

GET INVOLVED



WORKING TOGETHER TO TRANSFORM CARE

**DELIVERING GOOD OUTCOMES
FOR PEOPLE WITH A LEARNING DISABILITY**

TIME FOR A BETTER WAY OF WORKING

The Winterbourne View scandal was exposed more than 12 years ago. Despite many promises to bring about change, progress by the government, the NHS and local authorities has been too slow. As a result thousands of people with a learning disability and autistic people have been – and continue to be – traumatised by spending time in mental health inpatient units when they do not need to be there.

The experiences of people affected have not been acted upon, and lessons from previous failures have not been learned. We want to change that.

For years, people, groups, and organisations have been working and campaigning to uphold the rights of people with a learning disability and ensure people get the right support.

“It is time for a co-ordinated, sustained and resourced re-think”

² Dr Margaret Flynn, Dame Christine Lenehan, Dr Sheila Fish



WORKING TOGETHER TO MAKE A DIFFERENCE

Last year, a group of families with lived experience of their loved ones being in mental health inpatient units came together to think about what key principles, themes and actions need to be in place to ensure people with a learning disability can get the right support, in the right place, at the right time. This work has been built on by many others sharing their views, experiences and expertise, including people with a learning disability, other families and people working throughout the system. This has been coordinated through the Challenging Behaviour National Strategy Group (CBNSG).

This document summarises the co-produced principles and themes that have come out of this work so far, to transform care and deliver the right support for people with a learning disability, throughout their lives. Work is now underway to develop the specific actions needed, and to get this right, people from all across the system will need to work together.



“You have to get to crisis before anything gets done”,
Les and Elaine Bonner, family carers.

“I believe lifelong approaches are really important for people with learning disabilities and autism because we should have our lives valued just like anyone else.

It is about everyone working together to support people to have a good life and to live longer.”

Scott Watkin BEM, Head of Engagement at SeeAbility

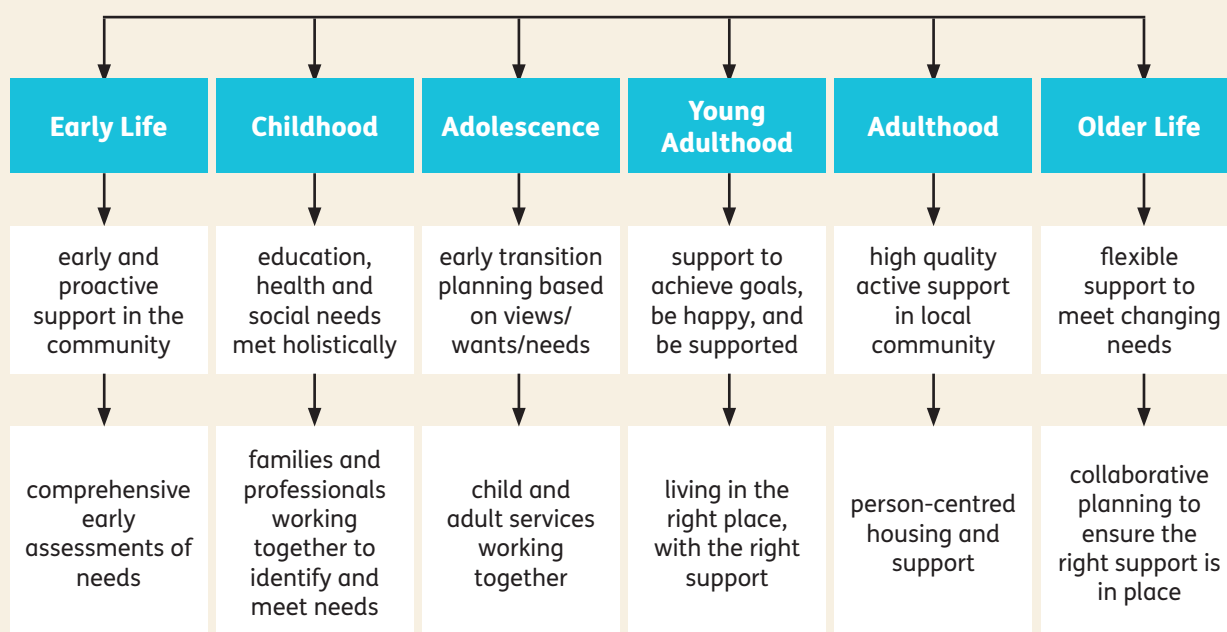
A LIFELONG APPROACH

The only approach that will work is one that meets the needs of children, young people and adults with a learning disability, throughout their lifespan, from early childhood to older age.

