

# Transforming Care: our stories

Learning from families' experiences to transform care for people on the autism spectrum, with a learning disability or both



As part of the Disability Partnership, with the support of the Challenging Behaviour Foundation

## The Disability Partnership



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# Introduction

In 2011, shocking abuse was uncovered at Winterbourne View Hospital, an inpatient unit for people with learning disabilities. This scandal led to the acknowledgement that there is a significant number of autistic people, those with a learning disability, or both, stuck, inappropriately, in inpatient settings – largely because services to support them in the community simply do not exist.

*Transforming Care* is NHS England's programme to close up to half of the inpatient mental health beds used by people on the autism spectrum, with a learning disability or both.<sup>1</sup> The programme and its national plan outlined in *Building the right support*<sup>2</sup> sets out how the NHS and local authorities in England propose to improve the lives of children and adults on the autism spectrum, with a learning disability, or both in inpatient settings.<sup>3</sup>

At the time of writing, NHS *Assuring Transformation* data put the number of people covered by *Transforming Care* at 2,500 (215 children, 2,285 adults).<sup>4</sup> This includes:

- 1,365 people who have a learning disability only
- 470 people who are autistic only
- 570 people who are autistic and have a learning disability.<sup>5</sup>

Another NHS Digital data set (the Mental Health Services Data Set) gives a much higher figure of 3,840 people with a learning disability and/or on the autism spectrum in inpatient settings.<sup>6</sup> The

National Audit Office found this discrepancy in figures to be a cause for concern.<sup>7</sup> For this report, we've relied on the *Assuring Transformation* figures, as this data set has been established for longer.

This is a group of potentially vulnerable children and adults, with a wide range of different needs within different legal frameworks. To meet their needs, *Transforming Care* needs to ensure that the right understanding, professional expertise and services are available.

We wanted to find out more about people's experiences of being in, getting out of and avoiding admission to inpatient units. We believed these experiences could tell us more about what is and is not working, and how this affects the lives of people with a learning disability, on the autism spectrum, or both, and their families. This will help uncover the important issues that *Transforming Care* needs to tackle.

The National Autistic Society and Mencap have worked together as part of the Disability Partnership<sup>8</sup> to interview the families of individuals in, or at risk of being in, inpatient care. We identified a variety of people across England, of different ages and backgrounds and with very different needs. The Challenging Behaviour Foundation helped identify families and gave ongoing input to the project. Between September 2016 and April 2017 we carried out three interviews with each family.<sup>9</sup> At the first interview, we asked questions about their family member's situation and how they got there. At later interviews, we asked what had changed since the last time we spoke.

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<sup>1</sup>This report refers to people who have a learning disability, people who are on the autism spectrum and people who may be both autistic and have a learning disability. We use the terminology "people on the autism spectrum, with a learning disability or both" to refer to all people to whom *Transforming Care* applies.

<sup>2</sup>NHS England (2015), *Building the right support*.

<sup>3</sup>When we refer to "inpatient settings", "inpatient units" or "mental health hospitals", we are referring to the range of inpatient mental health provision in which autistic people, those with a learning disability, or both, may be placed under section. This includes assessment and treatment units (ATUs).

<sup>4</sup>NHS Digital, *Assuring Transformation: Learning Disability Services Monthly Statistics* (May 2017). Accessed 6 July 2017.

<sup>5</sup>A further 95 are not autistic and do not have a learning disability.

<sup>6</sup>NHS Digital, *Mental Health Services Data Set (March 2017)*. Extracted 23 June 2017.

<sup>7</sup>National Audit Office (2017). *Local support for people with a learning disability*.

<sup>8</sup>The Disability Partnership was formed of The National Autistic Society, Mencap, Sense and Scope, as part of the Department of Health's Voluntary Sector Strategic Partners Programme.

<sup>9</sup>In some instances, we were not able to carry out all three interviews, which is acknowledged in the relevant stories.

The stories contained in this report, while all being unique to each family, highlight experiences in relation to five key themes:

- making sure the right services are available in the local community
- being heard and involved
- quality of care
- making plans for discharge and sticking to them
- specialist support and understanding.

Several of the stories in this report show serious failings of care, some of which have even been subject to serious case reviews. Others are no less shocking in the impact that they have had on people's lives: when people had been admitted to inpatient care, families always told us that their wellbeing had deteriorated in some way.

## We need to not only aspire for better, but also to deliver it.

From what families told us about their experiences, we have developed practical recommendations for NHS England, commissioners, the Care Quality Commission (CQC), providers and professionals in order to deliver on the promise of *Transforming Care*. These fall within six key overarching recommendations that need to be taken forward:

- 1 The Government** should urgently strengthen the law around the rights of people in (or at risk of) inpatient care.
- 2 NHS England** (including Specialist Commissioning) must commission more specialist community-based services in line with the *Building the right support Service Model*<sup>10</sup>, and closely scrutinise individual plans for discharge to make sure they are acted on.
- 3 Local health and social care commissioners** must commission community-based support and inpatient services in line with the *Building the right support Service Model*, including to prevent admission.
- 4 Inpatient care providers** must ensure their staff are trained and their practices do not rely on excessive restraint and medication.

- 5 The CQC (Care Quality Commission)** must robustly inspect inpatient services in line with the principles of *Transforming Care*, and ensure that they are only registering services in line with *Building the right support*.
- 6 Professionals working with people with a learning disability, on the autism spectrum, or both** must listen to individuals and their families and ensure that their voices are at the centre of all decisions about their support.

It is vital for children and adults with a learning disability, on the autism spectrum or both, and their families that *Transforming Care* works. We hope that the Government, NHS England, local commissioners, the CQC, providers and professionals will take note of the experiences families have shared and will act on our recommendations, so that together we can make sure that all children, young people and adults are able to enjoy the fulfilling and rewarding lives they have a right to.

## Thank you

With thanks to all the families and individuals who took part in interviews to tell their stories in this report.

We would also like to thank Viv Cooper, Bella Travis, Emma Austin-Garrod, Anna Nicholson, Henry Barnes, Tom Purser, Sarah Lambert and Janine Wigmore for carrying out the interviews and giving their insight into this report and its recommendations.

<sup>10</sup>NHS England (2015), *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*.

# Chapter one: Making sure the right services are available in the community

## Lived experiences:

Maisie and Sally, Laura and Jane, Ollie and Diane

### Maisie and Sally

Maisie is a teenager on the autism spectrum with complex mental health needs. She has been in inpatient units ten times since 2013, when she was 12 years old. In 2015, Maisie's mum, Sally, started the *Get Maisie Home* campaign with support from The National Autistic Society, aimed at reinstating an inpatient unit in Hull. This had closed in 2013 and it meant that Maisie was in an inpatient far from home in Sheffield. Following her campaign, plans for a new unit in Hull have been announced.

When we first interviewed Sally in September 2016, Maisie was at home, having been discharged two days earlier. She had been an inpatient for seven weeks, despite the fact it was supposed to be for two weeks. The hospital consultant had applied for Maisie to be sectioned on the grounds that she had depression, psychosis and a 'historical diagnosis of autism', despite autism being a lifelong condition. Local child and adolescent mental health services did not think Maisie had psychosis. When the family appealed the decision, Sally said that the judge at the hearing "rubber stamped" the application, without properly understanding autism – especially in women and girls.

Sally told us that most of the units that Maisie had been in were "hell on earth." In addition to being far from home at a young age, Sally said that the hospital environments, regimes and responses to behaviour were not appropriate for a child on the autism spectrum, and staff training in autism was generally very basic. There had been a number of safeguarding incidents, including Maisie copying other patients' self-harming behaviour or trying to escape. Communication with the family (even following serious incidents requiring visits to A&E) was lacking and Sally felt her concerns were not listened to.

Now, back at home, Sally told us that some support had been put in place, but a lack of co-ordination between health, education and social care meant that there were gaps – particularly for a child on the autism spectrum who does not have a learning disability. Maisie was due to start a phased return to education at a specialist school for three days a week, although Sally was having to push for support for the other two days. She was also pushing for appropriate mental health crisis support, to prevent Maisie from being admitted again.

When we met with Sally the second time, however, Maisie was back in a unit in York – although this time voluntarily. Prior to admission, the family had support from night sitters, but they were not trained to manage crisis situations. They also received some support from the local crisis team (whose introduction Sally had campaigned for), but its capacity had been limited. Sally explained that she had not wanted Maisie to be admitted, after the very negative previous experiences, but that there were no other options available and that she had become exhausted after 11 days of supporting Maisie in crisis without sufficient help.

Before this, Sally had managed to get a personal budget for art classes for the two days Maisie wasn't attending school. However, in December these had stopped, along with the school placement. Without structured activities, Maisie's motivation and mental health were affected.

Sally had found another provider who could offer bespoke support for Maisie, but the funding for it had been refused. Sally's local MP, Alan Johnson, was arranging a meeting with the commissioners to discuss it.

Maisie's autism diagnosis, along with one of post-traumatic stress disorder had been confirmed, so Sally felt more confident it wouldn't be questioned again in the future. But Sally was becoming worried that Maisie would simply be seen as a "yo-yo" patient who would continue to be in and out of mental health hospitals. She highlighted that a Care and Treatment Review (CTR) had been carried out when Maisie was in inpatient care before our first interview, but the recommendations had "no muscle".

When we met Sally for our last interview in late March 2017, Maisie was in a unit in Leeds, having come home for a few weeks. Rather than being aimed at assessment or treatment, Sally described this as a "holding placement" because the right services didn't exist locally. Following a meeting with her MP and with NHS England, there was an 'in principle' agreement to the bespoke support Sally had found, but she was worried as there was nothing in writing.

