

Accepted in Tizard Review of Learning Disabilities

Title: General hospital care for people with intellectual disabilities

Authors:

Gyles Glover

Christopher Hatton

Sebastian Fox

Abstract

Purpose

Design / methodology /approach

Finding

Research limitations / implications

Practical implications

Originality / value

Key words

Paper type

## **Introduction**

Hospital in-patient care is a critical event for people with intellectual disabilities. Many have additional physical conditions requiring occasional or sometimes frequent hospital care. For hospitals, caring for people with intellectual disability raises important requirements particularly in relation to communication, comprehension and consent. Following the Michael report into six well documented tragedies, NHS Hospitals are required to ensure they have systems in place to address these requirements. This paper reports findings from a recent survey to see how clearly these systems are in place.

## **Background**

'Death by Indifference', a campaigning document by third sector group Mencap (2007) described the deaths of six people with intellectual disabilities. The recurring theme was the failure of acute hospitals to identify and make provision for aspects of their needs which were related to their intellectual disabilities. Research (Heslop et al., 2013, 2014; Tuffrey-Wijne et al., 2014) has continued to identify at best patchy good practice concerning people with intellectual disabilities within acute hospital services, with poor practice having serious health consequences.

In 2008, an independent committee of Inquiry (Michael, 2008) made recommendations for all hospitals intended to minimise the risk of such failures happening in future. These were addressed to both providers and commissioners of health services and required the establishment of systems to ensure that the needs of people with intellectual disability work effectively identified, communicated and met.

The English Department of Health accepted these recommendations and Monitor, the regulator for most English NHS hospital providers, subsequently established six specific tests of compliance concerning reasonable adjustments for people with learning disabilities (Monitor, 2015, see Table 1). NHS hospital providers with foundation trust status have since been asked regularly by Monitor whether they comply with all six standards. A parliamentary question asked in January 2015 established that as at the end of March 2014, all NHS Foundation Trusts reported compliance with all six standards (UK Parliament, 2015).

Table 1 about here

As part of the 2014 round of self-audit of services for people with intellectual disabilities, Learning Disability Partnership Boards in England were asked to report the numbers of hospital admissions, out-patient and accident & emergency attendances involving individuals with intellectual disabilities at the hospitals serving

their local areas in the previous year. This question was intended to explore the extent to which hospitals were identifying intellectual disabilities, a necessary first step to making appropriate adjustments.

This paper presents their responses and considers the implications for the adequacy of the steps taken by hospitals so far.

### **Data sources and methods**

Learning Disability Partnership Boards are co-ordinating groups where health and social care commissioner and provider organisations for local areas in England join with self-advocates with intellectual disabilities and family carers to try and ensure that services work effectively together. In 2013 and 2014 they all undertook a self-assessment exercise comprising both self-rating against a set of quality standards and the reporting of a set of numeric indicators relevant to many aspects of the care of people with intellectual disabilities.

One group of the numeric indicators that Boards were asked to report covered the numbers of non-psychiatric hospital admissions, out-patient, and accident and emergency clinic attendances there had been for people in their area, and the numbers of these which involved people with intellectual disabilities. Guidance to Boards made clear the reference to the standards required by Monitor and drew attention to the introduction of specific questions in these areas as key elements in the new protocol for hospital inspections by the Care Quality Commission (see Baines & Hatton, 2015). They were advised to ask about general hospitals providing a substantial amount of care to their local residents and that for this exercise they were not required to ask about tertiary care services or patients admitted to more distant hospitals.

Data were reported to the Public Health England Learning Disabilities Team in customised Excel spreadsheets. They were collated and analysed using Microsoft Excel and Access. For this paper reported numbers of admissions and attendances at out-patient and accident and emergency departments are presented as rates per 1000 population; numbers for people with intellectual disabilities are also shown as a proportion of totals. Population figures for people with intellectual disabilities were taken from general practice registers reported in the 2013 to 2014 Quality and Outcomes Framework. For other people mid 2013 population estimates from the Office for National Statistics were used. In the case of inpatient

admission data, published Hospital Episode Statistics for clinical commissioning groups were consulted as a corroborative source.

As a rough check on the validity of the data reported we compared activity numbers for the total population with data published on the national Hospital Episode Statistics website. This was only partially successful. For in-patient admissions we were able to use data specifically for the areas for which usable admission data were reported; specialty specific figures are only reported nationally so we made a uniform adjustment for this.<sup>1</sup> For outpatient and accident and emergency admissions we were only able to look at the overall national rate as CCG or local authority level data are not published. For out-patient attendances it was possible to filter for non-psychiatric attendances.

