

Potentially preventable hospitalisations of people with intellectual disability in New South Wales

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The known: People with intellectual disability face stark health inequalities and barriers to health care. Overseas, their rates of potentially preventable hospitalisation are higher than for people without intellectual disability. These rates have not been assessed in Australia.

The new: Rates of potentially preventable hospitalisation are higher in NSW for people with intellectual disability than for the general population, particularly hospitalisations for acute conditions, including convulsions and epilepsy.

The implications: The frequency of potentially preventable hospitalisation of people with intellectual disability should be reduced. This will require determining the reasons for such admissions, and overcoming barriers to adequate care in the community.

People with intellectual disability face stark health inequalities, as featured prominently in the recent hearings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.¹ Both multimorbidity² and premature and potentially avoidable death³ are more frequent among people with intellectual disability. One of the aims of the National Disability Strategy (2010–2020) was to ensure that people in Australia with disabilities attain the greatest possible health and wellbeing throughout their lives.⁴ While the federal government has committed to some action through the National Roadmap for Improving the Health of Australians with Intellectual Disability,⁵ important deficiencies remain, including the exclusion of people with intellectual disability from the National Preventative Health Strategy.⁶ This exclusion may contribute to the fact that primary care for Australians with intellectual disability is dominated by administrative needs, such as documentation, at the expense of meeting their medical and preventive health care needs.⁷

One marker of poor access to appropriate primary and community-based health care is the higher rate of potentially preventable hospitalisations for people with intellectual disability than for people without intellectual disability, as reported overseas.^{8–11} In Australia, potentially preventable hospitalisations are a performance indicator of health care accessibility and effectiveness; twenty-two ambulatory care-sensitive conditions are encompassed by this indicator, including vaccine-preventable, acute, and chronic conditions.¹² One strength of this indicator is that it can be used to assess the needs of people with specific conditions or to identify the greatest burden for particular population subgroups. However, people with intellectual disability in Australia cannot be identified in the standard data collected on potentially preventable hospitalisations, hindering identification of priority health areas for this group, despite its recognised health disadvantages.

We aimed to address this gap in knowledge by using a linked administrative dataset to estimate the rates of potentially preventable hospitalisations of people with intellectual disability in New South Wales, and to compare it with rates for the general NSW population.

Abstract

Objective: To determine rates of potentially preventable hospitalisation of people with intellectual disability in New South Wales, and compare them with those for the NSW population.

Design: Retrospective cohort study.

Setting: Potentially preventable hospitalisations in NSW, as defined by the National Healthcare Agreement progress indicator 18, 1 July 2001 – 30 June 2015.

Participants: Data collected in a retrospective data linkage study of 92 542 people with intellectual disability in NSW; potentially preventable hospitalisations data for NSW published by HealthStats NSW.

Main outcome measures: Age-adjusted rates of potentially preventable hospitalisation by group (people with intellectual disability, NSW population), medical condition type (acute, chronic, vaccine-preventable), and medical condition.

Results: The annual age-standardised rate for people with intellectual disability ranged between 5286 and 6301 per 100 000 persons, and for the NSW population between 1278 and 1511 per 100 000 persons; the rate ratio (RR) ranged between 3.5 (95% CI, 3.3–3.7) in 2014–15 and 4.5 (95% CI, 4.2–4.9) in 2002–03. The difference was greatest for admissions with acute (RR range: 5.3 [95% CI, 4.9–5.7] in 2014–15 to 8.1 [95% CI, 7.4–8.8] in 2002–03) and vaccine-preventable conditions (RR range: 2.1 [95% CI, 1.6–3.0] in 2007–08 to 3.4 [95% CI, 2.2–5.2] in 2004–05). By specific condition, the highest age-standardised rate was for admissions with convulsions and epilepsy (all years, 2567 per 100 000 population; v NSW population: RR, 22.2; 95% CI, 21.3–23.1).

Conclusion: Age-standardised rates of potentially preventable hospitalisation are higher for people with intellectual disability than for the general population. The reasons for these differences should be investigated, and strategies for averting potentially preventable hospitalisation developed.

Methods

We undertook a retrospective cohort study, analysing two population datasets. For people with intellectual disability, we analysed information from a retrospective data linkage study of 92 542 people with intellectual disability in NSW, based on data collected during 1 July 2001 – 30 June 2015.¹³ Data for the overall NSW population (as the comparison group) was derived from information on potentially preventable hospitalisations published by HealthStats NSW.¹⁴ We included data without restrictions on age group.

