



Far less than they deserve

Children with learning disabilities or autism
living in mental health hospitals

MAY 2019

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Foreword from the Children's Commissioner, Anne Longfield



There are around 250 children with a learning disability, autism or both in England living in children's mental health wards. They are some of the most vulnerable children of all, with very complex needs, growing up in institutions away from their family home. For many of them this is a frightening and overwhelming experience. For many of their families it is a nightmare. I will never forget the stories I heard from mums and dads at a meeting I arranged for parents with children in these units and their tears of frustration and anger. Some of them have a child locked away in a series of rooms for months.

Others have to listen as they are told by institutions that their children have had to be restrained or forcibly injected with sedatives. They feel powerless and, frankly, at their wits end as to what to do.

While our research highlights some excellent staff working in hospitals, we were overwhelmed with stories of poor practice. This report was undertaken because of those stories I heard and I want to thank the parents I met and many others who have been in touch over the last few months. I want to also thank those children who shared their experiences with my team during our visits to hospital wards.

It is clear to me that too many children are admitted to hospital unnecessarily and that some are spending months and years of their childhood in institutions when they do not need to be there. This report also reveals shocking evidence of restrictive practices. Children talk about how disruptive and traumatic a stay in a mental health hospital can be. While some families talked about the excellent support their child had received, the quality of care overall is highly variable. The sister of a boy currently in a good hospital said care at his previous hospital had been 'a disgrace', with staff disinterested in helping children in their care. One family told my team that their son had not been washed for six months while in hospital. Others spoke about feeling ignored by services. Some families had even faced gagging orders where they had been prevented from speaking out about their children's care.

Children talked about being restrained, with one girl recalling a restraint which strained her wrist until it felt numb. Families and staff working in community settings revealed some hospitals have to call the police to deal with violent incidents. Others described children kept in seclusion in stark, bare rooms, environments that they said made them feel like prisoners not patients.

Successive government programmes have been introduced to address these long-standing problems, and yet the number of children in hospital remains stubbornly high, with community support for children with a learning disability or autism a postcode lottery. I am concerned that the current system of support is letting many children down and does not meet obligations under the United Nations Convention of the Rights of the Child.

This failure to provide earlier support to children when they are in school and living in the community, and particularly when they reach crisis point, has contributed to inappropriate hospital admissions and delayed discharges. That must change – and the focus on improving children's mental health services in the NHS Ten Year Plan is welcome, though it still falls short of what is needed to support all children who need help. I am also worried that no full replacement for Transforming Care is yet planned. That must happen and there must be ministerial accountability for delivering improvements.

A national strategy is needed to address the values and culture of the wider system across the NHS, education and local government so that a failure to provide earlier help is unacceptable, and admission to hospital is

no longer seen as almost inevitable for some children. Much better data should be collected on length of stay and delayed transfers of care in children's mental health hospitals, in the same way that this information is closely scrutinised in physical health hospitals, and NHS England should use incentives to reduce them.

We know more about the lives of these children and the impact it is having on their families, than we did. The onus is now on Ministers, the NHS, the CQC, Ofsted and local authorities to make sure that these most vulnerable of children are not locked out of sight for years on end simply because the system is not designed to meet their needs. Hospital admission may rarely be the right thing to do for children with a serious mental health condition. But it must always be in a child's best interests and as part of a managed process with clear timescales and a focus on keeping the length of stay as short as possible. This is clearly not happening at the moment and we have a system which is costing millions, yet is letting these children down.

A handwritten signature in black ink, reading "Anne Longfield". The signature is written in a cursive style. Below the signature is a short horizontal line.

Anne Longfield OBE
Children's Commissioner for England

Introduction

The Children's Commissioner's Office undertook this research to understand better the experience of children with a learning disability or autism who are stuck in child and adolescent mental health hospitals for long periods. The Children's Commissioner's Office used statutory powers to request data on stays in hospital and to visit children with autism and or learning disabilities to investigate their experiences. Around 40,000 children in England have a learning disability and challenging behaviour.¹ There is no good estimate of the total number of children with autism and challenging behaviour. These are the groups of children most at risk of unnecessary hospital admission. While there has been a national target to provide people with more care in the community, the number of these children identified in hospital has doubled. 250 children with a learning disability or autism were identified in a mental health hospital in England in February 2019, compared to 110 in March 2015.² NHS England state that the figure of 110 was due to under-identification of these children in the past and that the true figure for children with autism and learning disability in inpatient care in 2017 was 260. Even with the adjusted figures, the number of children in hospital has not reduced. It is very concerning that the NHS has failed to record accurately the number of children in long term inpatient care, their conditions and their outcomes.

A child with a learning disability will find it harder than other children to understand, learn and remember new things. They may need more support with everyday activities such as communicating, keeping safe and managing everyday tasks. The term 'learning disability' refers to a range including mild, moderate, severe and profound/multiple learning disabilities. Someone who has a severe learning disability will have little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing, washing, eating and keeping safe, have difficulties with social skills and need life-long support. Someone with a mild learning disability may only need extra help in particular areas, for example at school and with social activities.³ Autism is *"a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them"*. As with a learning disability, there will be a range of ways that autism impacts on different individuals. Some children have both autism and a learning disability.

It is harder for children with learning disabilities, autism or both to develop the communication and social skills which other children use to get them what they want and need. This may mean that their behaviours are much more challenging and they are unlikely to "grow out" of those behaviours on their own without skilled support to get their needs met in a different way. Behaviours might include hurting others, self-injury, destructive behaviours, eating inedible objects or other behaviours which put the child or other people at risk (eg running away). For some children this behaviour can include fire-setting or inappropriate sexual behaviour.⁴ Challenging spelling is sometimes the only way children have to communicate an unmet need. Common reasons for challenging behaviour include pain or ill health (for example banging head on wall due to earache), sensory needs, anxiety, to escape from a situation, or to receive something (for example drink or someone's attention).

¹ Estimating the number of children in England with learning disabilities and whose behaviours challenge, Emerson et al, 2014. There are significant challenges in estimating the numbers of children with learning disabilities or autism in England. For example, the data often records a child's primary need, but not secondary conditions. So, for example, a child with a learning disability and autism may only be recorded as having a learning disability, which makes it harder to get a full estimate of the number of children with autism (and vice versa). This makes it difficult for local commissioners to know how many children there are with these needs in their area.¹

² <https://files.digital.nhs.uk/24/7F4EEC/ldsm-Feb-19-ref.xls>, Table 2.

³ Paving The Way, Challenging Behaviour Foundation and Council for Disabled Children definition: www.pavingtheway.works

⁴ Emerson, E., & Hatton, C. (2007). The mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493-499.

Learning disabilities and autism are lifelong conditions, not “treatable” mental illnesses. This group of children are ending up in mental health wards for long periods of time because, as this report demonstrates, they are not getting the right support for challenging behaviour in the community. Hospital is not the right setting for them. Under the Mental Health Act, people with learning disabilities and autism can be sectioned with no mental health diagnosis if they are displaying challenging behaviour. Admission can happen when a child is at risk of harming themselves or others. This means that when community support is lacking, children are admitted unnecessarily or stay in hospital for too long. Children with a learning disability, autism or both should only ever go into an inpatient unit if they have a very serious mental health problem and specifically require a short period of inpatient assessment and treatment. Most of these children should never need to go into an inpatient unit. They are ending up in units are because of challenging behaviour due to unmet needs in the community. For children who do have additional mental health problems, it should still be possible to treat most in the community.

Who are they, where are they?

The majority of the 250 children with a learning disability or autism in mental health hospitals in England in February 2019 were on a general children’s mental health ward (130) but some were on a specialist learning disability unit (25) and 60 were on low or medium secure units (where there will be additional restrictions).⁵

Data provided to the Children’s Commissioner’s Office by NHS Digital shows that for children in hospital at the end of February 2019 on average, children with autism, a learning disability or both had spent 6 months (184 days) in their current hospital stay, and 8 months (240 days) in inpatient care in total⁶. Around 2 in 5 (95) children had spent at least 6 months in their current hospital spell with their current provider. Around 1 in 7 (35) had been there for at least a year.⁷

Nearly half (115 children) had been receiving inpatient services (across multiple providers) for at least 6 months across their current period of care, while around 1 in 5 (55) had done so for at least a year.⁸

⁵ Feb 2019 Assuring Transformation data, under-18s only, NHS Digital.

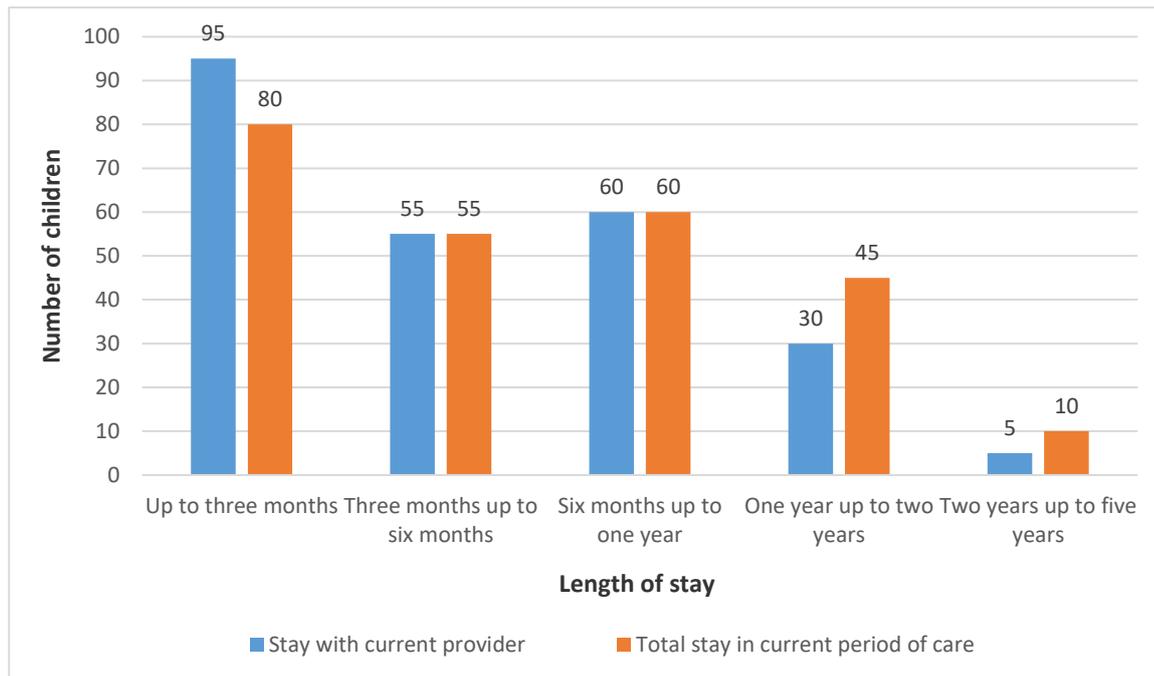
Inpatient CAMHS services in England offer care at four levels to support the effective management of differing nature of risk presented by children and young people under 18 years. Medium secure, low secure and Psychiatric Intensive Care Units (PICU) services provide a range of physical, procedural and relational security measures not required in general adolescent services to ensure effective treatment and care whilst providing for the safety of young people, staff and the public. Medium secure services accommodate young people with mental and neurodevelopmental disorders (including learning disability and autism) who present with the highest levels of risk of harm to others including those who have committed grave crimes. Low secure services accommodate young people with mental and neurodevelopmental disorders at lower but significant levels of physical, relational and procedural security. Young people may belong to one of two groups: those with ‘forensic’ presentations involving significant risk of harm to others and those with ‘complex non-forensic’ presentations principally associated with behaviour that challenges, self-harm and vulnerability. Psychiatric Intensive Care Units (PICU) manage short-term behavioural disturbance which cannot be contained within a Tier 4 CAMHS general adolescent service. Behaviour will include serious risk of either suicide, absconding with a significant threat to safety, aggression or vulnerability due to agitation or sexual disinhibition. Levels of physical, relational and procedural security should be similar to those in low security. General adolescent services provide inpatient care without the need for enhanced physical or procedural security measures.

