Co-Producing a Lifelong Action Plan

How to get support right for children and adults with a learning disability

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Introduction

In May 2011, an episode of Panorama exposed the horrific abuse of people with learning disabilities at Winterbourne View hospital - and made many members of the public aware for the first time of the inadequacy of support for people with a learning disability. The scandal rightfully kickstarted a programme to transform care, with the stated goal of supporting people with a learning disability and autistic people to be discharged from these inappropriate institutions, and instead ensure that they can get support, tailored to them as individuals, in their local communities.

But more than 12 years on, this still hasn't been achieved. Instead, we have had years of promises, reports, plans and pledges - none of which have delivered. Targets have been amended, delayed, and missed. The Transforming Care programme failed to deliver on its aims, and its replacement, Building the Right Support, is on track to do the same. There are still more than 2000 people with a learning disability and autistic people in inpatient units, despite the widespread recognition that these are not only inappropriate, but harmful. Plans to reform the Mental Health Act, so that people with a learning disability and autistic people would not be detained just because they had a learning disability or were autistic, have stalled.

The government set itself a target to halve the number of people with a learning disability and autistic people in inpatient units by March 2024. Not only was this missed, but the data shows that on the current trajectory, it will be another **six years**, minimum, before this target will be met.

What you are about to read is a plan to change this. We are a group of people and organisations that have come together to identify what the barriers are that are currently stopping children, young people and adults with a learning disability from living good lives in their local communities – and what actions are needed to overcome these. Working together, people with a learning disability, family carers, and people working from across all different parts of the system have co-produced a list of actions that we know will have a real impact.

The barriers are complex, but they are not impossible to overcome. What we need is clear political leadership, a willingness to think creatively, and resources to act on the big issues. Alongside this, there are things we can do in our everyday lives and practice that will make a big difference – and we can start doing these now. Working together in a co-ordinated way to common goals can drive real change.

This plan is built on several core principles, that run throughout the issues and actions. These are:

- **Interconnectedness** – these issues are not separate, they are connected. Many are interdependent and for any solution to be successful this needs to be taken into account
- **Lived experience and co-production** – listening to people with a learning disability, their families, and the people that support them, about what the issues are – and working with them as equal and valued partners to identify what is needed to fix them
- **A lifelong approach** – looking at the whole of the person and the whole of their life, and what is important to and for them
- **Focused actions** – the actions should be clear and specific, with accountability, monitoring, and evaluation
- **Belief in collective strength** – we can achieve more if we work together

A Skilled, Supported Workforce

Ensuring that all people working to support children, young people and adults with a learning disability have the skills that they need to do so, and are well-supported

1

Ensure that care and support workers are paid a fair wage for their work, recognising the skill required to support people with a learning disability to live good lives

People with a learning disability deserve to be able to live good lives in their local communities – but they need support to do this. Being a support worker involves empathy and understanding; training in how to support people with a learning disability, including people with a severe learning disability and people with a learning disability whose behaviour challenges; communication skills; adaptability, flexibility, and a willingness to take positive risks.

These are skilled jobs, but due to the low rates of pay available, support workers are leaving the sector, there is high turnover, and it is difficult to recruit and retain staff. This is bad for support workers, who are not being paid a wage that reflect the skills and responsibilities of their role, and it is bad for the people they support, who have the right to build relationships with their support workers, who need support workers who understand their preferences and support needs, and who, in many cases, find change distressing.

Research by ARC in 2023 found that **94% of** local authorities are paying rates for supported living services that **do not allow providers to meet their statutory obligation to pay the National Living Wage**.

Community Integrated Care's 'Unfair to Care' research found that **social care workers are being paid on average £8036 less than someone doing an equivalent role in the NHS.**

The Government needs to:

Match pay for support workers and social care workers to equivalent NHS bands

Support commissioners to proactively develop person-centred services and support within their local communities

2

The 2024 Mental Health Bill says that integrated care boards and local authorities need to “seek to ensure that the needs of people with autism or a learning disability can be met without detaining them” when exercising their commissioning and market functions. This duty aims to make it so that t people with a learning disability and autistic people can get support in their community, rather than being detained under the Mental Health Act, and is therefore a positive step in the right direction - but we are concerned that this duty does not go far enough to achieve its aims.

> *All children, young people and adults have the right to receive person centred support and services that are developed on the basis of a detailed understanding of their support needs, including their communication needs.*
>
> *This will be individually-tailored, flexible, responsive to changes in individual circumstances and delivered in the most appropriate local situation.*

The Challenging Behaviour Charter

> *[The UK Government] should intensify its efforts to guarantee the provision of sufficient community-based mental health services, providing early intervention and preventative support*

United Nations Human Rights Committee
2024

The wording of this duty is unlikely to be enough to ensure there are the right community services for people with a learning disability. When the financial crises facing local authorities - which is already seriously impacting on decisions around adult social care and special educational needs and disabilities - is taken into account, it becomes clear that creating a new duty without ensuring that there is ring-fenced funding available to develop and commission these services will not work.

Any introduction of a new duty around community support needs to be accompanied by resources and funding.

The Government needs to:

Introduce a strong duty on commissioners to develop community support for people with a learning disability within their local area , and back this duty with resources

The Department of Health and Social Care needs to:

Work with commissioners to share good practice examples of commissioning for people with a learning disability

The Department of Health and Social Care and the Ministry of Housing, Communities and Local Government need to:

Produce joint guidance stating that commissioners should engage in market-shaping, not just 'buying', if there are no existing services within their area that meet the needs of their local population with a learning disability

Advocacy

Making sure that children, young people and adults with a learning disability are able to access effective, independent advocacy that helps improve their lives

1

Ensure that people with a learning disability who are detained in inpatient units have access to skilled advocates

The NHS-commissioned Review of Advocacy, published in 2023, highlighted that access to skilled, independent advocacy for people in inpatient units is inconsistent and in many cases unavailable.

Among the issues highlighted were that children and young people were in many cases not covered by the advocacy contracts that local authorities had purchased, and that local authorities were unclear on their responsibilities in this area.

The Government needs to:

Respond to the recommendations of the Review of Advocacy, and set out an action plan for what actions they intend to take on these

The Department of Health and Social Care needs to:

Write to all a) ICBs and b) local authorities and ask them to clarify their funding arrangements for advocacy – they must ensure that advocacy is commissioned for children and young people as well as adults

Engage with the Department for Education on the proposed new standard for non-instructed advocacy that is currently being developed, and promote this

Introduce a national advocacy strategy and task force to plan and action required changes

2

The issues highlighted in the Review of Advocacy show that there are serious issues with advocacy for children, young people and adults in inpatient settings, but people with a learning disability and families have raised that advocacy in other areas is also frequently inadequate.

This occurs throughout different parts of the system – education, health, social care, housing – and requires a cross-governmental solution.

