

## The Challenging Behaviour Foundation

### Coproduced Lifelong Action Plan



This plan has some actions for people who make policies.



It tells them what they need to do to support people with learning disabilities who sometimes do things that are challenging.



We worked with people with learning disabilities and their carers to make these actions.



We are happy to talk to people about the actions, or about work they want to do.



If you want to talk to us, email [actionplan@theCBF.org.uk](mailto:actionplan@theCBF.org.uk)

## Workforce



We need more support workers.



Good support workers



- Understand how people feel



- Are trained to do their job well



- Can communicate with people with learning disabilities, even if they don't speak



Support workers are not paid enough.



Lots of support workers are quitting their jobs for jobs that pay more.



It is hard to find new support workers.



So people with learning disabilities can't build good relationships with their support workers over time.



Their support isn't as good as it should be.



## **The Government Needs To**



Pay support workers more.



Make sure people who plan services know the support is right for the person.



Make sure there is enough support for people with learning disabilities in their community.

# Advocacy

## 1. Advocacy in hospital



People with learning disabilities need good advocates when they are in hospital.



Sometimes, it's hard to find a good advocate.



Especially for children and young people.



Some local councils don't know what advocates they need to pay for.



Department  
of Health &  
Social Care

**The Department of Health and Social Care  
Needs To**



Tell hospitals and local councils to make sure there are enough advocates for everyone, and check that they do this.



Department  
for Education

Work with the Department for Education to make sure there are good advocates for children and young people.



Follow the recommendations in the Review of Advocacy and make a plan to improve advocacy.

## 2. Advocacy in the community



People with learning disabilities need good advocates in the community.



People with learning disabilities said they don't have enough advocacy for education, health, social care and housing.



### The Government Needs To



Work with a group of people, including people with learning disabilities, to make a plan for better advocacy and check that it's working.

# Early Intervention

## 1. Early support before crisis points



We need to help children and young people with learning disabilities and their families early on.



People shouldn't be waiting until things are very bad to get support.



Early support means people have a better life.



**The Government needs to**



Spend money on early support for all children and young people with learning disabilities.



Department  
for Education



Department  
of Health &  
Social Care

## The Department for Education and the Department of Health and Social Care need to



Write to councils, health teams and  
people who plan services for children with  
a learning disability.



Share things that help them make good  
early support services, and make sure they  
are doing them.

## 2. keyworkers



All children with learning disabilities should  
have a key worker.



Not just children who might need to go to  
hospital soon or have been in hospital.



This would mean children with learning  
disabilities would have better lives, less  
children need to go to hospital.



## NHS England Needs To



Give key workers to all children and young people with a learning disability.



## The Government Needs To



Pay for more key workers.

### 3. Assessing the Needs of Disabled Children



The needs of children with learning disabilities are not checked very well.



Everybody gets the same forms and questions even though people have different needs.



This means that children with learning disabilities and their families don't get the right support.





Families get blamed for their child's needs instead of getting support.



## The Department for Education needs to



Make a new way to check the needs of disabled children.



Make sure people are trained to work with children and families and check their needs.

## Growing Older



Nearly 2 out of 5 people with learning disabilities live with their family or friends.



People with learning disabilities are living longer.



We need to make plans to support them as they and their families get older.



### Local Councils need to



Know who lives in their area with a learning disability, and who is looking after them.



Talk to people with learning disabilities and their families about their future plans, like housing and support.



Review and update these plans regularly, especially if someone is getting older.



### Health teams need to



Work with councils to help them plan for the future.



Department  
of Health &  
Social Care

## The Department of Health and Social Care needs to



Keep track of how many people with learning disabilities live with their families and if they are getting help with planning for the future.



Share good ways to help people plan for the future, and check that these are happening everywhere.

## Health

### 1. Mental health



People with learning disabilities can have mental health problems.



But there aren't enough services that know how to help them.



There are strict rules about who can get help.



