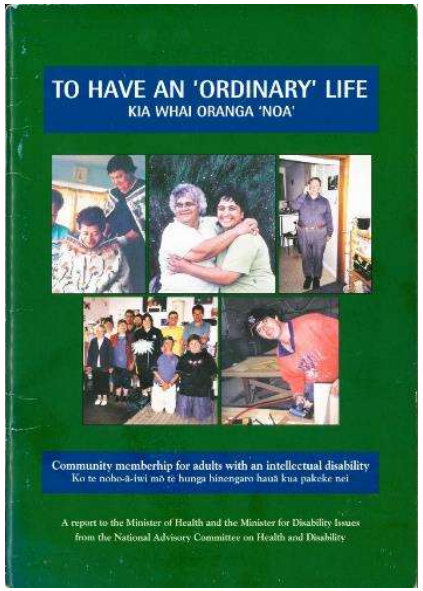
From Data to Dignity: Health and Wellbeing Indicators for New Zealanders with intellectual disability

ihc
IN YOUR COMMUNITY

To Have an Ordinary Life

“adults with an intellectual disability have difficulty accessing rights of citizenship. Their lives are very different from other New Zealanders and not consistent with the vision of the New Zealand Disability Strategy. Adults with an intellectual disability are seldom integrated into community life on their own terms, individual choices in the most fundamental of life decisions are not available to them, and their aspirations and goals are not supported”