## **Results**

The first observation is that a high proportion of the Learning Disability Partnership Boards did not answer the questions. 63 out of the 152 (41.4%) did not provide usable data for in-patient care, 83 (54.6%) for out-patients and 84 (55.3%) for accident and emergency attendances. An additional 30% of boards supplied some data but these were either incomplete or evidently inaccurate.

Table 2 shows the combined figures for all Partnership Boards providing usable data. We looked first at their likely accuracy on the basis of comparison of the total population figures to published sources. The most closely comparable national Hospital Episode Statistics figures were for hospital admissions data; national data for the areas which reported this gave a total admission rate of 268.7 admissions per 1000 population. The numbers reported to us give a rate of 255.8, 5% below the national figure. The rate for out-patient attendances was 20% below the national figure (1481.0 attendances per 1000 total population for non-psychiatric specialties) and that for accident and emergency admissions 29% above the national figure (343.8 per 1000).

Table 2 about here

Next, in the data reported to us we compared rates for people with intellectual disabilities to national totals. The reported rate of hospital admissions for people with intellectual disabilities was 13% higher than that for all people, for out-patient attendances 25% lower and for accident and emergency attendances 14% lower. 0.46% of

---

<sup>1</sup> This made very little difference as psychiatric specialties combined account for only 0.82% of hospital admissions

admissions were identified as involving a person with intellectual disabilities, as were 0.31% of out-patient and 0.36% of accident and emergency attendances. To put this in context, in the same year, GPs in these areas reported that the prevalence of intellectual disabilities in the adult population was 0.49% in the 89 areas reporting in-patient data combined and 0.50% in the areas reporting out-patient and accident and emergency data. This would suggest that either people with intellectual disabilities use hospital services less frequently than others or that their disability is less often identified by hospitals than by GPs.

Figure 1 about here

However the most striking finding is the very large range of the reported rates. Figure 1 presents rates per 1000 population for in-patient admissions and the two types of attendance covered for people with intellectual disabilities and for others. For people with intellectual disabilities the top of the inter-quartile range of reported rates of inpatient admission was more than three times the bottom, and for the outpatient and accident and emergency attendances it was more than four times. Rates reported for other people were more consistent with the tops of the inter-quartile ranges for inpatient and accident and emergency attendances, being slightly less than twice the lower quartile bound and for outpatient attendances 2.6 times. The tops and bottoms of the ranges in all cases are much more widely spread although the outlying data at the top and bottom of each range look implausible.

In the case of in-patient admissions, this level of spread far exceeds the range reported in annual hospital episode statistics. In nationally published data at the level of clinical commissioning groups (which are a comparable geographical size) the upper bound of the inter-quartile range for total admission rates is only 25 per cent above the lower and the maximum only twice the minimum.

Reported rates of admission and the two types of attendances of the three types of were significantly correlated. The pairwise correlations between rates of admissions and outpatient attendances was 0.86, between admissions and accident and emergency attendances and between the two types of attendances 0.72 in both cases; in all three cases  $p < 0.0001$ . All three rates were significantly, though very modestly correlated with IMD 2015 average deprivation scores for local authorities (admissions 0.27,  $p = 0.011$ ; out-patient attendances 0.38,  $p = 0.001$ ; accident and emergency attendances 0.33,  $p = 0.004$ )

Figure 2 shows the range of the reported proportion of admissions and attendances in which the individual concerned had intellectual disabilities. These show similarly wide ranges, with the upper bound of the interquartile ranges for inpatient admissions being 2.4 times the lower bound, and for out-patient and accident and emergency admissions 3 and 2.8 times respectively.

Figure 2 about here

## Discussion

In view of the health needs of the population of people with intellectual disabilities (Emerson & Hatton, 2014), it seems surprising that the rates of hospital admission and attendance for people in this group are not higher than overall total rates. However the comparisons we are able to make with the very limited amount of detail in the data available are not very satisfactory.

The most important driver of admission rates in the general population is population age. Admission rates are at under 30% of their overall total in childhood. They exceed the overall total at ages above 60, reaching 2.5 times that level at ages over 75 and four times at 90. People with intellectual disabilities are known to die at younger ages than others (Heslop et al., 2013, 2014); statistical allowance for this would be needed for a proper comparison of admission rates.

The wide range of values is not necessarily surprising. The pattern of adult settlement of people with intellectual disabilities is complex, reflecting variations in both the incidence of the disability and the geography of residential care placements to which people move in adulthood. It is common for London local authorities to settle people in areas where property is relatively cheap.

