

# A prospective study of hospital episodes of adults with intellectual disability

T. Iacono,<sup>1</sup>  C. Bigby,<sup>2</sup>  J. Douglas<sup>2</sup>  & J. Spong<sup>1</sup> 

<sup>1</sup> *Living with Disability Research Centre, La Trobe University, Bendigo, Vic., Australia*

<sup>2</sup> *Living with Disability Research Centre, La Trobe University, Melbourne, Vic., Australia*

## Abstract

**Background** Previous research has shown poor hospital experiences and dire outcomes for people with intellectual disability. The main objective of this study was to prospectively track episodes for adults with intellectual disability (ID) in Australian hospitals, with a focus on indications of the quality of care provided.

**Methods** A prospective audit of hospital records over 35 months yielded quantitative data about patient characteristics, frequency and length of hospital episodes, diagnostic assessments and outcomes, post-emergency department (ED) destinations and post-discharge recommendations. Fifty participants were recruited largely by identification on hospital ED entry. An audit of patients' hospital records was conducted towards the end of hospital episodes, using a tool developed for the study.

**Results** Participants were mostly men (70%), aged 42.9 years on average, living mostly with family (46%) or in supported accommodation (44%). Of 157 recorded episodes, 96% started in ED, 85% required urgent or semi-urgent care and 62% were in the first 3 months of study participation. Average time in ED exceeded the 4-h national benchmark, met in 40% of episodes. One or more diagnostic assessments were

conducted in 91% episodes and others in short stay units. Almost half (49%) resulted in a ward stay. With an extreme data point removed, <1–35 days were spent in wards. The most frequent diagnosis in 75% of episodes was for digestive problems, followed by nervous system problems then injuries. Median length of bed stays reflected data available for Australian refined diagnosis-related groups. High hospital re-presentations were found: for 67% of episodes in total, 26% ( $n = 12$ ) of which were within 72 h and 59% ( $n = 23$ ) within 30 days.

**Conclusions** Adults with ID presented frequently to ED and often had lengthy stays. We found no indication of poor care practices in terms of hospital staff willingness to keep patients in ED and conduct of diagnostic assessments. Frequent re-presentations, however, indicated failed hospital care at some level.

**Keywords** health services, hospital usage, intellectual disability

## Background

Previous investigations into hospital use by people with intellectual disability (ID) have focused on emergency departments (EDs). Preliminary findings from an Australian study showed that for 2005–2010, over 70% of people with ID accessing disability services ( $n = 51\ 452$ ) visited ED up to five times (Reppermund *et al.* 2017). These data were from a disability service's minimum data set, linked

Correspondence:

Dr Teresa Iacono, Living with Disability Research Centre, La Trobe University, PO Box 199 Bendigo, Vic., Australia 3052.

(e-mail: t.iacono@latrobe.edu.au)

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to ED and mortality data in New South Wales. In England, Glover *et al.* (2019) explored linked data across general practice and hospital databases. People with ID, particularly of working age (18–64 years), accounted for higher proportions of hospital episodes than non-ID patients over 2010–2014. Both ED presentations and planned admissions were over three times higher for people with ID, as was their number of bed days: for example, those of working age accounted for 1.13–1.44% of all bed days, despite representing only 0.64% of the population of this age.

Over-representation of people with ID in hospitals has been partly attributed to a failure of primary care to manage their frequent health conditions, including gastrointestinal problems, epilepsy, diabetes, cardiovascular disease and respiratory problems (Emerson *et al.* 2011). Hence, hospitalisations for these Ambulatory Care Sensitive Conditions (ACSC) are considered avoidable (Page *et al.* 2007) but contribute to frequent hospital presentations by people with ID (Glover and Evison 2013). Balogh *et al.* (2010) found yearly rates of 5.31–6.12 in a Canadian province, exceeding the five+/year benchmark indicating frequent ED presentations (Fuda and Immekus 2006). The highest average rates were for 20–29 (11.5) and 30–39 (13.1) year age groups for epilepsy (54.1) and schizophrenia (14.8), with significant differences found with non-ID patients across all but 70+ age groups for five of the seven ACSC (Balogh *et al.* 2010). Others have similarly shown that ACSC account for most hospital presentations by people with ID in Canada and the United States (Dunn *et al.* 2017), the United Kingdom (Glover and Evison 2013) and Norway (Skorpen *et al.* 2016).

In Australia, incentives to conduct comprehensive assessments with people with ID have been instigated to address concerns about their primary health care, thereby potentially reducing reliance on hospital care. GP reimbursement has been through the national health insurance scheme when using the Comprehensive Health Assessment Program, developed for patients with ID (Lennox *et al.* 2013). A steady increase in reimbursement claims for any form of comprehensive assessment of people with ID was found from 2007 (scheme introduction) to 2009 (Koritsas *et al.* 2012). There is some evidence that comprehensive GP health checks do not reduce

hospital presentations, except for ACSC (Carey *et al.* 2017).

