

Beyond Transforming Care What needs to change?//ASP December 2018

**About autism:** Autism is a lifelong disability which affects how people communicate and interact with the world. There are approximately 700,000 autistic adults and children in the UK.<sup>1</sup> Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

About us: The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people. We transform lives by providing support, information and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work. We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws. We have come a long way but it is not good enough.

## **Contents**

Contents1
Executive Summary
Introduction
What's happening?
The number of identified autistic people in mental health hospitals is increasing $5$
The number and proportion of young autistic people in hospitals is higher $^6$
Autistic people are often in mental health hospitals for a long time
Many autistic people have been flagged as not needing inpatient care anymore but are still in hospital9
Calling for change: the story so far
What needs to happen
What the National Autistic Society will do
How you can help

<sup>&</sup>lt;sup>1</sup> The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al. (2012) Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care.



## **Executive Summary**

Over a thousand autistic people are currently in mental health hospitals. That number has increased since March 2015, when it should have decreased. And, shockingly, the number of autistic people without an accompanying learning disability has increased by almost a quarter.

All too often this provision is inappropriate and fails to understand autism properly. As a result, many autistic people are at risk of being subject to traumatic and unnecessary restraint, seclusion and overmedication. Their families too often feel powerless to challenge people making decisions about their care, even if it's clear that their relatives are distressed and traumatised. **This is unacceptable**.

Each month, the NHS publishes information about the number of autistic people or people with a learning disability who are in inpatient mental health hospitals. It's called <u>Assuring Transformation</u><sup>2</sup> The National Autistic Society called for more information about autism within this, so we could understand better what is going on and why more autistic people are becoming stuck in hospital. This report sets out some of the findings from this new data.

We found that:

- The number of reported autistic people in mental health hospitals is increasing
- The number and proportion of young autistic people in hospitals is higher
- Autistic people are often in mental health hospitals for a long time
- Many autistic people have been flagged as not needing inpatient care anymore but are still in hospital

This appalling situation has to change. Autistic people must be free from trauma, overmedication and frequent restraint.

The NHS, locally and nationally, must prioritise:

- Making sure there are enough services in the community
- Making sure the money is available for community services
- Making sure mental health law reflects the needs of autistic people

Read on to find out more about this important issue.

<sup>&</sup>lt;sup>2</sup> NHS Digital. Assuring Transformation website.



### **Introduction**

Over a thousand autistic people are currently in mental health hospitals. All too often this provision is inappropriate and fails to understand autism properly. As a result, many autistic people are at risk of being subject to traumatic and unnecessary restraint, seclusion and overmedication.

#### This is a national scandal.

Autism is not a mental health condition. But, many children and adults on the autism spectrum in England develop mental health problems, often due to a lack of recognition of their autism and because of inappropriate support. Research suggests that more than 70% of autistic children have a mental health problem.<sup>3</sup> There is also a high prevalence of mental health problems in autistic adults. A National Autistic Society survey indicates that a third of autistic adults have developed severe mental health problems due to a lack of support.<sup>4</sup>

Without the right support for mental health problems, autistic people can fall into crisis or behave in a way that is considered challenging, meaning that they can be taken to a mental health hospital. If the right support is then not available to help someone move back to the community and close to their family and friends, they can end up 'stuck' in hospital, inappropriately – sometimes for years.

Since horrific abuse was uncovered in Winterbourne View in 2011, the Government, NHS England and others have worked to develop the Transforming Care programme, to reduce the reliance on inpatient mental health hospitals. In October 2015, NHS England published <u>Building the right support</u>, which set out its plans to reduce the number of people on the autism spectrum or with a learning disability in those hospitals by 35% to 50% by March 2019.<sup>5</sup>

But in October 2018, just a few months from the end of *Transforming Care*, 2,350 people on the autism spectrum or with a learning disability are in mental health hospitals in England.<sup>4</sup> 1,180 of them are autistic – a figure that has increased significantly since data collection began in March 2015, with the numbers of autistic people without a learning disability having increased by almost a quarter.<sup>7</sup> More than four in 10 of these autistic people (505) are under 25.

