Mental health data bulletin

What can we learn from mental health data on children and young people with learning disabilities and autistic spectrum disorders?

Policy background

In 2011, the Panorama programme uncovered horrific abuse of patients with learning disabilities at the Winterbourne View Hospital. This prompted an ambitious cross-Government programme of action known as Transforming Care[1] to reduce to a minimum the number of people with learning disabilities and autistic spectrum disorders (ASD) living in mental health inpatient units for assessment and treatment. Improving national data on this cohort has been central to this reform agenda, to inform and drive progress in all areas.

Key facts and stats[2]

At end February 2016, there were 170 mental health inpatients with learning disabilities and/or ASD aged under 18 years and 635 aged 18-25 years. The number of under-18s who received inpatient care *at some point* in the year (to February 2016) was much higher, at 430. (Equivalent figure not available for young adults).

The gender split was fairly even among under-18 inpatients with 49% girls: 51% boys. Among young adults aged 18-25 years, 76% were male, 24% were female, consistent with the wider inpatient population.

Children are more likely to be treated further away from home than other inpatients. Under-18s were admitted to inpatient units on average 79km from home, with roughly one quarter placed between 50-100km away and one quarter more than 100km away. Nearly one third (31%) of under-18s were admitted to inpatient care informally, compared to 9% of young adults and 11% of the inpatient population overall. Nearly two-thirds (62%) of under-18s were admitted for assessment and treatment (part 2 admissions).[3]

For young adults aged 18-25 years, 59% were subject to part 2, while 17% were detained under part 3 (no restrictions) and 14% with restrictions. Part 3 may be used when criminal proceedings are involved.

Young inpatients (<18 years) at the end of February 2016 had on average been in hospital for 285 days or around nine months - ten times longer than the 28-day limit for section 2 admissions for assessment.

1 Transforming Care: A national response to Winterbourne View Hospital: www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response
2 Statistics cited in this summary are described more fully and referenced throughout this data bulletin.
3 Implications of Mental Health Act 1983 are explained in the Code of Practice www.gov.uk/government/publications/code-of-practice-mental-health-act-1983

Around one third stayed for a year or more, 10 children who were inpatients for two to five years.

Care and Treatment Reviews (CTRs[4]) were developed to avoid unnecessary admissions and to plan towards discharge (or transfer) as soon as possible. CTRs should take place soon after admission, then every six months. 100 (60%) of the 170 inpatients under 18 years had not had a CTR and 105 (61%) children still had no scheduled CTR, worse than for other age groups. Only 35 (21%) of the 170 children in inpatient care had a planned transfer date, a much lower proportion than across all inpatients (32%) or 18-25 year olds (30%).

The Learning Disability Census collected information on inpatients' experience of care (there are concerns that these data on children and young people may no longer be regularly collected). 'Adverse experiences' include self-harm, accidents or physical assault; 'restrictive measures' include use of hands-on restraint and seclusion. The last Census showed that under-18s were by far the most likely age group to have experienced both adverse experiences and restrictive measures during the last three months. Among under-18s:

- 70 (41%) experienced both adverse experiences and restrictive measures
- 20 (12%) had adverse experiences only
- 25 (15%) experienced restrictive measures only
- 55 (33%) experienced neither.

Nearly two-thirds of children and young people (105) had been given anti-psychotic medication regularly in the last 28 days. 45 children and young people (27%) had rapid tranquilisation medication given to them, more than twice the proportion for all inpatients. There are serious concerns about the appropriate use of such medication.[5]

The average weekly charge across all inpatients was just over £3,500, ranging from up to £1,500 to over £6,500. Most children are in higher cost placements of more than £4,500 per week.[6]

In June 2016 (latest monthly data at time of writing), 41,500 children and young people with a learning disability or autism were waiting to see a mental health specialist (open referrals). This included:

- 15,015 children aged <18 years
- 26,550 young adults aged 18-25 years inclusive.

This is indicative of high levels of unmet need, consistent with recent research[7] and widespread anecdotal evidence from other services and families of disabled children and young people.

