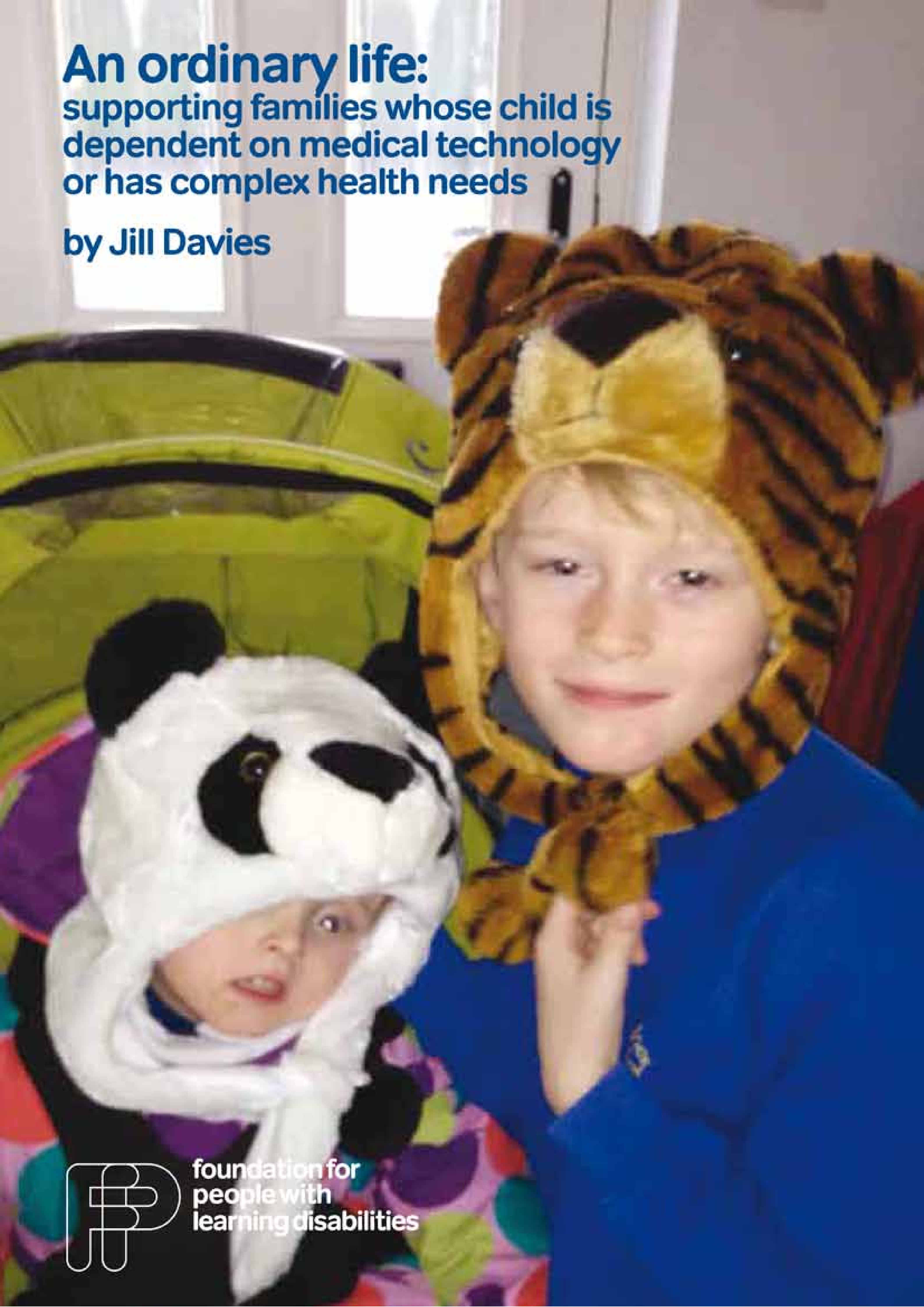
An ordinary life:

supporting families whose child is dependent on medical technology or has complex health needs

by Jill Davies



foundation for
people with
learning disabilities

Acknowledgements

‘An Ordinary Life’ is a Department of Health funded project run by the Foundation for People with Learning Disabilities. Its aim is to offer information to families who have a child with complex health needs or who is dependent on medical technology about ways they can seek support to lead as ordinary a life as possible.

We are extremely grateful to all the children, young people and families who took part in the first phase of this project. They spoke about their experiences and told us what they think will help other families in similar positions. Their input has been invaluable: without it this booklet would never have been written. Some of the families also contributed photos and video clips to accompany this booklet, which brings the information to life. Many thanks go to Karen Alkhina and Laura Jones who helped us develop a communication passport template.

I am also very grateful to the members of the project’s advisory group for their support and advice during this first phase of the project (please see Appendix 1 for more details) and to Christine Towers, Alison-Giraud-Saunders and Janet Cobb for all their help in the development of the booklet. Many thanks to Amanda Johnson from Housing Options, who wrote the appendices on housing adaptations and equipment, and Kate Ball and Claire Walsh who designed the booklet.

If you are a parent or professional who has read this guide, we’d love to hear from you. If you have tried some of the ideas or have suggestions on how we can improve on it, our contact details are:

jdavies@fpld.org.uk

fpld@fpld.org.uk

Foundation for People with Learning Disabilities
1st Floor
Colechurch House
1 London Bridge Walk
London SE1 2SX

May 2012

This booklet is not to be confused with the 1980 King’s Fund An Ordinary Life initiative, which helped transform thinking about the opportunities and support available to people with learning disabilities which led to the large hospital closure programme. This new booklet brings the spirit of the King’s Fund programme to a new generation of children and young people who today, in 2012, are still marginalised in society.

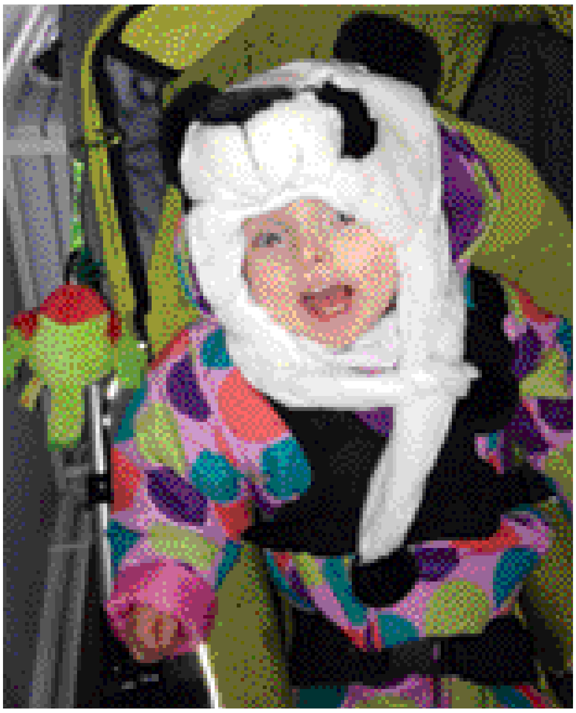
Contents

Introduction

The booklet is based on the initial findings of a project called 'An Ordinary Life'. We called it this because many children and young people with complex health needs and/or who are dependent on medical technology find it very difficult to do ordinary things like going to the local leisure centre or cinema, or visiting friends and family.

We interviewed the families of people who have complex health needs who are trying new ways of working or have ideas to make life better; their experiences have been written up in this booklet.

Over the next two years we will work with other families in five parts of England who are trying out ways to be supported in a more flexible, person centred way. Please see Appendix 2 if you would like to find out more about the project.



The booklet

We hope this booklet gives families in similar positions a chance to reflect on their own experiences and ideas on how to make life more 'ordinary'. The information is based on the experiences of thirteen families who have a child with complex health care needs who uses medical technology. They told us what life was like for them as a family – what were the barriers to leading an ordinary life and what had made their lives better. This is not a long booklet; we understand that, as parents, you have lots of other important demands on your time. We do hope that you may recognise some of the issues that are illustrated in some of the stories and that we give you ideas on how to change something that may be an issue for your family as well as signposting to more detailed information. We hear from families that there is a lack of practical information for them. We hope that this booklet can begin to close the gap.

We will update this booklet as we learn more about practical ways to support families in the second phase of the project. We'd like to hear what helps you and your family lead as ordinary a life as possible, to add to the learning to share with other families.

The booklet is divided into three sections:

1. Family life
In this section we explore some of the key issues experienced by children and young people and their family members through the stories of some of the families we interviewed.

2. Information to help families get an ordinary life – what can make a difference
In this section we will provide information and useful links on some of the ideas and practical things that people have used to improve the quality of family life.

3. Other useful contacts and resources
This section lists organisations and websites that can provide further information and support.

Family life

Here we feature the stories of some of the children, young people and families we interviewed. Most of the children lived with their biological families, but a few were fostered or adopted. We believe that the findings reflect the experiences of these families and drew on the most common issues to choose which stories to share.

Some of the key issues that came to light were:

- the challenges associated with getting housing adapted to suit the child's needs
- knowing what individualised funding from health and social care can be used for
- managing the transition from children's to adult services
- the difficulties in acquiring the right equipment or wheelchair
- and the benefits of employing your own team of support workers.

Every family we spoke to said they strove very hard for their family to have an ordinary life and for their child with complex needs to lead as full a life as possible. However, this took much planning and they had to break down many barriers to achieve this. Some of the young people are now adults, so their families had to work through the differences in funding and support for adults. They were all really keen to share their stories in order to help other families benefit from what they have learned. At the end of each story we highlight what helped, with links to more information.

Here are the stories:

Kaddy and Elijah's story

Elijah is five and has a range of complex health needs arising from having Apert syndrome. He lives with his mother, Kaddy, and spent most of his early life in hospital. He has a team of support workers who care for him over a 24 hour period. This has meant that lots of people have come into their lives, and at one point there were 14 different workers in his team. The support workers are employed by an agency, so Kaddy and Elijah have no say in who comes to work with them. Kaddy said:

"We never get enough time to know if we get on with the person from the nursing service".

