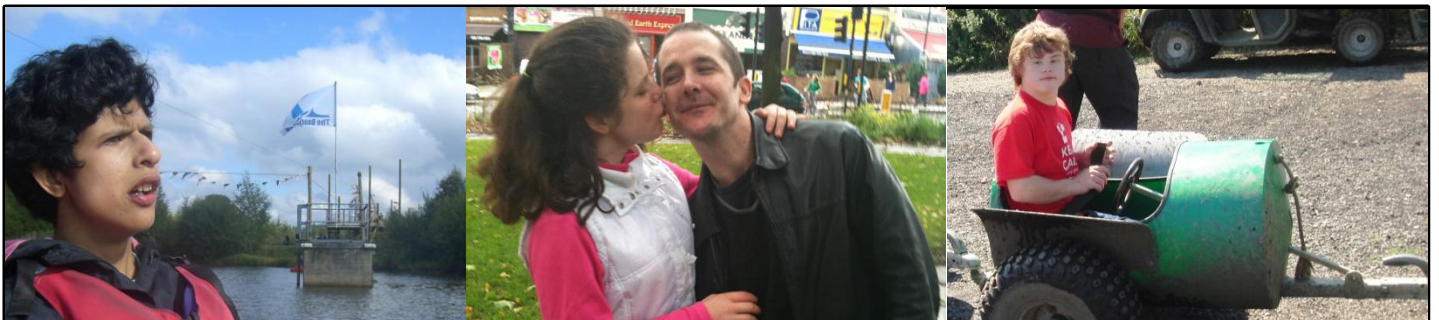




**The Challenging
Behaviour Foundation**
making a difference to the lives of people with severe learning disabilities

Planning for the Future Information Pack: Northern Ireland



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 the Association for Real Change (ARC) Northern Ireland for their help in providing information concerning organisations and legislation in N Ireland.*

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 closer to his family. Daniel is now in his twenties, he lives less than 2 miles from our family home and his accommodation and support have been designed to meet his needs.

Daniel's transition service and the supported living environment 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 is very unlikely that he would "fit" into anything! We have a much greater chance of success if we adopt a person-centred approach and design 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 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 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 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 challenging behaviour**. It is hoped that it will provide the tools families may 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 parents: it's never too soon to start thinking about future options for your son or daughter, particularly if they have severe learning disabilities and behaviour described as challenging.

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.

We hope the information in this pack is helpful.

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

- **Mencap's Information Services in Northern Ireland:** Telephone: 028 9069 1351/ 0808 808 1111, email: helpline.ni@mencap.org.uk or visit www.mencap.org.uk
- **Transition: a guide for parents and carers:** A guide offering advice and information for parents and carers about the transition process. Available from <http://www.mencap.org.uk/node/6071>
- **Contact a Family Northern Ireland:** A charity that provide support, advice and information for families with disabled children, no matter what their disability. Telephone: 028 9262 7552, email: nireland.office@cafamily.org.uk or visit www.cafamily.org.uk
- **Preparing for adult life & transition – Northern Ireland:** Free information pack produced by Contact a Family. Telephone 0808 808 3555, email helpline@cafamily.org.uk or visit www.cafamily.org.uk/advice-and-support/resource-library
- **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 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 or visit: www.learningdisabilities.org.uk

2. KNOW YOUR RIGHTS

The Bamford Review of Mental Health and Learning Disability (Northern Ireland, 2002) (reviewed again in 2009) outlines a clear vision for 'Promoting the Social Inclusion of People with a Mental Health Problem or a Learning Disability'. This includes valuing people and ensuring that they have '**full rights to citizenship, equality of opportunities and self-determination**'. It also sets out some key principles such as working in partnership with individuals and carers in the development, evaluation and monitoring of services. However translating policy into practice can be a challenge, particularly for people with complex needs, such as those with severe learning disabilities who display challenging behaviour.

This section lists the key 'tools' that can be used to develop the kind of individualised support for people with complex needs.

1. Person – Centred Planning

A key tool for improving the lives of people with learning disabilities identified within the health and social care sector is a **Person Centred Plan (PCP)**. Person-centred planning means starting with the individual and putting the support 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)

2. Supporting People, Changing Lives – The Supporting People Strategy (2005 - 2010, NI Housing Executive)

'Supporting People' aims to ensure that people who use support services will be informed and involved in, and can influence the design and delivery of services. Their overall aim is to commission housing support services that will improve the quality of life and independence of vulnerable people, based on principles of independence, choice, inclusion, partnership, equity, transparency. Northern Ireland Housing Executive is responsible for the delivery of the programme, including prioritising service development, and ensuring positive outcomes for service users. Consultation regarding the strategy's development for 2011-2015 finished in May 2013, and NI Housing Executive are now developing an implementation programme for the changes discussed. For further information, visit www.nihe.gov.uk.

