



National Centre of Excellence in Intellectual Disability Health Response to the IHACPA Consultation Paper on the Pricing Framework for Australian Public Hospital Services 2025–26

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Dear Professor Michael Pervan,

Pricing Framework for Australian Hospital Services 2025–26

We write on behalf of the National Centre of Excellence in Intellectual Disability Health to provide input on the IHACPA's policy approach, to develop the national efficient price (NEP) and national efficient cost (NEC) determinations for Australian public hospital services.

There are approximately 480,000 people with intellectual disability living in Australia. People with intellectual disability experience very poor health outcomes and multiple barriers to access to health care that meets their needs. The experience of this group was pivotal to the finding by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) of systemic neglect in health care for people with cognitive disability.

Our NSW data linkage work characterises the outcomes and health service at a near whole of population level for people with intellectual disability. These linkage studies identify about 1.1% of the NSW population with intellectual disability [1]. In the absence of any available source of population health data at a national level, NSW findings can be taken as nationally representative. Below is a summary of some of the relevant findings.

Health outcomes for people with intellectual disability are characterised by:

- premature mortality with median age at death being 27 years earlier than the general population [2].
- double the proportion of potentially avoidable deaths compared to the general population [2].
- four times the rate of potentially preventable hospitalisations [3].

Compared to the general population, acute health care interactions for people with intellectual disability are:

- *over-represented*, with double the rate of hospitalisations and emergency presentations [4].
- *costly*, with:
 - o admissions being on average twice as long and twice as expensive [4]
 - o double the rate of emergency department presentations and annual costs per person year therefore doubled [4]

- mental health costs being grossly inflated, with the 1.1% of people in NSW with intellectual disability accounting for 14% of inpatient mental health expenditure in a given financial year [5].
- *inefficient:*
 - with much higher rates of representation to emergency departments and inpatient units following discharge from mental health facilities even for first ever admission [6].
 - even when using admissions for epilepsy and seizures as an example with a clear clinical pathway, we see great discrepancies. Age-standardised admission rates per 100,000 people are 21 times higher for people with intellectual disability compared to the general population; the admissions are much longer than for the general population; and having intellectual disability is a key driver of readmission within 30 days [7].

A key issue in acute health care settings is that care is poorly tailored to the complex needs of people with intellectual disability. The complex needs of people with intellectual disability are not well known and tailored care is not currently supported by funding models. Our broader work suggests that optimal and efficient care requires adjustments to clinical approaches during the health care contact, as well as detailed planning and care coordination for admissions and discharges. This reflects the wide range of support needs of this population, which can only function effectively when mobilised in a coordinated and considered manner.

Core adjustments commonly needed in hospital by people with intellectual disability involve hospital staff taking extra time for:

- Optimising communication with the person and obtaining consent, including reasonable attempts at supported decision making.
- Gathering information from family, support workers and other clinicians to complement limited historical and diagnostic information obtainable from the person.
- Obtaining substitute consent where the person lacks capacity.
- Additional physical or behavioural examination and diagnostic tests where the person is unable to adequately describe their symptoms.
- Providing accessible information and reassurance to the person at all stages of an admission.
- Meeting behavioural support needs in the hospital.
- Otherwise meeting physical and cognitive support needs in hospital.

We strongly suggest that the Pricing Framework for 2025-26 and beyond includes the application of a multiplier to all Diagnosis Related Groups (DRG) for people with intellectual disability, rather than seeking to define the additional effort activity by activity. The complexity loading should be uniformly applied where it relates to people with intellectual disability, given the additional accommodations that are required for quality care to be provided. A complexity loading for intellectual disability supports the application of reasonable adjustments, recognises the additional complexity encountered during the admission and would facilitate approaches to better plan for and coordinate supports at discharge, which in turn would reduce readmissions.

As 'intellectual disability' is not currently routinely collected in hospital morbidity datasets at a national level, the inclusion of this multiplier across all DRGs in the Pricing Framework would greatly assist in helping us to collect these data at a national level.

Furthermore, an activity-based funding model has the capacity to incentivise what we know works for people with intellectual disability. For example:

- Preadmission multi-disciplinary planning for people with complex needs.
- Use of social work/occupational therapy teams in Emergency Departments and on admission.
- Opportunistic sedation clinics (for when it would be helpful to do multiple consented procedures while the person is under a general anaesthetic).
- Multi-disciplinary outpatient clinics for some diagnostic groups.
- Collaborative and multi-disciplinary discharge planning.
- Post-discharge care coordination for when care needs change.

The ABF model incentivised in the Pricing Framework for Australian Hospitals could drive better experiences in hospital and better health outcomes for people with intellectual disability.

We finally note and emphasise that acting on our proposal is squarely in line with Recommendation 6.32 of the Disability Royal Commission which calls for hospital funding models to be reviewed with a view to ensuring that adaptations and supports needed by people with cognitive disability can be routinely implemented.

We look forward to seeing our feedback incorporated into the Pricing Framework for Australian Hospital Services 2025-26 and beyond. We appreciate the opportunity to provide feedback. Should you require any further information, please contact me on +61 (2) 9348 2126 or at j.trollor@unsw.edu.au.

Yours sincerely;

Professor Julian Trollor

Director, National Centre of Excellence in Intellectual Disability Health, on behalf of the Driving Change Team (Sophie Howlett, Jim Simpson, Simon Cotterell and Dr Rachel Skoss)

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