The Challenging Behaviour Foundation

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

Planning for the Future (England)

Support options, housing, personalisation and transition to adult services

Contents

Thank you to all of those who have contributed to this information pack and checked its accuracy.

1. INTRODUCTION

At the Challenging Behaviour Foundation we are regularly contacted by families concerned about the availability of support and services to meet the needs of their family member. This ranges from children's to adults' services, the transition between the two, or out of area placements (either moving out of area because there is no local service, or trying to support the person to move back from an out of area placement). **Often there doesn't seem to be any support or service locally that can meet their needs.**

Frequently families find their family member is offered an out-of-area placement that may be hundreds of miles away from their relatives and community, and they may not be able to access the ordinary life opportunities that most adults take for granted, like college courses or employment, or access to a family life.

However, individuals with severe learning disabilities and behaviour described as challenging have the same rights as everyone else. Government policy and best practice guidance promotes a personalised approach to support and services – designing support around the person to meet their needs.

For a person with complex needs, including behaviour that is described as challenging, a person-centred approach to service design and development is crucial. The challenge is to make this happen when in the short term it is easier and quicker to ring round and find a vacancy in an existing service.

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. 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 the transition service was the product of a great deal of hard work and effort. It would have been much easier to try and "fit him" into an existing service. 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 around him. We know what works and we know what is important to him.

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

Parents and 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 sons' and daughters' support needs can be met and their future can be secure, safe 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.

Vivien Cooper

Vivien Cooper - Mother of Daniel & CEO the Challenging Behaviour Foundation

2. 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 having challenging behaviour. 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.

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 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 (EHC) plans this is in year 9 (aged 13-14), and should form part of the annual statutory review of their EHC plan. Equally for those without EHC plans planning should begin as early as possible.

Key point: One thing we would say to all parents: 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 behaviour described as challenging. When rushed – it can lead to care that does not meet the needs and support an individual requires.

Transition planning should begin with an assessment of your relative's needs. The local authorities 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, health and social care needs into adulthood (*All Change, Pavillion 2003).* Once the transition plan has been agreed it should be reviewed regularly as *'transition planning is a continuous and evolving process…. the transition plan can also change and grow over time' (*SEN Toolkit).

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 schools 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 those up to 25 years old with 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 all those who should be involved are 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. The information can be found on the Department of Health website (www.dh.gov.uk) under *'National Service Framework for Children, Young People and Maternity Services: Standard 8: Disabled children and young people and those with complex health needs' and 'transition into adulthood'.*

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 new 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 EHC plan. 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

- ***Transition Information Network***: 'My future choices' (free magazine) published 3 times a year. Telephone 0207 843 6006, email tin@ncb.org.uk or visit www.transitioninfonetwork.org.uk

- ***Preparing for adult life & transition:*** Fact sheet produced by Contact a Family. Visit www.cafamily.org.uk, Telephone 0808 808 3555 or email helpline@cafamily.org.uk

- ***Progress Magazine:*** A free 60 page magazine 'Aiding positive planning for your transition options'. Website: www.progressmagazine.co.uk. Available from your local Information, Advice & Support Services Network (Email iassn@ncb.org.uk), Mencap (Telephone 0808 808 1111) or Contact a Family (Telephone 0808 808 3555)

- ***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, Telephone 020 7803 1100, 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, Telephone 020 7803 1100, email:fpld@fpld.org.uk or visit www.learningdisabilities.org.uk

3. 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 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. It has become increasingly widely used in the planning and transition to adulthood starting at 14 years old.

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***. Think about what an 'ideal' scenario for your son/daughter 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.*** Many families known to the CBF are happy to share their experiences and can provide valuable insight into how to make things happen.

Whether you are facing transition or trying to change services or support for your son or daughter, 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).