⁶ The former figure relates to their spell with their current provider whereas the latter relates to all spells that children have had (across multiple providers) within their current period of care.

⁷ This includes at least 5 children who had been in their current hospital stay for at least two years.

⁸ This includes at least 10 children whose overall period of care had lasted for at least two years.

Figure 1: Current and total length of stay among inpatient children



Note: Numbers may not add up to totals reported in text because of rounding and suppression. Chart excludes the categories “5-10 years” and “10 years or more”, for which the numbers were suppressed.

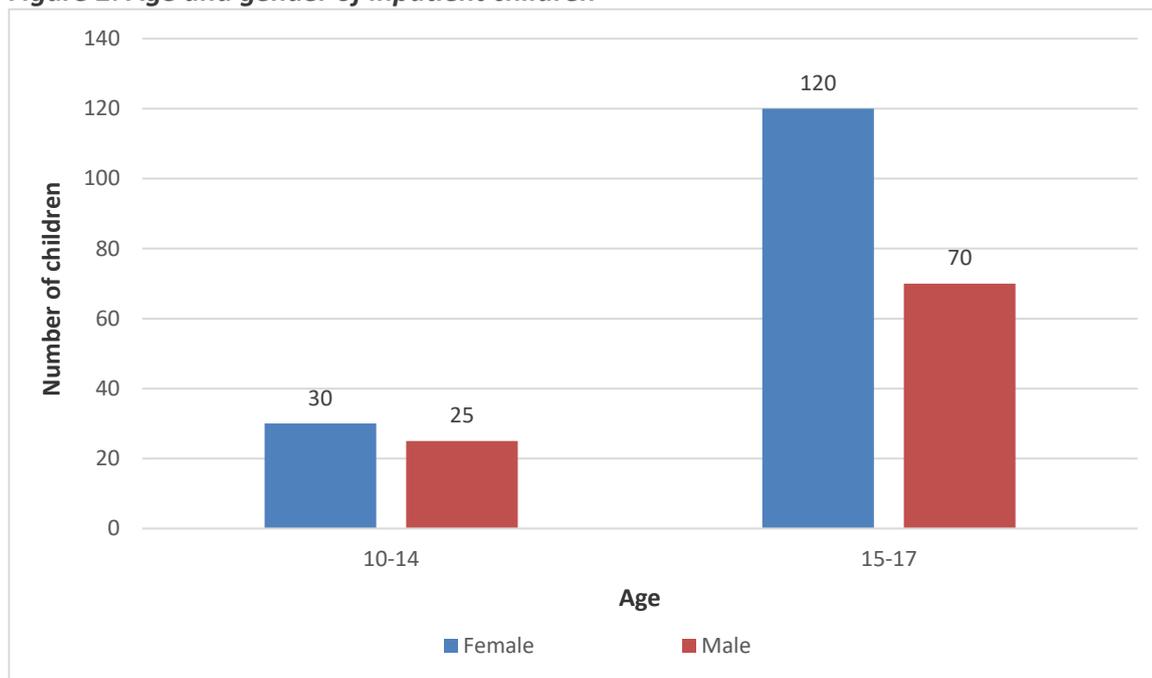
Nearly 1 in 4 children (60) had a total length of stay of at least 6 months *and* were in a ward at least 50 km (31 miles) from home. Around 1 in 10 children (25) had a total length of stay of at least a year *and* were in a ward at least 100km (62 miles) from home.

Nearly three quarters of these children have autism but not a learning disability. Around 1 in 7 have a learning disability only, and another 1 in 7 have both.⁹ Data provided to us by NHS Digital shows that of this group of children, nearly 4 in 5 were aged 15-17; the rest were almost entirely aged 10-14 (55 children).¹⁰ Around 60% were girls and 40% were boys, but this varied slightly by age. Among 10-14 year olds the gender split was approximately 55:45 (female:male), whereas among 15-17 year olds the proportion of girls was higher and the proportion of boys lower.

⁹ NHS Digital data February 2019

¹⁰ There may have been patients aged under 10, but the exact value was suppressed, which means it would be less than five but there may have been none.

Figure 2: Age and gender of inpatient children



Note: Numbers may not add up to totals reported in text because of rounding and suppression. Chart excludes 0-9 age category for which the numbers were suppressed.

NHS data shows us that around 3 in 5 children (155) were accommodated under the Mental Health Act 1983, while around 2 in 5 (95) had an “Informal” legal status instead.¹¹ Those children who are not detained under the Mental Health Act may be in hospital with their parents’ consent, but it is questionable whether parents feel they have any other choice than to consent to the treatment if they are unable to take their child home. Those detained under the Act have access in theory to a range of legal safeguards but their parents have no legal right to take them home. The review of the Mental Health Act raised significant concerns about how the legislation is working in relation to people with learning disabilities and concluded that the application of the Act for this group should be kept under review:

“We have heard throughout the Review that the MHA is being used inappropriately for people with a learning disability, autism or both, to deal with a crisis that has arisen because of a lack of good community care or placements... We have also heard significant testimony of, and been persuaded by, concerns from service users, families and stakeholders about the care people receive when they have been detained. It is particularly intimidating for a person with autism, learning disability or both to be removed from a place they are familiar with or from people they know, even if at the time there seemed little alternative... Instead of improving their mental health, the environment (including relationships with staff) has made them worse, not better. We accept this.”¹²

¹¹ NHS Digital Assuring Transformation data February 2019

¹² Modernising the Mental Health Act: Increasing choice, reducing compulsion, Final report of the Independent Review of the Mental Health Act 1983, December 2018
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778897/Modernising_the_Mental_Health_Act_-_increasing_choice_reducing_compulsion.pdf

Children's experiences of being in a mental health hospital

The Children's Commissioner's Office visited hospitals to speak to children about their experiences, as well as speaking to families and some children who had been discharged. Our research found that an admission to hospital can be at the least disruptive and potentially very traumatic for a child. This is particularly the case for a child with autism or a learning disability, where an unfamiliar, noisy and stressful hospital environment can exacerbate existing anxieties. Even before admission, the journey to hospital can be distressing. A community service described the experience of a 12 year old girl with autism who had been admitted to hospital after being in A&E for a whole weekend and having been hand cuffed and her legs restrained. The mother of a girl recently discharged from hospital said:

"Her first experience was an ambulance with a cage in the back. She found that really traumatic. These strangers were coming to take her away. She wasn't a risk to others – just to herself."

A girl in her early teens in hospital described her first impressions:

"When you first come in it's really hard...I've never stayed at anybody's house apart from mine.. It's a bit weird staying miles away from your home."

The wards visited had different levels of security, but were for the most part harsh and noisy environments: filled with the sound of doors being locked and unlocked. At one hospital there were also alarms that went off as staff responded to incidents. These sounds are an everyday part of the lives of children living in secure hospital settings. While security is part of the make-up of the hospitals, as units are working with children with a high level of risk of harm to themselves or others, this secure environment is by its nature hard to make therapeutic. There are many staff with bunches of keys and walkie-talkies who are needed to keep children 'under observation'. For some children, because of their level of risk, they need to be observed when going to the toilet and having showers. As one girl put it:

"It's not nice being on this ward. I'm locked in here."

Some wards made an effort to create a more homely environment, with pictures on the walls and children's personalised decor. Other wards are much starker in appearance, with peeling paintwork and an institutional feel. Even in those wards which are well decorated, it can be difficult to get away from the sense of being in an institution. Due to the high level of risk being managed, televisions are screwed behind locked cupboards, and rooms are often bare. Bathrooms can seem particularly bleak and institutional. Some children do not have bedding in their rooms, at least during the day, in order to prevent the risk that they will try to self-harm. Rooms can also be bare of their belongings because of the risk that they will destroy them.

The institutional nature of the hospital setting is inherently very different from living at home. For example, children eat lunch with thick plastic cutlery due to risks of self-harm, which makes it hard to eat. Meals often have to be ordered in advance, reheated rather than cooked fresh and dinner can be at 4pm.

"I am incredibly proud of the work we do here but we are a hospital, not a child's home...you become institutionalised...it's not the real world."

Hospital clinician

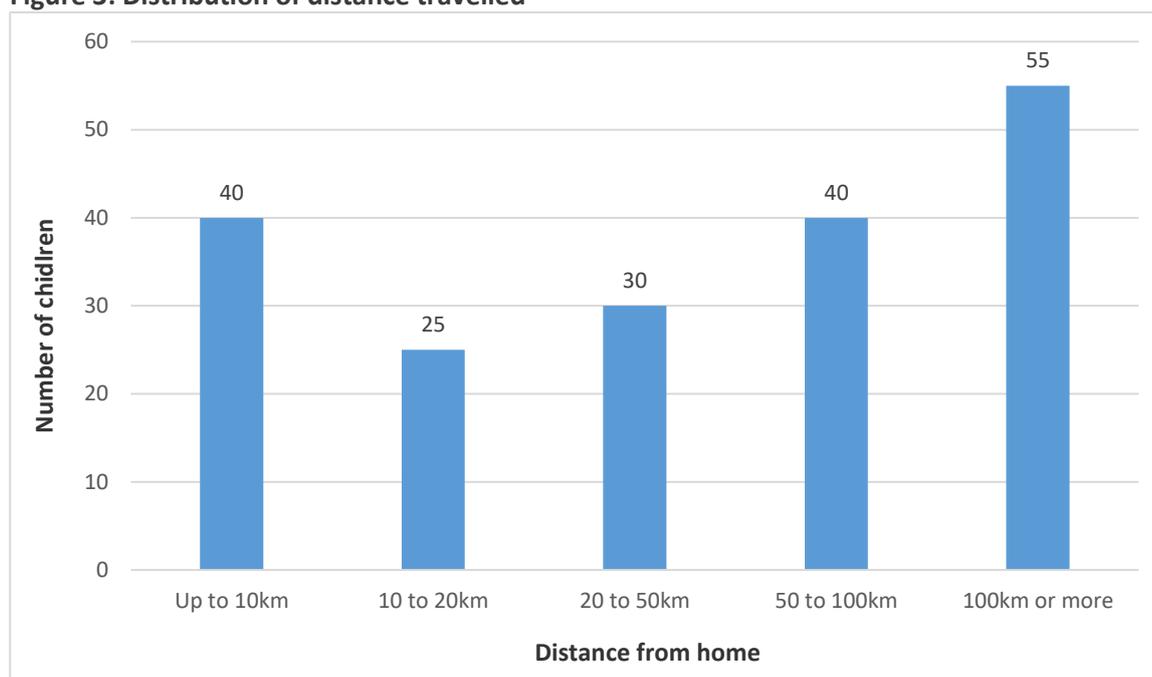
Right to family life

“Why is it that being close to your loved ones and being loved is not on anyone’s priority list?”

