

The Challenging Behaviour Foundation

Plan 2026-2029

Easy Read Summary

Who we are here to support



The Challenging Behaviour Foundation is a charity that works in England, Northern Ireland, Wales and Scotland



We support families of children, young people and adults with severe learning disabilities.



People with severe learning disabilities might show behaviour that is called challenging as a way to communicate what they need.



30,000 people or more with severe learning disabilities in the UK might behave in ways that are called challenging.



People with severe learning disabilities don't speak or speak a little bit.



People might take longer to learn new skills.



People need support with things like getting dressed, washing, eating or staying safe.



People need support for their whole lives.



When support is not right or something is wrong or needed some people hurt themselves,



hurt other people,



run away,



or eat things they should not eat.



People call this “challenging”.



The person isn't challenging, their behaviour is.



It might be how they tell people they are in pain,



or upset



or that they need something.



If someone doesn't speak, it is our job to try to understand them.



Too many people get scared or punish people with challenging behaviour.



Instead, they should work out what it means.



People with challenging behaviour might be stopped from doing the things they want to do.



Their family carers might not get enough help. This might lead to bad physical and mental health.



They might have to support their family member with things services should provide



This doesn't have to happen, if people get the right support from the Council and the NHS

Why we started and what we learnt



The Challenging Behaviour Foundation was started in 1997 by a family carer.



They wanted people to understand why people show behaviours that are called challenging and how to support them better.



Family carers are good advocates for people with severe learning disabilities.



But they are often ignored or blamed.



Family carers who contact the Challenging Behaviour Foundation are often in crisis.



Sometimes professionals tell them they can't look after the person they care for.



Sometimes the person they care for is in a mental health hospital.



They might be abused or neglected.



We support families when this happens.



We try to change policies so this doesn't happen again.



We have learnt that families need more support at certain times:



- When the person who needs support is a young child



- When they become adults



- When their family carers are getting older and are worried about the person's care after their death

What are things like now?



We want people who have behaviour that challenges, and their families to be properly supported, so they don't need us anymore.



There is a long way to go for this to happen for everyone.



Lots of organisations who support people with severe learning disabilities and their families are closing down.



Local community teams in some places say they can't help people with behaviour that is seen as challenging.



Services are not funded properly so families have to support people more.



This puts a lot of pressure on families and many are in crisis.



Some services are making their policies better but they might not be working with other services to do this.

Big ideas



There are two big ideas that run through everything we do.

1. Co-production



We include families of people with behaviour that challenges every time we do something.



For example, family carers run our training workshops with professionals



We have been working on ways to listen to views of people with severe learning disabilities who might have behaviour that challenges.



We think we have a good way of doing this.



We think other professionals should get the views of people they support and their families as much as they can.



This sometimes doesn't happen because professionals think it is too difficult.

2. Partnership working



We bring together family carers and experts.



We think this is the best way to learn from each other and come up with good ideas.



We have a group called the Challenging Behaviour National Strategy Group.

The group has family carers, people with learning disabilities, researchers, policy makers, professionals and care managers.



We work with other charities, self-advocates and researchers who want the same things we do.



Sometimes working with other people takes longer but we think it's important.

Our Goals

Goal 1:

What we want:



- We want families of people with behaviour that challenges to have information and support they need, when they need it



- We want people to know what rights they have and how to get them.

What we will do:



- We will use our Family Support Service to give information and support to families



- We will help families find our support when they need us



- We will help family carers support each other with emails and phone calls



- We will help family carers support each other on our podcasts



- We will keep information documents up to date and make new ones

Goal 2

What we want

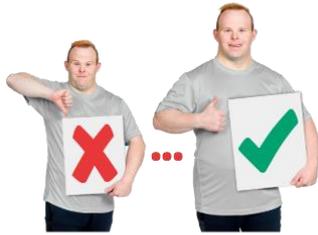


- We want families, professionals and staff to understand why people have behaviour that challenges.



- We want them to understand how to help people with behaviour that challenges to have a good life.

What we will do:



- We will use our Forward Together project to make services better in Kent and Medway, Manchester and Salford and Birmingham and the Black Country



- We will work with researchers to make good research and share the results



- We will give training workshops



- We will use our What Matters To Me project to show people how to find out what matters to people with severe learning disabilities

Goal 3

What we want:

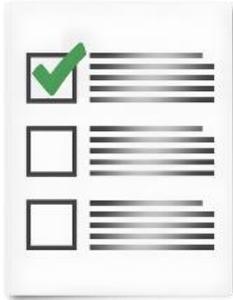


- We want decision makers to work with people who have severe learning disabilities.

What we will do:



- We will make sure the Challenging Behaviour National Strategy Group has the right members



- We will hold meetings that focus on getting things done



- We will keep working on our focus groups that run different projects



- We will campaign for policies to be written with people with severe learning disabilities and their families

Goal 4

What we want:



- We want The Challenging Behaviour Foundation to be a good place to work and volunteer.



- We want to be able to keep working for a long time.

What we will do



- We will keep listening to people with behaviour that challenges and their families to decide what we do



- We will apply for money from grants and trusts who want the same things we do



- We will do paid work for organisations who want to learn from people with behaviour that challenges and their families



- We will help our staff and volunteers to be happy and healthy



- We will keep spending our money well

How we will measure our progress



Family carers told us they get asked a lot of questions



So we will only ask them questions that matter

We want to ask 3 key questions:



- Have we made family carer's wellbeing better?



- Have we made support services better by sharing the best ways to support people with behaviour that challenges?



- Have people with behaviour that challenges and their families been able to change policies?

How we will be inclusive



We will work with more families from minority ethnic groups, families who earn less money and families from poorer areas.



We will work with all nations in the UK.



We will use our values in everything we do:



- **Inclusion:** working with people from diverse backgrounds



- **Understanding and compassion:** being understanding to everyone



- **Co-production and collaboration:** working with people with behaviour that challenges and their families



- **Integrity and independence:** always focusing on our goal to get people the support they need



- **Advocacy:** promoting the rights of people with severe learning disabilities and their families



- **Learning through experience:** getting better at our job by listening to feedback

How we developed this plan



We learnt from the work we have done before.



We spoke to our trustees and staff, family carers, people with learning disabilities, researchers and professionals.



Thank you to everyone that spoke to us.

Thank yous



Thank you to Jan Seamer.



Jan was a carer for her son who has severe learning disabilities.



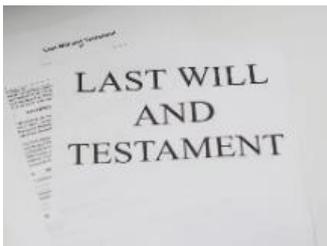
Jan worked with The Challenging Behaviour Foundation since it started.



She helped design training workshops.



She helped start the Challenging Behaviour National Strategy Group.



She left money in her will for the Challenging Behaviour Foundation.



Thank you to our funders:



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