4 https://www.england.nhs.uk/learningdisabilities/ctr/
5 For example, see research cited in the LD Census Sept 2013 Report: Further Analysis (p.15-16). http://content.digital.nhs.uk/catalogue/PUB14046/ld-census-further-sep13-repv2.pdf
6 Based on analysis of previous LD Census data. See HSCIC (April 2014), LD Census Report -Further Analysis. Table 6A of the accompanying data tables.
7 For example, Office of the Children's Commissioner (May 2016) Lightning review: Access to Child and Adolescent Mental Health Services 8 See http://content.digital.nhs.uk/mhsds

Data notes

Work is underway to develop a single, consistent mental health services dataset. This will include child and adolescent health services (CAMHS) data, mental health and learning disability statistics (MHLDS) and elements of the two data collections on inpatients with learning disabilities and autistic spectrum disorders: the Learning Disabilities Census and the Assuring Transformation Information Standard. In this analysis, we draw on:

1. **Learning Disability Statistics Annual Overview 2015-16** (which uses Assuring Transformation data) on under-18s and 18-25 year olds receiving mental health inpatient care at the end of February 2016.[8] Data on 18-25 year olds was provided through a special request to NHS Digital.

2. **Learning Disability (LD) Census data for September 2015**. The LD Census provided an annual snapshot of people with learning disabilities, autistic spectrum disorders and/or behaviour that challenges in mental inpatient care on 30 September in 2013, 2014 and 2015.[9] This has been superseded by the Assuring Transformation data collection.

3. **Mental Health Services Data Set (MHSDS)**[10] **on referrals for patients with a learning disability or autistic spectrum disorder** in June 2016, with data on young adults aged 18-25 years provided through a special request to NHS digital.[11]

The data requested is published online at http://content.digital.nhs.uk/media/22561/LDA-data-for-Under-18s-and-18-25sxlsx/xls/LDA_data_for_Under_18s_and_18-25s.xls.

Rounding conventions

Inpatient data is rounded to the nearest 5, with values under 5 suppressed. Percentages are rounded to nearest whole percentage point. Analysis of rounded data can give rise to small differences (up to 1 percentage point or 5 in absolute numbers) which would be avoided if unrounded data were available for analysis.

We have not tested the significance of these data, but where there are doubts about robustness, they are highlighted.

8 See Learning Disability Statistics Annual Overview England 2015-16 http://content.digital.nhs.uk/catalogue/PUB20824
9 See http://content.digital.nhs.uk/article/6468/Reports-from-the-Learning-Disability-Census-collections.
10 See http://content.digital.nhs.uk/mhsds
11 See http://content.digital.nhs.uk/mhldsreports.

1. Assuring Transformation data: inpatients with learning disabilities or autism[12]

Assuring Transformation data is reported by clinical commissioning groups (and Hubs) on mental health inpatients with learning disabilities and/or autism. At end February 2016:

- there were 170 inpatients aged under 18 years
- 635 aged 18-25 years.

The number of under-18s who received inpatient care at some point in the year to end February 2016 was much higher, at 430 children and young people. 59% were discharged or transferred during the year, but some were readmitted, so nearly half (48%, 205 children) were still in hospital at February 2016.

So the published data rather confusingly gives two different figures for the number of children and young people in inpatient care at February 2016: 170 and 205, the latter being an updated figure.[13] The data which follows in this section is based on the lower figure (N=170), used by NHS Digital in responding to our data request and in most of the published data tables.

Gender[14]

Among the under-18s in inpatient care at the end of February 2016, the gender split was fairly even: 49% girls, 51% boys. This differs significantly from other data on disabled children and young people, which generally shows a much clearer gender bias (two-thirds or more male).

Among young adults aged 18-25 years, 76% were male, compared to 24% female, in line with the inpatient population overall.

Learning disabilities or autistic spectrum disorders (ASD)[15]

Among the under-18s, the most common diagnosis was ASD (51%), followed by 28% with learning disabilities only and 15% with both.

This differs from young adults (aged 18-25 years), 50% of whom have learning disabilities only, 19% autistic spectrum disorders and 27% a diagnosis of both needs. Again, the breakdown for young adults is similar to the profile of the inpatient cohort overall: among inpatients of all ages, 58% have learning disabilities only, 16% autism only and 22% both needs.