Hospital clinician

A stay in hospital can mean a child being taken to stay somewhere far away from home. Official statistics reveal that 95 children were staying in a ward known to be more than 50 km (31 miles) from home.¹³ This accounts for roughly half of the children for whom the distance from home was actually recorded. 55 children (nearly a third) were in a ward known to be more than 100km (62 miles) from home.

Figure 3: Distribution of distance travelled



Note: Numbers do not add up to 250 because chart excludes 65 children for whom distance from home was unknown.

A teenage girl who had recently been discharged but was concerned she may need to be readmitted said: *“Hospital makes me worse... It’s the being away from home”*. Another girl explained that she self-harmed partly because she was in hospital: *“I tied a ligature¹⁴ because I wanted to stay off section and go home”*.

Admission often made it hard for children to see their families. One mum said she had to make a 200 mile round trip to visit her daughter *“She doesn’t want to go away from home but there isn’t any hospital in our county. That’s impacted on her recovery”*. A girl in hospital explained her mum had to take two trains and a taxi to visit her. In between visits, she would call but they did not always get to speak: *“My mum rings every day but I don’t get to speak to her if there are not enough staff to supervise it”*.

Families also recounted that they were prevented from doing things with their child on visits, often because the hospital felt this was too risky or did not have staff available to help facilitate this: *“She loves her dog...could we take her out with the dog?... no that’s too much risk.”*

¹³ Data published by NHS Digital as part of its ‘Assuring Transformation (AT) collection

¹⁴ Tying a ligature means tying something around your throat in order to self-harm

Families also said that their visiting times with their child could be limited by staff or they were sometimes told, having travelled a long way to see their child, that they could not visit because the child was too unwell to see them. A sister of a boy in hospital remembered that her mum was concerned about the safety of her son but was not able to get information from the hospital:

“They invited us for meetings. We spent 3 hours trying to get here and they’d say... oh we’ve had it. They’d say they’d ring her later but we wouldn’t find anything out. Me ma was panicking, seeing more and more marks on him.”

Families also spoke of the negative impact on siblings of having to travel long distances to visit their brother or sister and having to hold these visits in unfamiliar and intimidating hospital environments. This could damage the relationship between the sibling in hospital and the others at home.¹⁵

Relationships with other patients

In hospital, children are living alongside other children with very serious health problems (not all of whom have a learning disability or autism as children can be on mixed wards). This can mean they learn damaging behaviour from each other, such as more effective ways to self-harm. A girl with autism spoke about *“unhelpful conversations with other children... they talk about different ways that you can self-harm and suicide and stuff”*. Another girl explained how she knew how to tie a ligature: *“I’ve been told by my friends in my last unit”*. A girl felt hospital was helping her deal with her anger issues but then said: *“How do you expect me to get better when people are self-harming and talking about suicide around me. You can hear them making themselves sick”*. Many of the children had visible marks of self-harm, whether this be scars on their arms or neck or marks on their heads where they had banged their heads against the walls.

Additionally, children can be traumatised from witnessing or being the victim of aggressive behaviour from another child. When asked if he had friends on the ward, a teenage boy said no: *“you just keep your head down, don’t you?”* A girl at a different hospital said:

“Sometimes the other patients are not so good. One of the other patients attacked me one day and it happened again. Sometimes I feel a bit unsafe. I was really scared of them. I feel that they should have [stepped in] before it happened again.”

Another girl complained that on her ward: *“We can’t have posters up because people rip them down or paint all over it.”*

Sometimes children make friends, but because people are discharged at different times, these relationships can be disrupted:

“The thing is that people keep going in and coming out...you get really friendly patients and then they go. You make friends with the staff”. Another girl explained *“I had a friend here but she got discharged.”*

It can also be a traumatic environment for a child when they are witnessing another child in distress or being restrained. A mum described her daughter’s experiences of living on a ward. She particularly

¹⁵ The Challenging Behaviour Foundation and Mencap have published a resource called “Keeping in Touch With Home” (2016) which sets out good practice, legal duties and case studies on this issue. <http://pavingtheway.works/project/wp-content/uploads/2016/07/Keeping-in-touch-with-home-web-version.pdf>

disliked when serious incidents occurred and a child had to be restrained. This often meant that the children had to be brought together in a lounge area in order to free up staff to deal with the incident.

“Emma¹⁶ finds it really difficult being in a setting with other young people who are very distressed and require restraint... Having to see and hear other young people being restrained was really distressing... She could hear all the screaming. That’s gonna have an impact on all the other young people in that unit.”

Quality of care

The quality of care in hospital is highly variable, and in some cases very concerning. Some families spoke of the excellent support their children had received.

“The hospital have saved his life...the care from everybody, especially the coalface support workers... has been exceptional. He’s very safe there...and for the first time in many years he trusts adults. They listen to parents...I haven’t had that experience anywhere else. Professionals time and time again have not listened to me.”

Mother of a boy in hospital

Another parent explained:

“I can call in the middle of the night and they’ll let me know how she’s doing... We felt she was as safe as she could ever be. As a mum I feel I should be able to keep my daughter safe.”

Other families told shocking accounts of the treatment of their children, including cases of abuse of children by staff. A sister of a boy currently in a good hospital spoke to us of the poor quality of care that he said he had received in a previous hospital:

“The staff just couldn’t be bothered to deal with the children. They weren’t interested in helping the kids. It was shocking. The way they treated him was a disgrace really. They let him go for a wander in the streets on his own at stupid o clock in the night.

“Another girl - they didn’t encourage her to leave her bedroom. She was just crying and screaming. He heard staff screaming and swearing at the kids. They were never out of the office.

It knocked him back even further. He wasn’t supposed to have access to sharp things but he was coming out with marks on his wrists and neck.”

Families said that the physical care needs of their children had been neglected. Children had put on a great deal of weight due to an inappropriate diet and the side effects of medication. Dental and eye checks had not been completed and one family said that their son had not been washed for six months while in hospital. Families said that serious incidents could happen in hospital without families being told. They often felt ignored by services and not involved in their child’s care which meant that staff did not have a full picture of what their child was like and their individual needs. For example, they explained that their children were often so much easier to manage at home because they were happy and in a familiar setting but that staff in hospital could not see that and so didn’t see that side of the child. Families spoke of how although they were told their child would be getting assessment and treatment while in hospital, they didn’t see any evidence of this. Rather their children seemed to be being

¹⁶ Name changed to protect anonymity

warehoused in hospital. Parents also spoke about the power imbalance which meant they were scared to complain in case staff stopped them from visiting their child. Some families had even faced gagging orders where they had been prevented from speaking out about their children's care.

Accountability and inspection

This research demonstrated that the accountability and safeguards in place to protect children are not robust enough. Parents were concerned about the limited accountability in the system where NHS commissioners spot purchase support, often from independent providers and where a child lives far from home. Parents explained that commissioners (local NHS Clinical Commissioning Group teams) often do not visit children in hospital settings. While CQC inspections provide a certain amount of accountability families are concerned that it lacks the resources and expertise to fully hold these services to account. Moreover, the nature of these hospitals, being shut off from the community, mean that accountability requires more ongoing monitoring of the quality of support offered to individual children.

Parents were concerned about the rights they had to get their child out of hospital, given that they needed quite extensive packages of support in the community. According to government guidance, a child should have a Care, Education and Treatment Review (CETR) before admission to hospital, or if an admission was in an emergency the CETR should take place within two weeks of admission to hospital, and then there should be a new CETR every three months.¹⁷ The CETR is chaired by the commissioner (the person responsible for arranging and paying for the placement) and run by a panel including an independent clinical expert and an expert by experience.¹⁸ The CETR leads to a series of actions, which should be followed up. If they are not addressed then this should be escalated within the organisation and then to the regional office of NHS England. There is no formal central process for monitoring the implementation of actions documented within CETR. Families explained that this means that often many months after a recommendation has been made, there has been no action.

Hospital staff explained that quality of the CETR was variable depending on who was chairing them: some were more proactive and diligent than others. There is a lack of continuity in the chairing role so that the same chair is not present every time, which undermines their effectiveness. Parents also explained that the CETR process lacks teeth, meaning actions are often not followed up. As the process is run by commissioners it also doesn't always feel independent enough. Families also felt they would like more of a say in the process and to get more support – for example they don't always receive the paperwork in advance so feel at a disadvantage in the process.

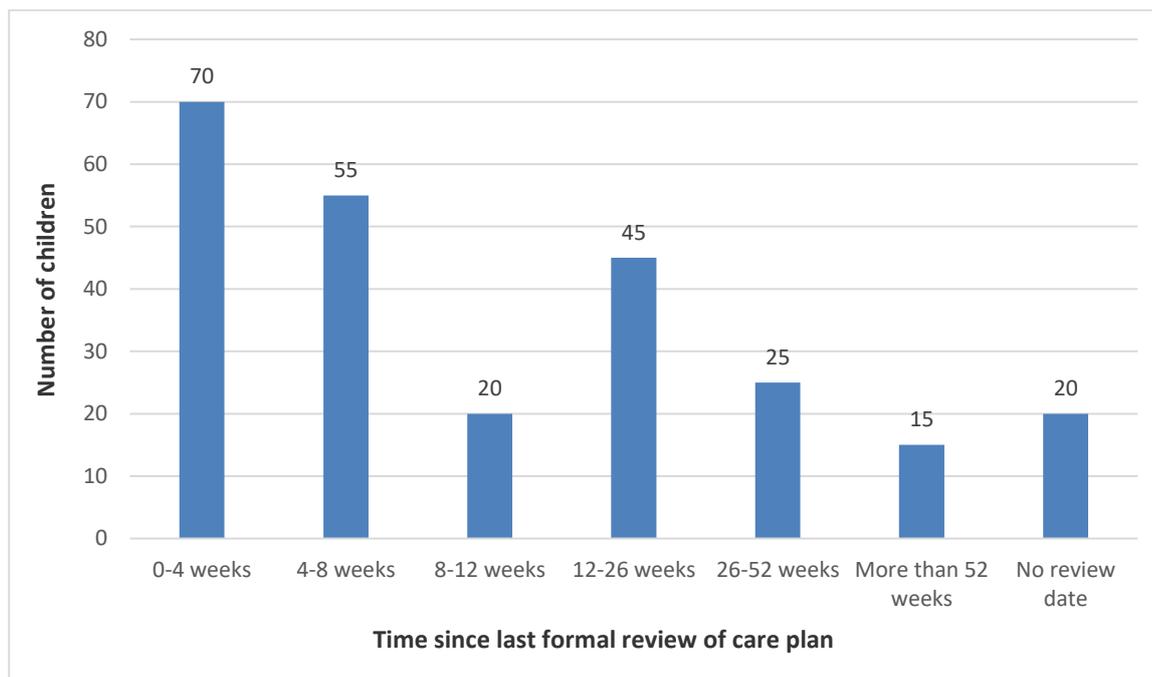
Data shared with us by NHS Digital showed that around 2 in 5 children (105) did not appear to have had a formal review of their care plan within the last 12 weeks, approximately 1 in 4 (60) had not a review recorded within the last 26 weeks, and roughly 1 in 7 (35) had not had a review recorded within the last year.¹⁹ These figures include the 20 children for whom a review date had not been recorded. See chart below for more detail.

