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

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

<u>Developing effective local services for children with learning disabilities whose behaviour challenges</u>

<u>Commissioning services for children and young people with a learning disability whose behaviour challenges</u>

<u>Commissioning services for adults with a learning disability</u> <u>whose behaviour challenges</u>

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

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.

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 needs to:

If the current three-year programme is successful, commit to continuing funding beyond this

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.

The Department of Health and Social Care needs to:

Introduce a statutory requirement for a Named Social Worker

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. We believe that this role could most effectively be filled by a Named Social Worker. By being a specific point of contact and able to build relationships with a child, young person or adult with a learning disability and their family, a Named Social Worker is able to advocate on their behalf and coordinate their care and support in a holistic and personcentred way. A scheme was piloted in 2018 and had positive outcomes for people with a learning disability as well as financial benefits.

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

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.



...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

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