3. Investing For Health NI Strategy (March 2002)

Investing for Health NI sought to address the differences in health experienced by people across Northern Ireland and to reduce inequalities in health. See <http://www.dhsspsni.gov.uk/index/phealth/php/ifh.htm>. For further information contact your specific Investing for Health Area Partnership:

- **Northern Investing for Health Partnership: 028 2531 1199**

- **Western Investing for Health Partnership:** 028 7186 0086
- **Well net; Investing For Health in the Eastern Board:** North Down and Ards 028 9151 0199, South and East Belfast & Castlereagh 028 9056 4936, North and West Belfast 028 9043 4004, Down and Lisburn 028 9266 5181
- **Southern Investing For Health Partnership:** Contact via website

A new strategy that builds on Investing for Health; 'Fit and Well – Changing Lives 2012 – 2022' is currently out for consultation. It seeks to stimulate action to improve the health and wellbeing of all people living in Northern Ireland.

4. Special Education Needs and Disability Order (SENDO) Northern Ireland 2005

The main aim of SENDO is to ensure accessibility to education for disabled young people. The new order develops the rights of children and young people with special education needs to attend mainstream education and bringing in disability discrimination laws to the entire education system within Northern Ireland.

For more information contact your local Education and Library board:

- **Belfast Education and Library Board (BELB):** Telephone 028 9056 4000 or email info.belb@belb.org.uk
- **South Eastern Education and Library Board (SEELB):** Telephone 028 9056 6200 or email info@seelb.org.uk
- **Southern Education and Library Board (SELB):** Telephone 028 375 12200 or email selb.hq@selb.org
- **Western Education and Library Board (WELB):** Telephone 028 8241 1411 or email info@welbni.org.uk
- **North Eastern Education and Library Board (NEELB):** Telephone 028 2565 3333 or email info@neelb.org.uk

5. Equal Lives Report (Northern Ireland, 2005) Review of Policy and Services for people with a Learning Disability in Northern Ireland.

The Equal Lives Report outlined that people with a learning disability in Northern Ireland do not experience the same life opportunities as others and that more must be done within learning disability services to ensure they are fully included within all aspects of life. The report proposes that learning disability services need to be based upon these five key values:

- Social-inclusion
- Individual support
- Empowerment
- Working together
- Citizenship

6. Autism Act (Northern Ireland) 2011

The Autism Act (2011) amends the Disability Discrimination Act 1995. It defines autism as a social communication disability and not a learning disability or mental health condition. Therefore, entitlement to some services and benefits for people with autism is no longer measured solely by:

- Mobility (can the person walk)
- Manual Dexterity
- Physical Co-ordination
- Continence
- Memory, ability to understand, learn or concentrate
- Ability to lift objects
- Speech, hearing and eyesight
- Perception of the risk of physical danger

7. Employment, Education and Training Opportunities

The Disability Employment Service offers a number of schemes to suit diverse needs. These are; The Job Introduction Scheme, Access to Work (NI), Employment Support, Workable (NI) and New Deal for Disabled People:

The Job Introduction Scheme is a job trial lasting 13 weeks. It offers an opportunity for a person with a disability to try out work and see if they are matched with the right employment. Employers receive a weekly grant of £75 for participating in this scheme, whilst the employee will receive a lump sum of money at the end of their 13 week employment.

Access to Work (NI) is a scheme available to help people overcome the practical problems at work caused by disability. It helps towards the cost of; specialised aids and equipment, travel to work, support workers, adaptations to the work environment, etc.

Employment and Support Allowance offers personalised support and financial help for someone who is not working due to an illness or disability.

Workable (NI) provides a flexible range of long term support to assist disabled people with employment barriers to find and keep work. It provides people with disabilities the chance to work alongside non-disabled people in a wide variety of jobs.

New Deal for Disabled People will benefit people with a disability by adopting a structured, supportive approach to helping them back into work.

For further information:

- Department of Employment & Learning website
<http://www.delni.gov.uk/index.htm>
- NI direct website <http://www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/employment-support/work-schemes-and-programmes.htm>

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

The best place to start is with 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 ongoing recording with a positive ‘vision’ of what life should look like for the individual and the support needed to achieve the vision, maintain it, evaluate and review it.

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.

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.

Transition

Although there are many transitions in peoples’ 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.

'Improving the Life Chances of Disabled People' states that families should be supported through transition to adulthood: 'Transition will be better planned around the needs of the individuals and service delivery will be smoother across the transition'. The Code of Practice sets out what should be happening at transition for children and young people with special education needs.