¹⁷ Care and Treatment Reviews (CTRs): Policy and Guidance Including policy and guidance on Care, Education and Treatment Reviews (CETRs) for children and young people, NHS England, March 2017

¹⁸ CETR Toolkit, NHS England, April 2017

¹⁹ NHS Digital notes that this is the date of the most recent formal review of this patient's individual care plan. Formal review means that a formal record of the review has been made and shared with the person, their family, care and/or advocate, other key providers and commissioners. This may include a Care Programme Approach (CPA) review. From January 2016 onwards, a null response was possible, this is coded as 'no review date'.

Figure 4: Time since last formal review of care plan



A review of a small sample of CETRs undertaken by NHS England in February 2018 found that the quality of reporting remained variable, although most showed clear actions recorded with who was responsible for following it up and the timescale it should be completed in. There was, however, a lack of consideration of previous CETRs and consideration of recommendations. Moreover, it was not always possible to get attendance from the right local authority teams, such as social care, and educational staff. 40% did not consider overuse of medication as part of the review. 59% did not include information on the child’s view of whether they were safe and 18% failed to record the parent or carer’s view on if their child was safe.

Families and charities have explained that in far too many cases it has taken media, intervention from politicians, and the threat of legal action to get their loved ones out of hospital. This is a real sign that the mechanism and safeguards are still not working. Further work is clearly needed to strengthen the CETR process and other accountability mechanisms.

The people delivering care

The research found significant variation in the quality of staff in hospitals and that many units were struggling with recruitment and retention, leading to the use of high numbers of agency staff.

There are some passionate and caring members of staff working in hospitals. It was clear that these were dedicated frontline professionals, working in very challenging situations. One staff member explained “you need to be a special breed of person to do this job”. On some wards staff were engaged in friendly conversation and banter with children, playing games like football or table tennis. On others, however, there was much less interaction: the children appeared bored and staff were chatting amongst themselves. Children said that the quality of staff could be highly variable. This contrast was apparent within hospitals as well as between them, varying by ward or by shift: “This shift understand me a lot more”. One girl explained:

“Some of them are really nice and some of them could be nicer. Certain things get on my nerves and one guy kept clicking his pen. I asked him nicely to stop but he kept doing it.”

While hospital managers talked about training they offered in autism and in positive behavioural support, staff were not always able to corroborate this and one staff member when asked if he had this kind of training said he *“learned on the job”*. Families and staff that the culture in some of these units can be institutional and that culture change is needed as well as staff training.

An issue that came up repeatedly was the struggle that inpatient units had to recruit and retain high quality staff, which then had an impact on efforts to improve training. Those working in the sector said that recruitment was a huge challenge, particularly of nurses. There have been significant declines in numbers of learning disability nurses nationally.²⁰

Children, parents and staff all spoke of the challenges when units had high levels of agency staffing. While many agency nurses can be excellent, the quality was seen as variable and there are inherent challenges for children with autism, in particular dealing with unfamiliar people and constantly changing staff teams. Staff coming in from an agency can be unfamiliar with the hospital and do not know the children’s individual needs which can lead to escalations in a child’s behaviour. Agency staff may also not receive the same levels of training and vetting that would happen for full time staff in a hospital.

A speech and language therapist working in the community explained that children with a learning disability or autism often communicate their needs non-verbally: *“their behaviour is communication”*. She described a boy nearly admitted to hospital because of his behaviour, which it turned out was caused by severe dental pain. Despite this, there was not always evidence of ward staff attempting to understand the causes of challenging behaviour and address this. On the contrary, a 12 year old girl with autism said the reason she self-harmed was because of her anxiety and she expressed that this was caused by not getting answers to her questions from staff before she went to bed: *“They didn’t answer my questions as it wasn’t time for the day shift to come on.”*

One hospital had a vacancy for a speech and language therapist which had not been filled for several months, despite the high level of communication needs of the children being cared for. It is important to state here that there were children with high levels of communication needs in units and it is challenging to capture their views in the format of a written report. Having spoken to experts in advance of this investigation this report aims to capture their experiences through describing how units felt through conversations with family members. Nevertheless, this of course is only capturing some aspects of their experiences.

Educating children in hospital

When children are spending months or even years in hospital, it is particularly important that they get access to high quality education.

While all the units had a full timetable of education offered, not all children were able to leave their wards to access the education units on site and some children got very limited education, particularly those with challenging behaviour. For example, there was one child receiving one 30 minute session per week. For many children, their previous experiences of education had been very negative, so it was difficult to get them engaged in education. Hospital staff said they tried to manage this by building

²⁰ At September 2018 there were 3,192 learning disability nurses working in hospital and community health services in England in June – the lowest since the NHS Digital records began in September 2009 when 5,553 were employed. Over the same period, there was a 12% fall in mental health nurses. <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/june-2018> . These figures cover nurses working in the NHS only, so we don’t know how many learning disability nurses are working in relevant roles outside the NHS (e.g. in independent sector inpatient units; working for agencies), although this reduction would indicate a reduction in the overall workforce.

education around a child's personal interests and building up the child's confidence: *"They all feel that they've failed...they're always telling me "I'm crap""* (teacher in hospital).

For some children, admission to hospital allowed them to get one to one support and engage in education when they hadn't been able to in the community. For others, the admission meant their education was seriously disrupted:

"She's taken away from home and her school. She's spent more of the last two years out of education. She doesn't know if she's going to do any of her exams now. It's had a massive impact on her education. They don't do a full school day."

Mother of a teenage girl recently discharged from hospital

It can be difficult to offer a varied curriculum in hospital, particularly where there is a wide range of abilities and some children need to focus on basic reading, writing and maths. One hospital teacher explained that children couldn't study subjects like French, Geography or History. A girl said she would like to go to college to study mechanics or plumbing but there were no opportunities to do that sort of vocational training in hospital.

Participating in activities and hobbies

The research explored whether children were able to get involved in activities to stop them getting bored and improve their quality of life. While there was evidence of activities being offered, access to these often depended on staff availability.

The units all showed efforts to provide children with a range of activities. At one hospital there were posters for movie nights, yoga and pamper nights each week. Another had access to a sports hall, trampolines, swimming pools amongst other facilities. At a third, there was a tuck shop and youth club style room, with a pool table, and a girl was completing her Duke of Edinburgh award with the help of staff. She said she was able to go out and play games with the staff. Pet therapy was offered and occasionally other animals were brought into the hospitals for patients to interact with, such as mini-horses or donkeys. Children valued the activities they were offered. One girl with autism said she enjoyed gardening, baking and arts and crafts as well as visits from animals. A boy mentioned he enjoyed going trampolining.

However, it is unclear how frequently children were able to participate in such activities. Sometimes children could not get off the wards to take part in activities because of staff shortages. One girl said: *"I hate it here. It's boring"* and explained she would like to go out more into the community to go shopping, doing normal teenage things, but that this depended on staff availability. She wanted to go home because there she had *"a lot more freedom"*. Children also said that activities were hampered by broken equipment – for example on one ward a table football table had been broken for a long time and in another ward the television had been broken and art supplies were unusable. *"People rip up your artwork. You can't do arts and crafts because other patients have smashed up all the stuff or eaten the paints"*. Activities could also be disrupted because of incidents on the wards: *"You could be watching a film in the lounge and an incident happens so the staff stop it and put it away"*.

Children spoke of systems where privileges and freedoms were earned with good behaviour. That means a child could arrive in a unit and start with very limited freedoms and need to earn these things, such as music to listen to and access to activities or 'ground leave'. Challenging behaviour could lead to these

things being withdrawn, *“my leave has been took off me”*, which could then increase the risk that a child’s behaviour would be challenging, in a vicious circle of increasingly restrictive practice. This is particularly concerning given that some children with a learning disability or autism may lack the capacity to understand a system like this.

Secluding and restraining children

Restraint and seclusion should always be a last resort. Nevertheless, staff speak of it as almost a matter of routine. Families also told us shocking stories of how their children had frequently been restrained and secluded in hospital.

Staff on mental health units are permitted to use restraint and seclusion to deal with incidents on the wards (such as when a child is self-harming or being aggressive towards others). This can mean using certain holds to keep a child still, injecting them with medicine to calm them down, or putting them in a seclusion room. Staff are not permitted to use deliberately pain-inducing restraint techniques in mental health wards, but children report that other techniques can still be painful. Research in 2011 found that people who had experienced restrictive physical interventions found them painful, emotionally distressing and indistinguishable from abuse and violence.²¹

Data on restraints for this group needs to be treated with caution because of issues with how restraints are recorded by hospitals.²² 75 children with a learning disability, autism or both in hospital were recorded as having been restrained in December 2018. This group received a reported total of 820 “restrictive interventions” (i.e. incidents of restraint).

The most common type of restraint was “Physical restraint – Excluding prone (face down)”. It accounted for 59% of all restrictive interventions in December 2018; 80% of restrained children experienced it.

