of the early narratives in this area (Hare, Gould, Mills, & Wing, 1999; Kumagami & Matsuura, 2009; Robinson et al., 2012; Scragg & Shah, 1994).

Studies on the prevalence of CJS interactions among autistic populations tend also to be characterised by methodological limitations such as biased samples and poorly-matched comparison groups (King & Murphy, 2014). In addition, the definition of offending varies, ranging from convictions (Hippler, Viding, Klicpera, & Happé, 2010), to self-reported criminal activities (Woodbury-Smith, Clare, Holland, & Kearns, 2006), making comparisons difficult. For these reasons, rates of 'offending behaviour' vary dramatically among autistic populations from as low as 2.74 percent (Hippler et al., 2010) to 48 percent for self-reported criminal behaviour (Woodbury-Smith et al., 2006). However, of the studies reviewed by King & Murphy (2014) that employed control groups and were thus deemed to constitute the best quality evidence available, all found that autistic people had the same, or fewer, number of offences than non-autistic people (Brookman-Frazee et al., 2009; Cheely et al., 2012; Hippler et al., 2010; Mouridsen, Rich, Isager, & Nedergaard, 2008; Woodbury-Smith et al., 2006).

1.2.2.2 Crime types

It has been postulated that the traits of autism may predispose individuals to committing certain types of crimes. Howlin et al. (2004) hypothesised that over adherence to rules and disruption of routine might cause some people to act out aggressively. Others have suggested that misinterpretation of social cues could result in inappropriate relationships which in turn may lead to sexually inappropriate behaviours, albeit inadvertently (Haskins & Silva, 2006; Murrie,

Warren, Kristiansson, & Dietz, 2002; Palermo, 2004). 'Special interests', common among autistic people such as interests in fire or computing, have also been linked to criminal behaviour, although often inadvertently (Barry-Walsh & Mullen, 2004; Dein & Woodbury-Smith, 2010; Freckelton, 2013; Murrie et al., 2002). For example, in the Aotearoa/New Zealand context, an autistic young person with particular interest in electrical fittings and wiring was prosecuted by police for taking two lightbulbs from a building scheduled for demolition after the Christchurch earthquakes in 2011 (McMurray, 2015).

Crimes against people have historically been most studied in relation to autism although there is a paucity of contemporary empirical research. Early research utilised case studies to highlight a link between violent crime and autism (Baron-Cohen, 1988; Simblett & Wilson, 1993) but this notion has been challenged by more recent research (Helverschou et al., 2015; Mouridsen, Rich, et al., 2008; Woodbury-Smith et al., 2006). Studies have shown that sexual offences constitute a larger percentage of total crimes committed by autistic people compared to non-autistic people, but autistic people are still less likely to commit sexual offences than non-autistic people (Dein & Woodbury-Smith, 2010; Kawakami et al., 2012). More recently, Cheely et al. (2012) found that autistic youth, when they did commit an offence, were more likely to commit offences against people (e.g., assault) than property (e.g., arson), compared to those without autism. In their review, King and Murphy (2014) assert that it is difficult to draw any conclusions from existing research because the majority of studies lack control groups, and/or utilise biased samples.

1.2.2.3 The role of co-occurring mental health conditions

An important area of research in relation to autism and CJS interactions is the role that mental health problems, common among autistic individuals, might play. In particular, it is postulated

that externalising disorders such as ADHD and conduct disorders may increase the risk of offending behaviours (Vermeiren, Jespers, & Moffitt, 2006). Authors have suggested that increased levels of offending among autistic people are related more to co-occurring psychiatric conditions, than to autism (Haw, Radley, & Cooke, 2013; Newman & Ghaziuddin, 2008). For example, among a cohort of autistic Swedish inpatients, those who were convicted of violent crimes had higher rates of psychiatric conditions and substance problems than those without a conviction (Långström, Grann, Ruchkin, Sjöstedt, & Fazel, 2009). Another Swedish study found that autistic individuals appeared to have a 39% higher risk of violent offending than the general population but concluded that this association was explained by co-occurring ADHD or conduct disorder (Heeramun et al., 2017).

There remains an unresolved debate in existing literature as to whether or not autistic people are at higher risk involvement with the CJS, and if associations with particular offence types exist. Moreover, extant literature focusses on discrete aspects of the CJS rather than the pathway through it (i.e., from police interactions, to courts, and to corrections). More robust research is required to better understand the prevalence of CJS interactions among autistic individuals and to examine the pathways through the CJS (Ali, 2018; King & Murphy, 2014; Lambie, 2020).

1.2.2.4 Victimisation

Although there is limited evidence, it is suggested that autistic individuals may be at a higher risk of experiencing abuse and victimisation than the general population. Most of these studies are on sexual victimisation of autistic individuals including unwanted sexual contact, sexual coercion, and rape (Brown-Lavoie et al., 2014; Edelson, 2010; Mandell et al., 2005; Sevlever et al., 2013). A reason postulated for a higher risk of sexual victimisation among autistic

individuals is that they have more limited sexual knowledge than the general population due to limited peer interactions and difficulties with social interaction (Briskman, Frith, & Happé, 2001). While early research indicated autistic males and females were equally at risk of sexual victimisation (Brown-Lavoie et al., 2014), a more recent study concludes females have elevated risk (Pecora, Hancock, Mesibov, & Stokes, 2019).

In comparison to literature on the victimisation of autistic individuals, research on individuals with intellectual disabilities is more extensive (Goodman et al., 1999; Havassy & Mericle, 2013; Lam & Rosenheck, 1998; Teplin, McClelland, Abram, & Weiner, 2005). Among individuals with intellectual disabilities, there is not only a greater risk of sexual victimisation than the general population (Bryson, Rogers, & Fombonne, 2003; La Malfa, Lassi, Bertelli, Salvini, & Placidi, 2004; Westcott & Jones, 1999) but also other types of abuse (e.g., physical abuse, neglect, and exploitation) (Swiezy, 2008). Because autistic people have high rates of intellectual disability or share certain vulnerabilities with people with intellectual disabilities, namely, social and communicative impairments, it follows that they may also be at increased risk of being victims of crimes (Pfeffer, 2016).

1.3 The United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international human rights treaty, adopted by the United Nations in 2006, and ratified by over 182 countries, including Aotearoa/New Zealand (UN General Assembly, 2007). The UNCRPD sets out what countries must do to ensure that all people with disabilities (including autism) have access to human rights and fundamental freedoms on an equal basis to everyone else. The

Articles in the UNCRPD cover a number of areas where disabled people have historically been discriminated against, such as health, education, and the justice system.

Autism in Aotearoa/New Zealand is relatively poorly reported and understood compared to other health conditions and there are gaps and failures to address the UNCRPD. In particular, Article 31 stipulates that signatories should collect data, including conducting research, to enable and track progress toward their obligations under the Convention. Given there is not currently any routinely collected data on autism in Aotearoa/New Zealand there is a failure to meet this obligation.

1.4 What does this thesis contribute?

1.4.1 Summary of gaps in the literature

This literature review has revealed several important gaps in extant research that this thesis will attempt to address.

It has revealed a void of quantitative data on autism in Aotearoa/New Zealand and an absence of any population-level lifecourse research. Notably, there is no registry for autism in Aotearoa/New Zealand and no recognised method for identifying cohorts of autistic people using population-level data. Therefore, autism research in Aotearoa/New Zealand is typically restricted to small clinical samples and research based on survey information.

The evidence base regarding medication use among autistic young people is limited. Few studies have explored the medications young autistic people are being prescribed, especially population-level studies and the examination of both psychotropic and non-psychotropic medications and levels of polypharmacy.

While studies exist exploring outcomes of autistic young people such as in education and the CJS, several notable gaps exist. For example, with respect to education, few studies have examined rates of suspension among autistic students, and evidence from these studies is conflicting. There has not been any research that has specifically examined the impact of education-based funding support for autistic students in relation to risk of suspension. While interactions with the CJS among autistic young people has been relatively well researched, these studies tend to be of small non-random samples and focus only on discrete aspects of the CJS (e.g., incarceration). There has not been a study which explores the pathway through the CJS.

1.4.2 Opportunities for autism research: the integrated data infrastructure

The Integrated Data Infrastructure (IDI) is a large research database, curated by Statistics New Zealand containing a wide range of data about people and households from Aotearoa/New Zealand from national administrative collections and surveys (Milne et al., 2019; Statistics New Zealand, 2017b). The breadth of data in the IDI represents one of its key strengths as it links data for an individual across multiple life domains, including but not limited to, health, education, and the CJS. Moreover, most of these are population-level data, making the IDI a world-leading source of information for research (see Chapter 2 for a detailed discussion of the IDI). Use of the IDI presents a unique opportunity for lifecourse research in Aotearoa/New Zealand, one that has yet to be explored with respect to autism, and which has the potential to make important contributions to international literature. This also presents as an opportunity to demonstrate that effective use of existing administrative data offers opportunities to better understand autism and meet Aotearoa/New Zealand's obligations under the UNCRPD.

1.4.3 Thesis objectives

The overall aim of the thesis is to develop an IDI-based autism case identification method and apply this method to better understand autism across the lifecourse, in particular the domains of health, education, and the CJS among youth.

The objectives of this thesis are to:

1) Explore how the IDI could be used for identification of autism among children and young people aged 0–24 years; describe differences in identified rates of autism by sex, age, ethnicity, deprivation, and urban/rural profile of residence; examine the types and rates of co-occurring mental health and related conditions in this group (Chapter 3).
2) Explore medication dispensing for autistic children and young people; compare dispensing and polypharmacy rates between those with autism, ADHD, and the general population (Chapter 4).
3) Quantify differences in suspension rates for autistic compared to non-autistic students; assess whether high need education-based funding reduces suspension rates for autistic students (Chapter 5).
4) Report the prevalence of CJS interactions among young autistic people and examine pathways through the system, including differences in offence types, compared to those without autism (Chapter 6).

2 Methods

2.1 Data

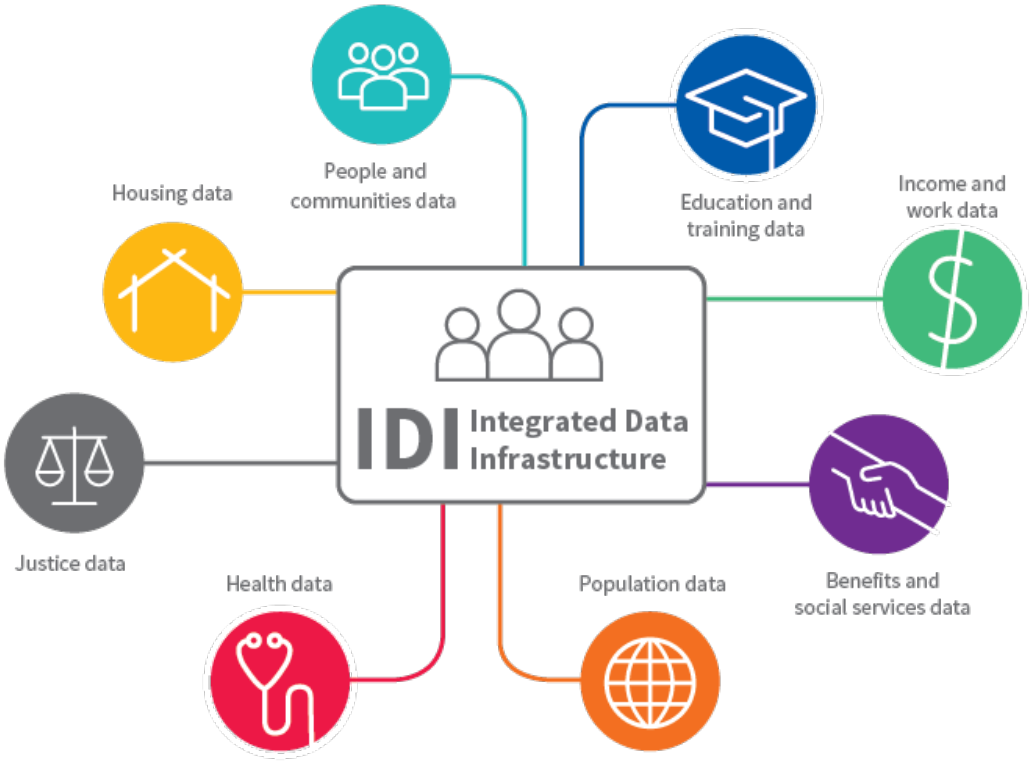
2.1.1 Integrated data infrastructure overview

The source of data for this thesis is the IDI, a large research database managed by Statistics New Zealand, containing a wide range of data about people and households from national administrative collections and surveys (Milne et al., 2019; Statistics New Zealand, 2017b). Statistics New Zealand was mandated to link cross-agency data as far back as 1997, however the IDI was not established until 2011. IDI data are accessible only via secure virtual environments known as Data Labs, and only in research facilities approved by Statistics New Zealand. These data can be used only by approved researchers and for projects that are in the public interest.

2.1.1.1 Data in the IDI

The breadth of data in the IDI represents one of its key strengths (see Figure 1). Restricted datasets cover: health, crime, education, census, housing, income and employment, and social welfare. Over time, new datasets are added to the IDI and existing datasets are updated periodically to extend time coverage and sometimes depth of information. In addition, a series of derived tables are available in the IDI that combine information from multiple datasets to produce core demographic variables such as age, sex, ethnicity, and residence information.

Figure 1: Data in the Integrated Data Infrastructure



Source: Statistics New Zealand

2.1.1.2 Data linking

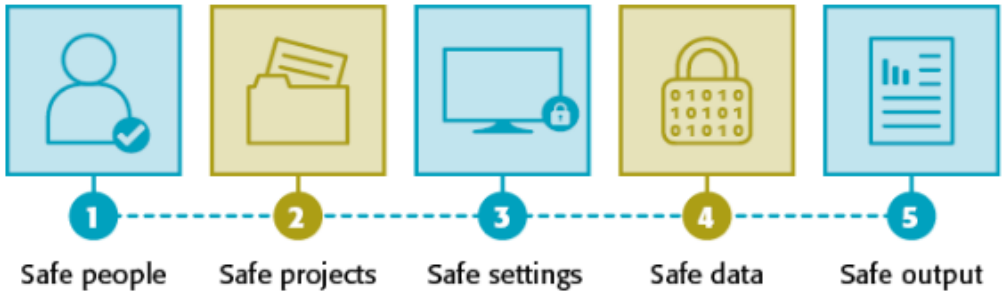
Data are linked within the IDI to the IDI 'spine' using probabilistic linkage methods (Statistics New Zealand, 2014). Data from different sources (e.g., health and education) can only be linked through the spine. For example, an individual's health and education data can be linked together only if each is independently linked to the spine. The IDI spine is intended to capture the ever-resident population of Aotearoa/New Zealand, including those born in New Zealand since 1920 (using birth records), those who arrived in New Zealand on a long term visa since 1997 (using immigration records), and those who have paid tax in New Zealand since 1999 (using IRD tax records) (Black, 2016). Data from the same agency can be matched prior to being linked to the spine using unique identifiers such as the NHI number for health data.

However, when data are linked to the spine, probabilistic matching is conducted utilising date of birth, first and last name, and sex information (Gibb, Kvalsvig, & Teng, 2019).

2.1.1.3 Data privacy

Statistics New Zealand employs the 'five safes' framework to ensure data privacy is protected (see Figure 2) (Statistics New Zealand, 2017a). This framework was originally developed in the United Kingdom Office for National Statistics (Ritchie, 2008). Access to the IDI is only provided if all of the 'five safes' conditions are met.

Figure 2: The Five Safes Framework



Source: Statistics New Zealand

1. 'Safe people' requires that researchers pass referee checks, attend confidentiality training, and sign a declaration of secrecy under the Statistics Act 1975.
2. 'Safe projects' means that research projects must be for the public good and approved by Statistics New Zealand.
3. 'Safe settings' necessitates that data can only be accessed through a secure virtual environment known as the 'Data Lab', and only in research facilities approved by Statistics New Zealand.
4. 'Safe data' involves having identifying information removed, researchers applying to access particular datasets, and gaining access only to the data they need.

5. ‘Safe output’ requires that researchers must confidentialise their results within the IDI environment and, prior to public release, all output is checked by Statistics New Zealand.

A range of legal requirements and Statistics New Zealand policies, protocols, and guidelines exist to protect IDI data (Bowden, Gibb, et al., 2020; Statistics New Zealand, 2017a). These include the Statistics Act 1975, the Privacy Act 1992, and the Tax Administration Act 1994 as well as guidelines and policy on microdata access, privacy, security, confidentiality, and data integration. In addition, regular privacy impact assessments are undertaken to systematically evaluate the benefits and risks associated with data integration.

2.1.1.4 Strengths and limitations of the IDI

Milne et al. (2019) summarised the main analytical strengths and limitations of the IDI (Milne et al., 2019). The strengths include:

1) Linkage of data from a range of government sectors permitting research of a much broader scope than previously possible in Aotearoa/New Zealand.
2) A large number of datasets in the IDI with national coverage, containing service use information for the entire Aotearoa/New Zealand population. These large sample sizes enable analysis of small sub-groups of the population and rare events that are typically not possible when utilising primary data.
3) The vast majority of data in the IDI being administrative which removes the risk of recall bias, an issue that arises when data are based on self-reports.
4) The possibility to load data from external sources into the IDI. This can be particularly beneficial when data are uploaded about a specific sample or cohort of individuals that can then be tracked longitudinally through the IDI. Uploading of data

into the IDI is carried out by Statistics New Zealand upon request but requires that appropriate permission and consent has been given.

5) A number of analytical advantages such as the ability to define specific groups of interest (e.g., autism), analyse short, medium and long-term outcomes, evaluate interventions, and link to family members such as parents or siblings.

The IDI must also be viewed in the context of a number of limitations. These include:

1) Concerns over data quality. The vast majority of the data held in the IDI are administrative and were not collected specifically for research. This means data have been collected by a range of agencies and the consistency of collection is variable. While quality is improving over time, each dataset has a nuanced set of quality concerns which researchers must understand to conduct robust research.
2) The absence of high-quality data documentation and metadata across all datasets. Comprehensive documentation is becoming available over time and a process is being undertaken to collate all of this centrally. However, lack of good quality data documentation continues to be a concern.
3) Incorrect data linkage. Both false positive and false negatives can have significant consequences for analysis. Incorrect linkage can cause selection bias, measurement error, and confounding. Moreover, incorrect linkage impacts certain socio-demographic sub-groups more than others.
4) Individuals with health issues not accessing health services and not captured in the IDI. Moreover, it is not possible to distinguish between an event that is not linked from the absence of an event.
5) Variable time coverage of datasets in the IDI. The majority of datasets held in the IDI are not available prior to 2000. In addition, the frequency with which data sets are

updated to include the most recent data, and how recent those data are, varies by collection. This limits the ability for researchers to track outcomes over long time frames.

2.1.1.5 Ethics

Statistics New Zealand do not require ethical review for IDI projects although they do require a researcher's organisations to support the project. Ethical approval was sought and obtained for this study (see Ethical approvals sub-section).

2.1.2 Health

Health data are used throughout the thesis, primarily to identify autism (see Chapter 3 for details), but also for examining pharmaceutical dispensing data to understand the medical burden of young autistic people, to identify co-occurring health conditions (both as outcomes and as confounders), and to determine measures of the complexity/level of need of autism.

2.1.2.1 National minimum dataset

The National minimum dataset (NMDS) is a national collection of all publicly funded hospital admissions in Aotearoa/New Zealand, including day patients (stays of either three hours or more but not overnight) and emergency department visits of greater than three hours (Statistics New Zealand, 2015b). NMDS data within the IDI are available from 1988. For every hospital event a range of information is recorded, including the date of admission, date of discharge, and primary and secondary diagnosis codes (using ICD-9 and ICD-10-AM).

2.1.2.2 Programme for the integration of mental health data

The programme for the integration of mental health data (PRIMHD), formerly the Mental Health Information National Collection (MHINC), is a national collection of publicly funded specialist mental health service use (PRIMHD activity) and diagnoses (PRIMHD classification) data (Statistics New Zealand, 2015a). Information in PRIMHD is sourced from DHBs and non-governmental organisations (NGOs) and available in the IDI from 2008 (data in MHINC are available from 2001). The services captured in PRIMHD are those which are targeted to approximately three percent of the Aotearoa/New Zealand population with the most serious mental health problems (Ministry of Health, 1994). PRIMHD does not capture mental health services provided in a primary care setting or by private providers.

Primary and secondary diagnosis codes (ICD-10-AM and DSM-4) are recorded in PRIMHD classification data. These represent the only national collection of formal psychiatric diagnoses in Aotearoa/New Zealand. However, there are some notable limitations. A number of individuals have contact with mental health services but do not have specific diagnoses recorded. This is typically because individuals had only brief contact with mental health services and there was insufficient time for a diagnosis to be assigned (Ministry of Health, 2017d). Approximately 37% of all records in PRIMHD have non-specific diagnoses assigned. Information reflecting the type of specialty mental health care and the team that provided the service is contained within PRIMHD activity data.

2.1.2.3 Socrates

The national collection of the Ministry of Health's Disability Support Services (DSS) clients is called Socrates. These data include information about individuals who apply or are referred for a needs assessment, conducted by a NASC agency, to access support services. A range of

information is included in Socrates including date of referral, diagnosis, and outcome of referral. Diagnosis information is provided to NASCs on referral. For autistic people, this will typically come from an ASD coordinator, paediatrician, or general practitioner. Socrates was established in 2008 however, on advice from the Ministry of Health, the data are considered robust for research use from 1 July 2010 (Ministry of Health, personal communication, November 1, 2018).

2.1.2.4 Pharmaceutical collection

The pharmaceutical collection (Pharms) is a national dataset of all claim and payment information from community pharmacies for government-subsidised medication dispensing (Statistics New Zealand, 2015c). Pharms data are available in the IDI from 2005, however, due to low NHI coverage (less than 90%), the Ministry of Health recommends that for research purposes, only data from 2007 should be used. Pharms data contain a wide range of information related to each medication dispensing such as the date of dispensing, medication dispensed, formulation, dose, and daily supply.

Importantly, Pharms data include dispensing information related to both specialist and general practitioner prescribing. Therefore, they provide insight into healthcare activity at the primary care level which is not otherwise available in the IDI.

2.1.2.5 Mortality collection

All deaths registered in Aotearoa/New Zealand and their underlying causes are collected in the mortality collection (Ministry of Health, 2017c). The collection uses ICD-10-AM coding and rules and guidelines for mortality coding from the World Health Organization (World Health Organization, 2003). Mortality data in the IDI is available from 1988, however, due to coronial

processes, to determine the facts of death, there is a lag in its availability, typically of around two years, compared to other IDI health datasets.

2.1.3 Education

The paper presented in Chapter 5 examines stand-downs and suspensions and does so in relation to those who have Ongoing Resourcing Scheme (ORS) funding. It draws on information from the following education datasets.

2.1.3.1 School enrolment

School enrolment data from the Ministry of Education capture students enrolling in their first year of school and those changing schools. These data indicate the date of enrolment and the school the student was enrolled in. Complete coverage school enrolment data are available from 2006.

2.1.3.2 Student interventions

These data capture a range of school interventions that can be linked to the student. These interventions include, but are not limited to, adverse educational outcomes such as stand-downs, suspensions, exclusions, and expulsions (complete coverage available from 2006), as well as supports for students such as ORS (complete coverage available from 2009).

2.1.4 Criminal justice system

The paper presented in Chapter 6 examines interactions with the CJS drawing on information from the following datasets.

2.1.4.1 New Zealand police recorded crime offenders data

These data include all alleged offenders who have been proceeded against by police including both court and non-court proceedings. The dataset includes substantial offences (e.g., robberies), attempted offences, aid and abet offences, and conspiracy offences. It excludes offences that can be dealt with by the police via infringement notices and offences that come under the authority of other agencies such as Customs and Inland Revenue. Offences are defined by the 2011 edition of the Australian and New Zealand Standard Offence Classification[1] (ANZSOC). The dataset covers the time period starting 1 July 2009 and is a national collection.

2.1.4.2 Ministry of Justice courts data

These data are a national collection of records of all charges disposed by the criminal courts. The data cover court charges from 1992 including charges that resulted in convictions and those that were dismissed, not proceeded against, or that resulted in diversion. Charges are also classified using ANZSOC.

2.1.4.3 Department of Corrections data

This dataset provides events and periods relating to how convicted offenders are being managed by the Department of Corrections. It includes information pertaining to community sentences, incarcerations, and remand. These data are a national collection and cover the period from 1998 onwards.

[1] See https://www.abs.gov.au/ausstats/abs@.nsf/mf/1234.0 for more details.

2.1.5 Core IDI datasets

2.1.5.1 Personal details

The personal details table contains information on an individual's sex, birth month and birth year, and ethnicity. These data are sourced from multiple collections in the IDI. With regards to sex, until recently statistical standards typically asked individuals only whether they were male or female, and did not use the terms gender or sex. A new statistical standard for gender, sex, and variations of sex characteristic, acknowledging and attempting to address issues related to a lack of inclusiveness with regards to intersex and transgender people, was released in 2021 (Statistics New Zealand, 2021). However, this thesis was limited to statistical standards at the time of data collection and was therefore restricted to the binary male/female distinction. Ethnicity information was sourced from multiple collections over time and the highest ranked source (based on quality ranking from Statistics New Zealand) was used to determine each individual's ethnicities. The thesis used the total concept approach, meaning that individuals can identify with more than one ethnic group. It used the New Zealand Standard Classification 2005V2.0.0 for major ethnic groups: European, Māori, Pacific, Asian, Middle Eastern / Latin American / African (MELAA), and Other.

Estimating the resident population

The IDI contains a core dataset that identifies individuals who are thought to be resident within Aotearoa/New Zealand on the 30th of June each year (i.e., the end of the fiscal year), using established methods for estimating the resident population from administrative data (Gibb, Bycroft, & Matheson-Dunning, 2016; Zhao, Gibb, Jackson, Mehta, & Exeter, 2017). To be included in the resident population, individuals are required to be alive and living in Aotearoa/New Zealand and to have engaged with key government services in the previous two

years (e.g., health, education, taxation). Total resident populations from this table are within 2% of official population estimates (Gibb et al., 2016).

2.1.5.2 Address notification

The address notification dataset contains an historical list of all registered address changes from 1 January, 2000. In particular, an individual's meshblock of residence can be identified from this table. Meshblocks are the smallest geographic administrative units for which statistical data are reported by Statistics New Zealand. Their size typically ranges from 30–60 dwellings or around 60–120 residents. These data are particularly important for assigning New Zealand Deprivation Index (NZDep) scores, and urban/rural profile of residence - two geographical measures that are used throughout this thesis.

2.2 Participant population

The approach to establishing a participant population throughout this thesis is based on the fact that the IDI contains population-level data. Therefore, we use populations based on estimates of the Aotearoa/New Zealand resident population. Populations for fiscal years can be drawn from the ERP table and for other periods, such as calendar years, they can be constructed manually (Gibb et al., 2016).

2.2.1 Identifying the autism population

The paper presented in Chapter 3 describes the autism case identification method used throughout the thesis to establish cohorts of young autistic people. The method draws on diagnosis information recorded in NMDS, PRIMHD, and Socrates to indicate individuals who are autistic. Due to variable time coverage of each of these three datasets, typical use of the method starts from 1 July, 2010 and ends 30 June, 2018. Autism is indicated if at least one

diagnostic code for autism across any of the three datasets is identified during the time period of interest (see Chapter 3 for details).

PRIMHD and NMDS were chosen as sources of information as they contain official diagnosis codes (e.g., DSM-4, ICD9, and ICD10-AM). These can be considered the gold standard in identification of conditions using administrative datasets. However, these two datasets rely on, in the case of PRIMHD, individuals utilising publicly funded specialist mental health services, and for NMDS, being admitted to hospital for publicly funded events. As presented in Chapter 3, these constitute relatively few identifications of autism. Socrates, on the other hand, does not use ICD or DSM coding, rather it relies on an arguably less reliable 'assigned diagnosis code'. However, it is a touchpoint in the Aotearoa/New Zealand health system that the vast majority of young autistic people will access. Therefore, while the validity of the coding may have some concerns, given available data, Socrates is critical to identifying autistic cohorts of a sufficient size using the IDI.

Sources of data that would be useful for the identification of autism but which are not included in the IDI are: diagnosis information from primary care, outpatient specialty, and, in particular, access to the original autism diagnosis. In addition, private coverage is variable, and Well Child visits do not record diagnostic information.

