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A case identification method for neurodiverse populations in Aotearoa New Zealand

Donald Beasley Institute

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Integrated Data Infrastructure Disclaimer

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

The Integrated Data Infrastructure and Ethical Approval

The administrative linked data referred to in this report is the Integrated Data Infrastructure (IDI). The IDI consists of longitudinal, matched, de-identified data on people and households in Aotearoa, available via a series of datasets containing data on more than nine million individuals. The IDI brings together information across multiple domains such as health, medical, social welfare, education, and criminal justice systems, offering a cross-agency data platform which researchers can use to gain insight into society to improve outcomes for all (Stats NZ, 2022).

Researchers access the IDI through a safeguarding process devised and managed by Stats NZ. Following linkage, all data is de-identified before being made available to approved researchers, who are required to submit applications to securely access the relevant datasets from Stats NZ through a 'Five Safes' ethical framework. In the current study, approval to access data was obtained from Stats NZ (Reference: MAA2019-79). Ethical approval was not required from Aotearoa's national Health and Disability Ethics Committee (HDEC) as studies utilising de-identified IDI data are considered minimal-risk observational studies.

Kā Mātāpono / Our Values

The Donald Beasley Institute (DBI) is an independent charitable trust specialising in disabled-led and inclusive disability research. The DBI is values-based and committed to conducting ethical and transformative research and projects that promote the rights of disabled people. The following values are central to all of the DBI's mahi:

- Whakatinana – Honouring Te Tiriti o Waitangi through our practice
- Whakarakatira – Being respectful
- Whakawhanaukataka – Being relational
- Whakamana – Being ethical
- Whakawhirinaki – Being accountable
- Whakakotahi – Being inclusive
- Whānau – Through uplifting whānau, our journey will be one of prosperity

A note on terminology

As a team of justice and disability researchers influenced by social and human-rights approaches to the conceptualisation of disability and diversity, we faced a dilemma in conducting this research. Meeting the aims of our study required us to identify neurodivergent people using a methodology that was primarily reliant on diagnostic (and medication-use) classification of individuals, challenging us to think about the terminology used in this report.

Influenced by the social model of disability, the neurodiversity paradigm purposely challenges deficit constructions of neurological pathology and is instead used to honour and accept each person's neurological condition as a natural form of human diversity (McGee, 2012) and as a valid identity (Neff, n.d., p.4). As this new construction "shifts from just checking diagnostic boxes to understanding personal experiences, it opens up opportunities for better understanding and acknowledgement of each other's diverse experiences with different neurologies" (Neff, n.d., p. 4).

The term 'neurodiversity' refers to the diversity of human minds, while the term 'neurodivergent' "encompasses people whose brain functions differ from the

neuronormative majority” (Neff, n.d., p. 9). Neurodivergence encompasses a wide range of specific, non-specific, hidden and/or undetermined diagnoses that include but are not limited to: Learning (intellectual) and/or Developmental Disability (ID/DD); Communication Disorders (CD), Autism or Autism Spectrum Disorder (ASD), Attention Deficit/Hyperactivity Disorder (ADHD); Specific Learning Disorders (SLD); Traumatic Brain Injury (TBI); and/or Foetal Alcohol Syndrome Disorders (FASD).¹ In this report, we use the terms 'neurodiversity' or 'neurodivergent/neurodivergence' when referring to the broad group of young people we focused on in our research, to acknowledge and affirm the conceptualisation and construction of difference outlined above, and in keeping with the preference of neurodivergent people in Aotearoa.