Two other common types of restraint were “Physical restraint – Prone” and “Seclusion”. Each accounted for around 1 in 8 incidents of restraint, and had been experienced by nearly half of restrained children (see chart below). Under guidance for treatment of adults, prone restraint should not be used at all.²³ The Government consulted on guidance on “reducing restrictive intervention of children” in 2017 but has yet to publish the guidance. In a parliamentary debate last month MPs of all parties argued that the delayed guidance should be published but the Government made no commitment to do so.²⁴

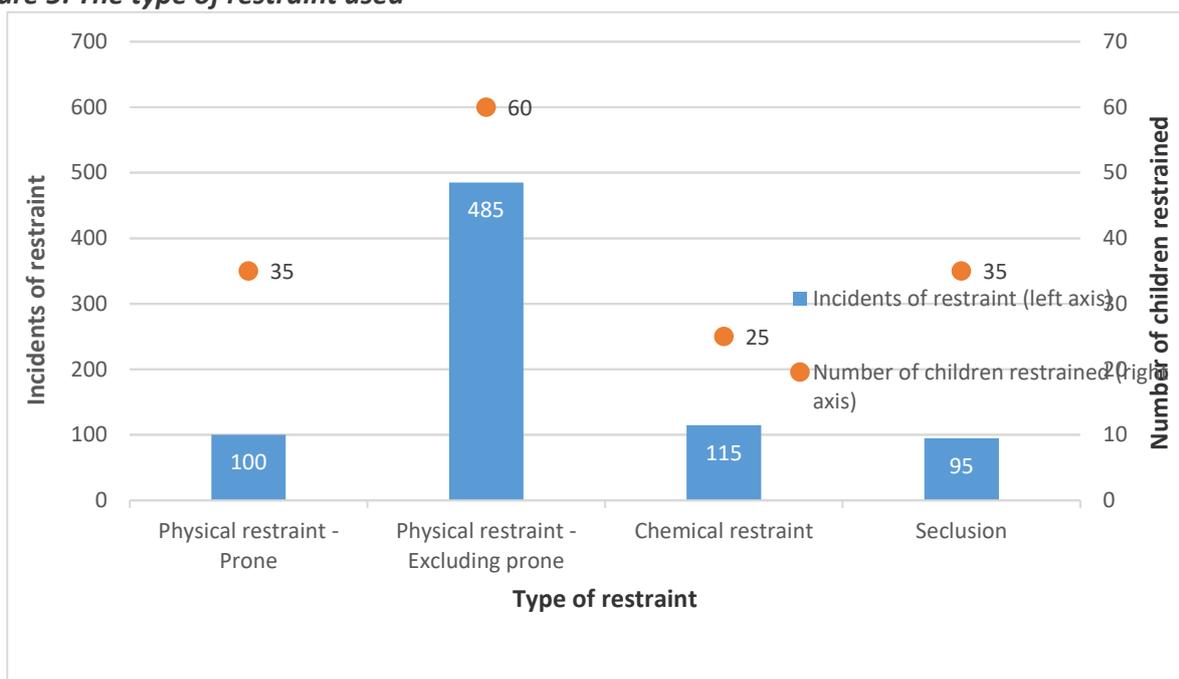
²¹ Macdonald et al (2011) “You squeal and squeal but they just hold you down” Restrictive Physical Interventions and people with intellectual disabilities: service user views. BILD, International Journal of Positive Behavioural Support.

²² Data published by NHS Digital, from the Mental Health Services Data Set (MHSDS). Some records may be duplicates, while additional reports of restraints in the same month could show up in future returns from mental health providers. The MHSDS is provider inputted data. It is concerning that some providers, particularly those in the independent sector, are not properly recording or reporting information on restrictive interventions, or are simply not reporting this information at all.

²³ Positive and Proactive Care: reducing the need for restrictive interventions, Department of Health, April 2014

²⁴ Commons Hansard 25 April 2019, v658, c974

Figure 5: The type of restraint used



Note: Numbers may not add up to totals reported in text because chart cases where restraint type was unknown, as well as cases of mechanical restraint and segregation where the numbers were suppressed.

Some data has already been published for those aged under 18. It shows that children aged under 18 are the age group most likely to be subject to restrictive interventions and, if they do, to experience twice as many instances of restrictive intervention as other age groups²⁵.

The Children’s Commissioner’s Office also requested more information from NHS Digital on the children who were restrained. Of the 75 children restrained in December 2018, 15 (1 in 5) were aged 10-14 and 60 (4 in 5) were aged 15-17.

Some hospital staff said they had tried to reduce restrictive interventions– for example one hospital had developed a whole programme of work to help staff de-escalate situations without using restrictive practice. They had a sensory room with lights and music and soft materials to help calm children down. Each child had a sensory box of things that helped them to relieve stress. In another hospital, however, while a girl mentioned that she had a plan for staff to help manage her challenging behaviour, staff working with her at that time did not have access to it. Despite being told that hospitals focused on de-escalation, there was not always evidence of staff working to avoid challenging behaviour with positive interaction. In one ward, a distressed girl was sitting on some steps being watched by three male staff members – their focus appeared to be monitoring for dangerous behaviour rather than interacting with her and defusing the situation.

The rooms where children are restrained are deliberately bare rooms – sometimes a nicely decorated room with a soft bean bag. In other places, a much starker room with perspex windows high up in the walls, bringing to mind images of an old-fashioned asylum. The experience of being restrained in a room like that would likely be extremely frightening for a child and escalate any challenging behaviour.

There is a lack of consistency and clarity of terminology around the use of restraint and seclusion, with a number of different terms and even euphemisms used. Several units had a particular room where

²⁵ <https://chrishatton.blogspot.com/2019/01/new-statistics-on-restraint-seclusion.html>

children were brought to be physically restrained by staff. In one unit, this was called an 'assessment room'. Similarly, the area for long term segregation in another hospital was called 'extra care'.

Discussion of restraint and seclusion is a particularly sensitive issue but some children spoke freely about their experiences. One girl said:

"I don't like being restrained...It's not very good. I don't like leg holds...When I said I don't feel comfortable they let go. They didn't immediately, but they did when I persuaded them. I don't like when they restrain me in my room ... when there's more than 2 people in my room."

She spoke of a restraint that had happened at a previous hospital:

"I got restrained with an arm round my back... it strained my wrist and it felt numb and had lumps."

Families and staff working in community settings spoke about hospitals calling in the police to deal with violent incidents which may then not be recorded as a restraint, but could be even more distressing for the child.

Medication

Another method of restraint that can be used in hospitals is known as 'chemical restraint'. This is where a child is given medication to reduce aggressive behaviour. The medications recorded as chemical restraint in published data are those administered on the spot. Long-term prescribed medication designed to have the same effect (typically antipsychotics, anti-anxiety drugs or anti-depressants) wouldn't be counted in statistics. These medications can have long-term effects on children who are still developing physically and mentally and so are equally of concern to those administered in response to an incident. Information on rates of prescribed antipsychotics amongst people in inpatient units is not currently published. The 2015 Learning Disability Census of inpatient units reported that 105 out of 165 children aged under 18 in inpatient units (64%) had had prescribed antipsychotic medication in the 28 days before the census.²⁶

One girl mentioned she was on various medications, some of which were to "calm her down". A mother of a boy in hospital said her son was "drugged up to the nines". A sister of a boy in hospital recounted how he had been restrained in an earlier hospital stay:

"They were restraining him and constantly injecting him in his leg and his bum. He'd get a bump/bruise on his leg because they kept injecting him in the same place."

"They were injecting him to calm him down. If he shouted at them, or turned away from them. They would come and restrain him, inject him and lock him in his bedroom. They were away with the fairies once they were injected."

²⁶ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-census-report/learning-disability-census-report-england-30th-of-september-2015>. Table 21

Long-term segregation and seclusion

Some children are spending far too much time alone away from other children on the wards. Under the Mental Health Act there are rules about being in 'long-term segregation' – when a child is away from other children on the ward but is interacting with staff and 'seclusion'- when a child is in a room alone. The children in long-term segregation were in their own areas of a ward, either in a dedicated long-term segregation unit, or in some cases, using parts of a ward or a whole ward which was not being used for other patients. Not all the children living in these situations were able to communicate their needs verbally. Of those who were, one boy said he was keen to move back with other children but said he got extremely frustrated and violent when around them. Another boy was very clear that he wanted to live separately from the other children. A girl in long-term segregation also expressed that she wanted to be there. *"I don't want to move from here. I feel much safer. I get scared when I'm in the community"*. It was not possible during this short research project to understand in detail why some of these children strongly expressed a desire to stay away from other children. One hypothesis could be that it relates to their autism. Another could be that they have had traumatic experiences and are frightened of other people. They could also have become institutionalised during their time in hospital. What was clear to us, however, was the need for all partners: commissioners, hospital staff, and community providers to work together to design the best support for these children with children's voices and their families at the heart of this process. This is clearly not happening in many cases.

The seclusion rooms had bare walls and either no furniture or a built in bed. They had a bathroom area which could be monitored through a window or a hatch and via CCTV. They were stark and bare rooms, which felt institutional and frightening, the opposite of a therapeutic environment. One girl described about her experience of being in seclusion: *"It's really cold in there. It feels quite closed in. You actually feel like a prisoner"*.

Staff said that these rooms are used as a last resort generally for a few hours, but potentially overnight or even for several days, when children become a risk to themselves or others. Families said that seclusion is used frequently and can be for longer periods. One said that their child had sometimes been secluded because of inadequate staffing levels. Children described instances of seclusion being used not as a last resort but as a threat: *"They said they would put me in seclusion if I didn't take my oral meds"*. Hospitals should be putting in place clear strategies for reducing the use of seclusion and restraint, but the evidence is unclear that this is happening.

Children in hospital when they don't need to be there

"I don't believe that many of these young people who come in should have come into hospital. There should have been the services in place to stop them."

Hospital clinician

While the focus of political attention has been on the number of children in inpatient settings, often the real problem is that children are in hospital because there are not the right services available in the community. This also means that children are spending more time in hospital than necessary.

Admission to hospital is by its nature a hugely disruptive and potentially traumatic experience for a child. This may well be necessary in some cases. One mum said: *"Admission to hospital is very valuable when it is needed"*. Nevertheless, it is shocking that so many children are spending far too long in hospital or are admitted when they should not have been. For example, a therapist caring for a boy said: *"this child should never have been admitted"*. Another hospital clinician explained *"It is deprivation of their liberty. They can't get six months of their childhood back."*

As part of this research, the Children's Commissioner's Office spoke to children who had remained in hospital longer than was necessary due to delays in getting them discharged into a community setting, often because the right staff were not available or a special school place had not been found. For example, one girl who had recently been discharged spoke of her frustration that this process took so long:

"Things weren't being put in place to get me home. It was really frustrating. They need to train more people in different types of therapy and get more staff in the community."

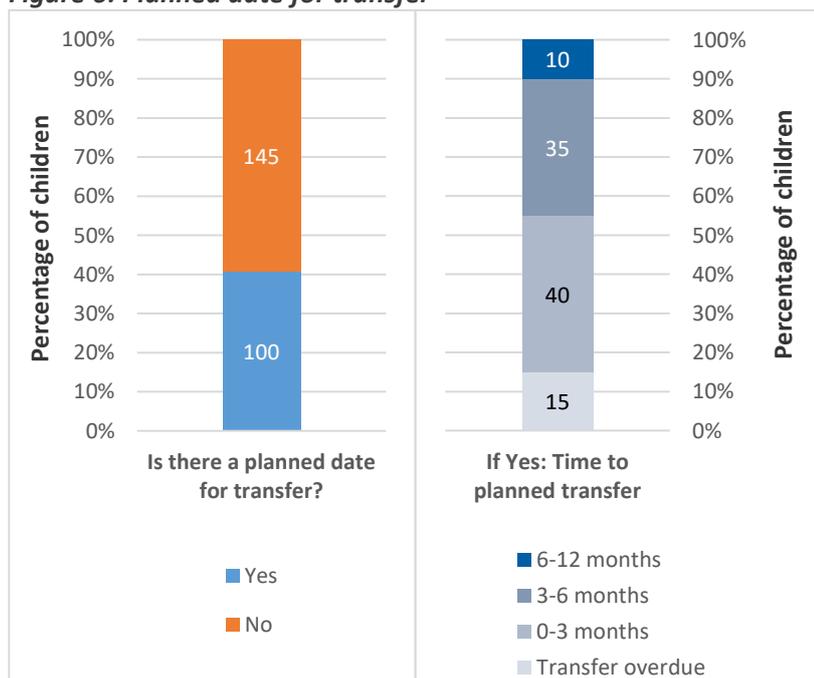
A mother of a teenage girl in hospital said:

"She's been in for two years and she's got to stay there until they find her a place. She doesn't need to be in the hospital any more but she's not allowed to come home. We would like her to be somewhere close to home that we can see her whenever we want and that she'll be safe, where no one can take advantage of her. In crisis situations nobody should have to feel like nobody's there for them. There's no support in the community where people can go."