- ***"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."* (Preparingforadulthood.org.uk)

FURTHER INFORMATION

- ***FAQ: 'Do I have to go this alone?' on the CBF website*** about circles of support (bit.ly/21wCAPR)

- ***Families Leading Planning*** (Telephone: 07780 675197 or visit www.familiesleadingplanning.co.uk)

- ***The National Autistic Society*** (bit.ly/1WsDQlG or call 0808 800 4104)

- ***Helen Sanderson Associates*** (bit.ly/1MahWTN or call 0161 442 8271)

- ***Foundation for People with Learning Disabilities*** (bit.ly/1GQ9OFN)

4. 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 they are entitled to.

Two pieces of legislation were introduced in 2014 to prevent their being a gap of support during the transition from children to adult's services. The ***Care Act (2014)*** allows families to ask for an assessment of likely 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 satisfy 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)*** has also replaced Special Educational Needs (SEN) statements with Education, Health and Care Plans (EHC plans). These plans apply to individuals from birth until they are 25 years old. Plans made about what support will be 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 takes into account that individuals with severe learning disabilities may not be able to make these decisions. The ***Mental Capacity Act (2005)*** outlines this:

This Act 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 all the support possible to help them make decisions and always ensure that his/her wishes are taken into account and that, for example, 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 wrong or bad
- 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 is unable to make a decision (i.e. they lack capacity) 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
- Professionals are required to 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.

OTHER CHANGES AFTER 18

Adults with moderate and severe learning disabilities 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.

Your ***rights as a carer*** may also change. When caring for a person who is likely to have needs beyond the age of 18, carers have the right to request for an assessment of needs for themselves. This equals the rights of the person you care for. It will consider what support carers might need so they can meet there needs alongside their caring role: e.g. have a job, take part in social activities etc.

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 cares*** (OPG 602) visit www.justice.gov.uk/about/opg.htm or telephone 0300 456 0300
- ***Using the Mental Capacity Act. A resource for families and friends of people with learning disabilities.*** Home Farm Trust. visit www.hft.org.uk or telephone 0117 906 1700

5. CHOICES

HOUSING

Individuals with a severe learning disability and 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

Until fairly recently, 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 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 son/daughter, 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 or by telephone: 030 006 161 6161.

CASE STUDY: David*

For the first 10 years of his life David 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.

As a result David was admitted to a special residential school for children with learning disabilities and subsequently, owing to deepening concern over his level of challenging behaviour when a young adult, to a special hospital. There were two very marked concerns when David came to live in a residential care setting at the age of 40, and which pointed the way to how support needed to be developed for him. One concerned his severe communication difficulties. David simply did not have the means to tell anyone how he felt, what he wanted and to share quality one to one time in a richly communicative manner. This worked against building a warm and meaningful relationship with him and limited him to primitive communication methods such as pushing and grabbing others to communicate his needs. Along with his towering height (6’ 3”), this mix of factors only served to add further to his ‘challenging reputation’. The other main concern was around his intense preoccupation with food and drink to the extent that it greatly limited his experience and access to what life can offer.

So much of David’s challenging behaviour was linked to the combined impact of communication deficit, impaired quality of life and previously ineffective ways of enabling him to break free of his obsessional focus on food and drink.

The way forward was clear, although positive outcomes were by no means certain. Perhaps the most remarkable feature of David’s story (and the success that has come his way) was the early recognition of his human qualities. David was and is an essentially loving person. In his own way he was telling others that he wanted more out of his life. The approach therefore was based on building on his strengths and on shaping a life far richer in terms of communication as well as enabling experience and enjoyment of day to day life alongside and sometimes entirely separate from food and drink. David will always be overly interested in food and drink but now there is a little more balance in this life. He has lost his ‘challenging reputation’ and has gained in wellbeing.

*the person’s name has been changed to protect their identity

With thanks to: MacIntyre Charity
www.macintyrecharity.org

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)
- 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
- This is not a complete package – accommodation is provided separate from care

CASE STUDY: Charlie*

Charlie has severe autism and behaviours that challenge as well as 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 all but the most basic of questions.