An exception to this rule is when we refer to literature that utilises alternative terminology, or when we discuss the method we developed and applied to identify neurodivergent young people within the IDI. In these contexts, we use condition-specific identifiers (for example, intellectual disability, Autism, and so on). To capture the required information within the administrative datasets that comprise the IDI, we used these conditions or diagnostic labels to identify the young people we sought to identify, including the overarching descriptors neurodisability or neurodevelopmental disability.² Neurodevelopmental disabilities are defined as functional difficulties resulting from problems in the development of the brain or nervous system related to genetics, birth trauma, traumatic brain injury, illness, or severe nutritional or emotional deprivation (Patel et al., 2011). Difficulties may relate to cognition, emotional functioning, and communication, which are often experienced in combination and diagnosed as clinically defined childhood neurodevelopmental disorders.³ Specific conditions encompassed within this broad grouping include: Intellectual Disability,

¹ In Aotearoa, the Learning Support Action Plan 2019-2025 defines neurodiversity as “a broad term that includes (but is not limited to) dyslexia, dyspraxia, dyscalculia, dysgraphia, autism spectrum disorder, foetal alcohol spectrum disorder, attention deficit/hyperactivity disorder, trauma related disorders, and auditory visual processing disorders. It is a challenging concept because it encompasses needs across a wide spectrum of degree and intensity, and can be complicated further when children and young people are ‘twice-exceptional’ (by having more than one condition), making it difficult to understand and respond to their needs” (Ministry of Education, 2019, p. 32).

² We have chosen to use the term neurodevelopmental disability to reflect the social model of disability, which recognises people as being disabled by societal attitudes and barriers.

³ The DSM V defines neurodevelopmental disorders (NDDs) as “A group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence” (American Psychiatric Association, 2013, p. 31).

Developmental Delay, Communication disorders, Autism / Autism Spectrum Disorder, Attention Deficit/Hyperactivity Disorder, Specific Learning Disorder (for example, Dyslexia, Dyspraxia), Traumatic Brain Injury, and Foetal Alcohol Syndrome Disorders.

1. He Kupu Whakataki / Introduction

1.1 Neurodiversity and the criminal justice system

Internationally, and in the context of Aotearoa New Zealand (“Aotearoa”), there has been increasing awareness that neurodiversity can both contribute to the extent to which young people engage with the criminal justice system (Hughes et al., 2012; 2015), and impact on their experience of that system (Mirfin-Veitch et al., 2014; Foster & Young, 2022; Lansdell et al., 2022). Both issues can be understood as compromising access to justice for this particular group of young people.

The prevalence of neurodivergent adults and young people within the criminal justice system

In 2012, the U.K. Children’s Commission contracted a small group of researchers to analyse the available evidence about the prevalence of young people with ‘neurodisabilities’ in secure settings in England. This was primarily achieved through a systematic review of the literature, culminating in a report entitled ‘*Nobody made the connection: The prevalence of neurodisability in young people who offend*’ (Hughes et al., 2012). Confirming anecdotal evidence, *Nobody made the connection* identified that young people who offended and were placed in secure settings also experienced a high rate of neurodisabilities. Between 23% and 32% of these young people were found to have a learning disability, between 60% and 90% had a communication disorder, and as many as 65% to 72% of young people in secure settings had a traumatic brain injury (Hughes et al., 2012). This influential report increased awareness of how many neurodivergent young people are likely to be present in the criminal justice system and how little the system is doing to meet their specific needs. It also highlighted the importance of identifying those who are neurodivergent early so that they have the opportunity to receive appropriate accommodations throughout their engagement with the criminal justice system, or in some cases, be diverted away from the justice system.

This earlier study was one of the catalysts for an increasing body of research regarding the overrepresentation of neurodivergent young people and adults in the criminal justice system. For example, a Canadian study that recruited a representative group of 80 justice-system-involved adults between the ages of 18 and 40 found that 17.5%

of the offending population had FASD, with only five of the 80 participants showing no neurodevelopmental impairment (McLachlan et al., 2019). Canadian and Australian studies have also reported that 89% – 93% of the criminal justice populations have at least one severe neuro-developmental impairment (Gibbs, 2021, p. 298). In addition, a meta-analysis of international research regarding the prevalence of ADHD in prison populations found that approximately 30% of incarcerated young people would meet the diagnostic criteria for ADHD (Young et al., 2015).