Data shared with us from NHS Digital showed that roughly 3 in 5 (145) children did not have a planned date for transfer.²⁷ Among the 2 in 5 (100) children who did have a planned date for transfer, it was more than 3 months away in 45 cases, and more than 6 months away in 10 cases. In 15 cases, the planned date had already passed, i.e. the transfer was overdue. Overall, only around 1 in 6 (40) children had a planned transfer date that fell within the next 3 months.

²⁷ Transfer could mean discharge into the community but it could also mean transfer to another unit or to an adult setting when a child turns 18.

Figure 6: Planned date for transfer



Note: Numbers inside the bars are counts (rounded to the nearest 5). Chart on the right excludes the categories “1-2 years”, “2-5 years” and “5+ years”, for which the numbers were suppressed.

These delays in getting children home can also mean that other children can't get a bed when they need it. A mum of a boy in hospital spoke of how she had waited five months to get him access to a bed in hospital. While waiting for a bed she called the local mental health service when he was in crisis and was told to call the police because “we're not a blue light service”. He was finally seen by his community mental health service after seven referrals and when he had already tried to take his own life multiple times. When he was finally admitted to hospital, he started to get the help he needed, including reengaging in education. He was due to stay there for 12 weeks but was still there after nine and a half months. This was because of a lack of community support because his local council has not got a special school place ready for him. The boy said:

“Right now I've been here for 10 months or so and when I leave it'll be more than a year. [When he first arrived they said he'd be there for 3 months]. That 3 months turned into six months and then 9 months. About 7 months ago I could have been out of here. It made me a lot worse having to wait for a school and every week they kept saying they'd find me a school and then it was wait another month.”

A long stay in hospital can make it harder for a child to be discharged. Speech and language therapists working in hospitals said that some children, particularly those with autism, can be reluctant to be discharged from inpatient care, as they have become institutionalised and have come to rely on the relationships they have built in the unit, the support they have received, and the structure of their daily timetable.

Getting support at home

It is clear that a lack of community support is driving some children into hospital. There is a consensus on the kind of support that needs to be provided in the community in order to prevent unnecessary hospital admission:²⁸

- > Early diagnosis
- > Support that addresses the causes of challenging behaviour, based on positive behavioural support²⁹
- > Strong early links with education services, with mainstream schools making children feel welcome, avoiding exclusions, addressing bullying and ensuring reasonable adjustments;
- > Better support within mental health services
- > Continued and joined up support for the child from a multi-disciplinary team (psychologists, OTs, speech and language therapy, social work) rather than passing them between services or providing a time-limited programme of support with a need for re-referral backed up by good EHC plans
- > Support for the whole family, including siblings. This should include short breaks and parenting classes and mental health support for the family
- > Keyworkers for each child. NHS England should set a clear timetable for when children will be provided with a keyworker and which group of children this will apply to so that children are tracked through the system and they and their families have a lead contact to keep them informed and help them navigate the system.
- > Regular screening to pick up any additional health needs and support to access wider health services

²⁸ These are our children, a review by Christine Lenehan, Council for Disabled Children, January 2017

Ensuring Quality Services for people whose behaviour challenges, LGA 2013

Early intervention for children with learning disabilities whose behaviours challenge, CBF Academic Expert Group, November 2014

Paving the Way, CBF, 2015

Building the Right Support, NHSE, LGA, ADASS, 2015

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, NICE guideline [NG11], May 2015

Learning disabilities and behaviour that challenges: service design and delivery, NICE guideline [NG93], March 2018

Developing support and services for children with a learning disability, autism or both, NHSE, 2017

²⁹ Positive Behavioural Support is the evidence-based framework to address challenging behaviour. PBS interventions are based on trying to understand and then address the causes of a child's behaviour, for example changes to their environment such as reduction in noise, or teaching the child new skills in order to help them address challenging situations [O'Neill, R. E., Horner, R. H., Albin, R. W., Storey, K., & Sprague, J. R. (1990). Functional analysis of problem behavior: A practical assessment guide. Sycamore Publishing Company, Sycamore: IL.] By contrast, a restrictive approach to challenging behaviour, such as shouting, restraint or putting a child in seclusion will fail to address these underlying causes and will increase the anxiety for the child and increase the challenging behaviour. The PBS framework is not a single therapy but includes a range of support including speech and language support and access to mental health services when needed. There is strong evidence that PBS approaches are effective but their use is limited in England. Oliver, C., Murphy, G. H., & Corbett, J. A. (1987). Self-injurious behaviour in people with mental handicap: a total population study. *Journal of Intellectual Disability Research*, 31(2), 147-162.

Harris P. & Russell O. (1989). The prevalence of aggressive behaviour among people with learning difficulties (mental handicap) in a single health district. Interim report. Norah Fry Research Centre, Bristol: UK.

Qureshi, H. (1994). The size of the problem. In E. Emerson, P. McGill & J. Mansell (eds.) *Severe mental retardation and challenging behaviours: Designing high quality services*. Chapman & Hall, London: UK.

Allen, D., Lowe, K., Jones, E., James, W., Doyle, T., Andrew, J., ... & Brophy, S. (2006). Changing the face of challenging behaviour services: The Special Projects Team. *British Journal of Learning Disabilities*, 34(4), 237-242.

The Positive Behaviour Support Academy defines PBS as:

"a multicomponent framework for developing an understanding of behaviour that challenges. It is based on the assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop a range of evidence-based support. The overall goal is to enhance the person's quality of life, thus reducing the likelihood of challenging behaviour occurring in the first place" pbsacademy.org.uk

- > Jointly commissioned residential services which also provide outreach support
- > Intensive support services to manage crises and help avoid hospital admission

Despite this consensus on what should be being provided, this comprehensive programme of support does not exist in practice except in small parts of individual services. Community for children with a learning disability or autism is a postcode lottery. Thresholds for services can be too high for children to access or services may not be available at all. One expert described it as a *“Cinderella service within children’s mental health, which is a Cinderella service within mental health, which is a Cinderella service in the NHS”*.

There is very limited information available on community support for children with learning disabilities, autism or both. The NHS Benchmarking project does publish some information on these services. In 2015/16 there were 2,289 contacts with children with learning disabilities made by community health services per 100,000 general child population. This had dropped by over a third by 2016/17 to 1,471 contacts with children per 100,000 population. Over the same year, the average waiting time for a routine appointment for children with learning disabilities increased from 32 days to 72 days. While the benchmarking sample does change in each year, these figures are often used to compare performance over time, and these are clearly concerning trends.³⁰

Speech and language therapists explained that the support available in the community can be highly variable locally. In some areas there may be no service at all, whereas in others there may be high thresholds depending on the age of the child, the severity of their condition or type of diagnosis. Children with autism may be excluded from mental health or speech and language support services because they don't fit the criteria for the service. The Bercow: Ten Years On survey showed that only 15% of respondents said speech and language therapy services were available as required in their local area.³¹ Moreover, the Local Area SEND inspections: one year on report from Ofsted and the Care Quality Commission found that access to therapy services was weak in half of the local areas inspected, and that they were *“too overstretched to deliver what was needed in local areas”* while *“funding was not keeping up with the rising number of referrals”*.³²

In addition, children’s services departments are experiencing increased demand. There has been a 26% increase in the number of children placed on a child protection plan between 2010-11 and 2017-18.³³ Councils are also facing a range of funding pressures (91% of local authorities overspent on their children’s social care in 2017-18)³⁴ which means that they are having to make difficult decisions about what support can be provided. Children with disabilities count as children in need under section 17 of the Children Act, so local authorities do have statutory responsibilities with regards to these children. Moreover, while this is not the case for all families, many of the children admitted to hospital have a mix of very complex needs, including social deprivation and living in families with a range of risk factors. A hospital clinician said that by the time a child is admitted to hospital: *“A lot of them have had really abusive, failed histories. They’ve been bounced around the system. There have been multiple failures... they’ll have had 10 or more placements”*. One hospital clinician said he felt that *“society turns a blind eye to these children”*.

³⁰ <https://chrishatton.blogspot.com/2018/03/dismantling-right-support.html>

³¹ Bercow: Ten Years On. An independent review of provision for children and young people with speech, language and communication needs in England, March 2018.

³² Local area SEND inspections: one year on, Ofsted and Care Quality Commission, October 2017

³³ Pressures on children’s social care, NAO, January 2019

³⁴ Ibid

Many children are not getting enough support in the community. A hospital staff member said *“people with autism... it’s really bad...they just don’t have the community teams”*. One clinician noted that a common pattern is that families can cope without support when a child is younger, but when they grow up and hit puberty this can lead to crisis situations *“Once they start getting taller than the parents it becomes unmanageable”*.

A teenage girl with autism said: *“I haven’t had any support in the community. I’ve been in CAMHS for 4 or 5 years this month”*. Her mother also spoke of their experiences trying to get help in the community: *“I feel like it is a postcode lottery. We’ve considered moving to get better access to services but that would mean moving away from extended family... I tried to contact our CAMHS crisis service – they’re meant to be open on weekends. They were closed all through March because of staff annual leave. She should be able to get the medical care that she needs closer to home and nearer her family.”*

This example highlights the particular problem of dealing with crisis situations in the community, which is when admissions to hospital can occur. At another hospital, a head of learning disability and autism support said: *“A great many of admissions could have been avoided if community teams had the skills to manage the distress and crisis. There’s currently often no way to build that support around the young person at the time of crisis in the community”*. A psychologist working in the community explained that admissions to hospital often happen when a child is in crisis and the decision is about managing their risk when there is not the right package of intensive support at home: *“a lot of professionals can’t sit with a level of risk in the community. When a crisis happens, the system panics. We know this because it’s happened so many times”*.

