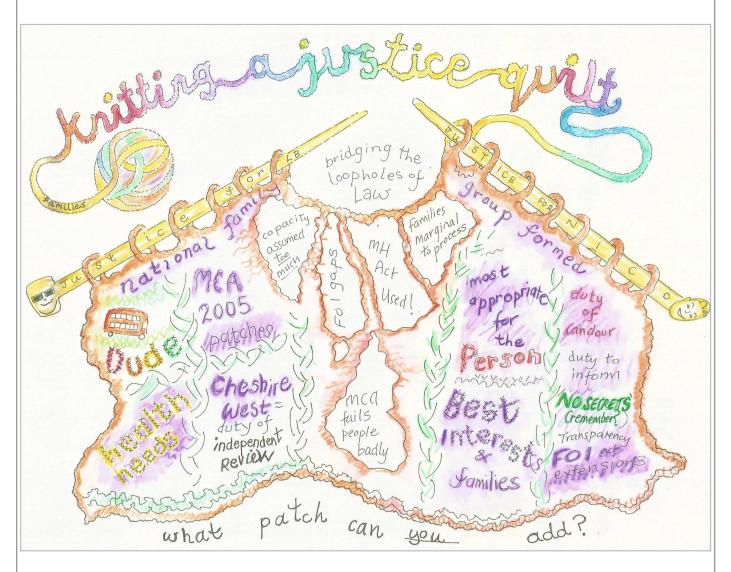
REPORT ON THE FIRST 7 DAYS OF ACTION



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We are very grateful to Mary O'Toole for permission to use her illustrations 'Knitting a justice quit' and 'Page one of a long story'.

Foreword from Mark Neary

My role in 7 Days of Action was to collect and curate the stories that families sent to the campaign and to write the final blog posts that were published daily throughout the 7 days. It became clear from the beginning that there had to be some base rules for the stories to have maximum impact:

- 1. The emphasis in the stories had to be on the dudes being detained. The families needed to become side figures in the stories. The aim was always to present 7 very human stories. We wanted readers to like the 7 dudes. We wanted readers to be interested in their stories. We wanted readers to relate on a basic human level to the dudes.
- 2. We made an editorial decision early on not to include any stories of dudes that have been discharged from ATUs and are now living at home. There was considerable pressure to include some "happy endings" stories but we didn't want the impact to be diluted by passing through a "positive" lens. WE make no apologies that we wanted to keep the pressure on the readers all week long with the relentless horror of the very real and very current stories.
- 3. From a journalistic point of view, we knew that each story needed a "hook". Although there were many similarities in the 7 dudes' stories, we wanted their individualism to come through.
- 4. We never sought out stories and only included stories that had the full consent and input of the family.
- 5. We presented each story, we hope, with equal status. We didn't see any of the dudes as more deserving than another.

www.sevendaysofaction.net

Introduction

There are 3,000 people with learning disabilities and/or autistic spectrum disorder who are in hospital for the purposes of assessment, care and treatment in England¹. The term Assessment and Treatment Unit (ATU) is often used to describe these inpatient hospital settings. In 2012 the Royal College of Psychiatrists (RCP 2014) undertook a feasibility study to examine the potential for a national clinical audit of the quality of healthcare experienced by people with a learning disability who are in ATUs. The RCP concluded that the focus for quality audits of ATUs should be cultural change, both at the level of organisations and individual healthcare workers, and on the experience of people with a learning disability, their families and carers.

Monday 18th April 2016 saw the start of a week-long campaign which made use of social media to raise awareness about the experiences of people who were receiving healthcare in ATU settings. The campaign message was that there are 3,000 human stories behind the numbers. The campaign was led by families of people who were detained in ATUs. Over the 7 days the campaign ran, 7 families published 7 stories about their family members. Each story emphasised the humanity of the person being written about. The stories were published on a dedicated blog site - https://theatuscandal.wordpress.com/

The campaign used social media to distribute messages and engage a wide audience who were invited to take action during the 7 days to create new additional content and contributions. Content generated during the campaign week was posted on the 7 Days of Action Facebook site or on Twitter tagged with the #7DaysofAction hashtag.

During the campaign week 72,580 hits were recorded of people having accessed the campaign blog.