In the Australian context, one study drew on a sample of 300 children who had been charged and appeared in three Australian children's courts, reporting that 48% of the children had a neurodevelopmental impairment (Baidawi & Piquero, 2020). Another Australian study found that amongst the youth (aged between 10 and 17 years) in the only youth detention centre in Western Australia, 89% of those assessed had at least one domain of severe neurodevelopmental impairment, and 36% were diagnosed with FASD. The majority (94%) of the young people diagnosed with FASD were Aboriginal (Bower et al., 2018). A further study interviewed participants who worked closely with young people with brain injuries and cognitive disabilities in the state of Victoria. This research reported that, from the participants' perspectives, young people with acquired brain injuries "appear very likely to be over-represented in the criminal justice system" (Lansdell et al., 2022, p. 5).

1.2 Neurodivergent people's experiences in the criminal justice system

Research has also highlighted that when neurodivergent young people and adults enter the criminal justice system, they experience poor outcomes at all stages of their criminal justice journey. For example, neurodivergent people are reported as experiencing inequity when engaging with the Police, who are often the first point of contact with the criminal justice system. Recent Aotearoa research explored disabled people's interactions with the Police and found that participants, including neurodivergent people, experienced unreasonable use of force by Police, overcharging and overloading of charges,⁴ and struggled to receive the reasonable accommodations they needed (Donald Beasley Institute, 2024). A recent Australian

⁴ Overcharging is when a charge is not supported by the available evidence and overloading of charges is the adding of additional charges that are unsupported by evidence (Donald Beasley Institute, 2024).

study also found inequity concerning charges. This study collected data from a sample of 300 children who had appeared in court and concluded that the neurodivergent cohort experienced a greater number of charges than neurotypical peers (Baidawi & Piquero, 2020).

Neurodivergent adults and young people also experience inequity during sentencing. Australian research has found that once autistic individuals enter the criminal justice system, they are perceived negatively within court proceedings and receive longer sentences than those who are not autistic (Foster & Young, 2021). Further research conducted in Queensland, Australia, examined the factors that judges considered when sentencing individuals with cognitive disabilities. The study found that while judges attempted to avoid incarcerating people with a cognitive disability, they balanced this approach by imposing tight supervision-based sentences. The authors argued that such sentences may lead to “a greater number of technical violations of community-based orders due to the potential complexity of surveillance, monitoring and reporting conditions” (Henderson & Bull, 2024, p. 95). Other recent studies have found that once neurodiverse defendants are charged with an offence, they are at a higher risk of incarceration (Anns et al., 2023; Bowden et al., 2021). Once incarcerated, neurodiverse individuals are deeply disadvantaged within prison systems (Gormley, 2022; Vinter et al., 2019).

Theorists have identified several factors that lead to neurodivergent young people’s negative experiences within the criminal justice system. For example, a lack of understanding of neurodivergence leads to legal professionals failing to work responsively with neurodivergent young people (Gibbs, 2022), a lack of screening and assessment leading to a failure to identify and accommodate neurodiversity (Bendo et al., 2024; Lansdell et al., 2022; McVilly et al., 2023) and Judges failing to take neurodivergence into account when sentencing an offender (Gibbs, 2022).

1.3 Calls for more data in Aotearoa

At the 2016 Aotearoa New Zealand Neurodisabilities Forum, it was noted that (at that time) there had been no specific study focused on the prevalence of neurodivergence within the population of people who offend in Aotearoa. Attendees at the forum sought more targeted research into this issue to achieve more neurodiversity-informed policy and practice and expressed the view that neurodisabilities were significantly over-

represented within the population of young people engaged in the youth justice system in Aotearoa (Lynch, 2016).