Poor-quality hospital care has been implicated in frequent hospital re-presentations. Returning to ED within 72 h, an international indicator of an ED discharge failure (Agency for Healthcare Research and Quality 2014), has not been studied for people with ID. Results of a Singapore study, however, indicated the following risk factors for a 72h ED return: arriving by ambulance, male gender, older age, nonambulant with a major emergency triage, and diagnosis of cardiac problems, abdominal pain or viral infection, and Chinese ethnicity (Chan *et al.* 2016). A return within 30 days has been an indicator of preventable hospital presentation (Kelly *et al.* 2015), defined as admittance for the same or worsening of a condition as the previous presentation; worsening of a chronic problem related to previous hospital care; a complication of the condition as a result of the care; and surgery to address a worsening or complication of a condition arising from the quality of care (Kelly *et al.* 2015). Kelly *et al.* (2015) found a 13% within 30-days re-presentation rate for people with ID, a non-significant difference to the 11% found for other patients, with 69% of ID re-presentations versus 23% for other patients being potentially preventable.

Other indications of poor-quality hospital care have come from direct reports by people with disability and their carers (Iacono *et al.* 2014). Failure to conduct appropriate diagnostic assessments and mismanagement of health conditions in large hospitals have been documented in the United Kingdom (Mencap 2012; Sheehan *et al.* 2016). Australian studies have reflected similar problems (Iacono and Davis 2003; Webber *et al.* 2010). Contributing factors include difficulties hospital staff have in identifying people with ID or their care needs, adhering to clinical guidelines and finding ways to support patient compliance with treatment regimes (Iacono *et al.* 2014). Findings emerging from the qualitative component of the study from which this report is drawn suggest positive but *ad hoc* practices to meet the care needs of this patient group (Bigby *et al.* 2018).

Difficulties with and use of various strategies to identify ID in patients have impeded research into their hospital usage and cross-study comparisons. There has been a reliance on retrospective database audits (Balogh *et al.* 2010; Reppermund *et al.* 2017;

Glover *et al.* 2019). Balogh *et al.* (2010) identified people with ID from four databases relating to use of medical or family services, education and hospital records, and Kelly *et al.* (2015) relied on flagging ID in hospital records. Reliance on GPs (Glover *et al.* 2019) or hospital staff (Tuffrey-Wijne *et al.* 2013; Kelly *et al.* 2015) to identify people with ID raises the potential to miss patients with mild ID or without observable indicators. This problem has been partly overcome in the United Kingdom through learning disability nurses (Kelly *et al.* 2015).

The exploration of hospital experiences of people with ID has been mostly retrospective, with post-hospital recruitment through disability services (Iacono *et al.* 2014). Besides the potential to document only exceptional experiences, retrospective studies may not capture current practices (Sheehan *et al.* 2016). Recently, these problems were addressed by combining retrospective audit data and recollections with prospective observations of patients with ID across United Kingdom hospital trusts (Tuffrey-Wijne *et al.* 2013, Tuffrey-Wijne *et al.* 2014). In the larger current study, there was similarly an attempt to obtain data from multiple sources: audits of hospital records, interviews of patients, their family or paid carers and hospital staff, and observations of care conducted during the hospital journey (Bigby *et al.* 2018).

In this study, we report on Australian data based on prospective tracking of people with ID through their hospital journey. The focus was potential indications of the quality of care provided, including frequency and length of hospital episodes, diagnostic assessments and outcomes, post-ED destinations and post-discharge recommendations.

## Methods

### Design

A prospective audit of records for adults with ID who entered participating hospitals was conducted. Data provided a basis for comparison with national and international benchmarks and studies.

### Ethical approval and consent

Ethical approval was obtained from participating hospital systems, disability organisations and La Trobe University. Written informed consent was

obtained directly from or on behalf of participants with ID by a next-of-kin for those without consent capacity.

### Participant recruitment

Recruitment was through public hospitals<sup>†</sup> in Victoria, Australia, which are owned by the State Government, with funding shared with the Commonwealth Government. Australian hospitals are managed by geographically based local networks and provide inpatient and outpatient services (Australian Institute of Health and Welfare [AIHW] 2018). Hospitals from across three networks participated: two metropolitan and one regional. One network comprised three metropolitan hospitals: two in the 200–500 bed category, and in 2015–2016, they had 60 642 and 56 958 ED presentations, respectively; the third was in the 100–199 bed category, with 39 932 ED presentations (2015–2016) (AIHW 2016). The second network included one metropolitan hospital in the 200–500 bed category, with 85 007 ED presentations (2015–2016). The third network had one regional hospital, in the 200–500 bed category with 50 042 ED presentations (2015–2016).

Two recruitment strategies were employed. Advanced recruitment relied on identifying adults with ID across hospital catchment areas through visits to key disability organisations providing accommodation services. Participant information was distributed to service users (or key contacts), and consent sought for adults with ID to participate in the event of a hospital episode. Individual participant details were provided by paid carers to the researchers once consented adults had entered a participating hospital. This strategy resulted in only five participants.