As previously described,¹³ people with intellectual disability were defined in our linked datasets by the presence of a Diagnostic and Statistical Manual of Mental Disorders (DSM) IV diagnostic code for intellectual disability in at least one disability dataset, or an equivalent International Statistical Classification of Diseases (ICD-10) diagnostic code in their health record. The ICD-10 codes included childhood

disintegrative and overactive disorders associated with mental retardation, intellectual development delay, mild to profound mental retardation, Down syndrome and other chromosomal anomalies associated with mental retardation, fragile X syndrome, and congenital malformation syndromes with known exogenous causes.

Potentially preventable hospitalisations were identified using the definition in the National Healthcare Agreement, progress indicator (PI) 18 (online [Supporting Information](#), table 1).¹² For the intellectual disability group, data for four of the twenty-two conditions were unavailable in the linkage data (congestive cardiac failure, angina, hypertension, cellulitis), so we also excluded HealthStats NSW data for these four conditions.

Statistical analysis

Rates of potentially preventable hospitalisation of people with intellectual disability were adjusted for age applying the direct standardised method with the standard Australian population.¹⁵ HealthStats NSW rates had already been age-adjusted with this method.

We compared the overall rates of potentially preventable hospitalisation of people with intellectual disability with those for the general NSW population as rate ratios (RRs) with 95% confidence intervals (CIs).¹⁶ We also compared the rates between 2001–02 and 2014–15 for each of the three hospitalisation subcategories (vaccine-preventable, acute, chronic).

We extracted the combined data for 2010–11 to 2014–15 and calculated the rates of potentially preventable hospitalisation by age and conditions, and compared the rates for people with intellectual disability and the general NSW population as RRs.

Ethics approval

The study was approved by the NSW Population and Health Services Research Ethics Committee (HREC/13/CIPHS/7; Cancer Institute NSW reference: 2013/02/446).

Results

Between 2001–02 and 2014–15, the age-standardised rate of potentially preventable hospitalisations of people with intellectual disability ranged between 5286 and 6301 per 100 000 persons; the age-standardised rate for the NSW population ranged between 1278 and 1511 per 100 000 persons. RRs ranged between 3.5 (95% CI, 3.3–3.7) in 2014–15 and 4.5 (95% CI, 4.2–4.9) in 2002–03 ([Box 1](#), [Box 2](#), A; [Supporting Information](#), table 2).

Potentially preventable hospitalisations, by condition type

RRs for potentially preventable hospitalisations for vaccine-preventable conditions ranged between 2.1 (95% CI, 1.6–3.0) in 2007–08 and 3.4 (95% CI, 2.2–5.2) in 2004–05 ([Box 1](#), [Box 2](#), B; [Supporting Information](#), table 2). For acute conditions, RRs ranged between 5.3 (95% CI, 4.9–5.7) in 2014–15 and 8.1 (95% CI, 7.4–8.8) in 2002–03 ([Box 1](#), [Box 2](#), C; [Supporting Information](#), table 2). For chronic conditions, RRs ranged between 1.0 (for several years) and 1.4 (95% CI, 1.2–1.6) in 2013–14 ([Box 1](#), [Box 2](#), D; [Supporting Information](#), table 2).

Potentially preventable hospitalisations, by condition

Convulsions/epilepsy was the most frequent indication for potentially avoidable hospitalisations of people with intellectual disability in all age groups, with the exception of 65 years or more (all ages: 2567 per 100 000 persons; range, 279 [15–24 years] to 636 per 100 000 persons [25–44 years]), followed by dental conditions (all ages: 1185 per 100 000 persons; range, 148 [15–24 years] to 428 per 100 000 persons [25–44 years]) ([Box 3](#); [Supporting Information](#), table 3).

