# New Zealand's Integrated Data Infrastructure:

What it tells us about people with intellectual disabilities and their families and whānau

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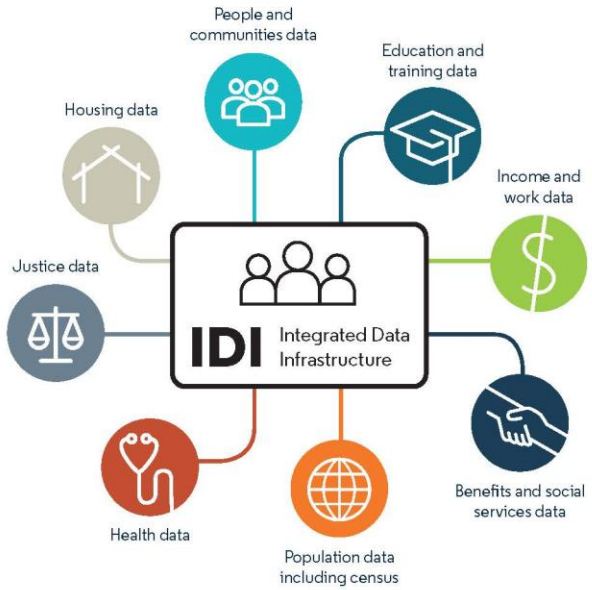
# What is the IDI?

- Integrated Data Infrastructure (IDI)
- Large, secure, de-identified database held by Stats NZ
- Links administrative and national survey data on health, education, income, housing, justice & more
- Enables whole-of-life population research

# Data in the IDI October 2025

Stats NZ Tatauranga Aotearoa

**Stats NZ's Integrated Data Infrastructure (IDI) is a large research database containing de-identified microdata about people and households.**




The IDI contains person-centred microdata from a range of government agencies, Stats NZ surveys including the 2013 Census, and non-government organisations. For more information about data in the IDI, see **www.stats.govt.nz/integrated-data/integrated-data-infrastructure**

The Longitudinal Business Database (LBD) complements the IDI with microdata about businesses. For more information about data in the LBD, see **www.stats.govt.nz/integrated-data/longitudinal-business-database**

Stats NZ operates a five-safes environment, balancing privacy and confidentiality with data insights.

For information about applying to use the IDI or to learn about how we keep the data safe, see **www.stats.govt.nz/integrated-data**

### Health data

- B4 School Checks – from 2008
- Cancer registrations – from 1995
- Chronic conditions – pre 1985
- General medical services claims – from 2002
- Health Tracker – 2006–2014
- InterRAI – from 2014
- Laboratory claims – from 2003
- Maternity – from 2003
- Mortality – from 1988
- National Booking Reporting System – from 2003
- National Needs Assessment and Service Coordination Information System (SOCRATES) – from 1988
- National non-admitted patient collection – from 2007
- NES enrolments – from 2019
- New Zealand Health Survey – from 2011
- Pharmaceutical – from 2005
- PHO enrolments – 2003–2018
- Population cohort demographics and addresses – from 2003
- PRIMHD – from 2008
- Privately funded hospital discharges – from 2001
- Publicly funded hospital discharges – from 1988
- Virtual Diabetes Register – pre 1985
- Health Service Users – from 2014

### Education and training data

- Early childhood education participation – from 2006
- Industry training – from 2001
- Schooling data – from 2004
- Targeted training – from 2001
- Tertiary Education – from 1994
- NSI – pre 1984
- Programme for the International Assessment of Adult Competencies – 2014
- Gateway Enrolment – from 2016

### Benefits and social services data

- Injury claims data – from 1994
- Early Start Project – from 2016
- Working for Families – from 1999
- Benefits – from 1990
- Child, Youth, and Family – from 1991
- Children's Action Plan – from 2013
- Family Start – from 2008
- Youth services – from 2004
- Student loans and allowances – from 1992
- Service Outcome Report Tool (SORT) participation – from 2004

