

INFORMATION SHEET



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

Transition and moving services (child to adult services / to a new adult service)

This information sheet may be useful for families who are:

- Planning for **transition** to adult services
- Planning for their family member to move to a different type of support.
- Thinking of a long term plan for their family member's future life.

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback:

www.surveymonkey.co.uk/r/cbfresources.

Transition: This could mean a lot of things to different people. In this context it means, the preparation period before a child moves from children to adult services. This should start as early as possible or at the age of 14 (Year 9), the child's school should initiate the transition process and involve the family in the planning process. A key point in transition is when a person turns 18 and their funding changes from children to adult services. If the young person continues in education they will remain under their Education, Health and Care Plan (EHCP) up to the age of 25.

We all think about the future to varying degrees. Sometimes we have clear goals and expectations, and sometimes our plans are more general and vague. This is also true for family members supporting someone with severe learning disabilities whose behaviour is described as challenging. Mostly, we all want to have a good quality of life – to be happy, fulfilled and to share our lives with others we care for and who care for us.

Families caring for someone with a disability may often feel a greater need to plan, but may find it harder to think about the future, particularly when they are dealing with challenging behaviour on a daily basis – it's an easy thing to put off to another day! If the person does not have mental capacity to make the plans for themselves, family members are the ones who take up this responsibility and early planning and knowing your rights will help.

If a child or adult has severe learning disabilities and challenging behaviour it is likely that meeting their needs is a complex challenge that requires a great deal of information and time to get right. It is therefore crucial to think not only about current needs and support, but also to plan ahead and to try to think of all eventualities (including an "emergency plan" for unexpected events). Early planning is particularly important if you need to arrange or organise accommodation and care staff for your relative, as this can take time and involves co-ordinating other people who will provide care.

Person Centred Planning (PCP)

The best way to meet someone's needs is by placing the person at the centre of the whole process. In the past, and in times of budget cuts, the typical approach has been to try to fit a person into what is available. The Government says that this is not acceptable and that a person centred approach should be adopted (Valuing People, 2001 and Valuing People Now, 2009).

PCP: it puts the person first, and focuses on what they want in the future. It is an ongoing recording tool with a positive "vision" of what life should look like for the individual and what support is needed to achieve the vision, maintain it, evaluate and review it.

A PCP should focus on the individual's strengths, abilities, likes and dislikes. A range of people should help the individual in creating their plan; including family members, friends, support staff and other professionals involved in the person's life (for example, an advocate or social worker).

A PCP should be a living plan – an individual's needs and wishes can change over time, and a PCP should be adapted to keep up to date with these changes.

For more information on Person Centred Planning see:

- **Families Leading Planning** - www.bit.ly/2oQu9md
- **The National Autistic Society** – www.bit.ly/2IHSblm or call 0808 800 4104
- **Helen Sanderson Associates** – www.bit.ly/1zI82my or call 0161 442 8271
- **Mental Health Foundation** – Thinking Ahead: a planning guide for families (Section 2) – www.bit.ly/2lr9FQr
- **Foundation for People with Learning Disabilities** – www.bit.ly/1GQ9OFN

A PCP should be the overarching plan that draws all other plans together (such as health action plan, behaviour support plan and care plan). It can cover information on:

- How the person can be supported and stay healthy
- Who is important to the person
- How best to communicate with the person or information about their communication passport
- What they want for the future in terms of housing, support, education, employment and leisure.

However, it should be noted that a **PCP has no legal power** – it is considered best practice, and does not have to be done by law. It is essential therefore that alongside a PCP, the key requirements are within the person's **Care and Support Plan**, which a local authority has a legal duty to arrange services following a care and support assessment.

Care and Support Plan: It sets out how the help required will be given to the person and **must** cover all of the assessed needs. People with severe learning disabilities often need support from one or more support staff (or personal assistants) at all times, this would be recorded as a staff ratio of 1:1, 2:1 etc.

For more information on Care and Support Plans see:

- **The Challenging Behaviour Foundation information sheet** - Getting the best support package: Ten Top Tips – www.bit.ly/2mjxf0g
- **Mencap** – www.bit.ly/2mi9lx5 or call 0808 808 1111
- **NHS Choices** - www.bit.ly/1yVYhNh

Circles of Support

To ensure the person is supported in a person centred way, some families may set up a circle of support.

Circle of Support: is a group of people who meet together regularly to discuss how to help an individual with learning disabilities to accomplish their goals, dreams and aspirations. Members of the group can include parents, siblings, other relatives, friends, and professionals.

A circle of support will put in place plans of realising and ways how the individual can achieve their goals in life. A circle is an important way of ensuring that the individual with learning disabilities has someone to support them, improve their social life and ensuring that there is always somebody representing them.

For more information on setting up a Circle of Support for your son or daughter, see:

- **The Challenging Behaviour Foundation 'Circle of Support FAQ'** - www.challengingbehaviour.org.uk/being-family-carer/circles-of-support-faq.html
- **Circles Network** - www.circlesnetwork.org.uk

Finding the right support

Having considered the individual's needs, strengths, interests, wishes and dreams in a person centred plan, finding the right support to achieve these goals will be the next step.

