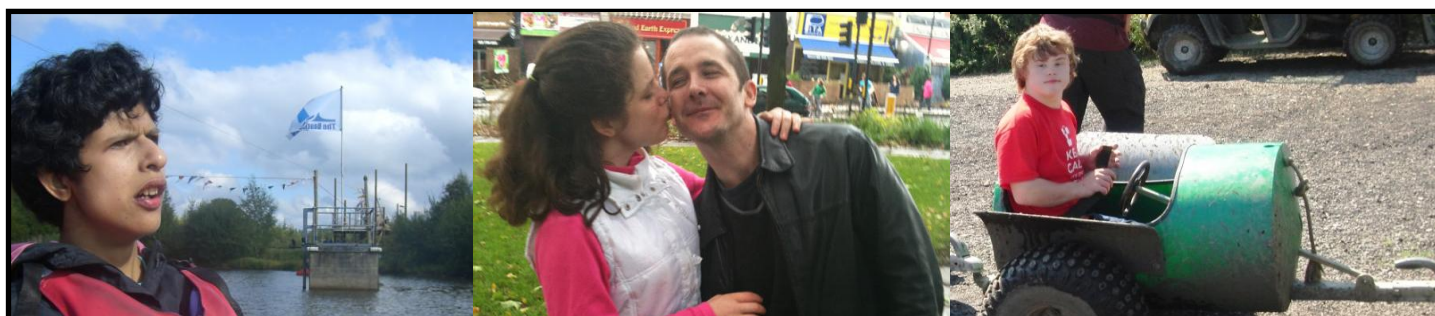




**The Challenging
Behaviour Foundation**
making a difference to the lives of people with severe learning disabilities

Planning for the Future Information Pack: Wales



How to Contact us

Email: info@thecbf.org.uk or Telephone: 01634 838739

For more information about the CBF visit: www.challengingbehaviour.org.uk

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**With thanks to Autism Cymru and Dawn Rooke (family carer) for their help in providing information concerning legislation and contact information for Wales.*

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.

However individuals with severe learning disabilities and behaviour described as challenging have the same rights as everyone else. 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 close to his family. Daniel is now in his twenties, he lives less than 2 miles from our family home and his accommodation and support has been designed to meet his needs.

Daniel's transition service and the supported living arrangement he moved into were the results 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.

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 appears easier and quicker to ring round and find a vacancy in an existing service.

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 of children or adults with severe learning disabilities who display 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 son or daughter is available and this pack has been specifically developed in partnership with families to help.



Vivien Cooper
Mother of Daniel
Chief Executive & founder Trustee of CBF
The Challenging Behaviour Foundation

1. WHERE TO BEGIN

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 display behaviour described as challenging.** 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.

Key point: One thing we would say to all families: it's never too soon to start thinking about future options for your relative, particularly if they have severe learning disabilities and behaviour described as challenging.

We hope the information in this pack is helpful.

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

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

Please see below for details of how to support us.

For more general information for families facing transition from children's services to adult services, we suggest the following starting points:

- **Preparing for adult life & transition:** Fact sheet produced by Contact a Family. Telephone: 020 7608 8700, email: info@cafamily.org.uk or visit www.cafamily.org.uk,
- **Careers Wales:** Telephone: 0800 028 4844 or visit www.careerswales.com
- **Transition Information Network:** "My future choices" (free magazine) published 3 times a year. Telephone 0207 843 6313 or visit www.transitioninforonetwork.org.uk
- **Progress Magazine:** a free 60 page magazine "aiding positive planning for your transition options." Visit: www.progressmagazine.co.uk. Available from your local Parent Partnership service. Telephone: 0207 843 6058, Mencap: (telephone 0808 808 1111) or Contact a Family: (telephone: 020 7608 8700)
- **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

2. KNOW YOUR RIGHTS

Recent Government policy has emphasised **equality & inclusion**: people with disabilities have the same rights to be fully included within society. However, translating policy into practice has created some challenges and it has been acknowledged that people with complex needs, including those with severe learning disabilities who display challenging behaviour, have not benefited as much as they should have.

The following section lists the key ‘tools’ that can be used to develop individualised support for people with complex needs.

