



**The Challenging
Behaviour Foundation**

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



Planning for Adulthood (England)
Support options, housing, personalisation
and transition to adult services



Contents

1. INTRODUCTION.....	3
2. LOOKING AHEAD	5
3. PERSON CENTRED PLANNING.....	9
4. CHANGES TO RIGHTS AT ADULTHOOD.....	13
5. CHOICES	16
6. FUNDING.....	31
7. SAFEGUARDS	37
8. FREQUENT CHALLENGES.....	41
9. WHO CAN HELP.....	45
APPENDIX: QUESTIONS TO ASK SUPPORT PROVIDERS	48

***Case studies are fictional but based on real life situations and the Family Support Service’s casework.**

Thank you to everyone who has contributed to this information pack and checked its accuracy.

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INTRODUCTION

All of us have plans for the future – either the near future or further ahead. Some of these plans are vague ideas, others are more concrete; some are simple to achieve, others take more thought and organising.

When your relative has severe learning disabilities and displays behaviour described as challenging, it is likely that they rely on support from the education, health and care system to meet their needs. Working across and in partnership with these systems can be complicated and daunting, involve a lot of different people and processes – and making things happen can take considerable time. It is for these reasons that planning for the future is important and needs to start early. I know from my own experience that it is important to understand your relative's rights, and to know what is possible, rather than just what is currently available.

When my son Daniel was 9 he was placed at a residential school over 250 miles away as there were no local services which could meet his needs. As he approached transition, we were clear that he needed a specialist service designed to meet his needs closer to his family.

It would have been much easier to try and "fit him" into an existing service, and this was the approach my local area was taking. But there was nothing locally and it was very unlikely that he would "fit" into anything! We had a much greater chance of success if we adopted a person-centred approach and designed his support and accommodation around him. We know what works and we know what is important to him. Daniel is now an adult, he lives less than a mile from our family home and his accommodation and support have been designed to meet his needs.

Daniel's return to his local area to a transition service, and then on to the single person service he needed, was not simple or straightforward – it was the product of a great deal of hard work and effort. It involved a lot of people and required navigating through various processes. At the root of it all was understanding what was important to Daniel – what worked for him and what he needed – and then finding a way to make that happen. He is happy now, enjoying life (still with challenges!) but the careful planning has paid off.

The key is to plan ahead and start as early as you can! Practical, accessible and timely information is essential, and this pack has been put together so that you don't have to do this on your own.

Family carers of children or adults with severe learning disabilities and behaviour described as challenging should be able to face the future in the knowledge that their loved one's support needs can be met, and their future can be safe, happy and fulfilled. Support and information to achieve this for your relative is available and this pack has been specifically developed in partnership with families to help.

A handwritten signature in black ink that reads "Vivien Cooper". The signature is written in a cursive style with a large initial 'V' and a long, sweeping underline.

Vivien Cooper - Family carer & CEO of the Challenging Behaviour Foundation

1. LOOKING AHEAD



While many families feel daunted and under-supported as they think about future options for their sons or daughters, there is an abundance of information available – if only you know where to look!



The purpose of this pack is to provide information specific to the needs of families caring for individuals with severe learning disabilities who are described as displaying behaviours that challenge. It is hoped that it will provide the tools families require as they start to plan for future support and opportunities for their sons and daughters, including education, housing, employment and community involvement for the individual.

We hope the information in this pack is helpful.

If you need further support you can contact the Challenging Behaviour Foundation's Family Support Team who offer casework support to families going through transition.

Contact us

- You can call the Family Support Service on **0300 666 0126**
- Or email us at support@theCBF.org.uk

We are open at the following times:

- Monday – Thursday: 9am – 5pm
- Friday: 9am – 3pm

TRANSITION PLANNING

Although there are many transitions in people's lives, in this pack the term **transition** is used to describe the period during which a young person is preparing to move into adulthood, i.e. from child to adult services, when young people are aged between 14 and 25 years old.

Transition should involve a range of people including the person and their family carers. The planning process should begin when it is clear what needs an individual will have once they turn 18. However, it is important to start as early as

possible so there is enough time to put the necessary support in place. For children with Education Health and Care Plans (EHCPs) this is in year 9 (aged 13-14), and must form part of the annual statutory review of their EHCP. Equally for those without EHCPs planning should begin as early as possible.

Key point: One thing we would say to all family carers: it's never too soon to start thinking about future options for your son, daughter or relative, particularly if they have severe learning disabilities and display behaviour described as challenging. When rushed it can lead to care that does not meet the person's needs or provide the support an individual requires.

Transition planning should begin with an assessment of your relative's needs. The Local Authority must indicate what needs are likely to be eligible for funding once the individual turns 18, in order for the individual to understand and plan appropriately for the care and support they are likely to receive. The assessment will then form the basis of a transition plan which sets out what you and your relative would like to happen when they become an adult, and the support that will be required to achieve this. It should incorporate all their needs (including educational, health, and social care), how services will meet these needs, and how the care provision will be funded. The Local Authority should provide a Local Offer as a starting point, which will inform families of the care and support provisions that are available in the local area.

Transition plans should be reviewed at least annually and cover all aspects of the young person's future, identifying the strengths and needs of the individual and including education, benefit entitlements, employment, housing, social and leisure opportunities and health and social care needs into adulthood. Once the transition plan has been agreed it should be reviewed regularly as *'Local authorities must ensure that the EHC plan review at Year 9, and every review thereafter, includes a focus on preparing for adulthood. It can be helpful for EHC plan reviews before Year 9 to have this focus too.'* SEND Code of Practice.

TRANSITION SUPPORT

It is often helpful to have one person co-ordinate the transition and planning. However, different areas have different ways of doing this, and therefore it is useful to find out what the specific service is in your local area.

Your relative's school should provide support. **Schools** have a legal duty to provide parents with information about transition, and **Head Teachers** are

responsible for convening the annual review meetings where transition is discussed.

In some areas the **Connexions** service can 'connect' all the stakeholders and co-ordinate the process. **Personal advisers (PA's)** working within Connexions provide a free and confidential information, advice and guidance service to all 13- to 19-year-olds and all individuals up to 25 years old who have a learning difficulty or disability. Your Connexions' Personal Advisor (PA) may be contacted through your child's school. If your child attends an out of area school, the Connexions PA attached to the school should liaise with the Connexions PA in your local area. For further information about whether there is a Connexions service in your local area contact your local authority.

A **Social Worker** or **Care Manager** may also be a key person who can co-ordinate the process and ensure that everyone who should be involved is included. They will be able to provide information about local services and support.

Some areas have specialist **Transition Workers** who aim to provide a range of support including advice for parents. Your local transition worker may be attached to the children with learning disabilities team, the adult team or the transition team within Social Services, and should ensure that there is good communication between the children's and adults' teams.

Your local **Learning Disability Partnership Board** will have a transition framework for your area and a Transition 'champion'. If you want to know more about how transition should work in your area, contact your local Partnership Board. Your local Council will be able to provide you with the Learning Disability lead contact who will have information about the Partnership Board.

KNOW YOUR RIGHTS

The [***Special Educational Needs and Disability \(SEND\): Code of Practice \(2014\)***](#) is guidance that accompanies the Children and Families Act 2014, a law that holds rights about disabled children's education. This document states there **must** be a transition planning meeting in Year 9 (age 13-14) of school and every year subsequently, with a focus of planning for adulthood. Furthermore, the document states that planning **must** be centred on the child's strengths and aspirations and what they want to achieve once they leave education. Planning **must** be built into the existing EHCP. The Act also requires that Local Authorities publish a "Local Offer", which includes information and care provided in the local area, including specific requirements for individuals preparing for adulthood.

