

Using Available Data Sources to Describe the Population of People with Intellectual Disability in New Zealand

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Craig Wright, Senior Advisor, NZ Ministry of Health

The Project Team

- Alixe Bonardi, Ian Axford Fellow, Assistant Director, University of Massachusetts Medical School
- Amanda Hinkley, Policy Analyst, Population Health Directorate, Ministry of Health
- Craig Wright, Senior Advisor, HDSS Directorate, Ministry of Health

Presentation Outline

1. Impetus

- Concerns about the health of people with an ID

2. Opportunities in current MoH data sets

3. Summary of findings so far

4. What the data can and cannot tell you

5. Next steps:

- work within MoH
- opportunities for partnership

Expectations of the government

...

“We expect the Public Service to understand that it needs to change in order to deliver faster, better, smarter, and better public services to thousands of New Zealanders who are dependent on [those] services”

-- Hon Bill English 22 July, 2009

(Transcript from Questions for Oral Answer)

Intention of data collection and analysis

- Initial investigation of data & opportunities
- Focus on people with intellectual disabilities (as a sub-group of the population)
- Availability & accessibility of good data
- Needs, utilisation, status and quality of life
- So that health systems and policies can:
 - better target resources
 - more readily respond to need
- A population health approach to improve health outcomes for New Zealanders (not just people identified with ID)

Current health and disability information needs

- Demographics:
 - age distribution,
 - ethnicity,
 - domicile grouping and location.
- Need and outcomes:
 - level of need (trends),
 - indicators and outcomes of service delivery,
 - mortality and morbidity,
 - health system utilization.

Opportunities in current MoH health data systems

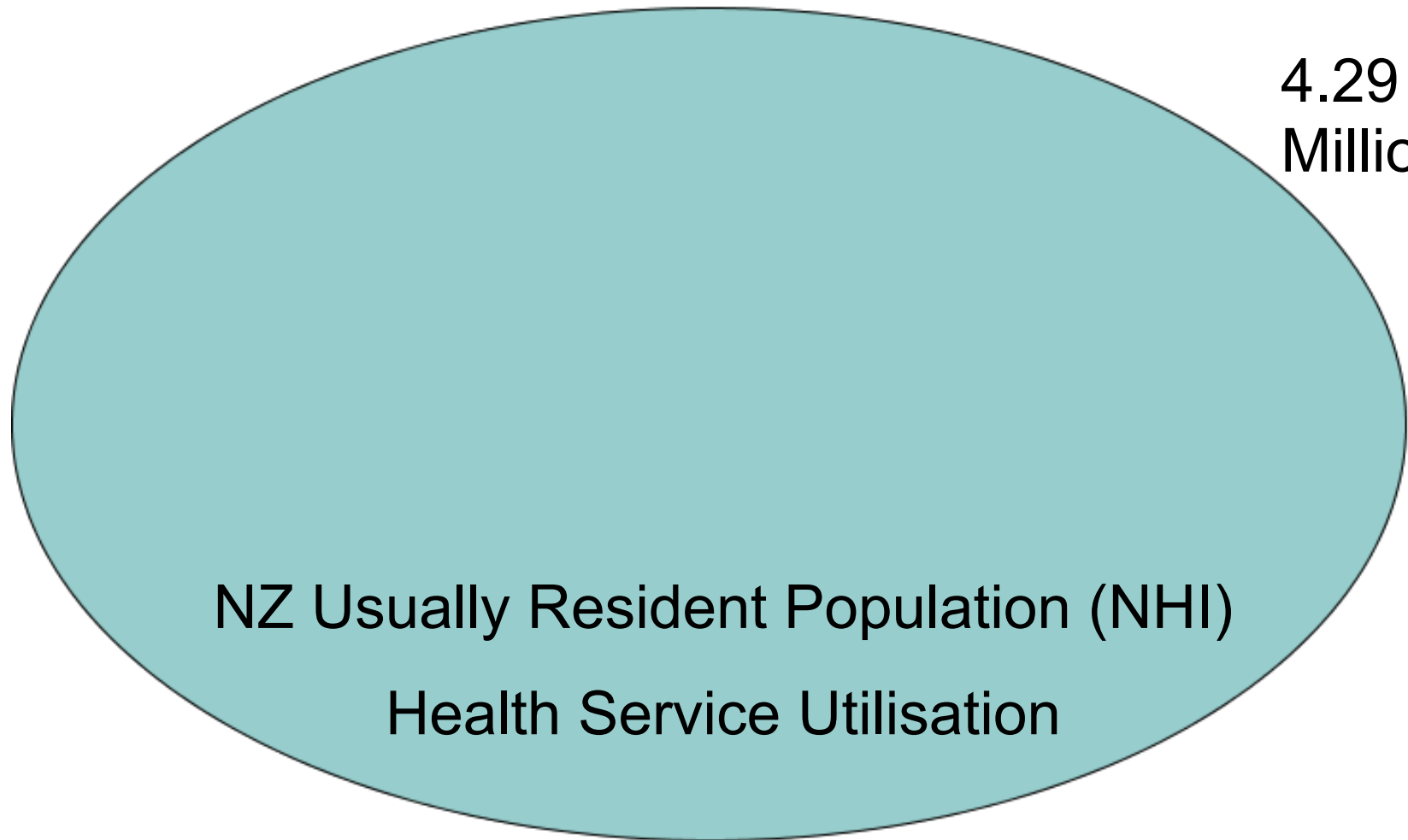
De-identified data frame representing 20,953 people who:

- Have accessed NZ government funded health services and have been identified with ICD-10 codes F70, F71, F72, F73, F78, F79 (Intellectual Disability)