1. Ten top tips: Professor Luke Clements

The Challenging Behaviour Foundation information sheet “Ten top tips” is aimed at family carers to ensure **good support** and **services** for adults (over the age of 18) with severe learning disabilities whose behaviour is described as challenging. Professor Luke Clements, an expert in community law, provides some basic legal information and action points highlighting what family carers can do to help their relative achieve their rights.

2. Statement on Policy and Practice for Adults with a Learning Disability (Welsh Assembly Government, 2007)

This states very clearly that in relation to challenging behaviour, local service provision should seek to ensure that people remain in their homes and local communities:

“Where this proves to be impossible to achieve, temporary alternative accommodation and residential support may be needed until they can return home or go to new long-term accommodation in the community. The Welsh Assembly Government encourages authorities to review the appropriateness of arrangements where individuals have been transferred to services outside of their local area. Such arrangements can create difficulties for families to maintain contact and for local care managers to monitor the standards of service provided and outcomes achieved.”

The deputy minister for children and social services recently gave an update on the actions and changes taken in Wales since the BBC Winterbourne Panorama Programme was broadcast in 2011. This includes strengthening their two inspection services; Healthcare Inspectorate Wales and Care and Social Service Inspectorate Wales.

3. The Carers' Strategy for Wales (Welsh Assembly Government, 2013)

This updated Carers' Strategy highlights the key outcomes that need to be achieved for carers. It also focuses on how they will accomplish these. These outcomes are that:

- Carers are not disadvantaged or discriminated against
- Carers receive a good and appropriate level of information
- Carers needs are assessed and met
- Carers are treated with respect
- Carers are involved in all decision making processes
- Carers are supported in maintaining their own health and wellbeing. This includes being supported outside of their caring role

4. Fulfilling the Promises (Welsh Assembly Government, 2001)

'Fulfilling the Promises' sets out the Welsh Assembly Government's strategy for learning disability services, and identifies four key principles: rights, independence, choice and inclusion.

A key tool for improving the lives of people with learning disabilities identified within 'Fulfilling the Promises' is a **Person Centred Plan (PCP)**. Person-centred planning means starting with the individual and putting the supports around them that will enable them to have the life that they want. **If you are not familiar with person-centred planning do take time to find out more as this approach can be the key to your son/daughter's needs being met** (See chapter 3 for further information).

5. The SEN Code of Practice for Wales (Welsh Assembly Government, 2004)

This document promotes a consistency of approach to meeting children's special educational needs and places the rights of children with special educational needs at the heart of the process, allowing them to be heard and to take part in decisions about their education. The SEN Code of Practice states that all young people with special educational needs should have a transition planning meeting in Year 9 (age 13-14) of school and every year subsequently. It also states that parents should be treated as partners throughout the transition planning process and the young people themselves should be involved in making decisions and exercising choices.

The Welsh Assembly Government (WAG) has produced a Handbook of Good Practice for children with SEN to accompany the Code of Practice in Wales. Section 3 examines Pupil Participation and provides some advice on useful strategies. A number of materials and case study examples can be found in the appendices. Visit www.wales.gov.uk.

6. Access to everyday services

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, visit: www.direct.gov.uk/en/disabledpeople/Everydaylifeandaccess

3. KNOW THE PROCESSES

There are a number of ways to translate policy into practice. This section looks at opportunities to ensure that individuals with severe learning disabilities and behaviour described as challenging are able to achieve a good quality of life with the support they need.

Person-Centred Planning

A good starting point is a detailed **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).

A PCP is an on-going recording with a positive ‘vision’ of what life should look like for the individual and the support needed to achieve the vision, maintain, evaluate and review it.

Anyone can be involved in creating a PCP, including family, friends, support staff, an advocate and social worker, as well as the individual themselves. You do not need to be a trained PCP facilitator to create one. It should focus on the individual’s strengths, abilities and preferences. It can cover information on how the person can be supported and stay healthy as well as who is important to the person and what they want for the future in terms of housing, support, education, employment and leisure.

In person-centred planning the process, as well as the plan, is owned and controlled by the person (and sometimes their closest family and friends).

The plan can be used to help obtain the services and support that the individual requires. The plan should be regularly reviewed and added to over time to keep it relevant and useful.