The size of population denominators and autistic cohorts identified in this thesis vary across the four published papers in this thesis. There are a number of potential reasons for this including variations in cohort definitions (e.g., age), study periods of interest, and exclusion/inclusion criteria. Moreover, IDI data are updated (refreshed) over time. New IDI refreshes can include greater temporal data coverage as well as modifications to existing data

such as improved linkage and data quality. Different IDI refreshes are employed across studies and therefore may also contribute to variation in analytical sample sizes.

2.3 Statistical methods

The study designs, variables used, and statistical analysis employed are described in each of the papers presented in Chapters 3 - 6.

2.4 Ethical approvals

This study was approved by the University of Otago Human Research Ethics Committee (Reference: H17/004). The study was reviewed as a 'Minimal Risk Health Research – Audit and Audit related studies' proposal. Access to IDI data was approved by Statistics New Zealand (Project reference: MAA2017-16).

3 Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand

3.1 Preface

This chapter contains an original manuscript, 'Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand'. It was published in *Autism* in 2020; *24*(8), pp.2213-2227 Doi: 10.1177/1362361320939329 (Bowden N, Thabrew H, Kokaua J, Audas R, Milne B, Smiler K, Stace H, Taylor B, Gibb S).

Limited quantitative data exists in Aotearoa/New Zealand on autism, in particular with respect to autism prevalence and population level analysis. The Statistics New Zealand IDI provides an unexplored opportunity for autism research in Aotearoa/New Zealand.

The objectives of this paper were to explore ways in which the IDI could be used to identify population level cohorts of young autistic people in Aotearoa/New Zealand, determine differences in identification rates of autism across sociodemographic subgroups, and examine relative rates of co-occurring mental health and related conditions for those with and without autism.

3.2 Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand

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Autism 2020; *24*, 2213-2227, doi: 10.1177/1362361320939329 (Bowden, Thabrew, Kokaua, Audas, et al., 2020)

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Statement of contribution

The concept for this study was conceived by Bowden, Kokaua, Audas, Milne, and Gibb. Ethical approval was sought by Bowden. Bowden conducted data analysis and wrote the first

draft of the manuscript. All authors subsequently helped revise the manuscript to its final version.

Abstract

Aotearoa/New Zealand has few estimates of the prevalence of autism and no national registry. The use of administrative data sources is expanding and could be useful in autism research. However, the extent to which autism can be captured in these data sources is unknown. In this study we utilised three linked administrative health data sources from IDI to identify cases of autism among Aotearoa/New Zealand children and young people. We then investigated the extent to which a range of mental health, neurodevelopmental, and related problems co-occur with autism. In total, 9,555 unique individuals aged 0-24 with autism were identified. The identification rate for eight-year-olds was 1 in 102. Co-occurring mental health or related problems were noted in 68 percent of the autism group. The most common co-occurring conditions were intellectual disability, disruptive behaviours, and emotional problems. Although IDI data may currently undercount cases of autism, they could be useful for monitoring service and treatment-related trends, types of co-occurring conditions, and for examining social outcomes. With further refinement, the IDI could prove valuable for informing the national incidence and prevalence of autism and the long-term effectiveness of clinical guidelines and interventions for this group.

3.3 Background

There is growing interest in autism research in Aotearoa/New Zealand, but a significant void in quantitative data (Ministries of Health and Education, 2016). Takiwātanga is a recently developed Te Reo Māori term used to describe autism in Aotearoa/New Zealand[2]. It derives from 'tōku/tōna anō takiwā' meaning 'in my/his/her own time and space'. While increasingly associated with strengths such as visual thinking, logic, and memory (Altogether Autism, 2019; Meilleur et al., 2015), autism/Takiwātanga can also have a variable effect on adaptive functioning (American Psychiatric Association, 2013a). It may be associated with intellectual disability, which affects 31 percent of individuals, mental health disorders, which affect 70 percent of individuals, and other medical conditions such as epilepsy, constipation, and sleep problems (American Psychiatric Association, 2013a; Baio et al., 2018; Simonoff et al., 2008). The aetiology of autism is understood to be multi-factorial and to involve a combination of genetic and environmental factors (Amaral, 2017; Kim & Leventhal, 2015; Trottier, Srivastava, & Walker, 1999).

International estimates suggest that the prevalence of autism is on the rise, partly due to improved identification, and partly due to changing definitions that now include autistic disorder and the broader spectrum of neurodevelopmental conditions such as Asperger's disorder and pervasive developmental disorder. Environmental causes and genetic/environment interactions have also been postulated to play a lesser role (Amaral, 2017). Recent estimates from the USA suggest 16.8 per 1,000 children (or 1 in 59) have autism (Baio et al., 2018). In Aotearoa/New Zealand, there is very limited data on the incidence, prevalence, age of diagnosis and management of autism (Eggleston et al., 2019; Thabrew & Eggleston,

[2] Takiwātanga was developed by Keri Opai in consultation with Matt Frost and Peter Galvin. Te Reo Hāpai can be accessed at www.tepou.co.nz.

2018). Ministry of Health publications still base autism prevalence numbers on older United Kingdom research from 2006, suggesting autism affects only one percent of the Aotearoa/New Zealand population (Ministries of Health and Education, 2016), but warn that these figures should be regarded as conservative (New Zealand Guidelines Group, 2010). An estimate from the most recent NZHS, during which families and whānau self-reported having received an autism diagnosis for their child, suggests that in children aged 2-14 years, the point prevalence may be as high as 1.6 percent (Ministry of Health, 2019a).

In Aotearoa/New Zealand, ASD Guidelines (Ministries of Health and Education, 2016) recommend that an autism diagnosis is made by a multidisciplinary team. This team comprises two or more of the following professionals with expertise in autism and related conditions: a paediatrician, psychiatrist, psychologist, speech-language therapist, and/or occupational therapist. The diagnosis for younger children is usually facilitated by paediatric child development teams and for adolescents via specialist child and adolescent mental health services within DHBs (Thabrew & Eggleston, 2018). Referrals can come from many sources, including schools. The service is free and available to those under 19 years old, but there can be a wait of several months, and some parents opt instead for a diagnosis through a private psychiatrist, psychologist or paediatrician. Children do not need to be identified with a diagnostic label within schools to receive needs-based academic support.

There are a number of touch points in the Aotearoa/New Zealand health system to facilitate early identification of autism. Well Child Providers (including Plunket nurses) proactively monitor developmental milestones in the first few years of life. The B4SC, a nationwide health screening programme for four-year-old children, also provides an opportunity to identify behavioural and developmental issues prior to children starting school (Statistics New Zealand,

2017). Healthcare providers, such as general practitioners, are trained to opportunistically elicit concerns regarding developmental milestones when children present for other reasons. However, despite these measures, there are significant delays in diagnosis and regional disparities in the way autism assessments are carried out and post-diagnostic support is offered (Ministries of Health and Education, 2016; Thabrew & Eggleston, 2018)[3].

Internationally, the use of individual and linked administrative data for research into autism is growing (Bachmann, Gerste, & Hoffmann, 2018; Coo, Ouellette-Kuntz, Brownell, Shooshtari, & Hanlon-Dearman, 2017; Cummings et al., 2016; Dodds et al., 2009; E. Lin et al., 2013; Maenner, Yeargin-Allsopp, Braun, Christensen, & Schieve, 2016; Nayfack et al., 2014; Schlenz, Carpenter, Bradley, Charles, & Boan, 2015; Vohra, Madhavan, & Sambamoorthi, 2017; Weiss et al., 2018). Utilising administrative data for health research has several advantages including the availability of large representative samples or coverage of entire populations, the ability to track problems and outcomes via regular collection of up-to-date data, long observation periods, and low cost. Disadvantages include variability of data quality, limited clinical detail, and potential public concern about administrative data being used for research purposes (Mazzali & Duca, 2015).

In Aotearoa/New Zealand, although separate administrative datasets have sporadically been used to report rates of autism (Ministry of Health, 2017a; J. Simpson et al., 2018), and combined case identification methods for mental health and related problems have been developed using the recently established IDI (Bowden, Gibb, et al., 2020; Social Investment Agency, 2019), the IDI has never been used for autism research. This paper explores the use

[3] For a more detailed overview of the way autism is diagnosed in Aotearoa/New Zealand, see: *How is ASD diagnosed? A resource to help identify autism spectrum disorder* https://www.health.govt.nz/system/files/documents/publications/how-asd-diagnosed.pdf

of the IDI as a potential source of ongoing information. Key aims of the study were to explore: 1) how the IDI could be used for identification of children and young people aged 0-24 years with autism, 2) how the IDI could be used to understand the types and relative rates of autism-related co-occurring conditions in this group, and 3) ethnic and socioeconomic-related differences in diagnosed autism via the IDI. This study does not aim to estimate autism prevalence in Aotearoa/New Zealand, given that currently available administrative data will not capture all cases of autism.

3.4 Methods

3.4.1 Integrated data infrastructure

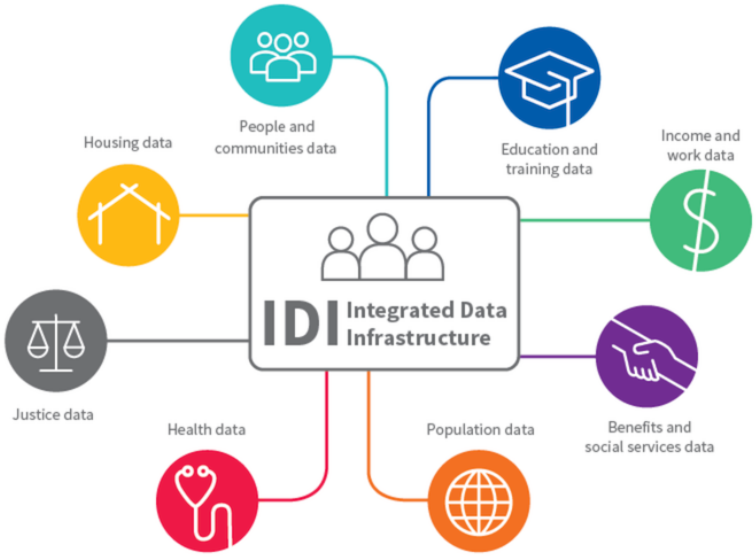
The IDI is a large anonymised research database managed by Statistics New Zealand, containing a wide range of administrative and survey data about people and households, linked at an individual level[4] (see Figure 3) (Milne et al., 2019; Statistics New Zealand, 2017a). This includes administrative data from government departments such as health and education, non-government sectors such as the Auckland City Mission, and survey data including the New Zealand census.

Data in the IDI are held in a secure environment and can be accessed by only approved researchers for projects that are in the public interest. Records are linked probabilistically by Statistics New Zealand, usually using name, date of birth, and sex[5]. The IDI enables use of cross-sectoral government data for research to improve outcomes for New Zealanders, including, but not limited to, policy and interventions research, and analysis of life outcomes

[4] For more details on the data contained within the IDI see https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure#data-in-idi
[5] For more details on data linking within the IDI see https://vhin.co.nz/guides/understanding-linkage-in-the-idi/

of population cohorts over time. Few countries have this capability (Atkinson & Blakely, 2017; Milne et al., 2019).

Figure 3: The Integrated Data Infrastructure



Source: Statistics New Zealand

3.4.2 Data privacy

Statistics New Zealand's 'five safes' framework (Statistics New Zealand, 2017a) is used to ensure data privacy: only approved researchers can use the IDI for projects that have a statistical or research purpose and are for the public good. All data are de-identified and only accessible via a secure connection from approved datalabs. Data and results must be aggregated and anonymised according to Statistics New Zealand protocols, and all results are checked for confidentiality by Statistics New Zealand prior to their release from the secure environment (Statistics New Zealand, 2017a).

Legal requirements to protect IDI data include the Statistics Act 1975, the Privacy Act 1993, and the Tax Administration Act 1994 (Statistics New Zealand, 2017a). In addition to legal requirements, a number of Statistics New Zealand policies, protocols, and guidelines exist

(Statistics New Zealand, 2017a). Regular privacy impact assessments for the IDI also provide a systematic evaluation of the benefits and risks associated with integrating data from a number of sources (Statistics New Zealand, 2017c).

3.4.3 Data

Three health datasets housed in the IDI were used in this study for autism case identification and were accessed from the March 2019 refresh of the IDI. Two additional datasets were used to identify co-occurring conditions. These datasets are each described below. Bowden et al. (2020) provide a more detailed discussion, in particular around their strengths and weaknesses for case identification (Bowden, Gibb, et al., 2020).

3.4.4 Identifying autism

3.4.4.1 Programme for the Integration of Mental Health Data

PRIMHD is a national collection of all publicly funded specialist mental health service use contacts, including DHB and NGO contacts. Diagnosis data are collected from DHBs that provide specialist mental health services including youth mental health services, and public inpatient and community based services (Statistics New Zealand, 2015a). Health professionals who contribute to these data include psychiatrists, psychologists, social workers and developmental paediatricians.

Individuals were classified as having autism if they had a primary, secondary, or provisional diagnosis code for: DSM-4 299.00 (autistic disorder), 299.10 (childhood disintegrative disorder), 299.80 (Asperger's disorder/pervasive development disorder NOS); ICD-10-AM F84.0 (autistic disorder), F84.1 (atypical autism), F84.3 (other childhood disintegrative disorder), F84.5 (Asperger's syndrome), F84.8 (other pervasive developmental disorders), and

F84.9 (pervasive developmental disorder, unspecified). The set of codes above was established from the literature (American Psychiatric Association, 2013b) in combination with local clinical consultation.

3.4.4.2 The National Minimum Dataset

NMDS is a national collection of publicly funded Aotearoa/New Zealand hospital discharges, including day patients (stays of three hours or more but not overnight) and emergency department visits of greater than three hours. Primary and secondary diagnosis codes (ICD-10-AM) are recorded for every hospital event (Statistics New Zealand, 2015b).

Individuals were identified with autism if they had a hospital discharge containing a primary or secondary diagnosis for autism using the ICD-10-AM codes noted above.

3.4.4.3 Socrates

Socrates is the national database of the Ministry of Health's DSS clients and service providers. When individuals apply for a needs assessment to access support services, they are assessed by a NASC and have their data recorded in Socrates. A range of disabilities can be recorded for an individual, including autism. The diagnosis of autism is provided to the NASC upon referral, typically from a developmental paediatrician, child and adolescent psychiatrist, general practitioner, or psychologist.

There have been a number of changes over time regarding ways that NASCs have assessed and funded people with autism. For example, despite the inclusion of Asperger's disorder in DSM-4 from 1994, anecdotally Asperger's was rarely funded. For the next 20 years, funding support was difficult to access. Some NASCs were flexible and stretched their funding. But for others

eligibility was rigid, and some NASCs required IQ tests to be performed by specific psychologists and declined funding to individuals with an IQ of one or two points above the threshold of 70. From April 2, 2014, as a result of years of advocacy work by families, clinicians and others, the Ministry of Health decreed that access to DSS no longer required a dual diagnosis of intellectual disability, and autism alone was an approved diagnosis for support (Ministry of Health, 2014, 2018).

Three assigned diagnosis codes, 1211 (autistic spectrum disorder (ASD)), 1206 (Asperger's syndrome), and 1207 (Retired – Other autistic spectrum disorder (ASD))[6] were used for case identification from Socrates.

3.4.5 Identifying co-occurring conditions

3.4.5.1 Pharmaceutical collection

The pharmaceutical collection contains information about government-subsidised medications dispensed by community pharmacies throughout Aotearoa/New Zealand (Statistics New Zealand, 2015c). The main advantage of using pharmaceutical data for case identifications is that they include information about both specialist and general practitioner prescribing. Therefore, they provide some insights into care at the primary level. On the other hand, diagnoses must be inferred from medications dispensed and therefore there is greater potential for false positives compared to diagnoses obtained from PRIMHD and NMDS.

[6] This code is no longer in use.

3.4.5.2 *Mortality collection*

The mortality collection was used to identify cases of fatal self-harm. The mortality collection contains information about the underlying causes of all registered deaths in Aotearoa/New Zealand (Ministry of Health, 2017c). These data are considered robust and of high quality.

3.4.6 Co-occurring mental health and related problems, and intellectual disability

Co-occurring mental health and related problems were identified using an existing case identification method for Aotearoa/New Zealand children and young people utilising the IDI (Bowden, Gibb, et al., 2020). This method draws on data from five sources (NMDS, PRIMHD, Socrates, the pharmaceutical collection, and the mortality collection) and permits the identification of 13 different mental health and related problem groups: anxiety, depression, emotional problems[7], bipolar disorder, substance problems, disruptive behaviours (ADHD, conduct disorders, and ODD), eating disorders, sleep problems, psychosis, personality disorders, self-harm, mental health not defined[8], and other mental health problems[9].

For the present study the method was extended to include intellectual disability. Cases of intellectual disability were identified using: ICD-10-AM codes, F70-F79 in NMDS and PRIMHD; DSM-4 codes, 317* 319*, 3180, 3181, 3182, and team type code, 12 (Intellectual Disability Dual Diagnosis Team) in PRIMHD; and assigned diagnosis codes, 1208 (intellectual disability, type not specified), 1209 (learning disability, type not specified), 1210

[7] This is a composite group (anxiety and depression) formed because a number of medications exist which are typically good indications of either but not specifically one in particular.
[8] This is a composite group which uses medications that are typically indications of a range of potential mental health problems but not one in particular. The group also contains a number of 'mental health not defined' diagnostic codes assigned to people with mental health problems that for whatever reason cannot be specified with more detail.
[9] This is a composite group created for the sake of completeness and includes all mental health diagnostic codes not otherwise used.

(developmental delay, type not specified), and 1299 (other intellectual, learning or developmental disorder) in Socrates.

3.4.7 Data preparation

Data preparation was carried out in SAS 7.1 within the IDI environment. There were two steps. First, cases of autism were identified over the six-year period from 2010/11 to 2015/16 for all individuals in the Aotearoa/New Zealand child and young person population (0-24 years). This time period was chosen because it overlapped with the most up to date and available data required for the mental health case identification method. A dichotomous autism indicator flagged individuals with at least one autism code in any of the three data sources. The modified mental health case identification method was then applied over the six-year period to add detail of co-occurring mental health, neurodevelopmental, and related conditions. The resulting data were analysed using StataMP15. All counts were randomly rounded to base 3 adhering to Statistics NZ confidentiality requirements.

3.4.8 Establishing the Aotearoa/New Zealand child and young person (0-24 years) population

The Aotearoa/New Zealand child and young person population (0-24 years) was calculated using existing methods for estimating a resident Aotearoa/New Zealand population (that is, a population of people currently living in Aotearoa/New Zealand) from the IDI (Gibb et al., 2016; Zhao et al., 2017). Individuals were included in the population if they had used key services in Aotearoa/New Zealand over the preceding two years. Individuals who had died or moved overseas were excluded. Case identifications were restricted to people from within this population.

3.4.9 Analysis

3.4.9.1 Demographic variables

The number of children and young people identified with autism across the six year period is presented overall, by gender, age, ethnic group, socioeconomic status, and urban/rural profile of residence. Five age categories were employed, each in five-year groups: 0-4, 5-9, 10-14, 15-19, 20-24. Age was measured at the end of the 2015/16 fiscal year. The 0-24 age range was chosen based on the World Health Organization definition of youth. The age groupings were chosen to be consistent with previous IDI-based case identification studies (Bowden, Gibb, et al., 2020; Social Investment Agency, 2019), and broadly reflect the way provision of secondary health services is organised. Six ethnic groups were used and are defined via the total concept approach, meaning that an individual can identify with more than one ethnic group. These were: European; Māori; Pasifika; Asian; MELAA; and Other.

Socioeconomic deprivation was measured using NZDep 2013 (Atkinson, Salmond, & Crampton, 2014). NZDep is an area-based measure that assigns a deprivation score based on the meshblock (i.e., neighbourhood) in which an individual was living. Scores were collapsed into quintiles with quintile 1 representing the least deprivation and 5 the greatest. The most recently registered meshblock of residence before the end of the fiscal year was used. If an individual did not have any registrations prior to the end of the fiscal year, the first update in the 12 months after the end of the fiscal year was used. Meshblock of residence was also used to determine the urban/rural profile of individuals. The Statistics New Zealand urban/rural classification has five categories: 1) Main urban (population of at least 30,000), 2) secondary urban (population 10,000-29,999), 3) minor urban (population 1,000–9,999), 4) rural centre (population 300-999) and 5) other rural (population <300) (Statistics New Zealand, 2016).

These were collapsed into two groups to form a binary indicator: urban (main urban, secondary urban, and minor urban area) and rural (rural centre and other rural).

3.4.9.2 Calculating identification rates of autism and co-occurring conditions

Identification rates for autism were calculated for the most recent fiscal year (2015/16) and restricted to the corresponding estimated resident children and young person (0-24) population in Aotearoa/New Zealand for that time period. Because autism is a chronic condition, an individual was deemed to have autism, and therefore included in the numerator, if at least one case identification was made at any stage during the six-year study period (2010/11 to 2015/16). Rates were calculated overall and by gender for each age category, ethnic group, deprivation level, and urban/rural profile. Rates of co-occurring conditions were calculated in the same way for both autism and non-autism populations[10]. In line with the Bowden et al. (2020) mental health case identification method, some conditions had age restrictions imposed to ensure clinical relevance and improved accuracy (Bowden, Gibb, et al., 2020). For example, personality disorders were restricted to those aged 18 and over, and substance problems to those aged 10 and over.

3.4.9.3 Standardisation and comparison of rates of co-occurring conditions

In order to compare like with like, particularly given the different demographic compositions of the autism and non-autism groups, rates of co-occurring conditions and rates of the cumulative number of co-occurring conditions were standardised to adjust for differences in demographic variables available in the study (sex, age, ethnicity, deprivation, and urban/rural). Marginal predictions from logistic regressions of the binary indicator of co-occurring condition

[10] The rates in this study are population rates for the 2015/16 Aotearoa/New Zealand youth ERP and specific sub-groups. They are not intended to be generalisable to any other point in time, or other population groups.

on a covariate binary indicator for autism and demographic variables were used. Adjusted rates of co-occurring conditions for both the autism and non-autism groups were generated as the average of the resulting predicted probabilities. Differences between adjusted rates were tested using Wald Z-tests, under a null hypothesis that autism has no influence beyond random variation, H_0: autism = 0 (i.e., a diagnosis of autism was not identified in the data). A similar process was used to estimate rates of cumulative conditions standardised for all measured demographics. A multinomial logistic regression was employed to calculate adjusted rates as the average predicted probabilities at each incremental level of cumulative conditions. A Chi-squared statistic was used to test any associations with autism, H_0: autism = 0, at each outcome level.

3.4.9.4 Changes over time in Socrates data

To understand the potential impact of changes made to the needs assessment process, the rate of intellectual disability was calculated separately for the autism group who were identified using only Socrates data prior to 2 April, 2014.

3.5 Results

In total 9,555 unique individuals aged 0-24 were identified with autism (see Table 1). Males were identified at nearly four times the rate of females. The ratio of males to females was greatest among the younger age groups, Asian and Pasifika populations and, to some extent, more deprived socio-economic groups. Across age categories the largest number of cases of autism was identified in the 5-9 age group. Over three quarters of the individuals identified as European (compared to 66 percent of the IDI-based youth ERP who identify as European), 21 percent as Māori (compared to 25 percent), 12 percent as Asian (compared to 16 percent), and only nine percent as Pasifika (compared to 13 percent). Cases of autism increased slightly as

deprivation increased, from 18 percent of total cases for the least deprived to 21 percent for the most deprived, matching the NZDep distribution of New Zealand's youth population. Almost 90 percent of identified cases resided in urban areas.

Table 1: Counts (and percentages[a]) of children and young people with autism by demographic category[b], 2010/11-2015/16

	Total (N=9,555)	Male (N=7,590)	Female (N=1,965)
Sex			
Male	7,590 (79%)		
Female	1,965 (21%)		
Age			
0-4	1,989 (21%)	1,596 (21%)	396 (20%)
5-9	3,135 (33%)	2,577 (34%)	561 (29%)
10-14	2,232 (23%)	1,779 (23%)	453 (23%)
15-19	1,533 (16%)	1,140 (15%)	390 (20%)
20-24	666 (7%)	498 (7%)	165 (8%)
Ethnicity[c]			
European	7,401 (77%)	5,853 (77%)	1,548 (79%)
Māori	1,980 (21%)	1,572 (21%)	411 (21%)
Pasifika	831 (9%)	672 (9%)	159 (8%)
Asian	1,176 (12%)	972 (13%)	201 (10%)
MELAA	213 (2%)	177 (2%)	39 (2%)
Other	165 (2%)	132 (2%)	33 (2%)
Socioeconomic Deprivation[d,e]			
Quintile 1 (least deprived)	1,737 (18%)	1,365 (18%)	375 (19%)
Quintile 2	1,851 (19%)	1,470 (19%)	384 (20%)
Quintile 3	1,848 (19%)	1,467 (19%)	381 (19%)
Quintile 4	1,995 (21%)	1,605 (21%)	390 (20%)
Quintile 5 (most deprived)	2,013 (21%)	1,602 (21%)	411 (21%)
Rurality[d,f]			
Urban	8,526 (89%)	6,777 (89%)	1,746 (89%)
Rural	924 (10%)	726 (10%)	192 (10%)

a Column percentages have been reported, the proportion of N, for each column total, that are attributable to each demographic sub-group.
b For individuals with multiple autism case identifications over time, demographics were measured at the time of the first case identification.
c Percentages can sum to greater than 100% with respect to ethnicity as individuals can identify with more than one ethnic group.
d Percentages sum to less than 100% for Deprivation and Rurality due to missing data.
e Socioeconomic deprivation is an area-based measure using NZDep 2013 (see Methods for details).
f Urban rural classification was based on the Statistics New Zealand standard urban rural areas (see Methods for details).

Table 2: Counts (and percentages[a]) of children and young people with autism by data source of identification, 2010/11-2015/16[b]

	NMDS	PRIMHD	Socrates
Overall (N=9,555)	2,058 (22%)	2,427 (25%)	7,359 (77%)
Sex			
Male (N=7,590)	1,575 (21%)	1,944 (26%)	5,913 (78%)
Female (N=1,965)	483 (25%)	483 (25%)	1446 (74%)
Age			
0-4 (N=1,989)	405 (20%)	60 (3%)	1,936 (97%)
5-9 (N=3,135)	564 (18%)	591 (19%)	2,676 (85%)
10-14 (N=2,232)	447 (20%)	816 (37%)	1,542 (69%)
15-19 (N=1,533)	411 (27%)	735 (48%)	861 (56%)
20-24 (N=666)	231 (35%)	222 (33%)	351 (53%)
Ethnicity			
European (N=7,401)	1,524 (21%)	2,142 (29%)	5,520 (75%)
Māori (N=1,980)	525 (27%)	378 (19%)	1,581 (80%)
Pasifika (N=831)	210 (25%)	108 (13%)	708 (85%)
Asian (N=1,176)	264 (22%)	162 (14%)	1,005 (85%)
MELAA (N=213)	48 (23%)	42 (20%)	171 (80%)
Other (N=165)	24 (15%)	48 (29%)	123 (75%)
Socioeconomic Deprivation[c]			
Quintile 1 (least deprived) (N=1,737)	291 (17%)	471 (27%)	1,326 (76%)
Quintile 2 (N=1,851)	354 (19%)	501 (27%)	1,428 (77%)
Quintile 3 (N=1,848)	372 (20%)	522 (28%)	1,431 (77%)
Quintile 4 (N=1,995)	474 (24%)	510 (26%)	1,503 (75%)
Quintile 5 (most deprived) (N=2,013)	534 (27%)	396 (20%)	1,590 (79%)
Rurality[d]			
Urban (N=8,526)	1,833 (21%)	2,142 (25%)	6,600 (77%)
Rural (N=924)	192 (21%)	261 (28%)	687 (74%)

a Row percentages have been reported, the proportion of N, for each row total, that are identified via each data source. Percentages sum to greater than 100% as case identifications for any given individual can be made across multiple data sources.

b For individuals with multiple autism case identifications over time, demographics were measured at the time of the first case identification.

c Socioeconomic deprivation is an area-based measure using NZDep 2013 (see Methods for details).

d Urban rural classification was based on the Statistics New Zealand standard urban rural areas (see Methods for details).

Table 2 shows the datasets from which autism diagnoses were sourced. Individuals can have a diagnosis in more than one dataset, therefore the row percentages sum to more than 100 percent. Approximately three quarters of autism cases were identified via needs assessments

(Socrates). One quarter of individuals identified with autism were captured in mental health settings (PRIHMD) and just under a quarter in hospital settings (NMDS). There was variation in the distribution of data source by age, ethnicity, and to a lesser extent deprivation. In particular, the percentages of individuals identified with autism through Socrates decreased markedly by age, from 97 percent for the youngest age group, to 53 percent for the oldest. Conversely, the percentage of individuals identified increased with age with respect to both NMDS and PRIMHD. People identifying as Pasifika or Asian, and to a lesser extent Māori, were less likely to be identified in PRIMHD relative to other ethnic groups. Those in the most deprived socioeconomic groups were more likely to be identified in NMDS and Socrates, and less likely to be identified in PRIMHD.