NHS England had also contacted local commissioners to find out why no CTR had been carried out when she was admitted in December, January or February. When it did take place, however, Maisie had been put on the spot by commissioners with direct questions and had not been offered advocacy. Maisie had started specialist PTSD therapy after an 18 month wait, although this had been interrupted by admissions to inpatient care.

Sally said, "it's left up to families to find out about sources of support and alternative providers when existing services are not suitable." She estimated that inpatient care over the past two years has cost around £350,000, and questioned what could have been achieved for Maisie if this money had been used to support her in the community.

## Laura and Jane

**This family asked to tell their story anonymously. We have changed their names.**

Laura is 12 years old and has a learning disability and microcephaly – her speech is limited. We spoke to her mum, Jane, three times over the year. Laura attends a school for children with special educational needs during the day.

When we first spoke, Jane told us that earlier in the year, the family had been hit by a crisis. Laura was living at home, but the family had been asking for help – in particular for Laura to attend a residential school – for three years. Jane told us, "Every one of my requests for residential schools was turned down because they said her needs were being met by the specialist school she attended. But they didn't address the fact of her challenging behaviour at home. Then crisis hit in July 2016 – I couldn't cope with her challenging behaviour anymore and I contacted social services to say I couldn't cope."

Laura moved into a children's home for children with learning disabilities. Jane was happy that the staff understood Laura's needs, although over the year she consistently complained that there was too much reliance on TV and iPads, rather than physical activity. When we spoke to her last, the TV in the lounge had broken, meaning that Laura was engaged in more activities. Jane saw this as a positive, but feared things would return to normal once the TV was fixed.

Jane was also concerned that Laura wasn't able to do things she enjoys, like swimming, because of the needs of the other children in the home, where there are only three carers to support four children.

After two years, Laura still does not have a finalised Education Health and Care Plan. Jane said, "There's so many parties involved when you have a disabled child. It's as exhausting dealing with all of them and constantly fighting and asking for support as it is caring for a disabled child."

## **Ollie and Diane**

Ollie is a young autistic man with Attention Deficit Hyperactivity Disorder (ADHD) and Down's syndrome. When we first met with his mum, Diane, Ollie had been living at home for around two months after two placements at residential homes had collapsed. Diane had not felt that Ollie was safe in either of them. He had been heavily medicated and his behaviour had become challenging. "The assessments themselves are fine," Diane told us. "They cover all his needs including challenging behaviour but the support listed in them never materialises."

They also had a CTR in the community. Diane said, "Lots of independent people came in and they see the residential home for what it is. They come from NHS England and they are good and there's a parental advocate. But the staff from the residential home didn't turn up for the CTR and afterwards said, 'we're throwing Oliver out because he's ruined our CQC report'."

Ollie's parents had been told by the last provider that if they did not take their son home that day, he would be sectioned.

Ollie's local authority, Redbridge, assessed his needs and identified that he needed three-to-one support. However, Diane could not find support workers who could meet his needs, meaning that Ollie and his family went without the support that the council had agreed they needed. In fact, Diane later handed £35,000 back to Redbridge that she wasn't able to spend due to a lack of suitably trained support workers. As a result, Ollie was spending most of his time in his bedroom, unable to get out into his community.

Diane had found somewhere in Norfolk that looked promising and could meet his needs. Redbridge Council supported this move. When we next caught up with Diane three months later, Ollie had moved into his new home the week before. He was beginning to settle and the signs were promising: it appeared that staff knew much better how to support him, especially if his behaviour became challenging. Diane was receiving daily calls, visits were easy to arrange, and accommodation was provided.

Over the next couple of months, things continued to progress, albeit slowly. When we last spoke in March 2017, Ollie was going out about once a week. This wasn't as much as Diane would have liked and she had some concerns that the third person in the three-to-one support for going out wasn't always available. Ollie is also often anxious about going out. Having come off medication when he left the last residential home, psychiatrists are now pushing for Ollie to have Risperidone, which Diane is resisting because of the dangers of taking it with a heart condition.

The staff however seem to understand Ollie and his needs better. While there have been issues, Diane's experiences mean that she is no longer afraid to speak up.

## What these experiences show

The biggest issue facing the families that we spoke to was the lack of appropriate services available in their local communities. This is the biggest challenge facing *Transforming Care*. Having the right services can help ensure that people do not face long stays in inpatient units or mental health hospitals, and importantly can help prevent admission in the first place.

## Preventing admission (and re-admission)

Preventing admission (and re-admission) is a fundamental concern in this report. Many of the stories here show that admission could have been avoided if the right support had been available in the community.

During our interviews with Diane, we found out just how close Ollie had come to being sectioned under the Mental Health Act – it had come down to a matter of hours, and he had to move home. Diane had the support of her local authority commissioners, who outlined a personal budget that was enough to meet Ollie's needs. But services with the expertise to support him just weren't available. This put a huge amount of strain on the family and Ollie wasn't able to go out. Again, with the support of the local authority, they found a new place for Ollie to live that would meet his needs.

In contrast, Jane has not had the level of support she needs from her local authority. Laura's Education, Health and Care Plan has been delayed for two years: the statutory requirement in the SEND Code of Practice is 20 weeks.<sup>11</sup> Jane also felt that the local authority didn't understand how Laura's challenging behaviour was affecting home life. As a result, residential school places weren't considered.

These two experiences show the importance of engaged and informed local authority commissioners. They need to play an active role in identifying the support that an individual needs in the community and then sourcing that support. The Service Model says, "Commissioners should develop a group of social care preferred providers that meet the needs of people with a learning disability and/or autism."<sup>12</sup> However, this is not happening consistently.

Local authorities and health bodies need to commission services based on accurate local data. Care and Treatment Reviews provide useful information about the support required to support someone in the community. They should be used to plan services locally, alongside other key data sources including Education Health and Care Plans (EHCP) and Joint Strategic Needs Assessments (JSNA).

The *Building the right support* Service Model outlines what should be on offer, including intensive support and crisis services.<sup>13</sup> These services both need to be available 24 hours a day, seven days a week. However, Roger (whose story is in chapter four) told us that he couldn't access intensive support at the weekend.

## Making sure discharge isn't held up

Other families that we spoke to said the lack of local community social care and mental health services was a reason for delayed discharge. Following assessment and treatment, many individuals still require ongoing mental health support.

Under the Care Act 2014, local authorities have a duty to provide a local market of services to meet the needs of their population. However, the same duties do not apply to the NHS. The previous Government's *No voice unheard, no right ignored*

<sup>11</sup>Department for Education (2015), *Special educational needs and disability code of practice: 0 to 25 years*.

<sup>12</sup>NHS England (2015), *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*.

<sup>13</sup>NHS England (2015), *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*.



Green Paper suggested introducing a sufficiency duty to health and social care commissioners specifically for people with a learning disability, on the autism spectrum or both.

However, the Government's response to the consultation did not take this forward. We believe the Government needs to look again. Introducing this sufficiency duty would help ensure that all the needs of children and adults with a learning disability, on the autism spectrum or both were met in the community.

In our final interview with Sally, she described Maisie's latest admission as a "holding" arrangement. Not because Maisie still needed assessment and treatment, but because there was nowhere in the community that could support her.

Community services, including community mental health teams and community learning disability teams, need to understand the needs of people with a learning disability, on the autism spectrum or both – and to be trained appropriately. Individuals must be able to rely on services that can meet and adapt to their individual needs, including communication needs.

## Making sure the right housing and support is available and that there is enough funding

The Service Model states that a variety of housing options should be available to support people locally. However, our stories show that this is not happening well or quickly enough – often because a suitable house is not available or the funding for it cannot be agreed.

Sally and Maisie's experiences also highlight that the responsibility for finding suitable care and housing often falls to the family. Sally had to get her local MP and NHS England involved to push for agreement for that care. Similarly, Shahana (whose story is in chapter two) told us that it was down to the family to find Fauzia's new placement, and Jessica (whose story is in chapter three) had to find suitable housing and

providers for Aaron. Commissioners should have knowledge of available and appropriate housing and support providers in the community, with flexibility to meet individual need. They should work with the family to find a suitable arrangement, but that does not mean that families should bear the burden of searching.

Local authorities also need to make sure that funding is available for adaptations to be made to housing, to meet sensory needs or support behaviour that challenges, and to fund any ongoing repairs or alterations required. Without these, an individual's needs will not be met, significantly increasing their risk of (re-)admission and placement breakdown.

## Recommendations

- **The Government should introduce a sufficiency duty on local authorities and NHS commissioners to ensure that sufficient services are made available to meet the health and social care needs of people with a learning disability, on the autism spectrum or both, in the local community.**
- **Transforming Care Partnerships should use the information from Care and Treatment Reviews to help inform commissioning plans, alongside other data sources, including EHCPs and JSNAs.**
- **CCGs (Clinical Commissioning Groups) must ensure that all staff working in community mental health services and community learning disability teams understand learning disability, autism and challenging behaviour, and can demonstrate how this knowledge is put into practice.**
- **CCGs must ensure that they are able to offer adapted mental health interventions for autistic people, and people with a learning disability in line with NICE (The National Institute for Health and Care Excellence) guidance/guidelines.<sup>14,15</sup>**

<sup>14</sup>NICE (2014), Quality standard on autism [QS51].

<sup>15</sup>NICE (2016), Mental health problems in people with learning disabilities: prevention, assessment and management [NG54].

- **In line with the National Audit Office's recommendation,<sup>16</sup> NHS England should develop measures to assess the effectiveness of community capacity to prevent admissions. It should then ensure that commissioners use these measures locally and nationally to ensure good quality housing supply.**
- **The Government should review its proposed funding reforms for supported housing taking account of the recent joint Work and Pensions Select Committee and Communities and Local Government Select Committee report. The new funding approach must ensure that both providers and lenders to the supported housing sector are able and willing to continue to provide suitable housing for those with the most complex needs.**

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<sup>16</sup>National Audit Office (2017). *Local support for people with a learning disability*.

