

Making it happen

Take action to get people with a learning disability, autism and/or challenging behaviour out of inpatient units

A guide for campaigners about
Transforming Care Partnerships



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Foreword



We are a group of families who have loved ones with a learning disability, autism and/or challenging behaviour. Our daughters, brothers, sisters and sons have been stuck in inpatient units, sometimes for years, because of a lack of appropriate support in the community.

We've seen the damage inflicted on the people we love. The solitary confinement, over-medication and physical restraints. Many of us have had to fight for our loved ones to live fulfilling, safe lives in the community, many others of us are still fighting.

This is a national disgrace, and it's still going on every day. Some of our family members have left inpatient units, but many remain inside.

For us, it's urgent.

This guide, 'Making it Happen', is for campaigners who want to make sure things change for people with a learning disability, autism and/or challenging behaviour. The new Transforming Care Partnerships are a real opportunity we need to use to achieve change locally, but we can't do this alone. We need campaigners like you to support us by taking action. As parents, we call on you to help us hold NHS England and local areas to account, through the new Transforming Care Partnerships. Promises have been made and they must be delivered.

Getting people out of units is only one part of the issue. Support must be provided to stop people going into units, and a good life must be made possible in the community. This guide was written to give you some practical things to do to make change happen. It's time we got our loved ones home.

Thank you.

David and Jill, Debbie, Shirley, Phill, Ann, Nina, Lynn, Luke, Jill and Lawrence, Paula, Sue, Leo, Helen, Jane, Wendy, Emma, Claire, Lisa, Steve, Shahana

Who is this guide for?



This guide is aimed at local groups, including local Mencap groups, National Autistic Society branches, self-advocacy groups and carers groups. Individuals could use it too.

It is for anyone who wants to know what they can do to campaign for people with a learning disability, autism and/or challenging behaviour to get out of inpatient units now that the Transforming Care Partnerships have been set up.

You may want to work together with other local people and groups. Contact the organisations at the end of this guide to find local groups near you.

The challenge



Thousands of people with a learning disability, autism and/or challenging behaviour¹ are currently stuck in inpatient units, because they can't get the support they need in the community.

This is a huge failure of our care system today.

Most people will never need to be in a unit, those who do should never be there for a long time. But the average length of stay is over five years, with the average cost per week around £3,500. Children and young people are among those being detained, often hundreds of miles from home.

Shocking abuse has been uncovered, for example, at Winterbourne View in 2011. Eleven staff from Winterbourne View were convicted of serious neglect and ill treatment and six were jailed when a journalist showed what was going on behind closed doors.

Some people have died in these places.

It's urgent that people with a learning disability, autism and/or challenging behaviour are cared for safely in the community, and we must make sure NHS England's plans become a reality.

¹ This guide is about children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. But in this guide we have used shortened terminology throughout.

Ann's story



When my son Simon was 18, he was living in a small care home near to our house and was a well-known and loved part of the community. But social services would not fund the level of support he needed, so things got worse and worse for Simon and he was sent to an Assessment and Treatment Unit, which is a type of inpatient unit.

The staff there didn't understand him and said he was dangerous. They were physically restraining him numerous times a day. He had never been restrained before, and his behaviour deteriorated quickly. This was when he was sectioned and sent to Winterbourne View, another Assessment and Treatment Unit.

Simon spent 15 months in Winterbourne View where he suffered abuse and neglect that BBC's Panorama programme exposed.

After this ordeal, his old home welcomed him back with open arms and Simon was able to return to the community he loved. It was an unbelievably happy occasion.

However, when Simon came home his behaviour was different. He was visibly more stressed and frustrated. I don't see how sending someone with Simon's needs away to a unit can ever be justified. There is not even a 'money' argument – Simon's package of care now costs about half as much as it did for him to be in Winterbourne View.

We worked with the care home and Simon got his own flat attached to the home where he could have his own space and the support he needs. Simon is now safe and living a full life, which is wonderful for me to see.

What has been promised?



After many years of work by campaigners, NHS England published a plan in October 2015 for getting people out of units and into the community. Their plan, 'Building the Right Support', says that 35-50% of all inpatient beds will close across the country, and the right support will be developed in local communities, by March 2019.

48 Transforming Care Partnerships have been set up to make this happen, and time is ticking.

What is a Transforming Care Partnership?

The partnerships are made up of people from the local Clinical Commissioning Groups (local health), NHS England (national health) and the local authority (social care). There is a Senior Responsible Officer in charge.

It is essential that each partnership also involves people with autism, learning disabilities and/or challenging behaviour and families who have lived experience of inpatient units.

To make sure 35-50% of inpatient beds close across the country by March 2019, each local partnership was asked to write a plan by July 2016. These plans explain how they will build and deliver the right community support so that people can move out of units and into their local community.

NHS England has made some money available to help ensure these plans become a reality.

How can we be sure that the type of care people receive will be better?

A 'Service Model' has been written which focuses on personalisation and well-being, in line with the Children and Families Act and the Care Act.

This must be used as a guide for commissioners who are building the right community support for people with a learning disability, autism and/or behaviour that challenges.

You can find the nine principles of the Service Model on Page 11 of this guide.

Who is in charge of making change happen?

NHS England is the organisation which holds overall responsibility for making sure the Transforming Care Partnerships are working properly.

Each Transforming Care Partnership has a Senior Responsible Officer who is in charge. You can find the contact details for the Senior Responsible Officers here: www.england.nhs.uk/learningdisabilities/tcp/

Take action in your area



Pressure from local campaigners is what helps bring about change. The next few years are important, as Transforming Care Partnerships work to build the right support in the community.