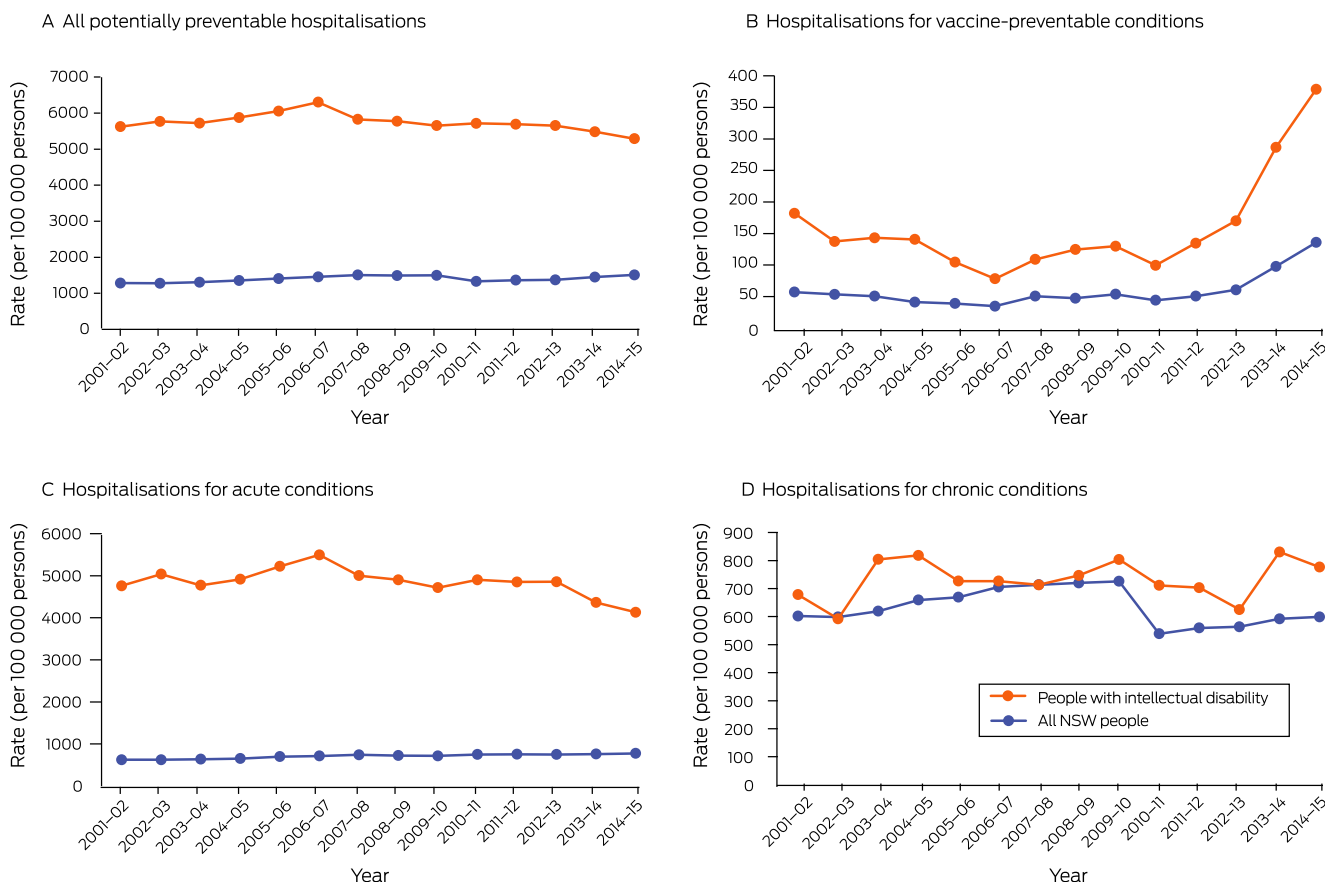
In each age group, the difference in rates of potentially avoidable hospitalisations for people with intellectual disability and for the general NSW population was greatest for convulsions or epilepsy (all ages: RR, 22.2; 95% CI, 21.3–23.1). The second greatest differences were for bronchiectasis for people aged 0–14 years (RR, 10.0; 95% CI, 4.1–24.7), 15–24 years (RR, 14.5;

1 Rate ratios (with 95% confidence intervals) for potentially preventable hospitalisations (per 100 000 persons) of New South Wales people with intellectual disability and of all New South Wales people, by year*

