



## Using population-level data for Takiwātanga | autism research in Aotearoa | New Zealand

#### ASfAR, 2023 Nick Bowden

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## **Presentation overview**

- Data source: the Integrated Data Infrastructure (IDI)
- Overview of autism research to date using the IDI
- Discuss a specific study looking at education based support and education outcomes
- New Māori- and Pacific-focussed workstreams
- Where too next?



## Language and community involvement



Autism Terminology Guidance From the Autistic Community of Aotearoa New Zealand

A Living Resource Created by Autistic People With the Support of Autism New Zealand

April 2022

Version 1

autismnz.org.

Language: We recognise that there is no one term that is preferred by all people from the Autistic and autism communities. However, in partnership with co-authors and in recognition of changing preferences, the terms 'Autistic person' and 'Autistic' have been prioritised.

**Community involvement:** Engagement with Autistic and autism communities, including co-production of knowledge is critical to our research. Research presented today include co-authors who are Autistic and who are from the autism community.



## Contributors

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Autism New Zealand, Brown University, Donald Beasley Institute, Harvard University, iNZight Ltd, Nicholson Consulting, Simply Resolution Ltd, Starship Hospital, University of Auckland, University of Canterbury University of Otago, University of Queensland, University of Sheffield, Victoria University

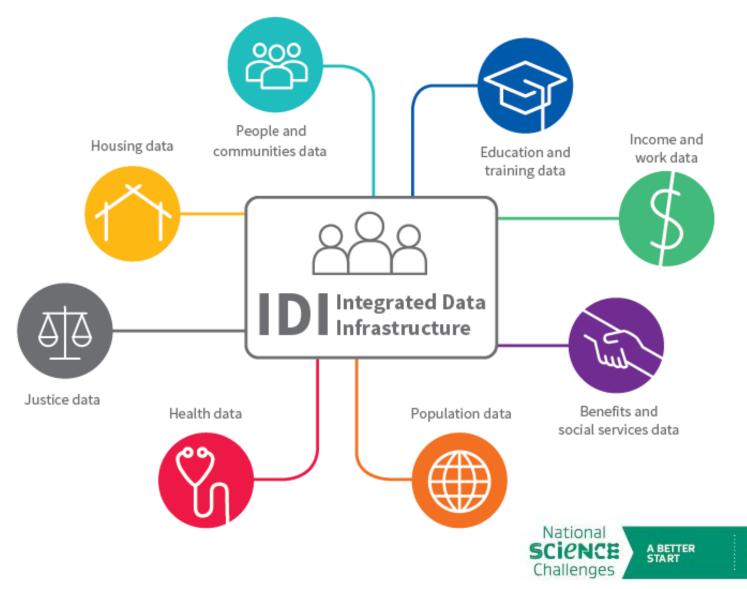


What is the Integrated Data Infrastructure?

- Large research database managed by Stats NZ
- Data from government agencies, surveys, and non-governmental organisations (NGOs)
- Whole of population data
- Linked, de-identified data on people and households



## What data are in the IDI?



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# Autism research using the IDI?

- Health
  - Identifying Autistic populations in the IDI
  - Rates of co-occurring neurodevelopmental and mental health conditions
  - Medication profile and polypharmacy
  - Mortality
- Education
  - Suspensions/standdowns and impact of education-based supports
  - School attendance
- Criminal Justice System
  - Police, courts, prisons
- Pacific-focussed
  - Understanding Pacific autism rates
  - Exploring the impact parental formal education level on Pacific autism diagnosis rates



### Suspension and support

JAMA Pediatrics | Original Investigation

#### Association Between High-Need Education-Based Funding and School Suspension Rates for Autistic Students in New Zealand

Nicholas Bowden, MCom; Sheree Gibb, PhD; Richard Audas, PhD; Sally Clendon, PhD; Joanne Dacombe; Jesse Kokaua, PhD; Barry J. Milne, PhD; Himang Mujoo, PhD; Samuel William Murray, MPP; Kirsten Smiler, PhD; Hilary Stace, PhD; Larah van der Meer, PhD; Barry James Taylor, MB, ChB