Ward security[16]

Children are less likely to be on medium or high security wards than adults. Only 10% of under-18s were on a medium secure ward, with less than five on a high secure ward.

18-25 year olds are slightly more likely to be on a medium secure ward, compared to all inpatients. 21% of 18-25 year olds were on a medium secure ward and 1% on a high secure ward.

12 See tables 8-11 on young inpatients (LD Statistics 2015-2016). Data on 18-25 year olds by special request.
13 Totals in table 8 and table 11, LD Statistics 2015-2016; the latter represents an updated figure. 14 Data request (AT data tab).
15 Data request - www.councilfordisabledchildren.org.uk/help-resources/resources/data-report.
16 Data request - www.councilfordisabledchildren.org.uk/help-resources/resources/data-report.

	Under 18 (N=170)	18-25 years (N=635)	All inpatients
General	51%	39%	45%
Low Secure	25%	36%	33%
PICU[5]	13%	2%	2%
Medium Secure	10%	21%	17%
High Secure	*	1%	3%

Source: Assuring Transformation (data request for <18s and 18-25 year olds, cross-referenced to all inpatients data (table 3, Learning Disability Statistics - Annual Overview, England 2015-2016).
Note: PICU=psychiatric intensive care unit.

Legal basis for admission[17]

Nearly one third (31%) of under-18s were admitted to inpatient care informally. This compares to 9% of young adults and 11% of the inpatient population overall.

Of the remainder, 62% of under-18s were admitted for assessment and treatment under part 2 of the Mental Health Act 1983.

A negligible number of children (under 5) were detained under part 3 of the Act, used for patients involved in criminal proceedings.

For young adults aged 18-25 years,

- 59% were subject to part 2, compared to 49% of the inpatient cohort overall
- 17% were detained under part 3 (no restrictions) and 14% with restrictions (e.g. requiring them to be held in a specified secure unit[18]). The comparable figures for all inpatients are 15% part 3 with no restrictions and 24% part 3 with restrictions.

Total length of stay[19]

Young inpatients (<18 years) at the end of February 2016 had on average been in hospital for 285 days or around nine months - ten times longer than the 28-day limit for section 2 admissions to inpatient care (for assessment[20]). Around one third stayed for a year or more, including 10 children who had been inpatients for two to five years.

Data on the larger number of children (430) who had received inpatient care at some point during that year, show that half (50%) stayed for up to six months, just over one fifth (22%) for between 1-2 years and 50 children and young people for longer than 2 years. This includes 10 who were inpatients for between 5-10 years and 10 who were inpatients for more than 10 years[21]. The average for this larger group of young inpatients was 471 days.

CTRs[22]

Care and Treatment Reviews (CTRs) were developed as part of the response to Winterbourne View, to stop people being admitted to mental health inpatient care when there are alternatives, such as a package

17 Data request - www.councilfordisabledchildren.org.uk/help-resources/resources/data-report.
18 See Mental Health Act 1983 Code of Practice for explanation of restrictions of liberty.
19 Table 10 (LD Statistics 2015-2016) on total length of stay i.e. continuous care episodes, which may include stays at more than one provider. Data not available on 18-25 year olds.
20 Section 2 under Part 2 of the Mental Health Act 1983. See above section on legal basis for admission.
21 Table 11 (LD Statistics 2015-2016). Figures rounded to nearest 10, actual number may be slightly higher or lower.
22 Tables 9 & 4 (LD Statistics 2015-2016). Breakdown not available on 18-25 year olds.

Total length of stay in inpatient care	<18 years inpatients at end Feb 2016 (N=170)	<18 years in inpatient care *at some point* in year to Feb 2016
Up to three months	45 (28%)	140 (29%)
Three months up to six months	45 (25%)	105 (21%)
Six months up to one year	25 (14%)	85 (18%)
One year up to two years	45 (27%)	110 (22%)
Two years up to five years	10 (7%)	30 (7%)
5-10 years	*	10 (2%)
10+ years	*	10 (2%)
Average stay	**285 days**	**471 days**

Note: '*' denotes <5, low numbers have been suppressed. Source: LDS 2015-16 reference tables (annual) tables 10 and 11.

admitted, it is for as little time as possible. CTRs should take place soon after admission and then every six months[23].

