

# *Transforming Care: our stories*

Tim Nicholls, Policy Manager, The National Autistic Society

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# What *Transforming Care* is trying to do – a timeline



- 2011 – abuse uncovered in Winterbourne View
- 2012 – The Department of Health review into Winterbourne View: *Transforming Care* and *Winterbourne View Concordat* outline proposal to move people into communities (end inappropriate placements by June 2014)
- Nov 2014 – *Winterbourne View: A Time to Change* report by Stephen Bubb criticises slow progress and made recommendations
- Jan 2015 - *Winterbourne View: Transforming Care Two Years On* DH and partners (e.g. ADASS) report on progress
- Jan 2015 – *Transforming Care: Next Steps* report from NHS England and partners on their proposals

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# What *Transforming Care* is trying to do – a timeline (cont'd)



- Feb 2015 – Simon Stevens said that residential hospitals for people with learning disabilities will close “in the next 12 - 24 months”
- Mar 2015 – DH publishes *No voice unheard, no right ignored*
- October 2015 – NHS England publishes *Building the right support*, the national plan to reduce the number of inpatient beds by up to 50% by March 2019. It formed 48 Transforming Care Partnerships
- At the same time, a Service Model gave guidance on the services needed in each area

**So, where have we got to?**

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# How many people?



## March 2015

People with a learning disability only	1,470
People on the autism spectrum only	295
People on the autism spectrum with a learning disability	540

## March 2016

People with a learning disability only	1,520
People on the autism spectrum only	435
People on the autism spectrum with a learning disability	560

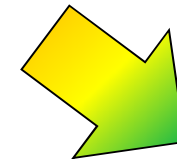
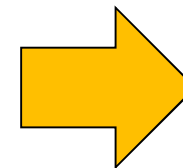
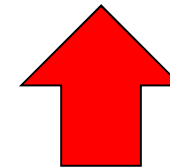
## March 2017

People with a learning disability only	1,395
People on the autism spectrum only	455
People on the autism spectrum with a learning disability	570

## December 2017

People with a learning disability only	1265
People on the autism spectrum only	515
People on the autism spectrum with a learning disability	600

OVERALL



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But...



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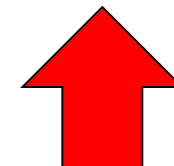
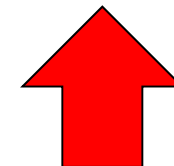
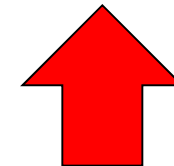
March 2017

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July 2017

People with a learning disability only	1,265
People on the autism spectrum only	515
People on the autism spectrum with a learning disability	600

Autistic people



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# What is happening?

- Too many people are in inpatient units, for too long, too far from home and their communities and families.
- We know this from the data. Assuring Transformation puts the average stay at over 1,000 days (December 2017).
- But we wanted to find out more about the stories, experiences and people behind the figures.

Working with Mencap The Challenging Behaviour Foundation, we interviewed **13 families** of people in, or at risk of admission into, inpatient care. We interviewed them **three times over a year** to find out what progress they were making, or what obstacles they faced.

Their stories informed our calls.

This is what they told us...



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# Making sure the right services are available in the community



“It’s left up to families to find out about sources of support and alternative providers when existing services are not suitable.”

*Sally, Maisie’s mum*

“The assessments themselves are fine. They cover all his needs including challenging behaviour, but the support listed in them never materialises.”

*Diane, Ollie’s mum. Because there were no available services, she handed £35,000 back to her local authority.*

“Every one of my requests for residential schools was turned down because [the LA] 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.”

*Jane, Laura’s mum.*

- Preventing discharge depends on having the right services in place.
- Using all the right data locally (including CTRs)
- Sufficiency duties?
- Making sure a variety of housing options are available and funded.

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# Being heard and being involved



- At least three of the families we spoke to had to launch national campaigns.
- Getting decision makers together is a big issue.
- Many families felt “lucky” to get senior people involved.
- Advocacy is patchy and too often doesn’t understand autism and/or learning disability.
- Families felt excluded from important decisions (particularly medication – more later).

“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?”

*David, Stephen’s dad*

[Shahana] 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.

*Interviews with Shahana, Fauzia’s aunt*

Recommendations made at Matthew’s Care and Treatment Review were not followed. Meanwhile he wasn’t getting an education, fresh air or exercise. The whole family felt powerless.

*Interviews with Isabelle, Matthew’s mum*

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# Inconsistent care quality



“I am concerned that none of the drugs seem to be beneficial to Kamau... 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.”

*Lorna, Kamau's mum*

“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... Everything is about seclusion, never about trying to prevent incidents in the first place.”

*Anna, Catherine's mum*

“A very vulnerable young man suffered a sequence of traumatic experiences which may adversely affect him for many years.”

*Quote from serious case review of Aaron's care*

- Overuse of medication, which has serious side effects.
- Too little reliance on behavioural approaches.
- Overuse of restraint and seclusion.
- Is the use of restraint being recorded and regulated properly?
- Not meeting other health and wellbeing needs.

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# Making plans for discharge from hospital and sticking to them



- Planning for hospital discharge doesn't start early enough – none started prior to admission.
- Plans to discharge someone are not progressed.
- CTRs aren't acted on.
- The right/senior enough people aren't involved in CTRs.
- People don't have the rights they need to make progress happen.

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.”... The last time we spoke to Roger, Michael still hadn't moved, despite having been cleared for discharge for seven months.

*Interviews with Roger, Michael's dad*

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.

*Interviews with Adele, Eddie's mum*

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# Specialist support and understanding



“I wanted to think she was in the right place but now I’m not even sure if they’re coping... 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.”

*Mark, Helen’s dad*

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...”

“There is very little support for young adults with autism and behavioural difficulties, rather than a learning disability.”

*Interviews with Karen, Rebecca’s mum*

- Understanding a person’s needs (particularly if those needs are complex) is crucial.
- Poor understanding leads to mistakes and misinterpretations of behaviour.
- Commissioners need to use their power to ensure training is happening, and recorded.
- 10 of our 13 families particularly highlighted poor understanding of autism (particularly if their relative does not have a learning disability as well).

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# Our recommendations



- There are many things that need to change to make *Transforming Care* work for everyone.
- These cover Government, NHS England, local commissioners, regulators (CQC), providers, and professionals.
- Our report details 43 things that we think that these bodies should take forward.

But, our six key priorities are...



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# Six overarching recommendations



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

NHS England must commission more specialist community based services and closely scrutinise individual plans for discharge to make sure they're acted on

Local health and social care commissioners must commission community support and inpatient services in line with the Service Model

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

The CQC must robustly inspect inpatient services in line with the principles of *Transforming Care* and ensure they only register services in line with it.

Professionals must listen to individuals and their families and ensure their voices are at the centre of decisions about their care and support.

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# Any questions?



You can find out more and read the report at:

[www.autism.org.uk/ourstories](http://www.autism.org.uk/ourstories)

If you have any other questions, please email [policy@nas.org.uk](mailto:policy@nas.org.uk).

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