<sup>&</sup>lt;sup>3</sup> Simonoff E. et al (2008), Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample, Journal of American Academy of Child and Adolescent Psychiatry 47: 4: 921-929.

<sup>4</sup> Rosenblatt M (2008), I Exist: the message from adults with autism, The National Autistic Society.

<sup>&</sup>lt;sup>5</sup> We often say "people covered by Transforming Care" to describe this group of people, including people on the autism spectrum, with a learning disability, or both who are in an inpatient mental health hospital. There are many different types of mental health hospital, including Assessment and Treatment Units, secure hospitals, forensic units and others. The Assuring Transformation data covers all these settings.

<sup>6</sup> NHS Digital. <u>Assuring Transformation: Learning Disability Services Monthly Statistics (October 2018)</u>. Published 15 November 2018. Accessed 16 November.

<sup>&</sup>lt;sup>7</sup> NHS England analysis of the most recent Assuring Transformation data from NHS Digital, which takes account of retrospective additions to the data. Breakdowns of patient category in the NHS Digital publications are as originally reported and therefore historical data are not updated each month. This means that figures can change if commissioners identify that there were more people in earlier months. NHS England tell us that the overall figure from March 2015 has been revised to 2,885. However, this is not reflected in the publicly-available Assuring Transformation



# The Transforming Care programme has failed. And in particular it has failed autistic people.

This report will look at what is happening now. What are the key things that need to change? And what are the opportunities to finally end this scandal and how can you help? There are issues in this report that exist across the nations in the UK, however, this report focuses on the *Transforming Care* programme that exists in England.

data sets. These publications suggest that the total number of people under Transforming Care in March 2015 was 2,395. Compared with the latest publicly-available figures (October 2018) this would show an overall reduction in all people under Transforming Care of just 2%, with an increase in all people on the autism spectrum of 40%, and in autistic people without a learning disability of 85%.



## What's happening?

Each month, the NHS publishes information about the number of autistic people or people with a learning disability who are in inpatient mental health hospitals. It's called Assuring Transformation.<sup>8</sup> This means we can tell that the number of people is not going down, like it should be.

Since our Transforming Care: our stories, we have also been calling for more autismspecific data. This is important because, while we could tell that there were more and more autistic people being identified in hospitals, we couldn't tell how long they were in there for, their average age, or how many were ready to be discharged but not able to leave. We said that a lack of knowledge about autism was holding back progress on Transforming Care, which meant more autistic people were getting stuck.

NHS Digital agreed to publish this new data. It was published first three months ago with information from August.

What do the latest figures, from October 2018 tell us?

The number of identified autistic people in mental health hospitals is increasing

In March 2015, analysis by NHS England of NHS Digital Assuring Transformation data suggests that of 2,855 people covered by Transforming Care<sup>9</sup> there were 1,100 autistic people. Of those people, 655 also had a learning disability, while 440 did not. Autistic people, both with and without a learning disability, made up 38% of all people covered by Transforming Care.<sup>10</sup>

But in October 2018, of 2,350 people overall under Transforming Care, half (1,180) were on the autism spectrum. At a time when numbers are supposed to have reduced by at least 35%, they have increased for autistic people. The increase in numbers of autistic people without a learning disability is of particular concern: by almost a quarter (24%). Urgent action is needed to put the right autism-specific support in place to address this.

These data rely on commissioners reporting to the NHS. At the beginning of the Transforming Care programme, some commissioners were not properly recording autistic people. As more autistic people were identified, data from commissioners have been 'retrospectively updated' to include them.

<sup>&</sup>lt;sup>8</sup> NHS Digital. <u>Assuring Transformation</u> website.

<sup>&</sup>lt;sup>9</sup> When we say "people covered by Transforming Care", we mean people on the autism spectrum, with a learning disability, or both who are in an inpatient mental health hospital. There are many different types of mental health hospital, including Assessment and Treatment Units, secure hospitals, forensic units and others. The Assuring Transformation data covers all these settings.