# Chapter two: Being heard and being involved

## Lived experiences:

Fauzia and Shahana, Matthew and Isabelle, Stephen and David

### Fauzia and Shahana

We first spoke to Shahana, Fauzia's aunt, in October 2016. By then, Fauzia – who is 19, is on the autism spectrum and has learning difficulties and Tourette's syndrome – had been happily living in the community in a residential care service for a couple of years. But her journey to get there had been long and traumatic.

Fauzia attended an autism-specific school during the week, but due to the distance from home and struggles with the daily transition to and from school, her behaviour became very challenging. After trying respite services at the weekend for a time, it was felt that a 52-week residential school placement would be best. However, Fauzia struggled being so far from home, so she started to self-harm and her Tourette's grew worse. Shahana told us, "in hindsight, she had also developed obsessive compulsive disorder (OCD). The staff really tried, but they were tired. Fauzia stopped accessing education: she needed assessment and treatment."

Fauzia's move to an inpatient unit was traumatic – there was no transition. Shahana said, "She was put in a private ambulance and tied down. The consultant at [the hospital] didn't know Fauzia was coming and the ward wasn't prepared for her."

Fauzia remained in hospital for two years. After being in seclusion for the first few weeks, she was moved to an "Extra Care Facility" – a room next to seclusion, separate from the main ward. "The only exposure she had to her peers was as they went past into seclusion," Shahana told us. For a year, she only received three half-hour sessions of education a week.

A major obstacle was that the right people weren't invited to meetings, so the family had to invite them, and social workers kept changing. Shahana found an education representative to attend, which resulted in Fauzia's education being increased to three half-hour sessions a day.

Shahana then heard about support that some charities are able to offer. She contacted the Challenging Behaviour Foundation, who invited her to a meeting with the Care Minister Norman Lamb. He got involved, visiting Fauzia and calling a meeting with national and local commissioners. "We were incredibly lucky," Shahana said.

At this point, there was still no discharge plan. "They gave her heavy doses of anti-psychotics, but she had no psychosis. They didn't acknowledge her Tourette's and so thought, despite a specialist assessment, that she was violent."

The family went to meet a different provider they had heard of. Fauzia now lives there. Shahana said, "It seemed too good to be true. That's the bit where we won the lottery." But after agreement that Fauzia could move, the process dragged out. The hospital didn't seem to give Fauzia the transition support she needed. For four months, the new provider went in to provide transition support for free.

But Fauzia did move. She got to choose the eventual moving date and that same afternoon, she was out in her new community visiting the park. Shahana said, "The change in Fauzia was profound and immediate."

Over the next two interviews, Shahana told us how Fauzia was doing more activities, and had graduated from visiting stables, to grooming the horses, to riding them. Her medication was significantly reduced and the staff understood how to support her behaviour. She still needs high levels of care and together they are considering Fauzia's further education. The provider was small and was recently taken over by a bigger company. Shahana told us that it's a worry that everything could change or that social services may want to move Fauzia.

Earlier this year, Shahana and Fauzia were involved in a *Dispatches* documentary, 'Under lock and key', telling her story. "It was quite a therapeutic process for Fauzia and the family. We knew she was traumatised, but we perhaps didn't address that and tried to move on instead," Shahana said.

Despite being an 'expert' inpatient service, Shahana feels that the staff didn't properly understand Fauzia or her needs, and didn't listen to her family. "The system is broken," she told us. The culture and attitudes need to change. "We need to commission better assessment and treatment units."

## **Matthew and Isabelle**

Matthew is a young autistic man with learning difficulties and complex mental health needs. He was sectioned in 2015 and taken to a general psychiatric intensive care unit. His parents, Isabelle and Robin, set up a campaign for him to move to an autism-specific inpatient provider. They were told it was the only place that could meet Matthew's needs. In March 2016, Matthew moved to an autism-specific hospital.

When we first met Isabelle, six months later, a discharge plan for Matthew still hadn't been developed, despite promises that planning would start on admission. Isabelle had serious concerns about Matthew's health and wellbeing – he was losing weight and his anxiety was increasing. Matthew was regularly being positioned face-down, prone restrained and injected with anti-psychotic medication. Despite being an 'autism-specialist' service, staff were unable to adapt their communication. Recommendations made at Matthew's Care and Treatment Review (CTR) were not followed. Meanwhile, he wasn't getting education, fresh air or exercise. The whole family felt powerless.

We next met Isabelle almost five months later: a lot had changed. Matthew had moved to a new residential service with a 16-19 learning programme. His mental health section had been lifted. Isabelle was much happier with the care he was getting: the environment was low arousal and structured, restraint was not used, specialist mental health support was brought in and Matthew was getting out and about with people. Isabelle was being involved in planning Matthew's care and was much happier with how his challenging behaviour was dealt with. She was hoping that a family holiday in March 2017 would test the waters in terms of thinking about Matthew coming home.

When we met Isabelle for the final time, in April, Matthew was still at the residential service and settled. Isabelle told us, "He's in a home and not an institution, he's out in the community several times a day and the family can take him out whenever they want. So what needs to be done is developing a long term plan for what life for Matthew looks like." Matthew was no longer being prescribed anti-psychotic medication and the next step would be a visit home.

Matthew's care plan is a "living document and updated all the time." It includes a positive behaviour plan. "All his care is about motivating him and supporting him to learn skills."

In March 2017, Matthew's story was featured in an episode of Channel 4's *Dispatches* documentary series, 'Under lock and key'.

## Stephen and David

Stephen is 34 and has Asperger syndrome. He has a long history of stays in inpatient mental health units. In September 2016, when we first spoke to his father, David, Stephen was detained under the Mental Health Act in a generic mental health unit and had been there for almost two years. Previously, Stephen had lived in a residential care service and had been receiving some outreach support.

At our first interview, David highlighted issues around information and advocacy. He had not been given any information about the Mental Health Act when Stephen was sectioned and had to carry out his own research. He told us, “It’s complex. I don’t really feel like I understand all the rights.” Stephen didn’t have an advocate, and an appointed lawyer for a section review had not worked out well, as Stephen finds new relationships and changes difficult. There also seemed to be no co-ordination between different aspects of Stephen’s care, which left the family confused.

Stephen had a CTR in August 2016, but most of the actions hadn’t been acted on.

These issues were still ongoing when we met David for the second time. An advocate had been appointed, but he didn’t make the reasonable adjustments that Stephen needed. David also told us there wasn’t any specialist autism support on the ward anymore. The psychologist and speech and language therapist Stephen was seeing had been told to stop seeing him. During this time, Stephen’s challenging behaviour increased slightly and was not well-managed. David told us, “There are strategies that work, but the ones they used are mental health ones that make things worse.” However, a move to a step-down service, to gradually support Stephen’s move back into the community had been proposed.

When we had our final visit, Stephen had made that move – although he was still under section. This service was chosen because it had a set of pathways leading to community-based care. It was more autism-specific than the last unit, but David was still not convinced it was right for Stephen – the severity of some of the other residents’ needs was affecting Stephen, and depressing him. Meanwhile, the community mental health provider did not have staff trained in autism who could support him in the community.

The problems around the co-ordination of care persisted and input from Stephen’s home local authority was a problem. David said, “Social services continually hold their hands back and let health pay and organise it... no one is holding their hands up and saying ‘it’s my job’.” David believes that until this lack of overall responsibility is addressed, no real progress towards bringing Stephen back into the community can be made.

David also made a complaint about the advocacy provider in the last unit, but didn’t feel that it was taken seriously. He was considering what steps to take next as it is vital support.

He said, “Stephen just falls between the gaps and no one takes ultimate responsibility for his case... Where is the pressure to get Stephen back into the community?”

## What these stories show

### Getting decision-makers together

At least three of the families that we spoke to had launched national campaigns following the admission of their loved one, raising concerns about the care they were receiving or how far from home they were. They did this because the system wasn't working and they felt they alone didn't have the legal rights or the power to change it. Others went to their MPs, met with ministers or talked to lawyers, and three featured in television documentaries.

As Shahana told us, getting the right people to attend meetings, to make decisions and ensure progress is made, can be a struggle – families told us that it was often down to them to do this. This should not be their responsibility, and without information and access to good advocacy services, it is even more difficult, as David's story above shows.

Common to several of the families we spoke to was the feeling that they were “lucky” to get senior people involved. For Shahana, it was attending a meeting with the Minister for Community and Social Care at the time, Norman Lamb, arranged by a charity. That led him to visit Fauzia and then call a meeting with NHS England and all the senior commissioners. In Matthew's case, his story got substantial media coverage and led to an online petition that gained hundreds of thousands of signatures, leading to a meeting with the next minister, Alistair Burt, and with NHS England.

However, this is clearly not an option for everyone, and neither Matthew nor Fauzia's families should have been in the position where the only option was to get a minister involved to move things forward. According to NHS England guidance on Care and Treatment Reviews,<sup>17</sup> a responsible commissioner is tasked with putting together a meeting, and inviting attendees. However, there is no guarantee that invitees will attend. The Government and NHS England should strengthen the CTR process to ensure

that the right people are actively involved so the right decisions can be made and actioned as quickly as possible. This should also be reflected in the CTR guidance.

### Advocacy, information and legal advice

At important times, Stephen didn't have the Independent Mental Health Advocate that he should have had, and when he did finally get support from one, it failed because they couldn't adjust their communication to work with him. The Service Model underpinning *Building the right support* rightly requires commissioners to ensure that independent advocacy is available.<sup>18</sup> However, further work is needed to make clear to commissioners how and when this advocacy should be offered – to make sure that individuals know it is available and what it is for. Individuals also need sufficient time with advocates, and may need an advocate to be flexible about when they can be around, to ensure that the advocate really gets to know their needs.