### Justice data

- Sentencing and remand – from 1998
- Court charges – from 1992
- New Zealand Crime and Victims Survey – from 2018
- NIA links – from 2009
- Recorded crime: offenders – from 2009
- Recorded crime: victims – from 2014

### People and communities data

- Auckland City Mission – from 1996
- Migrant Survey – 2012
- Drivers licence and motor vehicle registers – from 2006
- Disability Survey – 2013
- General Social Survey – from 2008
- Longitudinal Immigration Survey of NZ – 2005–2009
- Te Kupenga – 2013 and 2018

### Population data

- Border movements – from 1997
- Births, deaths, and marriages – from 1840
- Civil unions – from 2005
- Border movements – from 1997
- Visa applicants – from 1997
- Census – 2013, 2018 and 2023

### Income and work data

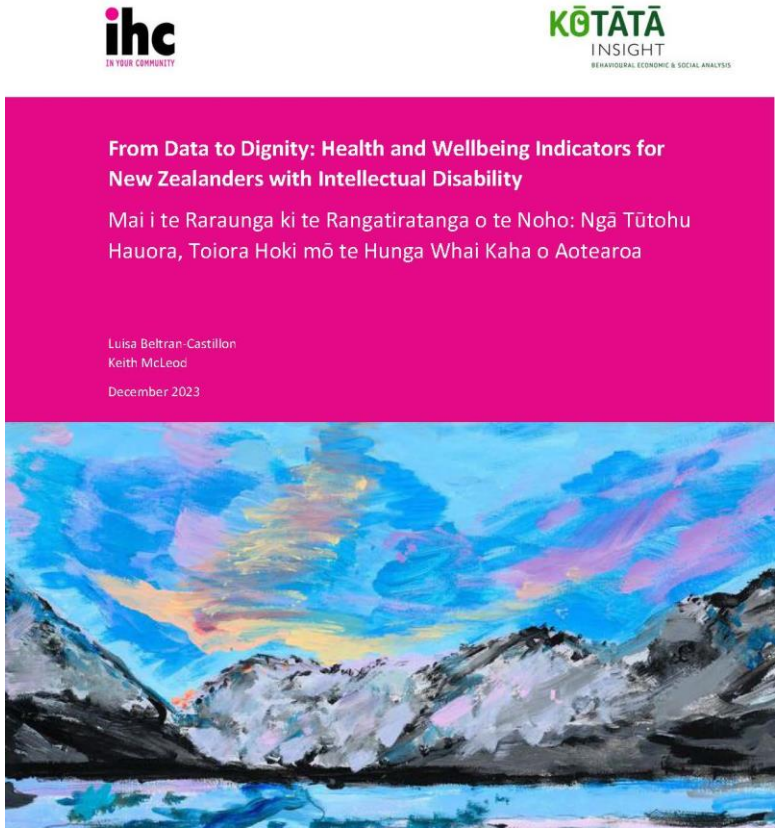
- Tax and income – from 1999
- Household Economic Survey – from 2006
- Household Labour Force Survey – from 2006
- NZ Income Survey – from 2006
- Survey of Family, Income, and Employment – 2002–2010
- Household Income and Living Survey – from 2024