Kaddy attended a 'Kindred Spirits' programme (a course aimed at working towards desirable futures for disabled children – see http://www.in-control.org.uk/related-pages/what-we-do/partners-in-policymaking/courses/kindred-spirits.aspx). She found out about personal health budgets and decided this was the way forward for her and Elijah. They have now applied for a personal health budget and are waiting to find out how much funding they will receive. A personal health budget would ensure Kaddy had a pot of money given to her from health funds to purchase the support she and Elijah needed, rather than be given what was on offer by the NHS. Having such a budget allows the individual more control over the support they receive, and in Kaddy's case it means she and Elijah can select the support workers themselves. The budget is based on a support plan which details the hours support Elijah needs along with money to advertise, recruit, train and pay annual leave support staff.

In order to make this possible she set up a circle of support for herself and Elijah, and asked some of those who attended the Kindred Spirits course with her to be members. Other people have joined the circle since then, including an occupational therapist and others with expertise in this area. They met to support Kaddy in drawing up a person centred plan for Elijah, which would be central to the assessment process for the personal health budget. A person centred plan is a way of planning all aspects of someone's life, which puts the person at the centre of the planning, and in Elijah's case, this fed into his support plan which determines the actual budget.

It is a good idea to have a circle of support when doing person centred planning, as having a wider network of people can make help to make change happen and offer practical support and expertise to your family. For example, one member of Kaddy and Elijah's circle was a good writer, so she was given the task of writing reports to give to the local authority to request that Elijah be assessed for a personal health budget, whilst another person was a clear thinker so they accompanied Kaddy when attending meetings with senior managers from the local authority. Kaddy didn't feel so lonely or that she had to do everything herself in order to make Elijah's life better, and now believes that:

"Every family needs a circle".

Key factors that helped the family:

- Working towards the goal of having a personal health budget - go to the section called **Individualised support and funding**. It includes information about personal budgets, direct payments and personal health budgets.
- Having a circle of support made Kaddy feel less isolated: she had a group of people committed to support change for Elijah and herself – go to the section called **Circles of support**.
- Having a person centred plan enabled Elijah and Kaddy to develop a support plan based on his unique needs and also set goals to ensure he is having fun in life too – go to the section called **Person centred planning**.

Pete's story

Pete is 19 years old and has fragile diabetes, autism and a high level of learning needs. Pete has always required lots of support to keep healthy due to his diabetes. Until he was 17 his mother had to come to his school every day to give his insulin injections and she has to sleep in the same room with him at night in case his blood sugar levels drop too low.

When he was about to leave school things came to a head. The college he wanted to attend said they would not give him a place unless he had someone with him at all times. This meant that Pete would have gone to a residential college, something his family did not want for him. The Transition team from the local authority who were supporting Pete and his mother knew that their area was piloting the new personal health budgets. They worked with Pete and his mother to draw up a support plan and it was agreed that he was to be given a combined personal health budget and personal budget for social care to support him throughout the week. The support plan was developed by the Transition team using person centred approaches, and helped identify what his and his family's dreams are for him for the future, along with his talents, what he likes and dislikes and what is important to and for Pete. Gathering this information helped Pete, his mother and the Transition team to develop a detailed plan of the kinds of activities and support he needed during the week and what kind of person would be best suited to support him. The budget is managed for them by a charity that provides information and support to people using direct payments and personal budgets (they are sometimes called brokerage services). They supported Pete and his mum in recruiting the personal assistants employed to support him; they organise payment of these workers and calculate the tax to be paid so his mum doesn't need to worry about that.

This has meant Pete now employs three male personal assistants to support him for over 30 hours per week. They are trained to give injections and to read Pete's blood sugar levels. One personal assistant worked in the school Pete attended and takes him out on the weekends, another attends college with him and the third supports him to go out and do things that other young people do, such as shopping and visiting his sister and her family. It means that his mother is now able to establish a life for herself and is able to work more hours.

"Before the personal health budget we were not able to do what others took for granted. The little things like the theatre, visiting friends. I had no freedom, no life and no choices. Now I'm taking on more work, as I can pay someone to look after Pete. It's given me control and choice in my life massively".

Key factors that helped Pete:

- Having a person centred plan that was developed with Pete and his family that reflects his needs – go to the section on **Person centred planning**.
- Having a good transition plan reduced stress for Pete and his mum as they were actively supported during the process – go to the section called **Transition planning**.
- Having a personal health budget meant he could remain living at home and attend the local college – go to the section called **Individualised support and funding**.

Violet's story

Violet is four and has a range of complex health needs. As her needs are unique, her parents are loath to leave her with other people apart from close family and the short-term breaks unit she uses for day care. She lives in an area where they are trying out personal budgets for children and young people. Violet's parents were keen to give it a go and, as a result of a fairly lengthy assessment process, they have an annual pot of money that can be spent to improve her quality of life. Initially, they found it difficult to know what to spend the money on, apart from paying trusted family members to support mum on trips or do some babysitting. They were able to use some of the money to buy a projector to show images and films on Violet's bedroom ceiling to help her relax at night. Violet is deaf, so she cannot hear soothing music that might help other children to fall asleep. Mum is now looking at Violet joining the local riding club for disabled people. A personal budget may also be useful for purchasing equipment. Violet's mum had to be persistent in order for her to have a wheelchair that was more practical. She was initially offered a wheelchair that was very heavy and this meant that it would have been very difficult to take Violet out in the car on her own. Knowing her rights made it much easier for Violet's mum to negotiate getting a better wheelchair. It was agreed that she be given a wheelchair that was much lighter to use and to fold and unfold, making it much easier to take Violet out on trips. Violet's mum said she could see that in the future having a personal budget that could be used for equipment would be a very good thing.

An area that is a concern for the family is dealing with emergencies, as Violet often becomes poorly. If Violet suddenly needs to go to hospital, both parents have to take her, leaving her brother to be cared for by a neighbour. Violet's mum said she used to 'wing it' and has now developed a plan for such emergencies. She keeps an overnight bag of her own clothes in her wardrobe in case Violet has to stay overnight, and always has a 'grab' bag of clothes and toys for Violet in case she has to go to hospital, and another for her brother if he has to stay with a neighbour or relative. She has a written list of the key people and professionals in Violet's life that she has given to her husband and mother in case she is not available: "the information I keep in my head and phone". She has written up all the key details about Violet in a plan called 'All about me,' which was developed by the nursing team at their local hospital. Some of the key areas in the plan include: diagnosis/ medical information; medication; my usual routine; important numbers and addresses; equipment used; pain control; pets; food and drink requirements. The plan belongs to Violet and she keeps it in her changing bag, so it goes everywhere with her.

Key factors that helped the family:

- Having a personal budget has enabled Violet to go out more and join new clubs, as well as to purchase a projector to help her go to sleep – go to the section called **Individualised support and funding**. It includes information about personal budges, direct payments and personal health budgets.
- Having a detailed plan written up so that people know how to support Violet should any emergencies arise – go to the section called **Emergency planning** for more information on developing information plans either for your child or family.
- Doing lots of research to make sure that what is offered is the best to suit Violet's needs. This gave her mum more confidence to speak up to have a better wheelchair – go to the section called **Knowing your rights**.

Felix's story

Felix is 12 and lives with his family in a busy city. He has nemaline myopathy, which affects muscle function throughout the body. He uses a powered wheelchair, has oxygen ventilation and is fed through a PEG (percutaneous endoscopic gastrostomy). He has a team of staff to support him through the day and night, co-ordinated by the Children's Continuing Health Care team. His mother feels the care he receives is excellent and this has freed his parents to be 'parents' as opposed to being the givers of pain, as his mother states:

"The physio he has to have is painful and I don't want to be hurting him every day – the carers do it so I can do the nice things with him".

Felix was in hospital until he was 18 months old and when he came home his family had to adjust to sharing their home with people caring for him. His mother said:

"We have had to learn how to work with the Primary Care Trust, to work with people who work in our house. In the beginning I had to understand my home is not just a home – it's a workplace for others".

The family had to learn how to deal with the range of staff who came into their lives, and they are passionate that other families need to be better prepared when they leave hospital with their child about how to deal with such intrusion.

As Felix requires so much equipment and has a carer with him at all times, he had to have the largest room in his home. In addition to this their home has had a number of adaptations, including hoists, a wet room and lift fitted from the hallway to their flat. These all took years to get agreed and completed; installation of the lift was only completed when Felix's family kept him off school for six months because of the risks involved in trying to get him in and out of the flat.

Having a powered wheelchair has given Felix the freedom to explore the city he lives in. However, as he uses such heavy equipment, it does prohibit leisure outings that are more than an hour's drive away because of the time it takes to pack and unpack all the equipment into and out of the car and flat. The family have only ever been on two holidays; the last one was funded through a charity that provided medical support.

Key factors that could have or did help the family:

- Being better prepared for life when Felix was discharged from hospital, as the family had to cope with using lots of equipment and sharing their home with paid supporters. Please see the section on **Attention to well-being** for more information about this.
- Having good support to keep Felix healthy. Please see the section on **Good health support** for more information on this.
- Having information on making adaptations to your home – go the sections called **Property adaptation, Design and changes to your property and Assistive technology** for more information on these.
- Having the opportunity to go on holiday as a family, and to make use of leisure activities in their local area. Please see the section called **Leisure opportunities** for more information on this.

Josh's story

Josh is 20 and lives with his mum, step-dad and two sisters. He has cerebral palsy and his youngest sister has Rett syndrome. He attends a day service for young people three days a week and has a team of personal assistants supporting him on the other two days. This means that his mother can work full-time.

Josh and his sister have a joint personalised budget, which means that their mother only has one account to administer. Josh has a budget made up of funding from the NHS, social care and the Independent Living Fund and his sister receives direct payments. Between them they have a team of seven personal assistants who provide flexible support to the family. Many of the team have known and worked with the family for many years. Having a personalised budget has given the family choice and put them in control, as Josh's mother said:

"It means I've got an ordinary life – I've gone to work and been successful in my job. At 20 Josh is still living at home. It means our own physical and emotional health is protected".

The family have had direct payments for many years, but problems arose when Josh reached 18 because his funding became the responsibility of adult services, whilst his sister was still a child. This meant that his mother would have had to administer two different accounts and organise separate personal assistants to care for Josh and his sister at the same time. His mother said:

"Adult and children's services were not working together, not seeing the family as a whole".

