Position statement on the importance of a NSW intellectual disability data set

The need for a minimum data set

About 1% of the population of NSW have an intellectual disability (ID).\(^1\)

People with intellectual disability usually have multiple complex health issues. People with an intellectual disability make more medical appointments and access more treatments and interventions than the general population. Despite this, they experience poorer health outcomes and shortened life expectancy.\(^2,3\)

People with intellectual disability experience poor health outcomes following hospitalisation (including avoidable re-admissions and death). As well as the human and financial cost of poor health for people with intellectual disability and their families, there is considerable financial cost to the health system.\(^4\) This has significant health care planning implications.

Currently there is no mechanism to retrieve current and historical data efficiently, to identify, monitor and evaluate service initiatives people with intellectual disability.

Research on health outcomes has largely relied on identification of participants through the disability sector because NSW Health does not have a standardised way of identifying and tracking patients with intellectual disability. As a result, there is very limited state (or national) data on specific health outcomes for people with intellectual disability.

Improvements in service provision for the health needs of people with intellectual disability within all tiers of the health system are needed. Unless people with intellectual disability are identified in a standardised manner it is not possible to fully identify their needs or evaluate progress being made.

As an example, the development and use of a comprehensive disability services data set of all people with intellectual disability linked with a WA Health dataset monitoring access to health services in Western Australia has led to a systematic method of monitoring health and service responses. It has also been a very useful advocacy tool for service development for people with intellectual disability.
A survey asking interested health professionals about a minimum data set

In 2013 the Research and Development subcommittee of the NSW Agency for Clinical Innovation Intellectual Disability Health Network, with ethics approval, surveyed academics, clinicians and researchers with an interest in the health of people with intellectual disability. One aim of this survey was to elicit views about the development of a disability data set. 105 people across NSW responded to the survey. They were involved with people with intellectual disability across all ages.5

Respondents were asked about:

- the importance of a NSW intellectual disability data set,
- views about its main purposes,
- whether the information collected should be de-identified or identified, and
- what basic information should be collected.

**Findings**

1. **The importance of a minimum data set**

86% of respondents thought it is very important or essential to have a NSW Intellectual Disability data set.

2. **Major purposes of a data set**

The major purposes of an intellectual disability data set were identified as follows.

- Identification of unmet need in service provision (76%)
- Cross agency coordinated state wide data (68%)
- Improved decision making about health plans for individuals (66%)
- Identification of areas for improvement in health promotion (60%)
- Individual comments suggested benchmarking purposes and data linkages to other data such as Medicare, PBS etc to allocation of resources and future health planning.

3. **Identification of data**

41% of respondents thought the information collected should be de-identified, while 32% were unsure and 27% thought it should be identified.

4. **Basic information types**

When asked about the basic information to be collected:

- 88% suggested basic demographic information (age, sex, postcode, CALD etc)
- 84% suggested medical and health information
- 84% suggested functional level of disability
- 79% suggested primary and comorbid diagnosis.
Need for Universal Identifier to be coded

Intellectual disability is not coded in health records as a co-morbidity for admission or discharge data. This needs to change as we move to Activity Based Funding for health and to the NDIA for disability services.

The literature shows that people with Intellectual disability have more complex health needs and longer admissions. We need data on disability to show that the National Weighted Activity Unit needs to have a factor for intellectual disability. There is a risk that without this recognition of greater need for people with an intellectual disability in the health system, hospitals may choose to not address health needs if they are not be adequately funded. The lack of data limits funding for services, as well as funding for planning and research.

Our recommendations

The NSW Agency for Clinical Innovation therefore proposes that NSW Health undertake work to develop a system for identifying and tracking people with intellectual disability as they enter and move through the health system.

The members of the NSW Agency for Clinical Innovation Intellectual Disability Health Network, based on data collected through its survey, and in the interest of improved health outcomes and health system efficiencies, recommend to NSW Health, that:

1. an identification/alert system for people with intellectual disability is coded on notes and in a data collection system
2. an appropriate minimum data set be established for people with an intellectual disability
3. the data set is an integrated part of the e-records systems and allows for linkages with other data such as NDIS and primary health care records such as Personal Electronic Health Records.


This position statement was written by the Members of the Intellectual Disability Health Network Research and Development Subcommittee.
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