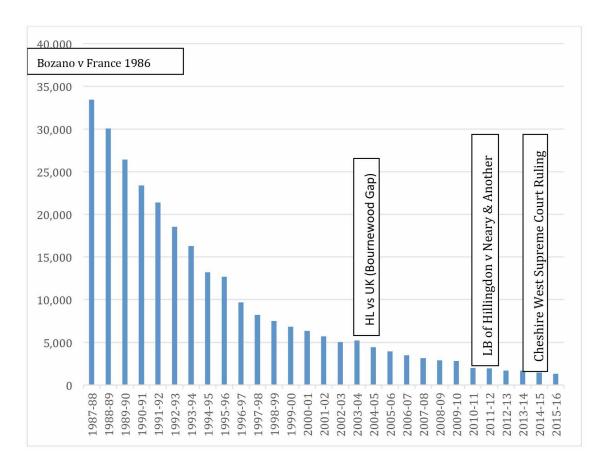
The campaign was for Eden, Stephen, Tianze, Thomas, Jack, Ryan, Connor, and Robert. They and their families needed their stories to be told and heard so that others don't have the same experience.

^{1:} NHS Digital Learning Disability Census Report - England, 30th of September 2015.

Some ATU Facts and Figures

Since the 1980s the process of deinstitutionalisation (Emerson & Hatton 2006) in the NHS appears to have led to a reduction in the number of available NHS England inpatient beds for assessment, care and treatment of people with a learning disability and/or autistic spectrum disorder.

Figure 1: NHS England Learning Disability Beds since 1987².



The Department of Health published the Winterbourne View Concordat and Transforming Care policy in 2012 which set a target for everyone with a learning disability in England who was inappropriately detained in hospital to have been discharged by 1st June 2014. Despite further reduction in the number of available NHS inpatient beds by 465 beds (27%) since 2013, the ambition to close all inpatient beds for people with a learning disability has not yet been met. Occupancy levels in NHS England beds between 2013 and 2016 averaged

^{2:} Data taken from KH03 collection from all NHS organisations that operate consultant-led beds open overnight or day only. Changes to the way data is collected mean only Q4 data provided from 2010/11. More information:

http://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-andoccupancy/

at 78.4%, with signs of some further reduction during 2016 to 73.6%³. In 2015 NHS England renewed its commitment to close inpatient beds and improve the quality of services for people with learning disabilities and/or autism through the Transforming Care⁴ and Building the Right Support⁵ programmes.





The Learning Disability Census Report (2015)⁷ provides information from providers, both from NHS England and from the independent sector, about their analysis of the quality of care and support which people in ATUs are experiencing. Overall in 2006, 20% of people in learning disability inpatient units were in independent sector services (Glover & Olson 2012); by 2015 the proportion of people who were in ATUs within the independent sector had increased to 46%. The Learning Disability Services Monthly Statistics⁸, which includes data from 40 independent sector providers, reported that as of July 2016, the proportion of people who were in an inpatient bed provided by the independent sector had further increased to 48.2%. In April 2016, CQC published the findings from their review of learning disability services that provided care for people with learning disabilities and challenging behaviours (CQC 2016). The CQC evaluated 150 care provider settings which met this definition: 71 were NHS Trusts, 47 were independent sector providers and a further 32 were care home settings.

^{3:} A of 30th June 2016. Data taken from KH03 collection from all NHS organisations that operate consultant-led beds open overnight or day only.

^{4:} NHS England Transforming Care for People with Learning Disabilities – Next Steps.

^{5:} NHS England Building the Right Support: A national plan for to develop community service and close inpatient facilities for people with autism who display behaviour that challenges, including those with a mental health condition.

^{6:} Data taken from KH03 collection from all NHS organisations that operate consultant-led beds open overnight or day only.

^{7:} HSCIC Learning Disability Census Report - England, 30th of September 2015.

^{8:} NHS Digital Learning Disability Services Monthly Statistics - England Commissioner Census (Assuring Transformation) - July 2016, Experimental Statistic.

Despite the decline in the availability of NHS beds, the number of people with a learning disability and/or autism who are in ATUs is not reducing at the same rate. NHS England's ambition within Building the Right Support is to achieve a 35-50% reduction in inpatient provision by 2018. At the current rate of change it would take up to 15 years

to halve the number of people with a learning disability who are in hospital.

The Royal College of Psychiatrists⁹ (RCP) argue that the term "Assessment and Treatment Unit" (ATU) is not a good way to describe the "complicated" "spectrum" (RCP 2013) of specialist inpatient services which provide care and treatment for people with a learning disability and/or autistic spectrum disorder. The RCP framework for categorising inpatient services identifies 6 categories of specialist inpatient setting, each of which provide different functions. The RCP acknowledge however, that all 6 types of inpatient unit involve some treatment and assessment as part of their model of care.