These stories also tell us that the quality of advocacy is as important as its independence. Understanding the individual's needs is key, as is the legal system. Autistic people and people with a learning disability may have particular needs and communication may need to be adapted. For example, an individual may be unable to communicate verbally and require the use of sign language, visual aids or a more creative approach if they don't use conventional communication. Advocates need specific training to make sure this happens. NHS England should write a specific requirement into the Service Model to provide advocates who have received training with the tools to make reasonable adjustments specifically for people with a learning disability, on the autism spectrum or both. This would improve both the supply and quality of advocacy.

Families also spoke to us about needing legal advice to drive forward progress – especially the actions outlined in CTRs. This shouldn't be the case. But when it is, families need access to lawyers who understand not only the legal framework, but the needs of the individual.

<sup>17</sup>NHS England (2017), *Care and Treatment Reviews (CTRs): Policy and Guidance*.

<sup>18</sup>NHS England (2015), *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*.

## Listening to families

Families are experts. They have a wealth of knowledge about their loved ones, which is a vital part of planning the care and support they should receive. They can also act as advocates in many ways. Yet David told us that, despite being invited to Stephen's Care and Treatment Review, he didn't receive any further information – including who the other people attending were. This made it harder for him to follow up with them afterwards to try to make sure progress was being made. NHS England guidance states that CTRs should be both person-centred and **family-centred**.<sup>19</sup> In their quality assurance role, responsible officers in Transforming Care Partnerships (TCPs) and NHS England regional directors should require proof that invitations have been extended to families and that the information for the meeting is passed on to them. If this has not happened, evidence should be provided showing why, and responsible officers should require this evidence.

This exclusion from key decisions about the wellbeing of family members was meant to be addressed by *No voice unheard, no right ignored*. However, this has not changed, showing that legal change is needed. Ultimately, the Government needs to ensure the CTR process is underpinned by the law to ensure it has the full force of the law, and that individuals' rights can be enforced if it is not followed.

Providers, including mental health hospitals, need to make sure they are also providing information to families about their rights and those of their loved ones. This should include rights under the Mental Health Act and Mental Capacity Act, among others. NHS England should promote the positive effects that family input has had on care planning, and share best practice with TCPs and providers.

## Recommendations

- **Building on *No voice unheard and no right ignored*, the Government must ensure that individuals and their families are heard, and their right to be heard is strengthened.**

- **In addition to reviewing CTRs, the Government needs to put them on a statutory footing, making the guidance binding for providers and professionals. This will ensure that the right people are invited to meetings and that families can make sure their right to be involved and heard is upheld.**
- **In addition, the Department of Health and NHS England should strengthen the CTR guidance to ensure that professionals and commissioners who are invited attend.**
- **NHS England needs to assure itself every area has sufficient high quality advocacy services.**
- **Advocacy providers should be required to have training in how to adjust their communication for autistic people and people with a learning disability. Training must also ensure they have an in-depth knowledge of autism, learning disability, challenging behaviour and the *Transforming Care* policy.**
- **Providers must ensure all individuals are given information about their care and their rights. This must be provided in an accessible format, in line with the Accessible Information Standard.**
- **Providers and commissioners must ensure families are given information about the care their loved one will receive, and their rights to challenge it. This should include referring families to independent sources of information, including charities.**
- **NHS England should promote best practice of involving families in care planning, with the consent of the individual if they have capacity, and assure themselves that families are being involved effectively in care planning for each individual.**
- **NHS England should assure itself that families are invited to CTRs and provided with all relevant information. This should also be a topic for the independent evaluation of CTRs recommended in chapter 4.**

<sup>19</sup>NHS England (2017), *Care and Treatment Reviews (CTRs): Policy and Guidance*.

# Chapter three: Inconsistent care quality

## Real stories:

Kamau and Lorna, Catherine and Anna, Aaron and Jessica

### **Kamau and Lorna**

Kamau is a 33-year-old autistic man from London. When he was younger, he was admitted twice to inpatient care for short periods, shortly after being prescribed anti-psychotics. In June 2014, he was sectioned after he was put on Depakote, and deteriorated further after being put on lithium. The reason given for the section was Kamau's challenging behaviour. However, when we spoke to his mother Lorna, she said that her son's behaviour hadn't been challenging prior to medication – something that professionals seemed to previously agree with, as anti-psychotics had been successfully withdrawn before.

For five months in 2014, Kamau was an inpatient in Doncaster, before moving to a low/medium secure unit in Essex, where he remains.

Lorna worries about the use of medication. She said, "I am concerned that none of the drugs seem to be beneficial to Kamau." Over the interviews we carried out with Lorna, the lack of a behaviour plan kept recurring. "I have raised my concerns with the psychiatrist and nurse at [the hospital] many times and with all the staff there. I've raised my concerns with as many people as possible and written letters, which the Challenging Behaviour Foundation has helped with. I've also raised these issues with Kamau's solicitor. There has been no outcome nor any response at all to my concerns."

Kamau's physical health and wellbeing deteriorated too. "His skin is very bad and is completely cracked on his feet. The last blood tests I knew the results for also said that his liver and kidneys were being affected by the medication." Over the year of our interviews, Lorna told us that she was pushing for Kamau to see a nephrologist. This had just happened by our last conversation.

We also wrote to Kamau's funding commissioners to raise issues around discharge planning and the use of medication. When we last spoke with Lorna in March 2017, Kamau still didn't have a discharge plan, but they were starting to discuss it, "which wasn't happening before." A few days earlier, Lorna had attended Kamau's latest CTR. She said, "This time, it feels like if a place were identified he could move out... I will need to push for him to leave. I am definitely dissatisfied. I'd like to know the names of the places that are being considered and that the right experts are being consulted. I also feel it is imperative that home is considered as one of those options."

Following the March CTR a new psychiatrist has been employed and she has gradually withdrawn lithium. Staff at the unit say they see no deterioration in Kamau since the withdrawal.

Lorna is concerned about the staff turnover. Kamau has had multiple psychiatrists over the past two years and when we last spoke to Lorna, the most recent one had resigned. The psychologist had also resigned, as had a number of the care staff. She is also worried that they don't understand autism. Lorna told us, "I don't think the staff are used to dealing with people with autism, they're used to people with a mental health diagnosis. It doesn't work with Kamau. If you shout at him, his challenging behaviour will get worse because of the loud, negative way he's being approached."



## Catherine and Anna

**This family asked to tell their story anonymously. We have changed their names.**

Catherine is 21 years old, is on the autism spectrum and has a learning disability and obsessive compulsive disorder (OCD), as well as some challenging behaviour. We first spoke to her aunt, Anna, in September 2016. She described the situation that Catherine was in as “horrific”.

Catherine was 16 when she first entered inpatient care. She has remained in inpatient care since, apart from one week where she lived in a community placement that broke down due to a lack of adequate support.

When we first spoke to Anna, Catherine was an inpatient at a low secure unit where she had been for about a year, having been at another Assessment and Treatment Unit (ATU) before. Anna told us that the family had been given no choice but to accept the move to this unit. The family weren't able to see Catherine often and had serious concerns about the care she was receiving, which they said was very restrictive. Anna told us, “she's not getting any treatment, it's just a holding pen because staff [in the unit] don't have the right skills, expertise or mindset. She's getting nothing while she's there at all. Everything is about seclusion, never about trying to prevent incidents happening in the first place.” Catherine's health and wellbeing deteriorated and her aunt said, “she's now in a worse state than she's ever been in the care system, it's so bad her mum and dad didn't recognise their own daughter when they went to visit her”.

Catherine's family spent months struggling to get her out of the unit. Concerns had been raised repeatedly to safeguarding and commissioners but the family had to keep pushing. By the time we spoke to Anna again, Catherine had moved to another inpatient unit which was medium secure. It was closer to home and although it was still an inpatient unit, the family was happier with the care and support Catherine was getting. “It's so much better”, Anna said. At that point, there had only been one instance of seclusion, but the family was phoned afterwards to explain why it had happened and what had been learned for the future to try to prevent it from happening again. The unit was also trying to improve Catherine's diet. However, there had still been no Care and Treatment Review and Anna was still having to chase it.

At our last interview, there still was no discharge plan, although some discussions had been had about ‘stepping down’ to a low secure unit. The family still feel that Catherine's needs “are genuinely important to the staff at the unit.” They have established behaviour strategies. Anna said, “They have identified trigger times, noise, when the light is changing, other people's distress. A mug of hot chocolate with marshmallows in and 1-1 with a member of staff works wonders. Staff can actually be bothered to sit and talk to her, which is so different to before.” Catherine's medication has also reduced significantly and she has started a self-medication programme.

However, it is still a restrictive environment and Catherine's family want to see her back in the community, living a full life and “not spending the rest of her life in inpatient care.”

## Aaron and Jessica

**This family asked to tell their story anonymously. We have changed their names. Only one interview was carried out with Jessica.**

Aaron is a young man with a diagnosis of autism and a learning disability. He was first admitted aged 18, in 2012. He was attending a specialist autism school with a view to starting a residential school placement. Due to an administrative error with his date of birth, the family realised that as he had reached 18, he would not be able to move into the residential placement. The family hit crisis.

The local authority did not offer an alternative education placement. There was no transition planning to adult services and Aaron only received support for 10 hours a week. Aaron's behaviour became increasingly challenging. In 2012, he was sectioned and after fifteen months in an Assessment and Treatment Unit (ATU) he was moved to a specialist autism hospital.

His parents initially agreed to a short period of assessment in the ATU as they had become exhausted due to the lack of support and hoped that Aaron would get the professional support he needed. Jessica told us she was told "this would set him up for adult life."