There are lots of ways you can put pressure on your local Transforming Care Partnership and help make a difference to other families, fighting to bring their loved ones home.

Here are a few options.

1. Make contact with your local Transforming Care Partnership

Get in touch with the Senior Responsible Officer by email or letter. You can find their contact details on the NHS England website here:

www.england.nhs.uk/learningdisabilities/tcp/

You could send the template letter on page 10 which will help you ask for a copy of the plans for your area and find out what new support and services are being planned.

2. Check your plans

If you have, or are sent a plan for your area, use the Checklist on page 11 to check how strong the plan is and whether there is anything missing. Write back and explain what you think it should include.

3. Get involved in delivering your local plan

As well as contacting your Transforming Care Partnership to check progress, you might want to ask how you can help them with delivering their plan. They should be interested in hearing from anyone who is, or has been, directly affected by the use of inpatient units. If you are interested in working with your Transforming Care Partnership you could add the extra section on page 10 to your letter.

4. Work together

Work with the regional self-advocacy and family forums to check progress on your local plan as a group. You can find out more about your local forum contacts here:

www.nationalforums.co.uk

You could also work with the Learning Disability Partnership Board, the Autism Partnership Board, the Health and Well-being Board, your MP or local councillors. You can find their details on your local council website. If campaigners work together, we can keep track of what is happening across the 48 Transforming Care Partnerships around the country.

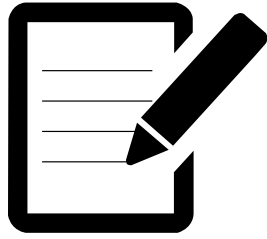
5. Ask the right questions

The 'Hospitals are not homes' booklet by the National Valuing Families Forum and the National Forum of People with Learning Disabilities has lots of questions you could ask to check progress. The booklet is in Easy Read. You can read it here:

www.inclusionnorth.org/uploads/attachment/737/hospitals-are-not-homes-easyread.pdf

Remember, we'd love to hear what you are doing. Tell us how you are engaging with the plan in your area, and what you find out about progress. You can do this by making contact with us using the contact details on page 12.

Template letter



Here is a suggestion for what to say when asking for an update from the Senior Responsible Officer of your local Transforming Care Partnership. If you are happy to, please add any personal experience, for example you may be a family member or carer for someone with a learning disability, autism and/or challenging behaviour. Say why this issue matters to you.

Dear Sir/Madam

My name is [name] and I live in [X]. I am writing to you as the Senior Responsible Officer for my local Transforming Care Partnership.

I have been following closely as NHS England plans have developed for getting people out of inpatient units. Now the Transforming Care Partnerships have been formed, we have an opportunity to make sure plans in our area deliver the best possible outcomes for people with learning disabilities, autism and/or challenging behaviour.

I understand that our local partnership should by now have written a detailed plan to ensure that children, young people and adults receive the right support locally when they need it, support to come out of inpatient units and stay out of them, and have the help they need to live in the community near their loved ones.

Please could you:

- **Share your plan with me**
- **Send me an update on what new support and services are being developed in my area**
- **Inform me of how many people from this area are currently in inpatient units**

Yours faithfully

[Name] [Address]

Add the following paragraph if you would like to use your experience to contribute to the work of the Transforming Care Partnership.

I am directly affected by the use of inpatient units and wish to use my personal experiences to support you in your work.

I would therefore be grateful if you could tell me how I can become more involved in ensuring the effective delivery of the plan in this area. I believe that my input will be valuable to you.

Checklist



Look at the plans written by your Transforming Care Partnership. What support and services are in place now in your local community? How much of the checklist below would you tick, if you were one of the individuals affected by the plan?

Here are the 9 principles of the new NHS England Service Model which sets out what 'good' looks like:

- I have a good and meaningful everyday life
- My care and support is person-centred, planned, proactive and coordinated
- I have choice and control over how my health and care needs are met
- My family and paid support and care staff get the help they need to support me to live in the community
- I have choice about where I live and who I live with
- I get good care and support from mainstream health services
- I can access specialist health and social care support in the community
- If I need it, I get support to stay out of trouble
- If I am admitted for assessment and treatment in a hospital setting because my health needs can't be met in the community, it is high quality and I don't stay there longer than I need to.

If there are any boxes above that you can't tick, ask your Transforming Care Partnership what they are doing to make sure the right support and services are in place.

Tell them what support and services you think need to be put in place.

Further support

We know campaigning for change isn't easy. If you need help or advice along the way please get in touch. And whatever information you get from your Transforming Care Partnership, please let us know. It's really helpful for us to know who is getting involved. **Thank you.**

Mencap

Contact your local Campaigns Officer for support, using the contact details listed here:
www.mencap.org.uk/get-involved/campaigning/campaign-locally

Contact our helpline for advice and information about anything related to learning disability.
Email helpline@mencap.org.uk or call **0808 808 1111**

Challenging Behaviour Foundation

For information and support for families caring for children and adults with severe learning disabilities whose behaviours challenge please visit www.challengingbehaviour.org.uk, call **0300 666 0126** or email support@theCBF.org.uk

For more information about our campaigning and influencing work please email drivingchange@theCBF.org.uk

The National Autistic Society

Contact the Campaigns Team at campaign@nas.org.uk and please refer to this guide or Transforming Care when contacting us.

Visit <http://www.autism.org.uk/get-involved/campaign/england.aspx> for more information.