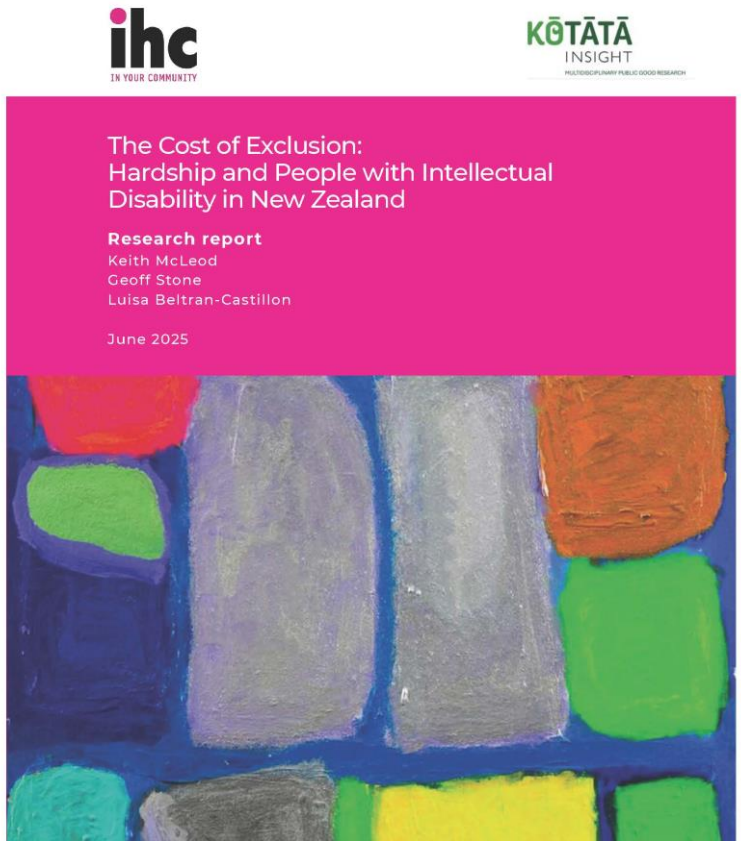
### Housing data

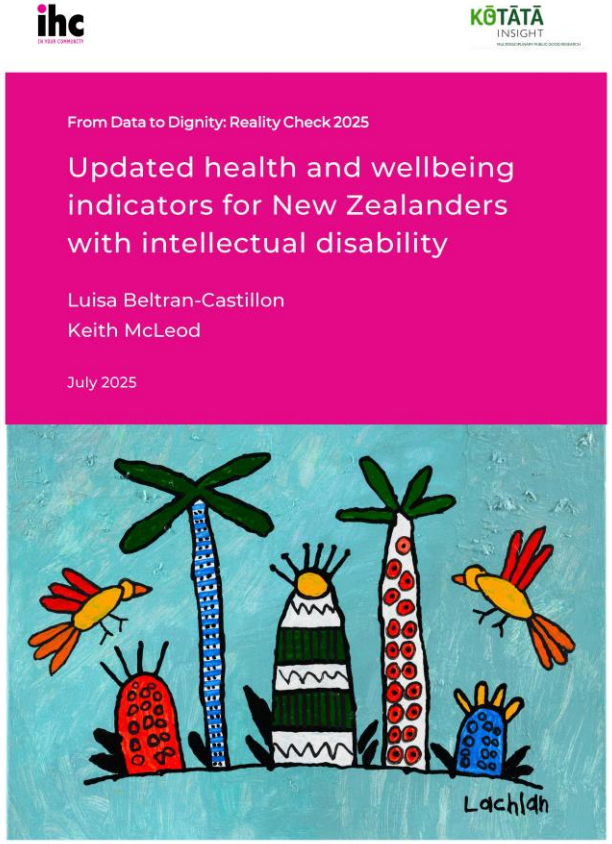
- Tenancy – from 2000
- Social housing – from 2000
- Emergency Housing – from 2016

# How We Used It

- Identified people with intellectual disability
- Focused on disparities and systemic exclusion




Reports: From Data to Dignity (2023), Cost of Exclusion (2025) Reality Check (2025 forthcoming)

# From Data to Dignity 2023 and 2025

- Used administrative and national survey data
- Measured wellbeing using the NZ Treasury's Living Standards Framework
- Original report used data from 2018 and new report uses data from 2023 (because of the Census!)