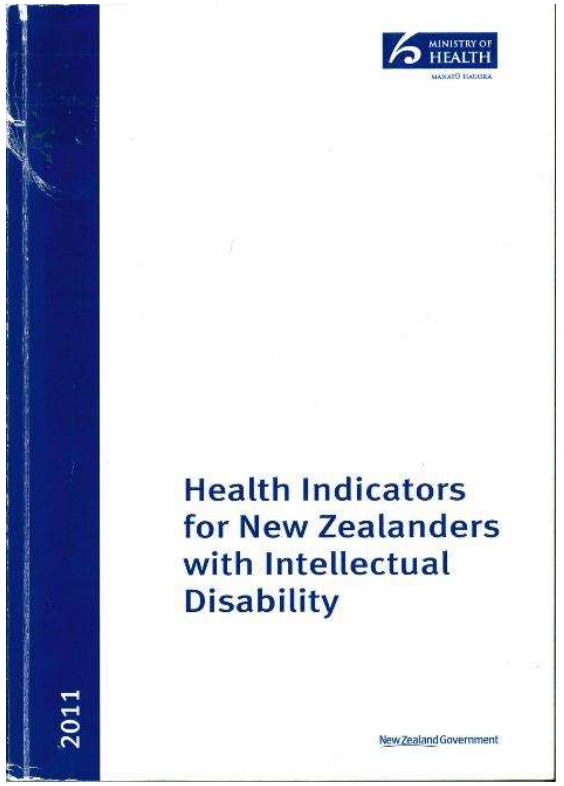


To Have an Ordinary Life

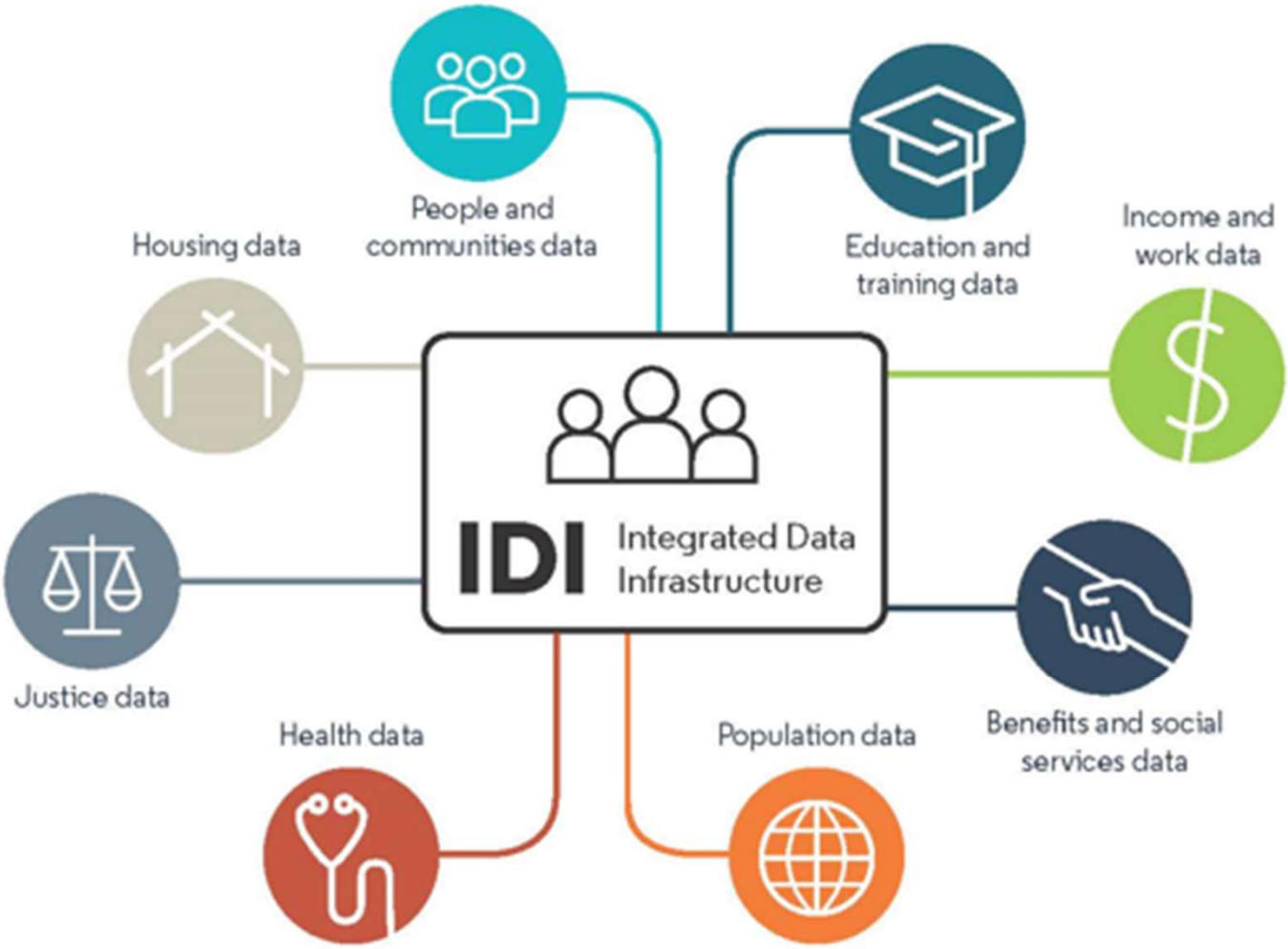
1. Systemic neglect of the development potential of intellectually disabled people;
2. Inadequate and improper health care provision;
3. Low levels of understanding among people in authority of the impact of their actions and decisions, on the lives of adults with an intellectual disability;
4. Worryingly high poverty levels;
5. Low educational opportunities;
6. Little opportunity to form sustaining personal relationships;
7. A lack of purposeful futures.

Health Indicators for New Zealanders with Intellectual Disability 2011

- 17 times more likely to be treated for a psychotic mental disorder
- 1.5 times more likely to be treated for one of the six most significant chronic health conditions
- Health costs 3 times higher
- Life expectancy estimates 23 years shorter
- Less likely to have had preventative screening



- Information about more than nine million individuals
- Information covering crime, education, health, medical, social welfare, tax data
- The ‘five safes’ framework
- Links everyone's records across multiple datasets before removing all identifiable features such as names, or unique identifies numbers



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
- Immunisation – from 2005
- 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

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
- Programme for the International Assessment of Adult Competencies – 2014

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

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
- Departures and arrival cards – from 1997
- Visa applicants – from 1997
- Census – 2013 and 2018

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

Housing data

- Tenancy – from 2000
- Social housing – from 2000

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 results are based in part on tax data supplied by Inland Revenue to Stats NZ under the Tax Administration Act 1994 for statistical purposes.