For further information :

- **Circles Network Wales:** Telephone: 029 2048 7575, email: deborah.hill@circlesnetwork.org.uk or visit www.circlesnetwork.org.uk
- **Families Leading Planning UK:** Telephone: 07780 675197, email: barbara@familiesleadingplanning.co.uk or visit www.familiesleadingplanning.co.uk

Transition

Although there are many transitions in a person's life, 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. Please note that the Welsh Government is seeking to change the law governing the way that a child's special educational needs and wider support needs are assessed, planned and met.

The transition planning process should begin in **Year 9** (age 13-14), involving a range of people including parents/family carers and should plan the support needed for the child to access opportunities as they enter adulthood. The transition review process should be led by the Head Teacher of the child's school, who has responsibility for the development of the transition plan, although this may be delegated. The first transition plan should be completed after the young person's annual review in year 9, and should form part of his/her overall person-centred plan. A transition plan should *"draw together information from a range of individuals within and beyond the school in order to plan coherently with the young person for their transition to adult life"* (SEN Toolkit).

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)

In the past, the transition plan has been seen as a separate entity from a person-centred plan. However, it makes more sense to incorporate it into an overall person-centred plan, which is an evolving plan. Person centred transition reviews are an opportunity for everyone to begin thinking in a person centred way at an earlier stage, to ensure that the person receives the support he/she needs to achieve the life they want, rather than "fitting the person in" to what is currently available.

The Person Centred Transition review process recommends that **Year 10** (age 14-15) reviews should look at the five "keys to citizenship":

- Self determination (including communication and advocacy)
- Direction (planning and tools for planning)
- Money (including employment opportunities, direct payments, Further Education and individualised budgets)
- Support (how to get what you need)
- Community involvement

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!

4. KNOW 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. **SNAP Cymru, Mencap Cymru, People First Wales**), and some provide more specialised information for people with specific needs.

The specific support that the **Challenging Behaviour Foundation** can provide for families caring for sons/daughters with severe learning disabilities who display behaviour described as challenging is explained in chapter 10.

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 organizing 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 information about services in your local area contact the National Brokerage Network through their website:
www.nationalbrokeragenetwork.org.uk or telephone 020 8275 6550.

Transition support

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 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 and family support team in your area, the adult team or the transition team within Social Services, and should ensure that there is good communication between the children and adult teams.



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Careers Wales have a legal duty to provide careers guidance services to all young people living in Wales who have difficulty in transferring to further education or training. They also provide information to adults with learning disabilities. There are about eighty Careers Centres across the country, where staff can provide careers information, guidance and advice. To find out further information, contact 0800 028 4844

5. KNOW THE 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"> • A “fit the person into what’s available” approach rather than a person-centred approach. You may still encounter people who take this approach, which can be seen as an “easier” option. 	<ul style="list-style-type: none"> • BUT - this should be challenged: there are many examples where a person-centred approach has proved to result in an improved quality of life for individuals with complex needs
<ul style="list-style-type: none"> • Lack of appropriate choice in existing housing opportunities 	<ul style="list-style-type: none"> • BUT - there are a number of organisations who can advise on a range of housing opportunities. Visit www.housingandsupport.org.uk, telephone 0845 4561497 or email enquiries@housingoptions.org.uk
<ul style="list-style-type: none"> • Lack of funding to meet high costs of support. 	<ul style="list-style-type: none"> • BUT – the law says that a disabled person’s assessed needs which meet the local authority’s eligibility criteria must be met. See the CBF information sheet “Ten top tips” by Professor Luke Clements
<ul style="list-style-type: none"> • Lack of adequate support to access mainstream Further Education opportunities 	<ul style="list-style-type: none"> • BUT - people with disabilities have the same rights as everyone else to continued education. The Higher Education Funding Council for Wales have been working with a range of colleges and agencies to try to ensure that the needs of students with learning disabilities are carefully assessed and programmes tailored to their individual needs. 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"> • BUT - by using individualised budgets and direct payments, people can be supported to access community facilities and employment opportunities (see chapter 8)
<ul style="list-style-type: none"> • Lack of appropriate choice of care support 	<ul style="list-style-type: none"> • BUT - 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 (see chapter 8)

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. These are outlined in chapter 6.

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.**

6. KNOW YOUR OPTIONS

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, including individual self-contained properties, housing networks, group homes, and shared accommodation schemes, and 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 or supported living is the best option for your son/daughter. A residential care home provides a complete package of accommodation and care, whereas supported living is a scheme where the accommodation is provided separately from the care support. The main advantages and disadvantages of each are set out below:

Residential Care Homes (see Case Study: David)

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.