FURTHER INFORMATION

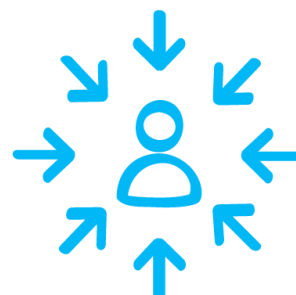
- ***Preparing for adult life***: A fact sheet produced by Contact. Visit www.Contact.org.uk Telephone 0808 808 3555 or fill out an [Online enquiry form](#)
- ***Prepared for the future***: Free information to prepare families when a young person with a learning disability is leaving school or college. Available from the Foundation for People with Learning Disabilities, email: fpld@fpld.org.uk or visit www.learningdisabilities.org.uk
- ***My kind of a future***: A free guide to help young people with learning disabilities prepare for the future. Available from the Foundation for People with Learning Disabilities, visit www.learningdisabilities.org.uk
- ***Transition Information Network***: www.councilfordisabledchildren.org.uk publish a magazine called 'My Future Choices' which is for disabled young people, families and professionals. It includes articles written by disabled young people about their experiences of transition, information about transition projects, the latest policy and charity news and resources. Email tin@ncb.org.uk
- ***National Development Team for Inclusion – Preparing for Adulthood***: has a variety of tools and resources to help prepare for adulthood including person centred planning. Visit www.ndti.org.uk

2. PERSON CENTRED PLANNING

The transition assessment should be built into a **person-centred plan (PCP)**. This involves a detailed plan of a person's transition, including key milestones for achieving goals.

WHAT IS A PCP?

A PCP ensures that an individual remains central to any plans made for their life, including their transition to adulthood. The PCP process is owned and controlled by the person (and sometimes their closest family and friends). It begins with the needs of the individual, and not with the availability of services.



WHAT SHOULD A PCP INCLUDE?

It includes a positive 'vision' of what life should look like for the individual, focusing on the individual's strengths, abilities and preferences. A PCP should also include the support needed to achieve the vision, maintain it, evaluate and review it. The plan can then be used to help obtain the services, and support, that the individual requires to achieve their 'vision'. The plan should be regularly reviewed and added to over time to keep it relevant and useful.

WHY IS A PCP SO IMPORTANT?

It focuses on core human rights such as having choices about the way an individual lives, being able to live as independently as possible and feeling included in society. Person-centred planning moves away from the philosophy of labelling an individual and instead focuses on their strengths, aspirations and quality of life.

WHO SHOULD BE INVOLVED IN DEVELOPING A PCP?

A range of people should be involved in creating the plan, including family, friends, support staff, an advocate and social worker as well as the individual themselves.

Your Social Worker or Care Manager will be a key person who can co-ordinate the process and ensure that all those who should be involved are included. They will be able to provide information about local services, support and opportunities.

Should you have any concerns about your son/daughter's current support and services, they will be the best people to contact in the first instance. If you do not feel that your concerns have been adequately dealt with then you should raise this with their manager.

Your local **Learning Disability Partnership Board** oversees all Learning Disability services in your area (your local Council will be able to provide you with the Learning Disability lead contact who will have information about the Partnership Board). Your Partnership Board is responsible for ensuring that people with Learning Disabilities are included in the local council's plans and are receiving the services they are entitled to.

CIRCLES OF SUPPORT

It is useful to have a circle of support when putting person centred planning in motion. This is where people who care about the individual such as family and friends can meet together, to discuss what's working and not working in a person's life. The meetings are often informal and personalised to the needs of the individual and the group. They provide a great way of focusing on the personal needs of the individual, as well as improving communication between families and professionals.

KEY POINTS

The key points to remember when you are trying to champion local individualised services or support for your family member are:

1. **Aim high.** Engage your relative in any way that is meaningful and appropriate and think about what an 'ideal' scenario for your relative would be. It may be that not all aspects of this vision will be achieved, but at least some will be.
2. **Identify 'allies'** that can help and support you. (The CBF is one!)
3. **Think creatively.** Don't accept that you can only choose from what is currently available.
4. **Don't give up** if you encounter barriers – barriers can be overcome.
5. **Find out what other families have done.** The CBF Family Carers' Email Network enables you to be in touch with a number of families around the UK. You can share experiences, information and receive support – without any obligation to reply or to identify yourself.

For more information visit [Family Carers' Email Network - Challenging Behaviour Foundation](#)

Whether you are facing transition or trying to change services or support for your relative, we know what a lengthy and difficult process it can be. There are times when you will forge ahead and other times when progress will seem painfully slow – and it may feel easier to ‘stay the same’ rather than try to change things. Don’t give up! Ask for help if you need it. At the CBF we know how hard it can be, and we will do all we can to support you.

Remember: It’s never too soon to start – and it’s never too late to change for the better!

KNOW YOUR RIGHTS

- **Valuing People Now (2007)** identified a key tool for improving the lives of people with learning disabilities: a Person-Centred Plan (PCP). *“A person-centred approach to planning means that planning should start with the individual (not with services), and take account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences of a person with a learning disability and covers such issues as housing, education, employment and leisure.”* Valuing People Now (2007). Although this is an older learning disability strategy, the principles still apply.
- **“The Children and Families Act (2014)** focuses on putting children and young people at the heart of planning and decision making through co-production and person-centred practice. It emphasises the importance of engaging young people and their families in all processes from developing and planning, particularly in relation to the Local Offer and Education, Health and Care Plans, and also in the commissioning of services and strategic decision making. In alignment with this the **Care Act (2014)** focuses on individual wellbeing with an emphasis on outcomes and person-centred practice.” ([Preparing for Adulthood: All Tools & Resources – NDTi](#))
- **CBF Family Carer Advocacy Resource** provides information for family carers who are advocating for or alongside their relative (aged 16 or over) [Family Carer Advocacy Resource – Challenging Behaviour Foundation](#)

FURTHER INFORMATION

- ***Circles of Support - Do I have to go this alone?*** (challengingbehaviour.org.uk)
- ***The National Autistic Society:*** [Making transition decisions \(autism.org.uk\)](http://autism.org.uk)
- ***Helen Sanderson Associates:*** Visit helensandersonassociates.co.uk
Or email info@helensandersonassociates.co.uk
- ***Foundation for People with Learning Disabilities:*** learningdisabilities.org.uk

3. CHANGES TO RIGHTS AT ADULTHOOD

There are many changes to consider – in education, healthcare and social care. Social Services are often split into children services (up until the age of 18 years) and adult services (post 18 years). This often means when a person turns 18 a change will occur as to which service is providing support, and the social service professionals working with your relative are likely to change, as well as what support your relative is entitled to. Please also see the CBF Family Carer Advocacy Guide: [Family Carer Advocacy Resource - Challenging Behaviour Foundation](#)



Two pieces of legislation prevent a gap of support during the transition from children to adult's services. The **Care Act (2014)** gives families the right to ask for an assessment of needs under adult services before their relative is 18 years old, meaning planning for the future is more effective. It also means that if adult services cannot meet the needs of the individual, they can continue to be supported by children's services after they turn 18. The **Children and Families Act (2014)** introduced Education, Health and Care Plans (EHCPs). These plans apply to individuals from birth until they are 25 years old. Plans for support required when an individual becomes an adult should be written into the EHC plan.

It is worth noting that some departments still have poor communication between child and adult services. For example, it is widely recognised that the Child and Adolescent Mental Health Service (CAMHS) stops at 16 years, but Adult Mental Health Services do not begin until 18 years, which often leads to gaps in care and support.

WHO IS INVOLVED IN MAKING DECISIONS?

When an individual with learning disabilities becomes an adult, it may be the case that families are less involved in decision making. For example, the law states that once an individual is 16 years old they are the primary decision makers concerning their educational support. However, this is only the case when the individual is judged to have the mental capacity to make such decisions.

The law acknowledges that individuals with severe learning disabilities may not be able to make these decisions.