Charlie was in a specialist school followed by a residential home in Hampshire. We were concerned about his behaviours and changes in him, so we moved house to be closer to him so we could monitor him. We always felt that nobody took our concerns seriously, and that they were the experts we were just parents! Following much pressure from us, our local authority funded a psychologist who assessed him. The psychologist confirmed what I had said for years, that Charlie had ADD. The psychologist felt the residential care home was too busy for him.

This was all that was needed to start of the process of moving him back to his home county where we decided to look at shared ownership. We agreed a budget with the authority, and found a Housing Association that was able to provide us with some funding and support. I applied for a deputyship from the Court of Protection. We did not have a circle of support except for us parents, so we were very aware of the responsibility in choosing appropriate activities and in choosing the property.

It was the best thing we have ever done for Charlie. He is so much calmer and relaxed. It was, however, very stressful as our first provider handed in their notice after just three months following a letter of complaint that I had written to them. In the end it all worked out well and Charlie has improved beyond our belief in only 18 months. He still comes home each month, and we go to see him each week.

*the person's name has been changed to protect their identity

With thanks to Charlie's mum

CASE STUDY: Stephen*

Stephen is in his early twenties, and has a profound learning disability, autism and health difficulties. From the age of thirteen, he spent seven years in a long-stay hospital, and his challenging behaviour was considered so serious that he might not be able to live independently outside of that setting.

Stephen is now living in his own home. Stephen's support team have used a range of techniques to ensure that he feels comfortable in his home and that instances of challenging behaviour are kept to a minimum. They have also ensured that there is a consistency of support in place which has allowed Stephen to develop more independence over time. One technique that has been used to increase Stephen's independence is the gradual introduction of new activities, such as food shopping. As a starting point, staff asked Stephen to get involved in writing the shopping list and deciding what food he wanted to buy. The next step was for staff to accompany him to the supermarket in the car and walk up to the shop entrance.

Stephen still displayed challenging behaviour as he neared the shop entrance, so the team tried going shopping at different times of the day until they found a period when the store was quiet and Stephen felt more confident. He now happily takes part in the weekly shop and has got to know staff in the supermarket. Stephen now goes out socialising and bowling, things which would once have been considered impossible.

A good relationship has been built between support staff and Stephen's parents with regular meetings being held to discuss how he is supported. This relationship has given staff further opportunities to understand Stephen better and ensure that the support they provide fits with his personality and preferences.

When Stephen first left the hospital he had to be physically restrained several times a day to avoid injuring himself or others. Incidents of challenging behaviour have now reduced from two or three times a day to around one a fortnight and his independence has increased to the point where overall support hours have been reduced.

*the person's name has been changed to protect their identity

With thanks to: United Response
www.unitedresponse.org.uk

CASE STUDY: Annie*

Annie is 31 years old and has a rare genetic condition. She presents with severe learning disabilities, autism and a hearing impairment. She has little spoken vocabulary and poor gross and fine motor skills (but she is ambulant) and displays challenging behaviours.

Annie lived at home and went to a local special school and then local day services. At age 27 she moved into a small local residential home but after 6 months the management, staff and clientele changed and her challenging behaviours increased in frequency and intensity. Annie was put on medication which included anxiety pills, anti-psychotics (Risperidone) and PRN (as required) medication. She gained 3 stone in just 18 months as a side effect of the medication!

At her psychiatrist's request 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 bathroom and 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 paid by social services (who are currently trying to obtain some funding from health).

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.

Annie no longer uses PRN medication or Risperidone and is much happier and relaxed with a package based around her needs. 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.

*the person's name has been changed to protect their identity

With thanks to Annie's mum

When you have identified a potential care provider or are visiting several placements, we have provided a list of questions to ask providers – see appendix.

Staying in the Family Home

With the move towards more personalised planning for the future, it is likely many individuals with severe learning disabilities and their families will choose to remain living together. This may involve employing care services using a direct payments package to provide support within the family home. Moreover, it may involve appropriate changes being made to the home to create self-contained accommodation, allowing the individual to have some independence.