Just-in-time recruitment proved more successful. Hospital researchers (nurses or allied health staff) at each hospital worked specific shifts to identify potential participants presenting to ED. Hospital researchers were trained in identifying possible participants according to whether they were known to the hospital as having ID or it had been recorded in their medical history, their physical characteristics (e.g. of Down syndrome) or they were accompanied

<sup>†</sup>Private hospitals also exist in Australia and are owned and run by not-for-profit companies or organisations (AIHW 2018).

by a disability support worker or family member who identified them as having ID. Presenting patients identified as having ID were invited into the study and consent obtained at an appropriate time. Forty-five participants were recruited.

### Data collection and analyses

Data collection occurred from December 2014 to October 2017, 3 months after the last participant had been recruited (35 months). As close to completion of a participant's hospital episode as possible, a hospital researcher conducted a medical record audit from electronic and paper-based ED and ward records. An audit tool developed for the study was used to record information on participant characteristics and history at that hospital (if available), reason for presentation, diagnostic processes and outcomes, movement through the hospital network and discharge processes. Contact points within the hospital were recorded (e.g. departments and services used), as well as other information, such as diagnostic screening and treatments recommended and/or received.

The medical audit data were entered in SPSS v 24. Descriptive analyses were run at the participant level for characteristics and time in the study and at the episode level (i.e. analysing each episode across combined participants) across variables. Values were summarised as means (*M*), standard deviations (*SD*), medians for non-normally distributed data, counts (*n*) and proportions (%), with the latter based on the relevant denominator for each variable under consideration.

## Results

### Participant characteristics

Participants were 70% men (*n* = 35) with a mean age of 42.9 years (*SD* = 14.5). Most lived with family (*n* = 23; 46%) or in shared supported accommodation (*n* = 22; 44%), with three (6%) in supported living and two (4%) living independently. Forty-four (88%) had at least one recorded chronic health condition; for some, up to five were reported (*M* = 2.3; *SD* = 1.3). For these participants, 44% had epilepsy; mental health problems, Type II diabetes, cardiovascular disorders or asthma were reported for 6–8%.

### Hospital episodes

Across participants, 157 hospital episodes (i.e. from entry to the hospital to discharge/exit) were recorded. Participants experienced 1–16 (*M* = 3.1; *SD* = 3.2; median = 2) hospital episodes across the study period. The time from participants' first hospital episode to the end of the last reported for the study was 1–137 days (*M* = 5.4; *SD* = 5.4; median = 2). Ninety-seven episodes were within participants' first 3 months in the study (61.8% of all episodes recorded, *M* = 1.9; *SD* = 1.6; median = 1; range = 1–9).

Five participants had seven planned admissions for various procedures (e.g. Percutaneous Endoscopic Gastrostomy insertion, renal stone removal); each had additional presentations to ED, not necessarily related to their planned procedure. All other episodes began in ED (*n* = 150). The remaining analyses focus on ED presentations, given it was the starting point for most hospital journeys recorded for the study.

### Emergency department

Summary data about ED presentations are in Table 1. For most, participants arrived by ambulance followed in frequency by private car. The person accompanying the participant was not recorded for 37% of episodes; otherwise, it was most often a family member, followed by a paid carer.

On ED entry, patients are assigned one of five triage codes ranging from requiring attention within seconds to within 120 min. Across the 150 episodes, 85% were coded as urgent (attend within 30 min) or semi-urgent (60 min) (Table 1).

The time spent in ED ranged from 1 to 30 h, with the 6.5 h average (*SD* = 4.7; median = 5.0) exceeding the 4 h national benchmark (AIHW 2016), which was met in 60 (40%) episodes. Diagnostic tests were recorded according to seven categories listed in the medical audit: blood test, X-ray, ultrasound, computed tomography, electrocardiogram, urinalysis and other. From none to the full range of tests listed on the audit, including others (e.g. blood sugar level analysis, and swabs), were recorded across the sample (*M* = 2.3; *SD* = 1.4; median = 2). At least one type was conducted in ED for 136 episodes (91%): in 113, these were blood tests (75%), an X-ray in 77 (51%), electrocardiogram in 57 (38%), urinalysis in 36 (24%), computed tomography scan in 35 (23%) and ultrasound in 16 (11%).

**Table 1** Characteristics of presentations to emergency department ( $N = 150$ )

Variable	Frequency, $n$ (%)
<i>Transport</i>	
Ambulance	88 (58.7)
Private car	54 (36)
Unknown/missing data	8 (5.3)
<i>Escorting person</i>	
Family	44 (29.3)
Paid carer	43 (28.7)
Other	2 (1.3)
None	5 (3.3)
Unknown/missing data	56 (37.3)
<i>Triage code</i>	
1 Immediate attention	3 (2)
2 Within 10 min	17 (11.3)
3 Within 30 min	73 (48.7)
4 Within 60 min	54 (36)
5 Within 120 min	1 (0.7)
Not recorded	2 (1.3)
<i>Destination</i>	
Self discharge <sup>a</sup>	1 (0.7)
Home	50 (33.3)
Short stay unit (SSU)	31 (20.7)
Ward	66 (44.0)
Transfer to another hospital network	2 (1.3)

<sup>a</sup>Destination unknown.