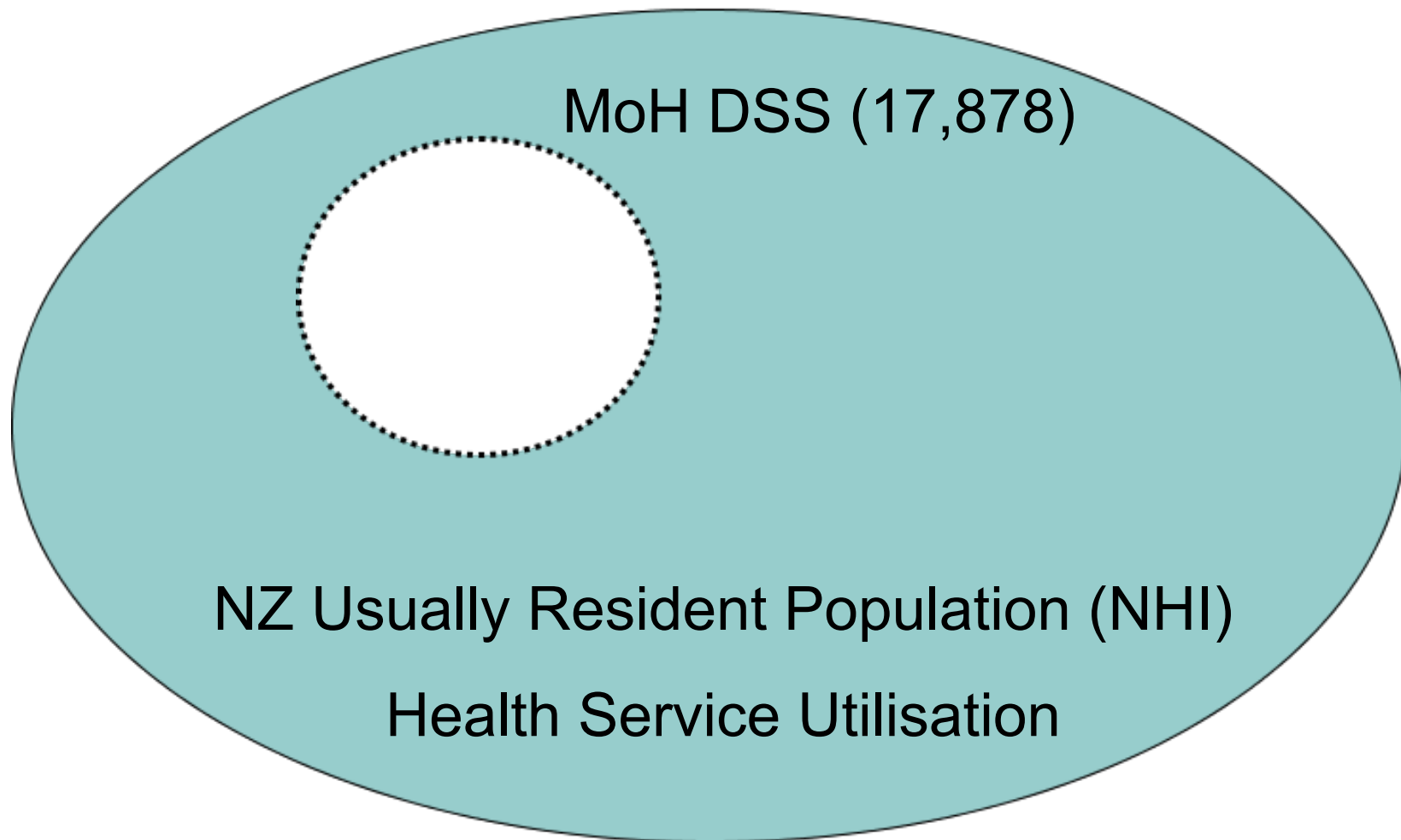
and/or

- Have received an ID residential or other service funded through the MoH's Disability Support Services.

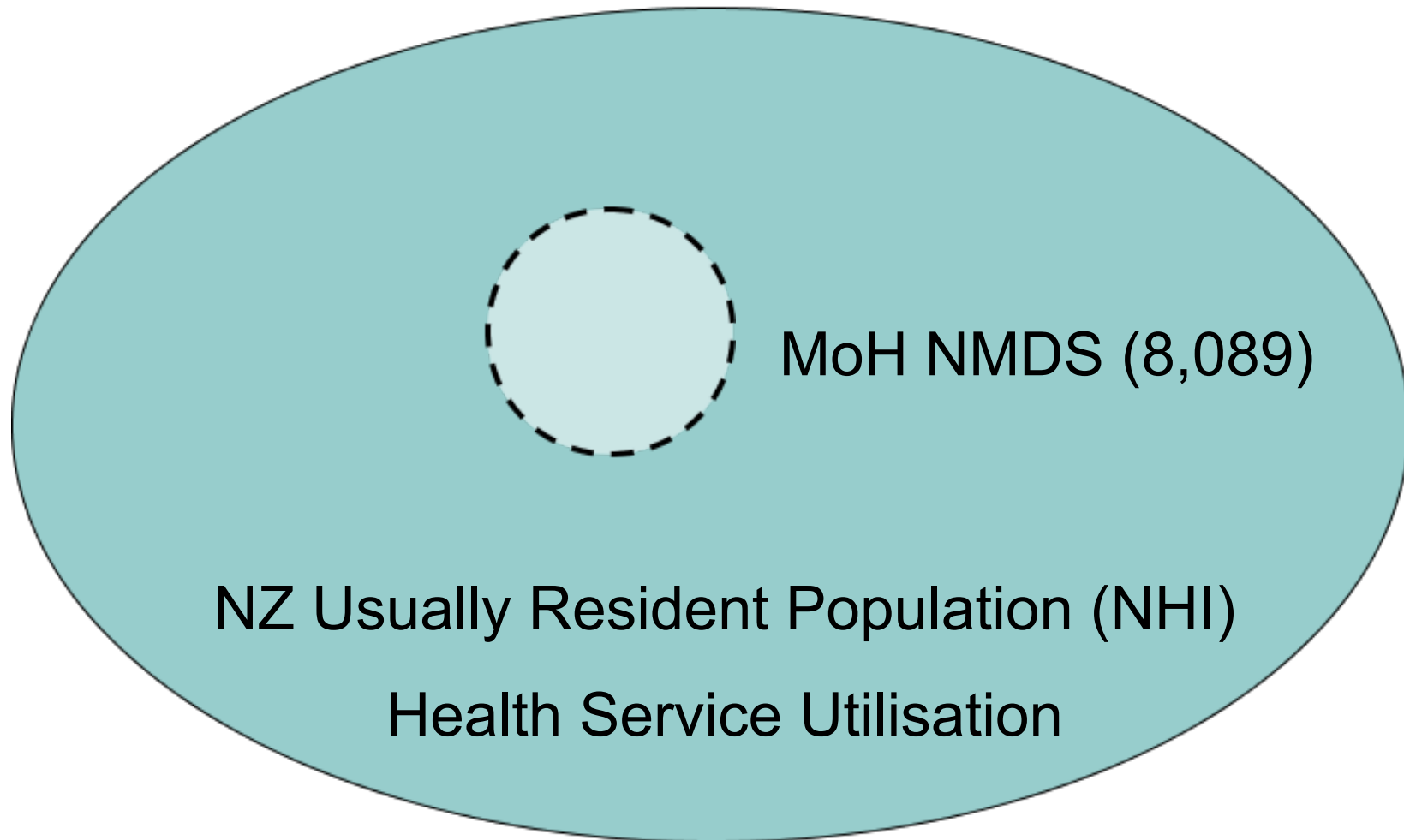
Opportunities in current MoH health data systems



