

## Housing barriers faced by people with a learning disability:

working together and co-producing solutions

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#### **About the Challenging Behaviour Foundation**

The Challenging Behaviour Foundation (CBF) is a small, national charity

We support the families of children, young people, and adults who have severe learning disabilities and behaviours described as challenging – such as pica (eating inedible objects, like stones or clothing), behaviours that hurt themselves or others, or breaking furniture – to make sure that their relatives can access the right support and live good lives





## The Challenging Behaviour – National Strategy Group

The Challenging Behaviour – National Strategy Group (CB-NSG) is made up of different people and organisations with expertise, who work together to find solutions to the problems that people with a learning disability, whose behaviour challenges, face





# What happens when you are trying to get a house?

In the person's shoes

Responsibility

Co-ordination

Drive

Evidence and understanding

Tickboxes and criteria

Costs

"things have to fail before you can get what you need"

## Working together to identify and coproduce solutions

All parts of the system need to work together to make sure that people with a learning disability whose behaviour challenges can get the right support

Because of this, people with lived experience and people working in all parts of the system need to work together to identify what the problems are and how to fix them

#### What needs to happen?

Over the past two years, people with a learning disability and family carers have been working with people from different parts of the system, including housing, to identify issues and co-produce solutions

The earlier slides cover some of the problems that make it difficult for someone with a learning disability whose behaviour challenges to get the right house, in the right place, when they need it – the next slides cover how to fix them

#### Thinking about housing differently

- The system is not currently working so what is stopping it from working? What do we need to do to the current system to make a system that will work?
- What are the pathways that someone with a learning disability/their family goes down? What are the points where things 'go wrong' – and what can be done to make them 'go right'?
- What are the issues that you come up against when you suggest
  ways of doing things differently and where have you had success
  in changing things? What are the things you would need to convince
  decision makers or that would convince you?

### 1. Increasing available capital funding

The biggest barrier to discharging people with a learning disability and autistic people from hospital is that there is not the right housing available. We also know that not being able to get a house that works is a big reason for people being admitted to inpatient units.

People we support have told us that getting capital funding for a house for their relative that meets their relative's needs while they are in the community is a postcode lottery.

When someone is in hospital, getting funding for housing is still hard because, even though there are some new ways people in hospital can get funding, there is not enough money available in the different funding 'pots'.

### 1. Increasing available capital funding

Increasing the availability of capital funding would make it easier for more people to be discharged from hospital. Having more funding available to people *before* they are admitted to hospital, rather than only being available if you are currently an inpatient, can stop them from being admitted – so that they don't experience the trauma or long lengths of stay that can happen in hospital.

#### Our ideas of what is needed:

- Improved access to funding options in the community
- An alternative to Section 117 funding that can be used for people with a learning disability and autistic people who don't have a mental health condition

### 2. Strategic Housing Plans

We are often told, and research supports, that one of the biggest barriers to getting housing right is that areas don't have a clear idea of what housing the people with learning disabilities living in their area need.

As people with a learning disability and their families grow older, needs can change, so housing might also need to change.

If a family carer passes away, that can also lead to changes in someone's housing situation – whether these are what the person wants or needs, or not.

### 2. Strategic Housing Plans

#### Our ideas of what is needed:

- Better involvement of housing representatives in transition planning
- Local authorities need to have better data on people with a learning disability in their area, and factors/particular situations that will trigger them to act
  - Example: if an adult with a learning disability lives with their family, and their family members approach retirement age, this should alert the local authority to work with the person and their family to think about future housing needs/options
- Make sure all new homes are 'M4(2)-compliant' making them more accessible, and easier to adapt in future

### 3. Keeping access to housing

When someone with a learning disability is detained under the Mental Health Act, after a certain point, they stop receiving housing benefit. If the house that they were living in before was being paid for by housing benefit, and this is no longer being paid, then they can lose their house.

As of March 2024, 56% of delayed discharges were because there wasn't suitable housing – so, if the house was previously suitable, being able to keep paying for it while someone would help avoid this situation. If the house wasn't fully suitable, there might be adaptations that could be made while someone is in an inpatient unit which could make it better for them.

### 3. Keeping access to housing

#### Our ideas of what is needed:

- There should be a mechanism to make sure that benefits being withdrawn doesn't mean that a person with a learning disability loses their house – this could be by introducing ring-fenced funding to cover 'double-running costs', like in the Community Discharge Grant, to maintain a house while someone is in an inpatient unit
- Increasing funding for the Disabled Facilities Grant, and increasing awareness that it can be used for people with learning disabilities, would make it easier for someone's existing home to be adapted – potentially stopping a crisis developing, or helping them to be discharged back home quicker

## 4. Access to short breaks/emergency accommodation

Short breaks and emergency accommodation can make it easier for people with a learning disability and their families to get support. If there is an issue with someone's house, they also provide a place that someone can go while repairs are made or a new house is found.