In the decade that has elapsed since this forum took place, new research has emerged with one study reporting that 64% of prisoners have had at least one TBI, with 32.5% of this group having experienced multiple TBIs (Mitchell et al., (2017) referenced in Gibbs, 2021). Another study found that young adults with ADHD were significantly more likely to interact with the criminal justice system at multiple points, including within Police proceedings, court charges, court convictions, and incarceration (Anns et al., 2023).

However, despite this growing and recent activity, the calls for more nuanced research about the prevalence and experiences of neurodivergent youth in the justice system in Aotearoa have persisted. For example, Gibbs (2022) identified a lack of data regarding women and girls with neurodisabilities in the criminal justice system, noting that “we have little evidence of the range of mental health and neurodisability issues specific to women and girls: these are often ‘hidden’ under male-centric research norms that study offender populations where women feature less than 10 per cent of the time” (p. 195).

The lack of disability-specific data and analysis can be seen in a recent report focused on children who have offended or are at risk of offending (Reil et al. 2022), which explores the characteristics, background and trajectories of children who offend. While providing significant evidence and insights across the youth justice population as a whole, the information is not viewed through a disability lens, nor does the report identify and discuss the specific experiences and needs of young people who are both neurodivergent and engaged with the justice system.

In the proposal for a Young Adult List in Aotearoa, Judge Walker and Judge Doogue referenced *Nobody made the connection* and noted that given the information from New Zealand practitioners, “it is likely that the New Zealand population will exhibit similar prevalence rates” (Doogue & Walker, 2021, p. 5).

Generating local evidence is crucial for guiding the development of effective and efficient policy and practice responses. Concerning neurodiversity in the criminal justice system in Aotearoa, this need for information has consistently been asserted

by neurodiversity self-advocates and their allies, as well as justice, health, and child protection professionals and officials. For example, FASD expert and criminologist Anita Gibbs (2021, p. 298) recently commented:

Several notable Youth Court judges, including former principal Youth Court judge Andrew Becroft (now Children's Commissioner), have been particularly vocal in highlighting the need for New Zealand to ascertain the prevalence rates of neuro-disabilities and provide neuro-informed criminal justice policies and practices [...].

Similarly, the New Zealand ASD Guideline and the Making Disability Rights Real Whakatūtu Ngā Tika Hauātanga both draw attention to a lack of research in this area, respectively stating:

Although it is generally accepted that autistic people/tāngata whaitakiwātanga and other disabilities have a higher likelihood of contact with the police, courts and criminal justice system than other people, little research on this could be found (Whaikaha Ministry of Disabled People & Ministry of Education, 2022, p. 219).

And:

New Zealand needs better data on the prevalence of neurodisability to inform targets, and indicators to ensure better service delivery in a justice context to people with a neurodisability. Data is critical to early, effective identification and intervention. If people with neurodisabilities do not access early support – for example, in an education context – they face an increased risk of interaction with the justice system and poor outcomes within it (Independent Monitoring Mechanism, 2020, p. 73).

1.4 Relevant treaties, conventions and strategies

Several key conventions, strategies, and legislation are relevant to the area of neurodivergent young people in the criminal justice system in Aotearoa New Zealand. These have been outlined below as all articulate the dual responsibility and need for systems and approaches to facilitate full and effective participation, and increased and improved data and evidence in this area.

Te Tiriti o Waitangi

Te Tiriti o Waitangi (the Treaty of Waitangi) is a constitutional founding document in Aotearoa. It sets out the partnership between *takata whenua* and the Crown. The New Zealand Courts have identified the principles of Te Tiriti o Waitangi, including partnership (Māori and the Crown of a relationship of respect, good faith, and shared decision-making), participation (the Crown and Māori will work together and Māori will participate at all levels of decision-making), and protection (the Crown will actively improve the wellbeing of Māori) (Human Rights Commission, n.d.). According to Te Tiriti o Waitangi, the government of Aotearoa have committed to protecting Māori *tamariki* and *raḡatahi* from harm and to ensuring they receive fair and equitable outcomes within the Criminal Justice System.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international agreement that outlines the obligations of governments to ensure disabled people have the same human rights as everyone else. In 2008, the New Zealand Government became one of the first countries to ratify the UNCRPD, followed by further ratification of the Convention's Optional Protocol in 2016. Article 13 of the UNCRPD requires States Parties to "ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, to facilitate their effective role as direct and indirect participants" (United Nations, 2006). Article 31 of the Convention also requires parties signed up to the convention to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention." This includes data relating to the justice system.