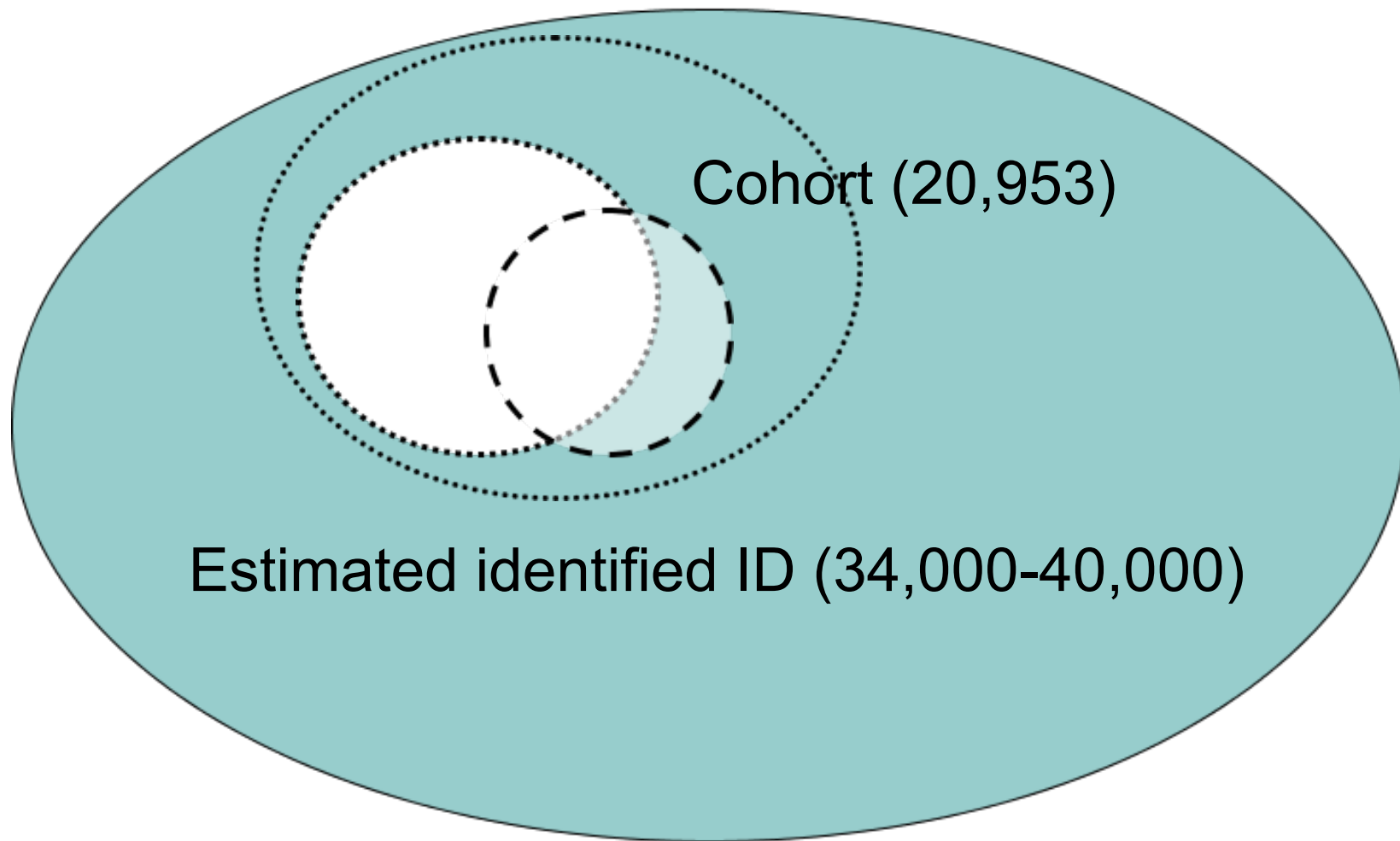
Opportunities in current MoH health data systems



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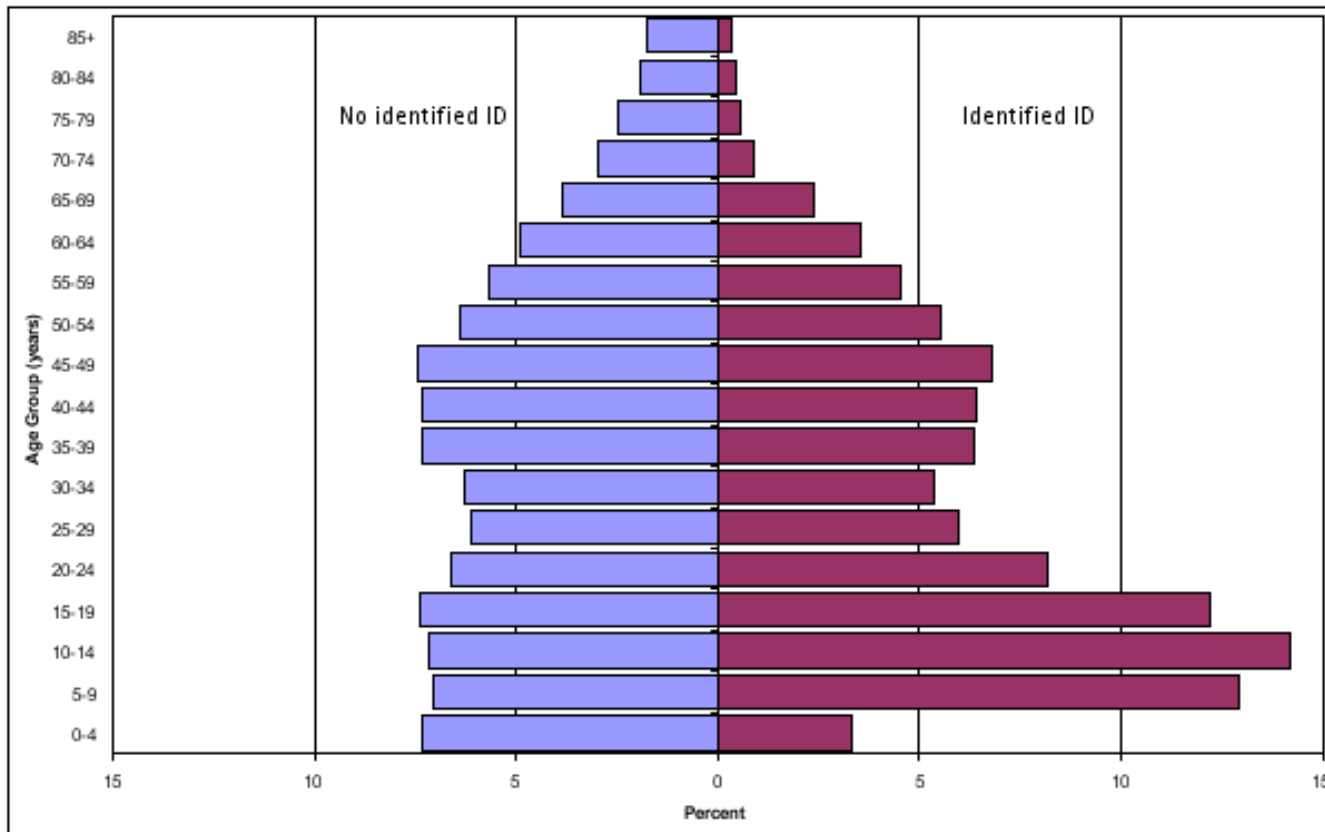
Opportunities in current MoH health data systems