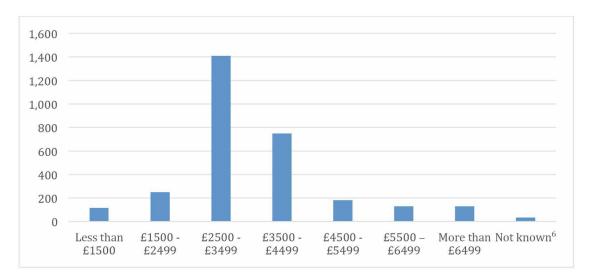
Table 1: Proportion of People in Specialist Learning Disability Service Provision as of 31st July 2016 by category as defined by the Royal College of Psychiatrists.

Category	Function	%
Category 1	High, medium and low secure forensic beds	52%
Category 2	Acute admission beds within specialised learning disability units	18%
Category 3 Acute admission beds within generic mental health settings		5%
Category 4 Forensic rehabilitation beds		5%
Category 5 Complex continuing care and rehabilitation beds		13%
Category 6	Other beds including those for specialist neuropsychiatric conditions	3%
NHS England defined other		

There are significant variations in the fees charged by providers of inpatient beds for people with a learning disability. The average fee was £3,564 per person per week, which equates to an annual charge to commissioners of £556 million a year.

^{9:} The Royal College of Psychiatrists People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services.

Figure 3: Range of Weekly Charges.



Provider fee charges for people's admission and stay in a specialist inpatient unit were funded from a range of commissioners:

- ▶ 49% of people were funded by NHS England Specialist Commissioning
- ▶ 45% of people were funded by Clinical Commissioning Groups
- ▶ 3% of people were funded by other NHS commissioners outside of England
- ▶ 3% of people were funded by Local Authorities in England
- ▶ 1% of people were funded by Other NHS Provider

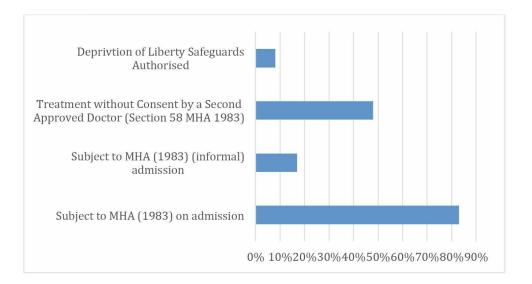
In October 2014, NHS England introduced Care and Treatment Reviews¹¹ (CTR), the ambition being to prevent avoidable admissions to specialist inpatient units for people with a learning disability or mental health need. CTRs were intended to bring additional challenge (2015c) in order to both question the appropriateness of an admission to hospital and consider alternatives. The CTR process includes involving 1 expert by experience, usually a family member or carer although it could also be a person with a learning disability, and an independent clinical reviewer (MHA CoP 1.7-1.12). The person who is funding the cost of care for the person whilst they are in an ATU (NHSE 2015c) is responsible for arranging for CTRs to take place. Between May and July 2016 there were 55 people (18%) who had a pre-admission CTR which took place before they were admitted to an ATU. A further 45 people (15%) had a post-admission CTR which took place after they were admitted. 210 people (67%) were admitted without a CTR taking place.

Of the 3,000 people who were in specialist inpatient units on the date of the 2015 Learning Disability Census, 83% were subject to the Mental Health Act (1983). Legal safeguards relating to care and treatment (DH 2015) were in place for 1190 people (48%) who were subject to medical treatment without consent as defined by Section 58 MHA (1983) and 195 people (8%) who were subject to authorisation of the Deprivation of Liberty Safeguards (DH 2013). The Deprivation of Liberty Safeguards were introduced through amendment to the Mental Capacity Act (2005) to resolve the incompatibility of Article 5

^{10:} NHS England Care and Treatment Review: Policy and Guidance.

of the European Convention of Human Rights with UK Law as identified in the HL vs UK (2004) "Bournewood" case. The Mental Health Act (1983) was also amended in 2007 to introduce the right to an independent statutory advocate, an Independent Mental Health Advocate (IMHA), for everyone detained under the Mental Health Act. As of July 2016¹¹, 1,525 people (69%) had used an IMHA and 475 people (21%) had used an Independent Mental Capacity Advocate¹².