When there isn't any alternative accommodation available, people with a learning disability can be admitted to inpatient units, just because it is the 'only' place where they can go – which isn't right.

Families we support tell us that if there was a suitable place in the community that they could have gone temporarily, their relatives would not have been admitted and wouldn't have got 'stuck' in hospital.

## 4. Access to short breaks/emergency accommodation

An example of good practice that keeps people with a learning disability living in their community is the Black Country's 'Crash Pad', which is short-term accommodation for people who would otherwise have been admitted to an inpatient unit. Between January and March 2024, 24 people with learning disabilities and/or who are autistic were supported within the community via the Crash Pad.

#### Our idea of what is needed:

 Local areas need to have ring-fenced funding that lets them develop, and maintain, short breaks services and alternative accommodation – based on the number of people with learning disabilities in their local area, and what their needs are

#### Navigating the system

As well as the practical issues involved in trying to get housing right, navigating the system to get a house can be very emotionally challenging for people with a learning disability and their families, particularly when considering that they are at the same time trying to navigate other parts of the system such as health, education, and social care. The solutions to the housing problems people face need to make it simpler to navigate, not more complicated.

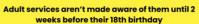


#### **One Person's Housing Journey**

This is a composite example, based on real experiences of real people

A young person with a severe learning disability, who is non-verbal, attends a residential school which supports young people up until they are 18

Transition planning is supposed to begin in Year 9, but this often doesn't happen - and even when it does begin early, housing is





Because of the delays in starting transitior planning, there haven't been assessment's of their needs or a chance to strategically plan housing - so there isn't planning for where the person will live as an adult, and

The local authority arranges for them to live in an out-of-area placement with other people with a learning disability - the only place they could find at short notice

Because no assessment was done, the local authority can't be sure that the placement will meet the person's needs, or that they will get on with other people living there



Moving into this new place is rushed, rather than as part of a smooth, planned transition

It's hard for the person's family to visit them, or for them to see their

The person tries to communicate that the placement doesn't meet their needs and that they don't get on with the other people living there

Because they are non-verbal, the support workers haven't had a chance to get to know them, and family are too far away to visit regularly and help explain how they communicate, the support workers don't understand what they are trying to communicate

challenge, this lack of understanding results in the property being damaged The placement withdraws the person's tenancy agreement due to property damage



28 days-notice is the statutory minimum for most tenancies held by people with a learning disability - this is not enough notice to be able to a) find a suitable tenancy and b) plan a smooth transition for the persor

Emergency accommodation is not available and the local authority can't find a tenancy that meets the person's needs - they are admitted to an inpatient unit as a last resort

The person is detained under the Mental Health Act as a result of their chollenging behaviour — which is, under the current act, something that you can be detained for if you have a learning disability even if you don't have a mental health condition



The person spends multiple years in a unit, and experiences trauma

The new environment within the inpatient unit, along with being away from the places and people that they know, causes the person to become more upset and for behaviours that challenge to increase – so they are restrained ar placed in long-term segregation

Because of the trauma of the inpatient unit, and the length of time they are there, it is agreed that they need 5-to-1 support to be discharged

> They also need a house that is much more specialised to support them with the increase behaviours that challeng

Issues accessing funding for a specialist house delays discharge for 18 months, and adaptations take another 6 months

The house that this person now needs has to be able to fit them and at least 5 others at all times so it needs to be larger and have plenty of room

Significant adaptations need to be made so to the person can be supported with behaviours to challer

The house that is needed now is therefore me expensive than the house that they would be needed before admission

There were multiple failures of the 'system', and at each of these points, different things could have been done better. By the time the person finally got a suitable house, they had spent years in different places and experienced trauma as a result of their experiences.

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#### What would have made that housing journey better?

When transition planning starts, on time, in Year 9, housing is actively involved

Funding can be accessed, making it possible to develop housing that meets the person's needs

Because their home meets their needs and they are well-supported by people who know them and how they communicate, the root causes of any behaviours that challenge are

identified and addressed



The person and their family are involved in thinking about what is needed, and this is planned for strategically

There is a smooth transition, over a few months, to help the person move from their residential school to their new home successfully

There is a plan for what will happen if a tenancy is withdrawn or the house becomes temporarily unsafe, and there is local emergency accommodation available if needed

If they are admitted to an inpatient unit, planning begins immediately to make sure that housing will be ready for when they are discharged, so there are no delays



#### What next?

What steps can be taken to address the issues we've discussed today?

Are there any that you can take, and what might you need to be able to do them?

What other barriers are there, and how can these be tackled?

Are the ideas we've suggested the right ones?

Are there any that you'd suggest in addition to these, or ones that you think need changing?



# The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

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Scan this QR code to see the 'Housing - Actions for Policy-Makers' section of the Co-Produced, Lifelong Action Plan

Scan this QR code to see a poster on 'Overcoming Housing Barriers' – how it should work, what actually happens, how to fix it, and resources to help do this