The initial annual review after the child's 14th birthday is named the **14 + Transition Review**. As a parent you may feel anxious about future plans being decided for a child at 14, however this is vital to ensure that the structure and support systems are being put in place to include all elements and also to look at the family as a whole. This also ensures that progress can be reviewed as well as developing a future plan. It is ultimately the responsibility of the school to ensure that the 14 + Annual Review and the Transition Planning Process are carried out.

The people that may attend the meeting are: the young person, parents/ carers, principle/ teacher, education coordinator, representation from Health and Social Care Trust, other Voluntary Organisations. The Transition Coordinator may attend the meeting however in many cases they may not unless that child might face difficulties.

The meeting should highlight a number of things for the young people, including their strengths, additional support needed, goals, and plans. The meeting should also address other contributing factors such as development of skills or health. The plan should highlight individuals or services that will help the young person.

Responsibility for co-ordinating, monitoring and reviewing the plan will fall to the school assisted by the Transition Coordinator, and may involve a specialist careers adviser and anyone else deemed necessary.

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 provide a range of information, support and advice. Some provide general information (e.g. Mencap, Skills NI etc), 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.

Transition support

Within Northern Ireland there are two **Transition Coordinators** for each board area and their role is giving advice and support to pupils who have a special education statement. Their role includes creating and implementing a person centred plan by working with the pupil, parents, school, careers service, health and social care trust professionals and health transition workers, voluntary and any other agencies involved. It is their job to oversee the provision of comprehensive and coordinated services and guidance about the choices available.

Transition Service contact details:

- Belfast Education and Library Board (BELB): Telephone (028) 9056 4000 or email info.belb@belb.org.uk
- South Eastern Education and Library Board: Telephone (028) 9056 6200 or email info@seelb.org.uk
- Southern Education and Library Board (SELB): Telephone (028) 3752 3811/ (028) 3751 2200 or email info@selb.org.uk
- Western Education and Library Board (WELB): Telephone (028) 8241 1411 or email info@welbni.org.uk
- North Eastern Education and Library Board (NEELB): Telephone (028) 2565 3333 or email info@neelb.org.uk

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 of 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. Contact the Northern Ireland Housing Executive www.nihe.gov.uk or telephone 0344 8920 900
<ul style="list-style-type: none"> Lack of funding to meet high cost of support 	<ul style="list-style-type: none"> BUT – a multi-disciplinary community care assessment should include an assessment of the person's housing needs. The law says that the trusts must meet the person's assessed social welfare need – this includes a need for residential or other accommodation. www.lawcentreni.org
<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 progress in education and SENDO NI is committed to the accessibility of education for all young people. A good starting point is the Department of Education and Learning; www.delni.gov.uk or telephone (028) 9025 7777
<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 opportunities 	<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 health and social care trusts 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 detrimental 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

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 health and social care trust should be adopting a person-centred approach and should therefore be prepared to develop a specialist **local** service or support package to meet your child’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 severe learning disabilities and challenging behaviour can, with the right support and adaptations live successfully in a range of housing, including individual self-contained properties, group homes and shared accommodation schemes, and can benefit from the full range of 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 in supported living 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, incorporating 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 health and social care trust specifying what is provided
- There are standards provided by social services that residential housing must adhere to

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
- The trust will require the client to contribute all of their benefits except £23.50 per week for the package that they receive. This means that the individual has only £23.50 a week for individual spending

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.

If you are considering a residential care home placement for your son/daughter, you should obtain a copy of the contract with the trust to ensure you are aware of what should be provided, and a copy of the most recent inspection report. Inspection reports are available on the Education and Training Inspectorate website, www.etini.gov.uk.

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

Supporting 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 under 25 years old, but mostly outside N Ireland. Specialist college places may be funded by your health and social care trust.

There are a number of social care trusts if the type of education or support needed is not available at your 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. 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.

For further 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
- **Association of National Specialist Colleges:** Telephone 0117 923 2830 or visit www.natspec.org.uk
- **Education and Library Board web pages:** See section 4

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.

Within Northern Ireland, the Department for Employment and Learning have a remit to support people with disabilities by ensuring that they have a number of services available. The Disability Employment Service (DES) assist adults with a disability get the right job or training. For further information visit www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/employment-support/work-schemes-and-programmes.htm.

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.