Figure 4: Legal Status on Admission and Deprivation of Liberty Safeguards Authorisation and Treatment without Consent (Section 58 MHA 1983).

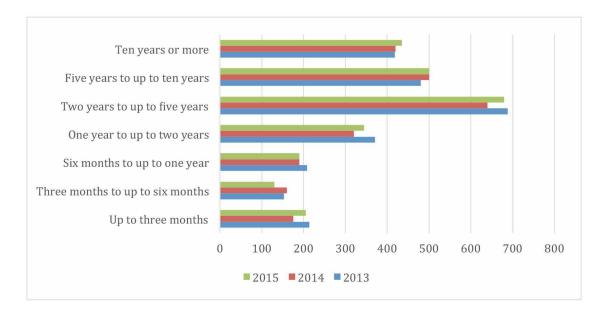


The Mental Health Act Code of Practice states that where it is possible to treat a person safely and lawfully without detaining them under the Act the person should not be detained and that the least restrictive options should always be considered (CoP 1.2-1.6). Where the Act is used it should be for the shortest time necessary. The Responsible Clinician (MHA CoP S36) has overall responsibility for care and treatment of people who are being assessed and treated under the Mental Health Act. The Responsible Clinician is responsible for authorising discharge from detention under the MHA (1983). Where there is disagreement with a Responsible Clinician about the continued need for detention, people are able to seek discharge through a Mental Health Tribunal, who will receive a report from the Responsible Clinician, a nurse from the inpatient ward and a social circumstances report from another professional (such as a social worker). On the date of the 2015 Census, 525 people who were in inpatient units (18%) had been subject to the Mental Health Act (1983) for up to a year; 1,025 people (34%) for up to 5 years; 500 people (17%) for up to 10 years; and 435 people (15%) for more than 10 years.

^{11:} NHS Digital Learning Disability Services Monthly Statistics - England Commissioner Census (Assuring Transformation) - July 2016, Experimental Statistic.

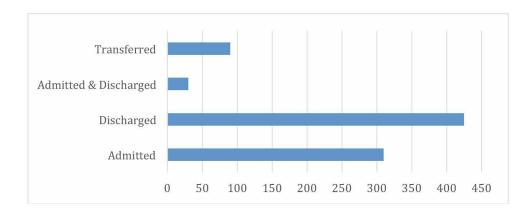
^{12:} People can have more than one type of advocate.

Figure 5: Time since legal status on admission under the Mental Health Act (1983) started.



The Learning Disability Services Monthly Statistics reported that more people were discharged from ATUs than were admitted between April and June 2016¹³.

Figure 6: Number of people who were admitted, discharged or transferred between ATUs between April – June 2016.



There is no minimum age for detention in hospital under the Mental Health Act (CoP S19). Children and young people under the age of 18 can be admitted to hospital for care and treatment. Parental consent for admission is not required if the child has competence or the young person has capacity to make the particular decision. The case of Gillick¹⁴ established that a child who had the ability to sufficiently understand fully what was involved in an intervention had competence to give consent. As of 31st July 2016, there were 110 children and young people in ATUs under the age of 18.

^{46 (21%)} of commissioners had not submitted their data as of the publication date 19th August 2016.

¹⁴ Gillick vs North Norfolk and Wisbech Area Health Authority 1986.

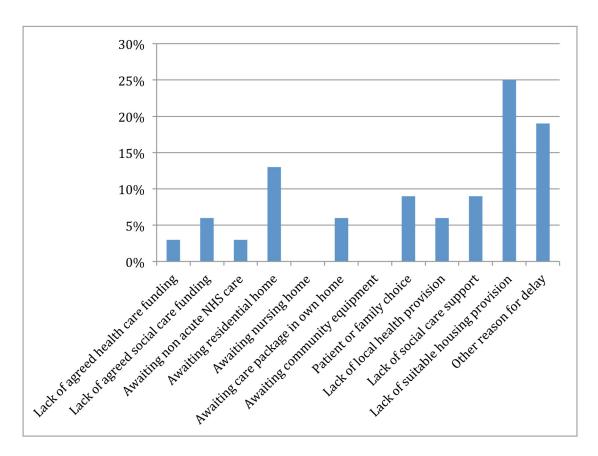
The Mental Health Act Code of Practice states that decisions about care and treatment should be appropriate to the person with clear therapeutic aims, promote recovery and should be performed to current national guidelines and/or current, available best practice guidelines (CoP 1.15-1.17). 23 percent of people who were in an ATU in July 2016 had been admitted on an unplanned basis. On the date of the 2015 Census, the main reason identified for 2,340 people (78%) who had been admitted for care and treatment in an ATU was reported as being:

- ▶ 23% of people were receiving behavioural treatment programme
- ▶ 39% of people were receiving care for mental ill-health
- ▶ 17% of people's behaviour had been assessed as being too high risk for the Ministry of Justice to agree any reduction in security level

In contrast to the RCP's perspective that specialist inpatient settings are designed to manage complexity, the 2015 Census reported that 85% of people in ATUs did not have a mental health diagnosis "severe enough to require treatment", and 73% of people did not have a behavioural risk "severe enough to require treatment". As of July 2016, 77% of people were in wards with general or low levels of security. According to their care plan, 950 people (32%) did not need inpatient care. These observations would benefit from further research to examine whether the current approach of professionally-derived frameworks for understanding and categorising levels of behaviour are successfully addressing care and support needs.

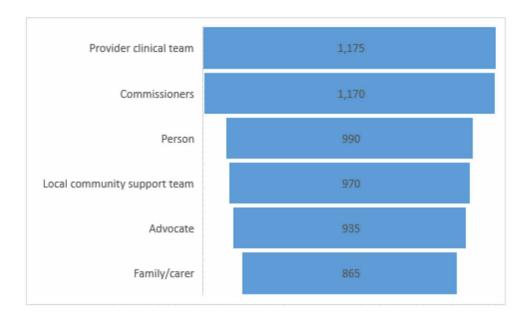
The CQC (2016) evaluation of services providing care for people with learning disabilities and challenging behaviours found failings in the quality of direct care due to a lack of person centred planning, people being admitted for long periods of time and discharge planning taking too long to arrange. As of July 2016 there were 160 people in ATUs whose care plan recorded that their discharge was delayed. The most frequent reason for a delay to discharge, a quarter of people who were waiting, was due to lack of suitable housing provision to meet their needs. A further 22% were waiting for availability of residential care or for family to make the decision in relation to which residential care home they felt best suited their family member's needs. Taken together, 47% of people who were ready to make the decision in relation to which residential care home they felt best suited their family member's needs. 47% of people who were ready to leave the ATU setting were delayed due to lack of suitable accommodation options to meet their needs.

Figure 7: Reasons for delay to discharge from the ATU as of July 2016.



The Mental Health Act Code of Practice (CoP1.18-1.21) states that providers, commissioners and other relevant organisations should work together to facilitate timely and supportive discharge from detention. Between May and July 2016, 455 people were discharged from, or transferred between ATUs. 1,200 people had a plan in place for transfer from the ATU to another setting which had an identified date for the transfer to take place as of the 31st July 2016. The Code of Practice (1.7-1.12) states that people should be fully involved in decisions about their care, support and treatment and that the views of family members and carers, if appropriate, should be fully considered when taking decisions. Figure 6 below shows the number of transfer plans which the person, their advocate and family or carer had agreed to.

Figure 8: Number of People who had agreed to the Transfer Plan details¹⁵.



The Care Quality Commission (2015) has published brief planning guidance for discharges from ATUs of people with a learning disability. The principles which CQC state should underpin discharge planning are:

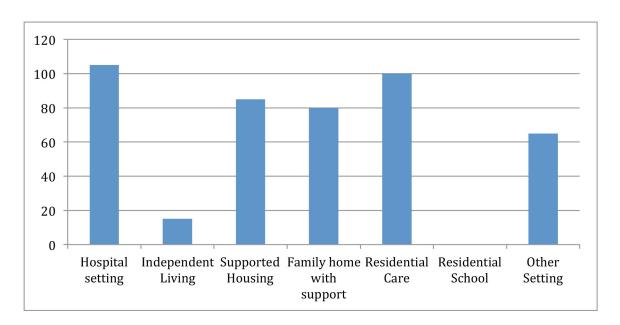
- ▶ A hospital is not a person's home.
- ▶ People should be supported to be discharged as soon as possible.
- ▶ National policy has been moving towards a social model of support, away from institutions, for over 40 years.
- ▶ Hospital care can be far from the person's home town, family, friends, and other support networks.
- Institutional care is rarely person-centred as it needs to focus on how the institution runs and meeting several people's needs. Person-centred support better meets the needs of people with learning disabilities.
- ▶ People with learning disabilities in long-term hospital placements are at increased risk of harm and are more likely to be subject to medications for behaviour and restrictive practices.