| Year | All conditions | Vaccine-preventable conditions | Chronic conditions | Acute conditions |
|---------|----------------|--------------------------------|--------------------|------------------|
| 2001–02 | 4.4 (4.1–4.7) | 3.2 (2.2–4.7) | 1.1 (1.0–1.3) | 7.6 (6.9–8.4) |
| 2002–03 | 4.5 (4.2–4.9) | 2.6 (1.7–3.8) | 1.0 (0.8–1.2) | 8.1 (7.4–8.8) |
| 2003–04 | 4.4 (4.1–4.7) | 2.8 (2.1–3.8) | 1.3 (1.1–1.5) | 7.5 (6.8–8.2) |
| 2004–05 | 4.3 (4.0–4.7) | 3.4 (2.2–5.2) | 1.2 (1.1–1.4) | 7.5 (6.9–8.2) |
| 2005–06 | 4.3 (4.0–4.6) | 2.7 (1.8–4.1) | 1.1 (0.9–1.3) | 7.5 (6.9–8.1) |
| 2006–07 | 4.3 (4.1–4.6) | 2.2 (1.5–3.4) | 1.0 (0.9–1.2) | 7.7 (7.1–8.4) |
| 2007–08 | 3.9 (3.6–4.1) | 2.1 (1.6–3.0) | 1.0 (0.9–1.1) | 6.8 (6.2–7.3) |
| 2008–09 | 3.9 (3.6–4.1) | 2.6 (1.8–3.9) | 1.0 (0.9–1.2) | 6.8 (6.2–7.4) |
| 2009–10 | 3.8 (3.5–4.0) | 2.4 (1.8–3.2) | 1.1 (1.0–1.3) | 6.6 (6.1–7.1) |
| 2010–11 | 4.3 (4.0–4.6) | 2.3 (1.6–3.1) | 1.3 (1.1–1.5) | 6.5 (6.0–7.1) |
| 2011–12 | 4.2 (3.9–4.4) | 2.7 (1.9–3.7) | 1.3 (1.1–1.4) | 6.4 (6.0–6.9) |
| 2012–13 | 4.1 (3.9–4.4) | 2.8 (2.1–3.7) | 1.1 (1.0–1.3) | 6.5 (6.0–7.0) |
| 2013–14 | 3.8 (3.6–4.0) | 2.9 (2.3–3.8) | 1.4 (1.2–1.6) | 5.7 (5.3–6.2) |
| 2014–15 | 3.5 (3.3–3.7) | 2.8 (2.2–3.5) | 1.3 (1.1–1.5) | 5.3 (4.9–5.7) |

* All age-adjusted rates of potentially preventable hospitalisations by category and year are available in the online [Supporting Information](#), table 2. ♦

2 Age-adjusted rates of potentially preventable hospitalisations, New South Wales, 2001-02 to 2014-15



95% CI, 5.2–40.5), or 25–44 years (RR, 11.7; 95% CI, 4.6–29.7), dental conditions for people aged 45–64 years (RR, 6.4; 95% CI, 5.4–7.5), and pelvic inflammatory disease for people aged 65 years or more (RR, 9.0; 95% CI, 1.2–64.7) (Box 3; Supporting Information, table 3).

In each age group, potentially avoidably hospitalisations of people with intellectual disability for asthma were less frequent than for the general NSW population (all ages: RR, 0.4; 95% CI, 0.4–0.4). People with intellectual disability aged 0–14 years (RR, 0.2; 95% CI, 0.1–0.2) or 15–24 years (no admissions) were also less frequently hospitalised for non-vaccine-preventable pneumonia (Box 3; Supporting Information, table 3).

Discussion

In the first Australian study of potentially preventable hospitalisations of people with intellectual disability, we found that age-standardised rates were higher than for the general NSW population, without clear patterns of change in differences during 2001–2015. Our findings are in line with findings from Canada, the United States of America, and the United Kingdom that rates of potentially preventable hospitalisation are higher for people with intellectual disability.^{8–11} We found that rates were particularly high for hospitalisations for acute conditions, for which overall rates were five to eight times as high for people with intellectual disability as for the general population; the rates for admissions with vaccine-preventable conditions were about three times as high. Differences in rates between people with intellectual disability and the general population were greatest for admissions related to convulsions

and epilepsy, and were also substantially higher for dental conditions and bronchiectasis, but lower for asthma.

To avert potentially preventable hospitalisations, understanding their main drivers is critical, but there is a dearth of research in this area for the general population, and even less regarding people with intellectual disability. Socio-demographic factors and comorbid conditions can influence rates of potentially preventable hospitalisation of people with intellectual disability.^{8,11,17} Research into the accessibility of health care has identified a range of factors that may contribute to elevated rates for people with intellectual disability, including poor uptake and engagement with preventive health care,¹⁸ a primary health care system driven by administrative rather than medical and preventive health factors,⁷ and general practitioners lacking confidence in providing health care for people with intellectual disability.¹⁹ Drivers of potentially preventable hospitalisations of people from the general population include inadequate access to health and other support services, lack of family and social support, non-adherence to treatment, mental ill health, and poor awareness or understanding of health conditions.^{20,21} Whether these factors are also important for people with intellectual disability requires further investigation, as does determining the proportion of reportedly potentially preventable hospitalisations that are actually appropriate.