# Health Findings

Compared to general population, people with ID are:

- 1.5x more likely to have COPD
- 1.6x more likely to have diabetes
- 3x more likely to have a mood disorder
- 13x more likely to be treated for psychosis
- 4x more likely to have dementia
- 3x more likely to visit ED
- 4x more likely to be hospitalised for avoidable reasons
- More likely to smoke & less likely to stop

# Education

Students with ID are:

- 2x more likely to be chronically absent
- 3x more likely to be suspended
- 5x more likely to leave school with no qualifications

Children and young people with ID are 2x more likely to not be enrolled at school

# Employment & Income

Statistics about working age adults with ID:

- Only 21% have paid employment
- 7x more likely to receive a benefit
- Largest income gap at ages 45–55 ($54K less per year)
- Live on $30K annually

Young people (15-24) 3x more likely to be NEET

# Housing & Living Conditions

- 3x more likely to live in social housing
- 4x more likely to be on the social housing waitlist
- More likely to live in mouldy, overcrowded homes
- More likely to live in the most deprived areas

# Safety & Justice

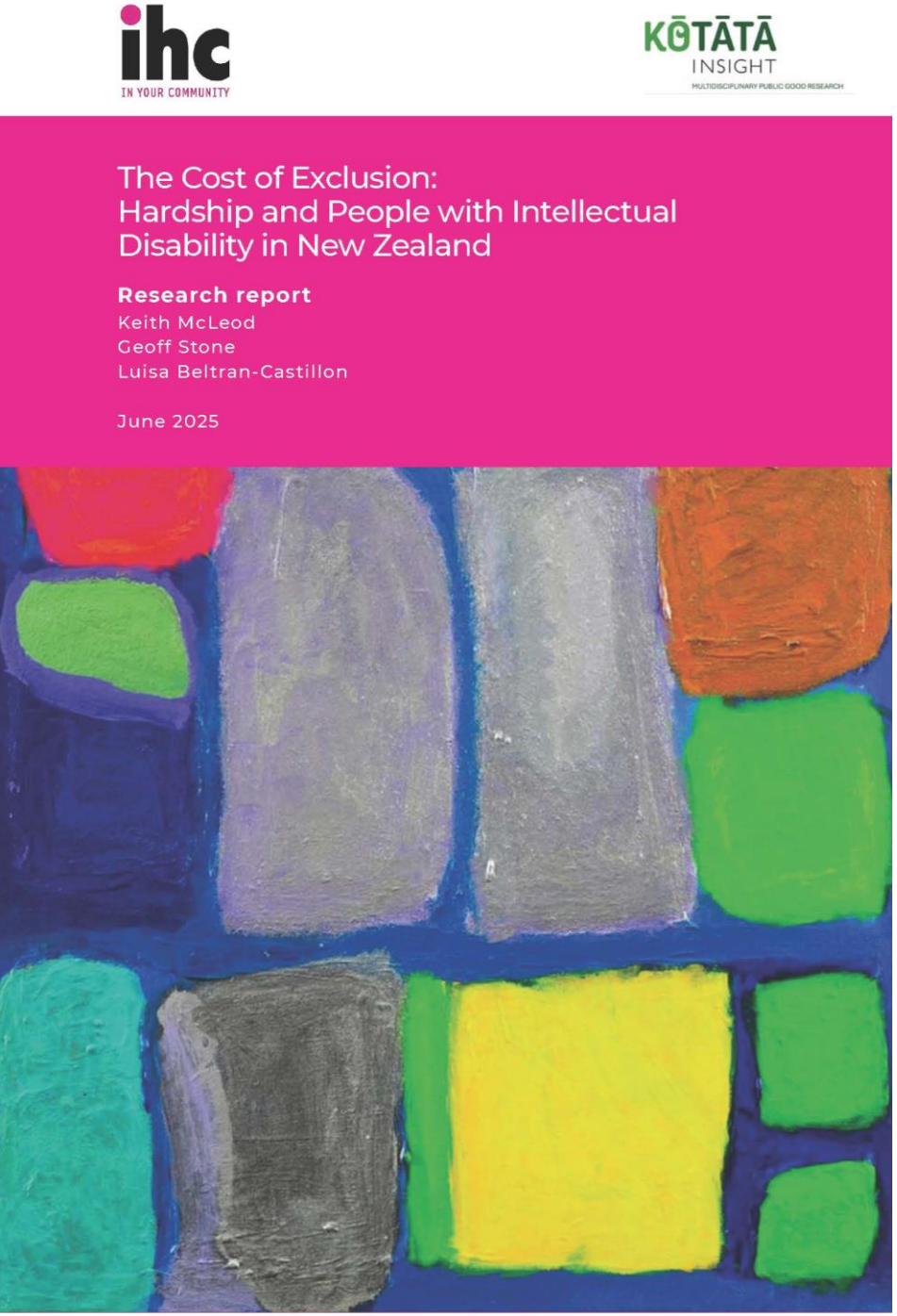
- Children with ID 7x more likely to be in state care
- Parents with ID 16x more likely to have children removed
- People with ID
  - 2x more likely to be victims of crime
  - 3x more likely to be imprisoned