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

- It may feel like the most logical solution
- The individual will already be familiar with the environment
- It will allow for continuing family carer support

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

- Uncertainty as to what will happen when relatives get older
- Funding may not cover the cost to make appropriate changes to family home and buy specialist equipment

CASE STUDY: Oliver*

Oliver is 27 years old and has many labels, including behaviour described as challenging. During his childhood and teenage years, he experienced a number of exclusions from school, and breakdowns in care packages. This was often the result of an over-reliance on restrictive practices, including both physical intervention and seclusion. For example, one college placement lasted only 9 days because of staff relying on prone (face down) restraint which consequently led to Oliver getting injured. During a day care package Oliver was secluded for 3 months. He would arrive at 9.00 be shown into a tiny room and stayed there until 3.30.

The family spent two years trying to get Oliver back into education. However, he had become increasingly anxious about being supported by new people, and in turn his challenging behaviours increased which made attempts unsuccessful. The continuous breakdown led to children's services suggesting Oliver attend a specialist residential college, but Oliver's family didn't agree this was the right solution for them and their son.

Instead, Oliver's family decided to set up Oliver's care and support in the family home. Adult social services gave 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. By taking Oliver's support back to basics – by withdrawing demands placed on him for example – his behaviour gradually improved. As it did, the family could introduce more activities for Oliver to do which they knew he would enjoy. During this intense period of managing and changing Oliver's behaviour the family were well supported by the local psychology team and social services. There was continuous reflection and analysis of Oliver's behaviour – what he liked, didn't like, what worked and didn't work. This helped form the basis of a positive behaviour support plan.

There are of course challenges: Oliver is still heavily reliant on his mum to deliver some of his care and also to manage his support package on his behalf. It's also expensive for his family to organise –they don't get housing benefits, and all costs for Oliver's activities are covered by the family. Oliver's parents acknowledge that if he wasn't an only child and if they weren't prepared to work together to continue providing his care and support, the set up would probably not work as well.

However, currently 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, and a reduction in injuries to Oliver, his family and the staff that support him.

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

With thanks to Oliver's mum

BROKERAGE

Brokerage is a way in which people can be helped to navigate the social care system. A **support broker** is an independent person who is trained to co-ordinate the process of organising and maintaining a support package for an individual. 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 ensures 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 about services in your local area, contact the **National Brokerage Network**: visit their website www.nationalbrokeragenetwork.org.uk or telephone 01279 504735.

CONTINUED EDUCATION

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.

Currently it remains difficult in practice to ensure adults with severe learning disabilities and behaviour described as challenging are accessing further education. Should it be identified in an individual’s PCP that there is a need for the person to access adult education, a local college or university should be prepared to set up a relevant course if there are none currently running, and if it can be shown that there is a demand for such a course. The individual may have to pay to attend the course, and sources of funding for this would have to be identified and possibly incorporated into the individual’s individualised budget. This may also be the case for transport to and from the place of education, or could be funded by a person’s Disabled Students’ Allowance.

CASE STUDY: Ben *

Ben is 55 years old, on the autistic spectrum, with severe learning difficulties and very limited speech. He moved in with his sister and her family after his parents passed away some time ago.

Ben attends a day service where he is engaged in a range of activities that include cooking, gardening and going to the gym. He also attends the local college where he is studying computing, art and music.

Ben’s behaviour began to change soon after he moved in with his sister’s family and both staff at the day centre and college began to find the new behaviour a challenge.

Previously, Ben would enjoy being with people he knew, he would be sociable to those he met and he would try to explain what he wanted. When people didn’t understand what he was saying Ben could become frustrated leading to verbal aggression and throwing things. These behaviours became more frequent and severe following the move.

Ben liked turning the room lights on and off at the start and end of his sessions, but he began to refuse to do this. During break times he started to run off and hide. He became very aggressive and refused to engage in tasks. Ben was finally asked to stop attending college after he damaged books in the library and urinated in one of the small study rooms.