National Databases linked through NHI

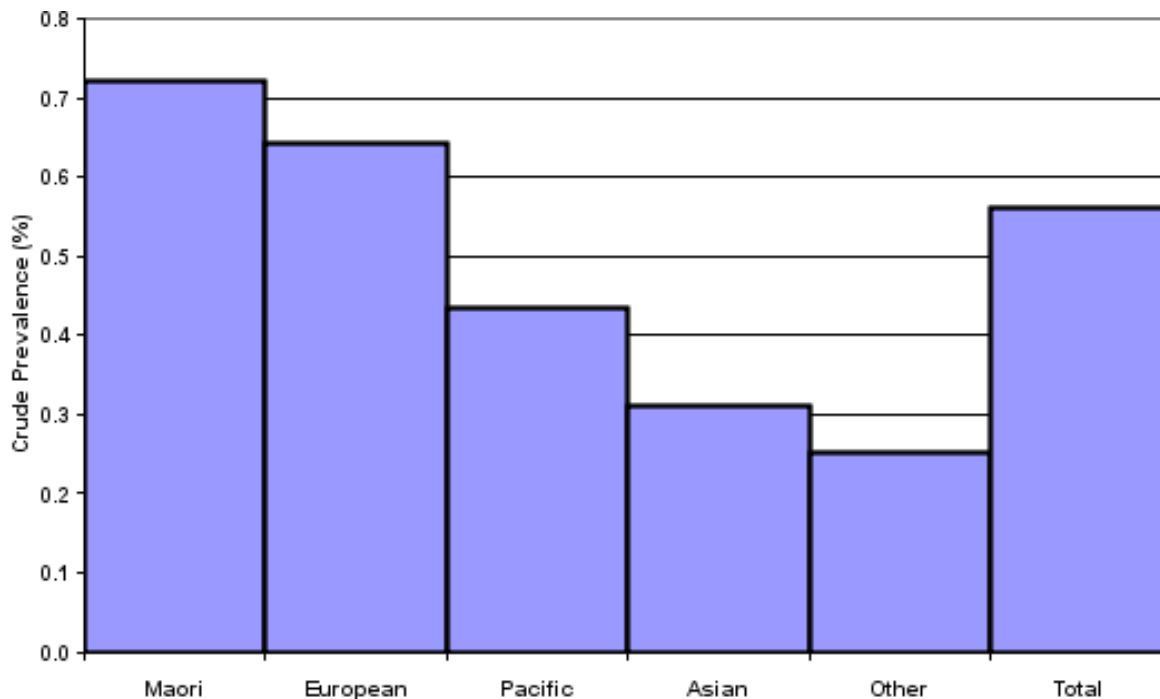
- Births Deaths and Marriages (BDM)
- National Minimum Dataset (NMDS)
- Non-admitted patient collection (NNAPC)
- Pharmhouse (Community Dispensing)
- Mental Health Information National Collection
- Primary Care Organisation Datamart
- CMS & CCPS (DSS payments and contracts)
- Socrates (NASC) data emerging

Preliminary Analyses: Population Pyramid



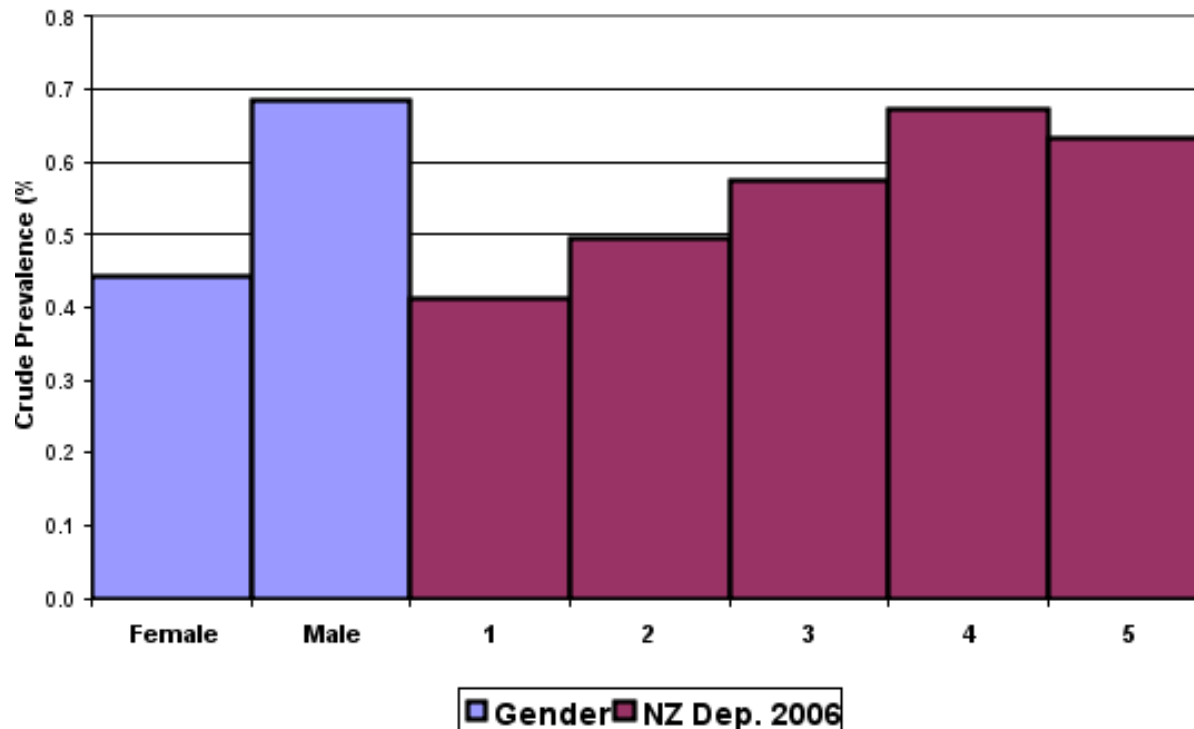
- Smaller numbers over age 50
- Identification of ID after age 5
- Identification may be 'presumed' prior to age 19, when formal assessment confirms identification