She learned that, in order to get the best for her children, she needed to know her rights and entitlements. Her family was one of the first in her area to try a direct payment, as a result of her pressure on the local authority. Similarly, she used her knowledge of the legislation and good practice to achieve a single personalised budget account for both her children, and for an extension to the house using a Disabled Facilities Grant.

Things that helped the family:

- Having a joint budget for Josh and his sister made the administration of the funding much easier – go to the section called **Individualised support and funding**. It includes information about personal budgets, direct payments and personal health budgets.
- Being aware of the correct legislation to push for the Disability Facilities Grant to happen – go to the section called **Knowing your rights**.
- Having information on how to make adaptations to your home – go to the sections called **Property adaptation, Design and changes to your property and Assistive technology**.

Information to help families get an ordinary life – what can make a difference

In this section we explore the ideas that the parents told us made a practical difference to their lives. You may already have lots of these in place, or you may think you would like to try some of the ideas yourself. If so, we give suggestions on who or what may be able to help you make it possible.

The suggestions are divided into the following sections:

For your son/daughter

- Circles of support
- Person centred planning
- Good health support
- Individualised support and funding
- Education
- Transition planning
- Emotional well-being
- Sexuality

For the family

- Emergency planning
- Attention to well-being
- Leisure opportunities
- Knowing your rights

Adaptations to your home

Circles of support

A circle of support is sometimes called a circle of friends. It is a group of people who meet together to help somebody achieve what they would like to do in their life. It might be, for example, about expanding their social circle, somewhere to live, a leisure activity or a holiday. The circle holder should be in charge and decides who they want to invite, what they talk about and where the circle should meet. Those with greater needs will usually require support from their family or someone who knows them really well to ensure the circle meetings are run and maintained. Circles can be as small or as large as required. Some circles comprise the child or young person and their immediate family.

Some young people have found that a circle of support or circle of friends can be really useful in getting the kind of life they want to lead. The young person assembles around them the people they know well and some of the people who may be able to support them in the future. It can include family, friends and professionals. There is value in inviting people from different perspectives, as they can bring in different viewpoints. For example, the family know the person best, a health or social care professional can support with specific tasks such as applying for a personal budget and a person of the same age brings an awareness of what's cool for young people at that moment in time. They participate in person centred planning, which is an on-going process as the lives of the young people develop and their aspirations change.

How to set up a circle for your son or daughter

See a circle in action – you may find it useful to see how Christian's mum supported him to develop his circle of support. Christian is a young man with complex health needs who requires support around the clock due to the unpredictable nature of his epilepsy.

To find out more visit: http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/?view=Standard

Circles work best if the family member has someone to support them to pull it together (often called a facilitator). Family members find it hard to ask for help, so by asking a friend or paid person to facilitate they feel more comfortable to call the first circle meeting. Some areas have people trained to do this, for example, person centred planning co-ordinators. Check with your local support groups or local authority if they do have such a service, or you may wish to employ a freelance facilitator (if you have a personal budget, it could be used for such a purpose).

Many families feel isolated and find it hard to pull together a circle of support as they have always had to do things themselves. Most people are usually flattered to be invited to join a circle, and some people may only be invited if they can bring certain skills at particular times of the person's life. For example, if a person is planning a move out of the family home, it is useful to invite the housing or resettlement officer to attend as they can offer unique information to the circle about that issue. Having a small circle does not mean it is any less effective than a larger circle, in fact, it can be very productive.

Further information on circles of support:

- See how to set up a circle and read about more examples of circles in practice at: www.learningdisabilities.org.uk/our-work/family-friends-community/circles-of-support/?view=Standard
- For information on enduring circles and the role of facilitators see: www.peteandwendycrane.co.uk/index.html
- Using Multi-Media online software tool that can help anyone to communicate and plan their lives.

  www.multi-me.com
- **Shop4Support**

  https://www.shop4support.com/s4s/ui/content/
- **Circles Network**

  http://www.circlesnetwork.org.uk/home.asp?slevel=0z&parent_id=1
- **Equal Futures**

  http://www.equalfutures.org.uk/

Person centred planning

Person centred planning is a way of planning for all aspects of a child or young person's life. The child or young person is at the centre of the planning. With support they need to decide how they want to make their plans, who they would like to help them, how they want to record the plan and who they need help from to make the plans happen. Person centred plans need to be revisited regularly as a person's life changes over time. Person centred planning is not an assessment. It should be about making change in a person's life and plans for the future. It is increasingly widely used across the UK, including during the person centred reviews held for all students with a Statement of Special Educational Need from year 9 onwards in schools.

To do this it is important to involve others and always the child or young person should be at the centre. The way people communicate should always be respected. For those who do not communicate verbally, support to prepare what is important to them is vital, via DVD clips or photographs or using objects of reference ahead of the planning session.

The key questions to think about in person centred planning

Who are the important people in a person's life?
These are the people the young person wants to be involved in developing their person centred plan and who can help them make things happen. These are the committed people in the young person's life: family, friends and others who know and care about them. They are the person's circle of support.

What are the person's strengths (or gifts)?
Finding out what the young person is really good at and what other people see as their gifts can help people think about the kinds of employment, educational course, career paths, activities or future housing options they may wish to pursue.

What is important to the person now and in the future (or dreams)?
This helps young people think about what is important to them. Some things will already be happening and these will need to continue. Other things will need to be planned for. Learning about what is important to young people can also help others to understand their preferences. Similarly, blue sky thinking (asking what a young person's dreams are) can provide ideas about what to pursue in the future.

What are the supports the person may need to make things happen to get the future they want?
People will need to identify key areas in which support is needed and to talk about how they can get that support. Looking after health needs is particularly important for children and young people with complex health needs and person centred plans should incorporate the person's health support needs. The best way to do this is to add a Health Action Plan to the person centred plan (see link below for an example of this).

What do we need to do?
This is also called action planning. This is a way to ensure that those things that the person wants to happen to make a positive future, actually happen. This would include identifying the people who are responsible for implementing the plan with the young person.

Further information on person centred planning:

– See person centred planning in action – you may find it useful to see how Christian's mum supported him to develop his circle of support and person centred plan. Christian is a young man with complex health needs who requires support around the clock due to the unpredictable nature of his epilepsy. This is the same clip shown to demonstrate a circle of support in action.

  For more information visit: http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/?view=Standard

– See Carys' story from the PMLD website, who had a person centred plan to help her move from school to college at http://www.pmldnetwork.org/what_do_we_want/carys_story.htm

– You can download 'My Personal Planning Book' by the Foundation for People with Learning Disabilities at http://www.learningdisabilities.org.uk/publications/personal-planning-book/

– You can download a paper called 'What is person centred planning?' at http://www.helensandersonassociates.co.uk/PDFs

– There is a website designed, planned and run by people with learning disabilities to help others stay in control of their lives at http://www.handsoffmyplan.co.uk

– If you want to develop a Health Action Plan to incorporate into the person centred plan, please see the following link for ideas at http://www.apictureofhealth.southwest.nhs.uk/wpcontent/uploads/2010/06/Health_Action_Plan_Guidance.pdf

Good health support

As a parent of a child or young person dependent on medical technology or who has complex health needs you will have a great deal of expertise in this area. The purpose of this section is to make people aware of the differences in services when your son or daughter moves into adulthood, and other useful information related to health needs.

One of the key issues to be aware of is to make sure your son/daughter is known to your GP. When they leave children's services, the GP will be responsible for co-ordinating their care when they move into adulthood. Children with complex health needs require the expertise of a paediatrician, but it is equally important to ensure their relationship with your GP is developed.

Young people with learning disabilities aged 18 and over are entitled to an annual health check with their GP, and the 2011 Green Paper 'Support and Aspiration' advocates that health checks should start from age 16 from 2015.

For guidance on health checks see:
http://www.rcgp.org.uk/clinical_and_research/circ/innovation__evaluation/learning_disabilities_resource.aspx

Ideally the findings from a health check would contribute to the development of a health action plan. Your local community learning disability team should be able to advise about this.

For more information on this see:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4098111

Many children will have packages of support through Continuing Health Care funding. Again, it is best for families to be prepared for the move into adulthood as there are changes from the children's to adult funding systems. It is best for parents to be well informed, as often staff in child and adult services are not aware of the differences themselves.

For more information on this see:
http://www.nhs.uk/chq/Pages/2392.aspx?CategoryID=68&SubCategoryID=681

Many children and young people with complex health needs may also require specialist support and guidance regarding end of life care, postural care, support around managing epilepsy, managing dysphagia and emotional well-being. Below are links to more specialist information in these areas.

- **End of life care**
  Some children are not expected to live into adulthood. For those children and their families, it is important that they are offered accurate information and advice to support them during this time. 'Together for short lives' is the voice for these children and their families, and incorporates the work of ACT (Association for Children's Palliative Care) and Children's Hospices UK. See:

  http://www.togetherforshortlives.org.uk/
  http://www.act.org.uk/page.asp?section=115&sectionTitle=ACT%27s+transition+care+pathway
- **Postural care (protecting body shape**
  Postural care is about using the right equipment and positioning techniques to help protect and restore body shape in people who find it hard to move, because they sit and lie in limited positions. It is essential to maintain good body shape because failure to do so can have serious consequences for a person's health and quality of life. The Postural Care Action Group is a group of organisations and individuals working to raise awareness about the importance of protecting body shape. To find out more about the group see: http://www.mencap.org.uk/posturalcare
- **Epilepsy**
  The NHS website has a comprehensive guide to epilepsy at:

  http://www.nhs.uk/Conditions/Epilepsy/Pages/living-with.aspx

  http://www.nhs.uk/ipgmedia/national/epilepsy%20action/assets/epilepsyandlearningdisabilities.pdf

  Young Epilepsy has a useful 'frequently asked questions' section on their website, along with epilepsy diaries for children and teenagers at:

  http://www.youngepilepsy.org.uk/all-about-epilepsy/frequently-asked-questions
- **Dysphagia (difficulty swallowing**
  Dysphagia is a medical term for difficulty with swallowing. Some people with dysphagia have problems swallowing certain foods or liquids, while others cannot swallow at all. It is usually caused by another health condition, such as a

condition affecting the nervous system, or gastro-oesophageal reflux disease (GORD) and can also occur in children as a result of a developmental disability. For more information see:

http://www.nhs.uk/conditions/dysphagia/pages/definition.aspx

- **Emotional well-being – see page 19.**

Individualised support and funding

Most children and young people who have complex health needs and/or may use medical technology receive support from their local Clinical Commissioning Group (formerly the Primary Care Trust) and/or local authority. This support has usually been in the form of nursing or support workers provided by an agency or the NHS or local authority. More recently there has been a big push from the Government for people with long-term illnesses or conditions to receive more individualised support (it is sometimes referred to as self-directed support). They call this 'personalisation'. Personalisation means that every person who is eligible for support (whether for health, social care, leisure, transport, education or employment) is to be empowered to shape their own lives and the services they receive, with their own pot of funding.