This means mental health problems are ignored and seen as just part of someone's learning disability.



## The Department of Health and Social Care and NHS England needs to



Make sure there are mental health services for children, young people, and adults with learning disabilities.



Train people who work in mental health to help people with learning disabilities.

## 2. Support in hospitals, GPs and medical services



People with learning disabilities and their families need support when they go to the doctor or the hospital.



Learning disability nurses can help.



There are learning disability liaison nurses in hospitals, and learning disability nurses in community teams.



**The Department of Health and Social Care and NHS England needs to**



Hire more Learning Disability Nurses.



Tell people about Learning Disability Nurses.

### **3. People with learning disabilities from Black, South Asian and other ethnic minority backgrounds living longer**



People with learning disabilities from Black, South Asian, and other ethnic minority backgrounds don't live as long as white people with learning disabilities.



All people with learning disabilities should stay healthy and live long lives.



**NHS England and health teams need to**



Read the “We Deserve Better” report and do what it says.

## Housing

### 1. More funding for houses for people with learning disabilities



People with learning disabilities need good housing.



If they can't find the right place to live, they might have to go to hospital.



If they don't have a place to live, they can't leave hospital.



**The government needs to**



Give more money to build homes for people with learning disabilities.



Work with local councils and housing providers to plan for more homes for people with learning disabilities.

## 2. Making plans for housing people with learning disabilities



Local councils need to know how many people need homes now and in the future.



Children and young people will need homes in the future.



People living with their family might need homes in the future.



**The Department for Levelling Up, Housing and Communities and the Department of Health and Social Care needs to**



Help local councils count how many homes are needed.



Make sure that housing, health, and social care services work together and deliver what local people need.

### 3. People with learning disabilities losing their home while in hospital



People with learning disabilities can lose their benefits while in hospital.



Housing benefits stop after a year.



This means people lose their home if they stay in hospital for more than a year.



**The government needs to**



Make sure people don't lose their homes when they go to hospital.





Pay for things like keeping up with bills while someone is in hospital.



Give more money to make homes better for people with learning disabilities when they leave hospital.

#### 4. Short breaks



People with learning disabilities need short breaks and places to stay when they need them.



But there aren't enough of these places.



**Local councils and health teams need to**



Work out how many places are needed.



Make sure there are enough places for people with learning disabilities.



Department of Health & Social Care

## The Department of Health and Social Care needs to



Give money to create more short breaks and places to stay for people with learning disabilities, and check these are delivered.

### 5. Homes for emergencies



People with learning disabilities need places to stay in an emergency.



If they can't find a place to stay, they might have to go to hospital.



Local councils and health teams need to



Make sure there are enough emergency places to stay for people with learning disabilities.

## The Department of Health and Social Care needs to



Give money to create more emergency places to stay for people with learning disabilities.

### 6. Housing adaptations



People with learning disabilities may live in the same home for a long time.



As they get older, they may need changes to their home to help them.



Department of Health & Social Care



Department for Levelling Up, Housing & Communities

## The Department for Levelling Up, Housing and Communities and the Department of Health and Social Care needs to



Work with local councils and housing providers to build homes that can be changed as people's needs change.



Make sure new homes are easy for everyone to use.

### Person-Centred Support

#### 1. Commissioning person-centred services



People with learning disabilities need the right support in their communities.



But there aren't enough services to help them.



People who plan services don't give new services enough money.



## The Department of Health and Social Care needs to



Share good ways of supporting people with learning disabilities to people who plan services, and check these are happening everywhere.



## The Department of Health and Social Care and the Ministry for Housing, Communities and Local Government needs to



Tell people who plan services that they should make new services if there aren't any good ones available, and check that they do this.

## 2. Small support services



Small Support services are person-centred.



They work with people and their family and friends.



They hire staff who know the person well.



They are part of the local community.



They stay with the person for a long time.



They are good for the economy, so the local area has more money.



### **NHS England and the Department of Health and Social Care needs to**



Tell people about small support services.