- 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



## Methods

#### Design

National retrospective cohort study of all enrolled students in 2018

#### Autism

Determine population of Autistic students

#### Outcome

Suspensions or stand-downs

#### Support

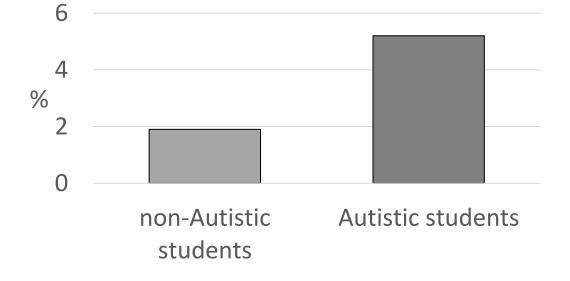
- Ongoing resourcing Scheme (ORS) funding



## Results 1

736,911 in participant population including 9,741 (1.3%) Autistic students

Suspension rates by autism status, 2018



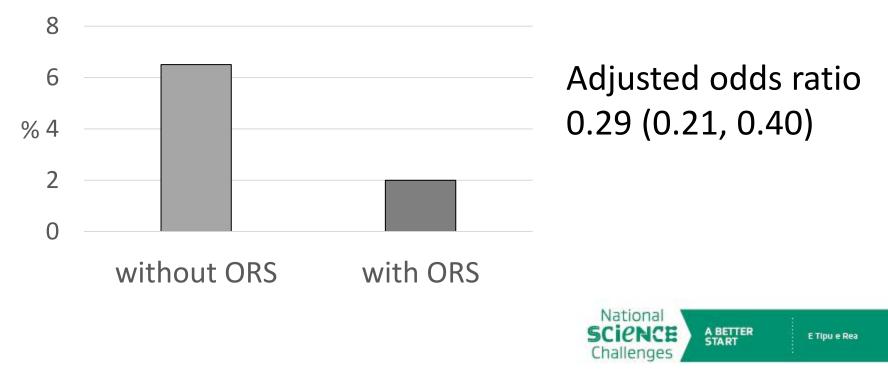
Adjusted odds ratio 2.81 (2.55, 3.11)



## Results 2

# 9,741 Autistic students including 2,895 (29.7%) with ORS funding

Suspension rates by ORS funding status, 2018



## Discussion

- Concerning that our findings show that Autistic students are being suspended at far greater rates than their non–Autistic peers.
- Positive that we are to be able to show that substantial funding support around these students is related to reduced suspension.
- Lots of future research opportunities



## Māori-focused IDI stream

- Team led by Dr Jess Tupou (Kāti Mamoe, Kāi Tahu) and includes A/Prof Reremoana Theodore (Ngāpuhi), A/Prof Andrew Sporle (Ngāti Apa, Rangitāne, Te Rarawa), Miss Tori Diamond (Ngāpuhi), Ms Fran Kewene (Waikato; Ngāti Maniapoto)
- Establishment of a pou herenga r
  r
  p
  ū to ensure research aligns with the needs and priorities of Autistic M
   āori and their wh
   ānau
- Explore clinical characteristics
- Generate baseline life outcome data for Autistic Māori in health, education, labour market, social service, and criminal justice system.



## Results: hospitalisations, 2019

	Māori (N=410,931)		non-Māori (N=1,169,823)	
	n	%	n	%
non-Autistic	50,973	12.5	110,244	9.5
Autistic	717	15.3	1,710	11.6
Autistic without ID	447	13.9	1,038	9.8
Autistic with ID	270	18.1	672	16.1



## Pacific focused IDI stream

- Team led by Dr Jesse Kokaua and Dr Troy Ruhe and includes Liam Kokaua, Betty Kolose-Pulefolau, Dr Siale Foliaki, Prof. Rose Richards, & Miss Faith Aldridge.
- Association between formal parental education levels and obtaining an autism diagnosis for their Pacific child



## **Results: parental education**

		OR	95% CI
Parents'	per additional year of	1.102	[1.06 to 1.15]
education	education		
Parents born in	Both parents	Reference	
Aotearoa/NZ	Father only	0.947	[0.78 to 1.16]
	Mother only	1.021	[0.80 to 1.31]
	Neither parent	0.377	[0.30 to 0.48]
English spoken	At least one parent	1.373	[1.07 to 1.76]
	Neither parent	Reference	
Additional	Yes	0.687	[0.54 to 0.87]
adults in	No	Reference	
household			



## Future work

- Wide range of outcomes of interest
- Wider range of supports of interest
- More complex (causal) analysis
- Exploring benefits to whānau



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#### **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/