New Zealand Disability Strategy 2016 - 2026

The New Zealand Disability Strategy (NZDS) guides the work of government agencies on issues affecting disabled people and aims to help realise the rights of disabled people by supporting the implementation of the UNCRPD into public policy (Office for Disability Issues, 2016).⁵ Outcome 4 of the NZDS recognises the importance of

⁵ The New Zealand Disability Strategy is currently being updated, and was out for consultation at the time of publication of this report.

disabled people being treated fairly and equitably by the justice system. The NZDS states that “[w]e will continue to be treated with fairness and respect at all stages of our journey through the justice system, regardless of whether we are victims, perpetrators, witnesses, or fulfilling a civic duty such as jury service” (p. 30).

The NZDS also requires the Government to collect data to inform investment decisions effectively. It notes that both quantitative and qualitative evidence are valuable for ensuring a good understanding of the issues, identifying the most effective interventions for disabled people, and measuring results against the outcomes sought by disabled people. It notes that “all too often we have been invisible because disability has not been counted, recognised or understood, and therefore our needs have not been considered” (Office for Disability Issues, 2016, p. 20).

The lack of Aotearoa-specific data and evidence regarding neurodivergent young people in the criminal justice system suggests that we are not meeting our obligations under Article 31 of the UNCRPD or the New Zealand Disability Strategy in relation to data and evidence in this area.

1.5 Using the Integrated Data Infrastructure to fill the data gap

Scholarship on the potential of IDI-based methodologies (Milne, 2022; Milne et al., 2022), and a growing body of research utilising the IDI to identify specific populations and explore social issues, such as educational pathways and involvement in the criminal justice system. For example, recent research utilised the IDI to explore New Zealand children’s contact with the criminal justice system but did not identify neurodiverse young people’s pathways into and out of it (Reil et al., 2022). Another research project developed a clinically relevant case identification method for use when researching topics related to the mental health of children and young people in Aotearoa, identifying over 82,000 unique individuals aged 0 - 24 with at least one specified mental health or related problem for the 2014/15 fiscal year (Bowden et al., 2020a) This approach was then drawn on to develop a case identification method for Autism in the IDI (Bowden et al., 2020b). Research utilising the IDI has also explored the associations between type 1 diabetes and educational outcomes in Aotearoa,

finding that type 1 diabetes was associated with lower educational outcomes (Bowden et al., 2023)

A recent study utilised the IDI to compare the suspension rates of autistic and non-autistic students, and to assess whether a specific type of educational funding currently provided to autistic students is associated with a decreased rate of school suspension. The results showed that high-needs funding was associated with a reduced chance of suspension for autistic children in Aotearoa (Bowden et al., 2022b). The IDI has also been used to explore the association between being in the custody of the chief executive of Oranga Tamariki (child welfare agency of New Zealand) and all-cause hospitalisation and mortality. This study had concerning results, identifying that the care and protection system before 2018 was not preventing children in its care from experiencing severe adverse outcomes, with children in care being 1.32 times more likely to be hospitalised than children who were not in care (Pugh et al., 2023). These resources all illustrate the potential of the IDI to shine a light on systems and experiences in Aotearoa that would otherwise not be accessible.