However the question the study was seeking to explore is the extent to which healthcare commissioners are actively monitoring the extent to which hospital care providers identify and make reasonable adjustments for people with intellectual disabilities. The broad conclusion is that around a half of commissioners were unable to answer these apparently simple questions. The questions were not new. They had been asked in identical form in the same exercise a year earlier and it was widely anticipated that this would be repeated. Findings of the previous exercise had been widely presented in meetings about the self-assessment exercise and to a national conference of specialist liaison nurses employed to improve the hospital care of people with intellectual disabilities.

The authors of the Michael Report cited in the introduction prefaced their chapter of conclusions and recommendations with a quotation from a report of the Parliamentary Joint Committee on Human Rights. 'Public authorities', they wrote, 'should never be allowed to treat their duties towards adults with learning disabilities under the Human Rights Act 1998 and the Disability Discrimination Act (including their positive duties under the Disability Equality Duty) as optional.' Our study suggests that in this important area, whilst many hospitals may recognise and be acting on their obligations in this area, many others still do perceive them as optional.



## References

Baines S & Hatton C (2015). *CQC inspection reports of NHS trusts. How do they address the needs of people with learning disabilities? An interim analysis*. London: Public Health England.

Emerson E & Hatton C (2014). *Health inequalities and people with intellectual disabilities*. Cambridge: Cambridge University Press.

Heslop P, Blair P, Fleming P, Hoghton M, Marriott A & Russ L (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Bristol: CIPOLD.

Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A & Russ L (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet*; 383; 889-95.

Mencap (2007). *Death by indifference*. London: Mencap.

Michael J (2008). *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Independent Inquiry into Access to Healthcare for People with Learning Disabilities.

Monitor (2015). *Risk Assessment Framework*. London: Monitor.

Tuffrey-Wijne I, Giatras N, Goulding L, Abraham E, Fenwick L, Edwards C & Hollins S (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 Services and Delivery Research*, Vol 1, Issue 13.

UK Parliament (2015). Written question 219034.

<http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2014-12-16/219034/>

Table 1. The six questions regularly asked by Monitor to Foundation Trusts

1. Does the Trust have a mechanism in place to identify and flag patients with learning disabilities and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients?
2. Does the Trust provide readily available and comprehensive information to patients with learning disabilities about the following criteria:
  - a. treatment options;
  - b. complaints procedures, and;
  - c. appointments?
3. Does the Trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities?
4. Does the Trust have protocols in place to routinely include training on providing health care to patients with learning disabilities for all staff?
5. Does the Trust have protocols in place to encourage representation of people with learning disabilities and their family carers?
6. Does the Trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports?

Table 2. Rates of admissions and out-patient and accident and emergency attendances per thousand population for people with ID and all people, and proportions of admissions and attendances where the person involved had ID.

	With ID	Total	Proportion with ID
In-patient admissions (89/152 usable responses)	290.2 (287.4 to 293.2)	255.8 (255.6 to 255.9)	0.46%
Out-patient attendances (71/152 usable responses)	896.4 (891.0 to 901.9)	1,187.5 (1,187.1 to 1,188.0)	0.31%
Accident and emergency attendances (73/152 usable responses)	382.9 (379.3 to 386.5)	445.0 (444.7 to 445.2)	0.36%

Figure 1. Reported rates of in-patient (IP) admissions and attendances at out-patients (OP) or accident and emergency (A&E) for people with intellectual disabilities (ID) and others.

