

P-06-1479 Stop the detention of learning disabled and autistic children, young people and adults in hospitals - Petitioner to Committee, 21 November 2024

Dear Carolyn Thomas

Here are our views in light of the document that you sent to aid the Petition Committee's consideration of our petition at their next meeting.

1. What are your thoughts on the attached document? Does it adequately address the issues you raised?

We had a positive meeting with the minister Sarah Murphy and welcome that the Welsh Government 'shares the campaign's view that a hospital bed is not a home and wherever possible people with learning disabilities should receive their care at home or as close to home as they can.' The fact that 'this is a key priority' for the Welsh Government and a 'specific commitment within the Learning Disability Strategic Action Plan 2022-2026' is a positive start.

We do, however, have some concerns.

The first concern is that this is a human rights issue. People have experienced human rights abuses, and we have evidence of ongoing human rights cases. We would like the Welsh Government to acknowledge this issue as the human rights issue that it is. It is not an access to services issue.

Secondly, despite the Welsh Government stating that they are 'undertaking a significant amount of work in this area to achieve this objective' and a lot of this work is being carried out beyond the public's view we are not seeing any real evidence of this on the ground. Stolen Lives cases are increasing, and people are remaining trapped in hospitals (some on DoLs). The Welsh Government states that 'we need to ensure people are aware of and can contribute to helping tackle these issues.' However, what we really want to know is what is the Welsh Government doing around the issue of avoidable and/or unlawful sectioning and what is it doing to get people out of hospitals and into their own homes in their own communities. A communication plan to better understand the progress of the 'behind closed doors' work that is happening would be beneficial.

In relation to data with regard to this issue, Stolen Lives has been asked to present a paper on this and I have attached it for you here.

We welcome that a Task and Finish Group has been established. However, we have concerns that such a 'complex area of work' is being rushed, with a deadline of March. We are also concerned that the group doesn't yet feel like a *collective* attempt to address the urgent policy issues at hand and doesn't yet have the specialism to do this. Furthermore, we want our engagement to continue beyond 'recommendations' – we need to see an action plan, with specific, measurable, attainable, relevant, and time-based goals. We need to be able to

hold people to account. So, there is a need for more cross-party scrutiny to ensure that this happens.

2. Do you have further questions in response?

We have raised concerns about the closure of specialist inpatient services, resulting in people with learning disabilities being detained in mainstream mental health provision. This has happened in Hywel Dda, for example. This has led to people being looked after by staff who are not trained in learning disability and/or autism, people being placed in even more unsuitable environments and subjected to restrictive practices (such as long-term segregation, seclusion and physical and chemical restraint), people being viewed under a mental health lens and even subjected to inappropriate forensic gateway assessments. As yet, our concerns on this issue have not been addressed.

We also have concerns about Mental Health Act reform. We would like to know what the Welsh Government is doing to prepare for this. Without the funding for good community support and provision, changes to the act, could have unintended negative consequences for people with learning disabilities and/or autistic people, such as more people being detained under DoLs or being criminalised.

Best wishes

Stolen Lives

A Paper presented to the Task and Finish Group by Stolen Lives on the need for improved data collection regarding people with learning disabilities and autistic people in secure hospitals.

2nd December 2024

The following paper outlines what datasets are available in England and Wales relating to information about people with learning disabilities and autistic people in secure hospitals and what issues there are with the datasets. Recommendations are made for what is needed in Wales.

In England:

In England, there are two main national datasets that collect information about people with learning disabilities and autistic people in secure hospitals. They are the Assuring Transformation Dataset and the Mental Health Services Dataset, and data from these is published monthly.

Assuring Transformation Dataset

Assuring Transformation is a data collection about people with a learning disability or autistic people who are in a mental health hospital and collects data about the care they are getting in hospital.

The Assuring Transformation information is collected by NHS England and is collected from NHS commissioners.

Commissioners hold, manage, and maintain Assuring Transformation. Commissioners are people who pay for services which includes hospital care.

Hospitals share information about the person's care with commissioners to be included in Assuring Transformation.