<sup>&</sup>lt;sup>10</sup> NHS England analysis of the most recent Assuring Transformation data which takes account of retrospective additions to the data. NHS Digital. Assuring Transformation: Learning Disability Services Monthly Statistics (October 2018). Published 15 November 2018. Accessed 16 November. Tab 2.



	Numbers in March 2015	Numbers in October 2018	% change
No of people covered by Transforming Care <sup>11</sup>	2,885	2,350	-18%
Number of autistic people in total covered by Transforming Care	1,100	1,180	+7%
Number of autistic people without a learning disability covered by Transforming Care	440	545	+24%

However, this is not updated in the publicly-available Assuring Transformation data sets. These publications suggest that the total number of people under Transforming Care in March 2015 was 2,395. Of these people, 835 were identified as being on the autism spectrum. These would show an increase in all people on the autism spectrum of 40%, and in autistic people without a learning disability of 85%. There is an important issue here: published data sets should accurately reflect the situation, so that we and others can hold decision makers to account.

The reasons for this increase are complex. Some people think that it may show that we are getting better at identifying if a person is autistic and that sometimes this only happens after a person is admitted to hospital. However, this means that autistic people have not had their mental health or social care needs met in their community and have hit a crisis. This underlines the need for better mental health support in the community and better diagnosis services, with shorter waiting times, to make sure that people don't reach crisis. Our conversations with autistic people and their families, including in our <u>Transforming Care: our stories report</u>, highlighted this lack of services. They told us that when they needed some mental health support, it just wasn't available or didn't meet their needs.

It's vital that the right mental health support is available for autistic people in every part of England. There is an opportunity to make this happen in the NHS' upcoming Long Term Plan. You can read more about what we think needs to change below.

#### The number and proportion of young autistic people in hospitals is higher

This is new information that has only been published since September 2018.<sup>12</sup> However, the number of autistic young people in hospital is particularly concerning. Of the 1,180 autistic people under *Transforming Care*, 505 are under 25 years old. That's 43% of all identified autistic people in mental health hospitals and over 20% of all people covered by *Transforming Care*. 205 autistic people in hospitals are under 18 years old.

<sup>&</sup>lt;sup>11</sup> As shown by Assuring Transformation data.

<sup>&</sup>lt;sup>12</sup> NHS Digital. <u>Assuring Transformation: Learning Disability Services Monthly Statistics (October 2018)</u>. Published 15 November 2018. Accessed 16 November. Tab 22.



When we look at all young people under *Transforming Care*, there are 720 people under the age of 25. 70% of them are on the autism spectrum.

If we look at all children under the age of 18, there are 250 under *Transforming Care*. 205 of them – or 82% - are on the autism spectrum. There are also significant issues with getting the right support for children and young people with a learning disability and helping them to get out of hospital.

Age	Number of people who have a learning disability <sup>13</sup>	Number of autistic people without a learning disability	Number of autistic people with a learning disability
Under 18	40	175	30
18 - 24	165	125	175
25 - 34	350	115	190
35 - 44	260	60	100
45 - 54	185	50	80
55 - 64	115	15	45
65 and over	20	*	10

Autistic people of all ages experience problems getting the right mental health support, but the high proportion of young autistic people under *Transforming Care* suggests that there is a particular problem with getting the right support for children. Child and Adolescent Mental Health Services (CAMHS) need to have staff who understand autism and can adjust traditional mental health interventions to meet the needs of autistic children.

#### Autistic people are often in mental health hospitals for a long time

The average length of stay in hospital for all people covered by *Transforming Care* is almost five-and-a-half years.<sup>14</sup> Of the 1,180 identified autistic people under *Transforming Care* in October 2018, over a quarter (28%) had been in hospital for over five years.<sup>15</sup> Around 20% had been in hospital for between two and five years.

Almost two thirds of identified autistic people in mental health hospitals had been in hospital for over a year. This is also a serious concern for people with a learning disability (whether or not they are autistic too), with over half (57%) in hospital for over a year.

<sup>13</sup> Ibid.