Support planning

The process starts with someone having a support plan developed to identify how much support the person needs (based on the principles of person centred approaches), along with an idea of how much this would cost and how the money is to be managed. An application is then made to the local authority and then the final sum of money is allocated to the individual. For social care, individuals may be offered a pot of money called a direct payment or personal budget. The Government is also trying out a more personalised approach to health care, through personal health budgets.

This way of supporting people is better established in adult social care than in children's services or the NHS, but new ways of working are being piloted in different places. The 2011 Government Green Paper 'Support and Aspiration' for children and young people with special educational needs sets out new ways of working, with one proposal being the option of a personal budget by 2014 for all families and children with a Statement of Special Educational Need or with a new 'Education, Health and Care Plan'.

Individualised funding

Local authorities vary in how far they have gone down the road towards personal budgets, but you have the right to ask for your money in this way. Below are the definitions of the various types of individualised funding sources.
Personal budgets for health or social care are funding allocated to meet assessed needs. Personal budgets can be managed in three ways:

1. The local authority or NHS can manage it for you
2. A third party can manage it for you (e.g. a service provider or an Independent User Trust)
3. You can receive it as a direct payment.

The latter is available everywhere for social care; currently only pilot sites can offer personal health budgets as direct payments. If a person lacks mental capacity to manage a direct payment, they can still be allocated one and have it managed by a 'suitable person'.

Parents of disabled children can receive direct payments. Family carers of adults may also be entitled to a personal budget to meet their own assessed needs as carers.

Social care

Direct payments are cash payments given to service users in place of receiving community care services they have been assessed as needing. They are intended to give users greater choice in their care. The payment must be sufficient to enable the person to purchase services to meet their assessed needs, and must be spent on services that meet the person's needs. The person receiving the payment needs to either employ people to provide support or ask a service to organise this for them. Many councils have commissioned support organisations to help service users handle the responsibilities to do with employing people.

Personal budgets are allocations of social care funding given to or identified for people after an assessment, which should be sufficient to meet their assessed needs. Users can either take their personal budget as a direct payment, or – while still choosing how their support needs are met and by whom – leave councils with the responsibility to commission the services. Or they can take some combination of this. A personal budget can provide a potentially good option for people who do not want to take on the responsibilities of a direct payment.

Further information on this
Many people like the idea of self-directed support. Some people are put off by the fact that they may have to deal with money and employing staff. This is not necessarily so. As noted above, having a personal budget does not mean you have to have a direct payment.

If you do choose a direct payment, you should be able to get help with this through local brokerage agencies or local Centres for Independent Living that can support people in managing all the various kinds of individualised funding.

You could:

- Ask your social worker or care manager about this.
- Look at the directory of support on the National Centre for Independent Living website at http://www.ncil.org.uk/directory.asp?action=get
- Read 'Getting it right: a guide for families of people with learning disabilities on choosing a support provider and improving the quality of support'. http://www.learningdisabilities.org.uk/publications/
- Look at the website www.in-control.org.uk . In Control pioneered this way of working and have lots of examples to share. In Control have also developed the Shop4Support website https://www.shop4support.com/s4s/ui/content/.

Personal health budgets

Something that is very new at the moment and is being tested in various places in England is a personal health budget. It is an amount of money that is spent on meeting the health care and well-being needs of people, usually with long-term illnesses and disabilities. It gives people more flexibility and choice over the range of health services or care they receive.

A care or support plan is developed with key health professionals or a local voluntary support organisation and then signed off by your local NHS Clinical Commissioning Group (formerly the Primary Care Trust). The plan sets out your health and care needs and how much money is set aside to pay for those. The budget can be managed by:

- The NHS, which will co-ordinate the services and budget for you (this is called a notional budget).
- An organisation independent from you and the NHS, for example, a voluntary organisation that holds the money on your behalf or an Independent User Trust (this is called a third party arrangement).
- You (this is called a health care direct payment). You can opt for a direct payment organisation to help you manage the direct payment.

The first two options are possible anywhere in the country. At present, only NHS Clinical Commissioning Groups (formerly Primary Care Trusts) in the pilot programme can offer health care direct payments.

Mitchell's story

Mitchell is 19 and has very complex health needs. He requires oxygen ventilation through the day and night, and has a team of nurses and support workers to support him. He was probably the first person in England to use a personal health budget (this was before they were even called that). His family were already using direct payments to fund the social care element of his support package. This had many benefits, including the feeling that the family were more 'in control', so they decided to try and get the health element funded through a direct payment too. It was impossible for the family to go on holiday or visit their extended family as the support workers employed through the health service were unable to accompany the family. After much work, funding was agreed and Mitchell and his mum now employ a team who know him really well and are able to work flexibly to meet his needs. Mitchell was able to celebrate his 18th birthday on holiday at a Center Parc and kept the same team of support staff as he moved into adulthood, thus reducing the stress caused by such changes at these times. To find out more about his story and how his family achieved this see: http://www.in-control.org.uk/media/6258/mitchell's%20story%20%20.pdf

Further information about personal health budgets:

- Read 'Understanding personal health budgets' by the NHS: www.dh.gov.uk/prod_consum_dh/groups/

dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117260.pdf and http://www.personalhealthbudgets.dh.gov.uk/

- For information about how Independent User Trusts can manage personal health budgets see http://www.in-control.org.uk/what-we-do/staying-in-control-health/latest-publications/personal-health-budgets-and-independent-user-trusts.aspx
- PeopleHub CIC is a personal health budgets network. The aim is to give a voice to people and family carers, to connect and empower people and to influence the development of personal health budgets. See http://www.peoplehub.org.uk
- Department of Health personal health budgets Learning Network

  http://www.personalhealthbudgets.dh.gov.uk/
- Personal health budgets and NHS Continuing Healthcare

  http://www.dh.gov.uk/health/2012/02/personal-health-budgets-and-nhs-continuing-healthcare/

Education

Education came up as an issue for several families interviewed. Whilst most of the children attended a special school, some did attend their local mainstream schools. The children and families had personal choices when it came to which school was the best to suit their needs. Some children were able to be stretched academically in mainstream schools, and had made friends from their local area as a result. One child had attended a mainstream primary school, but as he got older he found he was missing out on a peer group. He then moved into a special secondary school and, whilst he found friends, was not being challenged academically as much as he had been at mainstream school. Another young person had a split placement during the primary years – he attended both his local mainstream school and a special school. When he moved into the secondary school he found the transition between lessons difficult to cope with at the mainstream school and chose to attend the special school full-time. Some families raised issues such as needing to go to the schools to administer medical interventions; having to transport a child on school trips as the mainstream school did not hire a more accessible vehicle; and some children often missed chunks of school due to their health needs.

Suggested ways to address some of these issues include:

- If you are interested in how schools can make reasonable adjustments to support disabled pupils please see: http://inclusivechoice.com/files/making_reasonable_adjustments_for_disabled_pupils.pdf
- Consider asking the school to record podcasts for those who miss lessons through illness or having to leave class early to get to the next lesson.
- For children unable to attend school there are virtual on-line teaching academies, for example – http://www.nisai.com/uk/education/home
- A guide for schools to include children with complex health needs: http://councilfordisabledchildren.org.uk/resources/cdcs-resources/including-me
- For information about your rights if your child requires invasive procedures, see:

  http://councilfordisabledchildren.org.uk/resources/cdcs-resources/my-rights-your-responsibility/invasive-care
- For those thinking of mainstream school as an option, see Jessie's story:

  http://www.mencap.org.uk/campaigns/what-we-campaign-about/children-andyoung-people/jessies-story
- For organisations that promote inclusive education:

  http://www.csie.org.uk/index.shtml

  http://www.allfie.org.uk/index.html
- For general information about education and children with additional needs, see the Department of Education Special Educational Needs (SEN):

  http://www.education.gov.uk/schools/pupilsupport/sen

Transition planning

Planning for the future for your son or daughter can be a daunting time. Everyone wants their son or daughter to have a fulfilling life as an adult, but sometimes finding out how to achieve this and what is available can be hard. School and college offer predictability, but when a young person has to move on from this there is uncertainty about what the future holds. There has been a big shift in the way things work. In the past, following an assessment, the young person might have been offered a place in a day centre; now the future should be based on individual needs and preferences.

Transition planning at school

Ideally, person centred planning should be at the heart of the planning during transition to adult life. In England at Year Nine the young person with a Statement of Special Educational Needs will have a review organised by the school (called a person centred review). The transition review is laid down in law. It should involve family, friends and staff across different agencies that are supporting the young person. It is helpful if the plan is in a format that will be useful to the young person, (especially where the young person has high support needs and is unable to communicate their wishes in words), for example, through the use of pictures, photos or video clips. The meeting should include how to address health needs too. It will be reviewed each year until the young person leaves full time education. This should lead to a transition plan. The 2011 Government Green Paper ('Support and Aspiration') is proposing a single assessment process and 'Education, Health and Care Plan', spanning education, health, social care, and support into employment, along with access to better quality vocational and work-related learning options to enable young people to progress in their learning post-16.

At 16, and the last review before the end of compulsory education (which will be raised to 18 in 2015), the young person should have an assessment and report about further education and training needs. This is called a 'Section 139' assessment. It should fit in with the overall planning for the future. For all young people the goal after leaving full-time education is to lead a full and active life. Young people with disabilities have exactly the same aspirations as their non-disabled peers.