The Mental Capacity Act (2005):

- Applies to everyone over the age of 16, and

- Assumes that everyone can make their own decisions unless it is proved otherwise (i.e. they have the capacity to make decisions)
- Says that a person must be given appropriate support to help them make decisions, ensure that his/her wishes are taken into account and that preferred communication methods are used to explain the options available
- Says no-one should be stopped from making a decision, just because someone else thinks it is unwise
- Looks at each decision a person needs to make separately. It may be that the person lacks capacity to make a particular decision e.g. where they should live, but this does not necessarily mean that the person lacks the capacity to make any decisions at all e.g. what to eat, wear and do each day
- If it is decided that someone lacks the capacity to make a decision and a decision is made for them, it must be in the person's **Best Interest**
- When a decision is made for someone who lacks capacity, the decision must be the least restrictive option possible for the person eg. locking a knife drawer instead of preventing access to the kitchen
- Professionals must consult with family members and take their views into account to make a best interest decision. Family members have the right to challenge professionals if they feel they are not consulted. Ultimately families can ask for decisions to be referred to the Court of Protection and can apply for Legal Deputyship if they feel their involvement is limited.

Please see [Rights and Advocacy - Challenging Behaviour Foundation](#) for more information and resources.

OTHER CHANGES AROUND THE TIME OF TRANSITION

People with learning disabilities over the age of 14 are entitled to an **annual health check** in recognition that they may find it harder to communicate their symptoms or recognise changes in their body. It is the provider of care's responsibility to make sure an individual receives an annual health check.

For information about health including accessing healthcare appointments please go to the following link: [Health - Challenging Behaviour Foundation](#).

Your **rights as a carer** change when your relative turns 18. Unpaid carers including family members have the right to request an assessment of needs for themselves. A carers assessment will consider what support carers might need to

continue in their caring role. For more information please see [Accessing Support with a Carers Assessment \(challengingbehaviour.org.uk\)](https://challengingbehaviour.org.uk).

FURTHER INFORMATION

- ***'Meeting the Challenge: How do my family member's rights change as they become an adult?'*** Visit bit.ly/1R0jhvg
- ***Making decisions: a guide for family, friends and other unpaid carers*** (OPG 602) visit [OPG602 \(ouh.nhs.uk\)](https://ouh.nhs.uk)
- ***Using the Mental Capacity Act. A resource for families and friends of people with learning disabilities.*** Home Farm Trust. visit [Hft | Family Carer Support | The Mental Capacity Act](https://hft.org.uk) or telephone 0117 906 1700
- **CBF Family Carer Advocacy Guide** provides information for family carers who are advocating for or alongside their relative (aged 16 or over) [Family Carer Advocacy Resource - Challenging Behaviour Foundation](https://challengingbehaviour.org.uk)

4. CHOICES

HOUSING

Individuals with a severe learning disability who display behaviour described as challenging can, with the right support and adaptations, live successfully in a range of housing. This includes individual self-contained properties, housing networks, group homes, and shared accommodation schemes and they can benefit from the full range of accommodation options, from renting to home ownership.



Probably the biggest decision you will need to make is whether a registered care home, supported living or staying in the family home is the best option for your relative. The main advantages and disadvantages of each are set out below:

Residential Care Homes

In the past, a residential care home was virtually the only option available to people with severe learning disabilities and behaviour described as challenging, apart from living with their families. A common approach was for the local authority to search for an existing residential home that had a vacancy and was willing to take the individual. However, the culture of 'fitting the person into what is available' has gradually been changing, and forward thinking residential care home providers are much more flexible and person-centred than they were in the past.

A residential care placement provides a 'complete' service of accommodation and care support.

The **advantages** of this approach include:

- A complete, 'all in one' package
- The service is usually up and running and can be viewed
- There is a contract with the local authority specifying what is provided
- The home is inspected regularly by the Care Quality Commission (CQC) against a range of standards

The **disadvantages** of this type of service include:

- If there are any difficulties, the service provider can terminate the contract and the person has to move out
- The individual is unlikely to have any say over who else lives there

- The individual is likely to have to share facilities with others who live there eg. kitchen, bathroom, lounge etc
- The service provider determines the future direction of the service (e.g. expanding, closing, changing)
- The local authority will require the individual to contribute most of his/her benefit income to cover the cost of food, bills, and housing. As a result the individual will be left with a small personal allowance

If you are considering a residential care home placement for your relative, you should obtain a copy of the contract with the local authority to ensure you are aware of what should be provided, and a copy of the most recent CQC inspection report. CQC inspection reports are available from the CQC website: www.cqc.org.uk.

CASE STUDY: Khan*

For the first 10 years of his life Khan had a loving home life with his mother. But things were not easy for his mother. She had other children to care for and was a single parent with a child that needed constant 24-hour levels of support, owing to his severe epilepsy and intensifying levels of challenging behaviour.

Khan enjoyed being around his peers at school and was used to living with his siblings. His family felt that living in a small residential service would offer Khan the support he needed and the social opportunities he enjoyed.

The family visited some services but decided that a home that had three other young men living in it already would be the best fit for Khan. They saw that the residents had their own individual spaces and were supported to do things they enjoyed as a group as well as individually.

Khan moved in and is enjoying his independence, but his family still help him to manage his finances and are able to visit him regularly as the home is only a short car journey away.

Supported Living

Supported Living is an individualised approach that enables people to choose where they live, how they live and who supports them. Supported Living means that an individual's accommodation is separate from their care support.

The **advantages** of this approach include:

- The accommodation and the care support required can be tailored to specific individual need
- The accommodation is the individual's own home, either by tenancy or ownership/shared ownership. (Shared ownership is a scheme whereby people part buy and part rent the property they live in [HOLD and shared ownership and step by step guide_FINAL.pdf \(local.gov.uk\)](#))
- The individual can claim housing benefit and other benefits
- The individual can choose who provides their care support
- The individual is in greater control of both their accommodation and their care support. As accommodation and care are separate, it means that the person can have security of tenure, cannot be moved against their will, and may be able to change their care provider if they so wish

The **disadvantages** of this approach include:

- It can be daunting/difficult to make it happen
- It can take time and effort to set it up and find suitable accommodation and a provider that can meet your relative's needs
- This is not a complete package – accommodation is provided separately from care
- Some supported living services cluster people together and insist they all receive care from the same provider

CASE STUDY: Charlie*

Charlie is autistic with a learning disability and high support needs and displays behaviours that challenge. He also has a diagnosis of Attention Deficit Disorder (ADD). He has some verbal communication, but it is only clear to those who know him well, and he is unable to answer only very simple questions.

Charlie was in a residential service but struggled to live in the busy communal areas. Following much pressure from his family and support from a psychologist, the Local Authority agreed a residential care home would too busy for him due to his ADD.

Charlie's family decided to look at shared ownership as a way to ensure Charlies needs could be met in ways that worked for him. They agreed a budget with the Local Authority, and found information about shared ownership for people with disabilities on the internet (a scheme called "HOLD"), and a Housing Association that was able to provide some support. Charlie's mum applied for a Deputyship from the Court of Protection to enable her to enter into financial agreements on Charlies behalf.

It took some time to get everything in place, but eventually Charlie moved in and he is much calmer and relaxed. He still goes home each month, and his family go to see him each week.

CASE STUDY: Annie*

Annie is 31 years old and has a rare genetic condition. She has a severe learning disability, is autistic with high support needs and has a hearing impairment. She has little spoken vocabulary and poor gross and fine motor skills (but she is ambulant) and she displays a range of challenging behaviours.

Her social worker put her name forward for a new venture. This was a large ex-council residential home which has been re-designed into 6 self-contained flats.

Annie's flat has 2 bedrooms to accommodate her 24-hour care needs, a lounge / kitchen / diner and a bathroom and the lounge has beautiful bay windows overlooking the sea.

The house is owned by a housing trust, and she receives Housing Benefit, Disability Living Allowance, Severe Disablement Allowance and Income Support. She pays telephone, gas, electricity, water rates, TV licence & a weekly contribution to her care by standing order. Her 24-hour care costs and 5 days attendance at a day centre are funded by social services.