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 and Social Services Inspectorate Wales (CSSIW) 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 (for example expanding, closing, and changing)
- The local authority will require the individual to contribute all of his/her benefit income except £24.00 a week (current tax year) towards the cost of fees. This means that the individual has only £24.00 a week for individual spending

This culture of “fitting the person into what is available” has gradually been changing. Forward thinking residential care home providers are much more flexible and person-centred than they were in the past.

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 CSSIW inspection report. CSSIW inspection reports are available from the CSSIW website. Tel: 01443 848450, <http://wales.gov.uk/cssiwsubsite/newcssiw/?lang=en>

Supported Living (see Case Studies: Annie, Charlie and Stephen)

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

Continued Education (see Case Study: Ben)

A person with severe learning disabilities has the same rights as everyone else to continued education. Specialist residential colleges cater for people up to the age of 25. Further and adult education should be available post 25.

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 the Department for Children, Education, Life-Long Learning and Skills 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 and adult education. It should be identified in a person's PCP that there is a need for them to access adult education, a local college or university. They 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.

For more information:

- **Association of National Specialist Colleges:** Telephone: 01691 661234 or visit www.natspec.org.uk
- **52 Week School and Colleges List:** Telephone: 01634 838739 or visit www.challengingbehaviour.org.uk
- **Disability Rights UK:** Telephone: 020 7247 8765, email: enquiries@disabilityrights.org or visit www.disabilityrights.org
- **Department for Children, Education, Life-Long Learning and Skills:** Telephone: 0845 010 3300 or visit www.wales.gov.uk

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. An individual's strengths, abilities and support requirements should be taken into account when looking for employment, and employers have a responsibility to make 'reasonable adaptations' to accommodate people with disabilities, including learning disabilities.

A good place to start may be with the local Jobcentre Plus as they have schemes to support people into work and can offer advice about how employment may affect a person's benefits. See www.gov.uk or find details of your nearest office in the phone book. Other organisations such as Mencap Cymru, the British Association of Supported Employment www.base-uk.org also offer support in finding and maintaining employment.

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:

- **Planning your House:** a guide to help you with thinking about living arrangements. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone: 01634 838739, email info@thecbf.org.uk or visit www.challengingbehaviour.org.uk
- **8 Ways to get a House:** a guide which covers the different types of accommodation and how they are funded. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone: 01634 838739, email info@thecbf.org.uk or visit www.challengingbehaviour.org.uk
- **Housing and Support Alliance:** A national charity with a range of housing resources. Telephone: 0845 4561497, visit: www.housingandsupport.org.uk, or email enquiries@housingandsupport.org.uk (information sheets available)
- **Challenging Behaviour: A guide for family carers on getting the right support for adults/ teenagers:** Two guides produced by the SCIE that cover what family carers should expect from local services. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone: 01634 838739, email info@thecbf.org.uk or visit www.challengingbehaviour.org.uk
- **Challenging Behaviour Foundation: The Sustainable Hub for the Innovative Employment of Individuals with Complex Needs (SHIEC):** A project that aims to support people with learning disabilities into paid employment. Email: frank.proctor@thecbf.org.uk

6. CASE STUDIES

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 who needed constant 24 hour levels of support. This was due to his severe epilepsy and high levels of challenging behaviour.

As a result David was admitted to a special residential school for children with learning disabilities and subsequently, owing to concern over his level of challenging behaviour when a young adult, to a special hospital. There were two concerns when David came to live in a residential care setting at the age of 40, which pointed the way to how support needed to be developed for him. One concern was 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 his limited communication, 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

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. He 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. However, 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 better understand Stephen 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

CASE STUDY: Ben*

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

8. UNDERSTANDING THE FUNDING

Traditionally, local authorities have funded residential care and other traditional placements, through '*block booking*' agreements. Recent 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.

Direct Payments

When the Local Authority assess that a person's needs are eligible for a service and funding is agreed to meet those needs, the person can choose to take the funding from the Local Authority directly rather than have them organise the service. The person and/or their family take on the responsibility of organising and managing the way their needs will be met. This may involve directly employing helpers (usually known as 'personal assistants') or directly contracting with an agency. The person or their family will also be expected to keep records for monitoring and auditing by the Local Authority to show that the funding (that is the 'Direct Payments') is spent appropriately.