Unfortunately, Aaron had a traumatic experience in both the ATU and the specialist hospital. A serious case review later found that these placements had "completely failed." It further noted that, "A very vulnerable young man suffered a sequence of traumatic experiences which may adversely affect him for many years." This included heavy reliance on restraint (including floor restraint) despite the fact that Aaron had never been restrained previously. It also involved over-medication, seclusion and a number of safeguarding incidents and injuries.

At the specialist hospital, professionals removed Aaron's autism diagnosis without a proper assessment. As a result, he was arrested for assaulting staff – following 11 hours of floor restraint. Furthermore, he did not have access to an Independent Mental Health Advocate, and an independent social worker was excluded from meetings by the provider after raising concerns about the use of floor restraint. His anti-psychotic medication tripled in eight months. Jessica told us, "Aaron was a heartbeat away from spending the rest of his life in an isolated ward in a high-security hospital."

That placement finally broke down and Aaron was transferred to a rehabilitation unit – restrained in an ambulance by seven people, and having to wear a spit hood. Despite this bad start, Jessica feels that the new unit "worked wonders" with Aaron. Within three weeks of moving, his Haloperidol dosage had been reduced from 40mg a day to 9mg a day. A positive behaviour strategy was also put into action. The unit reassessed Aaron and reinstated his diagnosis of severe autism and a mild learning disability.

Jessica said that the fundamental difference in approach was simply kindness and empathy, together with an understanding of autism and the trauma Aaron had experienced (he was diagnosed with post-traumatic stress disorder, and the overmedication left him with difficulties speaking, eating and walking). He hasn't been floor restrained since. The family were listened to, kept fully informed and described their relationship with staff as 'exceptional'. Aaron was able to access activities in the community, including a successful holiday and unaccompanied leave to see his family.

Discharge was finally agreed in May 2015. Only now, two years later, is Aaron about to move into his new house – five years after being admitted.

Following all this, the CCG issued an apology to the family, as did the council's Adult Safeguarding Board. However, neither the ATU nor the hospital have apologised. Jessica was especially keen to highlight that, "there has been zero accountability." She told us that the hospital, despite being marketed as specialists in autism, seemed to have no autism expertise, and that the removal of Aaron's autism diagnosis was not an isolated case. The family feels, considering the cost of the care provided, that this is unacceptable.

## What these stories show

Some people with a learning disability, on the autism spectrum or both who develop challenging behaviour or mental health problems require assessment and treatment. It is vital that they are able to access high quality care and safe treatment for their mental health needs. However, the stories that we heard from families painted a mixed picture of how people have been supported and the quality of the care they have received. The effects are far reaching, affecting the quality of life of individuals in units, delaying discharge further and presenting challenges once they are discharged.

## The use of medication

Of particular concern was the use of medication – in particular psychotropic medication. Research from Public Health England has also found that people with a learning disability or on the autism spectrum are at greater risk of over-medication and widespread inappropriate use of medication.<sup>20</sup> NICE guidance outlines appropriate interventions (without medication) for people whose behaviour may challenge<sup>21</sup> and is also clear that medication should not be used to treat the core features of autism.<sup>22</sup>

Yet the use of medication among the individuals whose families we spoke to suggests that either professionals are unclear on how to support people in reducing challenging behaviour, or that behaviour is misinterpreted as a sign of psychosis or other conditions requiring medication. However, psychotropic medication is powerful and can have significant side-effects.

Kamau's experiences highlight the impact this medication can have. His challenging behaviour became worse following medication, and Lorna is extremely concerned about the effects it is having on his liver and kidneys. Another of the families we spoke to (Eddie and Adele, later in the report) told us that their relative was accidentally given an overdose when medication had been changed.

Aaron's story shows the positive outcomes of relying less on medication and more on behavioural support. Within weeks of receiving behavioural support, his medication dosage had been reduced by more than three quarters.

Yet it is behavioural support that Kamau and Lorna are waiting for – a wait that has been exacerbated by the high turnover of staff in the unit, including Kamau's psychologist. For people with a learning disability, on the autism spectrum or both, behavioural support should be planned for from the outset and put into action. Following the publication of the *Stopping the over-medication of people with a learning disability, autism or both* pledge (STOMP)<sup>23</sup>, NHS England should ensure that all providers are following its guidance. NHS England should also explore how it could require providers to follow guidance, for example by writing it into service specifications.

## Ending reliance on restraint and seclusion

Many of the families we spoke to raised restraint, which should only be used as a last resort, as a significant issue. This is particularly true of Aaron and Jessica. A serious case review following

<sup>20</sup>Public Health England (2015), *Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England*.

<sup>21</sup>NICE (2015), *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges* [NG11].

<sup>22</sup>NICE (2014), *Quality standard on autism* [QS51].

<sup>23</sup>[www.england.nhs.uk/2016/06/over-medication-pledge](http://www.england.nhs.uk/2016/06/over-medication-pledge).

Aaron's discharge from an inpatient unit found that restraint (including prone restraint and a spit hood) had been relied upon, with damaging results. In one instance, he was arrested, handcuffed and taken away in a police van. Although it appears that all the other parties have acknowledged that this was wrong, it is concerning that the provider has not apologised.

Guidance from the Department of Health<sup>24</sup> says that restraint must always be the least restrictive option to meet the immediate need and it is good practice to involve individuals and their families in planning, monitoring and reviewing how seclusion and restraint are used. However, our families' stories suggest that this is not happening. Catherine and Anna's experience shows an example where the provider has tried to learn from a situation where seclusion was used to try to prevent it from happening again. This gave Anna more confidence in the care Catherine was getting, as she felt that the service was adapting and learning. The Department of Health should amend this guidance for adults to say that families 'should' be involved, and need to publish promised guidance for children as a matter of urgency.

Providers are required to record the use of restraint and to provide this information to the Care Quality Commission (CQC) when it carries out inspections. Inspectors are required to look at these records when they attend, identify if frequent use is shown, check that staff are trained in safe restraint and that individuals' care plans follow the principles of positive behaviour support. However, as the families we visited told us, care plans and behavioural support plans can be delayed, poorly co-ordinated or non-existent. The CQC should train inspectors who are inspecting specialist services where these techniques are used and be strict in requiring documented care planning and clear evidence that it's being put into practice for all people in a unit under inspection.

Current guidance to CQC inspectors says that "where possible, [inspectors should] ask people about their experiences of being restrained."

We welcome this inclusion, but believe that it should be amended to ensure that it is followed at all times. Where restraint is used on a ward, it should be expected that an interview will take place, unless the wellbeing of an individual prevents asking them, in which case information should be sought from family or advocates. Where someone is not able to communicate verbally, other approaches will be needed. This may include more creative approaches, or obtaining information from those who know the person well.

## Meeting other health and wellbeing needs

The families we spoke to highlighted concerns over physical as well as mental wellbeing in hospital settings. Family involvement is not only important, it can also be extremely helpful. Because Lorna wasn't listened to about Kamau's allergy to soap, he developed dry skin and sores.

Other families told us about the importance of diet, getting regular exercise and meaningful activity. Many of their loved ones experienced marked weight loss or gain – often linked to medication, but also because dietary requirements were not met. This can have very serious consequences for an individual's physical and mental wellbeing.

It's vital that the provider meets all of an individual's needs while they are under hospital care. Families need to be listened to from the outset to draw up physical health plans. This should be part of a wider conversation about behaviour and communication needs. It will be beneficial to all parties, and providers should report back to parents about how agreed actions are being taken forward.

Underpinning many of these issues is a lack of understanding of autism, learning disability, challenging behaviour and the needs individuals may have. We look at this in more depth in chapter five.

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<sup>24</sup>Department of Health (2014), *Positive and Proactive Care: reducing the need for restrictive interventions*.

## Recommendations

- The Department of Health should strengthen the rights of individuals and families to challenge decisions about the use of medication, and should issue statutory guidance.
- The Department of Health should strengthen guidance on restraint and seclusion to increase family involvement.
- The Department of Education must publish guidance on restraint and seclusion for children and young people as a matter of urgency.
- Providers should ensure that behavioural support planning starts as soon as possible on admission (or before if possible). This should be carried out by professionals who can demonstrate a high level of understanding of autism, learning disability and behaviour that challenges, and support strategies.
- NHS England should encourage all providers to sign up to STOMP. It should monitor uptake and monitor the use of medication in units (as used to be the case in the Learning Disability Census).
- NHS England should explore using service specifications and provider contracts to embed STOMP principles in all services.
- The CQC should amend inspections guidance to ensure that evidence of restraint use is gathered and used in inspections and that individuals who have been restrained are asked about their experiences.
- The CQC should ensure all inspectors have received specialist training relating to restraint and seclusion and their use and impact on individuals – and appropriate alternatives.
- The CQC must alert the Government if they feel they lack powers in relation to recognised issues – for example around expansion, rather than registration, of a service.
- Commissioners should only commission providers who can demonstrate good practice around restraint and medication.

# Chapter four: Making plans for discharge and sticking to them

## Real stories:

Michael and Roger, Eddie and Adele

### Michael and Roger

**This family asked to tell their story anonymously. We have changed their names.**

Michael is 24. He is on the autism spectrum, has a mild learning disability and can sometimes exhibit challenging behaviour. When we first met Michael's dad Roger, Michael had been in a low secure inpatient unit under section 3 of the Mental Health Act for four months. Before that, he was in a residential care home with eight other people, and supported on a loose one-to-one basis. In the week before he was admitted to the inpatient unit, his anxiety increased. The community psychiatric team were due to see him the following Monday. However, Michael's challenging behaviour escalated over the weekend.