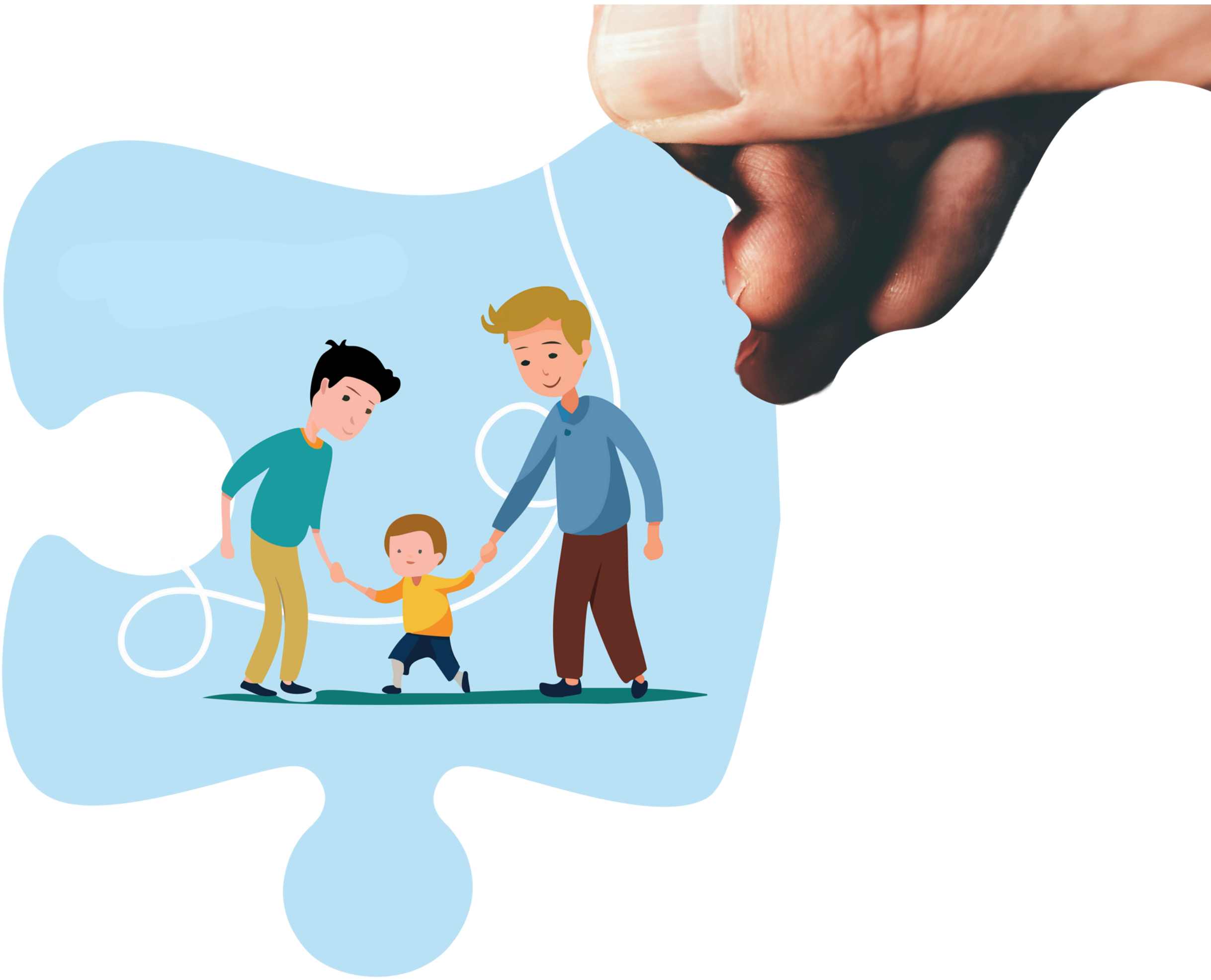
> “
>
> *We recommend: A national advocacy strategy is developed to oversee and support delivery of the much-needed changes identified within this report.*
>
> *Reviewers believe there should be a multi-agency task force, which includes family members and people with a learning disability and autistic people to oversee development of such a strategy and to monitor its implementation.*

A Review of Advocacy

The Government needs to:

Introduce a multi-agency taskforce, including people with a learning disability, autistic people and family carers, to oversee the development of a national advocacy strategy and monitor its implementation

Early Intervention



Giving children and young people with a learning disability the best start in life, and preventing crises from occurring

1

Invest in early intervention – waiting until things have reached crisis point is not acting fast enough

Getting the right support early on is crucial to helping children and young people with a learning disability live good lives. Evidence shows that early intervention can have positive outcomes for quality of life, but it also shows that, if support is available early on, this can lead to considerable savings over time.

The Government needs to:

Commit to investing in early intervention for children and young people with a learning disability, including those whose behaviour challenges

An approach to investing in and getting early intervention right will need the involvement of the **Department for Education** and the **Department of Health and Social Care**, among others

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

Write to a) local authorities, b) integrated care boards, and c) commissioners of services for children and young people with a learning disability to share resources and good practice on how to commission and support early intervention programmes

Resources

Why investing in early intervention for children with a learning disability is so important, with examples from practice

Developing effective local services for children with learning disabilities whose behaviour challenges

Commissioning services for children and young people with a learning disability whose behaviour challenges

How to develop local pathways for children and young people with learning disabilities and/or who are autistic whose behaviour challenges

Ensure all children and young people with a learning disability have access to a keyworker

2

The NHS Long Term Plan includes a commitment that "by 2023/24 children and young people with a learning disability and/or who are autistic with the most complex needs will have a designated keyworker". Currently, keyworker support is available to children and young people who are in inpatient settings or who are at risk of admission.

We believe that having a designated keyworker would have a positive impact on all children and young people with a learning disability and complex needs, not just those who are in inpatient settings or at risk of admission. If a keyworker is only available to children and young people who are "at risk of admission" or who have already been detained in inpatient settings, they are coming in at a point where these children and young people are already near – or in the middle of – a crisis situation. Crisis situations can sometimes be sudden, but in many cases they are the result of pressure building up over time as a consequence of people not being able to access the support that they need.

Having access to the right support early on means that children and young people are less likely to reach a point of crisis. We believe that ensuring that all children and young people with a learning disability and complex needs have access to a keyworker, even if they are not currently "at risk of admission", will help them and their families to navigate the system and avoid crises from occurring.

NHS England needs to:

Expand the keyworker scheme so that all children and young people with a learning disability and complex needs have access to a keyworker

The Government needs to:

Commit to funding the expansion of this scheme

3

Introduce a separate pathway for assessing the needs of disabled children

There is currently a “one size fits all” approach which means that disabled children are funnelled through an assessment that is not designed to assess and meet their needs or the needs of their families. This approach looks at an assessment of needs through a safeguarding lens – resulting in families being blamed rather than supported.

Disabled children, including children with a learning disability whose behaviour challenges, need specific support in order to live good lives, but frequently assessors do not have the specialist knowledge or training that would enable them to identify and meet these support needs. In addition to being ineffective, approaching the assessment of needs for disabled children through a safeguarding lens when there is no indication of any safeguarding concerns causes trauma to the child and their family.

Resources

The University of Leeds School of Law has produced two key reports on this issue:

Institutionalising Parent-Carer Blame (2021)

The prevalence and impact of allegations of Fabricated or Induced Illness (2023)

The Department for Education needs to:

Introduce a new distinct assessment pathway for disabled children which focuses on the needs of the disabled child and their family

Introduce a requirement for assessors to be suitably experienced and to have received specific training in the needs of disabled children and how to work with them and their families

See ‘Draft Guidance: Assessing the Needs of Disabled Children and their Families’ by Professor Luke Clements

This may include training in **augmentative communication** – for example, children with a severe learning disability are often non-verbal, but it is still important to ‘hear’ their views and preferences throughout this process

Growing Older

Getting support right for people with a learning disability as they and their families age

1

Put in place a strategic plan to identify and support people with a learning disability as they and their families grow older

The need to plan strategically to support people with a learning disability as they grow older was first highlighted over two decades ago, including in Valuing People and Mencap's Housing Timebomb report, but there are no current specific policy requirements to ensure that this occurs.

Recent research shows that 37% of adults with a learning disability and autistic people live with family and friends; a statistic that is largely unchanged over the last decade.

Beyond this, the much-welcome increase in average life expectancy for people with a learning disability means that people with a learning disability who live with and/or are supported by family members will do so for longer. This has in turn led to cases where families continue to support their relative into their old age, which can result in physical and mental health issues for the family carers and in the person with a learning disability not being able to get the right support.