Any discussion of data limitations or weaknesses is in the context of using the IDI for statistical purposes and is not related to the data's ability to support Inland Revenue's core operational requirements.

Finding the intellectually disabled population in the data

A diagnosis of intellectual disability

Treatment by health specialties for people with intellectual disability

Cognitive criteria defined as moderate to high cognitive needs, high cognitive needs, or very high cognitive needs

A need type of intellectual disability in a gateway assessment

47,055

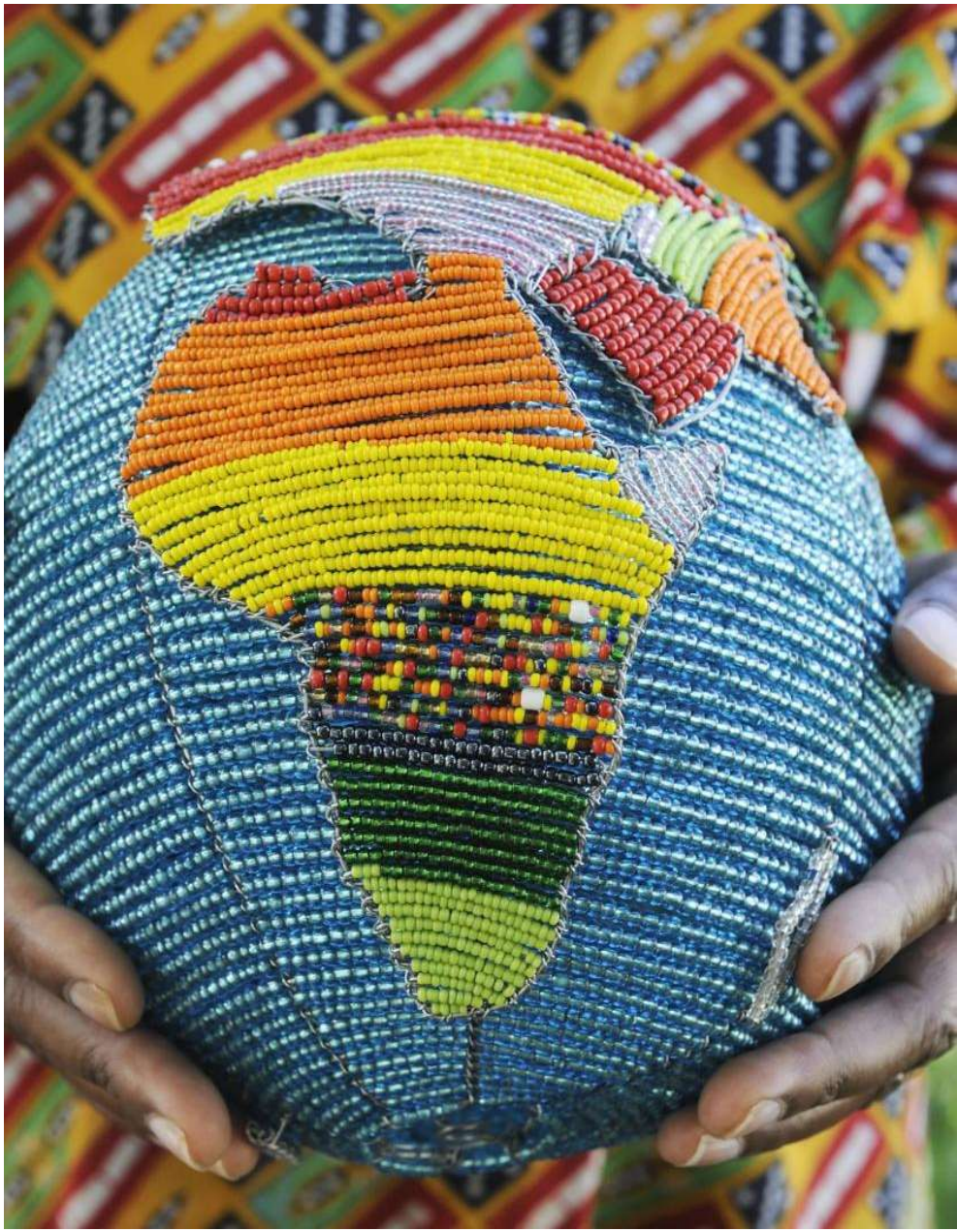
1% of the New Zealand population

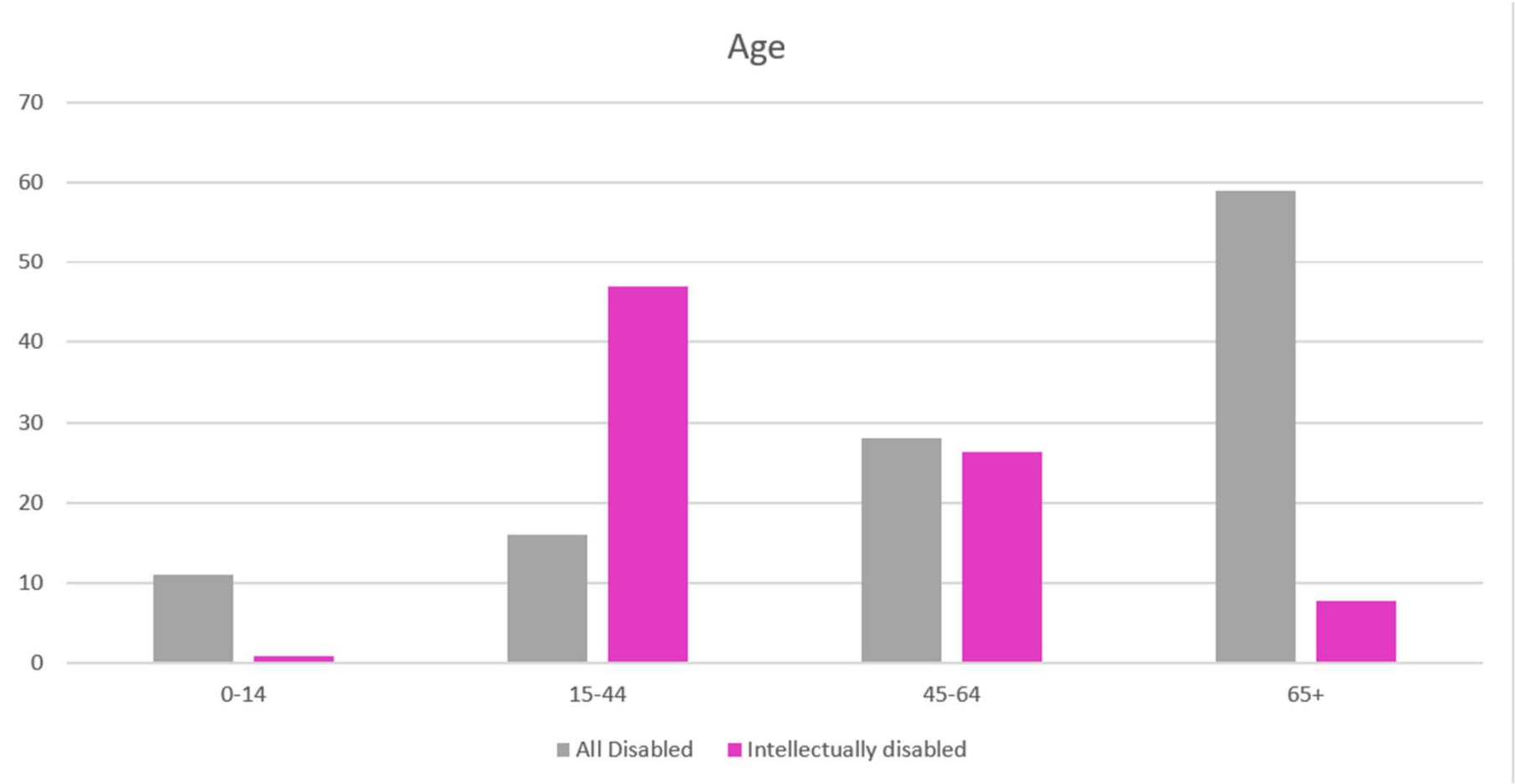
Life expectancy comparison

	Gen Pop 2008	ID Pop 2008	Gen Pop 2018	ID Pop 2018
Male	78	60	80	65
Female	82	60	84	66
Māori Male		N/A	73	62
Māori Female		N/A	78	63