She has her own bank account at her local branch and all her allowances are paid in and I've set up direct debits for all her expenses. I can oversee and manage the account and she has an arrangement to go in once a week with a carer to take out a set amount of money for day to day expenses. The carers keep a strict daily log of expenditure. Any further expenditure is negotiated via myself.

We can visit regularly on an informal basis, and she has a very busy and appropriate social life, choosing to join with others as and when she feels like it and not when it suits the staffing ratio.

Staying in the Family Home



Many young people do not move out of their family home at 18, and it is likely many individuals with severe learning disabilities and their families will choose to remain living together at least for a few years. This may involve using care services to provide support within the family home. It may also involve some minor or even major adaptations to the family home.

The **advantages** of remaining in the family home include:

- It may be the preferred and most logical option for everyone
- The individual will already be familiar with the environment
- It will allow the benefits and comforts of family life to continue alongside funded support

The **disadvantages** of remaining in the family home include:

- Uncertainty as to what will happen when relatives get older
- It can feel intrusive to have paid carers working to support your relative in your family home
- There may be a negative impact on other members of the family

CASE STUDY: Oliver*

Oliver is 27 years old and has many labels, including displaying behaviour described as challenging. During his childhood and teenage years, he experienced a number of exclusions from school, and breakdowns in care packages.

Oliver's family decided to set up Oliver's care and support in the family home. Adult social services awarded the family Direct Payments which enabled them to employ staff to support Oliver at home and in his local community. The family chose to employ university students who want to work in the learning disability field in the future. They found that short shifts, good terms and conditions, and excellent training means that this has worked well. Moreover, as the staff tend to be male, similar in age to Oliver, and do not have personal care responsibilities this enables them to act more as a mentor instead of traditional support staff which works for Oliver, the family and staff. The benefits of Oliver staying in his family home also mean the environment can be set up entirely to meet his needs: it is low arousal and can take his likes, dislikes and personality fully into account.

Living in the family home has meant Oliver has lots of community involvement and is well known and accepted locally. His behaviour is well supported, and this has led to a significant reduction in behaviours described as challenging.

Oliver's mum hopes that by showing that when Oliver is well supported and leads a good life his behaviour is well managed. If in the future Oliver needs to be supported full time outside the home this demonstrates how it can be achieved successfully.

Deciding where your relative lives is a very personal decision: it is important that the person is treated as an individual, they are supported to contribute as much as possible to the decision and the situation is constantly reviewed with the individuals' needs to make sure they are being met.

When you are choosing and visiting potential providers of services, or have identified a potential care provider, we have co-produced a list of questions to ask support providers – see appendix.

BROKERAGE

Brokerage is a way people can be helped to navigate the social care system. Through brokerage people can be helped to gain access to, funding for and receipt of the care and support they need or can help you identify how these needs might best be met and at what cost. Brokerage should ensure that the individual is fully involved and in control of choosing their own care package and its delivery. This is independent of whether people fund their own care or are supported in some measure by their council.



Brokerage can be provided by people who are specifically trained and employed as brokers or by members of the individual's family or friends who may not be paid to undertake the role. To find out more information **about the Support Brokerage Network** visit their website [About the Support Brokerage Network | Imagineer](#).

Some Local Authorities have their own Brokerage Team. Their role is the same as an independent broker and you should still be involved in planning how to meet your relative's needs. Information about how brokerage should work is here: [A short guide on brokerage and the role of brokers in relation to social care | Disability Rights UK](#)

FURTHER INFORMATION

Housing Support

- **8 Ways to get a house** and **Planning your house**: Two guides to help you with thinking about types of accommodation and planning living arrangements.
- **[Challenging behaviour: a guide for family carers on getting the right support for adults/teenagers](#)**: Two guides produced by the SCIE and CBF that cover what family carers should expect from local services. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone 01634 838739, e-mail info@theCBF.org.uk or visit challengingbehaviour.org.uk.
- **Learning Disability England**: A national charity with a range of housing resources. Visit: learningdisabilityengland.org.uk
- **Hft**: Provides local support services for people with learning disabilities throughout England. Website: hft.org.uk
- **CBF and PBS Academy resources: Questions to ask to check Positive Behavioural Support (PBS) is being used well**: Includes a PBS checklist for family carers which can be used when considering a school, a local authority, a day service or any other setting that could potentially provide PBS to support an individual with learning disabilities. Available from the PBS Academy and CBF. Free to family carers. Telephone 01634 838739, e-mail info@theCBF.org.uk or visit challengingbehaviour.org.uk / pbsacademy.org.uk
- **CBF Resource: Everybody Matters DVD**: Colleen and Shaun's stories show that everyone can be supported to live a full and active life in their community. You can order a copy from here: challengingbehaviour.org.uk
- **Advance Housing & Support for People with a Disability or Mental Health Condition (advanceuk.org)**: provide housing, support and other community

related services, specialising in supporting people with learning difficulties and mental health conditions.

- **Mencap:** Find out about housing advice, support and services you can access (mencap.org.uk)
- **Shared lives plus:** A scheme where an adult or young person who needs long term support is matched with a carefully approved Shared Lives carer, by their local Shared Lives scheme which are run or commissioned by council's adult social care services. (sharedlivesplus.org.uk)
- **Local Government Association - Housing for people with a learning disability or autistic people** (local.gov.uk)

CONTINUED EDUCATION

Currently it remains difficult in practice to ensure adults with severe learning disabilities whose behaviour is described as challenging have access to further education. If it is identified in an individual's EHCP that there is a need for the person to access adult education, a local college should be prepared to set up a relevant course if there are none currently running, and if it can be shown that there is sufficient demand.



There are a number of specialist residential colleges which provide accommodation, support and education for people with learning disabilities up to 25 years old. Specialist college places may be funded by your Local Authority if the type of education or support needed is not available at the local Further Education College.

CASE STUDY: Suki *

Suki is 18 and attends a SEN college with a focus on developing life skills. Suki has been accessing respite support at the weekends for a number of years and is transitioning to a supported living service near to her family home.

Suki has an EHCP and at her annual review it is recognised she has educational targets that she is still working towards. Suki's college allows learners to attend

until the age of 25. Suki continues to attend her college and her support workers help her to get ready and travel to the college every day.

Suki benefits from the familiarity of college whilst she is transitioning to her new supported living service.

KNOW YOUR RIGHTS

- **Ensuring Quality Services (2014)** states a model of care which is known to represent best practise. It states that commissioners should ensure that:
 - The individual is at the centre of planning and commissioning
 - Services such as housing and leisure activities should make appropriate adjustments to ensure support for individuals with a learning disability
 - Particular attention should be made during transition periods. Children and adult services should work closely together to provide support effectively
 - Education, health and social care services should work together to provide holistic support

Ensuring quality services for people with behaviour that challenges / Local Government Association

- **The Care Act (2014)** states the local authority must meet eligible needs of adults and carers when they have income or savings below the financial limit. Social services can still provide support for individuals whose income and savings are above the financial limit, however in this case the cost would need to be covered by the individual or carer themselves. If the person has eligible support or care needs, the local authority must produce a care and support plan for them, and a support plan for carers.