People with a learning disability also face particular health issues relating to ageing. For instance, people with a learning disability (and particularly people with Down Syndrome) are significantly more likely to a) develop Alzheimer's/dementia than the general population, and b) to develop these at a younger age.

Without strategic planning to a) identify, and b) work with people with a learning disability and their families to plan for the future, housing and support for people with a learning disability can be jeopardised. By identifying people with a learning disability and their families early on, and working with them to put in place plans for the future that suit everyone, quality of life can be improved and crises caused by abrupt and unplanned changes can be avoided.

The Department of Health and Social Care needs to:

Collect and monitor data on the number of people with a learning disability living with and/or supported by family carers

Collect and monitor local authority data on the percentage of people with a learning disability and their families who have received support to plan for the future

Analyse and publish national level data

Collect and distribute good practice examples to a) local authorities, and b) ICBs

Local authorities need to:

Ensure that they are aware of the number of people with a learning disability within their area

Introduce a mechanism for recording and monitoring the ages of people with a learning disability within their area and their families

Identify any people with a learning disability within their area who is a) living with, and/or b) supported by family members

Have a policy for contacting people with a learning disability and their families to create plans for the future, e.g., if a family carer is no longer able to provide support, if health and/or support needs change, if there is ill-health or bereavement, if mobility needs mean that the family home needs to change

Ensure that this policy includes reviewing and updating these plans at regular intervals

Ensure that people with a learning disability who live with ageing family carers are highlighted within local housing strategies

Integrated Care Boards need to:

Work with local authorities within their area to support them with planning for the future, and provide monitoring and oversight to ensure this occurs

Health

Addressing the health inequalities that children, young people and adults with a learning disability face, so that they can live good and healthy lives

1

Ensure that people with a learning disability have access to early and appropriate psychological support

While learning disabilities are not mental health problems, people with a learning disability can still have mental health issues.

Having specialist training and services for supporting children, young people and adults with a learning disability who are experiencing mental health problems is crucial in tackling mental health inequalities, but services are patchy, eligibility criteria are strict, and capacity is limited.

Without access to these specialised services, mental health issues can go unidentified or attributed to 'just being part of someone's learning disability'.

Research by the Nuffield Trust in 2024 found that **not only are mental health problems more common among people with a learning disability** than the general population, but that people with a learning disability are both **less likely to be referred to NHS Talking Therapies** than someone without a learning disability, and are **less likely to experience positive outcomes** from these therapies.

Specialist support – tailoring therapies to people with a learning disability and their needs – has better outcomes, but whether someone is able to access these depends on where they live.

The Department of Health and Social Care and NHS England need to:

Ensure that each area has a Child and Adolescent Mental Health Service (CAMHS) and an Adult Mental Health Service (AMHS) that can provide specialist support to children, young people and adults with a learning disability

Increase access to training that can support clinicians working within CAMHS and AMHS services to be able to support people with a learning disability

Put in place support for people with a learning disability and their families when they are visiting hospitals, GPs, and other medical services

2

When people with a learning disability need to visit hospitals, GPs, or other medical services, they can face significant barriers.

Learning Disability Liaison Nurses can help with supporting people with a learning disability and their families to access and navigate healthcare.

However, there is a shortage of learning disability nurses, meaning that people with a learning disability are not always able to access this vital support.

According to the Royal College of Nursing, between 2009 and 2024 the number of learning disability nurses employed by the NHS in England fell by 44%. Between 2015 and 2023, the number of acceptances onto learning disability nursing courses fell by 36% - and a number of universities have stopped offering these courses.

How do learning disability liaison nurses support equal access to healthcare?

- supporting people with a learning disability to communicate with and access healthcare services
- promoting the use of hospital passports
- providing support and expert advice to staff in hospitals
- acting as a ‘bridge’ between the hospital and community settings

Royal College of Nursing
2021

Unless there is a concerted effort to increase the number of nurses and ensure that training is available, this shortage will only get worse.

The Department of Health and Social Care and NHS England need to:

Recruit and train additional Learning Disability Liaison Nurses

Increase awareness of the role of Learning Disability Liaison Nurses

3

Tackle the lower life expectancy of people with a learning disability from ethnic minority backgrounds

People with a learning disability, on average, die 19 years earlier than people in the general population – an inequality that needs to be tackled. But research shows that people with a learning disability from Black, South Asian, and minority ethnic backgrounds have a dramatically lower life expectancy than their white counterparts.

The average age of death of people with a learning disability from minority ethnic backgrounds is 34 years, barely more than half that of their white counterparts (62 years).

NHS England and Integrated Care Boards need to:

Ensure that the recommendations of the 'We Deserve Better' report are carried out

In addition to this, multiple Learning from Lives and Deaths (LeDeR) reports have findings that indicate that people with a learning disability from black, black British, Caribbean, African or mixed ethnic backgrounds may be at greater risk of dying 'avoidable' deaths; however, due to the small sample sizes involved (with 94% of the cases analysed in 2022-2023 being white) this cannot be definitively proven.

NHS England needs to:

Commission specific research into whether people with a learning disability from black, black British, Caribbean, African or mixed ethnic backgrounds are at greater risk of 'avoidable' deaths

Make sure all people with a learning disability can access Annual Health Checks

4

Because people with a learning disability are both more at risk of developing certain health problems than the general population, and may find it more difficult to identify or communicate health issues that they are experiencing, they are entitled to Annual Health Checks, which are designed to identify health issues and treat them.

Annual Health Checks can have a positive impact on the health of people with a learning disability – identifying conditions like diabetes, heart disease, and gastrointestinal problems – and help overcome some of the health inequalities leading to premature deaths. But not enough people with a learning disability are receiving them.

To get an Annual Health Check, you have to be on your GP's Learning Disability Register. However, evidence suggests that only 26% of people with a learning disability are on the Learning Disability Register. With 78.1% of people on the Learning Disability Register receiving Annual Health Checks in 2022/23, this means that only approximately 20.7% of people with a learning disability received an Annual Health Check.

For more information about Annual Health Checks, see:

Annual Health Checks

Easy Read Guide to Annual Health Checks

Video: Harshi's Learning Disability Annual Health Check and Health Action Plan

Video: Charlotte's Annual Health Check and Health Action Plan

The Department of Health and Social Care and NHS England need to:

Ensure that all people with a learning disability aged 14+ are on the Learning Disability Register

Ensure all people on the Learning Disability Register are receiving Annual Health Checks

Housing

Getting housing right for children, young people and adults with a learning disability

1

Increase availability of capital funding for housing for people with a learning disability

The right housing is crucial to enabling people with a learning disability to be able to live good lives. Not being able to access the right housing, and the impact of this on (for example) behaviours that challenge, can lead to people with a learning disability being detained in inpatient units under the Mental Health Act because it is not possible to find anywhere else for them to live.

Alongside this, according to NHS Digital data, "lack of suitable housing provision" is the main barrier to discharging people with a learning disability and autistic people from these inpatient units - with over half of delayed discharges due wholly or partly to lack of suitable housing. As well as being the main barrier to discharge, the percentage of people for whom this is a barrier has risen significantly since statistics began in 2015.

There are sources of funding available to develop and adapt housing for people with a learning disability - but these are complicated and difficult to navigate. It is also inconsistent, with local authorities and integrated care boards having different eligibility criteria - meaning that a person with a learning disability in one part of the country might be able to access funding to get a house that someone in another area can't.

There are also sources of funding that you can only receive if you have been admitted and discharged from an inpatient unit - meaning that before you can get a house that will enable you to live a good life (and avoid being detained), you have to have been sectioned, often spending multiple years in hospital where you are more likely to be distressed, experience trauma, and be separated from family, friends, and the places you know.