It is concerning then that 100 (60%) of the 170 inpatients under 18 years had not had a CTR; much worse than the inpatient cohort as a whole, 39% of whom had not had a CTR. 105 (61%) children still had no scheduled CTR, again, a much higher proportion than amongst the inpatient population as a whole (39% of whom had no scheduled CTR).

Planned date of transfer[24]

Only 35 (21%) of the 170 children in inpatient care had a planned transfer date, a much lower proportion than across all inpatients (32%) or 18-25 year olds (30%).

40 children (23%) were reported not to need inpatient care any longer according to their care plan, 5 due to a delayed transfer of care, with the remainder 'working towards discharge'. Of the 130 who were deemed still to 'need inpatient care according to care plan':

- 30 were 'not dischargeable'
- 100 were under an active treatment plan.

Distance from home[25]

Distance from home is calculated by matching postcodes of the provider and the child's home. It is worrying that this information was not available for 10 children. Of the remainder, under-18s were placed, on average, 79km from the family home, with roughly one quarter placed between 50-100km away and one quarter more than 100km away (see table).

Comparing this breakdown to the inpatient population as a whole, children are more likely to be placed further away from home: more than 50% of under-18s are in inpatient units 50km or more away compared to 40% of all inpatients, with an average distance of 79km vs 66km respectively.

23 https://www.england.nhs.uk/learningdisabilities/ctr/
24 Data request (AT tab); LD Statistics 2015-2016, tables 9 & 4
25 LD Statistics 2015-2016, Tables 10 & 5

	No. of children <18 (N=170)	% of <18 inpatients (N=170)		% all inpatients (N=2650)
Up to 10km	35	20%		19%
10 to 20km	10	7%		11%
20 to 50km	30	18%		21%
50 to 100km	40	24%		19%
100km or more	45	27%		21%
Unknown	10	5%		9%
Average (km)	**-**	**79km**		**66km**

Source: Table 10 (<18s) compared to table 5 (all inpatients) (LDS reference tables, annual 2015-16).

Access to a care coordinator and use of advocacy[26]

Care coordinators are named individuals, usually one of the professionals working with a young person, who help to ensure that coordinated care plans are put in place to avoid or reduce to a minimum, the need for inpatient care. Nearly all children and young people have access to a care coordinator: 98% of under-18s and 96% of 18-25 year olds, similar to the inpatient population overall.

Advocates help people with learning disabilities to have their views heard and make choices about their care. This role can be fulfilled by a family member, an independent person, a non-instructed advocate or more formally under the legislation, an Independent Mental Capacity Advocate or an Independent Mental Health Advocate.[27] Almost all inpatients used advocacy: 80% of under-18s and 86% of young adults, a slightly lower proportion than the inpatient population as a whole, 89% of whom used advocacy.

2. Learning Disabilities Census, 2015[28]

The last Learning Disabilities (LD) Census was carried out in September 2015, providing an annual snapshot of people with learning disabilities, autistic spectrum disorders and/or behaviour that challenges in mental health inpatient care.

Although now over a year old, we report briefly here on two data items which raise serious concerns about the experience of children and young people in mental health inpatient settings. Voluntary organisations campaigning on behalf of people with learning disabilities are concerned that regular reporting of these data on children and young people may be discontinued.[29]

We also report on cost data, as this is lacking from most of the other national datasets on disabled children, drawn on for this analysis.

By way of background, at 30 September 2015, there were 165 under-18s in inpatient care (similar to the Assuring Transformation headline figure for February 2016), representing 6% of all inpatients.

26 Data request (AT data tab) and LD Statistics 2015-16, tables 8 & 3.
27 Types of advocacy are explained in this factsheet produced by the charity MIND: http://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/types-of-advocacy/#.WFKFtbKLSos
28 http://content.digital.nhs.uk/article/6468/Reports-from-the-Learning-Disability-Census-collections
29 This is highlighted by the Children's Rights Alliance in their annual 'state of children's rights' report for 2016 (health section, p.7) http://www.crae.org.uk/media/118311/crae_scr2016_b7_health-web.pdf

Adverse experiences and restrictive measures[30]

The LD Census reports on 'adverse experiences' and the use of 'restrictive measures' in three months leading up to Census day. Adverse experiences include self-harm, accidents or being physically assaulted; restrictive measures include use of hands-on restraint and seclusion. The Census collected information on each of these (and frequency) but a detailed breakdown for under-18s was not published in the main tables. At an aggregate level, among under-18s (N=165):

- 70 (41%) experienced both adverse experiences and restrictive measures
- 20 (12%) had adverse experiences only
- 25 (15%) experienced restrictive measures only
- 55 (33%) experienced neither.