Roger, and paramedics, visited the residential home and it was agreed that it would be safest for Michael to stay there. But a few hours later he was taken to a place of safety in a mental health hospital, and paramedics were called out again. After two days, he was transferred to an out of area learning disability inpatient unit. Roger told us, "I don't think that he should have been sectioned at all. If it hadn't been the weekend there may have been more support available and this could have been prevented."

During Michael's time in the unit there had been one reduction in his medication, but otherwise he was getting similar care and support to that which he received in the community. Roger said, "They haven't learned anything we didn't already know. If they had listened to us, and understood his needs better he wouldn't be there".

After three months at the unit, Michael had been cleared for discharge. However, only then did discharge planning start – it had not started at the time of admission. When we spoke to Roger for the second time, two Care and Treatment Reviews had been undertaken, but they hadn't amounted to anything. Roger felt they had been "a waste of time." No action plans had resulted from them.

The last time we spoke to Roger, Michael still hadn't moved, despite having been cleared for discharge for seven months. Although Michael had an advocate, Roger was not sure that she had much input into his care or discharge planning. She had not been involved in finding a new home for Michael, and was not part of a recent mental health tribunal.

However, a suitable placement had finally been found for him and a funding application was being processed. Planning was still underway, but it was hoped that in his new home Michael would have his own bedroom and lounge, and would be able to share communal spaces with four other residents. The placement is walking distance from many activities Michael enjoys and is close to his family.

## Eddie and Adele

Eddie is a young adult from Bristol who is on the autism spectrum and has a learning disability, ADHD and dyspraxia. (His autism diagnosis has been changed to a communication disorder diagnosis since the interviews took place.) When we first interviewed his mum Adele, Eddie was in a medium secure unit in Newcastle – around 300 miles away from his family. Eddie moved there in 2014 from a low secure unit in Northampton, where he had been since January 2013. This followed a short time at an autism-specific residential school, after previous school placements had broken down because of Eddie's anxiety.

The 17 months that Eddie spent in Northampton were an experience of “disappointing care and a deteriorating doctor-patient relationship,” Adele told us. “Eddie was over-medicated and essentially sedated,” received little education, fresh air or exercise while he was there. After lodging an official complaint regarding suspected abuse, Adele was informed that “the relationship had become untenable” and Eddie would have to move.

While Adele has been much happier with the care and support Eddie receives in Newcastle, the distance from home has been a real struggle. She receives one funded visit per month, and once arrived only to be told Eddie could not see her as it would be “unsafe” – Eddie was in seclusion and had a seizure later that day.

During the summer, Adele launched an online petition that received over 65,000 signatures and national media coverage.

At our first interview, Bristol commissioners were working with the family to draw up a plan for support in the community. When we met for the second time in January 2017, Adele told us that the hospital was very keen to involve Eddie's family, and everyone hoped that he would be able to move by June. Adele added that she believed the national media attention had “helped get it moving forward”, and previous Care and Treatment Reviews had needed “a good deal of pushing” to be acted on.

She also raised concerns about restraint use in the unit. Although it is recorded and monitored, she was very unhappy that techniques such as prone restraint were still being used. A recent incident had left Eddie with ligament damage.

When we met Adele for the final time in March, Adele told us there had been a couple more worrying incidents. Eddie had accidentally been given an overdose when his medication had changed, and had also been shoved by a member of staff. While Adele was told about both events and they were properly investigated, these events should not have happened.

Eddie's moving date had been pushed back, but everyone was still hopeful he would move by his birthday in August. (We have since heard that this is unlikely.) Plans had developed, and funding had been found to purchase a house. Adele was getting ready, along with commissioners and Eddie's social worker, to interview potential care providers. A month-long transition was also being planned. Adele hoped that in the future, less restrictive measures would be used to manage her son's behaviour. She said, “Eddie is Eddie and no amount of medication is going to change that. So we need to make sure he's happy and well-supported in his community.”

## What these stories show

### Planning early for discharge

NHS England's *Building the right support* is clear: discharge planning should begin on admission, if not before. None of the families we spoke to said that discharge planning began prior to admission, and many of the stories in this report show considerable delays. Similarly, none of the individuals had a Care and Treatment Review (CTR) before they were admitted.

In Michael's case, what should have been a short stay in an inpatient unit to receive assessment and treatment extended to almost a year because planning for his discharge started so late. Despite the fact that commissioners had been working with the family to plan for Eddie to move into the community, progress has been slow.

### Discharge planning may start early/on admission but actual discharge can be too slow

As Aaron and Jessica's story in chapter three shows, too often people who are ready for discharge are not being discharged in a timely way. *Assuring Transformation* data also shows that people often experience delayed discharge. The impact of this on individuals must be taken on board. Much of this will depend on a CTR, the actions outlined in it and how they are progressed. But people also need to remember that fundamentally this is an issue of an individual's rights.

### Making Care and Treatment Reviews work

Feedback from families about Care and Treatment Reviews (CTRs) indicates that the idea is positive – bringing everyone together and having independent people involved was felt to be beneficial. An important element of a successful CTR appears to be that it involved sufficiently senior commissioners (including from the local authority) and clinicians. The families we spoke to also reported that experts by experience had a positive effect on the

meeting – although we know from others that this experience is often mixed.

However, many people reported significant difficulty, frustration and delay when CTRs failed to result in positive outcomes. For example, when CTRs were simply not acted on and no one was held responsible for their progress. Roger told us that Michael's CTRs hadn't amounted to any changes and Adele felt that it took media attention to get things moving. Later, we hear from Rebecca and Karen, whose CTR helped Rebecca out of an inpatient unit. However, her care co-ordinator in the community did not even know that one had taken place, so it wasn't used.

Some of the families we interviewed reported that providers and professionals were disengaged or did not take part in the CTR process. Providers are vital to taking forward the recommendations of a CTR so that someone can progress towards discharge. Others highlighted that it was hard to get social care commissioners to attend – particularly if the CTR was held outside someone's home local authority. In short, there appears to be an unacceptable variation in the quality of CTRs.

To tackle this variation in the short term, NHS England should expand the 'Quality assurance reporting requirements' section of its CTR guidance.<sup>25</sup> The responsible officers and regional directors in NHS England who are responsible for overseeing CTRs need to require more evidence, in particular:

- Evidence of who attended the CTR, ensuring that professionals involved in providing care were there. If they were not, NHS England should ask why.
- Evidence that the people who attended were the right ones, and that they had knowledge and understanding of autism and learning disability.
- Evidence that the actions agreed upon show a clear path to discharge and assign responsibility to take action to professionals.
- Where a further CTR takes place, evidence of how previous actions have been worked towards. If actions have not been carried out, NHS England must find out why and use its powers to push the actions forward.

<sup>25</sup>NHS England (2017), *Care and Treatment Reviews (CTRs): Policy and Guidance*, p45.



To ensure that the promise of CTRs is realised in the long term and that they provide value for money, NHS England should commission an independent evaluation of CTRs, analysing how they interact with the CPAs (Care Programme Approaches) and Education, Health and Care Plans. This will identify best and worst practice, include the impact on individuals' quality of life and address concerns raised elsewhere, including by the National Audit Office.<sup>26</sup>

In the coalition Government's *No voice unheard, no right ignored* green paper, a number of rights were proposed, including statutory guidance providing for discharge planning. Following consultation, and a change of government, the response put a significant emphasis on CTRs. However, 18 months on, the experiences of families we've spoken to show that CTRs are not driving progress forward at an individual level. In addition, even the proposed non-statutory 'charter of rights' has failed to emerge. The Department of Health should urgently reconsider its approach and consult on key rights, engaging individuals and charities.

## Recommendations

- **The Department of Health should bring together individuals, families and charities to develop a new approach to rights and entitlements for people in inpatient care, including looking at the steps that could ensure timely discharge.**
- **The Department of Health should publish statutory guidance, complementing the Mental Health Act Code of Practice, stating that discharge planning must start on admission at the latest.**
- **NHS England should separately commission an independent evaluation of CTRs, the outcomes they deliver for individuals and their value for money.**

- **NHS England should clarify its CTR guidance to make sure that the right people are being engaged and actions are taken forward. Actions should also show a clear path to discharge.**
- **Where a discharge plan is not in place, NHS England must find out why and use its powers to remove obstacles in the system.**
- **Providers should highlight the importance of CTRs, CPAs and EHCPs to all relevant staff, encouraging them and giving them time to play a meaningful role.**
- **Providers and commissioners must ensure that information about CTR and Mental Health Act processes is fully accessible, available and actively promoted to individuals and families.**
- **Local authorities and Clinical Commissioning Groups must ensure that commissioners are able to attend CTRs. Other relevant professionals from the home area community team should also attend.**

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<sup>26</sup>National Audit Office (2017), *Local support for people with a learning disability*.

# Chapter five: Specialist support and understanding – in the community and in inpatient settings

## Real stories:

Helen and Mark, Rebecca and Karen

### Helen and Mark

**This family asked to tell their story anonymously. We have changed their names.**

When we first met with Mark, his daughter Helen had been living in a small flat with two-to-one support for a year. Her previous placement had broken down and she had been given notice. The flat was supposed to be a temporary placement while a more suitable placement was found, however no planning was taking place for the next move. Helen is autistic with mental health problems and a borderline learning disability. But the family have been consistently refused help by learning disability services because Helen's IQ is just over 70. Mental health services also said that Helen's needs are not within their remit as she is autistic, although she does have other mental health problems including extreme anxiety. Mark said, "these problems have worsened since her teenage years, we've had constant battles. She's gone from having a fruitful life to barely being able to function at all."