Current funding options and programmes haven't resulted in enough housing - of the right kinds - being developed for people with learning disabilities.

For example, the Affordable Homes Programme (which is currently running from 2021-2026) says that 10% of all housing built under the programme should be supported housing. This 10% is equivalent to 15,700-16,500 units of supported housing - but in 2023 the National Audit Office found that this target was on track to be missed, with figures from the Department of Levelling Up, Housing and Communities (now the Ministry of Housing, Communities and Local Government) forecasting that only half of this supported housing would be built.

The target of 10% also doesn't distinguish between supported housing for people with a learning disability and supported housing for other groups - such as older people, people experiencing homelessness, and others. The majority of supported housing built is for older people. This is both explained and exacerbated by the fact that it is currently more cost-effective for providers to develop and deliver (larger scale) supported housing for older people than it is to deliver (small-scale, often bespoke) supported housing for people with learning disabilities.

There are both issues with the levels of capital funding available, and with the routes for accessing this. The 2024 Supported Housing Review identified issues accessing Homes England/Affordable Homes Programme funding due to needing to meet the rent standard - which doesn't cover the cost of developing bespoke supported housing.

Recent research by the Learning Disability and Autism Housing Network and HousingLIN found that **£340m** of capital investment from public and private finance is needed per year to meet the need for supported housing for people with a learning disability and autistic people. Around **87%** of the capital funding used by housing providers to develop supported housing for people with a learning disability and autistic people since 2017 came from private and non-public finance – compared to ~8.5% from NHS England, ~3.5% from Homes England, and 1.5% from local authorities.

The Government needs to:

Increase the availability of capital funding available to develop housing for people with a learning disability and autistic people

Ensure ringfenced a) targets and b) funding through the Affordable Homes Programme to ensure the specific development and delivery of supported housing for people with a learning disability

Work with local authorities and housing providers to strategically plan for how to increase the supply of supported housing for people with a learning disability

Ensure that capital funding is available to stop people from being admitted to inpatient units - not just to get them out

Ensure that all areas have developed strategic plans for housing for people with a learning disability

2

In order to properly plan for how they can meet the housing needs of people with a learning disability within their area, local authorities need to develop a clear understanding of their a) current and b) future housing needs. This should include analysis of the number of children and young people within their area that will require housing in future, as well as the number of people with a learning disability currently living with family or friends who may require alternative housing in future.

Developing this understanding of housing need needs to be done in conjunction with assessments of health and support needs – these parts of the system need to be joined-up in order to successfully meet needs in a person-centred way.

One way to ensure that there is joined-up and strategic planning that includes housing is to ensure that housing representatives are involved in transition planning for young people with learning disabilities, alongside representatives from health, education and social care.

The Ministry of Housing, Communities and Local Government and the Department of Health and Social Care need to:

Work with local authorities to support them to conduct research and analysis of their local population, and to use this to develop housing that will meet these needs

Work with local authorities to support them to join up housing, health and social care

Promote the involvement of housing professionals in transition planning for young people with learning disabilities

3

Ensure that if someone with a learning disability is admitted to an inpatient unit, they do not lose their existing housing

One of the issues that people with a learning disability face is that, if they are detained in an inpatient unit under the Mental Health Act, they can lose access to benefits. One of these is Housing Benefit, which stops after 52 weeks in hospital (the current average length of stay in an inpatient unit for people with a learning disability and autistic people is over 5 years).

Because of this, if you have a learning disability and are admitted to an inpatient unit, you can lose your home.

With housing the main barrier to being discharged back into the community, maintaining existing suitable housing – or carrying out adaptations to existing housing that requires them – is crucial to ensuring that people with a learning disability do not get 'stuck' in inpatient units.

Benefits that stop after 28 days in hospital

- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- Attendance Allowance
- Carer's Allowance or the carer's element of Universal Credit'

'What happens to my benefits?'
Mental Health and Money Advice

Benefits that stop after 52 weeks in hospital

- Housing Benefit
- Support for Mortgage Interest

'What happens to my benefits?'
Mental Health and Money Advice

The Government needs to:

Take steps to ensure that the withdrawal of benefits does not result in housing being lost

Introduce ring-fenced funding to cover 'double-running costs', including the cost of maintaining a house while someone is detained in an inpatient unit

Increase funding for the Disabled Facilities Grant to support adaptations to be made so that people with a learning disability can be discharged back into their homes without delay

Access to short breaks and alternative/emergency accommodation

4

Children, young people and adults with a learning disability need to be able to access short breaks and/or alternative accommodation when it is necessary. Not being able to access support, including through short breaks and alternative accommodation - especially in crisis situations or in cases of emergency - is a major reason for people with a learning disability being admitted to inpatient units.

People with a learning disability should be able to access these 'crash pads' when they are needed, including if they are needed to prevent admission to inpatient units.

Currently, provision of short breaks and alternative accommodation is limited – many areas do not have these in place and where they do, there is not enough provision to ensure that they can be used by people who need them, when they need them.

The Department of Health and Social Care needs to:

Provide ringfenced funding for the development of short breaks services and alternative/emergency accommodation

Local authorities and Integrated Care Boards need to:

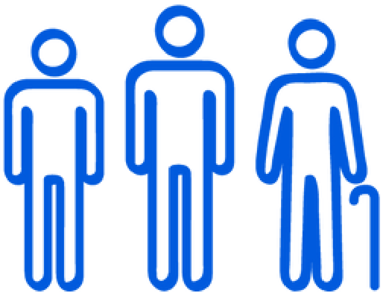
Identify what alternative accommodation is needed to support children, young people and adults with a learning disability in their area, and take steps to develop alternative accommodation and short breaks services within their area

Ensure that they have a sufficient supply of 'emergency accommodation' available to meet the needs of people with a learning disability

‘Future-proof’ housing

6

Many people with a learning disability will, if it is possible, live in the same house for a long period of time. This means that, if they are growing older in a particular house, they might need new or additional adaptations to support them as they age.



For example, people with a learning disability, and people with Down Syndrome in particular, are more likely to develop dementia at an earlier age – meaning that they might need adaptations to enable them to continue living in their homes.

The Ministry of Housing, Communities and Local Government and the Department of Health and Social Care need to:

Publish guidance on the need to consider whether housing for people with a learning disability can be adapted in future if needs change , and further promote existing guidance on adapting housing for people with learning disabilities

Work with local authorities and housing providers to develop housing for people with a learning disability that is adaptable

Ensure that the commitment (made in 2022) to mandate the M4(2) requirement in the Building Regulations as a minimum standard for all new homes is carried out without delay

