

INFORMATION SHEET



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

Planning for the Future

Introduction

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. Mostly we all want to have a good quality of life – to be happy and 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!

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.

The CBF relies on the support of our friends and colleagues to continue to provide free resources to families.

Please see below for details of how to support us.

This information sheet may be useful for families who are:

- planning for *transition*
- planning for their family member to move to a different type of support
- thinking of a long term plan for their future life.

Transition is the preparation and move from children to adult's services. This should start at age 14 (Year 9), when the child's school/college should start working with the family to plan, up until 25 years of age. A key point in transition is when a person turns 19 as this is when funding changes.

If a child or adult has severe learning disabilities and challenging behaviour it is likely that appropriately meeting their needs is complex and requires a great deal of information. It is essential therefore 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). This is particularly important if planning accommodation and staff support, as this can take time and needs co-ordination of a lot of things.

Person Centred Planning

The best way to plan 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).

A **Person Centred Plan (PCP)** 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 the PCP should be adapted to keep up to date with these changes.

For more information on Person Centred Planning see:

- **Families Leading Planning** - www.familiesleadingplanning.co.uk
- **Mencap Direct** - <http://www.mencap.org.uk/mencapdirect> or call 0808 808 1111
- **The National Autistic Society** - www.autism.org.uk/working-with/social-care-and-support/person-centred-planning.aspx or call 0808 800 4104
- **Helen Sanderson Associates** - www.helensandersonassociates.co.uk/reading-room/how/person-centred-planning.aspx or call 0161 442 8271
- **Foundation for People with learning disabilities** - <http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/p/person-centred-planning/>

It 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 and
- 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 **statutory power** – it is considered best practice, but does not have to be done by law. It is essential therefore that alongside the PCP, the key requirements are combined with the *Community Care Assessment / Continuing Health Care Assessment* and *Care Plan*, which the local authority has a legal duty to carry out.

Community care assessment: This is where social services assess whether a person needs help in their home or out and about. This help may include personal care (e.g. washing and dressing), mobility care (adapting home to help moving around e.g. a wet room) or domestic help (e.g. shopping and cleaning).

Continuing health care assessment: This is similar to the community care assessment, except it is assessed and funded by the NHS.

Care plan: This plan 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 Community Care Assessments and Care Plans see:

- **The Challenging Behaviour Foundation information sheet** - *“Ten top tips,”* by Professor Luke Clements, Cardiff Law School, Director of the Centre for Health and Social Care Law.
- **Mencap** - <http://www.mencap.org.uk/all-about-learning-disability/money-benefits-and-assessments/community-care-assessments> or call 0808 808 1111
- **NHS carers direct** - www.nhs.uk/CarersDirect/guide/assessments/Pages/Communitycareassessments.aspx
or
www.nhs.uk/CarersDirect/guide/assessments/Pages/Thecareplan.aspx or call 0808 802 0202
- **Citizens Advice Bureau** - www.adviceguide.org.uk/index/your_family/family_index_ew/community_care.htm#CommunityCareHowtogetacomunitycareservi
- **Disability Law Service** - <http://www.dls.org.uk/Advice/cc.html>

Circles of Support

To put a person centred plan in motion, some families may set up a circle of support for their son or daughter. Members of the circle are generally people who have supported the individual in their life and could include family members, close friends or professionals. The aim of the circle is to focus on the needs and wishes of the individual.

Members of the circle meet up regularly and discuss with input from the individual their hopes and goals for the future, and plans how to make this happen. A circle of support is important to ensure an individual will continue to have people around them in the future who are focused on supporting them and helping their voice be heard.

For more information on setting up a Circle of Support for your son or daughter, see our related section at www.challengingbehaviour.org.uk

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 - there is a wealth of Government policy which clearly states 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 other people may need to adapt in order to meet their needs - hence the need for careful planning.

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 what is required is already available
- to adapt some elements of what already exists to make it accessible, or
- to create something unique.

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.

If you are considering a support provider for your son/daughter, there are a number of questions to ask to help you decide if they are suitable. A selection of questions other families have found useful are listed at the end of this information sheet.

The **Care Quality Commission** hold 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/

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.drivingupquality.org.uk/whos-signed-up

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' - <http://www.learningdisabilities.org.uk/content/assets/pdf/publications/getting-it-right.pdf>

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:

- *Know your rights*: What people with learning disabilities are entitled to.
- *Know the processes*: How to plan personalised support and how transition works.
- *Know who can help*: Explores the range of support available to help families in planning for the future.
- *Know the challenges*: Details some common challenges for families, and how to overcome them.
- *Know your options*: Explores the different options available for housing, education and employment.
- *Understanding the funding*: Information to help families have more control over the funding available.
- *Safeguards & protecting the individual*: Focuses on how to protect individuals from harm once support is in place.

There are 4 different versions of the Planning for the Future guides covering each nation in the UK; England, Scotland, Wales and Northern Ireland.