Table 1 includes destinations post-ED. For most episodes, it was to a ward, considered by the hospital to be a formal admission, followed in frequency by discharge home and a short stay unit (SSU).

### Short stay unit

Short stay units provides intensive observation and treatment aimed to reduce inappropriate hospital admissions and to improve patient flow through timely assessments and treatments. Guidelines indicate that stays in SSU should not exceed 24 h (Department of Human Services 2017). Time in SSU occurred for 31 (21%) episodes. The 24 h benchmark was exceeded for two episodes only (0.5 and 60.1 h), with the overall average time within the guideline ( $M = 11.2$ ;  $SD = 12.9$ ; median = 7.4). Diagnostic tests were conducted in 15 stays in SSU (48%), mostly ultrasounds ( $n = 6$ ; 19%), followed by urinalysis and blood tests ( $n = 5$ ; 16% each). SSU was mostly followed by discharge home ( $n = 25$ ; 80.6%), with only six (19.4%) with a ward admittance.

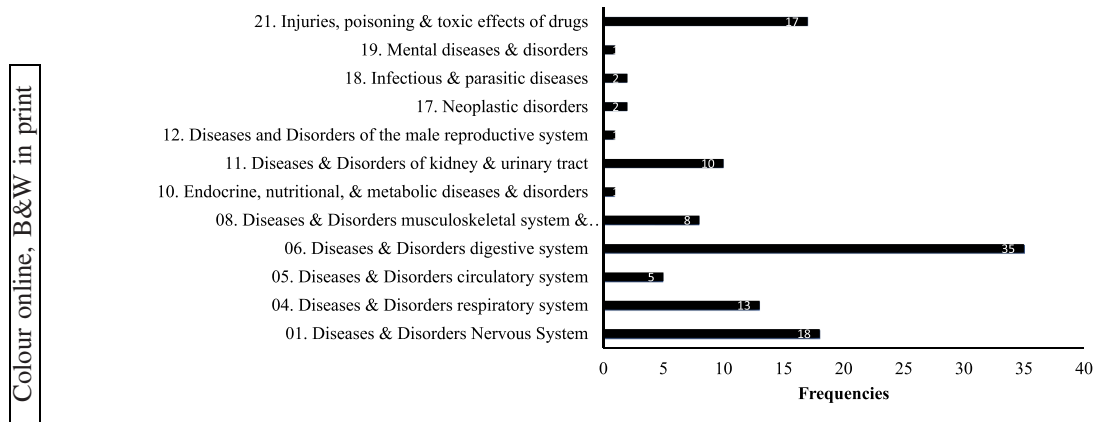
### Wards

Seventy-two episodes included a ward stay (directly from ED or via a SSU): 1–136 days (4.5 months) in one or more wards. The extreme was for one patient, classified as ‘homeless in hospital’ because of concerns about appropriate post-discharge accommodation. After removing patient’s data, the range was 0.2–34.9 days ( $M = 5.4$ ;  $SD = 7.0$ ; median = 3.1), which still showed a great variability in ward stay lengths. Most admissions were to a general medical ward ( $n = 33$ ; 45.2%), followed by a surgical ward ( $n = 14$ ; 19.2%), neurology ( $n = 7$ ; 9.6%), acute medical ( $n = 6$ ; 8.2%), intensive care unit ( $n = 5$ ; 6.8%), other ( $n = 4$ ; 5.5%), orthopaedic ( $n = 3$ ; 4.1%) and plastics ( $n = 1$ ; 1.4%).

### Diagnoses

A clear diagnosis was evident from the medical audit for 75% of episodes, for 4.7%, it was queried, and for 20%, it was not evident. For 113 with clear diagnoses, a researcher assigned a AIHW Australian refined diagnosis-related groups (AR-DRGs) (AIHW 2019) code, which was checked by a second researcher.

Figure 1 provides the distribution of AR-DRG codes across episodes. Most frequent were diseases and disorders of the digestive system ( $n = 12$ , 34% constipation) and the nervous system ( $n = 12$ , 67% seizures in patients with a history of epilepsy), injuries ( $n = 12$ , 59% from falls) and diseases and disorders of the respiratory system ( $n = 7$ , 54% pneumonia, including with aspiration). Bed stays were determined according to days in wards to enable comparison with the most recent Organisation for Economic Co-operation and Development data for Australia (2016), based on averages for days from admission (i.e. post-ED or SSU) to discharge (Organisation for Economic Co-operation and Development 2019; Table 2). Although the data are not directly comparable, overall, the median length of stay across AR-DRGs reflected the averages for Australian hospitals. Exceptions tended to exceed the Australian average, including for nervous system diseases and disorders, the second most frequent AR-DRG resulting in a ward admission. Length of stay was shorter for musculoskeletal and connective tissue conditions, but admission to a ward occurred for only five episodes.