<sup>&</sup>lt;sup>14</sup> NHS Digital. <u>Assuring Transformation: Learning Disability Services Monthly Statistics (October 2018)</u>. Published 15 November 2018. Accessed 16 November. Tab 8.

<sup>&</sup>lt;sup>15</sup> NHS Digital. <u>Assuring Transformation: Learning Disability Services Monthly Statistics (October 2018)</u>. Published 15 November 2018. Accessed 16 November. Tab 25.



Length of stay	Number of people who have a learning disability <sup>16</sup>	Number of autistic people without a learning disability	Number of autistic people with a learning disability
Up to three months	75	95	55
Three months up to six months	55	65	50
Six months up to one year	90	80	85
One year up to two years	135	85	100
Two years up to five years	260	105	130
Five years up to ten years	295	80	105
Ten years or more	220	35	105

Around 17% of autistic people under *Transforming Care* are in "acute learning disability settings" (90% of them also have a learning disability). They were more likely to have been in hospital longer. 44% had been in hospital for more than a year.

Around 18% of autistic people under *Transforming Care* are in generic mental health settings, rather than specialist or autism-specific units. The majority (83%) do not also have a learning disability. It is very important for them to be supported by staff who understand autism and the reasonable adjustments they need to make. Most (85%) of autistic people without a learning disability in generic mental health settings have been in a unit under a year. These stays may seem shorter but the data also shows that autistic people without a learning disability represent half of all admissions and re-admissions.<sup>17</sup> Admission, and a failure of community services therefore remains a big issue.

Some autistic people are in hospital because they have been 'diverted' there instead of the criminal justice system. This means that some people might have more restrictions in place meaning they can't be discharged at the moment. People in this situation tend to stay in 'forensic' hospitals. There were 460 autistic people in forensic settings in October 2018. Over a third of them had been in hospital for five years or more.

16 Ibid.

<sup>&</sup>lt;sup>17</sup> NHS Digital. <u>Assuring Transformation: Learning Disability Services Monthly Statistics (October 2018)</u>. Published 15 November 2018. Accessed 16 November. Tab 25.



# Many autistic people have been flagged as not needing inpatient care anymore but are still in hospital

Of the 2,350 people under *Transforming Care*, 665 have been identified as not needing inpatient care anymore. Over half (54%) are on the autism spectrum.

To be discharged, people need services and support in the community that will meet their needs. These needs might be very complex and require specialist support. However, we hear from autistic people and their families that too often that support isn't available.

To make sure that autistic people are not stuck in hospital, and to help current inpatients to leave hospital, these services need to be commissioned. You can read more about what we think needs to be done to make this happen below.



## Calling for change: the story so far

What we saw uncovered at Winterbourne View shocked us deeply. Soon after *Panorama's* exposé in 2011, we submitted a petition of 10,000 signatures calling for urgent action. Since then, we have worked hard to highlight the needs of autistic people throughout Government and NHS England's *Transforming Care* initiatives. This includes responding to the last Government's <u>No voice unheard</u>, <u>no right ignored</u> 'Green Paper', intervening in the landmark *Cheshire West* legal case to make sure that autistic people aren't illegally deprived of their liberty, and backing the <u>Seni's Law campaign</u> to change the law on restraint. For over a decade, we have also been calling for changes to the <u>Mental Health Act</u>.

Countless others - charities, families and individuals - have campaigned tirelessly too.

Last year we launched a report, called <u>Transforming Care: our stories</u>, with Mencap and the Challenging Behaviour Foundation, which followed 13 families over the course of a year. Each of them had a relative in a mental health hospital, at risk of admission or recently discharged. We wanted to know what helped and what got in the way of getting the right support for their loved ones to live in the community, where they wanted.

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

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

We made almost 50 recommendations to the Government, NHS England, local commissioners, the Care Quality Commission, providers and individual professionals. Since then, some things have changed and autism has risen up the agenda, being named a clinical priority in the NHS' Long Term Plan. We know more about the autistic people that are in hospitals because we have been successful in getting the NHS to publish more data, to improve transparency.