Preliminary Analyses: Ethnicity



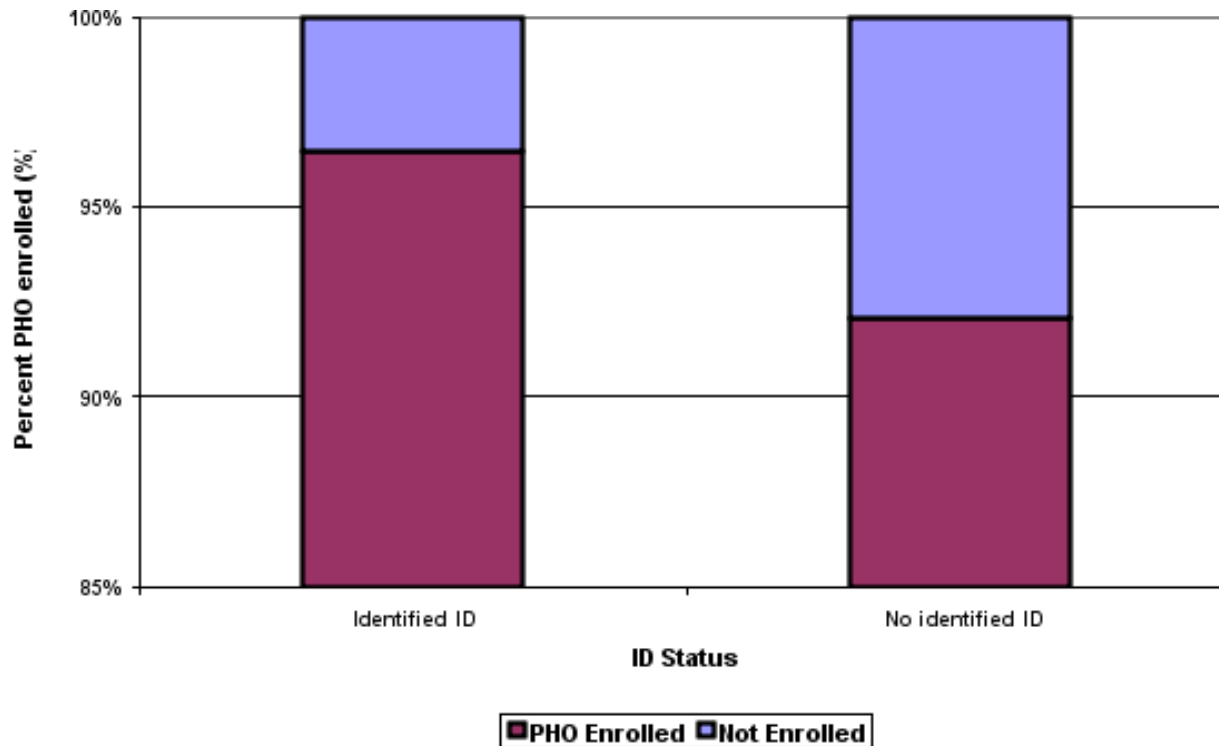
- 0.7% of Maori population identified with ID
- 0.4% of Pacific Island population identified with ID
- Other includes 'no ethnicity data'

Preliminary Analyses: Gender & Dep. Band



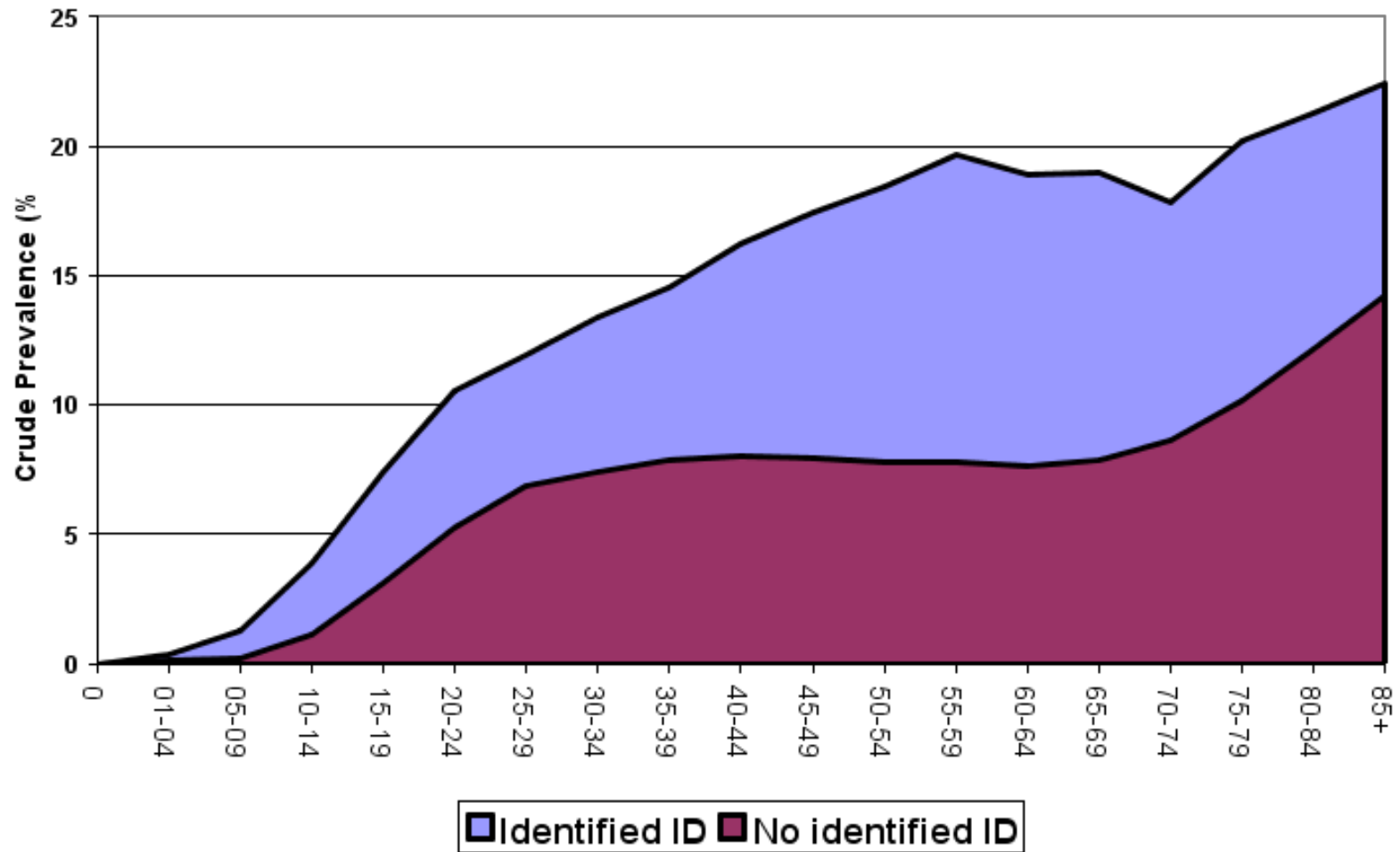
- 0.4% & 0.7% of Females and Males respectively *identified* with ID
- Increasing gradient with Deprivation
- Gradient drops in last Quintile (5)