Similar focus on the use of linked administrative data sets is also taking place overseas. For example, in Australia, a study that utilised linked administrative data from the disability, health and corrections sectors for the year 2014 sought to estimate the prevalence of adults with intellectual disability in the prison population in New South Wales. It found that 4.3% of those in prison in NSW had an identified intellectual disability, and further found that the number of people with an intellectual disability who were imprisoned was 3.7 times higher than the general population (Trofimovs et al., 2021).

1.6 Summary

There is increasing recognition that there is both an overrepresentation of neurodivergent young people in the criminal justice system and a lack of preparedness by the systems (and people) who have an obligation to support their access to justice more actively (Lansdell et al., 2022). However, despite acceptance of the need for systemic, policy, and practice change within the justice system, robust Aotearoa data and evidence have been lacking, resulting in a reliance on overseas estimates. The purpose of this report is to provide an overview of the first aim of a phased project designed to explore the involvement of neurodivergent young people in the Criminal

Justice System in Aotearoa New Zealand - the development of a methodology for identifying neurodivergent young people within the Integrated Data Infrastructure (IDI).

2. Developing a methodology for identifying neurodivergent young people within the Integrated Data Infrastructure (IDI)

As established earlier, linked administrative datasets enable the identification of neurodiverse people across multiple datasets and the exploration of their life outcomes. In the context of Aotearoa, the IDI presents an opportunity to examine the visibility (or lack thereof) of neurodiverse young people within and across various administrative datasets.

In the absence of both an international standard for classifying neurodiversity and a methodology for a case-identification approach for all neurodiverse conditions, the preliminary aim of this research was to develop a robust method for identifying neurodiverse children, adolescents, and young adults within the IDI.⁶ The method was not designed to capture true prevalence but instead to generate clinically meaningful cohorts of young people with any and specific neurodevelopmental conditions.

2.1 Datasets

Stage 1

The first stage in developing our methodology involved identifying a list of neurodevelopmental disabilities based on the DSM-V, noting that Traumatic Brain Injury was also included on the basis that TBI's are a neurodiversity highly relevant to a youth population. The initial list included:

- Attention Deficit Hyperactivity Disorder (“ADHD”),
- Autism Spectrum Disorder (“ASD”),
- Communication Disorders (“CD”),
- Language Disorders (“LD”),

⁶ Data science experts Nicholson Consulting conducted data extraction and preliminary analysis.
<https://www.nicholsonconsulting.co.nz>

- Foetal Alcohol Spectrum Disorder (“FASD”),
- Intellectual Disability (“ID”),
- Specific Learning Difficulties (“SLD”), and
- Traumatic Brain Injury (“TBI”) and other non-traumatic Acquired Brain Injuries (“ABI”).

As noted in the terminology section of this report, administrative data that can reliably be used to identify neurodivergence is largely limited to medical diagnostic codes. This means that young people with undiagnosed neurodiversity may not show up in IDI data, leading to undercounting of these communities. Conversely, the benefit of using diagnostic codes (such as ICD-9, CMAII, ICD-10-AM, and DSM-IV & V) is that they increase the reliability of the identification method, and can be compared with international jurisdictions.

Stage 2

Next, we identified five datasets to draw on to identify cases of these conditions. This included:

- diagnosis information from Accident Compensation Corporation (ACC) injury claims data;
- publicly funded inpatient hospitalisations from the National Minimum Dataset (NMDS);
- specialist mental health service use from the Programme for the Integration of Mental Health Data (PRIMHD);
- needs assessment information from Disability Support Services database (Socrates);
- and inference from medication dispensing from the Pharmaceutical Collection (Pharms).

The use of the Pharms dataset was informed by the work of Bowden et al. (2020), who used a panel of clinicians to determine which prescription drugs and their corresponding Chemical IDs were most likely associated with ADHD at various developmental timepoints.