FURTHER INFORMATION

- *Association of National Specialist Colleges*: Visit natspec.org.uk or email info@natspec.org.uk
- *National Bureau for Students with Disabilities*: (skill.org.uk)
- *Disabled Student Allowance (DSA)* (ucas.com)
- *Contact – Education beyond 16* (contact.org.uk)

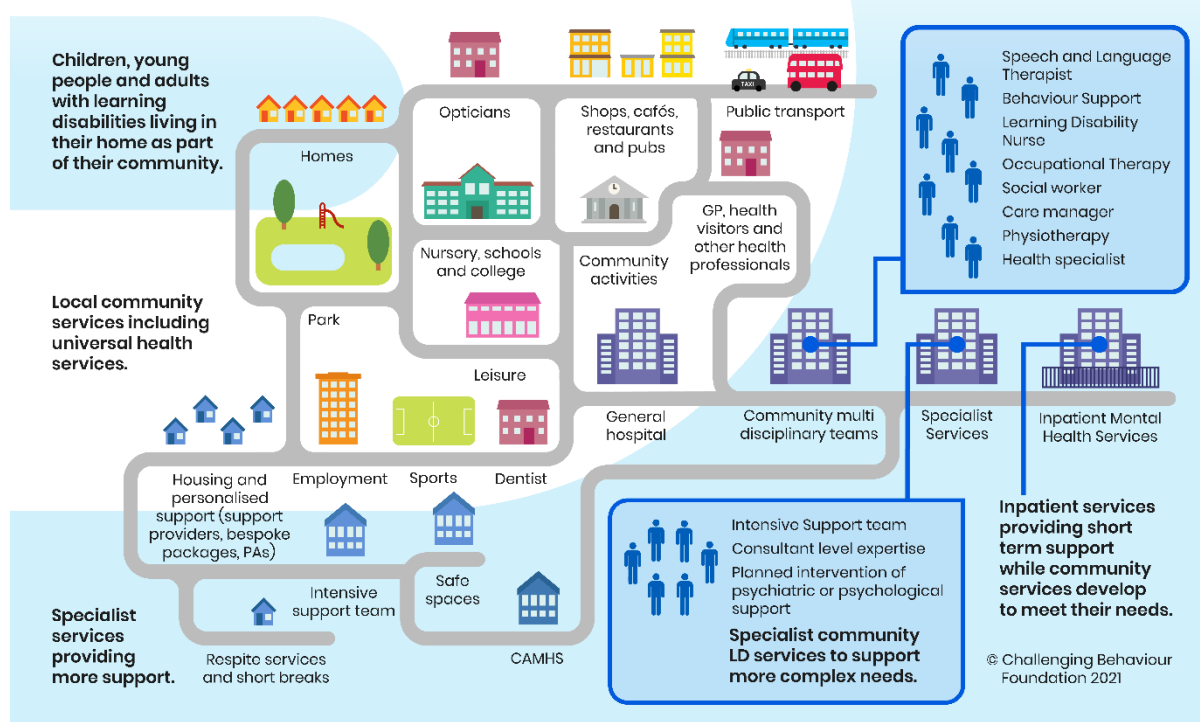
ACCESSING THE COMMUNITY



Individuals with learning disabilities have the same rights as everyone else including accessing community services such as the doctors, shops and restaurants. Appropriate support should be provided in order for individuals to exercise those rights.

Good community support for children, young people and adults with learning disabilities is...

 The Challenging Behaviour Foundation
making a difference to the lives of people with severe learning disabilities



There are traditional day services which offer a range of support activities in the local community. However, all communities have a duty under the Equality Act 2010 to make **reasonable adjustments** to enable people with disabilities to access them. Your relative's care and support plan should include community based activities and the practical help and support required to access them.

There are also clubs and events that are specifically designed for people with learning disabilities.

These include:

- Sports clubs
- Art and music groups
- Autistic friendly cinema screenings and theatre performances

- Nightclub events

KNOW YOUR RIGHTS

1. The focus of **Care Act (2014)** is on improving the *wellbeing* of adults needing care. Wellbeing includes the individual having control over their day-to-day life, and participation in work, education, training or recreation.
2. The **Equality Act (2010)** gives disabled people important rights of access to everyday services provided by local councils, doctors' surgeries, shops, hotels, banks, pubs, post offices, theatres, hairdressers, places of worship, courts and voluntary groups such as play groups. Access to services is not just about physical access, it is about making services easier to use for everybody. Service providers have an obligation to make **reasonable adjustments** to premises or to the way they provide a service. To find out more, go to www.equalityhumanrights.com.

FURTHER INFORMATION

Support with leisure activities:

- [Mencap](http://mencap.org.uk): Local Mencap groups offer support and activities. (mencap.org.uk)
- *County Sports Partnership*: You can contact CSP about local sporting and volunteering opportunities. Visit activeblackcountry.co.uk
- [Parasport](http://everybodymoves.org.uk): where you can search for disability sport and physical activity in the local area (everybodymoves.org.uk)
- [UK Sports Association For People With Learning Disability \(UKSA\)](http://uksportassociation.org): (uksportassociation.org)
- [Stay up Late](http://stayuplate.org): learning disability campaign promoting access to nightlife – because life doesn't stop at 9pm. (stayuplate.org)

- [Books Beyond Words](http://booksbeyondwords.co.uk): run book clubs for people with learning disabilities, to enjoy books without words in a social environment. (booksbeyondwords.co.uk)

EMPLOYMENT

Many people with learning disabilities want to have a job and like most people find being part of an organisation and contributing to the local community in this way very rewarding.

There are possible financial implications to paid employment that may need to be taken into consideration. Employment can affect the benefits an individual receives, and there are regulations about the type and amount of work someone can do without losing out financially. The Jobcentre Plus can give you more information about the regulations. See their website at [What is the Jobcentre Plus? \(jobcentreguide.co.uk\)](http://jobcentreguide.co.uk).

For individuals with severe learning disabilities an approach known as 'job carving' may be helpful. With a 'job carving' approach, an individual is assessed and their strengths, abilities and interests are noted and utilised to think about what sort of job the person would enjoy and what support or adaptations might be needed to enable them to perform it. This may be an existing job that the person can do with support or it may be a new role created with that individual in mind. This can be done in conjunction with a particular employer who will then support the individual in performing their role. This approach has been used successfully in America for several years and has seen individuals progress through jobs as they gain confidence and skills. For more information see: [Job carving and job design | British Association for Supported Employment \(base-uk.org\)](http://base-uk.org).

Job centres have schemes to help support people to find employment, and other local and national organisations such as [Mencap](http:// Mencap) also run schemes to help people find and maintain employment.

CASE STUDY: Ben*

Ben, 36, has spent most of his life in specialist services. He attended a special school from the age of four, moved to an Independent Specialist college at 18 and

then into residential care at 20. Ben has a severe learning disability and epilepsy. He finds it difficult to communicate and presents some behaviour that others find challenging.

In 2007, Ben moved into a single occupancy bungalow as part of a programme that enabled people to move from residential care to their own tenanted accommodation. Through person-centred planning, Ben demonstrated his happiness with his new living environment and began to show a keen interest in finding paid work.

The people working with Ben started to think about how they could re-structure his support package to help him gain paid employment. The staff had a good knowledge of Ben's skills and preferences; he preferred working on a one-to-one basis, avoiding crowds, and liked to work outside on tasks involving lots of physical activity.

The employment service approached employers and found three who were willing to 'job-carve' in order to create employment for Ben. Support staff who already knew Ben well, helped induct him into each job.

Ben began paid employment. His first job was three hours a week. He then started his second job, working three hours a week throughout August, and in September, began working a 10 hour week. He is working as a gardener and his tasks include mowing, weeding, planting and digging.

For Ben, the impact on his life of moving into his bungalow and into work has been incredibly significant. As a result of the changes to his life, his challenging behaviour reduced in frequency, his epilepsy appeared more controlled and his relationship with others improved. He appeared happier, more relaxed, more able and willing to communicate and more in charge of his life.

KNOW YOUR RIGHTS

- **“Valuing Employment Now: Real jobs for people with learning disabilities (2009)”** sets out the government’s goal to radically increase the number of people with moderate and severe learning disabilities in employment by 2025.
- The **Equality Act 2010** aims to protect disabled people and prevent disability discrimination. It provides legal rights for disabled people in the areas of employment, education and everyday services. The Equality Act 2010 makes it unlawful for an employer to discriminate against or harass a disabled person. Employers must make reasonable adjustments for disabled people, throughout the recruitment process as well as once a person is in post. To find out more, visit: [Equality Act 2010: guidance – GOV.UK \(www.gov.uk\)](http://www.gov.uk/equality-act-2010-guidance)
- [Equality Act 2010: What do I need to know? A summary guide to your rights \(gov.uk\)](http://www.gov.uk/equality-act-2010-what-do-i-need-to-know)

6. FUNDING

There are a range of ways that your relative's care and support might be funded across education, health and social care. Your relative's support may be funded by one or more sources and their Social Worker should be able to explain the options available.