# Comparison 2018 - 23

- Population slightly increased
- Possible delays in getting diagnosis for children
- Māori women with intellectual disability lower life expectancy compared to 2018
- No evidence life expectancy gap is closing in NZ
- Fewer visits to the GP
- Dementia rates rising in NZ, rising faster for people with ID

# Comparison 2018 - 23

- Women with ID still more likely to go to the emergency departments and have serious injuries
- Slight increase in potentially avoidable hospitalisations
- School engagement much lower in NZ, but this is worse for students with ID
- People with ID 18-24 more likely to not have a qualification
- Housing quality has improved slightly but people with ID much more likely to be waiting on social housing lists




# Hardship & Cost of Exclusion

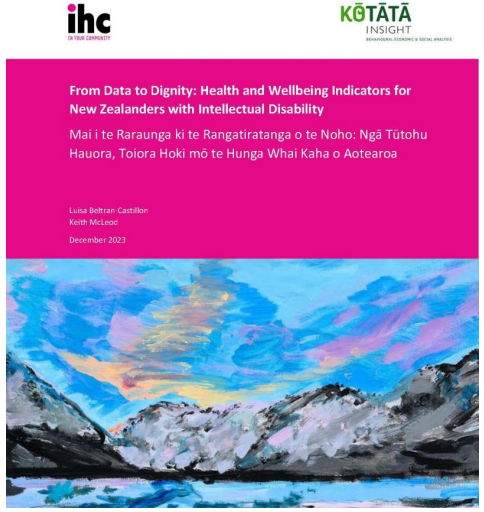
- 2-3x more likely to live in hardship throughout life
- Almost 50% cannot pay an unexpected bill
- 4x more likely to skip meals due to cost
- 3x more likely to lack transport
- Children with ID 7x more likely to miss school events, sports, social opportunities due to cost

# How does IHC use this data?

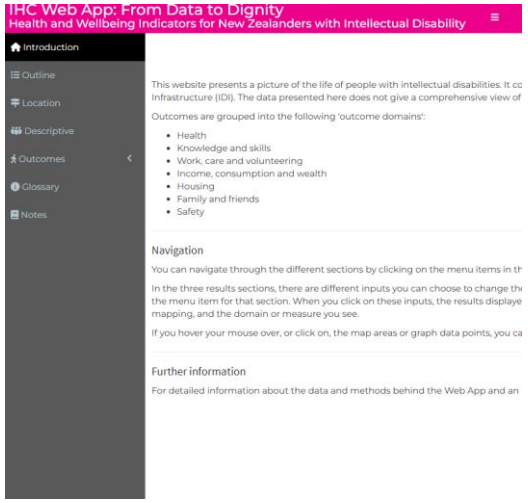
- Evidence building for advocacy
- Cost- benefit and economic framing
- Tracking systemic issues over time
- Making data accessible – for other NGOs and PWID
- Strategic leverage

# What’s next?

- 4 upcoming reports:
  - Workforce participation
  - Special school students
  - Māori with ID
  - Pathways through justice




- From Data to Dignity - https://www.ihc.org.nz/get-involved/advocacy/from-data-to-dignity-campaign




- Data to Dignity Web app - https://ihcnewzealand.shinyapps.io/IDI_report/

- The Cost of Exclusion - https://www.ihc.org.nz/get-involved/advocacy/the-cost-of-exclusion

# Resources