Over recent years, many individuals and families have campaigned to make *Transforming Care* work. People including Isabelle and Robin Garnett, Sally Hughes, Adele O'Hanlan and Sara Ryan have shared their loved ones' stories. These must be heard and acted on.

It's vital that all mental health staff understand autism and learning disabilities. We supported a recent <u>petition</u> from Paula McGowan, which called for a mandatory training programme for all NHS staff. The Government announced that they would do exactly that and a consultation on the content of that training will take place early in 2019. It is really important that this training gives professionals all the autism



understanding they need, and that those staff directly supporting and making decisions about autistic people have the highest levels of expertise.

Last month, we joined 61 of other organisations and 288 individuals in signing a <u>letter</u> <u>from Rightful Lives</u> to the Equality and Human Rights Commission, asking it to use its powers to open an inquiry into the system of inpatient care for autistic people and people with a learning disability.

After BBC Radio 4's File on 4, which followed the story of a young autistic woman who has been in seclusion in hospital for months, we wrote to the Health and Social Care Secretary calling on him to take urgent action. We asked him to visit a hospital unannounced to see it for himself. The Care Minister has replied on his behalf agreeing to this. She is arranging to join the Care Quality Commission on one of their inspections.

We are also supporting this <u>parliament.uk petition</u>, calling on the Government and NHS England to end the inappropriate detention of autistic people and people with a learning disability in hospital. **Please, sign this petition and share it with your friends and families.** 

But there are still too many people on the autism spectrum or with a learning disability who are stuck in mental health hospitals. Too often, the support they get is inappropriate and there is too much reliance on restraint, seclusion and medication. The impact on autistic people and their families is profound, long lasting and the trauma can last a very long time.

This has to change.



## What needs to happen

This national scandal has to end. The abuse uncovered at Winterbourne View led to a recognition that too many people with a learning disability or on the autism spectrum were in mental health hospitals and a national plan (in *Building the right support*) to change that.

But, in the development of Transforming Care, not enough attention was paid to the needs of autistic people. Autism was not central to plans as it should have been. We raised this as *Building the right support* was being developed and following that. For example, while Care and Treatment Reviews (CTRs) were introduced to help work towards discharging someone from hospital, they didn't meet the needs of autistic people. This meant that the right things weren't considered, such as the need for autism-specific support. The guidance for CTRs was changed to include autism better.

However, this alone won't change the situation. CTRs can't help people out of hospitals if there are not the services in the community to meet their needs.

A lot needs to change. NHS England must now take the opportunity to reaffirm its commitment to the programme and reducing reliance on mental health hospitals - and recognise that autistic people are being seriously impacted by the failures of the Transforming Care programme.

The Government needs to make sure that progress is being made on this new programme. This needs several different departments to work together. We believe that the Health and Social Care Secretary needs to chair a new cross-governmental group of all the relevant ministers to make this happen.

In our <u>Transforming Care: our stories</u> report, we set out nearly 50 recommendations. These are as important today as they were a year ago when we made them. We call on the Government, NHS, providers, regulators and all those named in the report to take those recommendations forward.

There are three issues that are fundamental. We believe that there are opportunities for each of these, and we call on the Government and NHS England to grasp those opportunities.

#### 1) Make sure there are enough services in the community

As this new data highlights, and the stories of the families in *Transforming Care: our* stories show, there are not enough services in the community to meet the needs of autistic people. This means autistic people develop more significant needs and often mental health problems like anxiety or depression. Without mental health support that understands autism, many people reach crisis point. At that point, there is currently not enough support available other than being admitted to hospital.



Services are needed at five critical points:

- **Preventative services**. These are often called "low-level" services and can include things like social groups and buddying or befriending. These are vital for autistic people to reduce isolation, improve wellbeing and stop them developing more significant needs.
- General mental health support. This means services to help autistic people maintain good mental health, and address any problems early on.
- Crisis support in the community. If earlier help doesn't work or circumstances become much worse, these are services to provide urgent and specialist help.
- Services to move out of hospital into. If autistic people do end up in hospital, they need services that can meet their needs in the community so that you can be discharged. This could involve social care, housing and mental health, as well as other services like speech and language therapy.
- Advice and support for families to get their relatives out. Families tell us that they need direct casework support, helping to make sure that all the right things are happening to get their relative out of hospital. Some great services exist for people with a learning disability and they help many people, but there isn't a casework service that works across the autism spectrum.