PERSONAL BUDGETS



The Local Authority has a duty in law to meet an individual's eligible social care and support needs. The sum of money provided in order to do this is called a Personal Budget. Since the Care Act 2014 came into force, the Local Authority must give everyone who has eligible needs a personal budget, giving people greater choice and power to make their own decisions about how their needs are met.

The Local Authority will tell you how much they think you are entitled to (this is known as an indicative budget) before you look at the Care and Support plan being created. The final allocation of the Personal Budget will be decided through the planning process and when the plan is 'signed off' by the Local Authority. Everyone involved should have transparent information about how the Personal Budget is calculated and how much money is in it. The money must be able to fund support to meet all individual's eligible needs – this means that the final amount may be more than the indicative budget.

You should also have a choice about how this Personal Budget is managed. There are several options:

- The money can be managed by the Local Authority who will purchase and organise the care and support, in line with the individual's needs and wishes.
- A third party known as an Individual Service Fund (ISF) can also be chosen to manage the personal budget. The person (and/or their family, advocate or carer) can choose an organisation to manage the budget on their behalf and work with them to plan care and support services and activities that will help them to meet their eligible social care needs. You can find more information here: [Individual Service Funds guide Aug2020 \(skillsforcare.org.uk\)](https://www.skillsforcare.org.uk)
- It can be managed directly by the individual or by someone on their behalf, like a family member, if the person does not have the capacity to manage

their care package. This is known as a Direct Payment, for more information about Direct Payments, see below.

- It can be decided that the personal budget is a “mixed package”: a combination of any of the three – whatever works best for the person to get their needs met!

DIRECT PAYMENTS

Part, or all, of the personal budget can be made available to the individual (or a relative if the person lacks the capacity to manage it) so they can plan and finance their support themselves. You can do this by requesting a Direct Payment, and Local Authorities should support people in making such a request. This means that the person and/or their family or circle of support is given the money, purchases the support they want and is in control of the services providing support. You cannot be forced to accept Direct Payments and can only be prevented from doing so in very specific situations. However, the Direct Payments can only be used to meet your relative’s eligible care and support needs.

If you use a Direct Payment to purchase care directly and employ Personal Assistants, you may become an employer. This could include paying wages and arranging contracts with employees. Any extra legal costs incurred by becoming an employer should be included in the personal budget. This can be appointed to a third party, such as a family member, who can organise the ‘business’ end. The Local Authority should support people to use and manage their direct payments to commission and buy the care they need.

If someone lacks the mental capacity to request direct payments in order to meet their care needs, an authorised person can request direct payments on their behalf. This person must be deemed as someone who will act in the person’s best interests, be capable of managing the payments, and of using the funding to meet the individual’s needs.

DIRECT PAYMENTS FOR ADULTS LACKING THE CAPACITY TO CONSENT

All councils have a duty to offer direct payments to eligible adults who lack the capacity to consent to receive them. When an adult lacks capacity to consent, a Direct Payment can be made to a willing and appropriate **‘suitable person’**, such as a family member or friend. The family member or friend then receives and manages the payments on behalf of the person who lacks capacity.

The Mental Capacity Act (2005) must be followed when Direct Payments are arranged for someone who is unable to make decisions about how their care is funded. The Mental Capacity Act is explained in more detail in the CBF Family Carer Advocacy Resource: [Family Carer Advocacy Resource - Challenging Behaviour Foundation](#).

The Local Authority can also agree to make the funding available to a Trust or a Deputy appointed by the Court of Protection.

- **A Trust** is a legal arrangement of a group of at least three people 'the Trustees' who will own and manage money and/or property for the benefit of another person. Trustees take responsibility for organising, managing and monitoring a person's funds on behalf of a person who lacks capacity to receive and manage a Direct Payment. Trustees set up a bank account in the Trust's name to receive payments and have legal obligations to fulfil. Trustees can only act jointly and unanimously in decisions regarding trust funds.
- A Property and Affairs **Deputy** is someone appointed by the Court of Protection to make decisions in the best interests of people who lack capacity. This type of Deputy can make specific on-going decisions as set out by the Court on behalf of the person e.g. to manage their bank accounts, to sign tenancy/mortgage forms or to receive a Direct Payment. One or more family member can take on this role, or another responsible person appointed by the Court. For the CBF guide to Deputyship, please go to the following link: [Deputyship - Challenging Behaviour Foundation](#).

CONTINUING HEALTHCARE FUNDING

Continuing Healthcare Funding is provided solely from NHS as part of a care package for anyone outside of hospital who has a continuing primary health need. This funding is used to meet health and related social care needs such as residential home costs, therapy, personal care etc. Eligibility for NHS Continuing Healthcare is determined through the use of a Decision Support Tool which looks at their level of need in 12 domains. For more information please see: [NHS Continuing Healthcare Decision Support Tool guidance \(publishing.service.gov.uk\)](#)

PERSONAL HEALTH BUDGETS

A personal health budget is an amount of NHS money that is allocated to support your relative's health and wellbeing needs. If they are eligible, your relative (or a family member or carer), will work with your local NHS team to plan how to spend the money and get the care they need.

A personal health budget allows you to manage your relative's healthcare and support such as treatments, equipment and personal care, in a way that suits them.

If your relative is eligible for Continuing Healthcare this works in a similar way to the Personal budget, where a care plan is devised with the person that identifies how this money will be used to meet their health needs. The money can be managed in a range of ways including the NHS, a third party or in the form of direct payments. Personal Health Budgets are available for people who do not receive Continuing Healthcare if they have other health needs at the discretion of your ICB.

JOINT FUNDING

There may be some people who will have eligible social care needs and eligible health needs that both need to be met. In such cases, these people will be eligible to have care packages funded jointly by the NHS and their Local Authority. The introduction of Personal Health Budgets, similar to Personal Budgets in social care, means that it is much easier to pool these budgets together.

The Local Authority should provide information to the individual about the possible benefits of joint funding, as well as drive integration with health professionals to combine funding when possible. Joint funding should not lead to duplicate processes or increased monitoring. In cases where an individual's care package is jointly funded, the Local Authority should 'take the lead' to oversee monitoring and assurance. The Local Authority should agree with the NHS how integration should occur, and to what extent. For example, the proportion each funding body provides can be equal, or different.

Local areas, now organised into Integrated Care Boards (ICBs), are encouraged to develop Integrated Personal Commissioning where all health and social care support will be fully joined up. More information on the IPC sites can be found at www.england.nhs.uk/commissioning/ipc/.

DISABLED FACILITIES GRANT (DFG)

A person with a disability who owns the property they live in, or is a tenant, may qualify for a disabled facilities grant. This can go towards the cost of providing adaptations and facilities that enable the disabled person to live independently and safely in their home, as well as to make caring for them easier. Such grants are given by Local Housing Authorities.

For a person under 19 years the grant is not means tested, but a financial assessment will be conducted for those 19 or over. If the disabled person is on certain benefits, they will not normally have to make a contribution.

Contact your local Housing or Environmental Health department of your local council for more information or visit [Disabled Facilities Grants: Overview - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/topics/disabled-facilities-grants).

BENEFITS

- **Universal Credit** – payment to help with living costs if you are on a low income, out of work or you cannot work.
- **Employment and Support Allowance (ESA)** – a benefit for people who have a disability or health condition that affects how much they can work.
- **Personal Independent Payments (PIP)** – available for 16–64 year-olds to help cover the costs of long-term ill health and disability.
- **Carers Allowance** – if you care for someone at least 35 hours a week and they get certain benefits.