Preliminary Analyses: PHO Enrolment

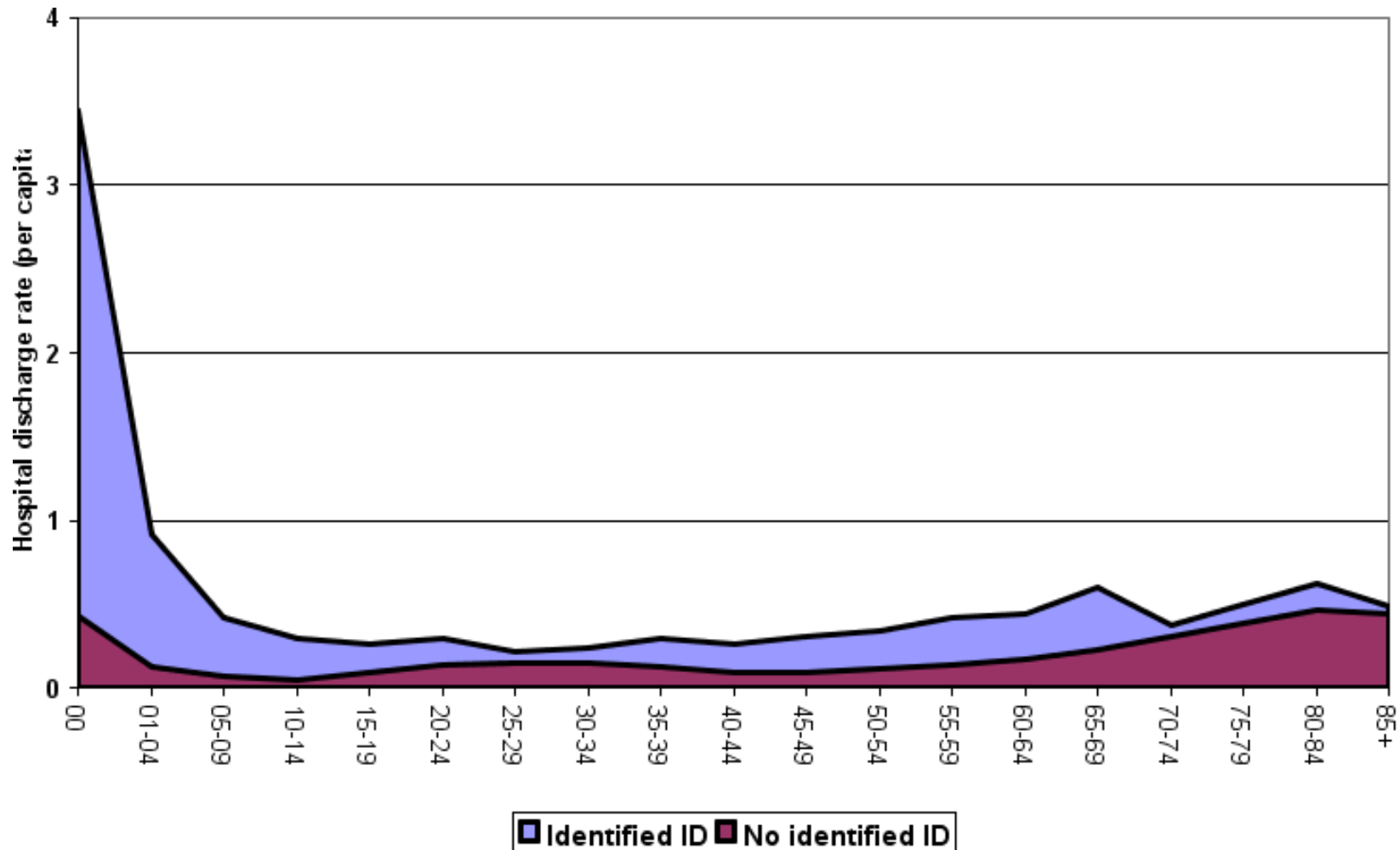


- Rate of PHO enrolment for people identified with ID 44% of people not identified with ID (3.5% : 7.9%)

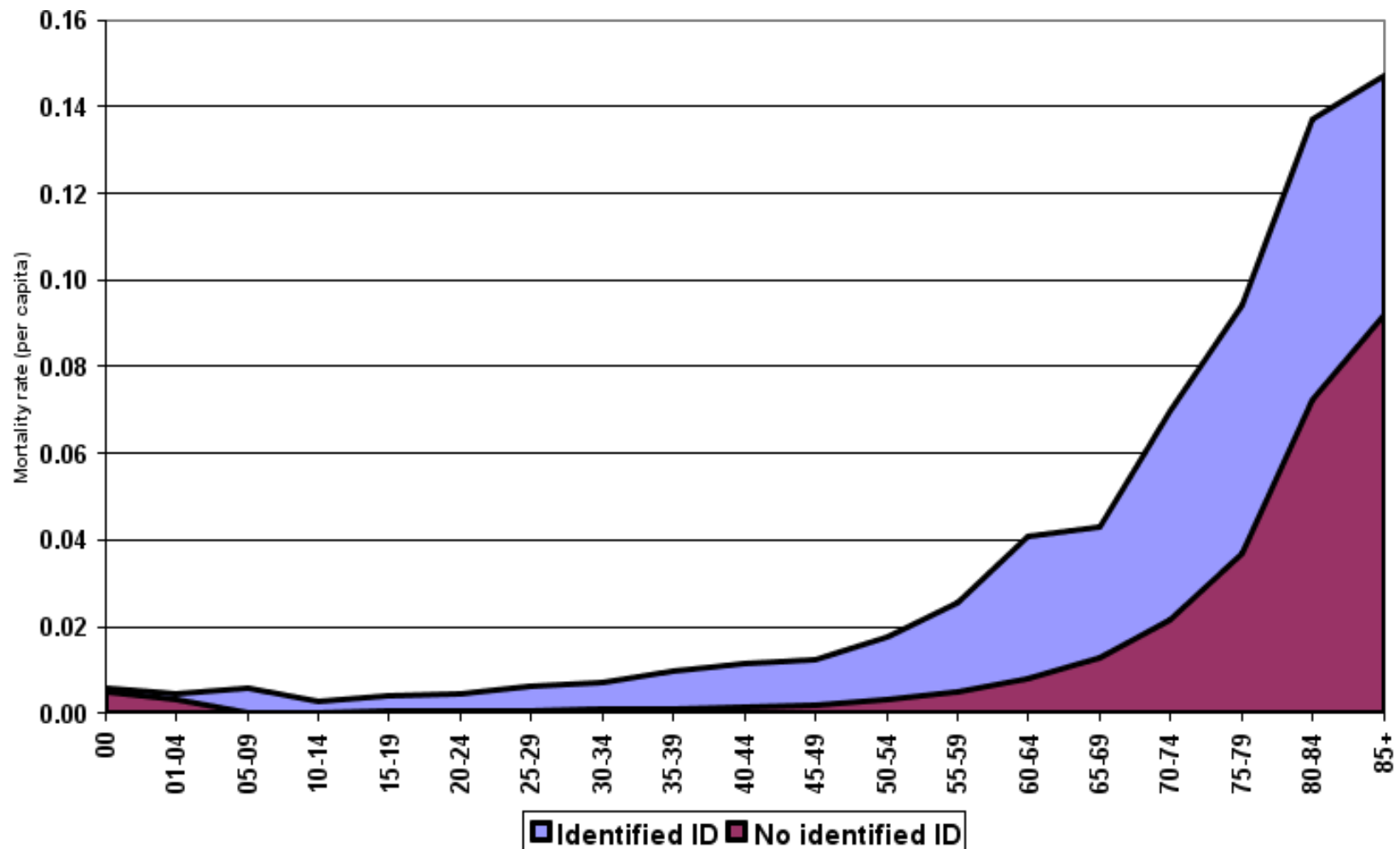
Preliminary Data: Chronic Disease (Mood Disorders)