The Assuring Transformation data collection includes information on:

- the number of people with a learning disability and autistic people getting care in a hospital and the type of hospital unit they are in
- how long they have been in hospital
- why they were sent into hospital
- their care during hospital stay
- how many people have moved from hospital to the community
- whether people have had their care plan checked, have a care co-ordinator and have regular reviews
- whether people have access to independent advocacy
- whether people are visited regularly by their commissioner
- the age, gender and ethnicity of people

More information can be found here:

[NHS England » What is Assuring Transformation?](#)

The latest AT statistics can be found here:

[Learning Disability Services Monthly Statistics, AT: September 2024, MHSDS: August 2024 - NHS England Digital](#)

The Mental Health Services Dataset

All activity relating to patients who receive assessments and treatment from Mental Health Services is within the scope of the Mental Health Services Data Set, where the patient has, or is thought to have:

- a mental health condition and/or
- a need for support with their mental wellbeing and/or
- a learning disability and/or
- autism or any other neurodevelopmental condition

The scope of the Mental Health Services Data Set requires patient record level data submission from services as follows:

For each patient attending a service located in England

- If the care is wholly funded by the NHS: the data submission for that patient is mandatory
- If the care is partially funded by the NHS: the data submission for that patient is mandatory
- If the care is wholly funded by any means that is not NHS: the data submission for that patient is **optional**.

For each patient attending a service located outside England, but commissioned by an English Integrated Care Board or NHS England specialised commissioner, the data submission is **optional**.

More information can be found below:

[About the Mental Health Services Data Set \(MHSDS\) - NHS England Digital](#)

Some issues have been flagged regarding the two datasets in England and there are differences in the inpatient figures between the datasets. For example, **the Assuring Transformation dataset only collects data on inpatients in specialist provision**, and the optional nature of data submission for the independent sector under the Mental Health Services Dataset means that the full picture is unclear. Restraints data is also only included within the Mental Health Services Dataset.

For further information, please see: [Chris Hatton's blog: What can the statistics tell us about people with learning disabilities and/or autistic people in inpatient units during COVID-19? Part 1 - number of people](#)

In Wales:

The Patients In MH Hospitals and Units Dataset (2015-2019)

In Wales this dataset provides information on residents in NHS hospitals and units for people with a mental illness or learning disability.

This has not been updated since 2019 and the Welsh Government website notes that there are currently no plans to update this data. (WG, 2024).

The last available data, published in November 2019, notes that on March 31st 2019 there were 87 resident patients in Wales.

This represents a decrease of 30 (26%) from 2018 and since 1979 the number resident on the census date has fallen by 2,186 (96%).

On 31 March 2019, 23 males and 7 females had been residents for 10 years or more.

The data from 2019 also revealed that 24 patients with learning disabilities (28 per cent of the total) were detained under the Mental Health Act 1983 and other legislation and that this was the largest percentage in the last 10 years.

The data here are collected from individual Health Boards by NHS Wales Informatics Service (NWIS). Agreed standards and definitions within Wales provided assurance that the data was consistent across Local Health Boards.

Limitations to data in Wales:

The data focuses on a small number of patients with learning disabilities. **It does not include data on autistic patients.** It does not cover smaller units due to confidentiality issues.

The data does not include Welsh residents who are patients at hospitals in England.

Each year, on 31st March, a census is taken of residents in NHS hospitals and units for people with a mental illness or a learning disability in Wales. It is a snapshot on that date so it is difficult to determine short stay and discharge (and where people may have gone).

It is unclear whether the data for people with learning disabilities refer to mental health hospitals or specialist inpatient LD provision or both. When it states hospitals/units for people with a learning disability this implies Assessment and Treatment Units, but we know that people with learning disabilities are also placed within mental health hospitals and the data does not appear to be available here.

There are two charts which give some indication of length of stay in units, but data for before 2015 contains some patients with an unknown duration of stay which is likely to have affected the figures for length of stay of 10 years or over.

There is similar information available from other parts of the UK, but the data is not exactly comparable due to local definitions and standards in each area.

Admission of Patients to MH Facilities Dataset (Oct 2022)

This dataset provides data on the number of patients admitted to mental health facilities both formally and informally, and patients subject to supervised community treatment.

It does not provide specific data on people with learning disabilities.

What we need:

A national dataset that collects information about all people with learning disabilities and autistic people in secure hospitals and units. This needs to include information on people in secure hospitals and units in Wales and those placed out of county in England.

The data from this dataset needs to be made publicly available on a monthly basis online.