Employment can affect the benefits an individual receives, and there are regulations about the type and amount of work someone can do without losing out financially. The Jobcentre Plus can give you more information about the

regulations. See their website at [Contact Jobcentre Plus: How to contact Jobcentre Plus - GOV.UK \(www.gov.uk\)](#) or telephone your local office.

KNOW YOUR RIGHTS

- The **Children and Families Act (2014)** states that families have the right to request a personal budget if they have an EHCP. Families also have the right to request a direct payment. This promotes better choice and control for families.
- The **Care Act (2014)** states that care and support plans for people over 18 must include a personal budget.

FURTHER INFORMATION

- [Personal Budgets and Direct Payments \(nhs.co.uk\)](#)
- '[Direct payments: frequently asked questions](#)', available free from the Social Care Institute for Excellence (SCIE). Visit: [scie.org.uk](#)
- [Independent Lives](#): provide a range of support services to help manage direct payments including advisors and payroll services for personal assistants. ([independentlives.org](#))
- [Penderels Trust](#): offers a number of services to support people make the most of their personal budget/direct payment, from advice and guidance when employing a personal assistant to money management and training. Email birmingham@penderelstrust.org.uk or visit [penderelstrust.org.uk](#)
- Information on "Deputies" and the "Court of Protection" including information booklets and application forms is available from: The Office of The Public Guardian [publicguardian.gov.uk](#)
- Becoming a Deputy: information sheet '[Getting legal authority to make decisions about money](#)' Available from the Challenging Behaviour Foundation.
- [Support Brokerage Network](#): Support Brokers act as independent facilitators working alongside people, supporting them to plan to live the life of their choice. ([imagineer.org.uk](#))

7. SAFEGUARDS



Individuals with severe learning disabilities whose behaviour is described as challenging are at increased risk of abuse. Abuse can take many forms, from the more obvious e.g. physical abuse to the less obvious e.g. financial or emotional abuse. The risks are increased because:

- They are likely to have poor communication skills
- Their behaviour is described as challenging
- They are likely to be dependent on others for day-to-day support

It is therefore essential that services and supports for individuals who have severe learning disabilities who display challenging behaviour are person-centred and understand why the person behaves as they do.

Different service providers may have different approaches to supporting people who display challenging behaviour. It is important that you check out the approach used by any service that you are considering using by asking for a copy of any policies relating to behaviour before you agree that it is suitable for your relative.

Services should have appropriate monitoring mechanisms in place to minimise the risk of abuse, detect potential abuse, highlight indicators of abuse and be aware of and prevent closed cultures. In addition, a number of other safeguards can be put in place to protect individuals.

STATUTORY REQUIREMENTS

1. Policies & procedures

The following policies and procedures should be in place and regularly reviewed and updated, with copies available on request:

- A comprehensive adult protection policy
- Behaviour management policy
- Physical intervention policy
- Risk assessments

In addition, there should be a clear complaints procedure. Complaints should be formally investigated, and findings acted upon.

2. Monitoring and Inspection

Services are checked by agencies to ensure correct procedures are in place to protect vulnerable individuals. Services for adults are inspected by the [CQC](#) (Care Quality Commission). Services for children (e.g. residential schools) are inspected by [Ofsted](#) (the Office for Standards in Education, Children's Services and Skills). Families should report concerns to the CQC. The CQC inspection framework consists of four key lines of enquiry:

- Is the service safe?
- Is the service effective?
- Is the service caring?
- Is the service responsive?
- Is the service well led?

Services can then be given one of four ratings; outstanding, good, requires improvement or inadequate. Inspection are available.

3. Staff checks

The Disclosure and Barring Service (DBS) is a UK agency that helps employers make safer recruitment decisions and prevent unsuitable people from working with vulnerable groups, including children. The DBS process requests criminal records checks and decides whether a person should be placed on or removed from a barred list. The DBS was created as a replacement for the Criminal Records Bureau and the Independent Safeguarding Authority.

By making statutory checks against the list, providers of care must not offer anyone on the list employment in care positions. Checks are requested as part of disclosures from the Disclosure and Barring Service.

OTHER SAFEGUARDS

▪ Separating housing and care provision

People whose behaviour is described as challenging who are placed in a registered care home are vulnerable to exclusion if problems arise. This could mean that a person is given notice to leave the service. However, if the housing provision is separate from the care provision, the individual can remain in their home, and the care provider can be changed if necessary. This situation enables the individual to have greater control of his/her life because they can change their care provider without losing their home.

▪ **Independent Advocacy**

An advocate is someone who helps make the wishes and opinions of an individual known, and often families act as powerful advocates for their family member. However, there may be conflicts of interest at times, and sometimes family carers are not aware of all the opportunities that are available. Independent advocacy aims to be an effective way to help the person with a learning disability to have a stronger 'voice', and you should ask about advocacy services available in your area.

However, it is important to note that advocacy for someone with severe learning disabilities whose behaviour is described as challenging is a skilled role and will require a great deal of time, commitment and expertise if it is to be done effectively.

There are different types of advocacy and their availability and funding for them varies: [What-is-Advocacy.pdf \(challengingbehaviour.org.uk\)](http://challengingbehaviour.org.uk/What-is-Advocacy.pdf)

Families rightly feel they should have a role advocating for their relative, and professionals often have a professional duty to advocate. An individual is best supported where families, professional carers, and independent advocates, all recognise their separate roles, but work together.

KNOW YOUR RIGHTS

According to the **Care Act (2014)**:

- If an adult needing care would experience substantial difficulty in participating in their social care assessment and / or the preparation of their care and support plan, then the local authority must make sure they have someone suitable to help.
- If the local authority is satisfied that there is some other person who is a suitable representative (e.g. a family member or friend) they will not need to provide an advocate.
- Local authorities must also provide an advocate for carers if they feel that the carer needs help to be fully involved in the preparation of their carers assessment or support plan.

FURTHER INFORMATION

- **CBF Family Carer Advocacy Resource:** [Family Carer Advocacy Resource - Challenging Behaviour Foundation](#)
- [Deprivation of liberty safeguards: resources - GOV.UK \(www.gov.uk\)](#) gives clear information about the Deprivation of Liberty Safeguards to ensure the correct process is followed when someone needs to be deprived of their liberty.

▪ **Deprivation of Liberty Safeguards (DOLS) and Deprivation of Liberty Orders**

People with severe learning disabilities should be cared for in ways that promote their independence, well-being and choice. However sometimes people with severe or profound learning disabilities are deprived of their liberty for treatment or care because this is in their best interests to protect them from harm. Where an adult has continuous supervision and/or is not free to leave their home or place they are staying, then a Deprivation of Liberty Safeguards (DoLS) authorisation will need to be put in place if they live in a registered care home or are in hospital. If they are living in their own home or in the family home, an application will need to be made to the Court of Protection for a Deprivation of Liberty Order. A DoLS is also needed for other specific restrictions on the person and family carers should be consulted as part of the process.

8. FREQUENT CHALLENGES

It is important to ensure that the process of developing appropriate adult services is well-planned and carefully managed and brings together all the people who have an interest in the individual. However, this can be a complex process, particularly for people with challenging needs. There are many reasons for this, and the table below shows some of the most common difficulties you may face – with some of the keys to tackling each issue set out alongside.