The advantage of this is that a person can tailor the support needed to suit his or her own preferences and select who delivers that support. This gives the person a sense of control. Whilst it is necessary for the person to consent to this option, they do not need to manage or run the scheme themselves but can nominate another or others to look after the day-to-day 'business'. Once this is in place, the Local Authority has a duty to make Direct Payments.

Support services are available to help individuals and their families along the path of exploring this option (contact your local authority). Support can also be accessed with recruitment, brokerage, budgeting, payroll, monitoring and general guidance.

Direct payments for adults lacking 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 individual (over 18 years old) lacks capacity to consent, a direct payment can be made to a willing and appropriate 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.

Capacity to consent

Consent is when someone accepts or agrees to something that somebody else proposes. For consent to be legal and proper, the person consenting needs to have sufficient mental capacity to understand the implications and possible consequences of his or her actions.

In cases where an individual is judged not to have capacity to consent, a group of involved people from a range of backgrounds (e.g. health, education, social services, family, advocate) can come together and discuss the issue and what course of action would be in the best interests of the person, and then make a decision on their behalf.

The 'Mental Capacity Act' (2005) is the law which sets out how people who are unable to make decisions are protected and what actions other people can take on their behalf. The Mental Capacity Act is explained in more detail in Chapter 9.

The Local Authority can 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 fulfill. Trustees can only act jointly and unanimously in decisions regarding trust funds.
- A **Deputy** is someone appointed by the **Court of Protection** to make decisions in the best interests of people who lack capacity. Decisions are in two areas; property and affairs and personal welfare issues. Once appointed a deputy can make specific on going decisions as set out by the Court on behalf of a person who lacks capacity e.g. to manage bank accounts, to sign tenancy/mortgage forms etc.

For further information:

- **The National Centre for Independent Living:** Telephone 020 7587 1663 or visit www.ncil.org.uk
- **Direct Payments quick guide:** Visit www.carersuk.org
- **The Social Care Institute for Excellence (SCIE)** has a booklet entitled "Direct payments: frequently asked questions" which is available free. Telephone 020 7089 6840 or visit www.scie.org.uk
- **Information about "Deputies" and the "Court of Protection":** Contact The Office of The Public Guardian. Telephone: 0845 330 2900 or visit www.publicguardian.gov.uk
- **Becoming a Deputy:** information sheet "Getting legal authority to make

decisions on money, property and welfare.” The information sheet provides a practical step by step guide to the application process to become a Deputy for your relative. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone 01634 838739, email:info@theCBF.org.uk or visit www.challengingbehaviour.org.uk

Individualised Budgets

The Department of Health has piloted a scheme whereby all the funds available to an individual, from various sources, are pooled into one budget (an Individual Budget) which the individual (or people appointed on his/her behalf) manage to arrange the care and support that he/she requires. This means that there is one ‘pot’ - all the money the person is entitled to goes in it, and it is used to meet the person’s needs. Everyone involved knows how much is in the ‘pot’.

‘The idea behind individual budgets is to enable people needing social care and associated services to design that support and to give them the power to decide the nature of the services they need. Key features are:

- A transparent allocation of resources, giving individuals a clear cash or notional sum for them to use on their care or support package
- A streamlined assessment process across agencies, meaning less time spent giving information
- Bringing together a variety of streams of support and/or funding, from more than one agency
- Giving individuals the ability to use the budget in a way that best suits their own particular requirements
- Support from a broker or advocate, family or friends, as the individual desires’
 (Department of Health)

Funds which go into the individual budget include those from local authority social care, Independent Living Fund, Access to Work, Supporting People, Disabled Facilities Grant and Integrated Community Equipment services. Some of these are explained below.

- **Independent Living Fund (ILF) closing in 2015**
 The Independent Living Fund was set up as a national resource dedicated to the financial support of disabled people to enable them to choose to live in the community rather than in residential care. Awards are in the form of regular four-weekly payments to individuals, which are used to buy personal care in the community. Recipients may use care agencies or employ personal assistants, but may not employ relatives who live in the same house. An ILF award can form part of an individualised budget. **However**, the ILF has stopped accepting any new applications and will permanently close in 2015.