Overall, approximately 57 per 10,000 children and young people in Aotearoa/New Zealand had received an autism diagnosis, as captured across the three data sets used, by the end of the 2015/16 fiscal year[11] (see Table 3). The male identification rate was 88 per 10,000 and the female rate was 24 per 10,000. Identification rates were highest among the 'other' ethnic group, followed by European, and lowest among Pasifika. Although rates of autism did not substantively differ between deprivation categories, they were higher among people living in urban compared to rural areas. When restricted to eight-year-olds, so as to be comparable with the CDC prevalence estimate of 1 in 59, the identification rate for autism was 98 per 10,000 (or 1 in 102). See Appendix 1 for identification rates by age.

[11] The population denominators used to calculate identification rates can be found in Appendix 1.

Table 3: Identification rates of children and young people with autism, 2015/16 (per 10,000)

	Total	Male	Female	Ratio (Male: Female)
Overall	57.4	88.4	24.2	3.6
Age				
0-4	22.0	33.9	9.3	3.6
5-9	89.7	141.6	34.6	4.1
10-14	85.5	135.4	33.3	4.1
15-19	58.7	88.4	27.3	3.2
20-24	33.0	47.4	16.9	2.8
Ethnicity				
European	67.5	104.7	28.6	3.7
Māori	49.2	75.9	21.1	3.6
Pasifika	38.6	60.4	15.7	3.9
Asian	44.7	69.4	16.7	4.2
MELAA	51.1	76.6	22.2	3.5
Other	85.3	129.1	38.2	3.4
Socioeconomic Deprivation[a]				
Quintile 1 (least deprived)	56.7	88.3	23.5	3.8
Quintile 2	60.6	92.5	26.5	3.5
Quintile 3	59.9	92.2	25.5	3.6
Quintile 4	59.2	92.5	23.4	4.0
Quintile 5 (most deprived)	52.9	81.1	22.8	3.6
Rurality[b]				
Urban	59.2	91.4	24.9	3.7
Rural	46.2	70.8	20.0	3.5

a Socioeconomic deprivation is an area-based measure using the NZDep 2013 (see Methods for details).
b Urban rural classification was based on the Statistics New Zealand standard urban rural areas (see Methods for details).

Table 4 presents the observed percentage of the autism and non-autism groups identified with different co-occurring conditions, as well as the adjusted ratio (autism: non-autism). The ratio has been adjusted for demographic variables to enable better comparison between the autism and non-autism groups (see Methods for details). Almost 70 percent of the 2015/16 autism children and young person population had at least one co-occurring condition, six times that of the general (non-autism) population. The most common co-occurring conditions in the autism group were intellectual disability (30%; 62 times more likely than in the general population), disruptive behaviours (30%; 14 times more likely), mental health not defined (29%; seven times more likely), and any emotional disorder, which included mixed anxiety and depression (28%; six times more likely). Compared to the general population, other co-occurring

conditions identified at high rates were ODD (18 times more likely), psychosis (16 times more likely), ADHD (14 times more likely), and anxiety (10 times more likely). Within the autism group, 23 percent had one, 15 percent had two, and nine percent had five or more co-occurring conditions (see Table 4). These proportions all exceeded those in the non-autism group and adjusted ratios between the two groups increased with the number of co-occurring conditions.

3.5.1 Changes over time in Socrates data

For case identifications made using only Socrates data prior to April 2nd, 2014 (examined due to changes in eligibility criteria for disability support), the rate of intellectual disability was 36 percent, compared to 28 percent for all other sources of case identifications. These differences were similar for both males and females.

Table 4: Co-occurring conditions among children and young people with and without autism, and adjusted ratios, 2015/16

Co-occurring Condition	Autism Overall Count	%	Non-autism Overall Count	%	Adjusted Ratio[e] (autism: non-autism) and 95% CI
Any condition	6,111	68.2	163,416	10.5	6.1 (6.0, 6.2)
Any psychopathology[a]	4,833	54.0	159,042	10.3	5.0 (4.9, 5.1)
Intellectual disability	2,679	29.9	6,537	0.4	61.9 (59.2, 64.5)
Any emotional	2,463	27.5	79,245	5.1	5.9 (5.8, 6.1)
Anxiety	1,530	17.1	27,891	1.8	10.2 (9.8, 10.6)
Depression	429	4.8	24,612	1.6	4.0 (3.7, 4.4)
Emotional	1,662	18.6	60,588	3.9	5.6 (5.4, 5.7)
Bipolar[c]	39	1.3	1,002	0.2	8.9 (5.9, 11.8)
Substance[b]	258	4.7	44,301	4.7	1.1 (1.0, 1.3)
Disruptive behaviour	2,697	30.1	22,035	1.4	13.9 (13.4, 14.4)
ADHD	2,403	26.8	18,699	1.2	13.8 (13.2, 14.3)
Conduct	108	1.2	2,205	0.1	7.2 (5.8, 8.6)
ODD	456	5.1	2,862	0.2	17.8 (16.0, 19.6)
Eating	69	0.8	3,066	0.2	6.5 (5.0, 7.9)
Sleeping	255	2.8	25,392	1.6	2.5 (2.2, 2.8)
Psychosis[b]	276	5.1	3,756	0.4	15.9 (14.1, 17.8)
Personality[d]	42	2.4	1,299	0.3	9.0 (6.3, 11.8)
Self-harm	159	1.8	9,954	0.6	4.1 (3.5, 4.7)
Other mental health	333	3.7	4,680	0.3	10.1 (9.0, 11.3)
Mental health not defined	2,625	29.3	68,559	4.4	6.6 (6.4, 6.8)
Number of co-occurring conditions	**Count**	**%**	**Count**	**%**	**Adjusted Ratio (autism: non-autism)**
0	2,847	31.8	1,387,926	89.5	0.4 (0.4, 0.4)
1	2,079	23.2	80,778	5.2	4.3 (4.2, 4.5)
2	1,308	14.6	42,126	2.7	4.5 (4.2, 4.7)
3	1,194	13.3	19,512	1.3	9.1 (8.6, 9.6)
4	732	8.2	10,395	0.7	11.7 (10.9, 12.6)
5+	801	8.9	10,602	0.7	14.4 (13.4, 15.3)
N	**8,955**		**1,551,342**		

a All co-occurring conditions examined excluding intellectual disability and self-harm.
b Restricted to the 10-24 year old population.
c Restricted to the 15-24 year old population.
d Restricted to the 18-24 year old population.
e Adjusted ratios standardised for age, sex, ethnicity, deprivation, and urban/rural profile.

3.6 Discussion

3.6.1 Key findings

Using a novel case identification method based on three linked IDI health datasets, we identified 9,555 autistic children and young people among the Aotearoa/New Zealand estimated resident population of 0-24 year olds for the 2015/16 fiscal year. Analysis of 2015/16 data yielded an autism identification rate of 57 per 10,000 children and young people (1 in 174 individuals) and 98 per 10,000 eight-year-olds (1 in 102 individuals). Autism was more common in males than females and in individuals of European ethnicity than in Māori and Pasifika populations. Although there did not appear to be any substantive deprivation-related difference in the identification rates of autism, there was a notably greater rate among those residing in urban compared with rural areas. Individuals with autism had considerably higher rates of most co-occurring mental health and related conditions, particularly intellectual disability, disruptive behaviour disorders and emotional disorders, compared to the general population.

Over three quarters of cases of autism were identified via the Socrates database. This is unsurprising given that most new diagnoses of autism are made in paediatric settings that available linked data cannot capture (Thabrew & Eggleston, 2018). Given that individuals captured via Socrates were being assessed for government-funded disability support, it is highly likely that the current method is skewed toward the identification of those with more severe autism and additional comorbidities, rather than individuals with less complex needs.

Comparing our rate of autism with that from the recent CDC study which found autism in 1 in 59 eight-year-olds (Baio et al., 2018), it is possible and understandable that the IDI-based case identification method undercounts cases of autism among comparable ages by roughly 40

percent. The undercount appears to increase with age (as measured in the 2015/16 fiscal year of analysis). This is most likely because the data do not enable us to look back far enough to the time of diagnosis for the older cohorts, and because autism did not become an approved diagnosis for disability support until 2014.

Despite knowing that we may not be capturing all cases of autism using this method, it is reassuring that relative rates across gender and ethnic groups are consistent with both international and national estimates. Our estimated male to female ratio of 3.6:1 lies between widely cited 4:1 estimates (American Psychiatric Association, 2013a; Baio et al., 2018) and the 3:1 estimate of Loomes et al. (2017) that they determine to be the 'true' ratio in a recent meta-analysis (Loomes, Hull, & Mandy, 2017). Patterns across ethnic groups are consistent with those seen in previous Aotearoa/New Zealand studies (Eggleston et al., 2019; Virues-Ortega et al., 2017) and the results of the NZHS (Ministry of Health, 2019a). They also reflect previous USA studies in which rates for minority ethnic groups (Hispanic and African American) were lower than European-American rates (Baio et al., 2018; Kogan et al., 2008).

The approach used to identify co-occurring mental health and related problems was based on an existing method (Bowden, Gibb, et al., 2020). A major limitation is that it does not detect all co-occurring diagnoses, as it considers only certain parts of the health system. In particular, diagnoses received in primary care or private care may not be detected as data from these sectors are not included in the IDI. Therefore, it is considered conservative for rates of co-occurring conditions. However, for the autism population identified in this paper, we believe it is more likely to be indicative of true rates of mental health problems. The health of young people with autism is heavily scrutinised and they are typically in frequent contact with the health system. In fact, the autism case identification method requires that individuals identified

with autism must have had contact with the health system and their details captured in administrative data. Furthermore, at each of these points of contact, multiple diagnoses can, and typically will, be recorded. Therefore, although symptoms of autism can often overlap with those of mental health conditions, they should be more likely to be identified among those with autism compared to the general population.

Rates of specific co-occurring conditions are consistent with, although often at the lower end of, epidemiological literature (Leyfer et al., 2006; Mattila et al., 2010; Salazar et al., 2015; Simonoff et al., 2008; Van Steensel, Bögels, & de Bruin, 2013; Virues-Ortega et al., 2017). Our estimated rate of co-occurring intellectual disability (30%) is in line with the recent CDC estimate of 31 percent and comfortably in the range of estimates in the wider literature of 16.7 percent to 84 percent (Postorino et al., 2016). Rates of ADHD, ODD, and conduct disorder are all consistent with, but marginally below, other studies (Leyfer et al., 2006; Mattila et al., 2010; Salazar et al., 2015; Simonoff et al., 2008). One notable exception is the rate of anxiety which is substantively lower than in previous studies (Salazar et al., 2015; Simonoff et al., 2008; Van Steensel, Bögels, & Perrin, 2011). This may be due to under-reporting of anxiety as it is perceived by some clinicians to be part of autism, anxiety being subsumed into the category of 'emotional problems', or to the lack of data from primary care where most children with anxiety are treated. More generally, under-identification of co-occurring conditions may still be an issue among the autism population. Despite children and young people with autism being in contact with health services it is likely that not all conditions will be captured in the data. This might explain why our estimates are at the lower end of epidemiological literature. Rates of single (68%) and multiple (45%) co-occurring mental health and related conditions are also similar to international estimates (Mattila et al., 2010; Simonoff et al., 2008; Van Steensel et al., 2013).

Despite the limitations of the case identification method, we feel it is useful to compare rates of co-occurring conditions among those with autism to the general population. The large difference in rates of co-occurring conditions between autism and non-autism groups highlights the former as a group with high and complex health needs. Overall, the autism group was six times more likely to be identified with any condition compared to the non-autism group. Specific conditions identified at significantly higher rates included intellectual disability, disruptive behaviours, psychosis, and anxiety.

The low relative rates of autism identified in Māori, and Pasifika children and young people are consistent with previous Aotearoa/New Zealand studies (Eggleston et al., 2019; J. Simpson et al., 2018). However, according to Elsabbagh and colleagues, these are unlikely to reflect true ethnically-based differences in prevalence (Elsabbagh et al., 2012). These differences are too large to be explained by the quality of ethnicity data capture. For Māori, access to the scope of autism services available (including diagnosis) is desired, however it is important that these services are culturally safe and able to respond to Māori direction (Bevan-Brown, 2004; Bevan-Brown et al., 2015; Durie, 2001). A history of institutional racism against Māori in many sectors, including the health sector, has led to disparities and inequalities in many areas of health (Harris et al., 2006). Inequitable access to services (Reid & Robson, 2000) and lack of cultural competency of care (Durie, 2001) likely affect receiving a diagnosis, including autism being misdiagnosed among Māori as behavioural problems, or overlooked completely (Bevan-Brown, 2004; Bevan-Brown et al., 2015).

Many of the institutional experiences of Māori were also visited upon those from other Pacific nations (Pasifika). However, traditionally, Pasifika would use a family or community-based

model of care for their children, in keeping with conventions adopted from their cultural homes. Thus, the initial responsibility for childcare would be within the confines of family or community before seeking professional help, especially if that outside help was foreign to the cultural values of a Pacific community. There is some evidence that these trends are changing over time, as subsequent generations of Pacific migrant adopt health attitudes and practices in line with those of other New Zealanders (Kokaua, Schaaf, Wells, & Foliaki, 2009; Ministry of Health, 2017b). Further research is required to determine and explain patterns of autism and related issues in Māori and Pacific communities in New Zealand, especially as international evidence suggests it is possible to close gaps between ethnic communities (Baio et al., 2018).

Our finding that socioeconomic status was not related to rates of autism is similar to that of some studies (Hrdlicka et al., 2016; Kelly et al., 2019; Larsson et al., 2005), but different to that of others (Durkin et al., 2010; Fountain, King, & Bearman, 2011; Li, Sjöstedt, Sundquist, Zöller, & Sundquist, 2014; Rai et al., 2012; Thomas et al., 2012). It has been postulated that systematic barriers facing socioeconomically disadvantaged people can make the health care system inaccessible to population pockets and therefore may affect receiving an autism diagnosis (Kelly et al., 2019; Pickard & Ingersoll, 2016).

Lower rates of identified autism among rural communities compared to urban areas is consistent with existing literature (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017). Geographic distance to healthcare providers, reduced autism awareness, including within schools and healthcare providers, and potentially cultural characteristics such as lower levels of education and socioeconomic status, are all postulated to contribute to the diminished identification of autism in rural areas.

Case identifications of autism made using only Socrates data prior to April 2, 2014 showed higher rates of intellectual disability, in the order of 30 percent. This illustrates a broader issue; that administrative data capture is subject to change over time. It is important that researchers are aware of such changes and potential implications, and tailor the method to suit their research needs.

3.6.2 Policy implications

The case identification method was developed to enable quantitative research that we believe will have significant policy impacts for the autism community in New Zealand. By identifying individuals with autism in the IDI, and linking to current and future data sets, we can examine how life trajectories of young people with autism differ from the neuro-typical population. Perhaps of greater value will be the examination of differences in life trajectories from within the autism population, and the exploration of the ways that different experiences and backgrounds might result in different outcomes. This will be particularly useful for education and transition from school policies, and will have implications for employment, independent living, justice system interactions, mental health, and aged care support.

While the focus of the method was primarily to enable future IDI-based autism research in New Zealand, the data presented in this paper have policy implications of their own. The ethnic distribution of identified cases of autism provides, for the first time, a quantifiable evidence base at the population level to substantiate previous concerns of inequitable access to diagnosis and supports (Ministries of Health and Education, 2016). Furthermore, the rates of co-occurring conditions demonstrate the complexity of autism cases in Aotearoa/New Zealand that will assist with policy and planning in health, education, income support, and justice. Finally, while the intent of the method was not to determine prevalence, we believe that, over

time, estimates of prevalence using this approach will become more accurate, particularly among younger age groups as more children come to the attention of health sectors, collecting administrative data, most notably, disability support. This will be useful in policy and planning, especially in education where there is a lack of information about the number of young people who need support.

3.6.3 Strengths and limitations

At present this method cannot be formally validated using currently available data within the IDI. A formal validation would help us quantify the level of undercount, as well as understand the accuracy of autism diagnoses the case identification method draws on. As discussed, based on existing international prevalence estimates, the method likely undercounts cases by approximately 40 percent among younger age groups, and this undercount increases with age. The absence of formal validation means we cannot comment with confidence on the rate of false positives among our autism case identifications. Autism diagnoses are often complex and have overlapping features with other neurodevelopmental conditions making false positives a concern. Previous US-based studies on the validity of autism diagnoses in administrative (insurance claims) data have reported positive predictive values (PPVs) high enough to suggest these are a valid means to identify true autism cases (Burke et al., 2014; Coleman et al., 2015). Anecdotally, clinicians in Aotearoa/New Zealand are typically very cautious when assigning an autism diagnosis, often preferring an initial diagnosis of 'Global Developmental Delay' even when autism is suspected. Furthermore, the NASC system, from which over three quarters of our case identifications are derived, requires an official autism diagnosis before support is provided. With this in mind, we expect that our method would have a PPV similar to these previous studies. Until validity can be demonstrated, researchers should be aware of and make explicit this limitation.

A further limitation is that the method employed for identifying rates of co-occurring conditions has not been formally validated (Bowden, Gibb, et al., 2020). Therefore, at the present time, there is no way to ascertain how accurate those rates may be. See Bowden et al. (2020) for a more detailed discussion around validation and further limitations of the mental health case identification method.

Other limitations include the use of administrative data for health analysis (a purpose for which it was not originally intended), restriction of data to three datasets within the IDI, and the absence of both primary care and paediatric data. Furthermore, there exists a degree of bias in the complexity of identified cases due to the data source and time periods identifications originate from. These limitations notwithstanding, the case identification method enables research into autism that supersedes existing approaches based on single data sources. Although the study period encompasses the switch from DSM-4 to DSM-5, due to a lag time of two to three years for DSM updates to be incorporated into public health services, this is unlikely to affect identification rates.

Key strengths of the study are the examination of whole population health data so that it was possible to identify a national population of children and young people with autism. This enabled analysis of differences between subgroups of gender, ethnicity and socioeconomic status and exploration of co-occurring conditions. We were also able to compare the identified autism population with the non-autism population.

3.6.4 Ethical issues

While it is legal to use administrative data in Aotearoa/New Zealand for research purposes, issues of ethics and social license have been raised, especially given the IDI now links these data sets at the individual level. As discussed in Bowden et al. (2019), more detailed review of these issues is critical, and particularly relevant to comparisons across ethnic groups which could have the effect of disadvantaging Māori and Pasifika (Bowden et al., 2019; Durie, 2006).

3.6.5 Further research and potential uses

Further research is needed to formally validate the autism case identification method described in this paper. This could be possible by using the NZHS (Ministry of Health, 2019b), which contains autism information and is scheduled to be added to the IDI. As the content of the IDI expands over time (and especially if primary healthcare data are added), the accuracy of the current method is likely to be improved. In line with previous findings from validation studies of autism case identification methods, one possibility may be to explore the value of requiring two or more instances of autism diagnosis information in the data to constitute a case identification (Burke et al., 2014; Coleman et al., 2015). The development and addition of a national autism registry may also have value. Once the validity of the case identification method has been sufficiently demonstrated, it can be used with more confidence to track the health of children and young people with autism. This will allow better understanding of pathways to risk and resilience, evaluation of the long-term impact of health and non-health interventions, and reduction of existing health disparities.

3.6.6 Conclusion

This study provides preliminary evidence that linked datasets within the IDI can be used to identify cases of autism and related co-occurring conditions among Aotearoa/New Zealand

children and young people. While it is important to bear in mind its limitations, the study demonstrates that the IDI has the potential to be a valuable source of information regarding wellbeing of children and young people with autism.

4 National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder

4.1 Preface

This chapter contains an original manuscript, 'National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder'. It was published in *Research in Autism Spectrum Disorders* in 2020; *24*(8), pp.2213-2227 Doi: 10.1016/j.rasd.2020.101642 (Bowden N, Thabrew H, Kokaua J, Braund, R).

Symptoms of autism and common psychological and physical co-occurring conditions are often treated using pharmacotherapies. However, international guidelines on pharmacotherapies for young autistic people are limited.

The objectives of this paper were to explore medication dispensing patterns for young autistic people and compare dispensing and polypharmacy rates among those with autism, ADHD, and the general population.

4.2 National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder

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Research in Autism Spectrum Disorders 2020; *78*, 101642, doi: 10.1016/j.rasd.2020.101642 (Bowden, Thabrew, Kokaua, & Braund, 2020)

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Statement of contribution

The concept for this study was conceived by Bowden, Thabrew, and Braund. Ethical approval was sought by Bowden. Bowden conducted data analysis and wrote the first draft of the manuscript. All authors subsequently helped revise the manuscript to its final version.

Abstract

Background: International data and guidance on prescribing for children and young people with autism are limited. National administrative datasets such as the Aotearoa/New Zealand IDI may offer a cost-effective and sustainable way to monitor prescribing trends in the context of clinical and systemic change.

Method: Medication dispensing for Aotearoa/New Zealand children and young people with autism was explored using the IDI. Psychotropic and non-psychotropic medication dispensing rates, and rates of polypharmacy within a one-year period were examined. Comparisons of medication use were made to children and young people with another neurodevelopmental condition, ADHD, and the general population.

Results: The vast majority (83%) of children and young people with autism were prescribed medication within a one-year period and they received a mean of four unique medications. High dispensing of antihistamine, asthma, gastrointestinal, and psychotropic medications was observed. Just over half (57%) of those with autism experienced polypharmacy of three or more medications, and 11% of 10 or more. Medication dispensing rates were significantly higher among the autism group compared to those with ADHD and the general population. Polypharmacy rates were higher among both the autism and ADHD group compared to the general population.

Conclusions: It is clear that Aotearoa/New Zealand children and young people with autism experience a significant and disproportionate medication burden. Although further investigation is needed to fully understand underlying reasons and clinical implications, the IDI appears to be a valuable means of monitoring prescribing trends over time.

4.3 Background

Autism/Takiwātanga[12] is a neurodevelopmental condition estimated to affect one in 54 children and young people (Maenner et al., 2020). While they may be imbued with numerous strengths, these individuals also experience greater levels of stress, developmental and occupational challenges, and comorbidities. Symptoms of autism and comorbid issues may be modified using psychotherapies (talking and behavioural therapies) and pharmacotherapies (medication) (LeClerc & Easley, 2015; Volkmar et al., 2014). Pharmacotherapies are most commonly used to address psychological comorbidities such as anxiety, depression, ADHD, conduct disorder, ODD, and sleep problems (LeClerc & Easley, 2015; Siegel & Beaulieu, 2012; Volkmar et al., 2014), and physical comorbidities such as epilepsy and gastrointestinal problems (Buie et al., 2010; Volkmar & Nelson, 1990).

International guidelines on pharmacotherapies for children and young people with autism are limited and typically offer only broad recommendations due to the limited evidence base (Thabrew et al., 2020). In the USA, the American Food and Drug Administration has approved only two drugs, namely risperidone and aripiprazole, for treatment of irritability in people with autism (LeClerc & Easley, 2015), therefore most other prescribing for autism symptoms occurs 'off-label'. In New Zealand, although national autism guidelines provide some recommendations for medication use, there is clinical disagreement about how to manage common problems, such as restricted and repetitive behaviours (Thabrew et al., 2020). As rates of prescribing for autism increase internationally (Horace & Ahmed, 2015), there is corresponding concern regarding the balance of clinical benefits and risks associated with such

[12] From 'tōku/tōna anō takiwā' meaning 'in my/his/her own time and space'. Takiwātanga was developed by Keri Opai in consultation with Matt Frost and Peter Galvin as a Te Reo Māori term used to describe Autism. Te Reo Hāpai can be accessed at www.tepou.co.nz.

medication use (Aman, Lam, & Van Bourgondien, 2005; Esbensen, Greenberg, Seltzer, & Aman, 2009).

Recent studies examining medication use among children and young people with autism have been predominantly focused on psychotropic medication, especially antipsychotic and anxiolytic medication (Fusar-Poli et al., 2019; Logan et al., 2012; Mandell et al., 2008; Meiri, Azoulay, & Menashe, 2018; Oswald & Sonenklar, 2007; Rosenberg et al., 2010; Spencer et al., 2013). Polypharmacy has been linked with increases in adverse drug reactions, drug-drug interactions, and health utilisation and costs (Baker et al., 2019). Somewhat surprisingly, few studies have analysed the prescribing or use of non-psychotropic medications in order to ascertain the total drug burden for children and young people with autism (Esbensen et al., 2009; Oswald & Sonenklar, 2007). Even fewer studies have made comparisons of medication use in children and young people with autism with those who have other neurodevelopmental disorders (Frazier et al., 2011) or no neurodevelopmental disorders (Madden et al., 2017) and, to the best of our knowledge, no examination of comparative rates of prescribing has been made using population level data.

Since 2011, the Aotearoa/New Zealand government has linked multiple national government datasets into a large research database known as the IDI (Milne et al., 2019; Statistics New Zealand, 2017a). Recent studies have demonstrated the potential value of the IDI for estimating and tracking rates of common mental health problems and associated prescribing practices (Bowden et al., 2019; Bowden, Gibb, et al., 2020). Given the current research gaps, the IDI may provide a valuable source of information for better understanding prescribing practices and/or improving the medication burden for children and young people with autism.

The aims of this paper are to:

- Explore the utility of linked, whole-of-population, IDI data to conduct exploratory research into prescribing patterns for children and young people with autism.
- Compare prescribing rates between those with autism, ADHD, and the general population.

4.4 Methods

4.4.1 Integrated data infrastructure

Data were sourced from the March 2019 refresh of the IDI, a large research database managed by Statistics New Zealand, containing a wide range of linked individual-level microdata about people and households in Aotearoa/New Zealand (Milne et al., 2019; Statistics New Zealand, 2017a). Data in the IDI are linked probabilistically by Statistics New Zealand, usually using name, date of birth, and sex[13], and then de-identified. They are held in a secure environment and can only be accessed by approved researchers for projects that are in the public interest. Outputs must be confidentialised and then checked by Statistics New Zealand before public release (Statistics New Zealand, 2017a)

4.4.2 Data

4.4.2.1 Pharmaceutical collection

Data on pharmaceutical dispensing were drawn from the community pharmaceutical dispensing collection (Statistics New Zealand, 2015c). These data include all government-

[13] For more details on data linking within the IDI see https://vhin.co.nz/guides/understanding-linkage-in-the-idi/

subsidised medications dispensed by community pharmacies in New Zealand. Pharmaceutical data were extracted for the 2015/16 fiscal year (1 July, 2015 until 30 June, 2016).

4.4.2.2 Autism

The autism population was identified using an existing IDI case identification method (Bowden, Thabrew, Kokaua, Audas, et al., 2020). This method utilises autism diagnoses data from three data sources: NMDS (hospital admissions), PRIMHD (specialist mental health services), and Socrates (DSS). Individuals were included in the autism population if they appeared in any of these datasets with an autism diagnosis over the six fiscal year period from 2010/11 until 2015/16[14].

4.4.2.3 Attention-deficit/hyperactivity disorder

The ADHD population was identified using a modified version of an existing IDI case identification method for mental health and related problems (Bowden, Gibb, et al., 2020). The original method draws on data from four sources: NMDS, PRIMHD, Socrates, and the pharmaceutical collection, however, to avoid selection bias, we excluded the latter given the outcome of interest for this study is pharmaceutical dispensing. Individuals were included in the ADHD population if they appeared in any of these datasets with an ADHD diagnosis over the six fiscal year period from 2010/11 until 2015/16. Individuals identified with both autism and ADHD were included in the autism group but not in the ADHD group. This decision was made because the primary purpose of the study was to provide a true portrayal of medication dispensing to children and young people with autism, inclusive of any co-occurring conditions.

[14] Consistent with existing IDI-based case identification methods, this time period was chosen as it reflects the best quality data available across all the health datasets used in this study.

However, as per Section 2.4.3, when comparisons were made between groups, co-occurring autism and ADHD were controlled for.

4.4.2.4 Demographics

Age and gender were sourced using data from the personal details table in the IDI. Age was determined as at 30 June 2016 and stratified into five-year age blocks: 0-4, 5-9, 10-14, 15-19, and 20-24, consistent with previous IDI-based case identification studies (Bowden, Gibb, et al., 2020; Bowden, Thabrew, Kokaua, Audas, et al., 2020). Gender was classified as either female or male.