The Government has funded a number of programmes during the past few years that focus on raising aspirations and opportunities at transition. They include:

- The Transition Support Programme (2008-11) www.transitionsupportprogramme.org.uk
- Getting a life (2008-11) www.gettingalife.org.uk
- Valuing Employment Now (2009-11) http://base-uk.org/knowledge/valuing-employment-now.
- And the USA model of obtaining employment via internship – Project Search. http://base-uk.org/policy/news/project-search-evaluation-published

The transition element of the 2011 Government Green Paper ('Support and Aspiration') is called 'Preparing for Adulthood'. This programme aims to provide knowledge and support to all local authorities and their partners, including families and young people, so they can ensure young people with special educational needs and disabilities achieve paid work, independent living, good health and community inclusion as they move into adulthood. See http://www.preparingforadulthood.org.uk for more information about this.

Social care needs and the transition

Social services may need to get involved if the young person requires social care. If the young person already has support from social services, someone from there should attend the Year Nine review. Otherwise social services must be informed if the young person is likely to need support from them when they are 18. The kind of support could be help with personal care, things to do during the day, short breaks or getting support into work. The young person will need a community care assessment and plan to ensure they meet the eligibility criteria for their local authority.

Health needs and the transition

One major aspect of the transition to adulthood to consider for this group of young people is their health needs. It is important that there is a health transition plan or Health Action Plan to support the young person at this stage, and to complement the other plans that the young person is being supported to make during the transition stage. Up until the age of 18 it is highly likely that your son or daughter was under the care of a community paediatrician (or Child Development Team) who co-ordinated care between various other health professionals. When a young person reaches 18, this no longer happens and it can be difficult to find a health professional who will continue to co-ordinate care, although the GP will provide some continuity. GPs are now expected to do annual health checks on most young people with learning disabilities from the age of 18 under something called the Directed Enhanced Service (DES).

The 2011 Government Green Paper 'Support and Aspiration' proposes that annual health checks should start from age 16. Young people with complex physical or emotional difficulties may have access to additional support from specialist learning disability services that are based in every local authority (usually known as Community Learning Disability Teams). It is very important that young people have a relationship with their family GP, as they will in the future play a central role in the commissioning of health care.

An important change in NHS funding happens at age 18. For children and young people up to this age, NHS Continuing Healthcare funding may be part of a combined package of funding that includes social care and education money. At age 18 a different system starts: NHS Continuing Healthcare for adults is funding for a complete package of health and social care for people whose 'primary need' is regarded as a health need. It is therefore likely that your son or daughter will have an assessment of their eligibility for NHS Continuing Healthcare. It is important for families to be fully informed and involved in this assessment and planning. For more detailed information about this, download 'What do I need to know about NHS Continuing Healthcare? Information for families of people with learning disabilities at www.learningdisabilities.org.uk

Checklist on health in the transition process:

Does the young person have a health transition plan or health plan or Health Action Plan?
It has been recommended by the Government that people with learning disabilities have a Health Action Plan that holds information about the person's health needs, the professionals who support those needs and appointments. The plan is based on a full health check. A person with a learning disability can get a Health Action Plan by asking a health facilitator to support them to develop a plan, act on it and keep it under review. The health facilitator could be anyone supporting a person with a learning disability, including you or another member of the family, or a member of the Community Learning Disability Team. The Health Action Plan should include the full range of services and supports the young person might need; for example medication taken, dentistry, eye care, speech therapy, occupational therapy or physiotherapy. Health Action Plans might also be created as part of a transition plan or person centred plan. Plans should be updated as any change in health occurs and provide information for any future health problems. Please see end of this section for a link to an example of a Health Action Plan.

Does your GP do annual health checks?

Is there a learning disability liaison nurse at your local hospital who can make sure the young person gets the tailored help they need?

Have you considered having a Hospital Passport?

This documents important information about your son or daughter to inform staff in hospital. For example, it will contain information on how to communicate with the young person, how he or she shows pain, the best way to give medication. Many Community Learning Disability Teams will have nurses available to support people to put these together. Please see end of this section below for an example of a Hospital Passport.

Decision making

When your son or daughter reaches 16, the law changes regarding any decision making. Some young people with learning disabilities may lack the capacity to make decisions for themselves. The Mental Capacity Act (2005) was designed to set out what should happen in England and Wales to assess capacity and support decision making if someone is unable to make a decision by themselves.

Hft, in partnership with the Foundation for People with Learning Disabilities and the National Family Carer Network, has developed guidelines to help families understand how the Mental Capacity Act (2005) applies to them (there is a section in the guidelines about the transition to adulthood). To download a copy and access DVD clips see: http://www.hft.org.uk/Supporting-people/family-carers/Resources/MCA-guide/.

See also:

- Making decisions The Independent Mental Capacity Advocate (IMCA) Service
  http://webarchive.nationalarchives.gov.uk/+/http://www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf
- Independent Mental capacity Advocate (IMCA) Resource
  http://www.scie.org.uk/publications/imca/

Advocacy

Advocacy ensures that minority and disadvantaged groups in society have a means to know about, and gain, the same life opportunities as others. During childhood, it is generally assumed that in most cases, parents take on the role of advocate for their children. As children move into adulthood, this shifts towards the young person taking on the advocate role themselves. Many young people with complex health needs may still need someone else to support and advocate for them.

Independent or citizen advocacy is about speaking up for someone who has difficulty in getting their voice heard. It is about spending time with them and getting to know their wishes and then supporting them to bring about the changes they desire in their lives. It is about putting the person in control of their lives. Independent advocates are very much involved with the person centred planning process and would be a key person in the circle of support.

Another possibility is for the young person or their supporter to contact a local advocacy group to develop the skills to advocate for themselves (self- advocacy). Some areas have strong advocacy organisations and in other areas such provision is patchy. Some families find the idea of independent or citizen advocacy difficult as they have always advocated on behalf of the young person. Others welcome this as an opportunity for the young person to explore what they really want independently of the family, recognising that the wishes of different family members may not be identical.

To find out more about the advocacy services in your local area, contact the Advocacy Resource Exchange (ARX) at http://www.advocacyresource.org.uk/

Further information on transition

Health related

- For further information about the transition to adulthood and health please read the Department of Health guidance ‘Moving on well’. It contains good practice around the move from children’s to adult health services and includes a transition plan used to aid young people through the process at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592
- For examples of a Health Action Plan and Hospital Passport see:

  http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=153

General transition

- For a practical workbook to help young people think about the future see: http://www.learningdisabilities.org.uk/publications/my-kind-of-a-future/ This is a workbook for young people.
- For a booklet aimed at families whose son or daughter with a learning disability is moving into adulthood see: http://www.learningdisabilities.org.uk/publications/prepared-for-the-future/
- Another guide for parents can be found at: www.cafamily.org.uk/pdfs/preparing_for_adult_life_web.pdf
- The Transition Information Network holds useful information about the transition at: www.transitioninformationetwork.org.uk and has a database of resources at: http://resources.transitioninfonetwork.org.uk
- For information about the new Government programme ’Preparing for adulthood’ see:

  http://www.preparingforadulthood.org.uk/
- There are various information and factsheets about transition on the Mencap website at:

  http://www.mencap.org.uk/all-about-learning-disability/transition-and-further-education, http://www.mencap.org.uk/search/apachesolr_search/transition
- ‘The Road Ahead’ provides information for young people with learning disabilities, their families and supporters at transition
- http://www.scie.org.uk/publications/tra/index.asp

Emotional well-being

All of us experience challenges around our emotional well-being at some stage in our lives, with one in four of us experiencing a problem with our mental health in any one year. Children and young people with learning disabilities and other forms of disabilities are not exempt from this. Research by Professors Eric Emerson and Chris Hatton from Lancaster University (2007), funded by the Foundation for People with Learning Disabilities, highlights that children with learning disabilities are more likely to experience poverty and social exclusion and it is these experiences that lead to a greater risk of mental ill-health.

These problems may be worsened for those with greater support needs, particularly if they are unable to communicate about their feelings or communicate their distress (it may result in behaviour seen to be challenging instead). As a result, changes in emotional well-being in children and young people with high support needs may easily be overlooked by those who care for them, particularly if they have high levels of medical needs. Research by the Foundation for People with Learning Disabilities (‘Making Us Count’, 2005) clearly identified that people with profound and multiple learning disabilities do experience mental health problems, often for similar reasons as other people. However, identifying those signs and symptoms that indicate changes in the emotional and mental well-being of people with profound and multiple learning disabilities takes longer to assess, and it is often the families who are best placed to identify such changes. Some of the key factors that contribute to a change in emotional well-being are physical health, loss and bereavement (this could be a change of support or bus driver who takes the child to school, as well as the loss of a family member), change and transition to adulthood.

Further information around emotional well-being:

- About the mental health needs of young people with learning disabilities see: http://www.learningdisabilities.org.uk/our-work/health-well-being/mental-health-young-people/?view=Standard
- 'All about feeling down' is an easy read booklet aimed at young people with learning disabilities to help them understand how it feels and what to do if they are feeling down: http://www.learningdisabilities.org.uk/publications/all-about-feeling-down/
- 'You are not alone is a booklet' aimed at parents who want to know what help is available if their son or daughter develops mental health problems: http://www.learningdisabilities.org.uk/publications/you-are-not-alone/
- 'Meeting the emotional needs of young people with learning disabilities' is aimed at parents and carers: http://www.learningdisabilities.org.uk/publications/meeting-emotional-needs-ypld/

Sexuality

Young people with disabilities have sexual needs like any young person. Some young people may require someone to be with them 24 hours a day. This can raise issues when they reach puberty and want privacy as they explore their sexuality. There are several useful booklets and charities that can offer more information in this area.

Further information around sexuality

For useful reading around sexuality and a podcast by Contact a Family see: 'Growing up, sex and relationships – a booklet to support parents of young disabled people' www.cafamily.org.uk/pdfs/GrowingUpParents.pdf.

'Growing up, sex and relationships – a booklet for young people' www.cafamily.org.uk/pdfs/GrowingUpYoungPeople.pdf

This booklet is a review of the resources addressing sexuality for people with learning disabilities: 'Sexual Health and Relationships: A Review of Resources for people with learning disabilities', http://www.healthscotland.com/documents/1185.aspx.