THE 'PROBLEM'	THE SOLUTION
<ul style="list-style-type: none"> • Encountering a 'fit the person into what's available' approach rather than a person-centred approach. 	<ul style="list-style-type: none"> • Challenge this! There are many examples where a person-centred approach has proved to result in an improved quality of life for individuals with complex needs, and the law says the individual's aspirations and needs must be taken into account when planning their care and support. For support challenging this issue, contact the CBF Family Support Service (0300 666 0126).
<ul style="list-style-type: none"> • Lack of appropriate choice in existing housing opportunities. 	<ul style="list-style-type: none"> • There are a number of organisations who can advise on a range of housing opportunities. Visit Transform Housing & Support or www.shelter.org.uk. Also check your Local Offer.
<ul style="list-style-type: none"> • Lack of funding to meet high costs of support. 	<ul style="list-style-type: none"> • The law says that a disabled person's assessed needs which meet the national eligibility criteria must be met. See the CBF information sheet "Getting the best support package: 10 top tips".
<ul style="list-style-type: none"> • Lack of adequate support to access mainstream Further Education opportunities. 	<ul style="list-style-type: none"> • People with disabilities have the same rights as everyone else to continued education. Local authorities have responsibility to improve the range of further education opportunities for young people with learning disabilities up to their 25th birthday. IPSEA have information here: Young people (aged

	16-25) I (IPSEA) Independent Provider of Special Education Advice Ask what action is being taken in your area.
<ul style="list-style-type: none"> • Lack of appropriate daytime opportunities including employment. 	<ul style="list-style-type: none"> • By using personal budgets and direct payments, people can be supported to access existing community facilities and employment opportunities. You can also ask your Local Authority to address gaps in their local offer. This would involve commissioning new, more specialised services.
<ul style="list-style-type: none"> • Lack of appropriate choice in care support opportunities. 	There are a number of ways to address this: many care provider organisations will work with you to find flexible and person-centred solutions, or you can employ your own staff team using direct payments.
<ul style="list-style-type: none"> • Difficulty for families to get their relative’s health needs met or to get reasonable adjustments made 	Parents can challenge this by referring to their legal entitlements. If your relative does not have mental capacity, parents have the right to be involved in decisions regarding their health. Also refer to the Equality Act which states services must make reasonable adjustments if there are barriers to accessing that service.

OUT OF AREA PLACEMENTS

If an individual has been identified as displaying challenging behaviour, it is likely that he/she will have difficulty accessing many local community services without significant support and/or adaptations to the service. Many local authorities have traditionally responded to this by purchasing ‘out of area’ specialist places. These are services that can meet the individual’s assessed needs but may be a long way from the family home. The implications of this strategy can be significant:

- It can have a negative effect on the individual and family in terms of family contact and involvement.

- It can result in the failure to develop local expertise and inclusive services and support.
- Research has shown that children placed out of area are more likely to move to adult services out of area.

However, there are now many opportunities for people with severe learning disabilities and behaviour described as challenging to be well-supported and have a good quality of life within their local community via a person-centred approach.

Your local authority should be adopting a person-centred approach and should therefore be prepared to develop a specialist **local** service or support package to meet your son/daughter's needs. **If all you are offered is an out of area placement you should be prepared to challenge this.**

HOSPITAL PLACEMENTS AND THE MENTAL HEALTH ACT

There are some situations where your relative may be placed in an inpatient unit. There are different ways an individual may end up in a hospital placement:

- They have been detained under the [Mental Health Act](#) ('sectioned').
- They have agreed to enter as a voluntary/informal patient for assessment and treatment.
- Placed in a hospital with a Deprivation of Liberty Safeguards authorisation in place. This applies when the individual lacks capacity but detention under the Mental Health Act is inappropriate.

Although a hospital placement may be helpful short term for specific reasons, it is not a suitable, long-term home.

FURTHER INFORMATION

- ['Meeting the Challenge: My family member has been sent to an inpatient unit – what do I need to know?'](#)
- [Building the Right Support](#): A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. It has been developed jointly by NHS England, Local Government Association and the Association of Adult Social Services

9. WHO CAN HELP?

To have the most positive experience of transition, the most important thing families can do is have a wide range of information on the possible options and start planning as early as possible. By starting early, you can identify challenges earlier and can start planning to overcome them before they arise. Good preparation now can set your relative up for the rest of their lives.

You may also want to join a local parent group, to discuss with other parents who have already been through the transition process what their experiences were like and if they have any helpful information to share.

Lastly, it is crucial to keep your relatives hopes, aspirations and needs at the forefront of all planning arrangements and be vocal about them with professionals who work with you to plan your relative's transition into adulthood.

There are a range of people that may be available to provide you with advice. Any of these could be a starting point to signpost you to sources of support.

VOLUNTARY ORGANISATIONS

Voluntary organisations provide a range of information, support and advice. Some provide general information (e.g. Mencap, Contact, etc), and some provide more specialised information for people with specific needs.



Challenging Behaviour Foundation

The CBF aims to work closely with family carers, professionals and commissioners in order to promote and develop small, individualised, high quality local services and support for people who have severe learning disabilities and behaviour described as challenging.

We are keen to work with those who want to achieve better outcomes for individuals with behaviour described as challenging and their families and carers, facilitating equality of access to local education and participation in the wider community.

Ways in which we may be able to help include:

- Talking through your options with you (call the Family Support Service to speak to a Family Support Worker: 0300 666 0126)
- Linking you with other families who have relatives who have severe learning disabilities and are described as having challenging behaviour (join the Family Linking Scheme or Family Carer Email Network)
- Linking you with people who can help you achieve the future of your choice for your relative,
- Providing information and support to both families and professional carers around understanding challenging behaviour and supporting behaviour change.

Mencap

The leading voice of learning disability, they work in partnership with people with learning disabilities to help them live life as they choose, e.g. help them to find employment, offer advice and deliver residential day services, etc.

Provides:

- A website which features the latest learning disability news, campaigns and a large amount of information related to learning disability,
- Services including housing, support, learning, employment and leisure. Local Mencap groups offer support and activities.

Telephone: 0808 808 1111

Website: www.mencap.org.uk

Contact

A national charity supporting families of disabled children by providing advice and information on their rights.

Provides:

- Online resource library,
- Resources including medical conditions and support available,
- Information on local support groups, Forums & networking (find local families or families with relatives with similar condition).

Telephone: 0808 808 3555

Website: [Contact - for families with disabled children | Contact](#)

Learning Disability England

Campaigns for better housing, support and rights for people with learning disabilities. Working with people with learning disabilities, families, advocacy organisations, housing and support providers and commissioners.

Provides:

- Membership and advice,
- Information and resources on housing, support, funding and rights,
- Hosts conferences and events,
- Identifies and shares good practice.

Telephone: 0300 1110444

Website: www.learningdisabilityengland.org.uk

Appendix: Questions to ask support providers

If you are considering a support provider for your relative, 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 Person Centred Plans used and updated over time? • What adaptations will you make to accommodate my relative's needs? • How will you encourage my relative to develop his / her skills? • Can you tell me how you will support my relative to express their individual personality / identity? 	
<p>Activities and choices</p> <ul style="list-style-type: none"> • What will be a typical weekday / weekend look like for my relative? • How will you support my relative to access community facilities? • How will you support my relative in trying new activities? • What transport is available to enable my relative to access community facilities? • How will you ensure my relative 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 	

QUESTIONS	RESPONSE/NOTES
<p>two?</p> <ul style="list-style-type: none"> • If a group activity is arranged that my relative does not wish to participate in, what will you do? • What sorts of choices will be offered? (ranging from breakfast cereal to activities and everything in between!) • Will my relative be able to access the internet? • How will you support my relative with nights out (and staying out late)? • How will you support my relative with long day trips? 	
<p>Family</p> <ul style="list-style-type: none"> • How do you support families to be actively involved in their relatives' 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 relative 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 relative'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 	

QUESTIONS	RESPONSE/NOTES
<p>of my relative?</p> <ul style="list-style-type: none"> • What professionals will my relative 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 staffs 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 relative be able to choose his/her staff support? • How will you guarantee continuity of staff, ensuring that my relative 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 relative have a good standard of spoken English? • What appropriate support will be put in place if English isn't my relative's first language? • How will you ensure staff that support my relative have the appropriate communication skills? What alternative communication methods are used? • If my relative 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 relative'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 relative for 	

QUESTIONS	RESPONSE/NOTES
<p>moving in?</p> <ul style="list-style-type: none"> • How will you prepare my relative if new people move in to the residence? • How will you support my relative in maintaining friendships and making new ones? 	

With thanks to the families who contributed to the questions for service providers.

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