World life expectancies

1. Lesotho 50.75 years
2. Central African Republic 53.10 years
3. Somalia 56.47 years
4. Eswatini 57.73 years
5. Mozambique 58.14 years
6. Kiribati 59.42 years
7. Chad 59.63 years
8. Guinea-Bissau 60.22 years
9. Zimbabwe 60.68 years
10. Sierra Leone 60.77 years
11. Guinea 61.01 years
12. Intellectually disabled Māori men 61.90 years
13. Equatorial Guinea 62.19 years
14. Botswana 62.25 years
15. Democratic Republic of Congo 62.35 years





Age comparison

Health outcomes

- More than twice as likely to have coronary heart disease
- 1.5 times more likely to have chronic obstructive pulmonary disease
- 1.7 times more likely to have diabetes
- More than twice as likely to have to go to hospital to have injuries treated
- Intellectually disabled women are more likely to need to go to hospital for an injury than any other group
- 3 times more likely to have been treated for mood disorders
- Almost 16 times more likely to have been treated for a psychotic disorder (this most likely includes usage of psychotropic medicines to control challenging behaviour)

Health outcomes

- Over 3 times more likely to have been treated for dementia
- Dementia appears earlier for intellectually disabled people (around 45) than for the non-intellectually disabled population
- Over 2 times more likely to have been treated for any type of mental health condition
- Intellectually disabled people take 1.5 times more different medicines
- Attend the hospital emergency department over 2.5 times more often
- Hospitalised over 3.5 times more often for something that could have been avoided, such as injuries, or skin infections,
- Secondary health costs are almost five times higher for intellectually disabled people

Children with an intellectual disability - wellbeing

- More likely to live in a low-income household
- 1.9 times more likely to have only one parent in paid employment
- 48% of families with a child with an ID have both parents working compared to 64% of families in the general population
- 24% of children with an ID live in the most deprived areas in NZ compared to 15% of the general child population. 44% of Pacific and 35% of Māori children with an ID live in the most deprived areas in NZ
- More likely to live in a mouldy home compared to the general population

Children with an intellectual disability - wellbeing

- 1 in 5 children with an ID live in a crowded home
- 36% of children with an ID live with a sole parent compared to 26% in the general population
- Children with an ID are 30% more likely to be born to teen parents
- Children with an ID are 7 times more likely to be placed into state care than general population
- Parents with an ID are 15 times more likely to have their child placed into state care than general population
- Almost 20% of children with an ID were reported by police as being present during a domestic violence call

Adults with an intellectual disability - wellbeing

- 69% of PWID have access to the internet compared to 91% of the general population. Less than 50% of PWID 45+ have access to the internet
- Reduced likelihood of travelling overseas by between one third to one half
- 31% of PWID hold a driver's licence compared to 89% in the general population
- 43% of PWID have a qualification compared to 87% of the general population
- 21% of PWID are in paid work in comparison to 78% of the general population
- PWID are 8 times more likely to receive a benefit

Adults with an intellectual disability - wellbeing

- 21% of PWID live in the most deprived places in New Zealand compared to 11% of the general population
- 39% of young PWID are NEET vs 13% of the young general population
- PWID have greater transience – moving to an average of 4.3 houses in five years compared to the general population who move to an average of 3.3 houses
- 3.3 times more likely to be a victim of crime
- 1.6 times more likely to have a criminal conviction
- 3.3 times more like to have been incarcerated

Interesting things

- Increase in life expectancy – needs improvement
- For PWID under 34 there is a significant increase in the number of PWID who have at least a level 1 qualification could the education system be becoming more inclusive?
- Māori PWID are the most likely to have a level 2 qualification
- Stats for Asian PWID could be unreliable due to small number of Asian PWID in NZ
- 83% of children with an ID live with a birth parent compared to 95% in the general population but this reverses as children age with 46% of 25 – 34-year-old PWID living with a birth parent compared to 18% of the general population

Where to from here?