The destinations of people who were transferred or discharged between May and July 2016 were another hospital (23%), community settings (62%) or another setting (14%).

18% of people returned to their family home with support after their time in an ATU.

¹⁵ Includes people with transfer plans which did not have an agreed transfer date.

Figure 9: Transfer of Care Destination for People who were discharged from ATUs between May and July 2016.



The Dudes

On each of the 7 Days of Action during the campaign week in April 2016 a different family told the story of their family members' experience of ATUs. The stories were analysed following a review of relevant literature and of themes identified by the families in planning for their second day of action in October 2016, using a directed content analysis process (Hsieh & Shannon 2005) to identify common themes.

Consideration did not appear to have been given to the least restrictive option (MHA CoP Guiding Principle 1)

Most people were admitted to an Assessment and Treatment Unit between their 16th and 18th birthday. At the time when they were admitted to the ATU, their family understood that the admission was for a short term period of assessment and treatment and that they would then return home. Half were admitted to hospital from their residential school. Nearly half were admitted following their parents requesting support from health and social care for short term respite.

The police were involved with 3 people's admissions to hospital. 1 person's parents were not told that the police were conveying their son to hospital. 5 of the stories told of the person being detained under the Mental Health Act (1983). Only 1 family recalled that the police had used their legal powers under Section 136 to convey their family member to hospital. 2 people were deprived of their liberty and subject to authorisation of the Deprivation of Liberty Safeguards.

Family members felt that their views were not taken into account (Guiding Principle 2) and that they were not listened to by professionals (Guiding Principle 3).

7 people's families described having being excluded from care, treatment and support planning for their family member. Sheehan et al (2016) observe that involvement of family members and carers in gathering of information to support care planning is important to avoid diagnostic overshadowing (Reiss et al 1982), where the person's presenting needs are attributed to their learning disability rather than a medical cause being considered. The experiences reported by the families included:

- ▶ Being refused access to their son whilst he was undergoing initial assessment. Several days later when granted access observing facial injuries.
- ▶ Telephone call access being restricted.
- Visits home being changed and frequency of visits being restricted.
- ▶ Being chastised by the Local Authority for putting details of their son on Facebook as part of a campaign to raise awareness.
- ▶ Family suggestions and research to support discharge planning being discarded by professionals.
- Family not being kept updated of discharge plans and arrangements.

Every story told during 7 Days of Action included evidence of the person and their family having experienced a negative impact on their psychological and emotional well-being.

The purpose and effectiveness of treatment and support ranged from unclear (Guiding Principle 4) through to compromising people's dignity (Guiding Principle 3)

NICE (2015) Guidance on challenging behaviour and learning disabilities is that antipsychotic medication should only be used in combination with psychological or other interventions. All 7 people whose stories were told by their families had been medicated with antipsychotics. 2 people experienced significant weight gain whilst taking medication, 1 of whom gained 16 stone. The stories documented during 7 Days of Action indicated that families did not understand the therapeutic benefits of their family member's medication regime.

Changes to physical health were also found in the stories of 2 people, both of whom were autistic, who experienced weight loss. Their preference for a particular diet was not followed, 1 was Chinese but was only offered Western food. Sheehan et al (2016) observed that people with basic physical health needs, defined as being not requiring specialist equipment or adaptation, were less likely to experience good quality physical health care assessments in psychiatric settings than those who were on general hospital wards.

5 people were subject to safeguarding alerts, 4 related to physical harm and one to self-harm. Manual and mechanical restraint (NICE 2015) was reported to have been used on 3 people.

Discharge planning was insufficiently supportive and inefficient (Guiding Principle 5)

Every family experienced transfers and movement of their family member between different types of care setting. People were usually moved, on average between 2 ATU settings. However, 1 person had moved between 4 different types of ATUs, which were between 40 and 200 miles from their family. 1 family reported spending 13 hours on each round trip to visit their family member in the ATU they had been moved to, which was in a remote and rural location.

Section 1.4 of the Mental Health Act Code of Practice states that detention under the Act should be used for the shortest time necessary in the least restrictive hospital setting available. The average length of stay experienced by the 7 people whose families shared their story during 7 Days of Action was 3 years. The longest length of stay was 7 years.