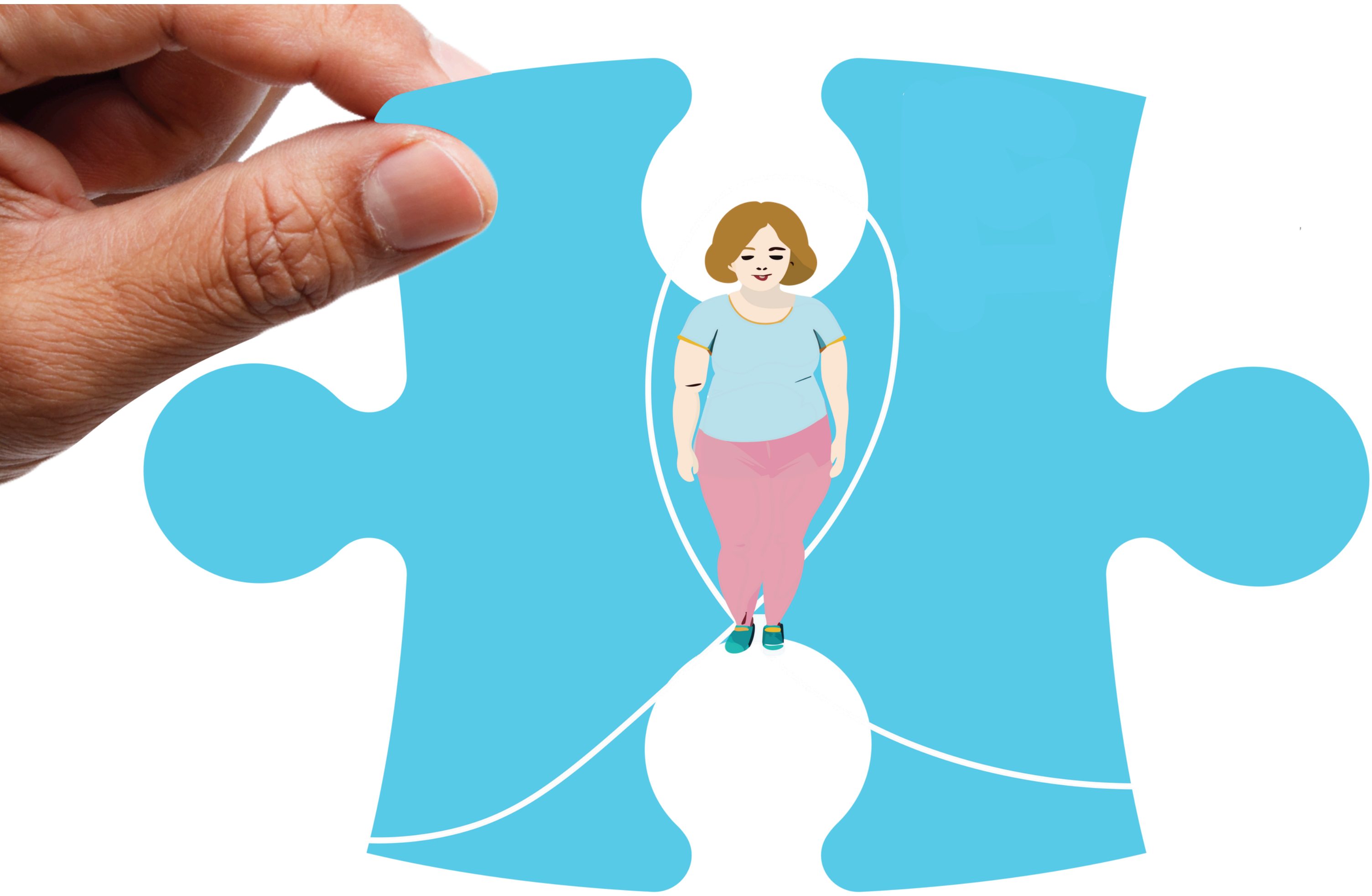
As well as the ability to adapt housing to meet changing needs, environmental factors need to be taken into account when developing housing for people with a learning disability. Anecdotal evidence suggests that in some cases, housing for people with a learning disability is being developed in areas that may be prone to flooding if sea-levels rise in future, as the land can be purchased more cheaply.

It is crucial that the safety and long-term security of housing for people with a learning disability is not jeopardised by environmental factors.

Local authorities and Integrated Care Boards need to:

Work together with housing providers to ensure that housing for people with a learning disability will not be developed in areas that are e.g., at risk of flooding

Person-Centred Support



Making sure that children, young people and adults are supported in a way that sees them as a person and as an individual, upholds their rights, and improves their quality of life

1

Ensure that commissioning is bespoke and person-centred

Support for people with a learning disability should be person-centred. For some people with a learning disability, for example people with severe or profound and multiple learning disabilities, support will have to be bespoke to them and their needs – they are unlikely to be able to 'slot into' existing services.

Commissioners need to be supported to develop and commission new and bespoke services if these are what is needed to meet the needs of someone with a learning disability in their area. However, many commissioners have reported not feeling supported to take 'risks' or not knowing what sorts of services can be commissioned.

The Department of Health and Social Care needs to:

Share good practice with commissioners to increase their knowledge of what services it is possible to commission

Resources

Why investing in early intervention for children with a learning disability is so important, with examples from practice

Developing effective local services for children with learning disabilities whose behaviour challenges

Commissioning services for children and young people with a learning disability whose behaviour challenges

Commissioning services for adults with a learning disability whose behaviour challenges

How to develop local pathways for children and young people with learning disabilities and/or who are autistic whose behaviour challenges

Extend the 'Small Supports' scheme

2

Small Supports is a programme led by NDTi that supports the development of small community organisations that provide person-centred support. NDTi and partners Beyond Limits, C-Change, Positive Support for You and the Local Government Association have worked to identify what conditions make it possible to establish and sustain these services, so that people with a learning disability and autistic people can live good lives in the community rather than being detained in inpatient settings.

Small Support organisations share nine key characteristics, including giving the person, their family, and their friends as much control as possible; recruiting staff by and around the person, rather than having the same staff working across different services; rooting the organisation in the local community; and "staying with" the person, not withdrawing support. As well as improving quality of life, Small Support organisations also benefit the local economy – for every £10 invested in care and support through Small Supports, an additional £6.90 is generated in value to the local economy.

NHS England needs to:

Extend funding for this programme, and/or other programmes that support the development of small-scale, person-centred services

The Building the Right Support Action Plan committed to supporting the development of Small Support organisations, with funding from NHS England for the next three years to expand the programme to different areas. However, for these organisations to be sustainable in a challenging market and with issues with staff recruitment and retention across the sector, there needs to be clear support for existing organisations and sustained funding for the long-term, not just the short-term.

NHS England and the Department of Health and Social Care need to:

Work with integrated care boards and integrated care partnerships to share information about the Small Supports programme (including case studies), and support people and organisations within different areas to establish and support organisations that share the nine key characteristics

3

Improve collaboration between Education, Health, Social Care, and Housing

Children, young people and adults with a learning disability need the different parts of the system to work together to support them, but too often this doesn't happen. Each of these different parts of the system – Education, Health, Social Care, Housing, and many others – work separately, with their own eligibility criteria and access processes. This disjointed approach is difficult for people with a learning disability and their families to navigate; it is ineffective; and it is not person-centred.

To get support right, there has to be a holistic approach – working together to support the whole person, rather than splitting their 'needs' into different sections without coordination. For this to happen, there needs to be willingness from the different parts of the system to work together, including sharing risks and sharing funding.

There also needs to be someone who is responsible for coordinating the different parts of the system and ensuring that they come together with the person with a learning disability and their families to plan and implement the right support.

The Department for Education, the Department of Health and Social Care and the Ministry of Housing, Communities and Local Government need to:

Produce joint guidance for local authorities explaining the importance of working in a joined-up way to support children, young people and adults with a learning disability

Ensure that people with a learning disability have access to culturally appropriate support

4

A person with a learning disability has the same right to be connected with their culture – including practices, religion, and traditions – as everyone else. However, too often people with a learning disability are not supported in ways that allow them to connect with or that respect their cultural backgrounds.

People with a learning disability from ethnic minority backgrounds and their families can be subject to discrimination (intentional or otherwise). For example, they experience significant health inequalities, compared to both people without a learning disability and people with a learning disability who are white.

For more information, click here

> …A young man from a minority ethnic background, whose settings seemingly do not appreciate the sensory significance of his cultural and religious background, including bright colours, cooking and prayers, which are not reflected in his daily life. Each visit by his mother starts with a hug and reciting a prayer together. This has a calming, reassuring effect and enables them to share a spiritual connection that has always been part of his life.
>
> Ethnic identity is important. For example, a speech and language therapist made a symbol card to represent this young man, using a picture of someone from an obviously different ethnic group. Her son was confused when this card was offered to him to put with the picture for his family's home, inviting a visit home; presumably thinking that this meant some strange young man might stay there instead of him.