4.4.3 Establishing the youth (0-24) population 2015/16

The base population used for this study was the IDI estimated resident youth (0-24) population of Aotearoa/New Zealand for the 2015/16 fiscal year[15]. This was created using established methods for a resident population within the IDI (Gibb et al., 2016; Zhao et al., 2017). The population aims to capture all individuals who were alive and living in Aotearoa/New Zealand as at 30 June, 2016. All individuals identified with autism or ADHD were drawn from this population. Those individuals in neither the autism nor ADHD groups were included in the negative (non-autism /non-ADHD) control group.

[15] The 0-24 age range was chosen as it is the age range mandated by one of the study's funders, A Better Start National Science Challenge (see https://www.abetterstart.nz/), a range based on the WHO definition of youth.

4.4.4 Analysis

4.4.4.1 Calculating medication dispensing rates

Observed dispensing rates for each medication were calculated by dividing the number of people who were dispensed the medication at least once during the 2015/16 fiscal year by the populations of interest for that fiscal year. Rates were presented as 'per 1,000 people'.

4.4.4.2 Calculating polypharmacy rates

Observed polypharmacy rates were calculated for each of five mutually exclusive incremental levels: 0 medications; 1-2; 3-5; 6-9; and 10+ medications. Rates at each level were calculated by dividing the number of people dispensed the respective number of different medications at least once during the 2015/16 fiscal year by the populations of interest for that fiscal year. Rates were presented as the percentage of individuals within each polypharmacy level.

4.4.4.3 Standardisation of medication dispensing rates

The age and gender distributions across the three populations of interest vary substantively. Therefore, in order to compare like with like, rates of medication dispensing were standardised for age and gender. In addition, co-occurring ADHD among the autism group is likely to confound rates, particularly for medications such as methylphenidate. Therefore, the standardisation process also controlled for co-occurring ADHD to capture the true effect of autism on medication dispensing.

For each medication, rates were standardised using marginal predictions from logistic regressions of the binary indicator of medication dispensing on covariate binary indicators for autism only, ADHD only, autism & ADHD, and demographic variables for age and gender. Adjusted medication rates for the autism, ADHD, and non-autism /non-ADHD groups were

generated as the average of the resulting predicted probabilities. For each medication, adjusted incidence rate ratios (IRRs) were calculated as the ratio of the adjusted rates (autism to ADHD and autism to non-autism /non-ADHD), as an intuitive way of representing the relative rates. Differences between adjusted rates were tested using Wald Z-tests, under the null hypothesis that medication dispensing to those with autism does not differ from those without autism beyond random variation, e.g., H_0: Adjusted $rate_{autism}$ = Adjusted $rate_{ADHD}$. A similar process was used to estimate standardised rates of polypharmacy. A multinomial logistic regression was employed to calculate adjusted rates as the average predicted probabilities for each group at each incremental level of polypharmacy. A Chi-squared test of association was used to test any associations with disorder groups at each polypharmacy level, H_0: Adjusted $rate_{autism}$ = Adjusted $rate_{ADHD}$ = Adjusted $rate_{non\text{-}autism/non\text{-}ADHD}$.

4.4.5 Data management

Data were extracted in SAS 7.1 and then analysed using StataMP 15 within the IDI environment.

4.4.6 Ethics approval

The University of Otago Human Research Ethics Committee reviewed the study for ethics consideration. The study was reviewed as a 'Minimal Risk Health Research – Audit and Audit related Studies' proposal and was approved. Access to IDI data was granted by Statistics New Zealand.

4.5 Results

4.5.1 Populations of interest

The study population, the estimated resident youth population for the 2015/16 year, consisted of 1,560,030 individuals. Among those, the case identification methods identified 8,907 children and young people with autism and 6,828 with ADHD, leaving 1,544,292 remaining in the non-autism /non-ADHD group (see Table 5). Among the autism group 1,593 children and young people (18%) were identified with co-occurring ADHD. In contrast to the general population, males outnumbered females in both the autism and ADHD groups by almost four to one and age distributions were centred around the middle age groups. The 0-4 year old ADHD group was considered too small to be used in any subsequent analysis.

Table 5: Populations of interest

	autism	**ADHD**	**non-autism/non-ADHD**
Total	8,907	6,828	1,544,292
Sex			
Male	7,092	5,316	793,824
Female	1,815	1,512	750,468
Age			
0-4	651	15	297,204
5-9	2,817	1,194	313,362
10-14	2,499	2,451	288,546
15-19	1,821	2,082	306,834
20-24	1,122	1,083	338,346

4.5.2 Medications dispensed to the autism group

For the autism group, among the top 30 medications dispensed, nine were antibiotics, five were psychotropics, five were forms of corticosteroids, three were antihistamines, three were asthma relievers or preventers, two were analgesics, two were antiemetics, one was a cream for dry skin, and one was for constipation (see Table 6 for details).

The most dispensed medication was paracetamol (to 389 per 1,000 individuals in the autism group). Other medications dispensed at relatively high rates included amoxicillin (258 per 1,000), ibuprofen (200 per 1,000), loratadine (135 per 1,000), salbutamol (134 per 1,000), and amoxicillin with clavulanic acid (111 per 1,000). In total the autism group was dispensed 20 different medications to 5% or more of the cohort.

Rates of medications dispensed varied by gender. Females were dispensed quetiapine at nearly twice the rate of males. Ondansetron, trimethoprim with sulphamethoxazole, cefaclor monohydrate, lactulose, and hydrocortisone with miconazole were all dispensed to females at higher rates than males by 40% or more. Methylphenidate, methylphenidate extended release, prednisolone, and fluticasone were all dispensed to males more frequently than females by approximately out 30%.

Medication dispensing rates to young people with autism also varied by age, typically declining as age increased. Of the top 30 medications dispensed, 23 showed patterns of reduced dispensing with age. For example, rates of paracetamol dispensing decreased by 64% from the 0-4 age group to the 20-24 age group. Medication dispensing rates that increased with age included the five psychotropics, fluticasone propionate, and flucloxacillin.

4.5.3 Standardised comparisons to the ADHD and non-autism/non-ADHD groups

The main difference in the types of medications dispensed to the ADHD and non-autism /non-ADHD groups related to psychotropics (see Table 7 below and Appendix 2). Among the top 30 medications dispensed to the ADHD group, seven were psychotropics (compared to five for the autism group) and included clonidine hydrochloride (to 40 per 1,000 individuals in the

ADHD group) and atomoxetine (29 per 1,000). In contrast, among the top 30 medications dispensed to the non-autism /non-ADHD group, none were psychotropics.

Table 6: Rates of medication dispensing (per 1,000 people) for the autism population, 2015/16

Medication	Overall	Male	Female	0-4	5-9	10-14	15-19	20-24
Paracetamol (An)	389	381	423	682	512	342	247	246
Amoxicillin (Ab)	258	253	278	498	347	228	152	136
Ibuprofen (An)	200	192	231	318	227	188	168	144
Loratadine (Ah)	135	136	132	235	176	122	84	83
Salbutamol (Ast)	134	137	119	189	169	140	89	70
Amoxicillin with clavulanic acid (Ab)	111	110	117	161	130	100	84	107
Methylphenidate (Ps)	92	98	69	9	109	133	74	32
Methylphenidate (ext. release) (Ps)	88	93	64	S	60	140	112	48
Risperidone (Ps)	87	87	86	18	48	112	105	142
Sodium Fusidate (Ab)	86	87	84	152	114	84	49	45
Fluoxetine (Ps)	84	79	102	S	26	100	152	128
Cetirizine (Ah)	76	74	84	92	82	67	72	78
Flucloxacillin (Ab)	74	73	81	55	60	80	86	96
Fluticasone (Ast)	58	62	45	55	78	70	33	29
Erythromycin ethyl succinate (Ab)	54	55	48	97	82	44	30	21
Prednisolone (Cs)	52	55	40	157	103	29	S	S
Hydrocortisone butyrate (Cs)	52	53	46	83	58	46	49	37
Lactulose (Gi)	51	47	68	78	69	38	25	59
Hydrocortisone (Cs)	51	50	53	129	67	37	35	21
Trimethoprim with sulphamethoxazole (Ab)	50	44	71	129	70	37	23	24
Chloramphenicol (Ab)	45	44	51	111	56	38	26	24
Fluticasone propionate (Ast)	45	46	45	18	33	59	53	51
Hydrocortisone with natamycin and neomycin (Cs+)	44	42	51	88	55	35	26	35
Cefalexin (Ab)	42	41	46	111	58	36	15	19
Cefaclor monohydrate (Ab)	41	37	56	74	59	35	23	21
Hydrocortisone with miconazole (Cs+)	38	36	50	78	39	25	36	43
Ondansetron (Ae)	38	34	55	88	45	31	21	32
Promethazine (Ah)	37	36	38	69	51	25	25	27
Quetiapine (Ps)	34	29	56	S	S	18	71	115
Cetomacrogol with glycerol (Cr)	34	34	35	74	48	23	21	19

Ab = antibiotic, Ah = antihistamine, Ae = antiemetic, An = analgesic, Ast = asthma, Cr = cream for dry skin, Cs = corticosteroid, Cs+ = corticosteroid plus antifungal, Gi = gastrointestinal, Ps = psychotropics.
S Data suppressed due to number of number of individuals dispensed a medication being less than 6.

Dispensing rates to the autism group were typically higher compared to the ADHD group. Of the 30 most frequently dispensed medications to the autism group, 15 were dispensed at significantly higher rates compared to the ADHD group. These included fluoxetine (132% higher), risperidone (118%), an emollient cream - cetomacrogol with glycerol (63%), cefaclor monohydrate (39%), cefalexin (39%), lactulose (37%), and ondansetron (32%). Six medications were dispensed to the autism group at significantly lower rates compared to the ADHD group and included methylphenidate and methylphenidate extended release (864% and 732% lower respectively), flucloxacillin (29%), salbutamol (28%), fluticasone (27%), and ibuprofen (7%).

Of the top 30 medications dispensed to the autism group all were dispensed at higher standardised rates compared to the non-autism /non-ADHD group. Most notably all the psychotropic medications were dispensed at significantly higher rates to the autism group including risperidone (6,131% higher), fluoxetine (1,251%), quetiapine (938%), methylphenidate extended release (928%), and methylphenidate (807%). Other medications dispensed to the autism group at significantly higher rates included lactulose (199% higher), promethazine (131%), cefaclor monohydrate (61%), hydrocortisone with miconazole (57%), and ondansetron (50%).

Table 7: Comparison of dispensing rates (per 1,000 people) for the autism, ADHD, and non-autism/non-ADHD populations, 2015/16

Medication	Adj. autism Rate	Adj. ADHD Rate	Adj. IRR autism to ADHD	Adj. non-autism/non-ADHD Rate	Adj. IRR autism to non-autism/non-ADHD
Paracetamol (An)	412	401	1.03	359	1.15***
Amoxicillin (Ab)	270	250	1.08***	235	1.15***
Ibuprofen (An)	206	220	0.93**	185	1.11***
Loratadine (Ah)	135	110	1.22***	96	1.4***
Salbutamol (Ast)	122	157	0.78***	108	1.14***
Amoxicillin with clavulanic acid (Ab)	115	116	0.99	94	1.23***
Methylphenidate (Ps)	30	245	0.12***	3	9.07***
Methylphenidate (ext. release) (Ps)	24	235	0.1***	2	10.28***
Risperidone (Ps)	73	34	2.18***	1	62.31***
Sodium Fusidate (Ab)	89	84	1.06	68	1.3***
Fluoxetine (Ps)	111	48	2.32***	8	13.51***
Cetirizine (Ah)	76	67	1.13**	54	1.41***
Flucloxacillin (Ab)	70	90	0.77***	67	1.04
Fluticasone (Ast)	46	59	0.78***	39	1.18***
Erythromycin ethyl succinate (Ab)	57	49	1.16**	41	1.38***
Prednisolone (Cs)	55	45	1.21**	47	1.17***
Hydrocortisone butyrate (Cs)	55	46	1.19**	40	1.37***
Lactulose (Gi)	63	46	1.37***	21	2.99***
Hydrocortisone (Cs)	64	61	1.04	52	1.23***
Trimethoprim with sulphamethoxazole (Ab)	55	44	1.23**	39	1.41***
Chloramphenicol (Ab)	55	52	1.06	51	1.08
Fluticasone propionate (Ast)	41	40	1.04	32	1.28***
Hydrocortisone with natamycin and neomycin (Cs+)	51	50	1.02	36	1.4***
Cefalexin (Ab)	43	31	1.39***	31	1.4***
Cefaclor monohydrate (Ab)	48	34	1.39***	29	1.61***
Hydrocortisone with miconazole (Cs+)	52	43	1.23**	33	1.57***
Ondansetron (Ae)	45	34	1.32***	30	1.5***
Promethazine (Ah)	39	33	1.15	17	2.31***
Quetiapine (Ps)	48	44	1.1	5	10.38***
Cetomacrogol with glycerol (Cr)	42	26	1.63***	32	1.3***

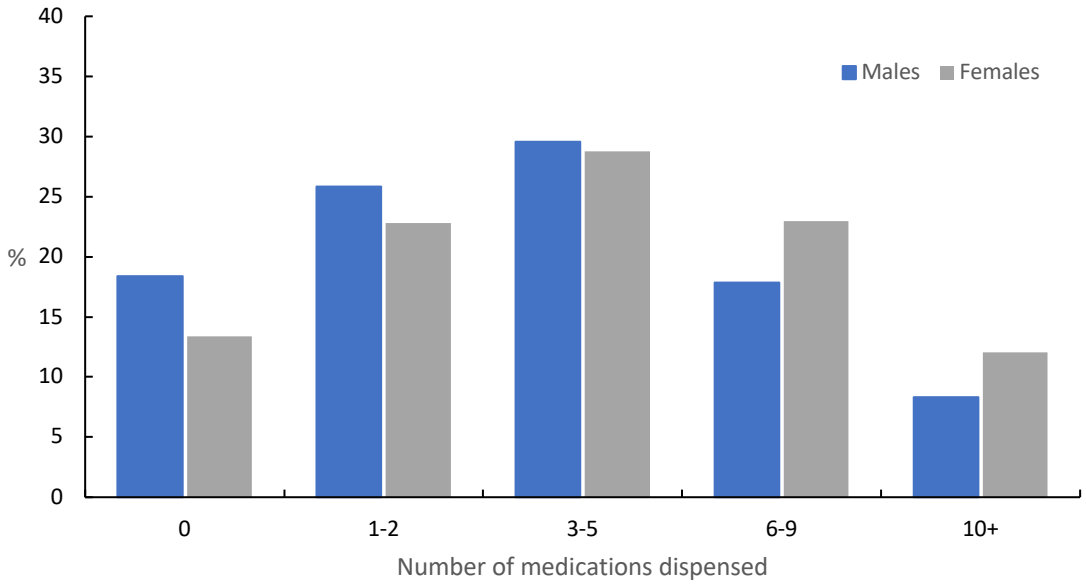
IRR = Incident rate ratio, the ratio of the adjusted autism rate to the respective adjusted non-autism rate.
Ab = antibiotic, Ah = antihistamine, Ae = antiemetic, An = analgesic, Ast = asthma, Cr = Cream for dry skin, Cs = corticosteroid, Cs+ = corticosteroid plus antifungal, Gi = gastrointestinal, Ps = psychotropics.
P-values were derived from Wald Z-tests under the null hypothesis that autism has no influence beyond random variation * p<0.1, ** p<0.05, *** p<0.01.

4.5.4 Polypharmacy

The mean number of unique medications dispensed to the autism group was 4.0 (standard deviation 3.8). For the ADHD group it was also 4.0 (3.6), while for the non-autism /non-ADHD group it was 2.9 (3.4).

For individuals with autism, observed polypharmacy rates varied by age and gender (see Figures 1 & 2). Males with autism were more likely to have no medication dispensed in the 2015/16 year (18%) compared to females (13%). Females with autism were more likely to be dispensed more than five medications and extreme polypharmacy rates (10+ medications in a year) were more common among females than males (12% vs 8%).

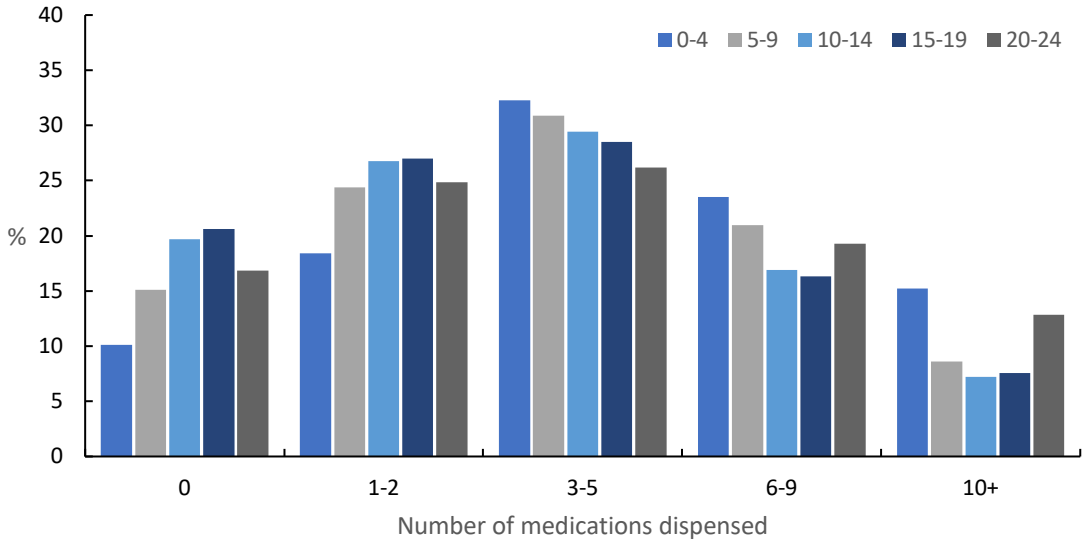
Figure 4: Polypharmacy rates for autism group, by sex 2015/16



Among individuals with autism, the youngest age group (0-4) was the least likely to receive no medications in the 2015/16 year (10%). Rates of zero medications dispensed increased with age (to 21% for the 15-19 age group), but decreased for the oldest age group (20-24) (to 17%).

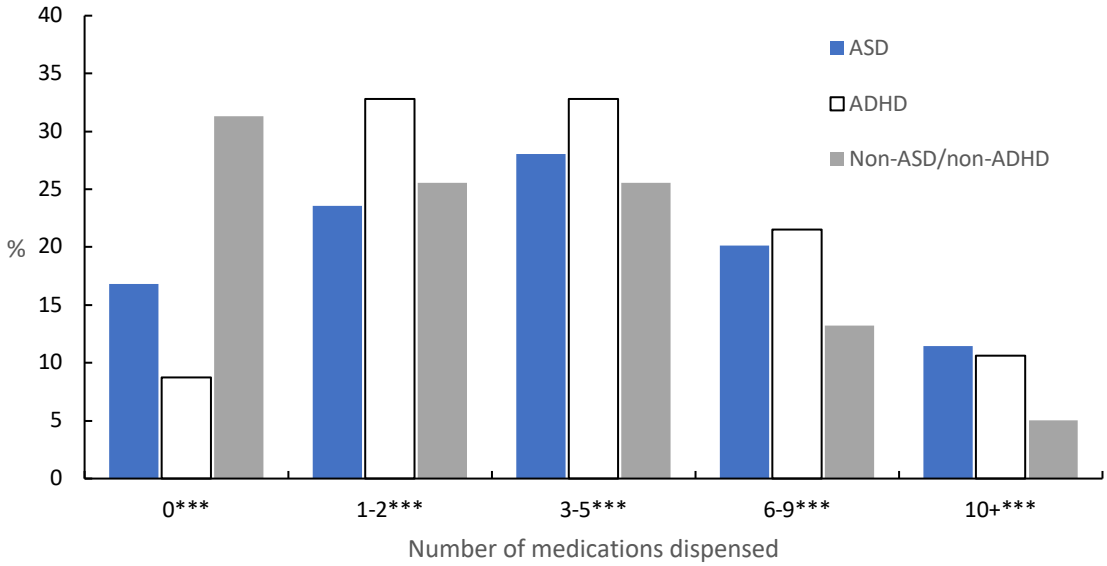
For polypharmacy of three or more medications, rates typically decreased with age except for extreme polypharmacy rates (10+ medications in a year) which were highest among the youngest (15%) and oldest age groups (13%).

Figure 5: Polypharmacy rates for autism group, by age category 2015/16



Polypharmacy rates standardised for age and sex varied significantly across the autism, ADHD, and non-autism /non-ADHD groups (see Figure 6). Rates of zero medications dispensed were highest in the non-autism /non-ADHD group (31%), nearly twice that of the autism group (17%), and three times that of the ADHD group (9%). Polypharmacy rates of three or more medications dispensed were highest for the ADHD group. For 6-9 medications, rates for autism and ADHD were similar (20% and 22% respectively) and nearly 50% higher than for the non-autism /non-ADHD group (13%). Extreme polypharmacy rates (10+ medications) occurred in 11 percent of individuals with autism, more than twice that of the non-autism /non-ADHD group and nearly 10 percent higher than the ADHD group.

Figure 6: Adjusted Polypharmacy rates for autism, ADHD, and non-autism/non-ADHD groups, 2015/16



P-values were derived from Chi-squared tests of associations across the three (autism, ADHD, non-autism/non-ADHD) groups, at each polypharmacy level.
* p<0.1, ** p<0.05, *** p<0.01

4.6 Discussion

To our knowledge, this is the first study to compare the numbers and types of all medications dispensed to a national cohort of children and young people with autism. It is also the first study to examine the relative medication burden experienced by this group compared to that experienced by children who have ADHD or the rest of the population.

4.6.1 Key findings

Aotearoa/New Zealand children and young people with autism experienced a significant medication burden, with around 83% being prescribed any sort of medication within a one-year period, and individuals being prescribed an average of four unique medications per year. These numbers are consistent with, but at the upper end of, previous findings from smaller studies from other countries (Esbensen et al., 2009; Logan et al., 2012; Oswald & Sonenklar, 2007). They are also comparable to, but slightly below, those of children and young people with ADHD, 88% of whom were prescribed any medication in the year (and a mean of four

medications), and higher than those of children without a neurodevelopmental disorder, 69% of whom were prescribed any medication (and a mean of 2.9 medications). Higher rates of psychiatric comorbidity which affect 70 percent of individuals with autism and other medical conditions, for example epilepsy and sleep problems, may explain some degree of this increased medication burden (American Psychiatric Association, 2013a; Simonoff et al., 2008).

Paracetamol was the most commonly used medication among the autism and non-autism /non-ADHD groups reflecting its use as the most commonly prescribed medication (Tomlin, Woods, Lloyd, & Tilyard, 2018). High rates of paracetamol dispensing were found particularly in the younger age groups as it is routinely used for teething, post-vaccination, and to help manage childhood fever. These rates would be expected to decline with increasing age. Of interest however, paracetamol was superseded by methylphenidate as the most dispensed medication to the ADHD group. Higher dispensing of antihistamines to those with autism compared to the non-autism /non-ADHD group may reflect higher rates of allergies among young people with autism (Miyazaki et al., 2015), or, particularly in the case of promethazine, off-label use for sleep problems, common among those with autism (Ministries of Health and Education, 2016). Similarly, comparatively high dispensing rates of asthma medications (e.g., salbutamol and fluticasone) are concordant with evidence regarding elevated rates of asthma in children with autism (Miyazaki et al., 2015). Lactulose is used primarily for constipation, and increased use among children with autism is probably related to higher rates of gastrointestinal issues experienced by them (Buie et al., 2010). It may also be related to the side-effect profile of some of the more frequently used psychotropics (Santarsieri & Schwartz, 2015). Gender differences in quetiapine prescribing among the autism group may be explained by the increased prevalence of anxiety and sleep disorders in females than males (Duncan, Cooke, Symonds,

Gardner, & Pringsheim, 2016). Similarly, the greater rate of stimulant prescription to males is in keeping with increased rates of inattention and hyperactivity in this group (Gaub & Carlson, 1997). The use of other agents, including antibiotics, is in keeping with the results of previous studies of children and young people with autism (Logan et al., 2012) and those in the general population (Tomlin et al., 2018).

Our results indicate 57% of children and young people with autism experienced polypharmacy of three or more medications, substantively higher than the study by Esbensen et al. (2009) who found 34% of young people aged 10-19 with autism experienced polypharmacy of three or more medications (Esbensen et al., 2009). We also found that females experienced polypharmacy, particularly six or more medications, notably more than males. This is in contrast to studies on psychotropic polypharmacy that found no association with gender (Rosenberg et al., 2010; Spencer et al., 2013) and therefore may merit further investigation. Furthermore, we noted patterns in polypharmacy rates varied by age. Polypharmacy of six or more medications were higher for those in the youngest (0-4 and 5-9) and oldest (20-24) age groups. This age profile understandably differs from studies looking at psychotropic medications only, where polypharmacy increases with age (Madden et al., 2017; Rosenberg et al., 2010; Spencer et al., 2013), and is not directly comparable to others such as the longitudinal study of Esbensen et al. (2009) who looked at 10-19 year olds and found that polypharmacy rates of three or more medications nearly doubled 4.5 years later (Esbensen et al., 2009). Although we noted the concerns by authors such as Baker et al. (2019) that variable inclusion or exclusion of subtypes of medications can make it difficult to compare rates of polypharmacy between studies, we did not separate the medications into those for long-term use versus those for short term (i.e., antibiotics) or those for use when required (i.e., analgesics), as the intent was to document the burden over a year.

Recent international estimates suggest the prevalence of autism is 1.9% (Maenner et al., 2020) while the prevalence of ADHD is 3.4% (Polanczyk, Willcutt, Salum, Kieling, & Rohde, 2014). Assuming rates of these conditions are the same in New Zealand, the case identification models employed capture approximately only one third of the children and young people with autism in New Zealand, and one sixth of those with ADHD. This is likely to be related to the current limitation of diagnosis-related IDI data to secondary level (specialist) clinical services and disability support, to which only individuals with more severe or symptomatic problems are referred. While current IDI datasets may be less useful for estimating the true prevalence of disorders, prescribing data originate from both primary and secondary level services, and are therefore reflective of true prescribing rates.

As indicated in other literature, while there are few recommendations for the use of psychotropics in those individuals with autism, their prevalence is notable. Within the top 30 medications for each category, there were no psychotropics for the non-autism /non-ADHD group, five for the autism group, and seven for the ADHD group. The most common psychotropics dispensed to children with autism were methylphenidate (e.g., Ritalin ®), methylphenidate (ext. release) (e.g., Concerta ®), risperidone (e.g., Risperdal ®), fluoxetine (e.g., Fluox ®), and quetiapine (e.g., Seroquel ®). The types of medications dispensed are similar to that described elsewhere including antipsychotics, stimulants, and antidepressants (Mandell et al., 2008; Rosenberg et al., 2010) and concordant with the self-reported prescribing practices of Aotearoa/New Zealand child and adolescent psychiatrists for ADHD, sleep disturbance, depression, and restricted repetitive behaviours (Thabrew et al., 2020). Risperidone was 62 times more likely to be used in the autism group, which aligns with the current medication management for autism internationally (Alfageh et al., 2019). However,

other guidelines have indicated that the routine use of pharmacotherapy is not recommended (Howes et al., 2018).

At the extreme end of polypharmacy (10+ medications), we observed significantly higher rates among the autism group, more than twice those of the non-autism /non-ADHD group. These relative rates are consistent with existing studies although the comparability is limited. In an adult study, polypharmacy rates (of six classes of medications or more) for people with autism were 48% compared to 33% in the non-autism group (Vohra et al., 2016). In another study, Madden et al. (2017) found that nearly 50% of young people with autism had a psychotropic medication, while the rate was only 7.7% among young people without autism (Madden et al., 2017). Our study also found that polypharmacy among children and young people with autism was generally similar to those with ADHD across the range of polypharmacy groupings. Standardised rates were marginally lower among the autism group for three or more medications, but marginally higher for ten or more. The pattern of these findings is consistent with those of Frazier et al. (2011), who observed higher rates of overall medication use by the ADHD group, but greater rates of polypharmacy among the autism group (Frazier et al., 2011). Despite the relative rates of comorbidities between children with autism and ADHD in the study population being unknown and the potential argument that children with autism and ADHD receive greater multi-disciplinary attention than those with other conditions, it is more likely that polypharmacy reflects the relative lack of availability of non-pharmacologic solutions and that it is associated with greater long-term risks.