Payments to existing users are to continue until 2015. For more information, telephone 0845 601 8815 or visit www.ilf.org.uk

▪ **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 towards the cost of providing adaptations and facilities to enable the disabled person to continue to live there. Such grants are given by local councils under Part I of the Housing Grants, Construction and Regeneration Act 1996. Contact your local Housing or Environmental Health department of your local council for more information, or request a booklet 'Disabled Facilities Grant' from 0870 122 6236, or email communities@twoten.com

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. Visit their website at <http://www.gov.uk/contact-jobcentre-plus> or telephone your local office (numbers are listed in the telephone directory).

9. SAFEGUARDS & PROTECTING THE INDIVIDUAL

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.

For further information:

- **Planning for the future introduction-** An information sheet for Family Carers that provides an introduction to support options and gives a number of questions carers should ask when considering whether a support provider is suitable for their son/ daughter. Available from the Challenging Behaviour Foundation. Free to family carers. Telephone 01634 838739, email: info@thecbf.org.uk or visit www.challengingbehaviour.org.uk

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. The main inspection agencies are CSSIW (Care and Social Services Inspectorate for Wales), Estyn (HM Chief Inspector of Education and Training in Wales) and HIW (Health Inspectorate Wales). Please visit their websites to view their inspection reports; <http://wales.gov.uk/cssiwsbsite/newcssiw/?lang=en>, <http://www.estyn.gov.uk/> and <http://www.hiw.org.uk/>

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.

For 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, email: info@thecbf.org.uk or visit www.challengingbehaviour.org.uk

▪ **Mental Capacity Act 2005**

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
- 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

For further information:

- www.publicguardian.gov.uk or telephone 0845 330 2900.
- A free guide; “Making decisions: a guide for family, friends and other unpaid carers” can be downloaded for free at www.justice.gov.uk.
- A Mental Capacity Act guide can also be downloaded for free at www.hft.org.uk

If your son/daughter is 16 or over, there is a duty to ensure that his/her wishes are taken into account when decisions are made, and that, for example, preferred communication methods are used to explain the processes and the options available. **If your son/daughter lacks capacity, there is a duty to consult family members, and any decision made must be in the person’s best interests.**

The act introduces two new criminal offences:

- Ill treatment of a person who lacks capacity
- Wilful neglect of a person who lacks capacity

The offences can apply to anyone caring for a person who lacks capacity including family, health, social care, hospital or care home staff, Attorneys or Deputies.

- **Deprivation of Liberty Safeguards**

People with severe learning disabilities should be cared for in ways that promote their independence, wellbeing 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.

In 2009 new safeguards came into place to protect vulnerable individuals from being deprived of their liberty unnecessarily. All hospitals and care homes who are caring for a person in a way which takes away a person's freedom must ask for an assessment to decide if it is right to restrict the person. Supported living is not subject to DOLS rules.

For further information:

- **Mental Capacity Act 2005 Deprivation of Liberty Safeguards: A Guide for Families and Carers** is available, which gives clear information about The Deprivation of Liberty safeguards to ensure that no-one is deprived of their liberty without good reason. Available from The Department of Health www.dh.gov.uk/publications or telephone 0300 123 1002

10. WHAT NEXT?

The Challenging Behaviour Foundation aims to work closely with parents/carers and professionals/commissioners in order to promote and develop small, individualised, high quality local services and support for adults and children who have severe learning disabilities and behaviour described as challenging.

We are keen to work with family carers, commissioners and professionals who want to achieve better outcomes for individuals with behaviour described as challenging and their families and carers, facilitating equality of access to local mainstream education (for under 25's) and participation in the wider community locally.

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. Tel: 0845 602 7885)
- Linking you with other families who have sons/daughters who are described as having challenging behaviour (join Family Linking Scheme and Email Networks)
- Linking you with people who can help you achieve the future of your choice for your son/daughter
- Providing information and support to both families and professional carers around understanding challenging behaviour and supporting behaviour change

The Challenging Behaviour Foundation: Last updated August 2013

The Challenging Behaviour Foundation

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

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

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

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

You can show your support at www.challengingbehaviour.org.uk

Make a £5 donation by texting Cbfd05£5 to 70070

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