- PWID in New Zealand need targeted intervention and investment from government
- IHC is developing a suite of policy ideas – grateful for input
- Completed a robust cost benefit analysis on funded annual health checks - have been advocating for this since 2008!
- IHC have a web application that contains all the data:
- https://ihcnewzealand.shinyapps.io/IDI_report/
- Completing six more research projects using data from the IDI

Additional research projects

1. **Update wellbeing indicators report five years on**
2. **Income, poverty and living situation**
3. **Intellectually disabled people in the workforce**
4. **Intellectually disabled students who attended special schools**
5. **Māori with ID**
6. **People with ID pathways through the Justice system**

National Health Strategy

1. Government funded comprehensive annual health checks for all intellectually disabled people
2. Targeted preventative screening programmes for intellectually disabled people
3. Mandatory curriculum and ongoing professional development for healthcare professionals including mental health professionals.
4. Policies that aim to improve the health literary and advocacy skills of intellectually disabled people their families and whanau.
    a. Health information in plain language, Easy Read and video format.
    b. Promotion of health literacy and advocacy skills.
    c. Better use of health passports.
    d. Lobby government for a national electronic healthcare record.
    e. Ensure that balanced evidence-based information is available about intellectual disability particularly to parents.

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trategy

5. Consideration of adopting twin track approach to all models of care across the lifespan.

6. Fund and accredit specialist intellectual disability healthcare positions and teams.

7. Ensure that the transitions between paediatric to adult to geriatric health services are seamless for intellectually disabled people.

8. Funding for carers and other people close to the intellectually disabled person to be part of the care team in a hospital setting.

9. Requiring public health organisations to develop policies to improve the health of intellectually disabled people.

10. Establishing disability liaison officers with first-hand experience of intellectual disability in hospitals.

11. Identify intellectually disabled people as a priority population in health, with monitoring of their health outcomes. This includes implementation of:

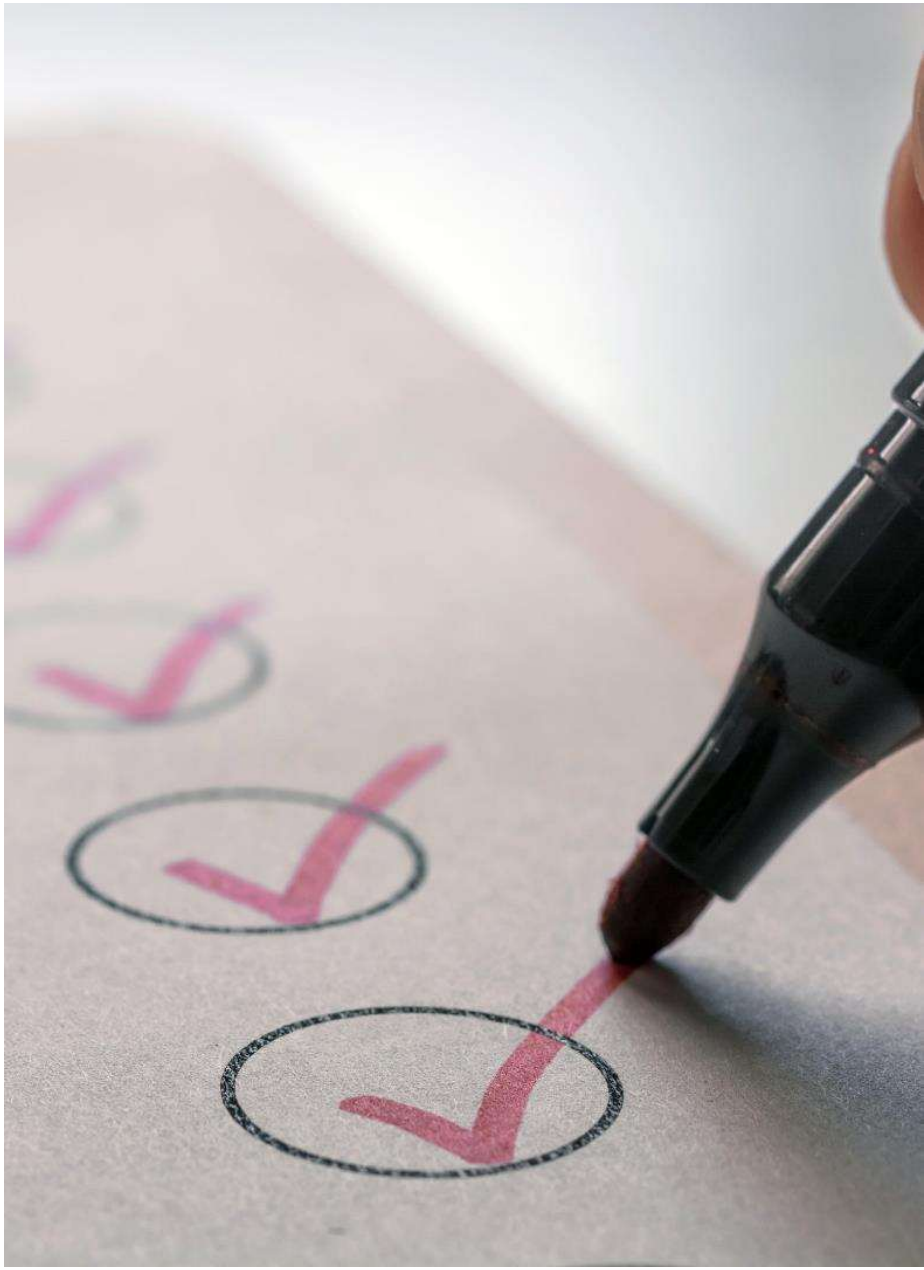
   a. an intellectual disability marker in health records.
   b. a national strategy aimed at stopping the over medication of intellectually disabled people with psychotropic medicines.
   c. a quantitative health wellbeing framework (that includes oral health).
   d. a mortality review service improvement programme about the deaths of intellectually disabled people (such as the United Kingdom's LeDeR).