Using Positive Behaviour Support we co-ordinated a series of meetings with staff from college, the day centre and his family. From the meetings it became apparent that Ben was feeling he had no control over his life and lacked confidence in communicating.

Following the meeting the day centre set up one to one support so that Ben could choose when he attended the centre and college. Ben also chose to use public transport instead of the borough bus service. He was supported to make decisions about what activities he wanted to do and about where he wanted to live.

Ben now lives in supported housing. He is more like he used to be, sociable and with the additional one to one support he has been able to develop new skills in computing and music. This has built his confidence, widening his verbal skills and Makaton vocabulary. Ben now uses public transport, something that was not thought possible before.

*the person's name has been changed to protect their identity

With thanks to Dawud Marsh
ICM Foundation

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
- ***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 people with care needs, and a support plan for carers. The plan must help the carer decide how this support will be given and what will be arranged using direct payment.

ACCESSING THE COMMUNITY

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

There is a growing push for individuals with learning disabilities to be able to access the same services and activities in their local community. For example, public transport training has been introduced in some areas to remove barriers to accessing local services and help individuals become more confident in travelling.

Moreover, there are increasing number of clubs and events that are specifically for individuals with learning disabilities.
These include:

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

There are also the traditional day services which offer a range of support activities in the local community. This includes a mixture of work, education and leisure. Day services are usually available to those over 16. Evening and weekend activities are also available.

KNOW YOUR RIGHTS

- The focus of ***Care Act (2014)*** is on improving the *wellbeing* of adults needing care. The definition of wellbeing includes the individual having control over their day-to-day life, and participation in work, education, training or recreation.

- 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

EMPLOYMENT

Many people with learning disabilities want to have a job and 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 www.direct.gov.uk or telephone your local office (numbers are listed in the telephone directory).

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 adaptions 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.

Job centres have schemes to help support people to find employment, and other local and national organisations such as Mencap (Tel: 0300 333 111, website: www.mencap.org.uk) 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 has now been in paid employment since July 2010. 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. He earns above the minimum wage, and Linkage is now working with Ben to sort out his finances with his new earned income and his benefit entitlement.

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 has reduced in frequency, his epilepsy appears more controlled and his relationship with others has improved. He appears happier, more relaxed, more able and willing to communicate and more in charge of his life.

Rex G. Richardson, Director of Care Services for Linkage says: “Ben’s success has led to a general reappraisal of the expectations we hold for all the people for whom we provide services. Opportunities in employment can be found for persons with the most complex difficulties. We are delighted for Ben in having a job, and proud of our relationship with his employers.”

Ben’s sister says: “The progress he has made has been quite remarkable. Moving into his one bedroom bungalow has built his self-esteem beyond recognition. Now he has moved into paid employment with support from the staff and the team from an Employment Project. You can see how proud he is of this achievement and a spin-off is that his challenging behaviour has reduced. I believe he is much happier and fulfilled.”

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: bit.ly/1TQuv9o

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. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone 01634 838739, e-mail info@thecbf.org.uk or visit www.challengingbehaviour.org.uk

- ***Learning Disability England:*** A national charity with a range of housing resources. Visit: www.learningdisabilityengland.org.uk or www.housingandsupport.org.uk

- ***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 www.challengingbehaviour.org.uk

- ***Hft****:* Provides local support services for people with learning disabilities throughout England. Telephone: 0117 906 1700. Website: www.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 www.challengingbehaviour.org.uk / www.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: bit.ly/1UC7C8q

Education Support

- ***Association of National Specialist Colleges:*** Visit www.natspec.org.uk or telephone 01691 661234

- ***52 Week School and Colleges List:*** Visit www.challengingbehaviour.org.uk or telephone 01634 838739

- ***National Bureau for Students with Disabilities:*** Visit www.skill.org.uk or telephone 0800 328 5050

Support with leisure activities:

- ***Mencap****:* Local Mencap groups offer support and activities. Telephone: 0808 808 1111. Website: www.mencap.org.uk.