Mark had concerns that the flat wasn't suitable and that the staff were not able to manage Helen's behaviour. Over the months, Mark pointed out that there was a substantial level of staff turnover and that the staff seemed inexperienced. Helen was often left to her own devices. Mark said, "They often sit in a separate room reading magazines, not engaging with Helen." Mark has made it clear that Helen needs to be constantly occupied but this hasn't happened. Professionals and a commissioner told Mark several times that Helen was at risk of being sectioned, but he and the commissioner both felt that this wasn't right for Helen and attempts were made to avoid it.

Although Helen was on medication that was prescribed by a psychiatrist several years earlier, there had been no psychiatric input for some time. As a result, her medication wasn't being reviewed.

When we next spoke to Mark, he told us that Helen had started doing some activities, but these weren't filling her days. It also took Mark a long time to get these set up for Helen. "She doesn't seem to have gone anywhere at all today," he said. "I don't think she's done anything."

When we last met Mark, Helen had moved again following a crisis situation. She had come within hours of being sectioned, but an emergency placement had been found just in time to prevent admission to a hospital hundreds of miles away. While Mark was pleased that an emergency placement had been found, he was disappointed that the previous placement was allowed to get to crisis stage, particularly as he had raised concerns many times.

The other residents in the new placement were different ages to Helen and had very different needs. However, Mark did feel that the staff at the home were more capable, and Helen initially seemed to be doing well. However, just a few weeks in, Mark was concerned about Helen's mental health and increased challenging behaviour, and about whether the placement could meet

her needs. He told us, “I wanted to think she was in the right place but now I’m not even sure if they’re coping.” There were still issues with a lack of structure to Helen’s day – she had no regular timetable, which Mark says is “absolutely essential to Helen’s wellbeing.”

Helen was still waiting for input from a psychiatrist, occupational therapist and speech and language therapist. Mark said, “I’m really worried she’ll be sectioned still. I have been clear from the start that it wasn’t just about moving her to the right place, she’ll need support for her mental health too.”

It has been recommended that Mark seeks a Care and Treatment Review, as Helen is still at risk of admission. However, in the past the commissioner has been reluctant to carry out a CTR. Mark said, “If she ends up in one of these places [an ATU] it’ll just destroy her. But I’m worried I can’t keep her out.”

## **Rebecca and Karen**

**This family asked to tell their story anonymously. We have changed their names. We only carried out two interviews with Karen and Rebecca: one in early in January, one in late March.**

When we first met Karen, Rebecca had been discharged from a general adolescent psychiatric unit about six months earlier. Rebecca is autistic and has mental health problems, but does not have a learning disability.

Karen told us that one of the reasons she had agreed to Rebecca being sectioned in February 2016 was the prospect of being guaranteed care and support after she was discharged. At that time, Rebecca had clinical depression and was suicidal. Karen was told that Rebecca would need to stay in the unit for two weeks. She stayed for over two months.

The unit was not appropriate for Rebecca. She struggled being so far from home and was restrained and sedated. She was on high levels of medication, which were questioned by the local Child and Adolescent Mental Health Services (CAMHS) team when they visited. Karen told us that the unit “did not cope with the behaviour of an autistic person, for example due to dealing with change or the environment.”

Rebecca left the unit in April, by which point she had grown dependent on diazepam. Karen was also worried that Rebecca was showing signs of post-traumatic stress, in the form of difficulty sleeping and waking screaming in the night. Her discharge came about as she was approaching 18, and was no longer able to stay in the adolescent unit. Issues around transition to adult services persisted when Rebecca was discharged.

After the discharge plan was drawn up, Karen told us it took months for the council and the CCG to organise support, and there was nothing in place for those months. Karen had to fight to get funding for art therapy – which really seemed to work and was recommended as part of Rebecca’s aftercare. When we met the second time, Karen told us that the CCG had tried to stop funding it. Only an intervention from her, the therapist, the local autism lead, an MP and The National Autistic Society meant that the funding was continued until at least October 2017.

Rebecca has only seen a psychiatrist once since being discharged. Karen told us that assessments for care and support resulted in direct payments that didn’t cover the full cost of support. Karen

had to sell her house and the family moved in with her parents. A carer's assessment provided Karen with some support – but the budget did not meet the full cost. This has an impact on everyone. Karen said, “There is very little support for young adults with autism and behavioural difficulties, rather than a learning disability. Even where budgets are available, there isn't enough suitable provision to spend them on.” Rebecca had a CTR before she was discharged, but it isn't being used in the community – in fact, her care co-ordinator wasn't even aware there had been a CTR.

Despite the fact that she has been sectioned, and being (as Karen strongly believes) at risk of future admission, Rebecca does not have a social worker. This is because she does not have a learning disability and the community mental health team are not getting involved.

Karen told us she feels let down. The detrimental impact of Rebecca's time in the unit continues, and the family live without the support they need.

## What these stories show

Over the year, we spoke to families whose loved ones in units had a variety of conditions and difficulties. These were different and often very complex, which reflects their vulnerability and the need for the **right** care and support. Understanding of the individual and their needs – particularly how multiple conditions might present themselves – came up again and again.

## Understanding people's needs

For all children, young people and adults with a learning disability, on the autism spectrum or both, understanding someone's needs, strategies that might help them and services that may be available is vital. In Karen's case, only the backing of professionals who understood Rebecca's need for art therapy stopped funding from being withdrawn.

It is vital that people get comprehensive assessments of their needs from people with the right skills. Following NICE Guidelines, professionals need to understand what may trigger behaviours that may challenge and support individuals with appropriate interventions.<sup>27</sup> This should include a complete look at someone's physical environment and housing needs (including sensory needs).

In other interviews, we frequently heard about behaviour being mistaken as aggressive or even as evidence of psychosis, leading to the use of restraint or medication. However, people with a learning disability, on the autism spectrum or both may (especially at times of anxiety) struggle to communicate or express their feelings. This can result in those feelings being expressed in a physical way. It is essential to understand the reasons behind the behaviour and address the underlying cause. This is the goal of positive behavioural support, which is discussed in more depth in chapter three. Positive behavioural support benefits individuals and the staff working with them. It can prevent situations that lead to restraint or where either the staff or individual are at risk of physical harm. Staff in health and care services may have heavy demands on their time, but training should be seen as an investment.

Providers and professional bodies (including the Royal College of Psychiatrists and Royal College of Nursing) have a role to play in providing and promoting training in autism, learning disability and positive behavioural support to their staff, and encouraging them to take it up. This should be incorporated into continuing professional development.

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<sup>27</sup>NICE (2015), *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*.

We encourage the use of the CQC's *Guide for inspectors on positive behaviour support for people with behaviours that challenge*, by inspection teams.<sup>28</sup>

Commissioners (both at CCG and NHS England level) can ensure training has happened, by outlining training requirements in service specifications and requiring proof that training has taken place before commissioning services – both inpatient and in the community – in line with the NHS England *Transforming Care Service Model*. Finally, commissioners should ask families for feedback on how well staff in services appear to understand learning disabilities and autism. They should take this feedback (including any complaints) seriously and use it to inform their commissioning decisions.

## Understanding autism

Although we spoke to people with a variety of needs, the lack of understanding of autism came through strongly. This was true of both inpatient units and the health and social care services in the community, which individuals need to live independently. This is particularly concerning as the number of autistic people recorded in inpatient units has increased by almost a quarter (24%) in the two years since March 2015.<sup>29</sup> Almost two in five people covered by *Transforming Care* are autistic and 45% of these autistic people do not have a learning disability. Put simply, if *Transforming Care* does not work for autistic people, it will not work.

The gap in services for autistic people, who fall between traditional learning disability and mental health services, is clearly shown in Helen and Mark's story. Helen has an IQ just above 70 and so was told she was not eligible for support from a learning disability team in the community. But the support she was given wasn't sufficient, and support workers didn't have the knowledge or experience Helen required.

Similarly, Rebecca found herself in a general adolescent psychiatric ward, where the staff did

not understand autism and could not support her properly. As a result, she was on high levels of medication and was frequently restrained. Karen told us that services for autistic people just aren't present in the community, and Rebecca still doesn't have a social worker.

These two stories don't exist in isolation. In some of the interviews, families raised serious concerns about diagnoses of autism being questioned or removed, which had a serious impact on their relatives' care and support. Poor understanding of autism was cited in our interviews with Shahana, Isabelle, David, Lorna, Anna, Jessica, Sally and Diane.

The *Statutory guidance implementing the adult autism strategy* outlines that autism training is required for all health and care staff.<sup>30</sup> This applies to staff in inpatient units and community health and care services alike. Commissioners have a duty to ensure that this statutory requirement is met and should check that it is included in specifications for services in the community. We also believe that there is little virtue in limiting training requirements to staff supporting autistic adults, when many staff will support both adults and children at times. Statutory guidance should be updated to expressly include the appropriate training for all health and care staff who work with autistic children.

Although finding an inpatient bed can be challenging, with few available beds and often an urgent need to find one, commissioners need to be sure they are sending individuals to places that will meet their needs. Providers should outline and be able to demonstrate their training credentials. Meanwhile, NHS England should audit inpatient services across England, including mental health hospitals, to ensure that autism training has been carried out.

To finally address the gap in services, NHS England should appoint a clinical director to work across NHS England to improve the commissioning of health services for autistic people.

<sup>28</sup>Care Quality Commission (2017), *Brief guide: Positive behaviour support for people with behaviours that challenge*.

<sup>29</sup>NHS Digital (April 2017), *Assuring Transformation: Learning Disability Services Monthly Statistics*. Accessed 1 June 2017.

<sup>30</sup>Department of Health (2015), *Statutory guidance implementing the adult autism strategy*.