Keeping in touch with home

Barriers that make it more difficult for people with a learning disability from ethnic minority backgrounds and their families to access services that meet their needs include:

- Language barriers
- Lack of knowledge/awareness of what support is available
- Views on caring and the role of the family
- Mistrust of services – often as a result of prior discrimination or poor communication
- Assumptions about what cultural views someone with a learning disability from an ethnic minority background and/or their family might hold
- Stereotyping/monolithic views of people from ethnic minority backgrounds – all people are individuals and there are many differences within and between different backgrounds

People with a learning disability from ethnic minority backgrounds, and their families, have the right not to experience discrimination due to disability, ethnicity, or religion. It is crucial that more work is done to support people with a learning disability and their families in culturally appropriate ways and to tackle the inequalities they face.

The Department of Health and Social Care needs to:

Produce guidance, including good practice examples, to support a) local authorities and b) integrated care boards to support people with a learning disability from ethnic minority backgrounds

Develop training on supporting people with a learning disability from ethnic minority backgrounds and their families

Integrated Care Boards need to:

Ensure that people with a learning disability are included in any strategies that they have for supporting and reducing health inequalities faced by people from ethnic minority backgrounds

Ensure that their strategy for supporting people with a learning disability specifically addresses support for people with a learning disability from ethnic minority backgrounds

Rights

Upholding the rights of children, young people and adults with a learning disability

1

Bring together different sources of data to improve monitoring and safeguarding

Reporting complaints, allegations, and concerns with services is one of the key ways of identifying safeguarding issues and abuse of people with a learning disability. However, there are currently a number of routes for reporting these. For example, they can be raised with the service directly; reported to the CQC; brought to the local authority; or taken to the Local Government and Social Care Ombudsman, among others.

Because these reports can be made to multiple places, it is difficult to capture a full picture of any concerns raised about a service. This could potentially result in issues being missed or dismissed, or an inability to identify patterns of concern due to not having all the data.

We recommend the establishment of a central database that can collect complaints, allegations and concerns from different sources, and which can then be used to monitor services. We believe that this would improve safeguarding and should help identify any issues/abuses at an earlier stage.

This recommendation builds on a similar recommendation made in Professor Glynis Murphy's second independent report on CQC's inspections and regulation of Whorlton Hall, and also reflects the findings of 'Safeguarding Children with Disabilities and Complex Health Needs in Residential Settings', which was produced following the abuse of 108 children at residential settings operated by the Hesley Group.

The Department of Health and Social Care needs to:

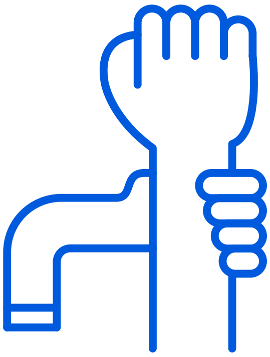
Establish a central database that can collect complaints, allegations and concerns from different sources, bringing them together so that they can be monitored and analysed and so that any patterns can be identified

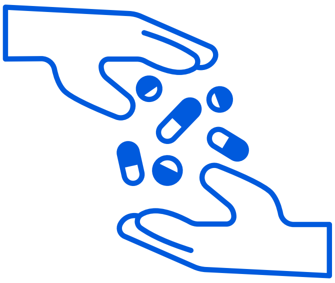
This is likely to require the involvement of the **Department for Education**, **NHS England**, **Ofsted**, and **CQC**, among others

Stopping the use of harmful restraint

2

Children, young people and adults with a learning disability, particularly those whose behaviour challenges, are frequently subjected to a range of restrictive interventions in order to control their behaviour. These interventions, including restraint, overmedication, and seclusion, are widespread and cause serious harm and trauma.





What are restrictive practices?

The term 'restrictive practices', commonly referred to simply as 'restraint', refers to a range of practices used to control behaviour and to restrict an individual's movement, liberty, and/or freedom to act independently. These generally fall under the following categories:

- **Physical restraint** – direct physical contact between the carer and person (e.g., being held on the floor)
- **Seclusion** – supervised containment or isolation away from others in a room the person is prevented from leaving (e.g., locking the person in a room)
- **Mechanical restraint** – materials or equipment used to restrict or prevent movement (e.g., arm splints)
- **Blanket restrictions** (including lack of access to certain places, belongings or activities)
- **Chemical restraint** – the use of medication in response to someone's behaviour (e.g., the use of sedative or antipsychotic medication such as Risperidone in response to behaviour that challenges rather than due to a diagnosis of psychosis)

In 2023, Baroness Sheila Hollins, an Emeritus Professor of Psychiatry of Learning Disability, published her report on the use of long-term seclusion - described in her report as solitary confinement - in inpatient hospitals for people with a learning disability and autistic people. The report confirmed that this had no therapeutic benefit, and instead caused serious harm and trauma.

This report backs up years of research that has found that children, young people, and adults are subjected to restrictive practices when they are unnecessary, and have experienced significant harm as a result of this. CQC's 'Out of Sight' report, published in 2020, details the human rights abuses that people with a learning disability and autistic people, as well as people with mental health conditions, face in mental health hospitals. Progress reports, published in 2021 and 2022, found that little had changed.

These restrictive practices are not only used in inpatient hospitals - they are also prevalent in schools. Research by the Challenging Behaviour Foundation and Positive and Active Behaviour Support Scotland, with additional analysis by the University of Warwick, surveyed 204 family carers and drew on an additional 566 case studies. This work identified that the use of restrictive practices against children with learning disabilities is widespread and causes physical and emotional harm. Over half of these cases included children between the ages of five and ten - the youngest child identified by this study as having experienced physical restraint and/or seclusion was two years old.

There is currently government guidance on the use of restrictive interventions against children and young people, but the evidence of this study - and many others - show that this guidance is failing for protect children and young people or to uphold their rights. While there is a commitment to update this guidance, and a consultation has been held, there is not yet a date for when this will be published,

In August 2024, the government committed to bringing Section 93a of the Education and Inspections Act 2006 into force from September 2025. This section, which mandates the recording and reporting of incidents of restrictive practice, is a positive step forward. However, it is not enough to require restraint to be recorded and reported - there must also be a focus on promoting person-centred approaches so that children, young people and adults are supported in the least restrictive way possible.

The Department for Education needs to:

Ensure families are informed when restraint is used on their child

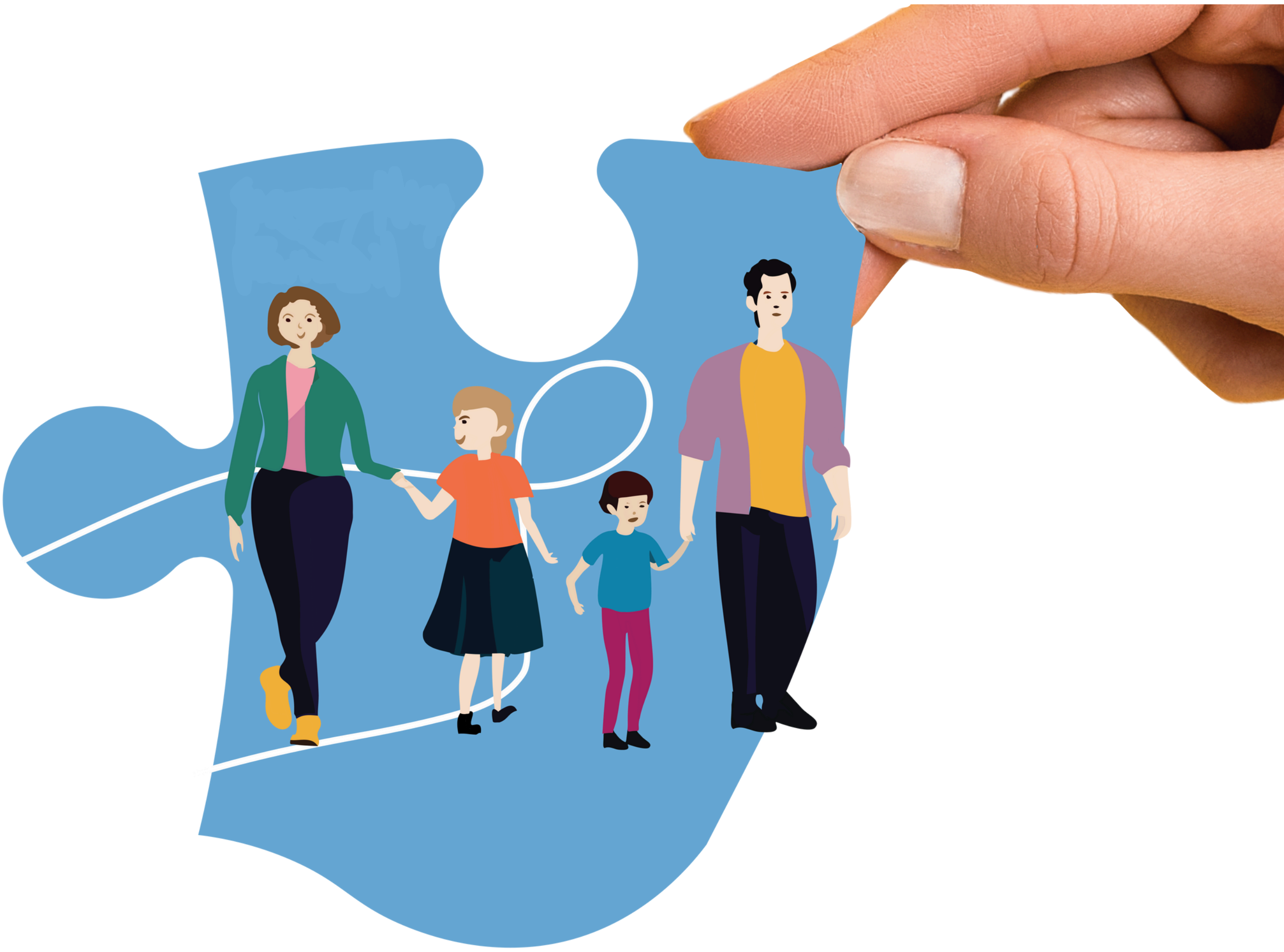
Introduce national training standards on use of force, restraint and other restrictive interventions in schools

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

Ensure that all guidance clearly defines restrictive practices

Clearly outline alternatives to restrictive practices, and support the implementation of these alternatives

Supporting Families



Making sure that the families of children, young people and adults with a learning disability are able to get the support that they need

1

Reform Carer's Allowance

Being able to get financial support can make a real difference to family members who support a relative with a learning disability, as well as all others who provide unpaid care. But there are serious issues with how Carer's Allowance currently works in the UK.

The 2024 Autumn Budget committed to increasing both the National Living Wage and the amount that carers can earn. This will mean that, from April 2025, carers will be able to earn up to £196 per week - a £45 per week increase - which equates to 16 hours per week at the National Living Wage. This is a significant step forward - but it does not address all of the issues with Carer's Allowance.

To claim Carer's Allowance, you must provide at least 35 hours per week care. However, if someone else who supports the same person claims Carer's Allowance, **you cannot claim even if you also provide 35 hours or more per week**. It can't be claimed if you study more than 21 hours per week, or if you receive a State Pension. Carer's Allowance is also deducted from Universal Credit entitlements. There is also a 'cliff-edge' - if you go over the earnings limit, the full amount has to be paid back.

These criteria mean that many people providing unpaid support to others, including family carers providing support to relatives with a learning disability, struggle with the cost of living. The high threshold for, and conditions of, eligibility mean that many people providing unpaid support cannot access it, and the low level of Carer's Allowance means that even those who are eligible struggle to make ends meet.

Research by Carers UK found that 2.6 million carers had given up employment in order to provide care and support in 2019 – and in 2023, 62% of carers had either given up employment (40%) or had to reduce their hours (22%) in order to provide care and support. A February 2024 report by the Centre for Social Justice found that 41% of carers who currently work are considering leaving the labour market or reducing their hours in the next year. However, many carers who have had to give up or reduce their hours want to work, but are barred from doing so by the eligibility criteria of Carer's Allowance and because they cannot access other support for the person they support.

The Joseph Rowntree Foundation (JRF) found that people providing unpaid social-care support are on average £414 a month poorer than if they were not providing this support – rising to over £600 a month (nearly £8000 a year) after six years of providing unpaid care and support. Family carers of people with a learning disability often provide continuous support throughout their relative's life, including well into their own 'retirement' - far longer than six years. The financial impact of caring for long periods, including into older age, is exacerbated by the fact that people receiving a State Pension are unable to receive Carer's Allowance, despite frequently providing significant amounts of support.

Linked with the reduced ability to work, carers are more likely than the general population to be in poverty. The JRF found that 22% of people providing over 20 hours of unpaid social care support per week were in poverty, compared to 18% of the general population – a finding supported by the Health Foundation. The Department for Work and Pensions (DWP) found that 1 in 5 households that receive Carer's Allowance live in food insecurity (nearly three times the rate of the general population), and 35% of carers receiving Carer's Allowance have had to cut back on food and heating.

While the steps introduced in the Autumn Budget 2024 are welcome, further reform of the Carers' Allowance scheme is needed to ensure that carers are supported.

The Government and the Department for Work and Pensions need to:

Increase the rate of Carer's Allowance

Increase the financial threshold for eligibility to incentivise and enable carers to work if they wish to do so