Brook, the national charity for sexual health for the under 25s, has a number of titles, including:

- Looking ahead (for males and females)
- Sexplanation board game.

  http://www.brook.org.uk/professionals/application/shop/?page=shop.browse&category_id=28.

The Family Planning Association has developed resources for parents of children with a learning disability at: http://www.fpa.org.uk/helpandadvice/parentsandcarers/if-your-child-has-a-learning-disability.

They have two very useful resources:

- 'All about us' – DVD/CD
- 'Talking together' – a workbook for parents.

CHANGE and the University of Leeds conducted research into sex and relationships in people with learning disabilities and have produced an easy-read report and 'Sex and relationships pack' aimed at people with learning disabilities. The pack contains booklets on a variety of topics such as friendships and relationships, sex and masturbation and can be bought as a pack or separately, see: www.changepeople.co.uk.

They can also be purchased from the Family Planning Association website (see above).

Emergency planning

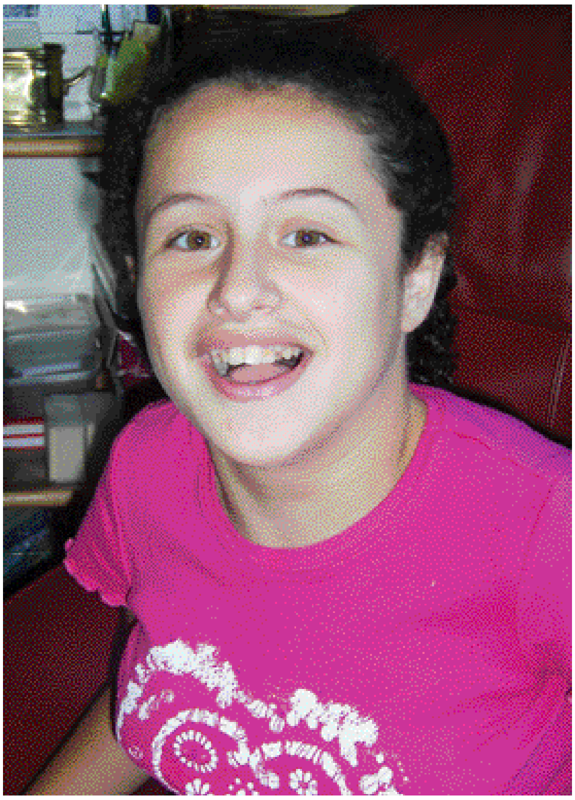
Most parents we spoke to said they did not have anything formal in place should an emergency occur. Emergencies could be of a medical nature, for example, if a child suddenly had to go into hospital. Or they could be of a social care nature, for example, if a parent became unwell resulting in them being unable to be the primary carer for their son or daughter for a time. Families said it would have been good to have a plan in place, with lists of key people who can be contacted in such emergencies along with important information about their son/daughter.

Violet's parents developed a plan based on the key information people needed to know about her, along with a list of key people and staff in her life. It is sometimes known as a communication passport, and is particularly useful for children and adults who are unable to communicate verbally about themselves. This is kept in her bag, which goes everywhere with her.

Ami's story

Ami has a rare metabolic disorder which requires a specialist diet fed to her through a gastrostomy tube, along with limited mobility and communication skills. A few years ago her mother broke her arm so it was impossible to care for Ami's medical needs and help her get ready for school on a week-day as her husband worked away from home. Although the family had never previously received social work input, a referral to the local social services department enabled Ami to have a time-limited package of support in the form of a support worker to get her ready for school each day for six weeks.

Ami's mother also has to deal with medical emergencies linked to Ami's metabolic condition. If this happens, Ami's mother contacts the consultant nurse at the London hospital who has responsibility for her Ami's care. On other occasions, usually if Ami's gastrostomy tube becomes detached from her stomach, the priority is to take her to the local hospital's Accident and Emergency unit.



Ami and her mother have helped us to develop an information pack based on the principles of the communication passport. It's called 'The book about me' and can be found in appendix 3. We hope this will be useful for others should emergencies occur when those who are closest to the child are not available.

Communication passport

Some people may already have a communication passport. Communication passports include the essential information about someone in a quick, efficient way. Generally, such passports should include sections such as:

- Activities I do
- Things I like
- Things I don't like
- Special people in my life
- My communication
- My daily routine
- How I eat and drink
- Food and drink I like
- How I get around
- My medical information (diagnosis, medication used, how I experience pain and pain relief, equipment used)

- Additional information
- My contacts (family, friends, professionals).

To see an example of a communication passport, see Appendix 3. Also, to make your own, you can download 'The book about me' from www.learningdisabilities/publications as a pdf you can write over.

Information and examples of plans and information required in emergency situations

- For more information on what a communication passport is, see the following:

  http://www.communicationpassports.org.uk/Home/

  http://www.communicationmatters.org.uk/page/communication-passports
- Scope has a template of a communication passport on their website:

  http://www.scope.org.uk/sites/default/files/pdfs/Communication/Scope_communication_passport.pdf
- For an acute hospital admission see:

  http://a2anetwork.co.uk/wp-content/uploads/2010/01/Good-practice-guildelines-_learning-disabilities_.pdf
- Grab sheet

  http://a2anetwork.co.uk/wp-content/uploads/2010/01/Grab-Sheet-Hospital-Information-Sheet.pdf

'Supporting you as an older family carer' is a booklet to support older family carers of people with learning disabilities to get the right support now and to plan for emergencies and the long term. It can be accessed via www.learningdisabilities.org.uk

Attention to well being

Bringing up children is a joyful experience, however most parents will acknowledge that at times it can be stressful. Finding out that your child has a disability is likely to be a significant turning point in your life and a whole new, unexpected and possibly challenging world opens up. Today, we are encouraged to take a positive view of the birth of a baby with a disability. At the same time, we need to recognise that it can affect relationships between parents, siblings and the extended family and friends. Similarly, difficulties with housing and finances may arise, as well getting to know the network of health and social care professionals who will come in and out of the child's life. Some families have to share their homes with a team of support workers 24 hours a day.

Information and ideas around looking after your well-being

Short-term breaks:
Caring for a child with a disability can be exhausting, and many families have to juggle the needs of their disabled child with those of their other children. This has been recognised and every local authority in England must provide breaks from caring for carers of disabled children. This is sometimes known as the duty to provide short breaks. Eligibility for this support is usually determined by a social worker.
For more information about the duty please contact your local authority or see: www.education.gov.uk/childrenandyoungpeople/sen/a0075231/short-breaks

Recognition of your own well-being and that of other family members:
Adjusting to different expectations for your child as well as coping with the day-to-day caring for all the family can place a lot of demands on your physical and emotional energy. There are several sources of information and support for parents that acknowledge the need for emotional support:

'First Impressions' – this booklet is aimed at parents of younger children, but includes practical information such as what financial support is available and a list of useful contacts: http://www.learningdisabilities.org.uk/publications/first-impressions/.

Contact a Family have a wide range of information and services for families across the UK: www.cafamily.org.uk

It can be very daunting when a child with complex health needs has been discharged from hospital. Knowing what to expect can reduce anxiety. The following is guidance for staff in developing pathways for children leaving hospital to go home (it is not aimed at parents, but you may find useful information contained in it):

- http://www.barnardos.org.uk/from_hospital_to_home.pdf
- 'Achieving timely simple discharge from hospital: A toolkit for the multi-disciplinary team' provides best practice guidance to discharge from hospital. It covers all ages and has a focus on practical steps health and social care professionals can take to improve discharge: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4088366.

Carers' assessments are available to those providing regular and substantial care to someone. It should be part of the process of assessment when the person you're looking after is being discharged from hospital, and anyway as a parent carer of a disabled child under 18. To find out more see: http://www.nhs.uk/CarersDirect/guide/assessments/Pages/Carersassessments.aspx

Below are links to information and resources that may be useful for different members of the family:

Fathers
The Foundation for People with Learning Disabilities has undertaken research with fathers of disabled children and produced a number of reports and booklets. See: http://www.learningdisabilities.org.uk/our-work/family-friends-community/recognising-fathers/?view=Standard

For further information about the needs of fathers see the following from Contact a Family: http://www.cafamily.org.uk/pdfs/fathers.pdf
http://www.cafamily.org.uk/pdfs/GAPFathers.pdf

Siblings
There is a range of resources aimed at supporting and recognising the roles of siblings. Contact a Family have a booklet for parents and a podcast by the sister of a young man with a disability:
http://www.cafamily.org.uk/pdfs/siblings.pdf
http://www.cafamily.org.uk/news/podcasts.html

The following organisations also have useful information and resources:
http://www.sibs.org.uk/
http://www.youngcarers.net/

Personal development programmes
Kaddy said she was fed up with fighting the system. She said:

"You can be buried in the system or you can overcome it. I've educated myself. Before I would kick and scream at professionals, now I need a solution to the problem".

She attended a personal development programme being held in her area, called 'Kindred Spirits'. For more information about this and other courses see: http://www.in-control.org.uk/related-pages/what-we-do/partners-in-policymaking/courses.aspx .

Leisure opportunities

Going on holiday can be seen as a way to wind down, but if you have a child dependent on medical technology there are lots of issues to address. All the parents we spoke to said it takes lots of planning, but most were prepared to do that planning in order for the whole family to benefit from a change of environment. Some families choose to go away with other families with a disabled child. Violet's family go away with another family and said they find it easier going away with people in a similar position. There are baby sitters on tap and it means the siblings have playmates too.

There are charities that can arrange holidays, such as the 'Make a wish' Foundation. Felix and his family have been on two holidays with a charity that enabled all the family to go away, with additional nursing support. These are the only two holidays they have been on as a family. Mitchell and his family were unable to go away until he received a personal heath budget. Having the budget meant they could use the money to pay for one of his personal assistants to go with the family and provide extra help on a break at Center Parc. Families are also entitled to short-term breaks and every local authority in England must provide breaks from caring for carers of disabled children. This could mean an opportunity for your child to access leisure activities. Eligibility for this support is usually determined by a social worker.

Further information

See 'Holidays, play and leisure' by Contact a Family (2010), which offers information about play and leisure in your area, holidays, days out, equipment and mobility, wish-granting charities, travel insurance and financial help for holidays at: http://www.cafamily.org.uk/pdfs/holidays.pdf .