Staff in one hospital said it was common when a child was admitted for their community placement to *“close behind them”*, so the placement would be offered to another child, which then made it difficult to discharge them because a new appropriate placement would have to be found. At another hospital a nurse said: *“There’s a sigh of relief from the community teams...they’ve got some respite.”*

Hospital staff also spoke of the funding battles and bureaucracy around arranging a community placement: *“It usually bobs back and forwards for months”*. Some of the challenges included the need to establish new services and getting them registered, funding negotiations and the different cultures and jargon of health and social care settings. Families and staff explained that the process of discharge can be particularly difficult when a child turns 18 as different legislation is relevant and services are organised by different teams at a local level. Another issue is the problems with the quality of data and information sharing between providers, local CCGs and local authorities. As one expert commented: *“Commissioners keep finding out about people they didn’t know they were responsible for.”*

The Lenehan review highlighted that the system is very dependent on a child receiving a correct diagnosis and meeting thresholds before access to support is granted.³⁵ This can make it difficult for children with the most complex conditions to receive the right support package at an early enough age before problems develop further. The review found that children with learning disabilities, autism and other complex needs can often fall through the gaps in existing services, with professionals feeling ill equipped to meet their needs because services are not set up around the individual needs of the child. For example, mainstream child and adolescent mental health services do not always have staff who feel they have the right skills to support these children and many of these services do not accept these children. A similar problem occurs in paediatric services who do not feel they have the skills to support

³⁵ These are our children, a review by Christine Lenehan, Council for Disabled Children, January 2017

children's mental health needs. Education services for children with special educational needs are also an important part of this local support and previous research by the Children's Commissioner's Office has demonstrated that far too many children with SEND are being excluded from school or home educated because of a lack of support for these needs.³⁶

There are a wider group of children living in residential special schools, some of whom are admitted into inpatient care from these placements. For example, a mother recounted how her child had been admitted to hospital from residential special school for purely financial reasons as the placement at school broke down when the local council refused to pay for the repair of a bedroom. Christine Lenehan also undertook a review of residential special schools which found highly variable quality and outcomes, with some examples of excellent practice but other schools being professionally isolated and some with a narrow focus on wellbeing without a wider focus on attainment and preparing for adulthood. This report does not focus on children's experiences in these schools but the Children's Commissioner's Office will be considering further work in this area next year.

Specialist community provision

For some of the children in hospital, work was being done to develop bespoke packages of support in the community to help them transition to an appropriate community setting which would be able to support their particular needs. Staff explained the importance of developing the right packages of support in the community which can be very expensive and take time and the right community provider. This is a cheaper option than a hospital place but is difficult to coordinate because of the challenges of convincing local authorities and community health commissioners of the need of such specialist, bespoke support, and of finding the right providers with staff with specialist expertise in the community.

Alderwood LLA

Alderwood LLA is a residential care and supported living service for young people and adults with autism and challenging behaviour. Alderwood has experience of supporting young people who have been discharged from hospital to live in the community. This involves building a core team of staff members around the young person so that they can trust and build relationships with that team. Education and support for daily living activities is provided as part of a package of specialist support and communication tailored around the child's autistic spectrum disorder and individual needs. There is also a strong focus on a young person's physical health such as reducing the need for unnecessary medication and a focus on their diet and exercise. In addition, children are able to go swimming, canoeing and bike riding and regularly get involved in grooming and care of animals at Alderwood's farm. The service also provides opportunities for the young people to go on holiday in a specialised home on the Norfolk Coast as well trips to a static caravan in a holiday park nearby.

Services like Alderwood LLA can be a more expensive option than other community residential care providers because of their specialist nature. This means that commissioners can often view them as a last resort if a child has not had a successful placement elsewhere. This means, however, that children can be stuck for months in hospital unnecessarily while commissioners consider cheaper alternatives before finally agreeing to a more expensive community placement. Action should be taken to enable areas to pool budgets as currently local authorities struggle to meet the costs involved in providing community support and it has not been seen as an NHS responsibility to provide this social care

³⁶ <https://www.childrenscommissioner.gov.uk/publication/exclusions-from-mainstream-schools/>
<https://www.childrenscommissioner.gov.uk/publication/skipping-school-invisible-children/>
<https://www.childrenscommissioner.gov.uk/2019/05/07/response-from-the-childrens-commissioner-for-england-to-edward-timpsons-school-exclusions-review/>

support, although it is the NHS that has to pay for the extended hospital stays.

The government and NHS England should work with local authority representatives like the LGA and ADCS to stimulate the market in this kind of provision, piloting and evaluating specialist support. For example, the multi-disciplinary model of treatment within a hospital to help a child get better and manage their challenging behaviour could be provided within the community to help avoid admission to hospital and help patients to get discharged home. As one community service manager explained to us *“I just don’t know what there is that could be offered in hospital that could not have been offered in the community”*

Crisis prevention services should be available in all areas of the country to prevent hospital admission. One hospital was developing a ‘safe haven’ model with a bedded unit to provide crisis support in the community and avoid hospital admission, but this was dependent on local authority funding and staff said this was very variable depending on the local authority. Another crisis prevention service that visited as part of this research was Starfish + in Norfolk.

Starfish +

Starfish + is a specialist learning disability service that provides an intensive multi-disciplinary therapeutic approach to children and young people up to 18 years. The service supports a small number of children and young people with learning disabilities when things have become very difficult for the child and their family due to complex and significant behaviour that is challenging and /or complex mental health needs. The service sees children in crisis situations where there is a risk that admission to hospital or moving into a residential school might be the next option. Children might need visits 2-3 times a week, or every day, and from more than one person (such as a psychologist and a speech and language therapist and a family support worker) for a short time to help things improve for the child and for everyone around them, so that unplanned moves and long stays away from home can be avoided. The service costs an estimated £211,000 per year to cover Norfolk, which equates to around the cost of one residential school placement whereas the service is able to prevent many more placements or hospital admissions.

NHS England needs to proactively encourage the development of intensive community support services for children with a learning disability, autism or both in every area, for example by providing specialist consultancy to local commissioners on how to develop such services and demonstrating the cost effectiveness of such approaches.

Financial incentives to keep children in hospital

Currently around half of inpatient mental health beds are operated by the private sector, and some staff and parents spoke of concerns about the perverse incentives on these organisations to admit patients and increase their length of stay: *“If you’re getting paid £12,000 a bed and can keep them in for 6 months”*. An NHS hospital had a clear focus on reducing length of stay as much as possible and was starting to provide intensive behavioural support services within the community, staffed with the same multi-disciplinary team that would be available in hospital, to help avoid admission and facilitate discharge. However, staff there felt that other hospitals were not as far ahead in adopting this approach.

Another hospital queried the idea that they had a perverse incentive to keep people in hospital because they felt it was possible to fill the bed with another patient relatively easily. They raised the perverse

financial incentive for local authorities to allow a child to be admitted to hospital and to delay the process of discharge, because while a child is in hospital their care is paid for by the NHS. There have been repeated calls for the wider use of pooled budgets to facilitate discharge from hospital but this practice has not become widespread. The NHS is rolling out what is known as New Models of Care, which is encouraging moving budgets between NHS specialised commissioning and local NHS commissioning to help providers move care into the community. As the Public Accounts Committee highlighted in its 2017 report, however³⁷:

“Money needs to move with the patient as they leave mental health hospitals to pay for their support in the community. There is a risk of unfunded pressures on local authorities if money does not move with the patient. In January 2017, NHS England agreed how money will move within the NHS for a specific group of patients: those who have been in specialised commissioning mental health hospitals for longer than 5 years as of 1 April 2016. This money will then need to move from the NHS to local authorities, which NHS England told us had started to happen. However, at the time of our evidence session, just £1 million had moved from specialised commissioning to other areas of the NHS out of an estimated £10.8 million that should have been released.”

It is important that these perverse financial incentives are quickly removed and that local commissioners have the budgets to move children out of hospital.

According to the National Audit Office in March 2017, weekly costs of an inpatient placement vary but on average costs were up to £3,500 per week, with many placements costing £5,000 a week and the most expensive placements reaching £11,000 per week³⁸.

There are now 250 children in inpatient settings. If all these children’s placements were priced at the average annual cost of £250,000³⁹, the total annual cost is an estimated £62.5m.

³⁷ House of Commons Committee of Public Accounts: Local support for people with a learning disability, 24 April 2017

³⁸ Local support for people with a learning disability, National Audit Office, March 2017.

³⁹ Estimated in Early intervention for children with learning disabilities whose behaviours challenge, Challenging Behaviour Foundation, November 2014: https://kar.kent.ac.uk/49229/1/CBF_early%20intervention.pdf

What has government done?

Successive government reforms have aimed to improve care offered to people with a learning disability. In 2011, a Panorama documentary highlighted shocking abuse experienced by patients at the Winterbourne View hospital and led to a government programme, Transforming Care, that aimed to shift care for people with a learning disability out of hospital and into the community and to improve quality and monitoring of inpatient care.

Transforming Care included the target that everyone inappropriately in hospital would move to community-based support as quickly as possible, and no later than 1 June 2014. All local areas would develop a register of all these people and a joint action plan. Local health and care commissioners were recommended to pool their budgets. Transforming Care had a focus on all ages but was not particularly focused on children.⁴⁰

The ambitious vision set out in Transforming Care was not delivered. An evaluation report found a range of barriers which were in the way of changing the system, which research for this report has found still exist today.⁴¹ These include: weak local leadership; a lack of focus on those within the community to prevent admission; limited rights for patients and their families; perverse financial incentives with local authorities disincentivised to facilitate community placements which they would have to pay for and clinicians disincentivised to discharge patients from units where they work. Inpatient settings were also often funded on a block contract and were considered the least risky option. The report found there was insufficient availability of community-based support, because of the difficulty for community providers to invest in staff, training and accommodation without having the confidence that commissioners would invest in them and that places would be filled and months before they were able to admit new clients and be paid for their care. Smaller community providers lacked the capital to make that upfront investment. These providers were often asked to take people at short notice.

An updated programme, Building the Right Support, was published in October 2015⁴² and set up 48 Transforming Care Partnerships across England, made up of local authorities, CCGs and NHS England specialised commissioners.⁴³ The programme included a target that, by March 2019 hospital care would only be needed for 1,300-1,700 people compared to 2,600. The programme, however, continued to have a focus on adult services: ADCS and the DfE were not listed as partner organisations, and there were no explicit targets for children under 18. The DfE did eventually become a partner in the programme in October 2016.⁴⁴

Building the Right Support set out how NHS England's specialised commissioning budgets would be aligned with local budgets to enable transformation and areas would be encouraged to pool budgets

⁴⁰ ADASS were involved as a key partner but ADCS and the Department of Education were not. The programme did, however, pledge that the Departments of Health and Education would work with independent experts to prioritise improvement outcomes for children and young people with challenging behaviour and guidance was published on children in residential care and hospitals. <https://www.gov.uk/government/publications/visiting-children-in-residential-special-schools-and-colleges>

⁴¹ Winterbourne View – Time For Change, Transforming the commissioning of services for people with learning disabilities and/or autism. A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb – 2014. 1,306 patients were admitted and 923 discharged between 2013 and 2014. 2,600 people remained in inpatient settings.

⁴² [Building the Right Support, national service model supplementary guidance for commissioners](#) and model service specifications

⁴³ [48 transforming care partnerships](#)

⁴⁴ Local Support for people with a learning disability, National Audit Office, March, 2017: <https://www.nao.org.uk/report/local-support-for-people-with-a-learning-disability/>

with local authorities. In addition, upfront investment was pledged and more promised after a spending review.⁴⁵

Speaking in a parliamentary debate in 2018, the Minister Caroline Dinenage explained that an evaluation sponsored by NHS England is “underway”.⁴⁶ Interim results showed that in quarter 3 of 2017-18, only 23 of the 48 transforming care partnerships had intensive support services for children and young people.⁴⁷ Further information shared with us from this evaluation shows that most survey respondents⁴⁸ felt that progress was being made at a local level to improve community services for people with a learning disability, autism or both although 23% disagreed with this. Moreover, some respondents also mentioned a lack of (or belated) focus on the wider aspects of Transforming Care, such as improving services for children and young people. 37% believed their local programme had not improved local commissioning of care and support and 46% said that it had not improved the joining up of health and care funding.