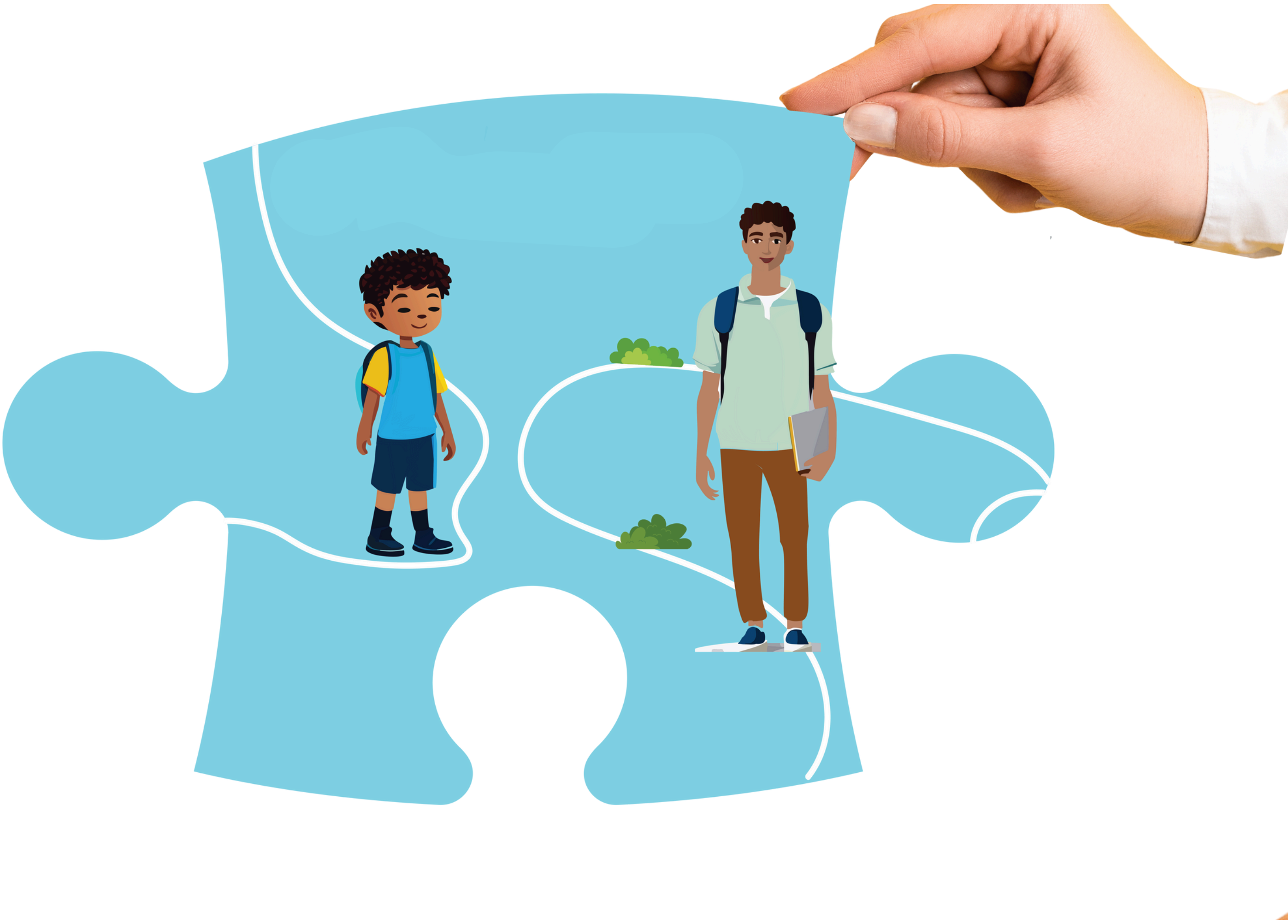
Change Carer's Allowance so that it is not deducted from Universal Credit entitlements

Enable people in receipt of a State Pension to claim Carer's Allowance

Enable people in more than 21 hours of education per week to claim Carer's Allowance

Cap and prevent large overpayment debts

Transition to Adulthood



Transitioning from children's services to adult's services is a critical time for young people with a learning disability - it is crucial to get this right

1 Ensure that there is a coordinated approach to transition to adulthood, bringing together children's and adult's services and the different parts of the system to work collaboratively together

Currently, there are significant issues with transition planning for young people with a learning disability. Transition planning is supposed to begin early, involve both children's and adult's services, and bring together the different parts of the system – Education, Health, Social Care, and Housing, for example – with the young person and their family to create a plan for the future.

But too often this doesn't happen – in some cases, adult services have only 'found out' about a young person with a learning disability a few days before their 18th birthday. The planning process is often complex, confusing, disjointed and hard to navigate.

> **“ In my experience nothing happens to prepare for adulthood! No one knows my son or has met him, and no one responds to emails about transition planning especially about independent living.**
>
> ***Family Carer***

Investing in transition planning at an early stage leads to positive outcomes for young people and their families. Failing to plan early can result in crisis situations including inappropriate admissions to inpatient mental health services, acute hospital wards and inappropriate out of area placements at distance from family and friends. There is often a heavy price to pay for the failure to plan both in terms of trauma to the young person and their family as well as increased financial costs due to the person requiring more intensive crisis support.

Transition is seen by young people with a learning disability and their families as a 'cliff-edge' - where rather than getting the right support, they fall off.
To address this 'cliff-edge', planning needs to start early and extend up to the age of 25 years. When young people transition to adult services, a lack of employment opportunities and meaningful activities, including the opportunity to socialise with peers, is often reported (particularly for people with complex needs).

Professionals and services should work collaboratively and maintain open channels of communication with the young person and their families. The means of communication should be tailored to the specific needs of the individual so that their voice can be heard and included in decision making processes. Too often the voice of the young person is not central to the process and families report being ignored and excluded. Family carers of a person with a learning disability often provide continuous and lifelong support to their relative and know and understand their needs best.

People with severe learning disabilities may be non-verbal and use alternative means of communication, so require staff who are trained in augmentative and alternative communication. Adapting the means of communication to suit the needs of the individual would enable them to fully understand and be included in decision making. A transition coordinator should work alongside other members of staff to deliver person-centred support and ensure that the individual and their family are fully included in each stage of the transition planning process.

Find more information and examples about person-centred, community support here

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

Write to all a) local authorities and b) integrated care boards to highlight the importance of starting transition planning early

Facilitate a transition community of practice including sharing examples of good practice and high quality training

Introduce a Transition Coordinator who is trained in augmentative and alternative communication and will help explain people's options, entitlements and rights, focusing on what is possible, not just available e.g. bespoke packages of care and support

Amend the Care Act 2014 to introduce a statutory age to start transition planning (aged 14 years) and ensure that there is a named social worker to lead the assessment and planning process and co-ordinate with other agencies

2

Under the Care Act 2014, local authorities are required to carry out an assessment of young people's support needs and prepare plans to meet needs if these are likely to extend beyond their 18th birthday. Planning should start when there is "significant benefit" to the child to do so, which families and professionals agree would be age 14. The Law Commission have recently consulted on a proposal to change the law to introduce a statutory age for transition planning. Investing in transition planning from the age of 14 will improve outcomes and reduce crisis situations.

Investing in transition planning at an early stage will improve outcomes and reduce crisis situations.

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

Amend the Care Act 2014 to introduce a statutory age for transition planning and ensure that there is a named social worker to lead the assessment and planning process and co-ordinate with other agencies

Ensure that transition support services extend to 25 years (on a case by case basis)

3

Introduce a national, cross-departmental plan for transition that is co-produced with young people with learning disabilities and their families

The Kids report 'On the cliff edge' calls for the government to publish a coordinated, national and cross-departmental plan for transition. The Minister for Special Educational Needs and Disability (SEND) should work together with named leads from relevant departments, including but not limited to the Department for Education, the Department for Health and Social Care, the Ministry of Housing, Communities and Local Government, and the Department for Work and Pensions. These key figures should co-produce this plan alongside young people with a learning disability and/or autistic people and their families, so that they are fully included in the planning process.

This plan should include an action to develop national standards that all local areas should adhere to. It is essential that any local areas who do not follow these standards are held accountable. We recommend that Ofsted and the CQC jointly review local areas' adherence to the national standards.

Named leads from relevant departments need to:

Work together alongside young people with SEND and their families to publish a cross departmental national plan for transition

Develop national standards for transition support and practice, including around data sharing, to avoid the need for young people and their families to repeat information multiple times

Ofsted and CQC need to:

Jointly review local areas and ensure that they adhere to the national standards

More information and guidance:

- CBF information packs: Planning for Adulthood - Challenging Behaviour Foundation and Transition Planning
- Kids: On the Cliff Edge
- Transition Information Network
- What Matters to Me: Transition Poster
- Cerebra's Transition Guides for Professionals and Families
- Local Government Association: Preparing for Adulthood - Young People with a Learning Disability and Autistic Young People
- NHS England Keyworkers: Children and young people keyworkers

We have worked to co-produce these actions and asks, building on years of work that has gone before it.

We are happy to engage with policy makers at a local, regional, and national level about how we can get things right for people with a learning disability whose behaviour challenges.

If you would like to talk about any of the actions in this plan, or any work you are planning on doing, please email actionplan@thecbf.org.uk