Hft's Family Carer Support Service's 2012 Holiday Information Guide is designed for people with learning disabilities and their families. Sections include tour operators, places to stay (UK and abroad), meeting specialist health needs, special interest holidays, insurance. http://www.hft.org.uk/Supporting-people/family-carers/Resources/Holiday-guide/.

Specific interests:

Cycling
http://www.getcycling.org.uk/special-needs.php

Horse riding
http://www.rda.org.uk/

Walking
http://www.disabledramblers.co.uk/

Gardening
http://www.gardeningfordisabledtrust.org.uk

Swimming
http://www.swimming.org/britishswimming/disability-swimming

Knowing your rights

Most of the parents said it helped to know their rights when it came to asking for help for their child. It could have been to access the most appropriate equipment or wheelchair, to apply for a personal budget, or to have adaptations made to the home.

People with disabilities and their family carers have rights with respect to the way they are treated by public bodies under the Human Rights Act (1998). For example, if a parent's serious health condition was neglected because of their caring role, this could be an infringement of their right to life. As a result of the Disability Discrimination Acts 1995 and 2005, and the Equality Act (2010), disabled people have rights in the areas of education, employment, access to goods, facilities and services (including large private clubs and transport) and owning or renting property. Whilst caring is not a 'protected characteristic' under the Equality Act, carers do have some protection from 'discrimination by association'. Public bodies are required to promote equality of opportunity. The Equality and Human Rights Commission has help-lines across the UK.

When there are difficulties and things go wrong, it is best to see if they can be resolved through meetings and discussions. It is helpful to keep a record in writing if there are problems. Local authorities have complaints procedures, which you can ask about. Obviously going to court would be a last resort, but you could ask questions if you felt that rights were being infringed. The need to complain formally should be an unusual occurrence, but it is important to ensure that poor or even criminal practice does not go unchallenged.

Useful links and information:

- http://www.equalityhumanrights.com
- 'When things go wrong' a National Family Carer Network fact sheet: www.familycarers.org.uk
- Contact a Family has a factsheet called 'The NHS and caring for your disabled child' (2010): http://www.cafamily.org.uk/pdfs/NHS_factsheet.pdf.
- 'Disabled children: a legal handbook' (2010) by Steve Broach, Luke Clements and Janet Read. This book aims to empower disabled children and their families through a greater understanding of their rights and entitlements. It sets out the law in key areas, in particular education, health and social services. To download PDF chapters of the book for free go to:

  http://www.councilfordisabledchildren.org.uk/resources/cdcs-resources/disabled-children-a-legal-handbook
- 'Cemented to the floor by law' outlines legal duties of public bodies to disabled children.

  http://www.councilfordisabledchildren.org.uk/resources/our-partners-resources/cemented-to-the-floor-by-law
- Using the law to fight cuts to disabled people's services

  http://www.centreforwelfarereform.org/uploads/attachment/270/using-law-to-fight-cuts.pdf
- Disability Rights UK

  http://www.disabilityrightsuk.org/
- Direct Gov

  http://www.direct.gov.uk/en/DisabledPeople/index.htm

Influencing policy

Sometimes family carers want to get involved in influencing policy, nationally and locally. The Government is increasingly recognising that the voice of family carers needs to be heard. In England, Learning Disability Partnership Boards have family carer representatives. They can meet other representatives through regional networks and representatives go to the National Valuing Families Forum. Many organisations supporting families with an adult member with a learning disability are linked through the National Family Carer Network, which gives these organisations a national voice. See: www.familycarers.org.uk .

The following are courses that are helpful to family carers:

- Caring with Confidence.
- Kindred Spirits.
- Partners in Policy Making courses for parents of disabled children and disabled adults.
- Sharing the Challenge courses for parents of disabled adults, developed from Partners in Policy Making courses:
  - www.caringwithconfidence.net
  - http://www.in-control.org.uk/related-pages/what-we-do/partners-in-policymaking/courses.aspx

Adaptations to your home

All the families we spoke to had adaptations made to their home to accommodate the needs of their child. These included lifts, extensions, wet rooms and hoists. It took a great deal of time to execute the plans and all said it had created much anxiety. Some families thought it would have been useful to talk to and perhaps visit the homes of other families in similar positions to have a better idea of what to consider. These decisions can have a huge impact on your home and families wanted to be better informed before making these decisions.

To support families through this process, we commissioned an expert in this area to write about the various factors to consider if a family needs to adapt their home and to explore some of the key aids and assistive technology that can enable your child to be more independent.

The following are included as appendices:

- Appendix 5: Adapting your home.
- Appendix 6: Design and changes to your home.
- Appendix 7: Aids, adaptations and assistive technology.

Further information

The Joseph Rowntree Foundation has made a short film on the housing issues affecting young people with a disability and their families: http://www.jrf.org.uk/work/film-housing-matters

Disabled Facilities Grant

http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/DG_4000642

Other useful contacts and information

Foundation for People with Learning Disabilities

http://www.learningdisabilities.org.uk/
The Foundation is a UK wide charity that aims to influence government and local authority policies and services through their work so that they better meet the needs people with learning disabilities, their families and carers.

1st Floor
Colechurch House
1 London Bridge Walk
London SE1 2SX
Tel: 020 7803 1100

Contact a Family

http://www.cafamily.org.uk/
Contact a Family is a UK charity for families with disabled children. They offer information on specific conditions and rare disorders.

209-211 City Road
London, EC1V 1JN
Tel: 020 7608 8700
Freephone helpline 0808 808 3555
Monday – Friday 9.30am – 5pm
Email: info@cafamily.org.uk

Council for Disabled Children

http://www.councilfordisabledchildren.org.uk/
CDC aims to make a difference to the lives of disabled children and children with special educational needs by influencing Government policy, working with local agencies to translate policy into practice and producing guidance on issues affecting the lives of disabled children.

Phone: 0207 843 1900
Email: cdc@ncb.org.uk
Council for Disabled Children
8 Wakley Street
London, EC1V 7QE

NDTi

http://www.ndti.org.uk/
The National Development Team for Inclusion (NDTi) is a not-for-profit organisation which works to promote inclusive lives for people who are most at risk of exclusion and who may need support to lead a full life.

Newlife

http://www.newlifecharity.co.uk/
Newlife exists to respond to children who may face both short term and enduring disability and those with their life expectancy limited through providing informed support to their families and carers. The needs of children with special needs and the needs of their families and carers, their health and their voices are all central to the work of the charity.

Newlife Centre
Hemlock Way
Cannock
Staffordshire, WS11 7GF
Tel: 01543 462 777

KIDS

http://www.kids.org.uk/
KIDS is the national charity working with disabled children, young people and their families across England.

Mencap

http://www.mencap.org.uk/
Mencap is the voice of learning disability

123 Golden Lane
London EC1Y 0RT
Telephone: 020 7454 0454
Email: information@mencap.org.uk

Scope

http://www.scope.org.uk/
Scope works with disabled people, of all ages, and their families, across England and Wales, offering practical, everyday support and deliver campaigns that can change lives.

Scope
6 Market Road
London
N7 9PW
England
Tel: 020 7619 7100

PMLD network

http://www.pmldnetwork.org/
The PMLD Network is a group of people committed to improving the lives of people with profound and multiple learning disabilities (PMLD).

SCIE Social Care Institute for excellence

http://www.scie.org.uk/topic/people/peoplewithlearningdisabilities
The Social Care Institute for Excellence (SCIE) is an independent charity that aims to improve the lives of people who use care services by sharing knowledge about what works.

Together for Short Lives

http://www.togetherforshortlives.org.uk/
They are the voice for children and young people who are not expected to live to adulthood and their families.

Tel: 0117 989 7820
Email: info@togetherforshortlives.org.uk
National helpline 0845 108 2201

Whizz - Kidz

http://www.whizz-kidz.org.uk/
Whizz-Kidz provides disabled children and young people with vital mobility equipment, opportunities to meet and have fun, and training to help them gain skills and look forward to a bright future.

Whizz-Kidz
4th floor
Portland House
Bressenden Place
London, SW1E 5BH
Tel: 020 7233 6600

WellChild

http://www.wellchild.org.uk/
WellChild help seriously ill children, young people and their families throughout the UK through their programmes of care, support and research.

16 Royal Crescent
Cheltenham
Gloucestershire GL50 3DA
Tel: 0845 458 8171

The Childrens Trust Tadworth

http://www.thechildrenstrust.org.uk/
The Children's Trust provides care, education, therapy and rehabilitation to children with multiple disabilities, complex health needs and acquired brain injury.

Tadworth Court
Tadworth
Surrey
KT20 5RU
Tel: 01737 365 000

Further information on health

Below we have listed further organisations websites that can offer more information relating to the various health needs of children dependent on medical technology and/or have complex health needs.

Health conditions

- **Diabetes**
  http://www.diabetes.org.uk/About_us/News_Landing_Page/Diabetes-UK-launches-DVD-to-help-people-with-learning-disabilities/

  http://www.diabetes.nhs.uk/areas_of_care/mental_health_and_learning_difficulties/

- **Asthma**
  http://www.asthma.org.uk/news_media/news/asthma_uk_launches_r.html

- **Healthy Heart**
  http://www.bhf.org.uk/publications/view-publication.aspx?ps=1000844

- **Downs heart group**
  http://www.dhg.org.uk/

General information on disability and health

- **NHS Choices**
  http://www.nhs.uk/livewell/childrenwithalearningdisability/pages childrenwithalearningdisabilityhome.aspx

- **Understanding disability and health**
  http://www.intellectualdisability.info/

- **Reasonable adjustments**
  http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments

- **Equal Access?**
  http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_109751.pdf

- **Good health care for all**
  http://www.learningdisabilities.org.uk/content/assets/pdf/publications/good-health-care-for-all.pdf?view=Standard

- **Department of Health Learning Disability section**
  http://www.dh.gov.uk/health/category/policy-areas/social-care/learning-disabilities/

- **UK Health and Learning Disability Network**
  http://www.ldhealthnetwork.org.uk/forms/healthjoin

- **Raising our sights: services for adults with profound intellectual and multiple disabilities**
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

- **Royal College of GPs Learning Disabilities – Resources**
  http://www.rcgp.org.uk/clinical_and_research/circ/innovation__evaluation/learning_disabilities_resource.aspx

- **General Medical Council Learning Disabilities**
  http://www.gmc-uk.org/learningdisabilities/

- **Royal College of Nursing**
  http://www.rcn.org.uk/__data/assets/pdf_file/0006/78765/003184.pdf.

  http://www.rcn.org.uk/__data/assets/pdf_file/0004/78691/003024.pdf.