Help people start their own small support services and check that they are doing this.

### 3. Education, Health, Social Care, and Housing working together



People with learning disabilities need different services to work together to support the whole person.



But often they don't.



This makes it hard for people with learning disabilities and their families to get the support they need.



We need someone to make sure everyone is working together. This person could be a Named Social Worker.



**The Department of Health and Social Care needs to**



Make sure there is a special person to help each person with a learning disability.

## The Department for Education, the Department of Health and Social Care and the Department for Levelling Up, Housing and Communities needs to



Tell local councils how important it is to work together to help people with learning disabilities, and check that they do this.

### 4. Connecting with culture



People with learning disabilities should be able to connect with their culture, like everyone else.



They should be able to do events and activities that fit their religion and traditions.



But sometimes, people with learning disabilities don't get the support they need to connect with their culture.



There are lots of reasons this happens, like





- Supporters not speaking the same language as them



- People not knowing what support they can get



- Not trusting services because of bad things happening in the past



- Supporters making assumptions about a person's culture



- People thinking that everyone from a minority ethnic background is the same



## The department of health and social care needs to



Give advice to local councils and health services about how to help people with learning disabilities from different cultures.



Train people who work with people with learning disabilities to understand different cultures.



**Health teams need to**



Make sure that people with learning disabilities from different cultures are included in plans to help people from ethnic minority backgrounds.



Make sure that their plans to help people with learning disabilities also help people from different cultures.

## Rights

### 1. Keeping information about services



Information about services are kept in different places.



So, sometimes it's hard to know if services are good or bad.



This can mean that problems are missed.



Department  
of Health &  
Social Care

**The Department of Health and Social Care needs to**



Put all the information about complaints and concerns in one place, so it's easier to see if there are any problems.



Work with other teams, like the Department for Education, NHS England, Ofsted, and the Care Quality Commission (CQC), to make this happen.



## 2. Stopping harmful restraint



People with learning disabilities can be restrained. This means they can't move fully.



People with learning disabilities can be made to be on their own.



People with learning disabilities can be given too much medicine.



This can happen in lots of places, like school, hospital and at home.



It happens more to people who do things that challenge others.



**The Department of Education needs to**



Tell families when this happens to their child.



Train all teachers about alternatives to restraint, and the importance of recording what interventions are used and telling families.



**The Department for Education and the Department of Health and Social Care need to**



Make sure everyone knows what restraint is.



Support people to use other ways to help people with learning disabilities, instead of using restraint.

## Supporting Families



Carers provide a lot of care and support, but it isn't always recognised



Family carers need more money.



People can get Carer's Allowance in the UK.



But it is not very good.



People don't get enough money. They only get £81.90 a week.



Only people who don't earn much money can get Carer's Allowance.



Some people have more than one carer, but only one person who cares for someone can get Carer's Allowance.



People who study for more than 21 hours a week can't get Carer's Allowance.



People who get a pension can't get Carer's Allowance.



You get less Universal Credit if you get Carer's Allowance.



Department for Work & Pensions

**The government and the Department of Work and Pensions needs to**



Give more money to carers.



Let people who earn more money get Carer's Allowance too.



Stop people getting less Universal Credit when they get Carer's Allowance.



Let people who get a pension get Carer's Allowance.



Let people who study for more than 21 hours a week get Carer's Allowance.

## Transition to Adulthood



When young people with learning disabilities turn 18, they need help to start their adult life.



Services should make plans for when young people turn 18 early.



Services like education, health, social care and housing should work with the person and their family to make plans for the future.



Often, this doesn't happen.



Sometimes, adult services don't know about a young person with a learning disability until they turn 18.



Department  
for Education



Department  
of Health &  
Social Care

## The Department for Education and the Department of Health and Social Care needs to



Tell councils and health teams why they should plan early for transition.



Share things that help young people transition to adult life, and check that councils, health and education are doing them.



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