- ***County Sports Partnership****:* You can contact CSP about local sporting and volunteering opportunities http://www.cspnetwork.org/

- ***Spogo:*** where you can search for local sport and physical activity www.spogo.co.uk

- ***Parasport****:* where you can search for disability sport and physical activity in the local area www.parasport.org.uk

- ***UK Sports Association For People With Learning Disability (UKSA):*** www.uksportsassociation.org or 020 7490 3057

- ***National Council for Voluntary Organisations****:* Connect organisations with the people, partners and resources they need to make the biggest difference www.ncvo.org.uk

- ***Stay up Late:*** learning disability campaign promoting access to nightlife – because life doesn't stop at 9pm. www.stayuplate.org

- ***Books Beyond Words:*** run book clubs for people with learning disabilities, to enjoy books without words in a social environment. www.booksbeyondwords.co.uk

6. FUNDING

Recently, government policy has moved towards enabling disabled people and their families to have more control over the funding that provides their care and support, and there are a number of opportunities available. Below we explain some of the funding options, however this list is not exhaustive and options often change. As a result, it is a good idea to ask your social worker what options are available to you.

PERSONAL BUDGETS

The Local Authority has a duty in law to meet an individual's eligible social care and support needs. A 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 meet all of the individual's eligible needs.

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.
- If available locally, a third party known as an Individual Service Fund (ISF) can also be chosen to manage the personal budget. This is where a provider can offer a service to meet needs of the person within the resources of the Personal Budget. You can read an example case study of how an ISF could work here: bit.ly/29ajwZ8
- Alternatively, 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. For more information about Direct Payments, see below.
- In addition, 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, or the personal budget can be made available to the individual 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 and purchases the support they want. This has the benefit of being completely in control of what services provide your support. The decision to receive funding in the form of direct payments should be based on the outcomes the individual wishes to achieve, and how they think these can best be achieved as well as getting value for money. A Direct Payment should not be taken just because it is seen as the cheapest option.

The person may acquire the responsibilities of an employer if they use a direct payment to purchase care directly and employ Personal Assistants. This may 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 a family member, who can organise the ‘business’ end. The Local Authority should support people to use and manage their direct payments in order to commission and buy the care they need.

If someone lacks mental capacity to request direct payments in order to meet their care needs, an authorized 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 payments, and finding a way of meeting 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, who may previously have been involved in the care of the person. 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 Chapter 9.

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 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.

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. Whether you are eligible for NHS Continuing Healthcare is not determined by having a particular diagnosis or condition, but based on an individual’s level of need regarding 4 indicators:

- Nature – characteristics of needs and intervention required to meet them
- Intensity – extent and severity of needs
- Complexity – how needs may interact, and level of skill required to manage needs
- Unpredictability – how hard is it to predict changes in needs

PERSONAL HEALTH BUDGETS

Similar to Personal budgets that meet social care needs, funding from the NHS can be provided to meet eligible health needs in the form of a Personal Health Budget. This money can used to pay for support (instead of a personal budget from social support), and to fund therapies, medication prescriptions, and specialist equipment.

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.

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. It is the Government’s long term goal for social care and health to be integrated, leading to a much simpler experience for those requiring funding to meet both their care and health needs.

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 a different proportion.

Local areas are being 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/.

SUPPORTING PEOPLE

The Supporting People programme was introduced by the Government in 2003, and aims to achieve a better quality of life for vulnerable people (including people with learning disabilities) by enabling them to live more independently and maintain tenancies. The Supporting People programme is administered via your local authority, and only funds housing-related support (personal care is not funded via this programme). Contact your local authority for details of Supporting People in your local area. The Supporting People funding can form part of an individualised budget.

DISABLED FACILITIES GRANT

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 social services.