Stage 3

The third stage of the process involved conducting a literature review of previous case-identification approaches using ICD-9 and ICD-10 codes. Rigorous and clinically relevant case-identification methods, which reflected the DSM-V definitions for neurodevelopmental disability, were used as a foundation for this case-identification method. A systematic review of TBI of the allocation of ICD-10 codes by hospitals was identified (Chan et al., 2015), as well as recent case identifications of ADHD and ASD (Bowden et al., 2020).

Stage 4

The fourth and final stage involved classifying and refining codes used to assign cases to specific neurodevelopmental disabilities by data source. The identified codes were reviewed by a multidisciplinary research team, comprising a child and adolescent psychiatrist with dual qualifications as a paediatrician, a speech-language therapist, a lawyer with expertise in ACC claims and claimants, three academic researchers specialising in neurodiversity, and a healthcare coding specialist. Most data sources (NMDS, PRIMHD, Socrates, and the ACC) provided specific diagnoses (for example, ICD-9-CM II, ICD-10-AM or DSM-IV) that fit into the eight different neurodevelopmental disabilities. When assigning cases to specific neurodisabilities by data source, relevant criteria were recorded in a separate document to provide audit records. The codes were reviewed by a range of professionals, who used a consensus approach to code selection (Bowden et al., 2020), which served as an additional quality measure.^{7 8}

Table 1 presents the datasets that each of the specific conditions were identified from.

Table 1: Sources of data for each neurodevelopmental condition

	ACC	NMDS	PRIMD	PHARMS	SOCRATES
Attention Deficit		√	√	√	√

⁷ Acquired Brain Injury was excluded because it can be caused by a range of different conditions and it was decided that more thorough investigation and further additional clinical consensus was required.

⁸ A full list of all individual codes and the data sources which were used to identify each subcategory of neurodiversity can be requested from the authors.

Hyperactivity Disorder					
Autism Spectrum Disorder			√		√
Communication Disorder		√			√
Language Disorders		√			
Foetal Alcohol Spectrum Disorder		√			√
Intellectual Disability		√	√		√
Specific Learning Difficulties		√	√		√
Traumatic Brain Injury	√	√			

Table 2 displays the final set of codes that were included in the method.

Table 2: Codes used to identify neurodevelopmental conditions

NDC group	Code (Description)
	ICD-10-AM Codes (NMDS and PRIMHD)
ADHD	F900 (disturbance of activity and attention)
ADHD	F908 (other kinetic disorders)
ADHD	F909 (hyperkinetic disorder, unspecified)
Autism	F840 (childhood autism)
Autism	F841 (atypical autism)
Autism	F843 (other childhood disintegrative disorder)
Autism	F845 (Asperger's syndrome)
Autism	F849 (pervasive developmental disorder, unspecified)
CLD	F801 (expressive language disorder)
CLD	F802 (receptive language disorder)
CLD	F808 (other developmental disorders of speech and language)
CLD	F809 (developmental disorder of speech and language, unspecified)
CLD	F800 (specific speech articulation disorder)
FASD	P043 (foetus and new-born affected by maternal use of alcohol)

ID	F700 (mild intellectual disabilities)
ID	F701 (mild intellectual disabilities)
ID	F708 (mild intellectual disabilities)
ID	F709 (mild intellectual disabilities)
ID	F710 (moderate intellectual disabilities)
ID	F711 (moderate intellectual disabilities)
ID	F719 (moderate intellectual disabilities)
SLMD	F810 (specific reading disorder)
SLMD	F811 (specific spelling disorder)
SLMD	F812 (specific disorder of arithmetical skills)
SLMD	F813 (mixed disorder of scholastic skills)
SLMD	F818 (other developmental disorders of scholastic skills)
SLMD	F82 (specific development disorder of motor function) (dyspraxia)
	DSM-IV codes (PRIMHD)
ADHD	31400 (attention deficit hyperactivity disorder, predominantly inattentive type)
ADHD	31401 (attention deficit hyperactivity disorder, combined type)
ADHD	3149 (attention deficit hyperactivity disorder, NOS)
Autism	29900 (autistic disorder)
Autism	29910 (childhood disintegrative disorders)
Autism	29980 (pervasive developmental disorder – NOS)
CLD	31531 (expressive language disorder)
CLD	3070 (stuttering)
CLD	31539 (phonological disorder)
CLD	3079 (communication disorder NOS)
ID	317 (mild mental retardation)
ID	3180 (moderate mental retardation)
ID	3181 (severe mental retardation)
ID	3182 (profound mental retardation)
ID	319 (unspecified mental retardation)
SLMD	315 (reading disorder)
SLMD	3151 (mathematics disorder)
SLMD	3152 (disorder of written expression)