**Figure 1.** Australian refined diagnosis-related group for episodes with a diagnosis ( $n = 113$ ) [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

**Table 2** Days in wards across AR-DRG ( $n = 61$ )

AR-DRG	Current study mean (SD) median	OECD mean
01. Diseases & Disorders Nervous System	$n = 13$ 9.1 (11.4) 4.3	4.2
04. Diseases & Disorders Respiratory System	$n = 9$ 4.6 (4.7) 2.8	4.3
05. Diseases & Disorders Circulatory System	$n = 3$ 7.1 (5.0) 7.6	6
06. Diseases & Disorders Digestive System	$n = 20$ 4.7 (7.8) 2.3	3.8
08. Diseases & Disorders Musculoskeletal System & Connective Tissue	$n = 5$ 3.5 (2.2) 3.1	5.3
10. Endocrine, Nutritional, & Metabolic Diseases & Disorders	$n = 0$	5.1
11. Diseases & Disorders of Kidney & Urinary Tract	$n = 4$ 4.3 (2.8) 5.0	3.3
12. Diseases and Disorders of the Male Reproductive System	$n = 1$ 0.2	
16. Diseases & Disorders of the Blood & Blood Forming Organs and Immunological Disorders	$n = 0$	4.5
17. Neoplastic Disorders	$n = 1$ 8.8	6.5
18. Infectious & Parasitic Diseases	$n = 1$ 2.1	5.6
19. Mental Diseases & Disorders	$n = 0$	18.1
21. Injuries, poisoning & toxic effects of drugs	$n = 4$ 6.2 (4.1) 7.3	6

AR-DRG, Australian refined diagnosis-related group; OECD, Organisation for Economic Co-operation and Development.

## Outcomes

Plans for what should occur following discharge were recorded for 143 (95.3%) episodes (Table 3). Few episodes were followed by continued care through hospital or rural district nursing systems. Recommendations were mostly for GP, outpatient and/or specialist care (57%).

## Re-presentations

Most episodes ( $n = 100$ , 67%) were second or subsequent ED presentations, with time between being <1–364 days ( $M = 46.9$ ;  $SD = 64.3$ ; median = 18). Twenty-six (26%) re-presentations were within 72 h across 12 participants (24%) ( $M = 2.5$ ;  $SD = 2.3$ ; median = 1); 59 (59%) across 23 participants (46%) occurred within 30 days ( $M = 2.6$ ;  $SD = 2.8$ ; median = 1, range = 1–12).

## Discussion

Overall, our data showed evidence of high hospital usage by people with ID through re-presentations and long stays in wards. Gender and age characteristics (70% male and on average aged 43 years) reflected those with the highest presentations to ED found by

Glover *et al.* (2019) (i.e. 57% male participants and mostly for 35–54 years), despite differences in how data were obtained (i.e. prospective tracking versus retrospective audit). Similarities with their study include the highest use of general medical followed by surgical wards, although their metric was based on hospital bed stays versus number of episodes resulting in ward stays. A concern with the current study was lack of planned admission data, but this may reflect that most adults with ID come to hospital via ED, found in the United Kingdom (Glover *et al.* 2019).

Participants' multiple chronic conditions also reflect previous findings of a history of epilepsy, occurring with high incidence in this group (Glover and Evison 2013). It is unsurprising that AR-DRG 01 that includes seizures and epilepsy was the second most frequently found and amongst the most frequent reasons for hospitalisations in previous studies (Balogh *et al.* 2010; Skorpen *et al.* 2016; Dunn *et al.* 2017; Glover *et al.* 2019). Other frequent diagnoses also reflected previous findings, in particular, from the Norwegian study of patients with ID presenting to hospitals on a yearly basis (2008–2011), using data linked across hospital records and a national disability register (Skorpen *et al.* 2016). The AR-DRG pattern found (Figure 1) reflects the Norwegian data in being mostly captured in the 10 most frequent diagnostic groups reported (Skorpen *et al.* 2016). In both studies, the highest rates were for digestive system problems, injuries and diseases of the respiratory and nervous systems, which in the present study was mostly pneumonia.

As with previous studies, we found evidence of high rates of hospital use for our participants with ID. Most episodes occurred within 3 months of participants' entry into the study and 67% were re-presentations, up to 12 times across participants. Therefore, many patients exceeded the threshold for frequent presentations of five within a year (Fuda and Immekus 2006). Furthermore, about a fifth of re-presentations, which occurred for almost a quarter of participants, were within 72 h, suggesting that in many cases, the discharge process followed in the previous hospital episode was unsuccessful (Agency for Healthcare Research and Quality 2014). This finding may reflect certain risk factors for our participant group, in particular being male and arriving by ambulance, previously associated with ED re-presentation within a short period (Chan