Sometimes even autism-specific services, like our own, might not have all the resources they need to support someone with very complex needs. Without commissioners stepping in to create options in the community, too many autistic people are admitted to hospital because there's no other option. This has to change: commissioners need to make sure that they are living up to their responsibilities to commission and fund services to meet the needs of people in their area.

NHS England is producing its Long Term Plan. This will be its strategy for the NHS for the next 10 years. Autism and learning disability are a 'clinical priority' in the plan, which is an opportunity to make better progress on *Transforming Care*:

- We believe the NHS should set up specialist autism teams in every area. These teams would run diagnostic services and support some people directly, as well as training and working with other services in the area to make sure they have the autism training and expertise that they need.
- Specialist autism teams will be key to preventing many admissions. However, we also hear that services are not available in the community to support autistic people when they are discharged from hospital. To address this, we believe NHS England should also establish an autism-specific commissioning support team, to help local commissioners make sure they have all the services they need.
- All health and care services need to be staffed by professionals who understand autism. They must know how to communicate with, support and make reasonable adjustments for autistic people, in line with the Autism Act statutory guidance.



### 2) Make sure the money is available for community services

Many people have raised concerns that a lot of NHS money is used to fund inpatient care that is inappropriate, often from private providers. Disincentives still exist that stop this from changing.

There are two issues with funding that holds back Transforming Care:

- When someone is admitted to hospital, the NHS pays for their care. When they are discharged, the council will often need to pay. That means there is a disincentive to discharge someone.
- Linked to the above, the lack of funding for social care services means that councils don't have enough money and may struggle to fund new services. Latest estimates put the black hole in adult social care funding at £1.5 billion by 2020-21.

However, we know that the right support in the community costs much less than mental health hospitals. NHS England, as part of its Long Term Plan, needs to make sure that its own money for community support, such as Continuing Health Care funding and extra money that should be available for people who have been in hospital for five years or more (called a "dowry") is properly used to benefit autistic people.

The National Autistic Society is part of the <u>Care and Support Alliance</u>, a coalition of over 80 of Britain's leading charities, campaigning alongside the millions of older people, disabled people and their carers who deserve decent care. We believe that the Government must tackle the social care funding crisis in its 'Green Paper' that will be published in the next few months.

We also believe that the financial disincentive to discharge people must be tackled. This will require health and social care commissioners pooling their resources and agreeing to spend them together to meet the needs of autistic people and people with a learning disability.

#### 3) Make sure mental health law reflects the needs of autistic people

The overwhelming majority (90%) of people under Transforming Care are detained in hospital under the Mental Health Act 1983. This Act defines autism as a "mental disorder", meaning that autistic people can be 'sectioned' because of their autism – despite the fact that autism is **not** a mental health condition. We are concerned that this makes it even less likely that commissioners will develop community services, as people can be admitted to hospital. This is wrong and we have been calling for it to change for many years. We explain more about this in this <u>video and blog on our</u> <u>website</u>.

There is an independent review of the Mental Health Act being led by a psychiatrist, Simon Wessely. **We recommended to him that a change should be made to the definition of mental disorder**. We strongly believe the Government should look at the definition of mental disorder as it considers its response to the Review.