4.6.2 Strengths and limitations

The major strength of this study is the examination of data at a national level, with every government-subsidised medication dispensed to our populations of interest being included in

our analysis. Suitable national positive and negative control groups were also utilised to place our findings into context. Key limitations of this study are that case identification methods for both autism and ADHD are unvalidated and rely on administrative datasets (Bowden, Gibb, et al., 2020; Bowden, Thabrew, Kokaua, Audas, et al., 2020). Therefore, the extent to which these methods undercount and/or falsely identify these conditions and the way this might affect our analysis is unknown. In addition, medication dispensing may not equate with actual medication use or adherence and it was not possible to tell who had prescribed any type of medication. Moreover, the indication for prescribing was not available in the data. Therefore, making assessments about pharmaceutical data and in particular the appropriateness of polypharmacy is challenging and data should be interpreted with caution. Neither an analysis of individual therapeutic drug classes nor a detailed examination of psychotropic prescribing was undertaken.

4.6.3 Ethical issues

While the use of IDI data for research purposes in Aotearoa/New Zealand is legal, ethical concerns regarding its use remain. As more extensively discussed in Bowden et al. (2019), further management of these issues is critical to the ongoing ethical use of the IDI (Bowden et al., 2019; Durie, 2006).

4.6.4 Future research

As this study was exploratory in nature, there are a number of possible directions for further research. Analysis of the predictors of medication dispensing and a more in depth analysis of psychotropic polypharmacy would be useful, as would an exploration of the impact of gender, ethnicity, socioeconomic status, and comorbidity on prescribing for children and young people with autism. Specific exploration of changing prescribing patterns for those aged 20-24 years,

differences in drivers of prescribing for children with autism and ADHD compared to those without these conditions and long-term effects of polypharmacy would also be valuable. Further validation of the IDI model is necessary and this can be undertaken via an analysis of medical case-records. In time, these measures should provide greater clarity regarding the clinical needs of children and young people with autism, as well as potential ways to reduce current inequalities in healthcare.

5 Association between high need education-based funding support and school suspension for autistic students

5.1 Preface

This chapter contains an original manuscript, 'Association between high need education-based funding support and school suspension for autistic students'. It was published in JAMA Pediatrics. doi:10.1001/jamapediatrics.2022.1296

Autistic students often face a number of challenges within schooling environments. However, the evidence base examining the extent to which autistic students are suspended from school relative to their non-autistic peers is sparse and inconclusive. Furthermore, no studies have evaluated the impact of education-based funding support for autistic students on school suspension.

The objectives of this paper were to quantify differences in suspension rates for autistic compared to non-autistic students and to assess the degree to which high need education-based funding might reduce suspensions for autistic students.

5.2 Association between high need education-based funding support and school suspension for autistic students

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Statement of contribution

The concept for this study was conceived by Bowden, Gibb, Audas, Dacombe, Milne, Murray, Stace, and Taylor. Ethical approval was sought by Bowden. Bowden conducted data analysis

and wrote the first draft of the manuscript. All authors subsequently helped revise the manuscript to its final version.

Abstract

Importance: Autistic students often experience poor educational outcomes which have implications for later life including unemployment, interactions with the criminal justice system, increased risk for substance abuse, and low socioeconomic status. Improving education outcomes is critical for ensuring autistic young people can reach their potential.

Objective: To assess whether high need education-based funding support for autistic students is protective of school suspension.

Design, Setting, and Participants: This was a national retrospective cohort study using linked health and education data from New Zealand's IDI. Data were obtained for school students aged 5-16 years for 2018 (n= 736,911). A novel case identification method was employed to identify autistic students (n = 9,741).

Exposures: High need education-based funding support (ORS), obtained prior to 2019.

Main Outcomes: Suspension from school.

Results: Of the study population (n = 736,911), 9,741 (1.3%) were identified as autistic. School suspension was experienced by 13,845 (1.9%) non-autistic students and 504 (5.2%) autistic students. After adjustment for demographics autistic students had significantly higher odds of suspension than their non-autistic peers (adjusted odds ratio 2.81 [95% CI 2.55, 3.11]). Among the 9,741 autistic students, 2,895 (29.7%) received high need education-based (ORS) funding. Suspensions were experienced by 57 (2.0%) autistic students with high need funding and 447 (6.5%) autistic students without high need funding. After adjustment for demographics, co-occurring conditions and level of disability support need, autistic students with high need funding had significantly lower odds of suspension than autistic students without high need funding (adjusted odds ratio 0.29 [95% CI 0.21, 0.40]).

Conclusion and Relevance: Disparities in suspension rates between autistic and non-autistic students underscore the challenges faced in providing inclusive education for all young people,

regardless of disability status. This study demonstrates that high need funding support is associated with reduced suspension rates among autistic students suggesting that, if appropriate supports are afforded to autistic students, a more inclusive education can be provided.

5.3 Background

Autism is a lifelong neurodevelopmental condition characterized by social and communication differences, restricted repetitive patterns of behaviour or interests, and sensory issues (American Psychiatric Association, 2013a). While associated with strengths such as visual thinking, logic, and memory (Altogether Autism, 2019; Meilleur et al., 2015), autism can also have a variable effect on adaptive functioning (American Psychiatric Association, 2013a). Therefore, individual needs for support in daily life can vary. Owing to improved identification methods, changing definitions, and increased awareness, autism prevalence has increased almost three-fold in the last 20 years and is estimated to affect 18.5 per 1000 children (or 1 in 54) (Maenner et al., 2020). Environmental causes and genetic/environment interactions have also been postulated to play a lesser role (Amaral, 2017; Panisi et al., 2021).

Challenges related to communication, sensory sensitivity, and strong preferences for known routines, can manifest as behavioural issues, exacerbated by unrecognized and unmet needs, and can make it difficult to cope in schooling environments for autistic students. (In this paper, identity-first language is used in recognition that this is the preference of most Autistics, although terms such as 'person with autism' are used. The authors acknowledge there is no single term preferred by all autistic people). Consequently, autistic students have high rates of educational difficulties such as low attendance and poor academic achievement (Barnard, 2000). However, contemporary literature quantifying the risk of school exclusion (e.g., suspensions) among autistic students is sparse and inconclusive. This is a concern as there is consistent evidence linking school exclusion to poorer academic achievement (Yaluma et al., 2021). Early studies have shown autistic students experienced similar or lower rates of suspensions compared to their non-disabled peers (Krezmien et al., 2006; Losen et al., 2014), however more recent studies have found higher rates of suspensions among autistic students

(Ambler et al., 2015; Krezmien et al., 2017). Inconsistency of extant findings might be attributed to differences in data collection methods, variable sample sizes, and policy environments(Krezmien et al., 2017).

There is a large body of evidence on the benefits of early intervention and support for the well-being of autistic individuals and their families (Whitehouse et al., 2021). The number and types of interventions available are wide-ranging and vary in their theoretical orientation and application (Sandbank et al., 2020; Whitehouse et al., 2021). In general, their purpose is to enhance everyday skills such as communication, and reduce problematic behaviours. A common finding is that early access to effective interventions during childhood supports early development and improves longer term quality of life (Fuller & Kaiser, 2020; Rogers & Vismara, 2008; Whitehouse et al., 2021). If appropriate supports are not provided at an early age, deleterious long-term effects are more likely.

Of critical importance are supports and interventions within schools to ensure young autistic children meet their potential (McLeskey & Waldron, 2007). Improved educational, psychosocial, and health outcomes have all been linked to school-based interventions and support (Hebron, 2018; Kokina & Kern, 2010; Macmillan et al., 2021; Whalon, Conroy, Martinez, & Werch, 2015). The importance of effective supports is reflected in Article 24 of the UNCRPD where signatories have obligations to provide quality and inclusive education for all young people with disabilities. However, there are few studies that assess education-based interventions and supports for autistic students against educational outcomes. A recent systematic review found significant improvement in academic skills, on-task behaviour, play behaviour, social cognition, social interaction, and verbal skills resulting from school-based

interventions (Macmillan et al., 2021). However, to the best of our knowledge, no studies have evaluated ways in which supports for autistic students might mitigate school exclusion.

A range of education-based learning supports is available in Aotearoa/New Zealand including early intervention, communication, behavioural, and high-needs services (Ministry of Education, 2021). ORS is a high need funding support for students who have substantial and complex ongoing levels of need (Education Counts, 2020). Criteria for ORS require students have either ongoing extreme or severe difficulty in learning, hearing, vision, physical or language use and social communication, or moderate to high difficulty with learning in addition to at least two other areas of moderate to high need. Funding is based on individual level of need, assessed by verified assessors within the Ministry of Education, and is not dependent on region or school. Approximately 1.2% of the Aotearoa/New Zealand school population receive the support of ORS funding at $USD 15,000 on average per funded student (Ministry of Education, 2017). The funding is provided to the school for teacher aide and specialist teacher support, as well as consumables to enable learning alongside other students. Other specialists (e.g., speech-language therapists, psychologists, occupational therapists) may also provide additional support to the school. Unlike in many high-income countries, ORS is a nationwide support system with a more universal focus to enhance the whole schooling environment. We hypothesize that high need funding may be protective of suspension for autistic students.

The objectives of this study were to:

1. Quantify differences in suspension rates for autistic compared to non-autistic students;
2. Assess whether high need education-based funding reduces suspension rates for autistic students.

5.4 Methods

5.4.1 Study design

This was a national retrospective cohort study using Aotearoa/New Zealand's IDI. The IDI is a large research database managed by Statistics New Zealand, containing a wide range of linked individual-level microdata about Aotearoa/New Zealand people and households (Milne et al., 2019; Statistics New Zealand, 2017a). IDI Data are linked probabilistically by Statistics New Zealand (usually using name, date of birth and sex) then de-identified (Statistics New Zealand, 2020).

5.4.2 Participant population

The base population was the IDI-ERP for Aotearoa/New Zealand school aged children (5-16 years) for the 2018 calendar year. This was created using established methods for a resident population within the IDI (Gibb et al., 2016; Zhao et al., 2017). The age range reflects the ages for compulsory education in Aotearoa/New Zealand (6-16 years) and includes five-year-olds, the typical school starting age. The age maximum was chosen to reduce selection effects from differential school drop-out after 16 years. To assess educational outcomes, the IDI-ERP was restricted to students enrolled in school in 2018.

5.4.3 Primary measures

5.4.3.1 Suspension

Suspensions were defined as removal of a student from school for no more than five days by the principal (referred to as a stand-down in Aotearoa/New Zealand) or formal removal of a student from school by the principal until the Board of Trustees determines an outcome. Under the Education and Training Act 2020, suspension is a legal process where the grounds for

suspension are that student misconduct causes, or may cause, harm to other students (New Zealand Legislation, 2020). Data were drawn from the Ministry of Education interventions table for 2018, the most recent complete calendar year available (Statistics New Zealand, 2015d). Suspension was indicated if a student had experienced either disciplinary action at least once during the 2018 calendar year.

5.4.3.2 Autism

The autistic population was identified using a novel IDI-based case identification method (Bowden, Thabrew, Kokaua, Audas, et al., 2020). This utilizes diagnostic information captured within three health datasets: NMDS (publicly funded hospital admissions), PRIMHD (publicly funded secondary specialist mental health service use), and Socrates (DSS). Many autistic children will have their diagnosis recorded in administrative data only at their first contact with health services. Therefore, we have used all available data and a young person was indicated as autistic if they had an autism diagnosis in one or more of these datasets between 1 January, 2010 and 31 December 2018.

5.4.3.3 High need education-based funding support

High need education-based funding support (ORS) information was extracted from the Ministry of Education interventions table from 2009 (earliest date available) to 2018 inclusive. Funding was indicated if an ORS start date was identified during this period. Once started, this funding continues for the duration of a student's schooling.

5.4.3.4 Level of disability support need

To determine the level of disability support need for autistic students, support package allocation (SPA) information captured within the Ministry of Health's Socrates database was

utilized over the period 1 January 2010 to 30 September 2020. The SPA tool provides a nationally consistent means of allocating resources and has five levels of need: very low, low, medium, high, and very high. The SPA level for each individual was determined using the most recent needs assessment prior to 2018. If there was no needs assessment prior to 2018 we used the first assessment after this year. A categorical variable was created reflecting each SPA level and an additional category indicating that no needs assessment had been conducted. Level of disability support need is assessed separately from ORS and the two have no administrative overlap.

5.4.3.5 Co-occurring conditions

Indicators for intellectual disability, behavioural problems (ADHD, conduct disorders, ODD), emotional disorders (anxiety, depression), and other psychological diagnoses were determined using previously described methods over the period 2010 to 2018 inclusive (Bowden, Gibb, et al., 2020; Bowden, Thabrew, Kokaua, Audas, et al., 2020). Dichotomous variables reflecting the presence of co-occurring conditions were established if at least one diagnostic indication across any of the datasets during the time period was identified.

5.4.4 Socio-demographics

Using information captured in the IDI personal details table, sex (male/female), age (at 31 December 2018, grouped into approximate Aotearoa/New Zealand school entry ages: 5-11 (primary); 12-16 years (post-primary)), and ethnicity were determined. Ethnicity used the major ethnic groups defined by the New Zealand Standard Classification: Asian, European, Māori, MELAA, Pasifika, and Other, and used the total concept approach, meaning participants can identify with multiple ethnic groups. European and Other (EO) groups were combined. Socioeconomic status was estimated using NZDep 2013, an area-based deprivation

measure based on residential address from the address notification table (Atkinson et al., 2014). NZDep was collapsed into quintiles (quintile one represents the least deprivation). Residential address was used to determine a binary indicator reflecting urban (populations of 1000 or more people) and rural (less than 1000 people) (see https://www.stats.govt.nz/methods/statistical-standard-for-geographic-areas-2018 for more detail) (Statistics New Zealand, 2019).

5.4.5 Procedure

Data were extracted using SAS 7.1 (SAS Institute Inc., 2014) and analysed using Stata MP version 15 (StataCorp, 2017). All counts were randomly rounded to base 3, adhering to Statistics New Zealand confidentiality requirements.

5.4.6 Statistical analysis

Reporting of analyses conformed to Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD) guidelines (Benchimol et al., 2015). Crude and adjusted analyses of the association between suspension and autism among the full population (objective 1) with adjustment made for socio-demographic characteristics (sex, age, ethnicity, deprivation, and urban/rural profile of residence) were conducted using complete-case two-level random intercept logistic multivariable regressions. The two-level models account for the correlation structure of the data with students nested within schools. To assess the association of ORS funding and suspension (objective 2), analysis was restricted to autistic students. The method of analysis was otherwise the same as for objective 1 with the inclusions of level of disability support need, and co-occurring conditions as covariates. We report unadjusted and adjusted odds ratios and associated 95% CIs.

Sensitivity analyses excluding students enrolled in a specialist school at any point during the 2018 year were conducted to account for the possibility that suspensions might be imposed differently within specialist schools. These schools were defined as: special schools, correspondence schools, alternative education providers, teen parent units, and activity centres. In addition, analyses stratified by level of disability support need were conducted to explore whether heterogeneity in characteristics of autism in relation to complexity of need may influence results.

5.4.7 Ethics approval

The study was approved by the University of Otago Human Research Ethics Committee (Reference: HD17/004). No further participant consent was required.

5.5 Results

5.5.1 Participants

The Aotearoa/New Zealand population aged 5-16 years for the 2018 calendar year contained 753,507 young people, with 736,911 enrolled in school. Autism was identified in 9,741 (1.3%) students. The socio-demographic characteristics of participants, stratified by autism, are presented in Table 8. Among autistic students, males outnumbered females by almost 4:1. Over three quarters of autistic students (79.5%) identified as EO, higher than non-autistic students (70.0%). The distribution of autistic students across deprivation quintiles was relatively uniform and the vast majority lived in urban areas.

Table 8: Sociodemographic characteristics of the 9,741 autistic students and 727,170 non-autistic students enrolled in 2018

	n (%) of children	
	Autistic students	**Non-autistic students**
Sex		
Female	2,031 (20.9)	357,393 (48.5)
Male	7,710 (79.1)	369,777 (50.2)
Age		
Age 5-11	5,994 (61.5)	431,625 (58.6)
Age 12-16	3,750 (38.5)	295,545 (40.1)
Ethnicity [a]		
Asian	1,236 (12.7)	110,010 (14.9)
EO	7,743 (79.5)	507,333 (70.0)
Māori	2,448 (25.1)	199,251 (27.0)
MELAA	201 (2.1)	13,938 (1.9)
Pasifika	954 (9.8)	102,246 (13.9)
Deprivation		
1 (least deprived)	1,992 (20.4)	160,281 (21.8)
2	1,857 (19.1)	139,272 (18.9)
3	1,848 (19.0)	130,350 (17.7)
4	1,854 (19.0)	129,267 (17.5)
5 (most deprived)	2,136 (21.9)	162,996 (22.1)
missing	54 (0.6)	5,004 (0.7)
Urban/Rural		
Urban	8,616 (88.5)	617,751 (83.8)
Rural	1,089 (11.2)	105,459 (14.3)
missing	36 (0.4)	3,960 (0.5)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African.
a Percentages do not sum to 100% as individuals can identify with multiple ethnic groups.

5.5.2 Suspensions

Table 9 shows that observed rates of suspension were more than two and a half times higher among autistic compared to non-autistic students. Regression estimates indicated an unadjusted increase in odds of suspension for autistic students of 3.15, attenuated slightly to 2.81 after adjustment for demographics. Full regression results are displayed in Appendix 3.

Table 9: Suspension rates of the 9,741 autistic students and the 727,170 non-autistic students and complete case unadjusted and adjusted odds ratios of suspensions on autism status (N=731,853)

	n	Suspension %	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
Autism				
Yes	504	5.2%	3.15 (2.86, 3.47)	2.81 (2.55, 3.11)
No	13,845	1.9%	(reference)	

* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence.

5.5.3 Impact of high need education-based funding support

Among autistic students, 2,895 (29.7%) received high need funding in 2018. The sociodemographic and health related characteristics of autistic students with and without funding are presented in Table 10. Funded students were systematically different from unfunded students. Compared to those not receiving funding, autistic students receiving high need funding were younger, more likely to be Māori, Pacific, Asian or MELAA ethnic groups and less likely to be EO, and more likely to live in areas of high deprivation. Funded students had higher levels of disability support needs than unfunded students and were more likely to have a co-occurring intellectual disability. Funded students were less likely to have co-occurring behavioural, emotional or other diagnoses.

Table 11 shows that rates of suspension were more than three times lower among autistic students with high need funding compared to those without high need funding. Regression estimates indicated the unadjusted odds of suspension is 69% lower for autistic students with high need funding (odds ratio 0.31). After adjustment for demographics, level of disability support need, and co-occurring conditions, this effect strengthened slightly (adjusted odds ratio 0.29). Full regression results are displayed in Appendix 3.

Table 10: Sociodemographic and clinical characteristics of the 2,895 autistic students with high need education-based funding and the 6,849 autistic students without high need education-based funding

	n (%) of children	
	with high need education-based funding	**without high need education-based funding**
Sex		
Female	606 (20.9)	1,428 (20.8)
Male	2,289 (79.1)	5,421 (79.2)
Age		
Age 5-11	2,001 (69.1)	3,990 (58.3)
Age 12-16	894 (30.9)	2,859 (41.7)
Ethnicity [a]		
Asian	564 (19.5)	672 (9.8)
EO	1,872 (64.7)	5,871 (85.7)
Māori	888 (30.7)	1,557 (22.7)
MELAA	75 (2.6)	126 (1.8)
Pasifika	474 (16.4)	483 (7.1)
Deprivation		
1 (least deprived)	438 (15.1)	1,554 (22.7)
2	480 (16.6)	1,377 (20.1)
3	522 (18.0)	1,326 (19.4)
4	597 (20.6)	1,257 (18.4)
5 (most deprived)	840 (29.0)	1,299 (19.0)
missing	18 (0.6)	27 (0.5)
Urban/Rural		
Urban	2,586 (89.3)	6,030 (88.0)
Rural	294 (10.2)	795 (11.6)
missing	15 (0.5)	24 (0.4)
Level of disability support need		
1 (lowest needs)	54 (1.9)	303 (4.4)
2	102 (3.5)	387 (5.7)
3	912 (31.5)	2,622 (38.3)
4	1,050 (36.3)	1,908 (27.9)
5 (highest needs)	582 (20.1)	384 (5.6)
6 (not assessed)	198 (6.8)	1,245 (18.2)
Co-occurring conditions		
Intellectual disability	1,290 (44.6)	1,329 (19.4)
Behavioural	675 (23.3)	2,394 (35.0)
Emotional	417 (14.4)	1,542 (22.5)
Any (other) psychological diagnosis	1,008 (34.8)	2,799 (40.9)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African.
a Percentages do not sum to 100% as individuals can identify with multiple ethnic groups.

Table 11: Suspension rates of the 2,895 autistic young people with high need education-based funding and the 6,849 autistic young people without high need education-based funding and complete case unadjusted and adjusted odds ratios of suspension on high need education-based funding status (N=9,687)

	n	Suspension %	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
High need funding				
Yes	57	2.0%	0.31 (0.23, 0.41)	0.29 (0.21, 0.40)
No	447	6.5%	(reference)	

* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence, level of disability support need, and co-occurring conditions.

5.5.4 Sensitivity analyses

Sensitivity analyses excluding students who attended specialist schools at any time during 2018, and models stratified by level of disability support need (see Appendix 3), showed no material difference in findings.

5.6 Discussion

This national retrospective cohort study, utilizing data from 736,911 school students in Aotearoa/New Zealand aged 5-16 years, found that autism was associated with significantly higher odds of suspension (adjusted odds ratio 2.81). Amongst autistic students, high need education-based funding support was associated with a significant and substantial reduction in odds of suspension, after controlling for characteristics associated with funding receipt, including demographics, co-occurring conditions, and level of disability support need (adjusted odds ratio 0.29).

Our finding that autistic students have higher odds of suspension than non-autistic students aligns with recent literature (Ambler et al., 2015; Krezmien et al., 2017). Given the negative consequences associated with school suspension (Committee on School Health, 2003) this demonstrates the need for more targeted resources to better support autistic students. Our effect

size (adjusted odds ratio 2.81) is larger than that reported by Krezmien et al. (2017) (odds ratio 1.9), however this might be due to differences in suspension criteria, such as legal frameworks, policy environments, and the maximum suspension length (Krezmien et al., 2017; New Zealand Legislation, 2020; U.S. Department of Education, 2021).

The finding that high need education-based funding support reduces suspension is encouraging. It suggests that, with appropriate supports, a more inclusive education can be provided to autistic students. It also aligns with evidence demonstrating the benefits of early interventions among autistic young people (Whitehouse et al., 2021), including in the school setting (Macmillan et al., 2021). We hypothesize several pathways that high need funding could reduce suspension rates. Recognition of the level of need of ORS funded students probably results in greater empathy and tolerance from the school, better relationships between school and family, leading to improved understanding and a more accommodating school environment. Funding would also enable a team to be placed around the student, dedicated teacher time, and an individualized education program, thus enhancing learner engagement and efficacy. A large proportion of ORS funding is used to employ teacher aides who work with students managing challenging behaviours. It is possible the teacher aide deters bullying which autistic students often experience (Maiano et al., 2016), causing autistic students to act out and resulting in disciplinary action. Furthermore, we cannot rule out that schools are more accommodating of funded autistic students as they do not wish to lose the funding.

An alternative explanation is that high need funding does not cause lower suspension rates, but instead students who receive high need funding are systematically different to those who do not, and these differences account for disparities in suspension rates. For example, students with high need funding may be less engaged with the regular curriculum and have less frequent

interactions with other students, providing fewer opportunities for conflicts leading to suspension. We controlled for this potential confounding through adjustment for level of disability support need and co-occurring health conditions, and conducted sensitivity analyses excluding the highest need students, and the effect remained. Nonetheless, it is possible that unmeasured confounding may explain some of the difference in suspension rates. Further research is needed to understand the pathways via which high need funding reduces suspension rates.

Our finding of high suspension rates amongst autistic students indicates that more must be done in Aotearoa/New Zealand to meet obligations under Article 24 of the UNCRPD. Strong evidence exists that links suspensions to school drop outs, and ultimately higher risk of engaging in substance abuse, violent behaviours, and interactions with the justice system, the so called "school-to-prison pipeline" (Wald & Losen, 2003). In light of our finding that high need education-based support reduces suspension rates for autistic students, expanding those supports and providing more widespread and targeted interventions might enable more inclusive provision of education and improve other life outcomes.

These findings also highlight the issue of ableism (Linton, 1998) and its relationship with high suspension rates among autistic students. Ableist assumptions and actions reinforce prejudices against disability and contribute to poorer educational outcomes and reduced employment (Hehir, 2002). Removing autistic students from school punishes them for their disability, contributes to disengagement from educational opportunities, and further exacerbates disparities in educational achievement. In accordance with Aotearoa/New Zealand's Learning Support Action Plan (Ministry of Education, 2019), more appropriate responses include

collaboration with families to identify triggers, support plans and strategies, and encouragement of better understanding of autism.

The high need funding scheme in Aotearoa/New Zealand (ORS) has limitations. It is capped to fund only a small percentage of the total student population, forcing disabled children to compete for funding (Tiso & Stace, 2015). In addition, ORS is based on a deficit model with an arduous application process, making it difficult psychologically and logistically to obtain funding. Furthermore, there is wide variation in support allocated via ORS, it does not cover all school hours, and may be reduced so that schools and parents could be left to fund the difference to maintain support. Addressing these limitations could improve the impact of ORS funding on school outcomes for autistic students.

5.6.1 Strengths and limitations

A strength of this study is the use of a large, contemporary, national sample of school aged children, allowing us to identify a sizeable group of autistic students. Additional variables available in the linked datasets allowed us to adjust for confounding and to undertake sensitivity analyses, reducing the potential for selection bias compared to previous studies (Parsons, Lewis, & Ellins, 2009; Starr & Foy, 2012). This study demonstrates that effective data linkage offers opportunities to better understand the educational experiences of autistic students. Without routinely collected disability data within education settings, linked datasets such as the IDI could be used to track progress toward achieving inclusive education goals, a priority under Article 31 of the UNCRPD (Ministry of Education, 2020).

The study also has limitations. The autism case identification method has not been formally validated and may not capture all cases of autism, or may detect false positives (Bowden,

Thabrew, Kokaua, Audas, et al., 2020). We could not measure 'unofficial suspensions' where parents are encouraged to keep their child away from school, with no formal exclusion being imposed (Radio New Zealand, 2021; Starr & Foy, 2012). Measuring these would increase the number of autistic students suspended, however it is not clear how this would affect our finding on the impact of education-based funding support. Lastly, our data do not include other schooling supports students might be receiving.

5.6.2 Implications and further research

The findings of this study could be used to justify an increase in the funding allocation for high need education-based supports and enable parents to advocate for better supports. Further research to understand the causal pathway between high need funding and suspension, to assess whether high need funding reduces suspension among non-autistic students, and to determine if high need education-based funding is associated with reduction in ethnic disparities in suspension remain important lines of enquiry.

5.6.3 Conclusions

High suspension rates amongst autistic students compared to their non-autistic peers highlight challenges in providing inclusive education for all, regardless of disability status. This study demonstrated that high need funding is associated with reduced suspension among autistic students suggesting that expanded and more targeted supports could ensure a more inclusive education.

6 Criminal justice system interactions among young adults with and without autism: a national birth cohort study in New Zealand

6.1 Preface

This chapter contains an original manuscript, 'Criminal justice system interactions among young adults with and without autism: a national birth cohort study in New Zealand'. It was published in *Autism* in 2021; 13623613211065541. Doi: 10.1177/13623613211065541.

There remains an unresolved debate regarding the relative rates of CJS interactions of young autistic people compared to the general population. Furthermore, studies typically examine small samples and tend to look only at discrete aspects of the CJS and not the pathway through it.

The objectives of this paper were to explore interactions with the CJS of young autistic adults at multiple touch points including with police, courts (charges and convictions), and prison, compared to the general population. To further understand these interactions, the study also examined the specific offence types of those charged in court.

6.2 Criminal justice system interactions among young adults with and without autism: a national birth cohort study in New Zealand

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Statement of contribution

The concept for this study was conceived by Bowden, Milne, Audas, Clasby, Dacombe, Forster, Gibb, Hughes, Taylor, and Mirfin-Veitch. Ethical approval was sought by Bowden.

Bowden and MacCormick conducted data analysis. Bowden wrote the first draft of the manuscript. All authors subsequently helped revise the manuscript to its final version.

Abstract

While sensationalist headlines and highly publicised criminal cases have led many to believe there is a link between autism and criminal behaviour, extant literature presents an unresolved debate. We sought to address this issue by examining the prevalence of CJS interactions among young adults with and without autism, and by assessing whether offence types differ between these groups. This was a national birth cohort study using linked health and CJS data. Cox proportional hazard models were employed to compare CJS interactions between young adults with and without autism, controlling for important sociodemographic characteristics. Data were acquired for 1,197 people with autism and 147,879 without autism. Young adults with autism had significantly lower rates of being proceeded against by police, charged in court, and convicted in court compared to those without autism. However, those charged with an offence were significantly more likely to be charged with serious and violent offences, offences against the person, and against property. Our findings indicate that, although young people with autism were not over-represented in the CJS, disparities in offence types and incarceration rates among those charged with an offence suggest the importance of identification and appropriate response to autism within the CJS.