**Table 3** Post-emergency department and short stay unit follow-up for episodes beginning in emergency ( $N = 150$ )

Recommendation	Frequency, $n$ (%)
<i>Continued care across all episodes<sup>a</sup></i>	
Hospital in the Home	5 (3.3)
Rural District Nursing Service	4 (2.7)
Other	15 (10)
None indicated	119 (79.3)
Missing	7 (4.7)
<i>Hospital follow-up across all episodes<sup>a</sup></i>	
GP	32 (21.3)
Outpatient clinic (OP)	31 (20.7)
GP & OP	16 (10.7)
GP & Specialist	2 (1.3)
Specialist	5 (3.3)
Other	25 (16.7)
None indicated	32 (21.3)
Missing	7 (4.7)

<sup>a</sup>Recommended continue care and/or hospital follow-up may have been suggested either at the time of discharge from emergency department, short stay unit or the ward, dependent on the participant's hospital pathway.

*et al.* 2016). Using another indicator of possible hospital care failings was that for 46% of participants and 59% of the re-presentations, subsequent presentations occurred within 30 days, which was higher than for male ID patients reported by Kelly *et al.* (2015). We were unable to determine if these re-presentations were for the same condition as for the previous presentation because the required information was not in hospital records. Hence, the extent to which these presentations arose from a worsening of the condition, chronic condition complications, or poor hospital care or intervention (Kelly *et al.* 2015) remains unknown. Nonetheless, the high rate of return within a month suggests that the discharge process, mostly referral to a GP and often a specialist, either was insufficient to prevent a re-presentation or recommendations were not followed. Regardless, the frequent recommendation for GP follow-up suggests attempts to encourage continued care through the primary health care system. Yet this system has been found inadequate to meet the often complex health care needs of people with ID, both in Australia and elsewhere (Balogh *et al.* 2010).

Lengthy stays have also indicated high usage patterns in previous studies (Balogh *et al.* 2010; Glover *et al.* 2019). Time in ED and the number of tests completed in the present study suggested a willingness of hospital staff to spend the time required to ensure required diagnostics were completed. Most episodes (60%) for our participants exceeded the <4-h benchmark that demonstrate hospital efficiencies in comparison with the national data of 27% (AIHW 2016). Almost all ED presentations included at least one, but often more diagnostic tests, some in SSU, but here, almost all stays met the 24-h benchmark (Department of Human Services 2017). These findings contrast with previous reports of diagnostic overshadowing (attributing presenting symptoms to the underlying disability resulting in a failure to conduct tests) or an unwillingness to conduct required assessments, considered to reflect discriminatory practices seen in

the United Kingdom. National Health Services (Mencap 2012) and also Australia (Iacono and Davis 2003), but over a decade previously. Further, such discriminatory practices were not evident in the qualitative data from the larger study. Rather,

hospital staff were focused on obtaining information needed to target diagnostic assessments, thereby avoiding unnecessary distress for participants or carers (Bigby *et al.* 2018).

A short stay unit may have provided an effective strategy for reducing admissions and an environment outside of ED to complete diagnostic and care processes, with most stays followed by discharge home. A close examination of the ward data shows that in comparison with previous studies, with some exceptions, stays did not exceed averages reported for certain AR-DRGs across Australian hospitals (Table 2). In contrast, in ward stays for Diseases & Disorders of the Respiratory System (AR-DRG 04), which included pneumonia (considered an ACSC and therefore preventable through vaccinations available in primary health care), there was large variation in ward days, with the median (2.8) being noticeably lower than the Organisation for Economic Co-operation and Development mean for Australia (4.3). The overall mean of 5.4 days was higher than that obtained by Glover *et al.* (2019) for their 18–64 year age group (3.4), but also quite variable even with an outlier removed. It was not possible to explore potential contributors to this variability in light of the limited participant numbers and episodes documented, which precluded valid comparisons. In particular, the few episodes across AR-DRGs did not allow for meaningful exploration of patterns across conditions and likelihood of admittance to wards.

Comparisons with national data (AIHW 2016) provide some insights into areas warranting further exploration. In particular, the arrival by ambulance rate (59%) was much higher than the average of 24% for 2015–2016 national data (AIHW 2016). A simple reason may be that many people live in supported accommodation, where disability service policy could require ambulance transport to avoid removing support from other group home residents. On the other hand, triage codes of urgent and semi-urgent (85%) were not substantially higher than the national combined proportion of 79% (AIHW 2016), suggesting once in ED, processes and judgments may not have differed to those for other patient groups.

### Clinical implications

Our findings suggest that, as shown previously and internationally, adults with ID in Australia are high



end users of hospitals, especially ED; however, implications are presented cautiously in light of the small participant number and absence of population sampling strategies. For our participants, on the whole, diagnostic processes were followed, but these may have reduced hospital efficiencies by extending time beyond national benchmarks. Using SSU to continue processes to arrive at a diagnosis may function as a reasonable adjustment for these patients. As a result of communication problems (e.g. understanding questions, providing history and symptom details), and potential distress arising from being unwell and in an unfamiliar environment, they may require more time and a quiet space and more time for hospital staff to consult with carers (Iacono *et al.* 2014, Glover *et al.* 2019). Additional time in ED or the use of SSU appeared insufficient, however, to address the medical care needs of this patient group, such that many returned to hospital after only short intervals.