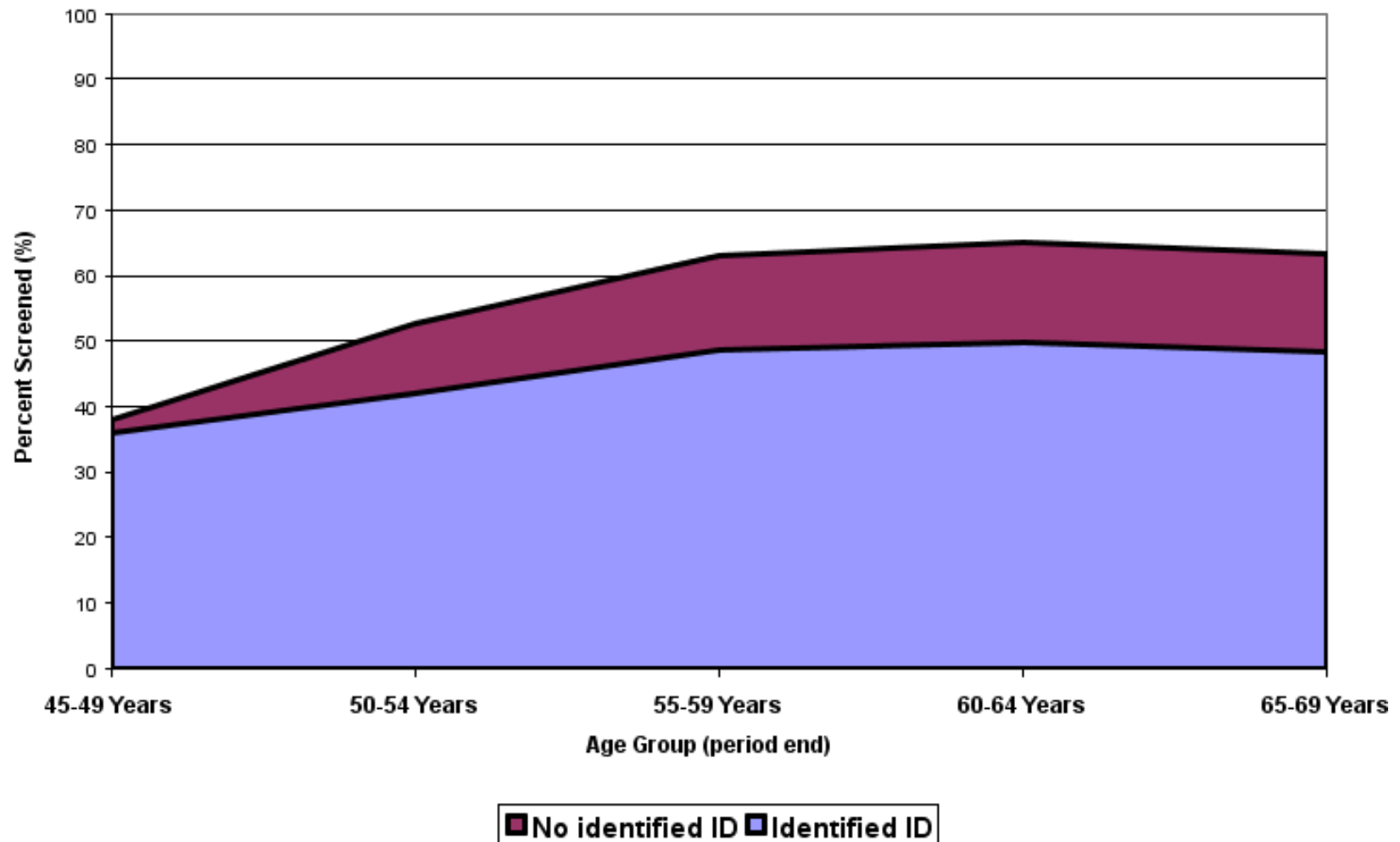
Preliminary Data: Hospital Discharge 2008