For a person under 19 years the grant is not means tested, but a financial assessment will be carried out for those 19 or over. If the disabled person is on income support, income-based jobseeker’s allowance or in receipt of guaranteed state pension credit, 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 request a booklet ‘Disabled Facilities Grant’ from The Communities and Local Government Publications: visit www.communities.gov.uk, telephone 030 3444 0000.

BENEFITS

- Employment and Support Allowance – a benefit for people who are unable to work due to illness or disability.

- Housing Benefit – helps with the costs of renting and other housing costs, but does not include mortgage costs.

- Disability Living Allowance/Personal Independent Payments - available for 16-64 year olds to help cover the costs of long-term ill health and disability. Personal Independent Payments were introduced to replace Disability Living Allowance (DLA) in 2013, however many people still receive Disability Living Allowance while it is being phased out.

EMPLOYMENT

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 www.direct.gov.uk or telephone your local office (numbers are listed in the telephone directory).

KNOW YOUR RIGHTS

- The ***Families and Children Act (2014)*** states that families have the right to request a personal budget if they have an EHC plan. 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 those over 18 must include a personal budget.

FURTHER INFORMATION

- ***Direct Payments: 'A parent's guide to Direct payments'*** (Department of Health) – telephone 0300 123 1002, email:dh@prolog.co.uk or visit: www.dh.gov.uk/publications

- ***'Direct payments: frequently asked questions',*** available free from the Social Care Institute for Excellence (SCIE). Telephone 020 7089 6840 or visit:www.scie.org.uk

- ***Independent Lives:*** provide a range of support services to help manage direct payments including advisors and payroll services for personal assistants. Telephone 08456 0123 99 or visit www.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. Telephone 024 7651 1611 or visit www.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 www.publicguardian.gov.uk, or Telephone 0845 330 2900

- ***Becoming a Deputy:*** information sheet "Getting legal authority to make decisions about money, property and welfare." Available from the Challenging Behaviour Foundation. Telephone 01634 838739, e-mail: info@thecbf.org.uk or visit www.challengingbehaviour.org.uk

- ***National Brokerage Network:*** connects with personal budget holders, carers, providers, and independent brokers supporting the development of all types of support brokerage. Visit wwww.nationalbrokeragenetwork.org.uk for regional phone numbers

- ***Citizens Advice Bureau:*** can advise you about what benefits you are entitled to www.citizensadvice.org.uk or 03444 111 444

7. SAFEGUARDS

Individuals with severe learning disabilities and behaviour described as challenging are vulnerable to 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 and challenging behaviour are person-centred and understand why the person behaves as they do.

Different service providers may have different approaches to managing 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 their behaviour management policy before you agree that it is suitable for your son/daughter.

Services should have appropriate monitoring mechanisms in place to minimise the risk of abuse, detect potential abuse, and highlight indicators of abuse within existing behaviour repertoires. 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 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 can report concerns to the CQC. Monitoring of services is done in light of the 10 fundamental standards of the CQC e.g. must have care that is tailored to individual needs and preferences, must not suffer any form of abuse or improper treatment, and the care provided must have suitably qualified, competent and experienced staff.

3. Staff checks (Protection of Vulnerable Adults scheme)

The Protection of Vulnerable Adults scheme (POVA) came into operation in 2004, and includes a list against which anyone who is employed to work with vulnerable adults is checked. Individuals should be referred to and included on the POVA list if they have abused, neglected or otherwise harmed vulnerable adults in their care or placed vulnerable adults in their care at risk of harm. By making statutory checks against the list, providers of care must not offer such individuals employment in care positions. POVA checks are requested as part of Disclosures from the Disclosure and Barring Service.

OTHER SAFEGUARDS

▪ Separating housing and care provision

In the past, people with behaviour described as challenging who have been offered a complete service (accommodation and support) from a service provider have been 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.

▪ 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 who is described as having challenging behaviour is a skilled role and will require a great deal of time, commitment and expertise if it is to be done effectively.