#### Limitations and future research directions

Despite attempts to address problems with retrospective audits or interviews exploring previous experiences, our prospective study was not without recruitment problems. Few planned episodes were documented because advanced recruitment met with little success. This strategy was time-consuming, requiring assistance from disability service providers to alert researchers to a future admission or an unexpected visit to ED by consented adults. This strategy ensured recruitment of people with a known ID, but not many who then went to hospital. The just-in-time strategy was more fruitful, but as with Kelly *et al.* (2015), hospital researchers were asked to identify those individuals they recognised as having ID. Australian hospitals do not have disability liaison nurses, as in the United Kingdom (Kelly *et al.* 2015), or a similar role, thereby requiring hospital researchers to be trained to identify people with ID. Further, resources did not stretch to a full-time presence in ED, although hospital researchers did attempt to determine when new presentations of potential participants occurred. It is likely that participants meeting study eligibility criteria, especially those with milder ID, were missed. Other researchers have been concerned about underestimating usage and stays by people with ID because of flaws in the strategy used here and because hospitals in many countries,

including Australia, do not identify, flag or track this patient group. Although exceptions are emerging, hospitals still rely on staff identifying patients with ID rather than on self-reports or carer-reports (Kelly *et al.* 2015, Tuffrey-Wijne *et al.*, 2014). Arguments have been made that hospital usage rates and stays would be higher if data for all patients with ID were captured (Glover *et al.* 2019). A counter argument comes from a lack of evidence that people with mild ID, those most likely to be missed, have the same complexity in care needs. Problems with identification plague most health care research in ID; hence, the full extent of this group's care needs remains unknown.

Although 150 episodes were documented across 35 months, participants numbered only 50. These data did not allow for meaningful comparisons or exploration of associations across variables such as age, living situation, diagnoses, re-presentations, ward admission and length of stay. As with many studies involving prospective data collection, further research with an increased sample size is recommended for valid statistical comparisons, but also required would be a standard period during which participants are recruited and followed. Such standardisation would assist meaningful comparisons across studies, but also require inclusion of a number of hospital networks within and across states.

#### Conclusions

The quantitative data reported here of ID hospital episodes studied prospectively revealed patterns that contribute evidence of this group's frequent ED presentations. Time in ED and multiple diagnostic assessments are an indication of concern about the quality of care provided and suggested a willingness of hospital staff to spend the time needed by this patient group, a finding that contrasts with previous research. Yet the frequent re-presentations, considered at both participant and encounter levels, suggest failure in hospital care. On the basis of this and previous studies, the complexity of hospital care needed by people with ID is apparent, requiring further investigation focused on exploring reasons for frequent re-presentations and potential for reducing these.

## Acknowledgements

Thanks are extended to the following for research assistance: Dr Cindy Cheng, Sophia Tipping, Dr Ruth Quibell, Erin Wilson, Phillip Brown, Caitlin Farmer, Linda Parker and Lydia Lipkewycz. We also acknowledge the support of Professor Nora Shields, Professor Nick Taylor, Professor Julian Troller and Dr Jane Tracy during the course of this study.

## Source of Funding

This report is funded with assistance from a grant offered under the National Disability Research and Development Agenda, jointly implemented by disability representatives from Commonwealth, State and Territory governments. However, the information and views contained in this research are not intended as a statement of Australian Government, or any jurisdictional policy, and do not necessarily, or at all, reflect the views held by the Australian Government or jurisdictional government departments.

## Conflicts of Interest

The authors have no conflicts of interest to declare.