## What the National Autistic Society will do

We will carry on campaigning in Parliament, with Government and in the media for better mental health support and less reliance on mental health hospitals for autistic people. This means, in particular:

- Calling on the Health and Social Care Secretary to visit a hospital. We wrote to Matt Hancock, the Health and Social Care Secretary, to ask him to visit a mental health hospital unannounced. Care Minister, Caroline Dinenage MP, replied on his behalf agreeing to this. She is arranging to join the Care Quality Commission on one of their inspections. We also think the Health and Care Secretary should visit some people who have left hospital, who are living in the community, to see how much better their care and support is there.
- Campaigning for an NHS Long Term Plan that really meets the needs of autistic people. We have been raising the unacceptable health inequality, including in mental health, faced by autistic people with the Government and NHS England, alongside many others. And now autism has been announced as a clinical priority in the NHS' upcoming Long Term Plan. We organised consultations with autistic people and family members and called on NHS England to reduce reliance on inpatient units, strengthen mental health support and improve diagnosis. The plan will be published next month and we will be watching for these things to be included. Once it is published, we will know where we need to campaign more.
- Calling for Government accountability for a new Transforming Care programme that works. We think it's vital that the Health and Social Care Secretary and other Government Ministers are accountable for making sure Transforming Care (or any subsequent programme) works. We will be calling for a Cross-Government Ministerial Group to do this, to make sure that all the right departments are involved.
- Campaigning for changes to the law on mental health. The Independent Review of the Mental Health Act reported on 6 December. We called for it to address the legal issues that mean autistic people are too easily detained, and to improve rights to advocacy and challenge decisions. We submitted important evidence and met with the psychiatrist leading the Review to make these points. While the Review hasn't recommended this specific change, it has told the Government to keep it under review. We believe the Government must finally tackle this fundamental issue and will push for the definition to be reviewed urgently.
- Pushing for all NHS staff to understand autism. Training and understanding is key for all health professionals. We campaigned for statutory training duties in the Autism Act, but we know that these have not been properly implemented. We supported Paula McGowan's petition for a mandatory training programme and were delighted with its success. A consultation is being launched by the Government in early 2019, which we will promote widely to make sure autistic people have their say. Alongside the All Party Parliamentary Group on Autism, we will be holding an inquiry into the Autism Act to see what has worked and what needs to be implemented better. This year-long project will be a great opportunity to push for better support for autistic people in all



aspects of their life, including mental health, housing and social care. These are all important parts of Transforming Care too.

- Campaigning to end the social care funding crisis. As part of the <u>Care and</u> <u>Support Alliance</u>, we have been campaigning to close the black hole in adult social care funding. This funding is vital to providing care and support for autistic people in the community, either to support them out of hospital or to stop them being admitted. As a result of this campaigning, future funding for working age adults' care will be included in the Government's upcoming Green Paper. We'll keep pushing for this to bring about the money that is needed. We also campaign as part of the <u>Disabled Children's Partnership</u> to increase funding for children's social care, in particular short breaks services, which are crucial to making sure that families and young autistic people get the support they need and avoid being admitted to a mental health hospital.
- Calling for an autism and education strategy. For many children and young people on the autism spectrum, problems begin with not getting the right support at school. Our <u>Held Back</u> campaign and report outlined the many failings in support across the country for autistic children. We believe, to make sure there is the right teacher training and the right kind of schools in every area, there should be a national autism and education strategy. We are currently raising this with the Education Select Committee and you can read more about our recent work here.

We'll continue to lobby Government, meet with MPs, raise these issues in the media whenever we can, and work with our branches across the country more widely too.

Beyond our campaigning, we want to set up a service to give direct case support to families with relatives in, or at risk of being admitted to, mental health hospitals.



## How you can help

There are two simple ways that you can help:

#### 1) Sign this parliament.uk petition

Sign <u>this petition</u> on the Parliament website. If it gets to 100,000 signatures, it will be debated by MPs, which would help make sure that the Government get to hear this incredibly important issue.

Watch our Director of External Affairs and Social Change, Jane Harris, explain more in this <u>video</u>. **Please**, **sign the petition and share it with your friends and families**.

#### 2) Share our information pages

When autistic people hit crisis, they need support from people around them. This is a really difficult time and finding out all the information that you need can feel impossible. We have worked with families with lived experience to <u>update our website</u> with crucial information. Please share this page with anyone you think might find it helpful.

We are also hoping to establish a service to support people and families in this situation. We will put more information about this on our website when we have it.