Under-18s were by far the most likely to have experienced both adverse experiences and restrictive measures in the three months leading up to the Census, compared to any other age group.

Rapid tranquilisation and anti-psychotic medication[31]

The Census collected information on the use of rapid tranquilisation and anti-psychotic medication. There are serious concerns about the efficacy and appropriateness of the use of such medication on people with learning disabilities.[32]

Nearly two-thirds of children and young people (105) had been given anti-psychotic medication regularly in the 28-days before Census day, including 20 who had also been given it when the need arose.

Forty-five children and young people (27%) had also had rapid tranquilisation medication given to them. This was a higher proportion than in any other age band (average for all inpatients was just 11%).

Cost of placements[33]

Lastly, it is worth noting briefly that the Learning Disabilities Census collected information on the cost per week of inpatient care, potentially a powerful lever for changing commissioning practices; we are not aware of cost data being collected in any of the other datasets drawn on in this analysis.

The average weekly charge across all inpatients was just over £3,500, ranging from under £1,500 to more than £6,500. Nearly half (47%) of weekly charges cost between £2,500 - £3,500, with one quarter of placements costing between £3,500 - £4,500. Previous analyses of the LD Census showed that over half (53%) of children were in placements costing more than £4,500 per week.[34]

3. Referrals of children & young people with a learning disability and/or ASD[35]

The Mental Health Services Data Set (MHSDS) provides monthly data bulletins on patients identified as having learning disabilities and/

30 Tables 16 & 20, LD Census initial Sept 2015 reference tables.
31 Tables 16 & 7, LD Census initial Sept 2015 reference tables.
32 For example, see research cited in the LD Census Sept 2013 Report: Further Analysis (p.15-16). http://content.digital.nhs.uk/catalogue/PUB14046/ld-census-further-sep13-repv2.pdf
33 Table 12, LD Census initial Sept 2015 reference tables.
34 HSCIC (April 2014), LD Census Report -Further Analysis. Table 6A of the accompanying data tables.
35 See http://content.digital.nhs.uk/mhldsreports data for June 2016. Age breakdown provided through a special request to NHS Digital published at LDA data for Under-18s and 18-25s (referrals tab).

or autistic spectrum disorders.

In June 2016 (latest monthly data at time of writing), there were 41,565 open referrals of children and young people aged 0-25 years with a learning disability and/or ASD, in other words, over 41,500 children and young people with a learning disability or autism who were waiting to see a mental health specialist. This included:

- 15,015 children aged under-18 years
- 26,550 young adults aged 18-25 years inclusive.

This is indicative of high levels of unmet need, consistent with recent research[36] and widespread anecdotal evidence from other services (e.g. special schools) and families of disabled children and young people.

4,090 (10%) of these referrals had been made in that same month and 4,465 ended that month, after patients were seen by a specialist and discharged.

70% of children and young people with open referrals were male and 65% of the young adults.

We requested an ethnic breakdown of these data, but around one in five had no data on ethnicity (not stated or not known), undermining the validity of comparisons.

36 Office of the Children's Commissioner (May 2016) Lightning review: Access to Child and Adolescent Mental Health Services

Health terms and definitions for the Children and Young People's Health Services data set

Glossary for reporting in the Children and Young People's Health Services data set, with some detailed descriptions and helpful cross-referencing to terms used by other services, available at: **www.bacdis.org.uk/policy/documents/ExplanatoryGlossaryofTerms.pdf**

Council for disabled children

The True Colours Trust

Data bulletin of an exploratory analysis commissioned by the Council for Disabled Children and the True Colours Trust.

by Anne Pinney

The full report and in-depth data bulletins can be found at www.councilfordisabledchildren.org.uk/helpresources/data-report