6.3 Background

Sensationalist headlines and highly publicised criminal cases lead many in the public to believe that people with autism are more likely to engage in criminal behaviour (Allen et al., 2008; Howlin, 1997; Howlin et al., 2004). However, contemporary literature is sparse and conflicted, with debate about whether people with autism[16] are over or under represented in the CJS (Cashin & Newman, 2009; Howlin et al., 2004; King & Murphy, 2014; Mouridsen, 2012; O'Brien, 2002).

The research literature examining whether individuals with autism are likely to commit criminal actions centres on the ways in which perceived behavioural traits associated with autism may impact offending behaviour. Some suggest that people with autism are less likely to offend because they tend to strictly adhere to rules (King & Murphy, 2014). Others suggest social naivety, disruption to routines, sensory processing overload, and special interests, may be factors that increase the risk of offending behaviour (Howlin et al., 2004).

Research on autism and the CJS can be grouped into two main types of studies: prevalence of autism in the CJS; and prevalence of CJS interactions among populations of individuals with autism (King & Murphy, 2014; Railey et al., 2020). Existing prevalence studies on autism and the CJS are characterised by methodological shortcomings: highly specialised (biased) samples, poor methods of identifying autism, and absence of controls for confounding factors (Ali, 2018; King & Murphy, 2014). King and Murphy (2014) claim that this makes direct

[16] The terms person with autism and autistic person are used interchangeably in this paper. The authors recognise that identity-first language (eg. autistic person) is preferred by some individuals, but also note that Autism New Zealand advises that: *"...there is no single term preferred by all people on the autism spectrum and other stakeholders to refer to autism/takiwātanga. Many people (particularly adults) in the autism/takiwātanga community prefer to use identity-first language to refer to themselves as being autistic. Some prefer to describe themselves as being on the autism spectrum, or as having autism. Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder."*

comparisons among these studies difficult, but more importantly brings into question the robustness of findings. In spite of this, the conclusions drawn from these studies, that people with autism are over represented in CJS populations, has shaped some of the early narratives in this area (Hare et al., 1999; Kumagami & Matsuura, 2009; Robinson et al., 2012; Scragg & Shah, 1994).

Studies on the prevalence of CJS interactions among people with autism also tend to be characterised by methodological limitations such as biased samples and poorly-matched comparison groups (King & Murphy, 2014). In addition, the definition of offending varies, ranging from convictions (Hippler et al., 2010) to self-reported criminal activities (Woodbury-Smith et al., 2006), making comparisons difficult. For these reasons, reported rates of 'offending behaviour' vary dramatically among autism populations, from 2.74 percent (Hippler et al., 2010) to 48 percent for self-reported criminal behaviour (Woodbury-Smith et al., 2006). However, of the studies reviewed by King & Murphy (2014) that employed control groups and were thus deemed to constitute the best quality evidence available, all found that people with autism had equal or lower rates of CJS interactions than those without autism (Brookman-Frazee et al., 2009; Cheely et al., 2012; Hippler et al., 2010; Mouridsen, Rich, et al., 2008; Woodbury-Smith et al., 2006).

Crimes against people have historically been most studied in relation to autism although there is a paucity of contemporary empirical research. Early research utilised case study methodology to highlight a link between violent crime and autism (Baron-Cohen, 1988; Simblett & Wilson, 1993), but this notion has been challenged by more recent and robust research (Helverschou et al., 2015; Mouridsen, Rich, et al., 2008). With respect to sexual offending, studies have shown that among those who have committed a crime, sexual offences

are more common among people with autism, but they are still less likely to commit sexual offences than people without autism (Dein & Woodbury-Smith, 2010; Kawakami et al., 2012). Subsequently, Cheely et al. (2012) found that youth with autism, when they did offend, were more likely to commit offences against people (e.g., assault) than property (e.g., arson), compared to those without autism.

As evidenced above, there remains an unresolved debate in existing literature as to whether people with autism are at higher risk of involvement with the CJS, and if predispositions to certain offence types exist. Furthermore, the majority of existing literature tends to focus on one or more discrete aspects of the CJS, not the pathway through it (i.e., from police proceedings through to convictions and sentencing). It is therefore evident, and widely recommended, that more robust research in this area is required to better understand the prevalence and nature of CJS interactions among individuals with autism, and to examine the respective pathways through the CJS (Ali, 2018; King & Murphy, 2014; Lambie, 2020).

Under international law, all signatory states to the UNCRPD have a number of legal obligations to disabled people, and therefore people with autism, including:

i. ensuring equal recognition before the law
ii. providing for effective access to justice
iii. protecting the liberty of the person
iv. and collecting data to demonstrate it is meeting its obligations (UNCRPD articles 12, 13, 14, and 31).

We argue that a methodology to support robust data collection is the key to meeting all these obligations. This need has been recognised by the Aotearoa/New Zealand government when it acknowledged its reliance on international prevalence data to inform local practice due to the

current gap in data (Office for Disability Issues, 2019). This issue has been further acknowledged in Aotearoa/New Zealand through the funding of the present study, which is in turn part of a wider research project designed to contribute to the development of an evidence base relating to young people with neurodevelopmental impairments in the CJS. This project utilises New Zealand's world leading IDI, a large whole-of-population research database containing linked data across multiple government agencies and national surveys. It therefore has the potential to assist Aotearoa/New Zealand and other countries by contributing previously unknown information about the prevalence of CJS interactions experienced by this diverse group of young people.

The objectives of this study were to:

1) explore the utility of utilising linked administrative data to develop an evidence base relating to CJS interactions among young people with autism.
2) report the prevalence of CJS interactions and examine pathways through the system among young people with autism compared to those without autism.
3) assess whether offence types differ for young people with autism and without autism.

6.4 Methods

6.4.1 Study design and data source

This was a national birth cohort study, utilising linked administrative data contained within the IDI. The IDI is a large, whole-of-population research database containing administrative and survey data[17], linked at the individual level[18], and managed by Statistics New Zealand (Milne

[17] For more details about the data contained within the IDI see https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure#data-in-idi
[18] For more details on data linking within the IDI see https://vhin.co.nz/guides/understanding-linkage-in-the-idi/

et al., 2019; Statistics New Zealand, 2017b). It includes data from government departments including health, education, and the CJS, and survey data such as the New Zealand census. IDI data can be accessed only by researchers who are approved by Statistics New Zealand to do research which has been deemed to be for the public good. All data in the IDI have been de-identified. Clearance for access to data was approved by Statistics New Zealand. The study was reviewed as a 'Minimal Risk Health Research – Audit and Audit related studies' proposal and received ethics approval (Reference: HD17/004).

6.4.2 Participant population

The participants comprised a three-year birth cohort, born in Aotearoa/New Zealand between July 1, 1992 and June 30, 1995. This cohort was chosen to maximise the sample size, while at the same time allowing for a follow up period for the majority of the cohort until 25 years of age due to the time coverage of available IDI data. The cohort was identified using birth record data from the Department of Internal Affairs.

The period of interest for CJS interactions for this cohort was from the participant's 17th birthday until their 25th birthday. The rationale for this period is that young people in Aotearoa/New Zealand are subject to the Adult Court from age 17 and are generally accepted to be young adults within the CJS until they are 25. Individuals who, prior to their 17th birthday, spent more than two years outside of Aotearoa/New Zealand or died, were also excluded. The overseas stay exclusion was imposed to ensure each member of the cohort interacted with the Aotearoa/New Zealand health system for approximately the same period of time, and hence had equal chances of being identified with autism.

6.4.3 Primary measures

6.4.3.1 Autism

Autism status was determined using an novel IDI-based case identification method (Bowden, Thabrew, Kokaua, Audas, et al., 2020). This method draws on diagnosis information contained within three health datasets: publicly funded hospital discharge data, NMDS; publicly funded secondary specialist mental health service use data, PRIMHD formerly MHINC; and the Ministry of Health's DSS dataset, Socrates. An individual was considered to have autism if at least one diagnosis code for autism was identified in any of the three datasets from birth until the end of the event window. Diagnosis codes included: DSM-4 codes for autistic disorder (299.00), childhood disintegrative disorder (299.10), and Asperger's disorder/pervasive development disorder NOS (299.80) within PRIMHD; ICD-10-AM codes for autistic disorder (F84.0), atypical autism (F84.1), other childhood disintegrative disorder (F84.3), Asperger's syndrome (F84.5) other pervasive developmental disorders (F84.8), and pervasive developmental disorder, unspecified (F84.9) within PRIMHD or NMDS; and assigned diagnosis codes of ASD (1211), Asperger's syndrome (1206) and other ASD (1207) within Socrates. The time coverage of these datasets varies. NMDS was available from birth for the cohort, MHINC/PRIMHD from 1 July, 2001, and Socrates from 1 Jan, 2008. Autism was considered to be a lifetime condition and therefore the covariate in the model was not considered time varying.

6.4.3.2 Criminal justice system interactions

Four CJS interactions were utilised in this study: police proceedings (legal actions initiated by the New Zealand Police against an alleged offender for an offence) drawn from the New Zealand Police Recorded Crime Offenders data; court charges and court convictions drawn from Ministry of Justice courts data; and incarcerations drawn from Department of Corrections

data. These interactions were observed over the eight-year event window starting at the time of participants 17th birthday through to their 25th birthday[19]. Each CJS interaction was constructed as a dichotomous variable, where '1' indicated any interaction, and '0' no interaction, with the corresponding date of interactions also extracted.

6.4.3.3 Total charges

Total charges were counted as the number of distinct sets of charges laid against participants over the event window. If multiple offences were recorded on the same day, these were combined, and thus contributed one offence to the total.

6.4.3.4 Offence types

The seriousness of charges was examined using a dichotomous indicator reflecting offences punishable by imprisonment of two years or more. This indicator was derived from a categorisation defined in the Criminal Procedure Act 2011[20].

To examine specific offence types, the third edition of the ANZSOC[21] was employed. ANZSOC is a three-level hierarchical framework (divisions, sub-divisions, and groups) that provides a uniform system for classifying criminal behaviour and is used in Australia and Aotearoa/New Zealand (refer to Table 12 for details). Dichotomous indicators for aggregate offence types were created and examined separately: offences against people (ANZSOC divisions 1-6), offences against property (ANZSOC divisions 6-9, and 12), offences against organisations, government and community (ANZSOC divisions 10-11, and 13-16), and violent

[19] The December 2019 refresh of the IDI contains justice data across all three domains until June 2019. Hence for those born after June 30, 1994, the event window is censored to some degree due to availability of data.
[20] See Section 6 of the Act for more details www.legislation.govt.nz/act/public/2011/0081/latest/DLM3360039.html
[21] See www https://www.abs.gov.au/ausstats/abs@.nsf/mf/1234.0 for more details.

offences (ANZSOC divisions: 2 and 3; ANZSOC subdivisions: murder, attempted murder, abduction and kidnapping, deprivation of liberty/false imprisonment, robbery; and the ANZSOC group manslaughter [does not include driving causing death]). ANZSOC divisions were examined separately, but due to small numbers results are not presented here.

Table 12: Australian and New Zealand Standard Offence Classification (ANZSOC) Divisions

Division	Description
1	Homicide and related offences
2	Acts intended to cause injury
3	Sexual assault and related offences
4	Dangerous or negligent acts endangering persons
5	Abduction, harassment and other offences against the person
6	Robbery, extortion and related offences
7	Unlawful entry with intent/burglary, break and enter
8	Theft and related offences
9	Fraud, deception and related offences
10	Illicit drug offences
11	Prohibited and regulated weapons and explosives offences
12	Property damage and environmental pollution
13	Public order offences
14	Traffic and vehicle regulatory offences
15	Offences against government procedures, government security and government operations
16	Miscellaneous offences

6.4.4 Socio-demographic variables

Sex (male/female), age (in years), and ethnicity (major groups using the New Zealand Standard Classification 2005 V2.0.0 and the total concept approach meaning individuals can identify with more than one ethnic group: European; Māori; Pacific; Asian; MELAA, and Other) were drawn from the IDI personal details table. Area deprivation (NZDep2013) and area of residence (Auckland, Wellington, rest of the North Island, Canterbury, rest of the South Island) were derived from address notification data as at 17 years of age. NZDep is a socio-economic measure of deprivation, defined at the meshblock (neighbourhood) level that an individual

resides. NZDep scores were collapsed into quintiles, 1 representing the least deprived and 5 the most.

6.4.5 Procedure

Data were accessed from the December 2019 refresh of the IDI. Data were extracted using SAS 7.1 (SAS Institute Inc., 2014) and analysed using Stata MP version 15 (StataCorp, 2017). All counts were supressed if less than 20 and randomly rounded to base 3, adhering to the confidentiality requirements of Statistics New Zealand.

6.4.6 Statistical analysis

RECORD guidelines were used to inform the reporting of analyses (Benchimol et al., 2015). The birth cohort was described descriptively by socio-demographic subgroup as at age 17 (the start of the event window) by autism status. Observed rates of CJS interactions for each of the four levels examined were also presented for those with and without autism.

To examine the association between autism and each level of CJS interactions we used Cox proportional hazards models (StataCorp, 2021). HRs for autism on different levels of CJS interactions were estimated separately in four different models with the robust variance estimator (D. Y. Lin & Wei, 1989). Participants stopped contributing to the Cox model on the date of their first CJS interaction, death, the start of a period of overseas travel that lasted greater than three consecutive months (93 days), or their 25th birthday (right censored).

To examine crime types, we undertook two additional series of Cox proportional hazards models, replicating the above analysis but for specific offence types:

1. for the whole participant population

2. for the sub-set of the participant population who were charged with one or more offences.

Finally, to examine total charges, we employed a modified Cox proportional hazard model for multiple failure data using the Andersen-Gill method (Andersen & Gill, 1982). This method assumes that all failure types are equal, meaning that each subject enters at time 0, the time of last failure.

We reported crude and multivariable adjusted HRs and 95% CIs for all analyses. Adjusted models included sex, age, ethnicity, NZDep2013, and area of residence. Two-tailed tests at the 5% level defined significance.

6.4.7 Community involvement

Engagement with the autistic community and co-production of knowledge is important to our research. One of the co-authors of this study is an autistic adult, a well-respected representative of the autism community with a long history of community involvement. This co-author contributed to the study design and provided feedback on manuscript drafts to help ensure its contents, including the interpretation of results would be acceptable to the autistic community.

6.5 Results

6.5.1 Participant population

The full birth cohort contained 175,170 children. However, the final sample included 149,076 after excluding those who spent two or more years overseas or died prior to their seventeenth birthday (Figure 7). The final sample included 1,197 (0.8%) young people with autism and 147,879 (99.2%) without. Their socio-demographic patterns are displayed in Table 13.

Figure 7: Participation flow chart

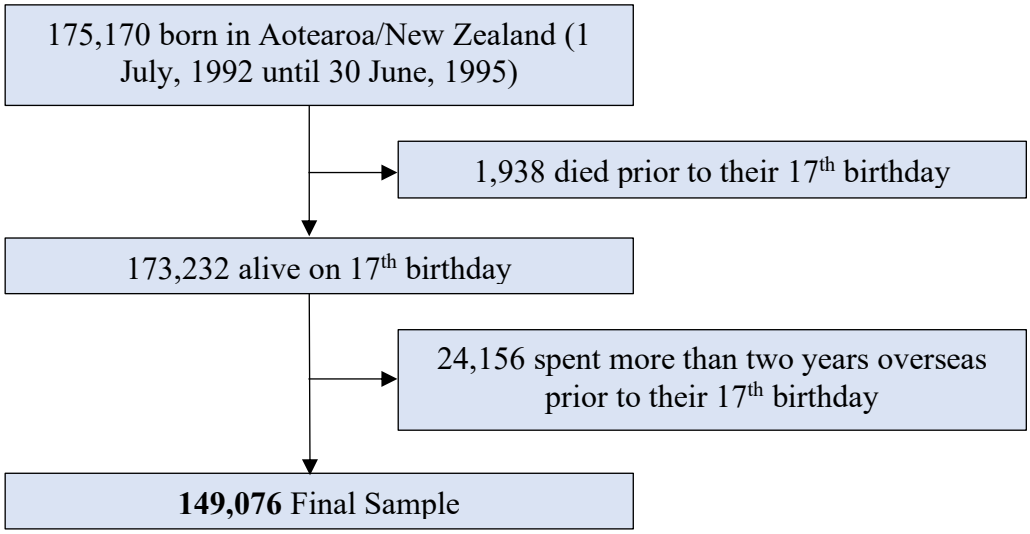

Table 13: Sociodemographic characteristics of the 1,197 young people with autism and the 146,863 without autism at baseline (age 17)

	Autism	**Without autism**
Sex	**n (%)**	**n (%)**
Male	945 (78.9%)	75,795 (51.6%)
Female	252 (21.1%)	72,084 (49.1%)
Ethnicity[a]		
European	1,080 (90.2%)	113,616 (77.4%)
Māori	240 (20.1%)	43,902 (29.9%)
Pasifika	60 (5.0%)	16,794 (11.4%)
Asian	54 (4.5%)	6,834 (4.7%)
MELAA[b]	12 (1.0%)	1,425 (1.0%)
Other	6 (0.5%)	1,110 (0.8%)
Socioeconomic Deprivation[c]		
Quintile 1 (least deprived)	231 (19.3%)	28,845 (19.6%)
Quintile 2	243 (20.3%)	26,820 (18.3%)
Quintile 3	228 (19.0%)	26,322 (17.9%)
Quintile 4	255 (21.3%)	27,501 (18.7%)
Quintile 5 (most deprived)	231 (19.3%)	35,196 (24.0%)
Region[d]		
Auckland	360 (30.1%)	41,664 (28.4%)
Wellington	138 (11.5%)	15,459 (10.5%)
Rest of N. Island	381 (31.8%)	54,888 (37.4%)
Canterbury	153 (12.8%)	17,832 (12.1%)
Rest of S. Island	168 (14.0%)	16,455 (11.2%)

a Percentages sum to greater than 100% as individuals can identify with multiple ethnic groups
b Middle Eastern, Latin American, African.
c Values missing for 9 young people (0.8%) with autism and 3,195 (2.2%) without autism.
d Values missing for <6 young people (<0.5%) with autism and 1,578 (1.1%) without autism.
..S indicates data were suppressed due to unrounded counts of <6.

The autism cohort comprised 78.9% who were male compared to 51.6% in the comparison (non-autistic) group. The vast majority of the autism cohort were identified as European (90.2%), comparatively more than in the non-autistic group (77.4%), while in contrast only 20.1% of people with autism were identified as Māori and 5.0% as Pasifika, compared to 29.9% and 11.4% respectively in the comparison group. The distributions across deprivation quintiles and region were relatively similar in each group, however, among the most deprived group, there were substantively fewer young people with autism compared to the general population.

6.5.2 Criminal justice system interactions

Overall, crude analyses indicated 282 young people with autism were proceeded against by police during the eight-year event window, yielding a prevalence of 23.6% (Table 14). Court charges were laid against 16.8% of those with autism, 12.8% were convicted in court, and 2.0% were sentenced to prison. In comparison, observed rates of police proceedings (28.9%), court charges (21.4%), and court convictions (17.2%) were consistently higher for those without autism, while incarceration rates were marginally lower (1.7%).

In unadjusted time-to-event models, young people with autism had significantly lower hazards of police proceedings, court charges, and court convictions than young people without autism (Table 15). After adjusting for sociodemographic differences (sex, ethnicity, deprivation, and area of residence), the associations amplified to the extent that young people with autism had a 37.6% lower hazard of being proceeded against by police, 39.2% lower hazard of a court charge, and a 43.1% lower hazard of a court conviction. In contrast, in both unadjusted and adjusted models, the hazards of incarceration were not statistically significant ($p=0.736$ and $p=0.968$ respectively).

Table 14: Rates of criminal justice system interactions of the 1,197 young people with autism and the 146,853 young people without autism

	Autism	Without autism
Proceeded against by police	**n (%)**	**n (%)**
No	915 (76.4%)	105,426 (71.8%)
Yes	282 (23.6%)	42,450 (28.9%)
Court charge		
No	999 (83.5%)	116,439 (79.3%)
Yes	201 (16.8%)	31,437 (21.4%)
Court conviction		
No	1,044 (87.2%)	122,589 (83.5%)
Yes	153 (12.8%)	25,287 (17.2%)
Incarceration		
No	1,173 (98.0%)	145,377 (99.0%)
Yes	24 (2.0%)	2,502 (1.7%)

Table 15: Unadjusted and adjusted time-to-event hazard ratios (HR) estimates, together with 95% CI, of criminal justice system interactions for autism

	n	Unadjusted HR (95% CI)	Adjusted* HR (95% CI)
Overall			
Proceeded against by police	282	0.738 (0.656, 0.830)	0.624 (0.555, 0.702)
Court charge	201	0.708 (0.616, 0.815)	0.608 (0.528, 0.699)
Court conviction	153	0.662 (0.563, 0.777)	0.569 (0.484, 0.668)
Incarceration	24	1.071 (0.717, 1.602)	1.008 (0.674, 1.508)

* Adjusted for gender, ethnicity, deprivation, and area of residence.

6.5.3 Number and type of offences

Among the full cohort, the total number of charges for young people with autism during the event window was slightly fewer compared to those without autism (0.89 on average per person vs. 0.95) (Table 16). In general, young people with autism had similar crude charge rates (whether or not they had a charge as a percentage of the population) compared to young people without autism. They had marginally higher crude rates of charges for serious offences (9.0% compared to 8.1%), violent offences (7.3% compared to 5.8%), and offences against property (9.8% compared to 8.5%), but marginally lower rates of offences against the person (10.3% compared to 10.6%) and offences against organisations, government and community (11.0% compared to 16.6%). In contrast, among the those who were charged with at least one offence,

young people with autism were charged with more offences in total (5.30 on average per person over the eight-year window) compared to those without autism (4.48) and had markedly higher crude rates of all offence categories except offences against organisations, government and community.

Adjusted time-to-event count models indicated that, among the full cohort, the autism group had a significantly lower hazard for court charges. Time-to-event models also indicated significantly lower hazards for offences against the person as well as offences against organisations, government and community. No statistical difference in hazards was found for serious offences (p-value 0.342), violent offences (p-value 0.626), and offences against property (p-value 0.715). In contrast, for those with at least one court charge, time-to-event count models indicated young people with autism had a significantly higher hazard for the number of court charges. Significantly higher hazards were also found for serious offences, offences against the person, violent offences, and offences against property. In contrast, results showed significantly lower hazards among the autism group for offences against organisations, government and community.

Table 16: Rates of offence types by autism status, together with unadjusted and adjusted time-to-event hazard ratios (HR) estimates for the full birth cohort and those with at least one charge

Offence Type	Autism N=1,197 Mean (sd)	Without autism N=146,853 Mean (sd)	Unadj. HR (95% CI)	Adj*. HR (95% CI)
Full participant population				
Total # charges	0.89 (3.53)	0.95 (3.59)	0.86 (0.69, 1.08)	0.76 (0.61, 0.96)
	n (%)	**n (%)**		
Serious offences	108 (9.0)	11,922 (8.1)	1.07 (0.88, 1.30)	0.91 (0.75, 1.11)
Offences against the person[a]	123 (10.3)	15,657 (10.6)	0.90 (0.75, 1.07)	0.72 (0.60, 0.86)
Violent offences[b]	87 (7.3)	8,649 (5.8)	1.19 (0.96, 1.46)	1.05 (0.85, 1.30)
Offences against property[c]	117 (9.8)	12,585 (8.5)	1.10 (0.92, 1.32)	0.97 (0.80, 1.16)
Offences against organisations, government and community[d]	132 (11.0)	24,513 (16.6)	0.61 (0.51, 0.72)	0.52 (0.44, 0.61)
Conditional on at least one court charge				
	Autism N=201	**Without autism N=31,266**		
	Mean (sd)	**Mean (sd)**	**Unadj. HR (95% CI)**	**Adj*. HR (95% CI)**
Total # charges	5.30 (7.25)	4.48 (6.64)	1.15 (0.95, 1.38)	1.23 (1.01, 1.47)
	n (%)	**n (%)**		
Serious offences	108 (53.7)	11,922 (38.0)	1.62 (1.33, 1.97)	1.76 (1.44, 2.14)
Offences against the person	123 (61.2)	15,657 (49.9)	1.33 (1.11, 1.58)	1.23 (1.03, 1.48)
Violent offences	87 (43.3)	8,649 (27.6)	1.74 (1.42, 2.15)	1.93 (1.57, 2.39)
Offences against property	117 (58.2)	12,585 (40.1)	1.57 (1.31, 1.88)	1.71 (1.43, 2.06)
Offences against organisations, government and community	132 (65.7)	24,513 (78.2)	0.71 (0.60, 0.84)	0.73 (0.61, 0.86)

a Includes ANZSOC divisions 1-6.

b ANZSOC divisions: 2 and 3; ANZSOC subdivisions: murder, attempted murder, abduction and kidnapping, deprivation of liberty/false imprisonment, robbery; and the ANZSOC group manslaughter [does not include driving causing death].

c Includes ANZSOC divisions 6-9, and 12.

d includes ANZSOC divisions 10-11 and 13-16.

sd = standard deviation.

* Adjusted for gender, ethnicity, deprivation, and area of residence.

6.6 Discussion

This national birth cohort study is the first to utilise linked administrative health and CJS data to examine pathways through the CJS for a national population of young adults with and without autism. After controlling for key sociodemographic characteristics, young people with autism in Aotearoa/New Zealand were found to be at lower risk of being proceeded against by police (37.6% lower), as well as being charged (40.3% lower) or convicted in court (43.6% lower), than people without autism. In contrast, the risk of being incarcerated was not significantly different between those with and without autism. These findings are consistent with previous studies examining the prevalence of CJS interactions among young people with autism (Brookman-Frazee et al., 2009; King & Murphy, 2014; Mouridsen, Rich, et al., 2008; Woodbury-Smith et al., 2006) and in stark contrast with earlier small sample studies that indicate those with autism were overrepresented in the CJS (Hare et al., 1999; Kumagami & Matsuura, 2009; Robinson et al., 2012; Scragg & Shah, 1994).

The finding that young people with autism are less likely to be proceeded against by police, even less likely to be charged in court, and less likely again to be convicted, is a positive one which challenges the stereotypes that confront people with autism. It may suggest that the Aotearoa/New Zealand CJS (inclusive of police, court officials, judges and lawyers) is being responsive to people with autism and effectively diverting them out of the system. This is consistent with the hypothesis of King and Murphy (2014), and could be the result of growing recognition and understanding of autism within the CJS and steady progress toward a more accommodating system. It also suggests positive engagement with the guidance of General Comment 24 on the implementation of the UNCRPD, which asserts that: ‘Children with developmental delays or neurodevelopmental disorders or disabilities… should not be in the child justice system at all’ (United Nations Committee on the Rights of the Child, 2019).

The time period of the present study overlaps with an increasing awareness of the impact of neurodevelopmental impairment and neurodiversity in the youth and adult CJS in New Zealand. Over the last decade this awareness has led to advances in this space. For example, successive Principal and Senior Youth Court judges have highlighted the prevalence and impact of neurodiversity among young offenders and have advocated for more responsive practice in the Youth Court (Peirse-O'Byrne, 2014). This has resulted in a Young Adult List being piloted within the Porirua District Court designed to be responsive to individuals aged between 18 and 25, recognising that both maturation and neurodiversity impact on a young adult's trajectory through the criminal court (Walker & Doogue, 2019).

Nonetheless, a distinct feature of our findings on pathways through the CJS is that, despite the risk of involvement at the police and courts level being significantly lower among those with autism, the risk of incarceration is not. In fact, our findings show that conditional on being charged with an offence, young people with autism have higher rates of incarceration (13%) compared to those without autism (8%). This runs counter to the consideration above, that the Aotearoa/New Zealand CJS is being responsive to those with autism and warrants further research and reflection. There is a significant body of research that has considered autism in the context of sentencing with researchers such as Mayes (2003) and Freckleton (2012, 2013) asserting that autism may impact on a defendant's fitness to plead, culpability, criminal responsibility and on their ability to manage being imprisoned (Freckelton, 2012, 2013; T. A. Mayes, 2003). For example, behaviours common among autistic individuals, such as limited expressions of emotions, gaze aversion, and difficulties with discourse management, all have the potential to adversely affect sentencing (Foster & Young, 2021). In New Zealand, disability can be taken into consideration at sentencing as part of a pre-sentence report or at the request

of the offender. However, this is not explicit in the New Zealand Sentencing Act (2002) and no data are currently available on the effectiveness of this process. Given the results of this study, where young people with autism appear to be imprisoned at a similar rate to their peers without autism despite lower rates of convictions, it is timely to consider this issue in more depth. This should include consideration as to how prior diagnoses of autism and understandings of individual needs within other sectors and services should inform the CJS through data linkage.