## References

- Agency for Healthcare Research and Quality (2014) Improving the emergency department discharge process: environmental scan report. Armstrong Institute for Patient Safety and Quality, Rockville, MD.
- AIHW (2016) Emergency department care 2015–16: Australian hospital statistics. In: *Health services series*. Canberra. Available at <https://www.aihw.gov.au/reports/hospitals/emergency-department-care-ahs-2015-16/contents/table-of-contents>
- AIHW (2018) Australia's health 2018. Canberra. Available from <https://www.aihw.gov.au/reports/australias-health/australias-health-2018/contents/table-of-contents>
- AIHW (2019) *Australian Refined Diagnostic-Related Groups (AR-DRG) data cubes*. Available at <https://www.aihw.gov.au/reports/hospitals/ar-drg-data-cubes/contents/data-cubes>
- Balogh R., Brownell M., Ouellette-Kuntz H. & Colantonio A. (2010) Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability—a population perspective. *Journal of Intellectual Disability Research* **54**, 820–32.
- Bigby C., Douglas J. & Iacono T. (2018) Enabling mainstream systems to be more inclusive and responsive to people with disabilities: Hospital encounters of adults with cognitive disabilities. *Report for the National Disability Research and Development Agenda Living with Disability Research Centre*. La Trobe University, Melbourne. Available at: <http://hdl.handle.net/1959.9/563533>
- Carey I. M., Hosking F. J., Harris T., DeWilde S., Beighton C., Shah S. M. *et al.* (2017) Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment. *Journal of Epidemiology and Community Health* **71**, 52–8.
- Chan A. H. S., Ho S. F., Fook-Chong S. M. C., Lian S. W. Q., Liu N. & Ong M. E. H. (2016) Characteristics of patients who made a return visit within 72 hours to the emergency department of a Singapore tertiary hospital. *Singapore Medical Journal* **57**, 301–6.
- Department of Human Services (2017) *Guidelines for emergency department short stay units*. Primary Health Victorian Government Department of Human Services, Melbourne, Vic. Available at <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/guidelines-emergency-department-short-stay-may-2017>
- Dunn K., Hughes-McCormack L. & Cooper S.-A. (2017) Hospital admissions for physical health conditions for people with intellectual disabilities: systematic review. *Journal of Applied Research in Intellectual Disabilities* **31**, 1–0.
- Emerson E., Baines S., Allerton L. & Welch V. (2011) *Health inequalities & people with learning disabilities in the UK: 2011*. Improving Health and Lives: Learning Disabilities Observatory, England.
- Fuda K. K. & Immekus R. (2006) Frequent users of Massachusetts emergency departments: a statewide analysis. *Annals of Emergency Medicine* **48**, 9–16.
- Glover G. & Evison F. (2013) Hospital admissions that should not happen: admissions for ambulatory care sensitive conditions for people with learning disabilities in England. Improving Health and Lives: Learning Disabilities Observatory.
- Glover G., Williams R., Tompkins G. & Oyinlola J. (2019) An observational study of the use of acute hospital care by people with intellectual disabilities in England. *Journal of Intellectual Disability Research* **63**, 85–99.
- Iacono T. & Davis R. (2003) The experiences of people with developmental disabilities in hospital wards and emergency departments. *Research in Developmental Disabilities* **24**, 247–64.
- Iacono T., Bigby C., Unsworth C., Douglas J. & Fitzpatrick P. (2014) A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Research* **14**, 505, 1–8.
- Kelly C. L., Thomson K., Wagner A. P., Waters J. P., Thompson A., Jones S. *et al.* (2015) Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: a single-site study of 30-day

- readmission rates. *Journal of Intellectual Disability Research* **59**, 835–44.
- Koritsas S., Iacono T. & Davis R. (2012) Australian general practitioner uptake of a remunerated Medicare health assessment for people with intellectual disability. *Journal of Intellectual and Developmental Disability* **37**, 151–4.
- Lennox N., Brolan C. E., Dean J., Ware R., Boyle F. M., Taylor Gomez M. *et al.* (2013) General practitioners' views on perceived and actual gains, benefits and barriers associated with the implementation of an Australian health assessment for people with intellectual disability. *Journal of Intellectual Disability Research* **57**, 913–22.
- Mencap (2012) *Death by indifference: 74 deaths and counting, a progress report 5 years on*. Mencap. London. Available at <http://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>.
- Organisation for Economic Co-operation and Development (2019) *OECD.Stat: health care utilisation*. Available at [https://stats.oecd.org/Index.aspx?DataSetCode=HEALTH\\_PROC](https://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_PROC)
- Page A., Ambrose S., Glover J. & Hetzel D. (2007) *Atlas of avoidable hospitalisations in Australia: ambulatory care-sensitive conditions*. Public Health Development Unit, Adelaide. Available at <http://www.aihw.gov.au/reports/hospitals/atlas-avoidable-hospitalisations-australia/contents/table-of-contents>
- Reppermund S., Srasuebkul P., Heintze T., Reeve R., Dean K., Emerson E. *et al.* (2017) Cohort profile: a data linkage cohort to examine health service profiles of people with intellectual disability in New South Wales, Australia. *BMJ Open* **7**, 1–10.
- Sheehan R., Gandesha A., Hassiotis A., Gallagher P., Burnell M., Jones G. *et al.* (2016) An audit of the quality of inpatient care for adults with learning disability in the UK. *BMJ Open* **6**, e010480.
- Skorpen S., Nicolaisen M. & Langballe E. M. (2016) Hospitalisation in adults with intellectual disabilities compared with the general population in Norway. *Journal of Intellectual Disability Research* **60**, 365–77.
- Tuffrey-Wijne I., Giatras N., Goulding L., Abraham E., Fenwick L., Edwards C. *et al.* (2013) Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study. *Health Serv Deliv Res* **1**.
- Tuffrey-Wijne I., Goulding L., Giatras N., Abraham E., Gillard S., White S. *et al.* (2014) The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed-methods study. *BMJ Open*, 4.
- Webber R., Bowers B. & Bigby C. (2010) Hospital experiences of older people with intellectual disability: responses of group home staff and family members. *Journal of Intellectual and Developmental Disability* **35**, 155–64.

Accepted 1 March 2020