## Recommendations

- The Department of Health should mandate Health Education England to update the curricula for all relevant health and care professionals working with people with a learning disability, on the autism spectrum or both, to include understanding of the needs of people with those conditions, challenging behaviour and mental health problems.
- NHS England must ensure that training requirements for staff in all NHS England-commissioned services meet the needs of people with a learning disability, on the autism spectrum and behaviour that may challenge in all services in line with the *Building the right support Service Model*. To demonstrate this, NHS England should carry out an audit of inpatient settings to ensure training requirements are being met.
- NHS England should review whether further training requirements should be outlined.
- The *Statutory guidance implementing the adult autism strategy* should be followed by all local authorities and CCGS and should be updated to expressly include the training of all health and care staff who work with autistic children.
- To improve understanding and commissioning of support for autistic people, NHS England should appoint a clinical director for autism, who should work across departments.
- Providers should maintain an up-to-date log of staff training on autism, learning disability and positive behaviour support and make it available to commissioners.
- Commissioners (NHS England and CCGs) should require this log as evidence when commissioning places. They should also ask families for their opinions of the understanding of learning disability, autism and challenging behaviour.
- Providers and professional bodies should promote training to staff.
- Providers should incorporate training on positive behaviour support into staff continuing professional development.

# Summary of recommendations

**The Government** should urgently strengthen the law around the rights of people in (or at risk of) inpatient care.

1. The Department of Health should bring together individuals, families and charities to develop a new approach to rights and entitlements for people in inpatient care, including looking at the steps that could ensure timely discharge.
2. The Government should introduce a sufficiency duty on local authority and NHS commissioners to make sure that sufficient services are available to meet the health and social care needs of people with a learning disability, on the autism spectrum or both, in the local community.
3. The Department of Health should publish statutory guidance, complementing the Mental Health Act Code of Practice, stating that discharge planning must start on admission at the latest.
4. In addition to reviewing CTRs, the Government needs to put CTRs on a statutory footing, making the guidance binding for providers and professionals. This will ensure that the right people are invited to meetings and that families can make sure their rights to be involved and heard are upheld. Building on *No voice unheard and no right ignored*, the Government must make sure that individuals and their families are heard, and that their rights to be heard are strengthened.
5. The Department of Health and NHS England should strengthen the CTR guidance to ensure that professionals and commissioners who are invited attend.
6. The Department of Health should strengthen the rights of individuals and families to challenge decisions made about the use of medication by issuing statutory guidance.
7. The Department of Health should strengthen guidance on restraint and seclusion to increase family involvement.

8. The Department of Education must publish guidance on restraint and seclusion for children and young people as a matter of urgency.
9. The Government should review its proposed funding reforms for supported housing, taking account of the recent joint Work and Pensions Select Committee and Communities and Local Government Select Committee report. The new funding approach must ensure that both providers and lenders to the supported housing sector will be able and willing to continue to provide suitable housing for those with the most complex needs.
10. The Department of Health should mandate Health Education England to update the curricula for all relevant health and care professionals working with people with a learning disability, on the autism spectrum or both, to include understanding of the needs of people with those conditions, challenging behaviour and mental health problems.
11. *The Statutory guidance implementing the adult autism strategy* should be followed by all local authorities and CCGs and should be updated to expressly include the training of all health and care staff who work with autistic children.

**NHS England** (including Specialist Commissioning) must commission more specialist community-based services in line with the Service Model, and closely scrutinise individual plans for discharge to make sure they are being acted on.

1. Transforming Care Partnerships should use the information from Care and Treatment Reviews, alongside other data sources including EHCPs and JSNAs, to help inform commissioning plans.
2. In line with the National Audit Office's recommendation,<sup>31</sup> NHS England should develop measures to assess the effectiveness of community capacity to prevent admissions. It should then make sure commissioners use these measures locally and nationally to ensure good quality housing supply.

<sup>31</sup>National Audit Office (2017), *Local support for people with a learning disability*.

3. NHS England should commission an independent evaluation of CTRs, the outcomes they deliver for individuals and value for money.
  4. NHS England should clarify its CTR guidance to make sure the right people are being engaged and actions are taken forward. Actions should also show a clear path to discharge.
  5. Where a discharge plan is not in place, NHS England must find out why and use its powers to remove obstacles in the system.
  6. NHS England should assure itself that families are invited to CTRs and provided with all the relevant information.
  7. NHS England should encourage all providers to sign up to STOMP. It should monitor uptake, as well as the use of medication in units (as was previously carried out in the Learning Disability Census).
  8. NHS England should explore using service specifications and provider contracts to embed STOMP principles in all providers.
  9. NHS England needs to assure itself that every area has sufficient high quality advocacy services.
  10. NHS England should promote best practice of involving families in care planning, with the consent of the individual if they have capacity, and assure themselves that families are being involved effectively in care planning for each individual.
  11. Commissioners should only commission spaces from providers who can demonstrate good practice around restraint and medication.
  12. NHS England must ensure that training requirements for staff in all services meet the needs of people with a learning disability, on the autism spectrum and with behaviour that may challenge, in line with the *Building the right support* Service Model. To demonstrate this, NHS England should carry out an audit of inpatient settings to ensure that training requirements are met.
  13. NHS England should review whether further training requirements should be outlined.
  14. To improve the understanding and commissioning of support for autistic people, NHS England should appoint a clinical director for autism, working across departments.
  15. Commissioners (NHS England and CCGs) should require this log as evidence when commissioning places. They should also ask families for their opinions on the understanding of learning disability, autism and challenging behaviour.
- Local health and social care commissioners** must commission both community-based support and inpatient services in line with the *Building the right support* Service Model and aim to prevent admission.
1. CCGs must ensure that all staff working in community mental health services and community learning disability teams understand learning disability, autism and challenging behaviour, and can demonstrate how this knowledge is put into practice.
  2. CCGs must ensure that they are able to offer adapted mental health interventions for autistic people, and people with a learning disability in line with NICE guidance.
  3. Advocacy providers should be required to have training in how to adjust their communication for autistic people and people with a learning disability. Training must also ensure they have an in-depth knowledge of autism, learning disability, challenging behaviour and *Transforming Care* policy.
  4. Commissioners should consider only commissioning spaces from providers who can demonstrate good practice around restraint and medication.
  5. Local authorities and CCGs must ensure that commissioners are able to attend CTRs. Other relevant professionals from the home area community team should also attend.
  6. Commissioners (NHS England and CCGs) should require provider training logs as



evidence when commissioning places. They should also ask families for their opinions of the understanding of learning disability, autism and challenging behaviour.

**Inpatient care providers** must ensure their staff are trained and their practices do not rely on excessive restraint and medication.

1. Providers must ensure all individuals are given information about their care and their rights. This must be provided in an accessible format, in line with the Accessible Information Standard.
2. Providers and commissioners must ensure families are given information about the care their loved one will receive, and their rights to challenge it. This should include referring families to independent sources of information, including charities.
3. Providers should make sure that behavioural support planning starts as soon as possible on admission (or before if possible). This should be carried out by professionals who can demonstrate a high level of understanding of autism, learning disability and behaviour that challenges, and support strategies.
4. Providers should highlight the importance of CTRs to all relevant staff, encouraging them and giving them time to play a meaningful role.
5. Providers and commissioners must ensure that information about CTR and Mental Health Act processes is fully accessible, available and actively promoted to individuals and families.
6. Providers should maintain an up-to-date log of staff training on autism, learning disability and positive behaviour support and make it available to commissioners.
7. Providers and professional bodies should promote training to staff.
8. Providers should include training on positive behaviour support in staff continuing professional development.

**Professionals working with people with a learning disability, on the autism spectrum or**

**both** must listen to individuals and their families and ensure that their voices are at the centre of all decisions about their support.

**The Care Quality Commission (CQC)** must robustly inspect inpatient services in line with the principles of Transforming Care, and ensure that they are only registering services in line with *Building the right support*.

1. The CQC should amend inspections guidance to ensure that evidence of restraint use is gathered and used in inspections and that individuals who have been restrained are asked about their experiences.
2. The CQC should ensure all inspectors have received specialist training relating to restraint and seclusion and its use and impact on individuals – and appropriate alternatives.
3. The CQC must flag to the Government if they feel they lack powers in relation to recognised issues – for example around expansion, rather than registration, of a service.

# Glossary of abbreviations

<b>CCG</b>	<b>Clinical Commissioning Groups</b> commission health services locally.
<b>TCP</b>	<b>Transforming Care Partnerships</b> are groups of CCGs and local authorities, combined with NHS England who work together to plan services for people with a learning disability, on the autism spectrum or both.
<b>ATU</b>	<b>Assessment and treatment units</b> are inpatient units for people who have a learning disability and need intensive support. They are supposed to be short term services.
<b>CQC</b>	<b>Care Quality Commission</b> oversees the quality of health and social care services in England.
<b>CTR</b>	<b>Care and treatment reviews</b> are meetings that bring together individuals, families' commissioners, professionals and an expert by experience to check if someone's care is right. They can also agree on actions for discharge.
<b>MHA</b>	<b>Mental Health Act</b> governs when someone can be sectioned and their rights if this happens.
<b>EHCP</b>	<b>Education, Health and Care Plans</b> (formerly 'statements of special educational needs') document the support that a child with special educational needs requires.
<b>CPA</b>	<b>Care Programme Approach</b> is a way of planning and reviewing services for people with complex needs, including some people with a learning disability.
<b>JSNA</b>	<b>Joint Strategic Needs Assessments</b> collect information about the health and care needs of a local authority's population. Local authorities then use this information to plan the services they need.



## About The National Autistic Society

We are the UK's leading autism charity. Since we began over 50 years ago, we have been pioneering new ways to support people and understand autism. We continue to learn every day from the children and adults we support in our schools and care services.

Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, their families and friends. And we support professionals, politicians and the public to understand autism better so that more autistic people of all ages can be understood, supported and appreciated for who they are.

**Until everyone understands.**



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