We recommend the data collected should include:

1. The age, gender, ethnicity of people. Also may want to cover LGBTQ+
2. Information on primary, secondary or tertiary diagnoses – e.g. Learning disability, autism, ADHD, mental health, dementia. (With MH reform, it will be important to keep a check on number of additional co-occurring MH diagnoses).
3. Number of people who have been at threat of admission to secure hospitals and units (joint working with social services for data collection).
4. Information on where people were living prior to admission. This is important for flagging where people may have been inappropriately placed and where sectioning could have been avoided. This should include people who were placed in a community placement that was deemed unsuitable for their needs according to local authority/health board/family prior to admission.
5. Data on admissions by legal status showing those admitted formally and under which section of the Mental Health Act, and those who were admitted under DoLS (Mental Capacity Act). (Also important to keep a record of number of people placed under DoLS and to see if this number increases with MH Act reform).
6. Were detained subject to a legal framework which is not the least restrictive to meet their needs.

7. Is the person detained under a forensic or non-forensic pathway? (Important to keep a check of MH Act reform. Do we see an increase of people detained under the forensic pathway? Do the numbers in prisons increase when the provision to detain in psychiatric settings is removed?).
8. Identifying data for category of low/ medium/ high secure setting.
9. The number of people with a learning disability and/or autistic people getting care in a hospital and the type of hospital they are in (Assessment and Treatment Unit/non-specialist, NHS or operated by an independent provider).
10. Size of setting (for example number of beds) and staff-to-person ratio.
11. Staff qualifications (for example, LD trained, autism trained, trauma-informed, human rights trained...)
12. Name of Health Board or Local Authority that the person comes under -This is important for noting potential trends and whether person is out of county or country (for example, Stolen Lives has noted that there is a tendency for people from Cardiff to be placed in St Andrews in Northampton).
13. Data on how long person has been in hospital.
14. Information on the use of seclusion, restraint, long-term segregation. This should include an outline of the policy and practice for each setting and also detailed figures on the rates of use for each person. Is there a Reducing Restrictive Practice lead? Reviews of the use of RP?
15. Information detailing refusal of regular contact with family (for any reason).

16. Information detailing if the person has experienced any human rights violations. [guide mental-health-human-rights-practitioner-guide learning-disability.pdf](#)
17. Information on the use of psychotropic medication. This should include prescribed daily long-term usage, PRN usage and short-term usage.
18. Regular updated information on the average length of stay someone spends across all units. It is important to distinguish this. Figures should not be for each individual unit because the way people get transferred around implies several "short stays", this is a misrepresentation of experience.
19. Data on inpatient deaths. This should include all causes (and suicide rates).
20. Data on numbers of Mental Health tribunals, managers hearings, formal complaints etc.
21. Data on access to independent advocacy service/Learning Disability/Autism support specialist? Detail of provision and take-up rates of this.
22. Data on numbers of people (patients) invited to care reviews. Are people being supported to have a say in their care and in long term planning?
23. Data on allocation of care-coordinators and regularity of formal reviews for care plans. Is care planning person-centred? Does it include the family?
24. Data on whether people have had an Annual Health Check /have a health profile.

25. Whether people are visited regularly by their commissioner (to determine how well the commissioner knows the person they are commissioning services for).
26. It would be useful to have a map of all available placements/beds and step up/step down to build an understanding of what provision is currently there.
27. Data on transition planning and processes in preparation for discharge
28. Details on the numbers of people who have moved from hospital to the community. It is not enough to simply state number of people who have been discharged, it would be beneficial for planning and policy to know the pathways back to community living. Has the person been moved from one hospital to another? Has there been a step down/step up approach?
29. Data on cases where there has been a failure to draft or implement appropriate aftercare provision as owed by the duties in s117 of the Mental Health Act 1983.
30. Trauma-informed support for the person discharged and the family?
31. Data on readmissions (How long it has it been since the person was discharged? Possible factors leading to readmission, etc.)

Without good quality data it is hard to build a picture of what is happening to people with learning disabilities and autistic people in Wales before, during and after admission to a secure hospital or unit. Good quality data can be used to help prevent admission, can be used to support the person whilst an inpatient and can be used by NHS Wales to track and plan inpatient provision. Moreover, it can be used to plan and commission good quality community services.

Good quality data makes for good quality research and analysis, which, in turn, can help inform and shape both local and national policy decisions - the quality of the insights, and the accuracy and reliability of the conclusions drawn can only be as good as the quality of the data.