We found that convulsions/epilepsy was the leading indication for potentially preventable hospitalisations of people with intellectual disability, consistent with an earlier report that hospital admissions for epilepsy were 54 times as frequent for people with intellectual disability than for other people.⁸ One explanation for this finding would be that a larger proportion

3 Rate ratios (with 95% confidence intervals) for potentially preventable hospitalisations (per 100 000 persons) of New South Wales people with intellectual disability and of all New South Wales people, 2010–11 to 2014–15, by age and condition*

| Condition | All ages | 0–14 years | 15–24 years | 25–44 years | 45–64 years | 65 years or more |
|---------------------------------------|---------------------|---------------------|---------------------|---------------------|---------------------|--------------------|
| Vaccine-preventable | | | | | | |
| Pneumonia and influenza | 2.9 (2.6–3.3) | 4.8 (3.9–6.0) | 3.9 (2.2–6.8) | 4.2 (2.8–6.4) | 3.3 (2.2–4.8) | 1.4 (0.9–2.1) |
| Other | 2.6 (2.2–2.9) | 2.1 (1.7–2.7) | 1.7 (0.8–3.6) | 2.7 (1.9–3.8) | 2.7 (2.0–3.6) | 2.7 (1.5–5.0) |
| Chronic conditions [†] | | | | | | |
| Asthma | 0.4 (0.4–0.4) | 0.1 (0.1–0.1) | 0.3 (0.2–0.3) | 0.3 (0.2–0.4) | 0.4 (0.3–0.6) | 0.2 (0.2–0.4) |
| Bronchiectasis | 2.6 (2.1–3.2) | 10.0 (4.1–24.7) | 14.5 (5.2–40.5) | 11.7 (4.6–29.7) | 1.9 (1.1–3.6) | 1.2 (0.7–2.1) |
| Chronic obstructive pulmonary disease | 2.2 (2.1–2.4) | 3.0 (1.2–7.5) | 5.1 (1.3–20.9) | 5.3 (3.0–9.2) | 2.9 (2.4–3.4) | 2.0 (1.8–2.3) |
| Iron deficiency anaemia | 1.8 (1.6–1.9) | 3.3 (1.8–6.1) | 1.3 (0.9–1.9) | 1.9 (1.5–2.4) | 1.8 (1.5–2.2) | 1.2 (1.0–1.5) |
| Rheumatic heart diseases | 1.2 (0.8–1.6) | 2.1 (0.7–6.6) | 1.7 (0.3–9.8) | 1.6 (0.4–6.6) | 0.8 (0.3–1.9) | 0 |
| Acute conditions [‡] | | | | | | |
| Convulsions and epilepsy | 22.2 (21.3–23.1) | 14.8 (13.7–16.0) | 22.6 (19.4–26.3) | 25.7 (22.2–29.7) | 25.4 (21.6–29.9) | 11.9 (8.8–16.3) |
| Dental conditions | 5.6 (5.4–5.9) | 3.1 (2.9–3.3) | 7.2 (6.3–8.4) | 11.1 (9.7–12.8) | 6.4 (5.4–7.5) | 2.3 (1.6–3.2) |
| Ear, nose, throat infections | 2.8 (2.7–2.9) | 2.5 (2.3–2.7) | 1.5 (1.3–1.9) | 2.4 (1.9–3.1) | 3.6 (2.5–5.3) | 2.2 (1.3–3.7) |
| Pelvic inflammatory disease | 0.8 (0.7–0.9) | 1.2 (0.1–10.7) | 0.6 (0.4–1.0) | 0.8 (0.5–1.1) | 0.2 (0.1–0.4) | 9.0 (1.2–64.7) |
| Perforated/bleeding ulcer | 1.8 (1.5–2.3) | 2.7 (0.1–58.8) | 1.6 (0.5–5.4) | 1.6 (0.8–3.2) | 2.7 (1.6–4.5) | 1.4 (0.9–2.4) |
| Pneumonia (not vaccine-preventable) | 1.0 (0.7–1.3) | 0.2 (0.1–0.2) | 0 | 1.9 (0.6–6.2) | 2.3 (0.7–7.7) | 1.7 (0.5–6.1) |
| Urinary tract infections | 3.4 (3.2–3.6) | 2.4 (2.1–2.7) | 2.2 (1.8–2.6) | 4.1 (3.4–5.0) | 5.3 (4.5–6.4) | 2.6 (2.3–3.0) |