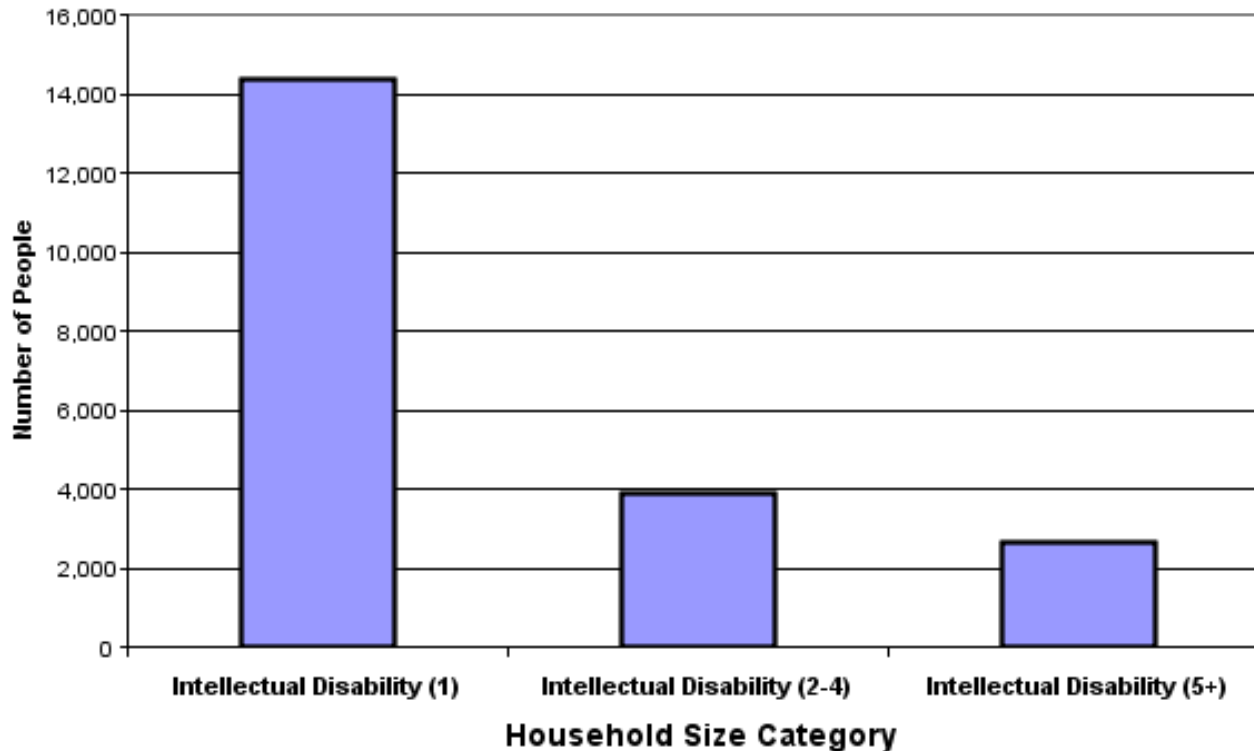
Preliminary Data: Mortality 2008



Preliminary Data: Utilisation (BSA 2006-2007)



Preliminary Data: Domicile Information



- Over 14 thousand people live in households where only one person has been identified with ID

What the data can tell you:

- Emerging demographic patterns that may change service demands
- Trends over time and in comparison to general ('background') population
- Significant population health indicators (e.g. incidence of chronic disease)
- Utilisation of health services – GP contact, Hospital Discharge, Outpatient, Emergency Department, Mental Health Services

What the data can NOT tell you:

- No direct measure of quality of life
- Why people have higher rates of chronic disease and mental illness
- Information about people who are not captured in the current data frame but have an ID
 - People who have not accessed health services
 - People who do not receive ID-specific DSS supports
- Why people with identified ID not accessing health services
 - e.g. health behaviours, unmet need/barriers to access, choosing not to access services

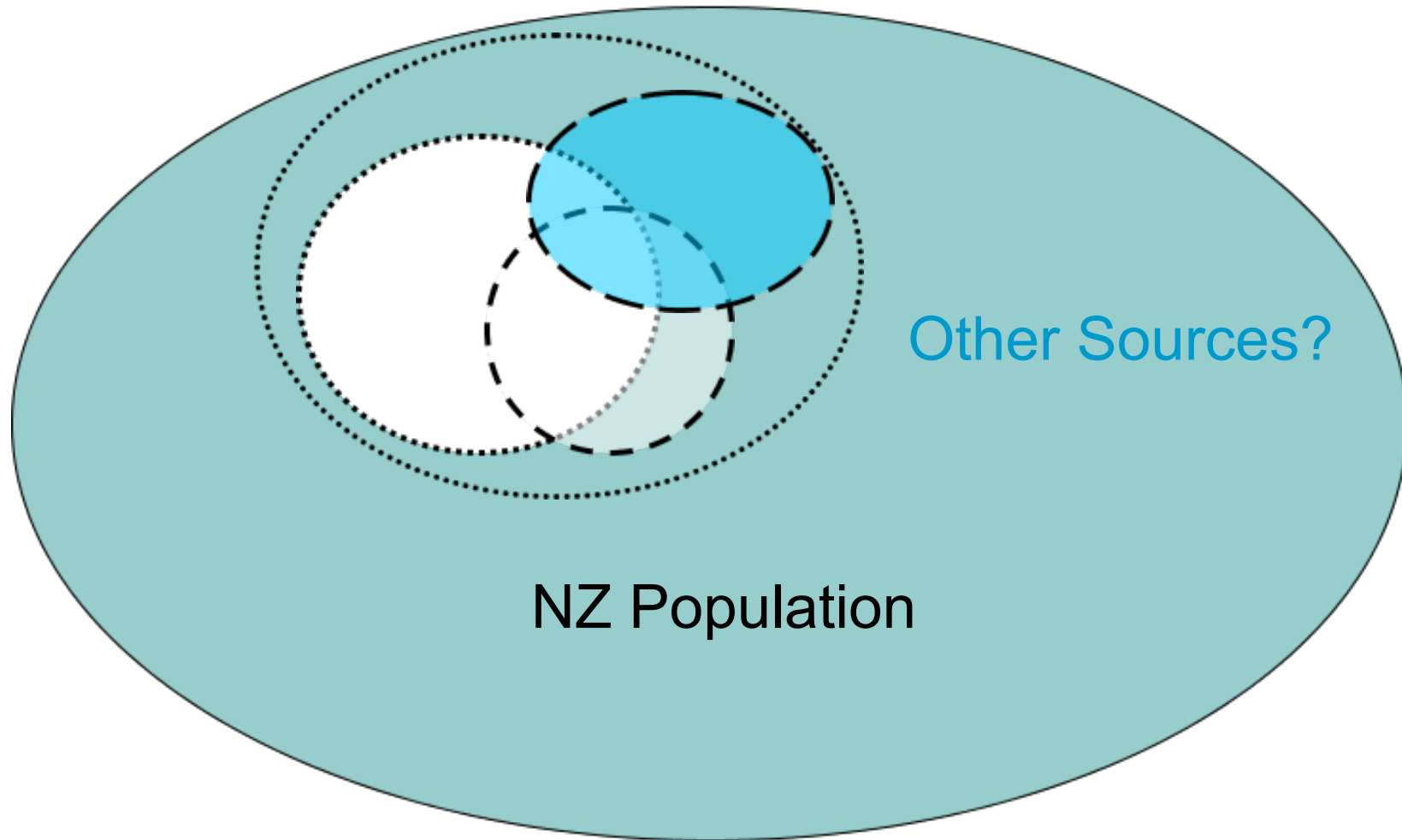
Issues:

- Important to understand population trends, demographics and knowing where people live for service planning
- Necessary to identify service models that enable the best outcomes so they can be expanded
 - This requires good data & the identification of appropriate (sensitive) indicators
- Options to improve health of people with ID in NZ currently under review within MoH
- Work with DHB / providers will be facilitated by a better understanding of the population with ID.

Next Steps under consideration:

- Expand the data frame to better describe the population?
 - Merge with other data systems

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- Expand the data frame to better describe the population?
 - Merge with other data systems
- Periodic reporting of national health indicators for people with an ID?
 - Priority indicators: Mortality, chronic disease, psychiatric indicators.

Contacts

Craig Wright, Senior Advisor, HDSS Directorate, Ministry of Health
Craig_Wright@moh.govt.nz

Amanda Hinkley, Policy Analyst, Population Health Directorate,
Ministry of Health
Amanda_Hinkley@moh.govt.nz

Alixé Bonardi, Ian Axford Fellow (New Zealand)
Assistant Director, Center for Developmental Disabilities
Evaluation and Research, University of Massachusetts Medical
School
Alexandra.Bonardi@umassmed.edu