Human Rights, Equalities and Duty to Reduce Inequality

"No free man shall be seized or imprisoned, or stripped of his rights or possessions, or outlawed or exiled, or deprived of his standing in any other way, nor will we proceed with force against him, or send others to do so, except by the lawful judgement of his equals or by the law of the land." (Clause 39 of Magna Carta 1215)

Human rights are enshrined in law dating back to the Magna Carta (1215), which established the principles of due process and equality. In the 20th Century, the United Nations Declaration of Human Rights and the European Convention of Human Rights uphold the right to liberty and protection against arbitrary and unexplained detention by the State (Bozano v France (1986)). In the UK, the Human Rights Act (1998) brought these rights into law. Commissioners are required to take account of European and UN Conventions and UK law when arranging care and treatment for people with a learning disability.

1948	UN Declaration of Human Rights	http://www.un.org/en/universal-declaration-human-rights/
1950	European Convention on Human Rights	http://www.echr.coe.int/Documents/ Convention_ENG.pdf
1957	The Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (the Percy Commission)	http://navigator.health.org.uk/ content/report-royal-commission-law- relating-mental-illness-and-mental- deficiency-percy-commission
1983	Mental Health Act	http://www.legislation.gov.uk/ ukpga/1983/20/contents
1989	UN Convention on the Rights of the Child	http://www.unicef.org.uk/UNICEFs- Work/UN-Convention/
1995	Disability Discrimination Act	http://www.legislation.gov.uk/ ukpga/1995/50/contents
1998	Human Rights Act	http://www.legislation.gov.uk/ ukpga/1998/42/contents
2005	Mental Capacity Act	http://www.legislation.gov.uk/ ukpga/2005/9/contents
2006	UN Convention on the Rights of Persons with Disabilities	http://www.un.org/disabilities/convention/conventionfull.shtml
2007	Mental Health Act 2007 Amendments to the Mental Health Act 1983	http://www.legislation.gov. uk/ukpga/2007/12/pdfs/ ukpga_20070012_en.pdf
2007	Deprivation of Liberty Safeguards	https://www.gov.uk/government/ publications/deprivation-of-liberty- safeguards-supreme-court-judgments
2010	Public Sector Equality Duty	https://www.gov.uk/government/ groups/review-of-public-sector- equality-duty-steering-group
2014	Care Act	http://www.legislation.gov.uk/ ukpga/2014/23/contents/enacted/ data.htm

A Final Word

The Beach Boys' version of 'Sloop John B' was released fifty years before 7 Days of Action in April 1966. Here, the lyrics are updated by @KaraChrome for Steven, Connor, Eden, Chris, Jack, Thomas, Robert, Stephen, Tianze, Claire, Stephanie, and all the other dudes who just want to go home.

I'm stuck in an ATU
Five years after Winterbourne View
Seems like I'll be here forever, I want
to go home
The NHS say
I'll have to ask my LA
I feel so broke up
Just want to go home.

So close long-term Units down
Take me back to my home town
Somewhere I can be safe, a place of
my own
And give proper thought
To what I need for support
I feel so broke up
I want to go home.

Connor got put inside
A hundred days later, he died
His inquest found neglect, so Southern
Health lied.
They still spin and hedge
Claim failings 'alleged'
I feel so broke up
He never went home.

So close long-term Units down
Take me back to my home town
Somewhere I can be safe, a place of
my own
And give proper thought
To what I need for support
I feel so broke up
I want to go home.

Verita One and Two
Mazars and Hunt's UQ
Monitor, NHSI, the CQC
It's painfully clear
Money's why we're still here
We all feel broke up
We want to go home.

So close long-term Units down
Take me back to my home town
Somewhere I can be safe, a place of
my own
And give proper thought
To my need for support
I feel so broke up
I want to go home

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3,000 people with learning disabilities and/or autistic spectrum disorder are in hospital for the purposes of assessment, care and treatment in the UK. In March 2016 the first 7 Days of Action took place to raise awareness about the 3,000 human stories behind these numbers. 7 families published 7 stories about their family members on the campaign's blog site https://theatuscandal.wordpress.com/

Published in support of the second 7 Days of Action (10-17 October 2016) this briefing paper summarises what is known about ATU provision and demonstrates how practice fails to meet the Mental Health Act Code of Practice Guiding Principles.

More information about the second 7 Days of Action can be found on the campaign's website:

https://www.sevendaysofaction.net/

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