Different types of advocacy:

- ***Citizen advocacy*** – this advocate develops a long term relationship with individuals and speaks up for them. They are often a volunteer (unpaid) and independent of service providers and families.
- ***Peer advocacy*** – individuals with learning disabilities advocate on behalf of other individuals with learning disabilities.
- ***Case advocacy*** – similar to citizen advocacy, except it is not intended to have a long term basis. Only focuses on one issue or set of issues. Also known as crisis or short term advocacy.

- ***Paid independent advocacy*** – volunteers are always in short supply and sometimes when a major problem arises involving multiple people requiring advocacy, paid advocates are employed.
- ***Independent Mental Health advocacy*** – this is a statutory right for people detained under most sections of the Mental Health Act. The advocate is independent of Mental Health services and helps the individual know their rights and speaks up so their opinions can be heard.
- ***Independent Mental Capacity advocacy*** – these advocates act as a safeguard for individuals who lack the capacity to make important decisions such as where to live, and medication treatment. These advocates are usually instructed to advocate when there is no one independent of services (e.g. a family member) able to represent the individual.

Families rightly feel they should have a role advocating for their relative, and professionals often have a professional duty to advocate. However, both will lack the objectivity of an independent advocate and may have conflict of interest. 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.

▪ Deprivation of Liberty Safeguards

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 necessary 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. A DoLS is also needed for other specific restrictions on the person. Local authorities and the Court of Protection authorise DoLS and family carers should be consulted as part of the process.

FURTHER INFORMATION

- ***A guide for advocates -*** 'A guide for advocates supporting people with learning disabilities who are described as having challenging behaviour' is available from the Challenging Behaviour Foundation. Free to family carers. Telephone 01634 838739, e-mail:info@thecbf.org.uk or visit www.challengingbehaviour.org.uk

- ***Deprivation of Liberty Safeguards (DoLS) at a glance*** 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. Available to download at www.scie.org.uk/publications/ataglance/ataglance43

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
• **Encountering a 'fit the person into what's available' approach rather than a person-centred approach.**	• 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).
• **Lack of appropriate choice in existing housing opportunities.**	• There are a number of organisations who can advise on a range of housing opportunities. Visit www.housingandsupport.org.uk or www.shelter.org.uk. Also check your Local Offer.
• **Lack of funding to meet high costs of support.**	• 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" by Professor Luke Clements.
• **Lack of adequate support to access mainstream Further Education opportunities.**	• 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. The Young People's Learning Agency supports Local Authorities in this task. Ask what action is being taken in your area.
• **Lack of appropriate daytime opportunities including employment.**	• By using personal budgets and direct payments, people can be supported to access 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.

• **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.
• **Difficultly 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.

Valuing People (2001) stated that '*providing services for people who present significant challenges is one of the major issues facing learning disability services.'* Valuing People: The Story So Far (a report published by the Department of Health in 2005) stated that '*People with complex needs are not benefiting as much as others from the Valuing People changes…There are still too many people who are being sent away from their local communities in order to get a service*.'

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?’ bit.ly/1XxleB6

- ***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 bit.ly/1RDnlAo

9. WHO CAN HELP

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 a Family, etc), and some provide more specialised information for people with specific needs.

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 Family

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: www.cafamily.org.uk

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 201 0455
Website: www.learningdisabilityengland.org.uk

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.

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.

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
Person centred approach • 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?	
Activities and choices • What will be a typical weekday / weekend 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 two? • 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?	

QUESTIONS	RESPONSE/NOTES
• How will you support my relative with nights out (and staying out late)? • How will you support my relative with long day trips?	
Family • 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?	
Behaviour Support • Can I see your behaviour management/ physical intervention/ adult protection policy? • How will you meet the behavioural needs of my relative? • 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
Support staff • Will my relative be able to choose his/her staff support? • How will you guarantee continuity of staff, ensuring that my relative has: 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?	
Other • 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 moving in? • 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 Jen Fookes and Mal and Richard Wasilewski for contributing to the questions for service providers.

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