SLMD	3154 (developmental coordination disorder)
	Team Type codes (PRIMHD)
ID	12 (intellectual disability dual diagnosis team)
ID	26 (intellectual disability)
	Diagnosis codes (SOCRATES)
ADHD	1201 (attention deficit/hyperactivity, e.g. ADD, ADHD)
Autism	1211 (autistic spectrum disorder (ASD))
Autism	1206 (Asperger's syndrome)
Autism	1207 (retired - other autistic spectrum disorder (ASD))
CLD	1701 (mute)
CLD	1202 (language delay)
CLD	1799 (other speech disorder, specified)
CLD	1203 (speech delay)
CLD	9006 (social communication disorder)
FASD	1106 (foetal alcohol syndrome)
ID	1208 (intellectual disability, type not specified)
SLMD	1205 (dyslexia)
SLMD	1209 (learning disability, type not specified)
SLMD	1210 (developmental delay, type not specified)
SLMD	1299 (other intellectual, learning or developmental disorder)
SLMD	1204 (motor delay, developmental dyspraxia)
	Chemical codes (Pharmaceutical collection)
ADHD	1389 (Dexamfetamine sulfate)
ADHD	1809 (Methylphenidate hydrochloride)
ADHD	3880 (Methylphenidate hydrochloride extended release)
ADHD	3998 (Atomoxetine)

2.2 Limitations and future directions

At this point, the case identification method presented here has not been formally validated against other data sources. The next stage in our phased project is to apply, and later to formally validate, the case identification method for neurodivergent young people. It is already clear that a thorough review of medical and diagnostic records

would help to establish the validity of the diagnostic codes used for case identification in this method. As with any method of case identification, when using administrative data, there is high reliance on the quality of service-use records. As noted above, potential gaps in identifying conditions, differences in help-seeking behaviours related to different conditions, or inconsistencies in definitions across different services can lead to skewed data, making robust case identification challenging.

Another significant challenge in identifying neurodiversity within administrative data is the variation in definitions for each subgroup of neurodiversity used across studies, countries, and systems. These differences in definitions can contribute to the variation observed in prevalence data relating to neurodivergence across different jurisdictions. Furthermore, the data contained within the IDI does not yet include comprehensive primary healthcare data or privately sourced diagnoses, meaning that some neurodivergent people and groups will be invisible within administrative data.

3. Whakamutuka / Conclusion

This report has provided an overview of a new method for identifying neurodivergent young people in Aotearoa New Zealand's IDI. Our aim for this first phase of our staged project was to develop a code set to identify neurodiversity via administrative data in the Aotearoa IDI. The method we developed to identify "cases" of neurodiversity within the IDI provides a way to identify neurodiversity within administrative datasets, including showing where neurodiverse children, adolescents and young adults are, and are not, "showing up". Case identification methods, such as the one described here have the potential to be used to monitor and evaluate supports and interventions aimed at improving outcomes for neurodivergent children, adolescents, and young adults. Linked administrative datasets, such as the IDI, offer an opportunity for researchers, practitioners, and policymakers to monitor trajectories for neurodivergent communities in a robust and effective way, both illuminating systemic disadvantage and informing strategies to address it.

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**Whakarakatira te tākata,
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