Annual health checks

- Overseas research has shown that intellectually disabled people experience much higher rates of potentially avoidable death – nearly half of the deaths for intellectually disabled people in the UK in 2022 were avoidable (White, et al., 2023).
- Intellectually disabled people have a risk of death more than three times higher, even after adjusting for differences in comorbidity (Carey, et al., 2017).
- A comprehensive annual health check is available for intellectually disabled people in Australia, the United Kingdom, and in the United States.
- Many of these checks have been in place for over ten years, and there is lots of evidence on how effective they are.

Annual health checks have shown:

- A possible five-year increase in life expectancy – similar checks for geriatric populations have shown such an increase (Lennox, et al., 2007)
- An increase in the improved detection of new health problems – one controlled study showed a 60% increase in new diagnosis with an average 2.54 additional health problems identified. A study using data from these controlled studies showed an increase in health costs of only $60 (NZD) per year for participants in the check. (Lennox, et al., 2007)
- an uptake of preventative medicine and screening for participants. (Lennox, et al., 2007)
- 27% reduction for potentially avoidable hospitalisations (Carey, et al., 2017)
- improved seizure control and weight management (Carey, et al., 2017)
- Reduction of self-reported pain, falls and ER visits (Aronow & Hahn, 2005)
- Resolution of psychiatric problems by the identification of underlying physical problems (Ryan & Sunada, 1997)
- 20% reduction in emergency room visits for intellectually disabled people with severe health needs (Carey, et al., 2017)



Annual Health Checks CBA

Health check cost	
Use of CHAP tool (per person)	$11
Sixty-minute patient co-payment for GP (per person)	$147
One visit with practice nurse to run through check and order tests	$60
Estimated increase in health costs due to use of health check (per person)	$60
Total health check cost (per person)	$278.00
Current intellectually disabled pop	47,000
Total cost of health check for cohort (annual)	$13M
Benefit of annual health check – reduce Potentially Avoidable Hospitalisations	
Number of PWID who had a PAH in 2018	8460
Cost for this cohort to have a PAH (annual)	$63M
Cost saved if PAH reduced by 27%	$17.1M

References

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