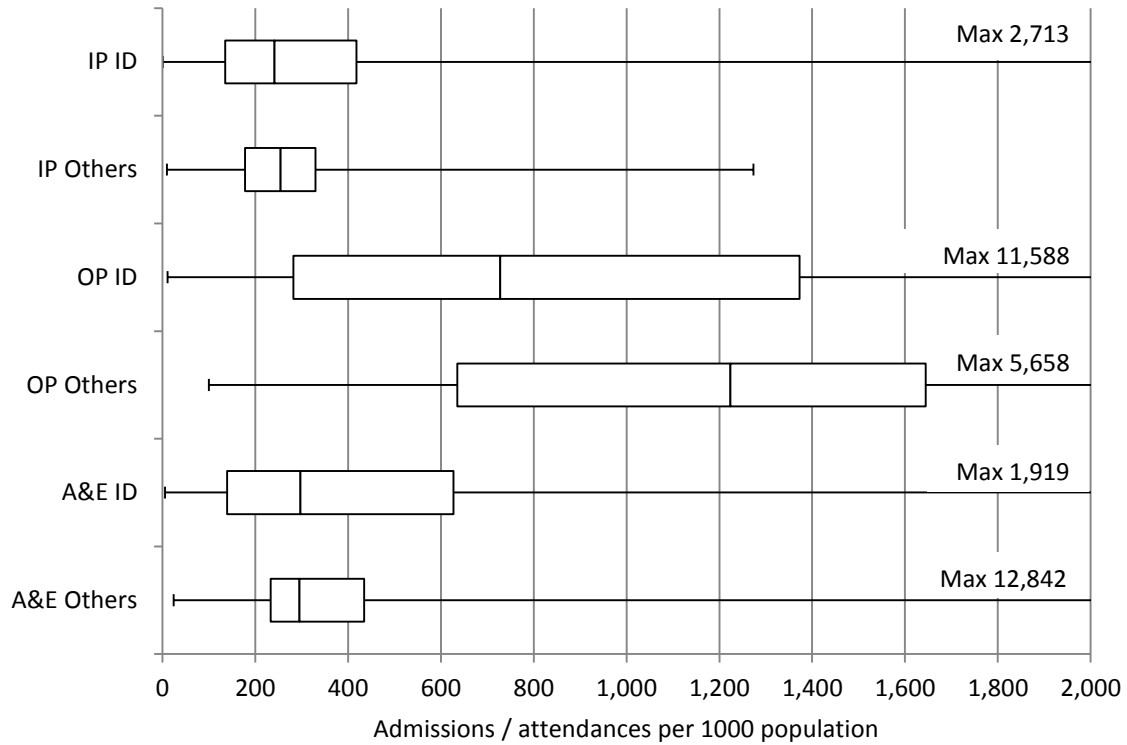


Figure 2. Proportions of in-patient (IP) admissions and attendances at out-patients (OP) or accident and emergency (A&E) reported to involve people with intellectual disabilities (ID).

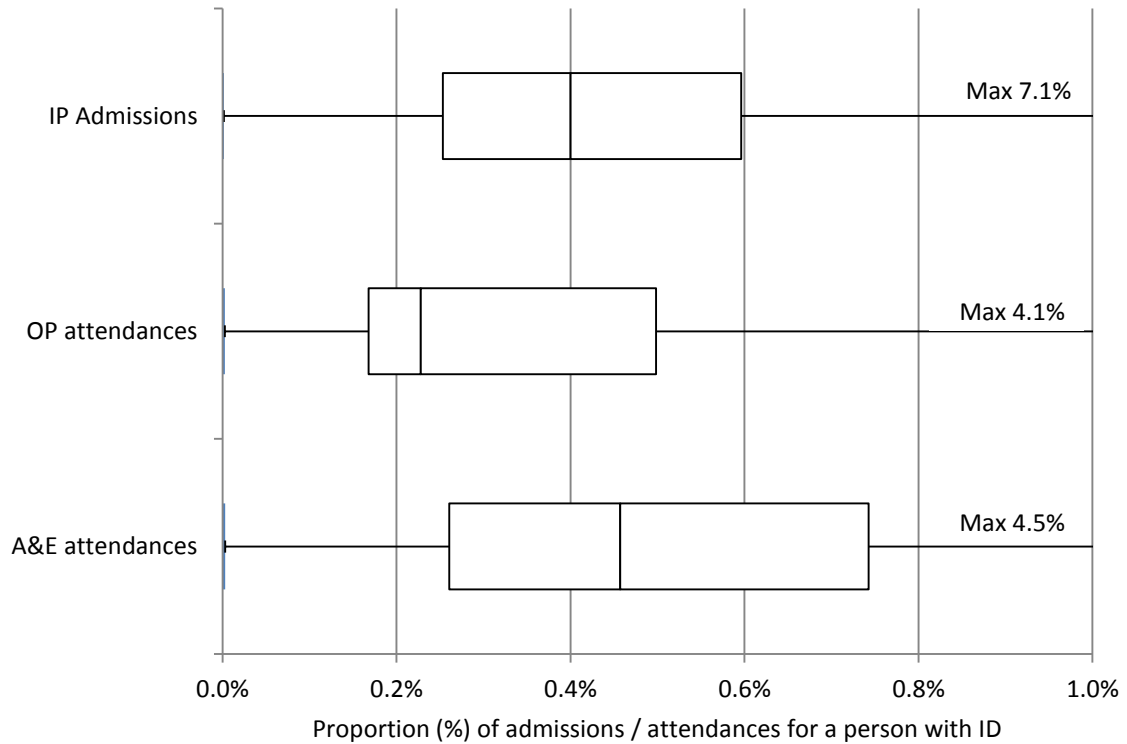




Figure 3. Reported rates of in-patient (IP) admissions and attendances at out-patients (OP) or accident and emergency (A&E) for people with intellectual disabilities (ID) and others.

Figure 4. Proportions of in-patient (IP) admissions and attendances at out-patients (OP) or accident and emergency (A&E) reported to involve people with intellectual disabilities (ID).