There will be a range of options for all aspects of the plan:

- to see if the services required are already available
- to adapt some elements of what already exists to make it accessible, or
- to create something unique to meet the person's needs (there are different options available including support in your own home, shared house or supported accommodation).

A good service or support package should enable a person with severe learning disabilities to live an 'ordinary' life and to have **choice** and **control** over what they do, where, when and who with. This may require adaptations to the environment and will certainly need sufficient funding and sufficient support from appropriately trained staff.

The **Care Quality Commission (CQC)** carry out regular inspections to make sure service providers are offering people a safe, caring and high-quality service. You can check CQC reports about your relative's service provider on their website: www.cqc.org.uk. Where the person in a care service (such as independent or supported living accommodation) has their own tenancies, the CQC does not have a right to inspect the premises unless authorised by the tenant.

The **Driving up Quality** code aims to help people with learning disabilities get the best support possible from their service providers. Check whether your relative's service provider has signed up to the code here: www.bit.ly/2oBcVtW.

For further information on support such as service providers and personal assistants, please see:

- 'Getting it Right – A guide for families of people with learning disabilities on choosing a support provider and improving the quality of support' - (Contact the CBF for a copy.)
- **CBF**: Planning for the future information pack – www.bit.ly/2nwlu7W (Contact the CBF for a hard copy)
- **Skills for Care**: Employing your own personal assistant – www.bit.ly/2kAt5Vn

Equal Rights

The options for a person with severe learning disabilities and challenging behaviour should be the same as everyone else - they have the same rights as everyone else. Sometimes these rights are not met because individuals do not have the appropriate level of support they require in order to access those rights. For example, a person may not be able to visit their local swimming pool or cinema regularly, because suitable support plans are not put in place. This is unacceptable – the law (Equality Act 2010) and a number of government policies clearly state that people with severe learning disabilities and challenging behaviour **should** be supported to exercise choice and control to be part of their local community (Valuing People, 2001).

This means that a child or adult with severe learning disabilities whose behaviour is described as challenging has a right to:

- Live in their local area
- Have a family life
- Use community facilities (e.g. leisure centres)
- Access learning opportunities (e.g. college).

People with severe learning disabilities will require support to achieve this, and in addition service providers (including gyms, restaurants, leisure centres, colleges, transport providers, etc.) need to make reasonable adjustments to enable access to their services.

Emergency Plans

Unexpected emergencies (such as placement breakdown, family carer illness or challenging behaviour while in the community) happen all the time and it is important to have an emergency plan in place. Such a plan will help ensure continuity of care should an emergency arise. An emergency plan should include details of persons to be contacted in

case of an emergency and the person's health action plan or passport. Always consult others when creating an emergency plan and if you have had a carers assessment, your local authority should offer you help to develop an emergency plan. Also, note that in some areas there are **emergency card schemes** for carers whose family member relies on them for support. These schemes have been set up by local carer centres or local authorities or local Trusts. Once registered on the scheme you will be provided with a card and a unique identification number which will identify you when a call is made to the 24 hr emergency call centre. The call centre will dispatch help to your relative accordingly, following your emergency plan details on their system.

For more information on Emergency Plans

- For more information contact your local carers centre or trust or local council for more information on emergency carer card schemes in your area
- **Carers UK** – www.bit.ly/2osPOUU
- **Mental Health Foundation** – Thinking Ahead: a planning guide for families (Section 7): www.bit.ly/2lr9FQr

What next?

There are a range of tools and opportunities to develop creative, individual and flexible support tailored to meet an individual's needs; however it can sometimes be hard for families to know where to begin. The Challenging Behaviour Foundation information pack 'Planning for the Future' gives more information on the following themes:

- *Person centred planning*
- *Changes to rights at adulthood*
- *Choices*
- *Funding*
- *Safeguards*
- *Frequent challenges*
- *Who can help*
- *Questions to ask care providers*

The Mental Health Foundation produced a guide for families so they have the information they need at hand to think about and plan for the future of their relatives. See Thinking Ahead: a planning guide for families: www.bit.ly/2lr9FQr

Learning Disability England (LDE), formerly known as Housing and Support Alliance, has a number of information resources on housing and support options. See link for more information: www.bit.ly/2oB44s9

The Challenging Behaviour Foundation has also produced two housing guides:

- 8 Ways to get a house (contact the CBF directly for a copy)
- Planning your house (contact the CBF directly for a copy)

Please visit www.challengingbehaviour.org.uk to view or download these information packs, or contact the Challenging Behaviour Foundation if you would like to order a copy. (Information packs are free to family carers; and available to professionals at a small cost).

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The Challenging Behaviour Foundation

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

If you have found this information useful, please consider making a donation.

You can show your support at www.challengingbehaviour.org.uk/support-us.

Make a £5 donation by texting CBF DN05 to 70085

Or email us to get involved at support_us@thecbf.org.uk