Our exploration of offence types revealed that among young people with autism who were charged with offences, the number and type of offences differed from young people without autism. They had higher numbers of total charges, and were significantly more likely to be charged with a serious offence (offences punishable by two or more years in prison) than those without autism. We also found that among those charged with at least one offence, young people with autism were at higher risk of being charged with offences against the person, violent offences, and offences against property, and lower risk of offences against organisations, government and community. These findings build on a sparse contemporary literature of which King and Murphy (2014) concluded only two studies were methodologically robust enough to confidently draw any conclusions. We concur with Cheely et al. (2012), who found that young people with autism who were charged with an offence were significantly more likely to be charged with crimes against the person compared to those without autism. However, our findings that young people with autism who were charged with an offence were at *higher* risk of offences against property and had significantly more total offences compared to people without autism, were in contrast with other studies (Cheely et al., 2012; Kumagami & Matsuura, 2009). Importantly, the overall rate of serious offences, offences against the person, offences against property, and violent offences among young people with autism were

less than, or equal to, the non-autistic population due to the low base rate of offending in the autism group. Such variation illustrates the importance of understanding patterns of offending and pathways through the CJS for young people with autism in considering effective responses.

It is possible that variation in offence types might in part be explained by the fact that the disabling experiences of young people with autism may have more severe consequences when other people are involved. For example, people with autism are likely to be at greater risk of their behaviour being misunderstood or perceived to be socially unacceptable when they are interacting with people (as opposed to property) which may then lead to offending behaviour, specifically offences against the person, and violent offences. Furthermore, individual advocacy may be more successful when offences are of a less serious nature, or for offence types that do not directly involve another person. Society may be more understanding, for example, when autistic individuals face charges of offences against property or organisations.

Given young adults with autism who were charged with offences had more serious charges against them in comparison with young people who were not autistic, the higher incarceration rate identified may reflect and be appropriate to the type and seriousness of the charges. However, it is important to consider whether these young people had been identified as autistic before or at any stage during the formal legal proceedings. If autism is not recognised during legal proceedings, autism-related accommodations will be absent and may create serious disadvantage for the autistic young person and contribute to discriminatory practice within the court and wider legal systems. Limited or uninformed understandings of autism or a tendency to interpret court-room behaviours, such as a lack of eye contact or apparent lack of remorse, through a neurotypical lens can result in harsher penalties, including incarceration, for young people with autism (Brewer & Young, 2015).

6.6.1 Strengths and limitations

The research has a number of strengths. The most significant was the ability to construct a multi-year national birth cohort and subsequently track these individuals through to their 25th birthday. During this observation period we were able to utilise linked data to identify those with and without autism and examine interactions with the CJS at multiple touch points including police, courts, and corrections. We were also able to examine specific offence types to better understand reasons why the pathway through the CJS appears to differ for those with and without autism. Linked data also enabled us to account for early exits during the study period (i.e., immigration and death).

Our findings must also be considered in the context of several limitations. Firstly, there is a risk of misclassification bias as the study utilised an unvalidated method for identifying autism. This method is based on administrative service use data and is not intended to identify true autism prevalence. Therefore, it likely undercounts those with autism and may also result in incorrect identifications (Bowden, Thabrew, Kokaua, Audas, et al., 2020). Comparable contemporary prevalence estimates from Scotland (1.22% among young people aged 16-24) and Sweden (1.76% among young people aged 18-27) suggest the method may undercount autism prevalence by approximately 35-55% (Idring et al., 2015; Rydzewska et al., 2019). This is particularly apparent in the relatively low autism rates among Māori and Pasifika that likely reflect inequitable access to services and a lack of culturally appropriate care (Bevan-Brown, 2004; Durie, 2001; Murray, Kokaua, & Bowden, 2020; Reid & Robson, 2000). Moreover, we suspect that among this cohort the method may be biased toward capturing more complex cases of autism, to the extent that a number of these individuals might be completely disengaged with society and at very low risk of criminal activity. In this case, our findings of lower risk of CJS interactions may to some extent be explained by the characteristics of the

sample. Secondly, the analysis is restricted to associations rather than causal inference. For example, we have not examined the contributing effect of confounders such as co-occurring conditions (e.g., intellectual disability, substance abuse, and ADHD) that have been associated with increased risk of offending (M. K. Simpson & Hogg, 2001; Welte, Barnes, Hoffman, Wieczorek, & Zhang, 2005; Young et al., 2011). This is an important consideration in any attempt to attribute risk of autism specifically on CJS interactions. Lastly, while the birth cohort is representative of those born in Aotearoa/New Zealand at the time, it is not reflective of the Aotearoa/New Zealand population as a whole. Importantly, our population (by definition) excludes migrants to Aotearoa/New Zealand, who make up approximately 31% of young people aged 20-24 living in Aotearoa/New Zealand (Statistics New Zealand, 2013).

6.6.2 Further research

Other research notes the importance of protective factors such as employment, housing, family support as well as risk factors such as co-occurring conditions for CJS involvement (Helverschou et al., 2015; Kawakami et al., 2012; Rava, Shattuck, Rast, & Roux, 2017). The extent that these factors have an impact within the Aotearoa/New Zealand context is for future research. In particular, victimisation, which is evidenced to be disproportionally experienced by people with autism (Brown-Lavoie, Viecili, & Weiss, 2014; Edelson, 2009; Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005; Sevlever, Roth, & Gillis, 2013) and is in turn a known risk factor linked to subsequent offending, could be examined further utilising the IDI.

The finding of lower offending rates among the autism population could be the result of growing recognition and understanding of autism within the CJS and steady progress toward a more accommodating system that has been gaining momentum, particularly over the last

decade in New Zealand. It is important this progress continues in a way that draws on and is closely informed by the voices and lived experiences of autistic individuals in line with Critical Autism Studies approaches (Davidson & Orsini, 2013; Fletcher-Watson et al., 2019; O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow, & Orsini, 2016), and the UNCRPD. The evidence base must continue to be developed and data revisited over time, with particular emphasis placed on understanding the context which leads to the incarceration of young autistic individuals.

Additional research is also required to formally validate the method employed to identify individuals with autism (Bowden, Thabrew, Kokaua, Audas, et al., 2020). Once a suitable data source becomes available to validate against, improvements to the accuracy of the method, such as by requiring at least two autism codes for an autism identification, could be explored.

6.6.3 Conclusions

Our findings indicate that, although young people with autism were not over-represented in the CJS, disparities in offence types and incarceration rates among those charged with an offence suggest the importance of identification and appropriate response to autism within the CJS. This study has also shown that effective data linkage offers the opportunity to enable better understanding of pathways through the CJS for young adults with autism.

7 Discussion

This thesis used IDI data to conduct whole-of-population lifecourse research on autistic young people in Aotearoa/New Zealand in the domains of health, education, and the CJS. The thesis aimed to:

1. establish a method to identify cohorts of autistic young people using administrative data in Aotearoa/New Zealand and identify rates of common co-occurring mental health and related conditions
2. understand the medication usage of young autistic people compared to those with ADHD and those without either autism or ADHD
3. explore suspension rates among autistic students and the extent to which high-need funding support is associated with change in suspensions
4. explore interactions with the CJS, including with police, courts, and prison of young autistic adults compared to the general population.

These research objectives were developed to establish population-level autism research in Aotearoa/New Zealand and to fill gaps in current knowledge related to health, educational, and CJS outcomes for autistic young people.

7.1 Main findings

The main findings from the thesis were:

- Existing administrative data can be used to identify autistic individuals. Using data until 2015/16, this method identifies a cohort of 9,555 autistic children and young people (0.57% of the Aotearoa/New Zealand ERP of 0-24 year olds) (Chapter 3).

- Rates of autism detected using this method are highest among males (0.88%), those aged 5-9 (0.90%) and 10-14 years (0.86%), and Europeans (0.68%) and lowest amongst Māori (0.49%), Pasifika (0.39%), and Asians (0.45%), as well as those living in high deprivation (0.53%) and rural areas (0.46%) (Chapter 3).
- Autistic people have high rates of co-occurring mental health and related conditions with 68% affected by at least one condition, including intellectual disability (30%), emotional conditions (anxiety and/or depression) (28%), and ADHD (27%) (Chapter 3).
- Autistic people face a high medication burden. In a one-year period, 57% experienced polypharmacy of three or more medications (36% higher than non-autistic people), and 11% experienced extreme polypharmacy of 10 of more medications (over twice that of non-autistic people) (Chapter 4).
- Autistic students experience nearly three times the odds of suspension from school than non-autistic students (adjusted OR 2.81; 95% CI 2.55-3.11) (Chapter 5).
- High need education-based funding support (ORS) is associated with a significant reduction in suspension among autistic students (adjusted OR 0.29; 95% CI 0.21-0.40). This means that those with ORS funding experience suspension at approximately the same rate as their non-autistic peers (Chapter 5).
- Young autistic adults are less likely to have CJS contact than their non-autistic peers in terms of police proceedings (adjusted HR 0.62; 95% CI 0.56-0.70), court charges (adjusted HR 0.61; 95% CI 0.53-0.70), and court convictions (adjusted HR 0.57; 95% CI 0.48-0.67) (Chapter 6).
- If charged with a crime, however, autistic people tend to be charged with more serious offences (adjusted HR 1.73; 95% CI 1.44-2.14) (Chapter 6).

The findings highlight a range of challenges faced by autistic people over the lifecourse. They also illustrate the effectiveness of supports, planning, and advocacy. Moreover, the findings demonstrate the usefulness of the IDI as a data source for autism research but raise issues around data collection to better report on and monitor inequities.

The case identification method used to identify autism is novel and developed for the purposes of this research. It enables identification of autistic individuals using linked, population-level administrative data in the IDI for the first time in Aotearoa/New Zealand. Lower rates of autism identified using this method compared to international prevalence estimates (Baio et al., 2018) and variation by population sub-group (e.g., lower rates among Māori, Pasifika, those living in areas of high deprivation, and those living in rural settings) underscore challenges associated with obtaining an autism diagnosis in Aotearoa/New Zealand (Eggleston et al., 2019; Thabrew & Eggleston, 2018). Differential under count of autism by population sub-group (e.g., lower rates among older age groups) may also reflect barriers to DSS access. Rates of co-occurring conditions identified among autistic young people generally align with extant literature (Leyfer et al., 2006; Mattila et al., 2010; Salazar et al., 2015; Simonoff et al., 2008; Van Steensel et al., 2013; Virues-Ortega et al., 2017) and highlight the complexity of autism that extends beyond an autism diagnosis alone.

Examination of medication dispensing demonstrates the significant medication burden young autistic people experience, consistent with, but at the upper end of, extant literature (Esbensen et al., 2009; Logan et al., 2012; Oswald & Sonenklar, 2007). (Esbensen et al., 2009; Logan et al., 2012; Oswald & Sonenklar, 2007). In the absence of indication information on medication prescribing, making assessments about pharmaceutical dispensing and in particular the appropriateness of polypharmacy is challenging and data should be interpreted with caution.

These levels of medication use may be the result of disproportionally high rates of co-occurring psychiatric and physical health conditions that autistic young people experience and may reflect appropriate treatment (Al-Beltagi, 2021; American Psychiatric Association, 2013a; Isaksen et al., 2013; Lugo-Marin et al., 2019; Matson & Shoemaker, 2009; Simonoff et al., 2008). However, in the absence of clear guidelines for the use of pharmacotherapies for young autistic people (Thabrew et al., 2020), and the greater risk of adverse drug reactions and drug-drug interactions associated with polypharmacy (Baker et al., 2019), the high levels of medication use are concerning.

The analysis of school suspension rates reveals that autistic students are at greater risk of suspension compared to non-autistic students. This result aligns with recent findings in relation to suspension, but also with other challenges faced by autistic students within education such as higher rates of bullying, lower attainment levels, and low rates of tertiary enrolment (Krezmien et al., 2017; Montes & Halterman, 2006; Munkhaugen et al., 2017). However, the study demonstrates this risk can be attenuated by specialised high need funding, to the extent that suspension rates among autistic students with such funding are approximately the same as non-autistic students. This highlights the benefits of comprehensive and targeted support for autistic students and aligns with existing evidence that has demonstrated support within and beyond education improves quality of life and well-being (Macmillan et al., 2021; Whitehouse et al., 2021).

The analysis of CJS interactions finds that young autistic adults have significantly lower rates of being proceeded against by police, charged in court, and convicted in court, compared to non-autistic young people. These findings help to dispel the myth that autistic people are more likely to offend. They are in contrast to earlier studies based on small and non-random samples

(e.g., forensic populations) (Hare et al., 1999; Kumagami & Matsuura, 2009; Robinson et al., 2012; Scragg & Shah, 1994), but support the findings of more recent and methodologically robust research that utilises large unbiased samples (Brookman-Frazee et al., 2009; Cheely et al., 2012; Hippler et al., 2010; Mouridsen, Rich, et al., 2008; Woodbury-Smith et al., 2006). An interpretation of the findings is that advocacy and a more accommodating CJS that recognises and understands autism are appropriately working to divert young autistic people out of the system. In contrast, an examination of offence types reveals that, among those charged with an offence, autistic people are more likely to be charged with serious offences (punishable by two or more years in prison), indicating there may be a threshold for understanding and that discrimination persists.

7.2 Implications

Relatively low rates of autism identification highlight challenges and inequities associated with obtaining an autism diagnosis. Given there is a large body of literature that reports the immediate and long-term benefits of early support for autistic individuals and their families (Whitehouse et al., 2021), and that support is typically contingent on receiving a diagnosis, it is crucial that a timely and equitable diagnostic process exists. If these supports are not provided in a timely manner, autistic children are at risk of a range of academic, social, and behavioural difficulties (Lang, Regester, Rispoli, et al., 2010; Lang et al., 2013; Watkins et al., 2015). These in turn can result in long-term deleterious effects on their social inclusion, employment, adaptive functioning, and overall quality of life (Fuller & Kaiser, 2020; Rogers & Vismara, 2008; Whitehouse et al., 2021). As discussed by Eggleston et al. (2019), streamlining referral pathways and assessment processes to reduce wait times and minimise delays in the diagnostic process, and improving access to multidisciplinary assessment are required (Eggleston et al., 2019). Moreover, effective implementation of recommendations

included in the Aotearoa New Zealand Autism Guideline will improve early identification and facilitate early diagnosis (Whaikaha - Ministry of Disabled People and Ministry of Education, 2022). These include comprehensive developmental surveillance and monitoring of developmental milestones at all Well Child visits, eliciting and valuing parental concerns regarding child development, and improving timely access to diagnostic services.

Lower rates of autism identification among groups who already experience differential access to the social determinants of health (e.g., Māori, Pacific, and those living in high deprivation) reflect a general pattern in Aotearoa/New Zealand whereby health systems do not provide accessible or appropriate healthcare, thus perpetuating and exacerbating, existing inequities (Statistics New Zealand and Ministry of Pacific Island Affairs, 2011; Waitangi Tribunal, 2019). While disparities in autism prevalence rates by sociodemographic sub-group are not uncommon, temporal evidence from the USA (e.g., converging rates of autism by ethnic groups over time) indicates that these are unlikely to reflect true ethnic based differences in prevalence (Yuan, Li, & Lu, 2021) and more likely reflect other factors such as access to diagnostic services, racism, and different cultural values (Maenner et al., 2021; Ruhe et al., 2022; Yuan et al., 2021). This is consistent with experiences of Māori, where inequities are a long-term consequence of a history of colonisation and institutional racism that have negatively impacted on health and well-being (Waitangi Tribunal, 2019). For Māori, diagnosis and access to autism supports and services are desired (Bevan-Brown, 2004). Therefore, inequities in diagnosis could be reduced by providing and improving access to culturally appropriate and responsive diagnostic services (Bevan-Brown, 2004). Likewise, for other groups, appropriate diagnostic services should be provided to ensure all young people and their families, regardless of their ethnic and socioeconomic background, receive the care and support they require. In accordance with the Aotearoa New Zealand Autism Guideline, this requires improving the cultural

competency of the existing health workforce, targeted recruitment and strategies to increase ethnic-specific autism-related workforces, as well as ensuring diagnosticians are aware of the potential for bias based on ethnicity that can lead to delayed- and mis-diagnosis (Whaikaha - Ministry of Disabled People and Ministry of Education, 2022).

The thesis findings also highlight the issue of ableism (Linton, 1998), the active discrimination and social prejudice against people with disabilities (including autism), and related policy implications. Ableist assumptions and actions reinforce prejudices against disability. For example, removing autistic students from school and subjecting them to the CJS punishes them for their disability and can further exacerbate existing inequities in health, education, and the labour market (Hehir, 2002). The thesis demonstrates the value of education-based funding and the findings could be used by parents, whānau, teachers, and schools to advocate for increased and better supports. They could also be used to justify an increase in the ORS funding allocation, which currently supports only 1.2% of the student population, as well as more broadly for other education based supports such as early interventions services, learning and behaviour resource teachers, and the Positive Behaviour for Learning programme (Ministry of Education, 2017). Prioritising strategies for students and those working with them such as implementing support plans, seeking appropriate funding supports, and providing professional development and educational opportunities to help staff and students better understand autism would help autistic students achieve their full potential (Ministry of Education, 2019). The findings in relation to autistic young people's interactions with the CJS suggest increasing awareness of the impact of autism acts to appropriately divert some out of the CJS, but this understanding seems to pertain only to less serious charges. More responsive practices, such as the Young Adult List that has been piloted within the Porirua District Court and is designed to be responsive to the impact of neurodiversity, could be expanded (Walker & Doogue, 2019).

The New Zealand Sentencing Act could be amended to explicitly permit disability (including autism) to be taken into consideration at sentencing as part of a pre-sentence report or at the request of the offender. Moreover, consideration as to how prior diagnoses of autism and understanding of individual needs within other sectors and services could inform the criminal justice practices.

The study also has implications for data collection and monitoring, including meeting obligations under the UNCRPD. Previously, there has been a void of quantitative data on autism in Aotearoa/New Zealand and no research conducted at a population level. This thesis has demonstrated that effective use of existing administrative data offers opportunities to better understand autism and meet Aotearoa/New Zealand's obligations under the UNCRPD such as Article 31, to collect appropriate information, including statistical and research data. Moreover, Chapter 5 contributes data around the right to education (Article 24) and in particular Part 2, Sections (c), (d), and (e) which pertain to ensuring accommodations and supports are provided to disabled students to facilitative effective and inclusive education. Likewise, Chapter 6 provides insights on Aotearoa/New Zealand's progress toward ensuring equal recognition before the law, providing for effective access to justice, and protecting the liberty of the person for autistic people (Articles 12, 13, and 14). In the future, these studies could be periodically repeated to monitor progress toward meeting obligations, and expanded to cover additional aspects of education, the CJS, and other areas the UNCRPD covers (e.g., health and employment).

Records of when children first receive their autism diagnosis and data from primary care are missing from centrally collected administrative data. These data would enable identification of autistic people who are not referred to, or do not apply for, DSS. The upcoming Aotearoa/New

Zealand health system reform 2022 offers an opportunity to improve our data collection, not just in relation to autism, but for health in general (Department of the Prime Minister and Cabinet, 2021). For research purposes, centrally collating these data and linking them to the IDI would enable wider capture of autism, reducing the likelihood of misclassification bias and enabling even more robust research. This could be formalised by creating an autism registry. While the number of individuals being diagnosed with autism appears to be increasing (Ministry of Health, 2021a; Ruhe et al., 2022), the exact number of autistic people in Aotearoa/New Zealand remains unknown. This makes it challenging to best support these people and their whānau, and for policy makers to plan ahead. The establishment of registry would be a significant improvement on the status quo, improving understanding of the prevalence of autism in Aotearoa/New Zealand, how to reach these individuals, and enabling better analysis of their needs to help plan for and provide services. However, formation of an autism registry would first require consultation with all key stakeholders, especially in relation to issues such as data sovereignty, the type of data that would be collected, and how data would be collected and used. Beyond health, consideration should be given to collecting autism data more broadly, such as in education and the CJS. A broader capture of data on autism would be useful for research, monitoring, and progressing meeting obligations under the UNCRPD.

7.3 Validity of the case identification method

A limitation of the autism case identification method is that it has not been validated. Therefore, the extent to which it undercounts cases of autism (false negatives), and incorrectly identifies autism (false positives) is unknown. However, existing international research examining the validity of autism diagnoses recorded in administrative data suggests they are reliable predictors of true autism diagnoses (Burke et al., 2014; Coleman et al., 2015). In other words, the positive predictive value (PPV), the proportion of those indicated as autistic who are

autistic, is high. Discussions with representatives from the health and disability sector suggest administrative data in Aotearoa/New Zealand should be no different. Consultation indicated that clinicians err on the side of caution when assigning an autism diagnosis and even when an autism diagnosis is suspected, they often prefer an initial diagnosis of 'Global Developmental Delay'. The disability support system, where the majority of autism cases are identified, requires an official autism diagnosis before support is provided. For these reasons, the case identification method probably has a high PPV, that is, individuals identified through the method are likely to be "true" autism cases.

While PPV is an important measure of diagnostic accuracy, it ignores undercount. As such, other measures such as sensitivity and negative predictive value (NPV) should also be considered when evaluating the accuracy of the autism case identification method (Bickford et al., 2020). It is speculated that the undercount of autism using the case identification method could be in the order of 40% based on international autism prevalence estimates (Baio et al., 2018; Bowden, Thabrew, Kokaua, Audas, et al., 2020). Moreover, given the observed differences in rates of autism identified by population sub-group, selection bias may be a concern. More specifically, it is possible that the complexity of cases captured by the method varies by population sub-group. For example, autistic Pasifika are less likely to be identified using the method, and those who are might be those requiring higher levels of support. While validation of the method would provide some insights into this issue, parallel work is underway to better understand the extent of selection bias issues within certain population sub-groups (K. Smiler and J. Kokaua, personal communication, 2020). More specifically, work to examine relative rates of co-occurring intellectual disability and ORS funding (as proxies for autism with high support needs) and Asperger's syndrome (as a proxy for autism with low support needs) between Pasifika and non-Māori/non-Pasifika autistic young people is ongoing (J.

Kokaua, personal communication, 2020). In the meantime, this limitation needs to be made explicit when using the method, and particular care should be taken in the interpretation of results if the method is used to undertake sub-population analysis.

A challenge regarding validation is that there is no dataset in Aotearoa/New Zealand, either within or outside of the IDI, that could be considered a gold standard. Two key contact points in the health system that could potentially be useful are when the initial autism diagnosis is made and when autistic people meet with DHB ASD coordinators. However, the information pertaining to these events is kept with individual health providers and DHBs and not collated into a national collection. Discussions have been undertaken concerning the possibility of a one-off extract of data from DHB ASD coordinators, which would form a snapshot of autism in Aotearoa/New Zealand, but progress on this ultimately sits with the Ministry of Health / Health New Zealand.

Alternative sources of information have been explored, including the NZHS and Growing Up in New Zealand data that both include parent-reported information about whether their child has ever received an autism diagnosis. It is possible there may be some value in validating the method against these, however parent reported data would not be considered a gold standard. In accordance with the New Zealand Autism Spectrum Disorder Guideline, diagnoses made by a multidisciplinary team, comprising two or more professionals with expertise in autism and related conditions including paediatricians, psychiatrists, psychologists, speech-language therapists, and/or occupational therapists, would be considered gold standard (Ministries of Health and Education, 2016). Therefore, the most feasible existing approach to validation may be via individual medical record review permitting access to these diagnoses. This approach is resource intensive and would require substantial funding, appropriate permissions, and ethical

review, and researchers with the expertise to undertake such a process. Furthermore, it would provide only a snapshot in time and may need to be repeated periodically to ascertain how changes within the health system or changes pertaining to autism diagnosis affect the validity of the method. With this in mind, the best way forward would be the development of centralised primary care data collection, including routine collection of neurodevelopmental diagnoses.

This limitation notwithstanding, initial applications of the method have indicated some face validity. For example, as reported in Chapter 3, the male to female ratio and relative rates of autism by ethnic group are consistent with existing studies (Bowden, Thabrew, Kokaua, Audas, et al., 2020). Furthermore, the prevalence of co-occurring intellectual disability and mental health conditions (Chapter 3) and examination of medication dispensing including polypharmacy (Chapter 4) are in line with extant literature (Bowden, Thabrew, Kokaua, & Braund, 2020). Encouragingly, as more data becomes available over time, the method identifies autism at a rate that is trending closer to international prevalence estimates. For example, among 5-11 years olds in 2018 the method identifies autism in 1.4% of children (or 1:73) (Chapter 5). In contrast, among the same age group this compares to 0.9% using 2015/16 data (Chapter 3), and reflects a substantial reduction in the level of undercount over time. The extent to which this trend will continue is unknown. Therefore, periodic updates of the application of the method will be important.

7.4 Strengths and limitations

The thesis has a number of strengths. Most notably, the ability to construct national cohorts of autistic young people via the IDI enables population and sub-population analysis and mitigates limitations associated with small samples. It also permits the analysis of rare outcomes such as school suspension and incarceration. The IDI further enables comparison of autistic

populations to the general population, or to other groups such as those with ADHD. Moreover, co-occurring conditions such as intellectual disability can be accounted for in statistical analyses. Linked health and non-health data mean that life outcomes beyond health can be examined, including in education and the CJS. The research is distinct from most international research in being able to utilise these linked data at a whole-of-population level. Linking and use of multiple datasets within the IDI also improves measurement and coverage of key sociodemographic measures such as ethnicity which draws on Census, birth, and health data (Teng, Gibb, & Sporle, 2017). Likewise, the ability to link individuals to geo-coded residential address information via multiple sources, and the coverage of matching is another major strength of the IDI (Gibb & Teng, 2017). The ability to link to mortality records as well as to immigration data means that loss to follow-up due to death or overseas travel can be accounted for. Finally, the IDI enables cost-effective research without the need for primary data collection.

The study must also be considered in the context of a number of limitations. The research uses an unvalidated case identification method where the extent of misclassification error is unknown. Moreover, the method may be biased towards the capture of more complex (higher support need) cases of autism, particularly among minority ethnic groups and older age groups. This could have variable effect on study findings. For example, autistic people with relatively high levels of support need, in particular those with co-occurring intellectual disability, might be less likely to achieve academically or obtain employment or high incomes. Furthermore, at the extreme, these individuals may be less likely to engage in society and therefore less likely to experience adverse outcomes such as disciplinary school outcomes or interactions with the CJS.

The use of administrative data for research (a purpose for which it was not originally intended) comes with challenges (Mazzali & Duca, 2015; Milne et al., 2019). For example, only those who access services are captured in the data, meaning selection bias is a concern. In addition, important confounding information may not be captured in administrative data which can bias results.

The use of administrative data tends to result in a deficit focus because most administrative data capture negative events (Atatoa Carr, Paine, & Prickett, 2021). This is a problem because it risks defining people based only on their adverse experiences and is particularly relevant for autistic populations who face a range of inequitable outcomes. While this thesis has explored health conditions, medication use, adverse educational outcomes, and interactions with the CJS, care has been taken to frame these in a non-deficit way. Moreover, where possible, positives have been extracted from the data, such as establishing evidence around the benefits of education support.

7.5 Future work

This thesis has taken a lifecourse approach and explored outcomes among autistic people from childhood through to adolescence and early adulthood. It has included diagnosis of autism and co-occurring conditions during childhood, educational outcomes during adolescence, and CJS interactions for young adults. There is considerable potential to extend the work beyond young adulthood and through the adult and older adult stages of the lifecourse. For example, labour market outcomes, particularly during young-to-mid adulthood, remains a key unexplored area. Obtaining and retaining employment represents a major challenge for autistic people. Social and communication differences, presence of co-occurring intellectual and psychiatric conditions, and difficulties adjusting to change have been found to hinder employment

opportunities for autistic people (Holwerda, Van Der Klink, Groothoff, & Brouwer, 2012; Howlin et al., 2004). Extant research has shown that rates of unemployment among autistic adults is extremely high and ranges from 50-75% (Hendricks, 2010; Roux et al., 2013; Shattuck et al., 2012; Toft et al., 2021). Retaining employment and underemployment (work that does not fully utilise the experience, skills, and qualifications of the worker) are also challenges for autistic people (Baldwin, Costley, & Warren, 2014; Taylor, Henninger, & Mailick, 2015; Taylor & Mailick, 2014). Understanding labour market outcomes for autistic people in Aotearoa/New Zealand would be beneficial, especially given that poor labour market outcomes are associated with poverty, poorer health, and increased reliance on social welfare and social housing. Likewise, over time, the IDI could provide a key source of information for mid to later life outcomes such as additional chronic conditions and increased risk of mortality. Moreover, the interplay between life events, e.g., the effect of poor educational outcomes on labour market outcomes, and the so-called school-to-prison pipeline, could also be examined. In time, the IDI could be used to build a picture of autism over the lifecourse to enable better understanding of the challenges of autism and identify points for intervention and support to improve quality of life.