The Health Service Journal published a freedom of information request in December 2018 which found that a third of CCGs still do not have appropriate community crisis support services for children and young people with autism and learning disabilities, despite NHS England’s pledge to put these in place by March 2019.⁴⁹

The latest benchmarking of Transforming Care Partnerships in September 2018 found that while all TCPs now have a risk register, only 38 of the 48 include children, they are not all kept up to date and are not always being used to plan services effectively.⁵⁰

The Transforming Care programme came to an end in March 2019. There has been no announcement of a national programme to replace it. However, the NHS Long Term Plan, published in January 2019, set out new and continued commitments to the transforming care agenda. There is a commitment to continue to improve access to care in the community, so that more people can live in or near to their own homes and families. For example, pledges in previous reports are repeated, that local providers will be able to have more control over budgets for commissioning inpatient care in order to reduce avoidable hospital admissions, enable shorter lengths of stay and end out of area placements. This will include work to reduce waiting times for diagnosis of autism and provide better support for families during this process. NHS staff will be given better training on learning disability and autism.

NHS England will expand the STOMP-STAMP programme to stop overmedication⁵¹, work with the CQC to implement recommendations on restricting the use of seclusion, long-term segregation and restraint, and by 2023/24, all care commissioned by the NHS will need to meet new Learning Disability Improvement Standards.

⁴⁵ A parliamentary debate in 2018 confirmed that NHS England has transferred £50m to Clinical Commissioning Groups to close beds and invest in community alternatives and by the end of the programme NHS England will have invested over £50 million in transforming funding for transforming care partnerships to establish community support teams including those supporting children. Additionally, the Department of Health and Social Care has provided capital grants of over £23 million for housing to support people to return to the community or to prevent admission. The Minister also outlined that further investments would be put in place between 2018 and 2019. Commons Hansard, 5 July 2018, v644, c581

⁴⁶ Commons Hansard, 5 July 2018, v644, c585

⁴⁷ Commons Hansard, 5 July 2018, v644, c561

⁴⁸ This included professionals working in health and social care as well as people with a learning disability and/or autism, their families and experts by experience.

⁴⁹ Health Service Journal, 10 December 2018. Website accessed February 2019: <https://www.hsj.co.uk/policy-and-regulation/most-ccgs-failing-to-provide-learning-disability-crisis-support/7023979.article>

⁵⁰ NHS England

⁵¹ <https://www.england.nhs.uk/learningdisabilities/improving-health/stamp/>

By 2023/24, children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker. Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital. Keyworker support will also be extended to the most vulnerable children, including those who face multiple vulnerabilities such as looked after and adopted children, and children and young people in transition between services.

The NHS Long Term Plan acknowledges that more people have been identified in inpatient settings and pledges that by March 2023/24, inpatient provision will have reduced to less than half of 2015 levels. For the first time a target has been set to reduce the number of children in inpatient care. The plan states that no more than 12 to 15 children with a learning disability, autism or both per million, will be cared for in an inpatient facility. While this focus on children is welcome, this target lacks clarity and ambition, particularly in relation to targets for adults.

NHS England pledges to monitor the number of people in inpatient care and focus on reducing length of stay and supporting earlier transfers of care out of hospital. Every area will be monitored against a '12-point discharge plan' to ensure discharges are timely and effective and areas will still need to have risk registers to seek to prevent admissions. CETRs will continue to be used and the existing Care, Education and Treatment Review (CETR) and Care and Treatment Review (CTR) policies will be reviewed in partnership with people with a learning disability, autism or both, families and clinicians.

The plan also pledges increased investment in intensive, crisis and forensic community support to help reduce preventable admissions to inpatient services. Every local health system will be expected to use some of their growing community health services investment to have a seven-day specialist multidisciplinary service and crisis care. The plan pledges continued work with partners to develop specialist community teams for children and young people, such as the Ealing Model, which has evidenced that an intensive support approach prevents children being admitted into institutional care. **Ealing's Intensive Therapeutic Short Breaks Service** provides mental health and social care support for children and their families, to help children stay at home. A typical child being referred might be displaying violence towards other family members, high levels of anxiety, sleep problems and other severe needs such as absconding or fire-setting. Children referred to the service often have a short period of respite care while their individual needs are assessed and a plan is put in place. It provides intensive behavioural support and brings together all of the professionals working with a child once every three months to work on the child's positive behaviour support plan. The service has demonstrated improved outcomes for children and created savings for the local authority by avoiding hospital admissions. Out of 43 children who have used the service over the last ten years only 5 have ended up in residential care. The service has identified a gap locally (which is mirrored nationally) in provision for children with high functioning Autistic Spectrum Disorder. Ealing has also established a new service called Building my Future, which is funded by national pilot funding. The aim is to work with children with additional needs to improve life skills and avoid school exclusion. This is a good example of an early support multi-disciplinary service which does not have access thresholds and can reach out to children with additional needs in the community and put preventive support in place. The involvement of youth services in the programme has been particularly successful, encouraging children to get out into the community. An evaluation of the cost benefit of the service found that it would be likely to help make savings for the commissioners.⁵² The evaluation found the mean total cost of

⁵² Positive behavioural support for children and adolescents with learning disabilities and behaviour that challenges: an initial exploration of service use and costs. Valentina Lemmi, Martin Knapp, Caroline Reid, Catherine Sholl, Monique Ferdinand, Ariane Buescher and Marija Trachtenberg. Tizard Learning Disability Review. VOL. 21 NO. 4 2016, pp. 169-18

services, including both education and health and social care services, was £1,273 per week. The evaluation stated that this was around £66,000 per year compared to £171,176 for a 52 week residential school placement and £487, 396 for a secure unit.

Conclusion

This research has shown that too many children are admitted to hospital unnecessarily and spending months and years of their childhood in institutions when they do not need to be there. This report includes shocking evidence of poor and restrictive practices and heard from children about how traumatic a stay in a mental health hospital can be. It is particularly concerning that this report comes at the end of the Government's Transforming Care programme but that there has been so little change. Despite report after report and successive government programmes to address this problem, the number of children in hospital remains unacceptably high.

The Children's Commissioner is concerned that the current system of support for those with learning disability or autism in this country is letting children down. It does not meet our obligations under the United Nations Convention on the Rights of the Child. In particular, the right to live with parents and maintain relations and contact if living away from home (article 9) and the right to a full and decent life with participation in the community (article 23).

This report focuses on this group of children, partly because there is more data collected on this group which demonstrates the problems they face and partly because these children are particularly vulnerable. This research has nevertheless demonstrated the need for a wider investigation of the care of children in inpatient care. There are many children in mental health inpatient care with undiagnosed autism sometimes co-occurring with other mental health conditions. Girls with autism may not get diagnosed in the community and can develop co-occurring mental health problems, like eating disorders or psychosis and end up being admitted for this reason but may still not get a diagnosis of autism. There are also many issues with inpatient care which relate to all children in mental health settings and not just those with autism or a learning disability. It is therefore wrong to have a process with clear data collection and safeguards in place for those labelled as having autism, or where this is a primary diagnosis, but no equivalent for other children in the same unit. Clinicians spoken to as part of this research felt that the safeguards under Transforming Care should happen for any admission into inpatient mental health care. Other experts, however, pointed out that these safeguards are not yet robust enough and emphasised need to continue a focus on this particularly vulnerable group.

From this research, speaking to children and their families and experts who have been working in this field, the clear message was the need to focus on children's journeys before they are admitted into inpatient care. Children, families and staff working in this area spoke again and again about the failure to provide appropriate support to children when they are in school and living the community, and particularly when they reach a crisis point has contributed to inappropriate hospital admissions and delayed discharges.

Recommendations

A cross Government plan to provide community support for children

- > Ministers should publish a fully funded national strategy to replace Transforming Care with a focus on children. Accountability and scrutiny at a Ministerial level is vital to achieve real change, as successive reports and programmes have failed to deliver improvements.
- > The programme should have clear baselines and targets for what support is in place in each local area and where gaps exist, with a timetable for these to be filled and accountability for local partnerships.
- > Better data should be collected on length of stay and delayed transfers of care in children's mental health hospitals, in the same way that this information is closely scrutinised in physical health hospitals, and NHS England should use incentives to reduce them.

A new parent covenant to guarantee parental involvement

- > Providers should sign up to a parent covenant to involve families in a child's care
- > Children and their families should also be closely involved in the development of the strategy.

There should be new funding for the right support in the community to enable children to stay with their families.

- > A new national strategy should include a programme of support with evaluated good practice demonstration projects, an 'invest to save' fund to encourage locally commissioned community services, supported by a learning network to share best practice.
- > The Care, Education and Treatment Review process should be strengthened
- > At a regional level, NHS England should work with local commissioners to reduce length of stay and reduce the risk of admission. Local authorities need to maintain and make proper use of risk registers to identify these children and provide the right local support.⁵³

Training on LD and autism

- > All NHS staff and education staff should have the training to help spot children at risk and work together to make sure families are getting the right support.
- > Commissioners who are planning and purchasing support needed training to commission specialist services within the community, rather than the cheapest available provision
- > Inspectors need more training to identify whether services are providing specialist support

A programme to ensure excellent care within hospitals

- > The Government must review quality standards and establish new mechanisms of accountability and oversight.
- > Hospitals need to focus on recruitment of high quality staff with the right values and investing in face to face initial training and CPD

⁵³ Challenging Behaviour Foundation paper (FIND) which references:

Arron, K., Oliver, C., Moss, J., Berg, K., & Burbidge, C. (2011). The prevalence and phenomenology of self-injurious and aggressive behaviour in genetic syndromes. *Journal of Intellectual Disability Research*, 55(2), 109-120.

McClintock, K., Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: A meta-analytic study. *Journal of Intellectual Disability Research*, 47(6), 405-416.

Gore, N. J., Hastings R., & Brady (under review for TLDR). Building the Case for Early Intervention: Making use of what we know to prevent emotional and behavioural difficulties amongst children with disabilities.

- > Improving care in hospitals also means increasing access to education and meaningful activities, increasing access to appropriate therapies and behaviour support, and supporting contact with families.
- > Much more must be done to reduce the use of restrictive interventions, including better training for frontline staff and a greater focus on ensuring that children with communication difficulties can understand what is expected of them. More transparency is needed over restraint approaches from providers with monthly publication of data.⁵⁴

⁵⁴ Sen's law is a new piece of legislation which will require units to publish and review their data on restrictive intervention and publish a reduction plan. The CQC will also have tougher enforcement standards including training for inspectors and updated guidance for units. The Care Quality Commission is currently conducting a review of restraint within inpatient settings. It is vital that these measures achieve greater transparency and accountability within the system.

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