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

As a result David was admitted to a special residential school for children with learning disabilities. Following deepening concern over his level of challenging behaviour as a young adult, he was admitted 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 persons name has been changed to protect their identity

With thanks to: MacIntyre Charity
www.macintyrecharity.org

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 off 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. 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 persons 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 persons 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 subsequently 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 psychiatrists 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 persons 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 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 persons name has been changed to protect their identity

With thanks to Dawud Marsh
ICM Foundation

8. UNDERSTANDING THE FUNDING

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 health and social care trust 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 your local health and social care trust directly rather than have them organise the service. The person takes 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 will also be expected to keep records for monitoring and auditing by the health and social care trust to show that the direct funding (that is 'Direct Payments') is spent appropriately.

The advantage of such a scheme is that a person can tailor the support needed to suit his or her own preferences and choose who delivers that support. This places the person in 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 health and social care trust 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 health and social care trust). 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 '**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.

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 (Health, Welfare & Finance Bill) is a piece of legislation that is still under discussion and should be enforced in 2013/14. It aims to ensure people with disabilities are provided with support to help them make decisions for themselves. People will also be presumed to have capacity to make their own decisions unless proved otherwise.

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.

For further information:

- **The National Centre for Independent Living:** Telephone 020 7587 1663 or visit www.ncil.org.uk
- **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
- **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

Individualised Budgets

The Supporting People strategy ‘Supporting People, Changing Lives’ (NI Housing Executive, 2005) sets out to replace a multifaceted system of numerous funding sources with one ‘Supporting People’ Fund. 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’.

Funds which go into the 'Supporting People' Fund include the Independent Living Fund and the Disabled Facilities Grant. These are explained below:

▪ **Independent Living Fund (ILF) – closing in 2015**

The Independent Living Fund was set up to enable disabled people to choose to live in the community rather than in residential care. The Independent Living Fund is there to finance personal care in the community, either by using care agencies or employing personal assistants. The Independent Living Fund is funded by the Department of Social Development in Northern Ireland. **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 further information contact www.nidirect.gov.uk/the-independent-living-fund or telephone (0845) 6018 815

▪ **Disabled Facilities Grant (DFG)**

A person with a disability who owns the property they live in, or is a tenant, may qualify for a disabled facilities grant towards the cost of providing adaptations and facilities to enable the disabled person to continue to live there. An assessment must first be carried out by an occupational therapist. Contact your local health and social services trust, or visit www.nihe.gov.uk or www.nidirect.gov.uk/home-adaptations-and-equipment-disabled-facilities-grants

For further information on benefits and entitlements:

- The Benefits Enquiry Line. Telephone 0800 220 674, visit www.nidirect.gov.uk or www.citizensadvice.co.uk or contact Citizens Advice Regional Office on (028) 9023 1120

9. SAFEGUARDS AND 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 support for individuals who have severe learning disabilities and behaviour described as challenging 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 Northern Ireland Regional Adult Protection and Procedural Guidance 2006” sets out an organisation’s obligations in publishing policy and procedures. To download, go to:

<http://www.hscboard.hscni.net/publications/LegacyBoards/001%20Regional%20Adult%20Protection%20Policy%20and%20Procedural%20Guidance%202006%20-%20PDF%20249KB.pdf>

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

- A comprehensive adult & child 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

All services are checked by agencies to ensure correct procedures are in place to protect vulnerable individuals. The main inspection agencies for Northern Ireland are NISCC (Northern Ireland Social Care Council) and the Regulation and Quality Improvement Authority (RQIA). Health boards are obligated to conduct a minimum of two inspections a year. Inspection reports can be viewed by the public.

Social service residential housing has the additional quality assurance that authorised personnel from the Department of Health and Social Services have the right of entry at any time.

Services for children (e.g. residential schools) are inspected by The Education and Training Inspectorate.

3. Staff Checks (ACCESS NI and NISCC)

ACCESS NI is a service where anyone who is employed to work with vulnerable adults is checked. This system enables organisations to check the full criminal history of staff and volunteers in prescribed posts, known as 'regulated positions'. As a part of the safeguarding within Northern Ireland for children and vulnerable adults it is a criminal offence for anyone who appears on this list to apply for a regulated position. Employers must also check under law and it is a criminal offence not to check. Visit <http://www.dojni.gov.uk/accessni>

The Northern Ireland Social Care Council (NISCC) is the regulatory body for Social Care workers in Northern Ireland. Social Care workers registered with the NISCC must comply with recognised standards or training, conduct and practice. Those who provide poor practice or behave inappropriately will be investigated by the NISCC. You can check online if a Social Care worker is registered. Visit www.niscc.info

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

10. WHAT NEXT?

We know that 'there are still too many people who are being sent away from their local communities in order to get a service' (Department of Health 2005). 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 people 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 the CBF's Family Linking Scheme and E-mail 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