Māori and other sub-populations (e.g., Pasifika and those living in high levels of deprivation) already face inequitable outcomes beyond health, such as in education, the labour market, and the CJS (Bishop, Berryman, Cavanagh, & Teddy, 2009; Latu & Lucas, 2008; Marriott & Sim, 2015; Ministry of Business Innovation and Employment, 2017; Theodore et al., 2018). While not a focus of this thesis, it would be reasonable to speculate that, among autistic people, these inequitable outcomes may be magnified due to the additional challenges autism imposes. If so, this takes an already disadvantaged group and adds another complication, potentially worsening outcomes. Further research is required to understand the interplay of multiple

disadvantage and the extent to which it exists among autistic young people. In particular, to honour commitments outlined in Te Tiriti o Waitangi, and in particular the principle of Oritetanga (equity), research on autistic Māori remains an important line of enquiry. As summarised in their scoping review on Māori and autism, Tupou and colleagues (2021) find that, since the seminal work of Jill Bevan-Brown, literature on Māori and autism is relatively sparse (Bevan-Brown, 2004; Tupou et al., 2021). While Māori understandings of autism and access to diagnostic and support services have received attention, the review finds significant gaps in the literature and a clear need for kaupapa Māori autism research – research by Māori, for Māori, and with Māori (Smith, 1999). Moreover, the authors call for research that is driven by Māori and from within autistic communities. Likewise, other groups, including ethnic minorities and those living in high levels of deprivation, are also worthy of attention to understand and learn the nuanced ways that each community is affected and responds to their autistic members.

It is clear that autism has an impact on the lifecourse of autistic people, but it is likely that it also impacts on the lives of those close to them, such as parents and siblings (Hastings et al., 2005). A strength of the IDI is that individuals can be linked to family members and therefore opportunities for research in this space exist. Family systems theory suggests that four subsystems comprise the family unit: marital, parental, sibling, and extended family and that these all interact and affect each other (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). Understanding the impact of autism on all subsystems of the family is important in making sure the necessary support and services are provided. Research in this area has typically focussed on parents of autistic children (Boyd, 2002; Shu & Lung, 2005; Stoner & Angell, 2006). It is well understood that having an autistic child can impact on a parent's physical and mental health, employment, and income (DeRigne, 2012; Gray, 2006; Kogan et al., 2008;

McCall & Starr, 2018; Witt et al., 2011). However, there has been little New Zealand-based research in this space (Shepherd, Landon, Goedeke, & Meads, 2021) and further population-level research would be beneficial.

Research on so called 'typically developing siblings' of autistic individuals has primarily focused on the sibling relationship, how this develops over time, and the resulting effect on social and communication development, behavioural problems, and emotional difficulties across the lifecourse (Ferraioli & Harris, 2009; Orsmond & Seltzer, 2007; Yoder, Stone, Walden, & Malesa, 2009). There is evidence that typically developing siblings may be at heightened risk of social and behavioural adjustment problems, but having an autistic sibling can also have positive effects, developing the nurturing and caring side of the sibling (Ferraioli & Harris, 2009; Orsmond & Seltzer, 2007; Yoder et al., 2009). It appears that no studies have investigated ways in which having an autistic sibling might impact outcomes in education, the labour market, and the justice system and the IDI could be utilised to explore these.

While the thesis presents descriptive analysis and focusses on associations, there is potential for related future work to explore causal relationships. Experimental designs such as randomised control trials (RCTs) are often the preferred means to determine causal pathways, however, in many instances RCTs cannot be conducted for either practical or ethical reasons (Gianicolo, Eichler, Muensterer, Strauch, & Blettner, 2020). In such circumstances, one option is to simulate experimental designs using observational data. Methods for evaluating causality using observational data include regression-discontinuity, interrupted time series, difference in differences, and instrumental variables (Angrist, Imbens, & Rubin, 1996; Gianicolo et al., 2020; Hammerton & Munafò, 2021; Lechner, 2011). For example, a difference in differences approach could be pursued to better understand the relationship between ORS funding and

suspension among autistic students by utilising the longitudinal nature of the data including before and after and individual receives funding. In the future, a regression-discontinuity approach could be pursued if the highest needs review, currently being undertaken by the Ministry of Education, results in an increase to the budget allocated to ORS funding (Wylie, 2022).

7.6 Conclusion

This collection of studies demonstrates the value of employing linked population-level administrative data to conduct lifecourse research into the experiences of autistic children and young people as they interact with health, education and criminal justice systems. The findings describe challenges and inequities experienced by autistic people in Aotearoa/New Zealand including disproportionately high rates of co-occurring physical and mental health problems, higher risk of suspension from school, and evidence of differential treatment within the criminal justice system. The study also highlights the value of effective support policies and advocacy in improving these outcomes. It changes the landscape of autism research in Aotearoa/New Zealand by demonstrating ways in which the IDI can be utilised to improve understanding of autistic people and their experiences. It also identifies further opportunities for cost-effective research such as examination of labour market outcomes for autistic people and research to understand the experiences of parents and siblings of autistic children.

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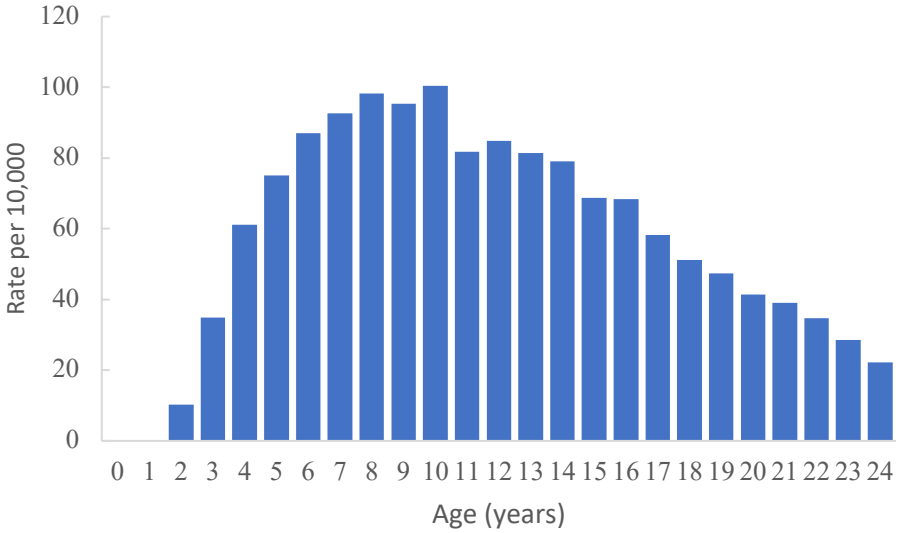
Appendices

Appendix 1

Table 17: Population denominators, 2015/16

	Total	Male	Female
Total	1,560,297		
Sex			
Male	806,382		
Female	753,915		
Age			
0-4	297,945	153,198	144,747
5-9	317,418	163,185	154,236
10-14	293,562	150,219	143,346
15-19	310,800	159,414	151,386
20-24	340,566	180,369	160,200
Ethnicity			
European	1,028,172	526,179	501,990
Māori	385,728	197,931	187,797
Pasifika	203,829	104,304	99,525
Asian	243,162	129,690	113,469
MELAA	34,638	18,399	16,239
Other	18,636	9,993	8,646
Deprivation			
Quintile 1 (least deprived)	299,271	153,573	145,695
Quintile 2	280,983	145,335	135,645
Quintile 3	284,454	146,772	137,682
Quintile 4	300,843	155,946	144,894
Quintile 5 (most deprived)	372,282	192,048	180,231
Urban/rural			
Urban	1,352,484	697,293	655,191
Rural	187,527	97,500	90,027

Figure 8: Identification rates of autism (per 10,000) by age, 2015/16



Appendix 2

Table 18: Rates of medication dispensing (per 1,000 people) for the ADHD population, 2015/16

Medication	Overall	Male	Female	0-4	5-9	10-14	15-19	20-24
Methylphenidate (ext. release) (Ps)	368	369	365	n/a	337	470	356	202
Methylphenidate (Ps)	362	369	337	n/a	608	439	209	219
Paracetamol (An)	309	294	361	n/a	460	307	255	247
Ibuprofen (An)	201	184	260	n/a	206	190	207	208
Amoxicillin (Ab)	199	186	242	n/a	294	193	174	147
Salbutamol (Ast)	147	148	143	n/a	181	160	121	133
Amoxicillin with clavulanic acid (Ab)	103	100	115	n/a	111	82	107	133
Flucloxacillin (Ab)	96	94	103	n/a	88	91	101	108
Loratadine (Ah)	93	89	107	n/a	143	104	69	58
Cetirizine (Ah)	64	58	83	n/a	78	56	68	55
Fluticasone (Ast)	63	63	65	n/a	80	78	42	47
Sodium Fusidate (Ab)	60	58	67	n/a	93	69	49	30
Fluticasone propionate (Ast)	50	48	56	n/a	43	59	43	44
Fluoxetine (Ps)	47	40	69	n/a	15	35	69	61
Risperidone (Ps)	43	48	26	n/a	60	50	32	33
Quetiapine (Ps)	41	35	62	n/a	S	16	63	105
Erythromycin ethyl succinate (Ab)	40	32	71	n/a	S	13	50	127
Codeine phosphate (An)	40	38	50	n/a	70	33	37	25
Clonidine hydrochloride (Ps)	40	40	38	n/a	75	54	20	6
Doxycycline (Ab)	40	35	56	n/a	S	16	76	66
Hydrocortisone butyrate (Cs)	38	34	52	n/a	35	39	40	36
Hydrocortisone (Cs)	35	29	58	n/a	58	39	22	25
Prednisone (Cs)	34	29	50	n/a	10	28	49	47
Phenoxymethylpenicillin (Ab)	32	29	44	n/a	33	29	35	30
Fluticasone with salmeterol (Ast)	31	30	34	n/a	38	26	27	44
Hydrocortisone with natamycin and neomycin (Cs+)	30	29	36	n/a	38	34	22	30
Chloramphenicol (Ab)	29	29	30	n/a	55	24	20	25
Atomoxetine (Ps)	29	29	30	n/a	28	34	26	28
Lactulose (Gi)	29	23	50	n/a	40	27	22	30
Trimethoprim with sulphamethoxazole (Ab)	28	25	38	n/a	50	28	19	19

Ab = antibiotic, Ah = antihistamine, Ae = antiemetic, An = analgesic, Ast = asthma, Cr = cream for dry skin, Cs = corticosteroid, Cs+ = corticosteroid plus antifungal, Gi = gastrointestinal, Ps = psychotropics.
S Data suppressed due to number of number of individuals dispensed a medication being less than 6.

Table 19: Rates of medication dispensing (per 1,000 people) for the non-autism/non-ADHD population, 2015/16

Medication	Overall	Male	Female	0-4	5-9	10-14	15-19	20-24
Paracetamol (An)	359	346	373	685	469	286	193	184
Amoxicillin (Ab)	235	224	248	408	312	198	149	124
Ibuprofen (An)	185	176	195	241	202	180	159	147
Salbutamol (Ast)	108	112	103	151	145	109	75	64
Loratadine (Ah)	96	93	100	150	141	89	58	49
Amoxicillin with clavulanic acid (Ab)	94	93	94	120	117	73	74	86
Sodium Fusidate (Ab)	68	69	67	148	93	50	31	23
Flucloxacillin (Ab)	67	67	66	56	69	75	72	62
Cetirizine (Ah)	54	51	57	58	61	55	50	46
Hydrocortisone (Cs)	52	48	57	136	57	30	22	20
Chloramphenicol (Ab)	51	52	50	143	50	28	20	19
Prednisolone (Cs)	47	53	40	133	84	21	0	0
Erythromycin ethyl succinate (Ab)	41	40	43	68	58	35	27	21
Hydrocortisone butyrate (Cs)	40	36	45	59	46	35	32	30
Fluticasone (Ast)	39	42	36	35	66	48	27	21
Trimethoprim with sulphamethoxazole (Ab)	39	35	43	86	62	25	14	10
Ethinyloestradiol with levonorgestrel (Oc)	37	0	76	S	0	4	81	91
Hydrocortisone with natamycin and neomycin (Cs+)	36	35	37	90	41	22	16	15
Hydrocortisone with miconazole (Cs+)	33	29	38	91	26	16	17	19
Cetomacrogol with glycerol (Cr)	32	30	35	83	34	20	15	13
Fluticasone propionate (Ast)	32	32	33	5	29	46	43	37
Cefalexin (Ab)	31	30	32	64	53	21	11	9
Ondansetron (Ae)	30	25	36	35	32	22	27	34
Phenoxymethylpenicillin (Ab)	30	26	34	22	32	28	39	29
Cefaclor monohydrate (Ab)	30	25	34	66	39	19	13	12
Dextrose with electrolytes (Gi)	29	30	28	109	33	7	1	1
Oil in water emulsion (Cr)	26	24	28	67	28	15	11	10
Doxycycline (Ab)	25	22	29	0	0	13	64	46
Codeine phosphate (An)	25	21	29	4	7	11	38	61
Clotrimazole (Af)	24	11	38	28	14	10	25	41

Ab = antibiotic, Ah = antihistamine, Ae = antiemetic, An = analgesic, Ast = asthma, Cr = cream for dry skin, Cs = corticosteroid, Cs+ = corticosteroid plus antifungal, Gi = gastrointestinal, Ps = psychotropics, Oc = oral contraceptive, Af = antifungal.

S Data suppressed due to number of number of individuals dispensed a medication being less than 6.

Appendix 3

Table 20: Unadjusted and adjusted odds ratios of suspension on autism status using 2-level random intercept logistic models with students nested within schools (N=731,853)

	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
Autism		
Yes	3.149 (2.855, 3.474)	2.814 (2.546, 3.110)
No	1 (reference)	
Sex		
Male	1 (reference)	
Female	0.377 (0.363, 0.392)	0.377 (0.362, 0.392)
Age (years)		
5-11	1 (reference)	
12-16	3.087 (2.890, 3.298)	3.205 (3.004, 3.419)
Ethnicity [a]		
Asian	0.313 (0.288, 0.341)	0.316 (0.289, 0.346)
EO	0.759 (0.730, 0.790)	0.747 (0.715, 0.781)
Māori	2.359 (2.272, 2.448)	1.954 (1.878, 2.034)
MELAA	0.790 (0.679, 0.920)	0.712 (0.609, 0.831)
Pasifika	1.244 (1.183, 1.308)	1.004 (0.952, 1.059)
Deprivation		
1 (least deprived)	1 (reference)	
2	1.247 (1.157, 1.343)	1.233 (1.144, 1.329)
3	1.649 (1.534, 1.772)	1.599 (1.487, 1.720)
4	2.080 (1.938, 2.233)	1.917 (1.784, 2.061)
5 (most deprived)	2.896 (2.699, 3.106)	2.417 (2.247, 2.600)
Residential location		
Urban	1 (reference)	
Rural	0.829 (0.781, 0.879)	1.024 (0.964, 1.088)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African.
* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence.
a The reference population for each ethnic group is all those who do not identify with that group.

Table 21: Unadjusted and adjusted odds ratios of suspension on high need education-based funding status using 2-level random intercept logistic models with students nested within schools (N=9,687)

	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
High need funding		
Yes	0.305 (0.225, 0.413)	0.288 (0.207, 0.401)
No	1 (reference)	
Sex		
Male	1 (reference)	
Female	0.431 (0.321, 0.578)	0.438 (0.322, 0.594)
Age (years)		
5-11	1 (reference)	
12-16	1.423 (1.151, 1.759)	1.099 (0.877, 1.376)
Ethnicity [a]		
Asian	0.437 (0.293, 0.652)	0.676 (0.421, 1.086)
EO	1.659 (1.247, 2.207)	0.914 (0.639, 1.307)
Māori	1.265 (1.024, 1.562)	1.300 (1.028, 1.645)
MELAA	0.297 (0.093, 0.952)	0.350 (0.105, 1.161)
Pasifika	0.903 (0.632, 1.289)	1.049 (0.710, 1.551)
Deprivation		
1 (least deprived)	1 (reference)	
2	0.908 (0.661, 1.248)	0.936 (0.673, 1.300)
3	1.094 (0.806, 1.486)	1.150 (0.837, 1.580)
4	1.352 (1.005, 1.819)	1.385 (1.014, 1.892)
5 (most deprived)	1.091 (0.804, 1.479)	1.202 (0.866, 1.669)
Residential location		
Urban	1 (reference)	
Rural	1.100 (0.816, 1.482)	1.099 (0.803, 1.504)
Level of disability support need		
1 (lowest needs)	0.819 (0.438, 1.530)	0.822 (0.433, 1.559)
2	0.359 (0.172, 0.748)	0.367 (0.174, 0.775)
3	1 (reference)	
4	1.564 (1.232, 1.986)	1.367 (1.067, 1.750)
5 (highest needs)	3.025 (2.227, 4.108)	2.772 (1.994, 3.852)
6 (not assessed)	1.141 (0.840, 1.551)	1.011 (0.735, 1.390)
Co-occurring conditions		
Intellectual disability	0.744 (0.586, 0.944)	0.786 (0.608, 1.016)
Behavioural	3.545 (2.915, 4.312)	2.221 (1.795, 2.747)
Emotional	2.185 (1.771, 2.694)	1.222 (0.967, 1.544)
Any (other) psychological diagnosis	3.550 (2.901, 4.344)	2.220 (1.772, 2.782)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African.
* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence, level of need, and co-occurring conditions.
a The reference population for each ethnic group is all those who do not identify with that group.

Table 22: Sensitivity analysis 1, Unadjusted and adjusted odds ratios of suspension on autism status using 2-level random intercept logistic models with students nested within schools (N=722,718) – excluding students enrolled in specialist schools

	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
Autism		
Yes	3.364 (3.036, 3.729)	2.989 (2.691, 3.321)
No	1 (reference)	
Sex		
Male	1 (reference)	
Female	0.369 (0.355, 0.385)	0.369 (0.354, 0.384)
Age (years)		
5-11	1 (reference)	
12-16	3.034 (2.837, 3.245)	3.164 (2.962, 3.380)
Ethnicity [a]		
Asian	0.314 (0.288, 0.342)	0.312 (0.284, 0.342)
EO	0.762 (0.732, 0.795)	0.735 (0.701, 0.769)
Māori	2.350 (2.261, 2.443)	1.946 (1.868, 2.028)
MELAA	0.801 (0.686, 0.936)	0.709 (0.605, 0.831)
Pasifika	1.235 (1.172, 1.301)	0.988 (0.935, 1.044)
Deprivation		
1 (least deprived)	1 (reference)	
2	1.252 (1.159, 1.352)	1.239 (1.147, 1.338)
3	1.653 (1.535, 1.781)	1.608 (1.491, 1.733)
4	2.085 (1.938, 2.244)	1.934 (1.795, 2.084)
5 (most deprived)	2.881 (2.679, 3.098)	2.422 (2.246, 2.612)
Residential location		
Urban	1 (reference)	
Rural	0.836 (0.786, 0.888)	1.026 (0.964, 1.092)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African.
* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence.
a The reference population for each ethnic group is all those who do not identify with that group.

Table 23: Sensitivity analysis 1, Unadjusted and adjusted odds ratios of suspension on high need education-based funding status using 2-level random intercept logistic models with students nested within schools (N=8,022) – excluding students enrolled in specialist schools

	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
High need funding		
Yes	0.318 (0.221, 0.456)	0.308 (0.209, 0.454)
No	1 (reference)	
Sex		
Male	1 (reference)	
Female	0.376 (0.270, 0.523)	0.387 (0.275, 0.544)
Age (years)		
5-11	1 (reference)	
12-16	1.278 (1.024, 1.594)	1.045 (0.824, 1.325)
Ethnicity [a]		
Asian	0.432 (0.282, 0.664)	0.645 (0.386, 1.078)
EO	1.549 (1.144, 2.096)	0.844 (0.574, 1.242)
Māori	1.298 (1.038, 1.623)	1.304 (1.014, 1.678)
MELAA	0.344 (0.107, 1.103)	0.413 (0.123, 1.381)
Pasifika	0.922 (0.627, 1.356)	1.026 (0.670, 1.570)
Deprivation		
1 (least deprived)	1 (reference)	
2	0.898 (0.641, 1.257)	0.923 (0.650, 1.309)
3	1.094 (0.791, 1.513)	1.125 (0.802, 1.579)
4	1.431 (1.049, 1.953)	1.442 (1.038, 2.003)
5 (most deprived)	1.206 (0.877, 1.658)	1.281 (0.906, 1.811)
Residential location		
Urban	1 (reference)	
Rural	1.027 (0.749, 1.409)	1.041 (0.745, 1.454)
Level of disability support need		
1 (lowest needs)	0.856 (0.461, 1.591)	0.880 (0.464, 1.667)
2	0.341 (0.157, 0.741)	0.355 (0.161, 0.782)
3	1 (reference)	
4	1.623 (1.267, 2.078)	1.403 (1.084, 1.816)
5 (highest needs)	3.290 (2.365, 4.576)	3.008 (2.102, 4.303)
6 (not assessed)	1.063 (0.771, 1.464)	0.962 (0.688, 1.344)
Co-occurring conditions		
Intellectual disability	0.726 (0.561, 0.941)	0.750 (0.567, 0.991)
Behavioural	3.443 (2.799, 4.235)	2.197 (1.751, 2.756)
Emotional	2.097 (1.674, 2.626)	1.258 (0.978, 1.618)
Any (other) psychological diagnosis	3.402 (2.756, 4.200)	2.125 (1.677, 2.693)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African.
* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence, level of need, and co-occurring conditions.
a The reference population for each ethnic group is all those who do not identify with that group.

Table 24: Sensitivity analysis 2, Unadjusted and adjusted odds ratios of suspension on high need education-based funding status using 2-level random intercept logistic models with students nested within schools (N=3,516) – stratifying by level of disability support need: SPA3

	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
High need funding		
Yes	0.221 (0.116, 0.419)	0.309 (0.158, 0.605)
No	1 (reference)	
Sex		
Male	1 (reference)	
Female	0.414 (0.233, 0.734)	0.426 (0.237, 0.766)
Age (years)		
5-11	1 (reference)	
12-16	1.884 (1.312, 2.707)	1.344 (0.917, 1.971)
Ethnicity [a]		
Asian	0.352 (0.169, 0.736)	0.562 (0.236, 1.335)
EO	1.765 (1.049, 2.970)	0.855 (0.441, 1.657)
Māori	1.340 (0.909, 1.976)	1.354 (0.884, 2.075)
MELAA	0.721 (0.167, 3.113)	0.794 (0.174, 3.615)
Pasifika	0.648 (0.318, 1.320)	0.812 (0.376, 1.754)
Deprivation		
1 (least deprived)	1 (reference)	
2	0.961 (0.531, 1.739)	0.980 (0.533, 1.799)
3	1.399 (0.803, 2.435)	1.524 (0.863, 2.691)
4	1.200 (0.671, 2.148)	1.293 (0.709, 2.358)
5 (most deprived)	1.532 (0.893, 2.629)	1.713 (0.960, 3.057)
Residential location		
Urban	1 (reference)	
Rural	0.965 (0.544, 1.714)	0.896 (0.491, 1.634)
Co-occurring conditions		
Intellectual disability	0.627 (0.400, 0.983)	0.706 (0.439, 1.135)
Behavioural	3.740 (2.617, 5.343)	2.456 (1.663, 3.627)
Emotional	1.970 (1.321, 2.940)	1.051 (0.675, 1.637)
Any (other) psychological diagnosis	3.466 (2.427, 4.950)	2.260 (1.522, 3.358)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African. SPA – Support Package Allocation.

* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence, level of need, and co-occurring conditions.

a The reference population for each ethnic group is all those who do not identify with that group.

Table 25: Sensitivity analysis 2, Unadjusted and adjusted odds ratios of suspension on high need education-based funding status using 2-level random intercept logistic models with students nested within schools (N=2,886) – stratifying by level of disability support need: SPA4

	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
High need funding		
Yes	0.191 (0.114, 0.319)	0.219 (0.128, 0.376)
No	1 (reference)	
Sex		
Male	1 (reference)	
Female	0.442 (0.271, 0.720)	0.517 (0.316, 0.845)
Age (years)		
5-11	1 (reference)	
12-16	1.188 (0.839, 1.683)	0.945 (0.662, 1.348)
Ethnicity [a]		
Asian	0.527 (0.259, 1.074)	0.532 (0.230, 1.229)
EO	1.403 (0.862, 2.283)	0.638 (0.344, 1.181)
Māori	1.016 (0.707, 1.459)	1.070 (0.718, 1.596)
MELAA	Omitted due to perfect prediction	
Pasifika	0.875 (0.460, 1.662)	0.854 (0.429, 1.702)
Deprivation		
1 (least deprived)	1 (reference)	
2	0.741 (0.428, 1.283)	0.740 (0.428, 1.281)
3	0.909 (0.542, 1.525)	0.972 (0.580, 1.630)
4	1.435 (0.888, 2.319)	1.549 (0.953, 2.519)
5 (most deprived)	0.687 (0.404, 1.166)	0.759 (0.438, 1.316)
Residential location		
Urban	1 (reference)	
Rural	1.031 (0.625, 1.698)	1.139 (0.686, 1.889)
Co-occurring conditions		
Intellectual disability	0.771 (0.517, 1.151)	1.055 (0.691, 1.610)
Behavioural	3.134 (2.251, 4.363)	2.078 (1.465, 2.948)
Emotional	1.753 (1.223, 2.512)	1.190 (0.808, 1.752)
Any (other) psychological diagnosis	2.399 (1.713, 3.360)	1.685 (1.171, 2.424)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African. SPA – Support Package Allocation.

* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence, level of need, and co-occurring conditions.

a The reference population for each ethnic group is all those who do not identify with that group.

Table 26: Sensitivity analysis 2, Unadjusted and adjusted odds ratios of suspension on high need education-based funding status using 2-level random intercept logistic models with students nested within schools (N=933) – stratifying by level of disability support need: SPA5

	Odds ratio (95% CI)	Adjusted* odds ratio (95% CI)
High need funding		
Yes	0.164 (0.083, 0.326)	0.220 (0.107, 0.454)
No	1 (reference)	
Sex		
Male	1 (reference)	
Female	0.246 (0.098, 0.617)	0.235 (0.094, 0.590)
Age (years)		
5-11	1 (reference)	
12-16	1.332 (0.710, 2.499)	1.070 (0.547, 2.097)
Ethnicity [a]		
Asian	0.617 (0.181, 2.099)	0.842 (0.219, 3.242)
EO	1.546 (0.635, 3.765)	0.681 (0.234, 1.981)
Māori	1.073 (0.551, 2.092)	1.024 (0.502, 2.088)
MELAA	Omitted due to perfect prediction	
Pasifika	1.725 (0.517, 5.756)	1.275 (0.396, 4.109)
Deprivation		
1 (least deprived)	1 (reference)	
2	1.206 (0.453, 3.212)	1.164 (0.443, 3.059)
3	1.499 (0.575, 3.905)	1.545 (0.590, 4.041)
4	0.686 (0.243, 1.936)	1.051 (0.390, 2.836)
5 (most deprived)	1.085 (0.401, 2.935)	1.078 (0.394, 2.951)
Residential location		
Urban	1 (reference)	
Rural	2.322 (0.962, 5.605)	2.251 (0.925, 5.480)
Co-occurring conditions		
Intellectual disability	0.504 (0.263, 0.967)	0.467 (0.231, 0.944)
Behavioural	3.491 (1.857, 6.562)	2.586 (1.320, 5.066)
Emotional	2.735 (1.480, 5.052)	2.006 (1.011, 3.978)
Any (other) psychological diagnosis	3.506 (1.686, 7.291)	1.960 (0.909, 4.227)

Abbreviations: EO – European/Other. MELAA – Middle Eastern, Latin American, African. SPA – Support Package Allocation.

* Adjusted for age, sex, ethnicity, deprivation, urban/rural profile of residence, level of need, and co-occurring conditions.

a The reference population for each ethnic group is all those who do not identify with that group.