Principles that all parts of the system should uphold:

Support	Accountability	Honesty	Valuing families
Rights	Safeguarding	Respect	Person-centred

What needs to happen at each stage of life



What needs to be in place to make that happen:

Mechanisms		
Flexible funding	Pooled budgets	(Independent) Care, Education and Treatment Reviews
Multi-disciplinary teams	Intensive support teams	Dynamic support registers

Consistent approaches	
Comprehensive assessments	Specialist, individualised support
Adequate funding	Integrated and collaborative working

RESPONDING TO CHANGING NEEDS

The focus must be on early intervention to prevent needs escalating, crises, and inappropriate admission to inpatient mental health settings. But the system also needs to be flexible and able to respond quickly if needs change. Good community support will both stop children, young people and adults being inappropriately admitted or re-admitted to inpatient units, and enable people who are inappropriately detained to be discharged.



TO BE EFFECTIVE, ANY PLAN TO TRANSFORM CARE SHOULD...

<p>Focus on delivering good outcomes for children, young people and adults with a learning disability who may also be autistic</p>	<p>Be co-produced – all stakeholders inputting ideas, experience and solutions</p>	<p>Be based on the belief that more can be achieved by working together</p>
<p>Ensure people with lived experience are central to the plan</p>	<p>Take a lifelong approach, the right support in the right place at the right time</p>	<p>Acknowledge the need for all parts of “the system” to work together in a coordinated way</p>
<p>Include and reflect the need for concurrent and complementary work to take place in different parts of the system by different stakeholders</p>	<p>Consist of focused outcomes with SMART (Specific, Measurable, Achievable, Realistic, Timebound) targets</p>	<p>Provide a process and mechanism for accountability</p>
<p>Include and build on the good work that individuals and organisations are already doing – and align with existing good practice guidance and initiatives</p>	<p>Link to any initiatives/ funding opportunities that fit with the plan</p>	<p>Be regularly reviewed and adapted, with progress monitored and evaluated</p>

WORKING TOGETHER TO DRIVE CHANGE

We believe that the only way to get the change we all want to see is by everyone involved working together. We need to build on what we all know works, and start taking action that delivers good outcomes for people with a learning disability.

Between us all, we have the experience, expertise and influence to create the change needed for people with learning disabilities to have the right support, in the right place, at the right time. Working together, we can make this happen.



Scan to find
out more

BE PART OF MAKING IT HAPPEN

Find out more about the work done so far and next steps by visiting
www.challengingbehaviour.org.uk/action-plan

Email actionplan@thecbf.org.uk to get involved

“It’s going to be a struggle but the struggle’s worth it. And actually, the evidence from other countries is that the struggle works – if we can organise families and professionals and user organisations together, we can take this on.”

Professor Jim Mansell CBE

“Working together we can drive this change – to really make a difference and deliver the positive outcomes we all want to see.”

Family Carers¹

This lifelong plan is being co-developed to deliver good outcomes for children, young people and adults with a learning disability, who may also be autistic, and their families. The Department of Health and Social Care ‘Building the Right Support’ action plan covers a wider population, including autistic people who do not also have a learning disability. The principles and actions in the lifelong co-produced plan may align with ideas or solutions that autistic people or organisations who work with them also call for.

1 www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/brokencbffinalreportstrand1jan21.pdf

2 <https://www.norfolksafeguardingadultsboard.info/about-us/an-overview-of-safeguarding-adults-reviews-sars/coalition-for-change/>