Housing

The Challenging Behaviour Foundation has also produced two housing guides:

- 8 Ways to get a house
- Planning your house

These guides aim to explain the different housing options available to people with learning disabilities, and the support available to access these options.

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).

Further support

The Challenging Behaviour Foundation can also link you up with other families to share any challenges you meet or ideas you may have.

- Family Linking Scheme – links you up with a fellow family carer who you can contact via phone or email and talk about any concerns you have.
- Family Carers' Email Network – an anonymous network where you can email family carers with specific questions or share your experiences.

Please download our application forms for the family linking scheme and/or email network via our website:

- <http://www.challengingbehaviour.org.uk/supporting-you/for-families/family-linking-scheme.html>
- <http://www.challengingbehaviour.org.uk/supporting-you/for-families/family-carers-email-network.html>

Or you can ask for an application via telephone: 01634 838739 or email: info@thecbf.org.uk

Questions to ask:

If you are considering a support provider for your son/daughter, there are a number of questions you could ask to help you decide if they are suitable:

QUESTIONS	RESPONSE/NOTES
<p>Person centred approach</p> <ul style="list-style-type: none"> • Can you provide an example of how you have changed your practice to meet the needs of an individual? • Can you tell me how you ensure that you always adopt a person centred approach? • How are PCPs used and updated over time? • What adaptations will you make to accommodate my son / daughter's needs? • How will you encourage my son / daughter to develop his / her skills? • Can you tell me how you will support my son / daughter to express their individual personality / identity? 	
<p>Activities and choices</p> <ul style="list-style-type: none"> • What will a typical weekday / weekend be like for my son / daughter? • How will you support my son / daughter to access community facilities? • How will you support my son / daughter in trying new activities? • What transport is available to enable my son / daughter to access community facilities? • How will you ensure my son / daughter has transport at the time it's needed, to access community facilities? • Are activities organised on a group or individual basis, or combination of the two? • If a group activity is arranged that my son / daughter does not wish to participate in, what will you do? • What sorts of choices will be offered? 	

<p style="text-align: center;">QUESTIONS</p>	<p style="text-align: center;">RESPONSE/NOTES</p>
<p>(ranging from breakfast cereal to activities and everything in between!)</p> <ul style="list-style-type: none"> • Will my son / daughter be able to access the internet? • How will you support my son / daughter with nights out (and staying out late)? • How will you support my son / daughter with long day trips? 	
<p>Family</p> <ul style="list-style-type: none"> • How do you support families to be actively involved in their son's / daughter's lives? • As a family member, if I wanted to, could I actively be involved in support e.g. interviewing staff? • Can you put me in touch with other families of people you support so that I can hear their views? • Can I visit / contact my son / daughter at any time? Can I visit without an appointment? • Are parents' consulted / involved in reviewing policies? • How will you keep me involved in changes about my son / daughter's care? 	
<p>Behaviour Support</p> <ul style="list-style-type: none"> • Can I see your behaviour management / physical intervention/adult protection policy? • How will you meet the behavioural needs of my son / daughter? • What professionals will my son / daughter have support from? (in-house & external) • Do you have a behaviour specialist / consultant or a behaviour team? • Do you use a positive behavioural support approach? (the recommended approach for challenging behaviour) Can you give me examples of this? • Do you use physical restraint? Are all your staff trained to use this, and is the training accredited by the British Institute of Learning Disabilities? • Do you use PRN (given as needed) medication as a way of managing challenging behaviour? How many people living here take medication to manage challenging behaviour? 	

QUESTIONS	RESPONSE/NOTES
<p>Support staff</p> <ul style="list-style-type: none"> • Will my son / daughter be able to choose his/her staff support? • How will you guarantee continuity of staff, ensuring that my son / daughter has: <ul style="list-style-type: none"> a) appropriately fully-qualified staff at all times b) staff with whom he / she is familiar? • Do you use agency staff? • What induction, training and ongoing support do your staff receive? (Look out for PBS/MCA training – can you give examples of this?) • Do all the staff that will support my son / daughter have a good standard of spoken English? • What appropriate support will be put in place if English isn't my son / daughter's first language? • How will you ensure that staff that support my son / daughter have the appropriate communication skills? What alternative communication methods are used? • If my son / daughter doesn't like a particular member of staff, how will you manage this? 	
<p>Other</p> <ul style="list-style-type: none"> • How will you ensure my son / daughter's health needs are monitored and met? • What does your complaints procedure involve? • How many safeguarding alerts were raised here in the last year? • How will you prepare my son / daughter for moving in? • How will you prepare my son / daughter if new people move in to the residence? • How will you support my son / daughter in maintaining friendships and making new ones? 	

With thanks to Jen Fookes and Mal and Richard Wasilewski for contributing to the questions for service providers.

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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
Make a £5 donation by texting Cbfd05£5 to 70070
Or email us to get involved at support-us@thecbf.org.uk