* All age-adjusted rates of potentially preventable hospitalisations by category and year are available in the online [Supporting Information](#), table 3. † Data for diabetes complications and nutritional deficiencies not included because of small case numbers. ‡ Data for eclampsia and gangrene not included because of small case numbers. The category "Convulsions and epilepsy" is included under acute conditions in the National Healthcare Agreement list of potentially preventable hospitalisations.¹²

of people with intellectual disability have epilepsy than the general population. A recent systematic review found that about 22% of people with intellectual disability have epilepsy, and that its prevalence increases with the severity of their disability.²²

We had no information about why people with intellectual disability were hospitalised with convulsions and epilepsy, or whether these hospitalisations were avoidable. A study in Western Australia found that adults with intellectual disability were more than nine times as likely to die as the result of convulsions and epilepsy as adults without intellectual disability.²³ Guidance for managing epilepsy in people with intellectual disability is available, but robust research that could inform service responses to people with both intellectual disability and epilepsy, including how unnecessary hospital admissions can be averted, is needed,²⁴ as is investigation of the capacity of the health care workforce to meet their needs. In light of our findings, and the prevalence of epilepsy among people with intellectual disability, it is important to assist primary and community-based health care providers to provide appropriate care.

In our study, avoidable admissions of people with intellectual disability with vaccine-preventable conditions were about three times as frequent as for the general population, particularly with influenza and pneumonia. A recent report for the National Disability Insurance Scheme Quality and Safeguards Commission co-authored by one of the authors (JT) identified low vaccination coverage as a potential contributor to mortality in disability care; 14–48% of people with a disability had not received an influenza vaccine in the 12 months preceding their deaths, and 25–83% had not received a pneumococcal vaccine.²⁵ Vaccination rates among people with intellectual disability have been little investigated. A recent study found that vaccination coverage among UK children with intellectual disability were lower than among other children,²⁶ and vaccination coverage for hepatitis B and influenza among children and adolescents with intellectual disability in Taiwan was also lower than for those without intellectual disability.^{27,28} A recent review that more broadly examined vaccination status in people with disability found that knowledge in this area was inadequate.²⁹ Our findings highlight the need to better understand vaccination uptake by people with intellectual

disability, the reasons for their incomplete vaccination coverage throughout life, and why vaccine-preventable conditions are leading to their hospitalisation.

We also found higher rates of potentially preventable hospitalisations for dental conditions. People with intellectual disability have poorer oral health than other people, and probably also receive less preventive dental care and have poorer access to dental services.³⁰ A review found that barriers to access to dental services for children with intellectual disability included physical inaccessibility, the poor dental health literacy of carers, and dental health workers lacking knowledge, experience, and skills regarding people with intellectual disability.³¹ Removing these barriers may reduce the number of people with intellectual disability unnecessarily admitted to hospital with dental conditions.

The lower rate of preventable admissions for asthma is interesting, as asthma rates for people with intellectual disability are thought to be comparable with or higher than rates for people without intellectual disability,³² and adults with intellectual disability are more likely to die as the result of asthma than other people.²³ Our findings also contrast with those of an earlier study that people with intellectual disability, after adjusting for age, sex, region, and disease prevalence, were twice as likely to be admitted to hospital with asthma.⁸

Strengths and limitations

We analysed data drawn from large samples and directly compared age-adjusted rates of potentially preventable hospitalisations for people with intellectual disability and the overall NSW population. However, we could not include four of the conditions used to define potentially preventable hospitalisation in Australia. Further, we applied this definition rather than the specific definition for people with intellectual disability

employed by other authors.⁸ We could not analyse our data by the severity of intellectual disability, adjust for the relative prevalence of the included conditions in people with intellectual disability and in the general population, or explore the reasons for differences in rates of potentially preventable hospitalisations throughout life.

Conclusion

Our findings indicate that people with intellectual disability are hospitalised for conditions that could be managed in the community at higher rates than people without intellectual disability. This conclusion could not have been reached by directly assessing medical records, as intellectual disability status is not adequately recorded in Australian medical health records. Our findings provide additional evidence that the Australian health care system, particularly primary and community health care, are not sufficiently equipped to meet the complex health care needs of people with intellectual disability. Systemic action to remedy this problem could include a national population health strategy for people with intellectual disability, reforming Australian health care and improving the capacity of health care providers to meet their needs, and improving the health literacy of people with intellectual disability and people in their support networks.

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Supporting Information

Additional Supporting Information is included with the online version of this article.