- **Easy read information for people with learning disabilities**
  www.easyhealth.org.uk

  www.change-people.co.uk

  http://www.apictureofhealth.southwest.nhs.uk/

  http://www.rcpsych.ac.uk/publications/booksbeyondwords/aboutbbw.aspx

Appendix 1

Members of the Advisory Group

- Alison Giraud-Saunders (Chair) – Independent consultant and chair, National Family Carer Network.
- Dr Alison Austin – Department of Health.
- Professor Bernie Carter – University of Lancaster.
- Janet Cobb – UK Health and Learning Disability Network.
- Nic Crosby – In Control.
- Beverly Dawkins – Mencap.
- Jo Fitzgerald – parent adviser and In-Control
- Dr Susan Kirk – University of Manchester.
- Carol Lynagh – SEN and Disability Division, Department for Education.
- Rosie Noble – Contact a Family.
- Linda Partridge – WellChild.
- Dr Megan Thomas – Consultant Community Paediatrician.

Appendix 2

Background to 'An Ordinary Life'

During the past few decades more and more children with complex health needs have been surviving into adulthood. Now, through better health care and the use of medical technologies, we have a group of children and young people who require very individual and family centred support to ensure that they can make the most out of life. This means that some children require medical technology on a 24-hour basis, such as long-term ventilation, enteral feeding, or an internal pump to manage pain relief.

They are often living with severe learning and physical disabilities, perhaps as a result of premature birth, chromosome abnormalities or acquired brain injury. These children have multiple disabilities and medical needs, so they are often in hospital for long periods of time. While their medical needs are often well attended to, their social, emotional and developmental needs are often not prioritised. This project aims to address this.

The children we are working with

Dr. Sue Kirk, a leading academic in this field has undertaken much research with this group of children. The most common forms of medical technology used by the group of children and young people covered by her (1999) research were:

- 69% gastrostomy.
- 14.8% IV therapies.
- 14.3% tracheostomies.

They form a diverse group of children and young people with the following key characteristics:

- Cause of dependence varies, including congenital, genetic, chronic illness, accident or prematurity.
- Age at onset can range from being born prematurely to adolescence.
- Duration of the health needs can be temporary to lifelong.
- Prognosis and life expectancy varies.
- Incidence and severity of associated disabilities varies.
- Frequency of using technology can be continuous, daily or intermittent.

The prevalence of this group of children is unknown in the UK. However, research by Kirk (1999) estimated that there were approximately 6,000 children, with most being less than two years of age. There were regional variations, with a higher incidence noted in Northern Ireland and North-West England.

The project

The project aims to improve the quality of services to children who need long-term care and their families, through supporting families to develop individual, personalised, person-centred planning solutions. This is a very positive way to support families where there is a technology-dependent child; it gives them the flexibility to choose the type of care and support that meets their needs as a unique family, rather than relying on generic packages. Children who are technology-dependent can miss out on being part of a community, interacting with neighbours, having friendships, going to birthday parties and other family outings/activities. The project will increase their chances to do those ordinary things that others take for granted through developing packages of support that allow the children and their families to access leisure and other universal services.

The project will improve the quality of support and/or services to children who need long-term care and their families through achievement of the following outcomes:

a. Families with technology-dependent children will be made aware of how to take up person centred planning approaches to care.

b. Many more families will adopt family-centred approaches to care.

c. A large number of health and social care staff will be better informed about how to support individual families and encourage them to take a family-centred approach.

d. The quality of life for many technology-dependent children will be much improved – for them and their families.

How will the project do this?

This is a three year project and the main areas of activity are:

- To map the experiences of at least ten children and young people with complex health care needs who are aged up to 19 years, through interviews with the person, their family and key professionals involved in their care.
- To write a booklet summarising the experiences and approaches described in the interviews.
- To identify five NHS Trusts to participate in the study and recruit five technology dependent children or young people and their families from each area to take part and try out new ways of working. These may include arranging training in person-centred approaches, self-directed support and individualised funding if required for families and stakeholders in each area. The families will be supported to implement their ideas that will improve the quality of life of the family as a whole.

In the final year of the project we will evaluate the project and promote the findings at regional seminars to showcase the work and to inspire other families and staff that family centred approaches can really happen. We will also update the booklet from the first phase with more stories gathered from the families involved in this part of the project.

Appendix 3

Example of a communication passport

Introducing...

The book about me

My name is

This book will tell you lots of useful information about me. Please read it so you know how to support me.

What's in this book?

What's in this book?

Instructions

The purpose of this booklet is for others to find out crucial information about a child or young person with high support needs in a short time-frame. It could be used by a new support worker at home, staff at a short-term break service, a learning assistant or teacher at school or a nurse if the person has had to be admitted into hospital. It also contains essential information should an emergency situation occur – whether it is a social care or medical emergency.

Here are some tips for completing it:

Whenever possible, encourage your son/daughter to complete this with you, making sure the information is meaningful. Some children and young people may want to design and complete it themselves. You may want to make a short DVD clip to accompany this information.

You may want to recruit one or two other people who know your child well to help you complete this, for example, their teacher, social worker, personal assistant or health staff.

The best way to encourage people to look at the communication passport is to use photos and /or images (for example, try clip art) rather than relying too heavily on words.

There is no pre-determined size of what this should be. The key is that the booklet is colourful and engaging to the reader. Most people get them laminated as then they last longer.

If your son/daughter uses specialist equipment (communication aids, wheelchairs, standing frames etc.) it is best to include pictures of each piece, and if positioning when in the wheelchair or for feeding is important, include pictures of those too.

Not all the sections in this template will be relevant – just use those sections that are appropriate to your child.

Remember that this information may be made available to people you do not know, so only add information that you and your son/daughter feel comfortable sharing. For example, if your son/daughter does not like being hugged or touched by unfamiliar people, make sure that is written down.

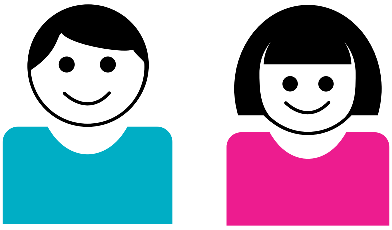
It is best that this booklet is kept on the child/young person at all times, for example, in their change or school bag.

It is useful that the key people to be contacted in an emergency also have an up-to-date copy of the booklet.

This booklet was developed by parents taking part in a FPLD project called an ordinary life. We are very grateful to Karen Alkhina and Laura Jones for helping us shape this booklet.

foundation for
people with
learning disabilities

Essential information you need to know about me



Date of birth

Where I live

Diagnosis/Medical condition(s)

Allergies

Medication(s)

Equipment and assistive technology used regularly
e.g. communication aides, wheelchair, mobility aids, feeding equipment.

What to do in an emergency

999

If I have a medical emergency please follow these key steps

If its an emergency of a social nature

e.g. I am due to be picked up from school but no one has turned up, please follow these steps.

Key things not to do in an emergency

My key contacts

Please see below for a list of people I would want to be contacted in an emergency.

Information about next of kin

Name	Relationship to me	Mobile number	Address	What support might they provide in an emergency

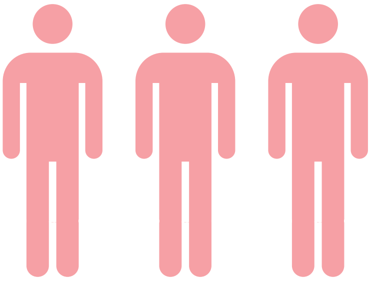
Emergency contact information of other family members in order of priority

Name	Relationship to me	Mobile number	Address	What support might they provide in an emergency

Information about organisations, services and professionals that may be able to provide support in an emergency

Name	Relationship to me	Mobile number	Address	What support might they provide in an emergency

Important people in my life



This tells you about all the main people in my life such as family, friends, teachers, personal assistants, pets, etc.

Name	Relationship to me	How often I see them	What we like to do together

People who help to keep me healthy and safe

This tells you about the main health and social care professionals in my life.

Name	Relationship to me	Telephone/mobile	How often I see them

How I like to communicate

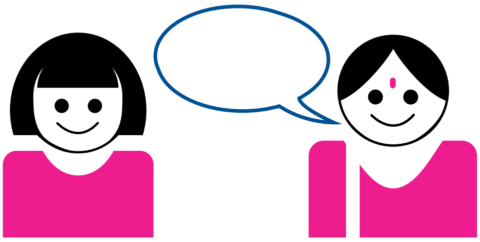
This tells you how I communicate with others. You could include things like how people know when I'm happy/sad/in pain, what assistive equipment I may use.

How I like to communicate e.g. verbally, sign language, communication aids etc.

If I find it difficult to communicate verbally, I often use these behaviours to tell you what I want

When I do this	It means this	Please do this

How I like you to communicate with me

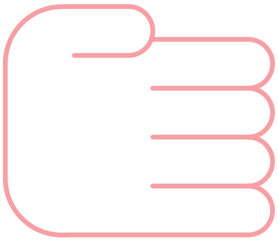


How I like you to communicate with me e.g. objects of reference, signing, speaking slowly

If I require you to use communication aids this may help you to use them

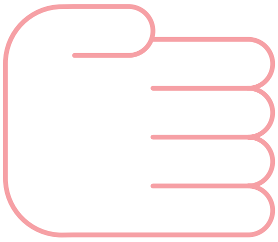
Communication tool	When to use it	How I respond

How you can support me



	What can I do for myself?	What do I need help with?
Mobility		
Personal care and hygiene		
Feeding		

How you can support me



	What can I do for myself?	What do I need help with?
Dressing		
Health needs e.g. taking medication		
Doing activities and things I enjoy		

What I like

I like going to...	My favourite toys/activities are...
I like doing...	My special interests are...
My favourite foods are...	I also like...

What I don’t like

I don’t like going to. . .	Toys/activities I don’t like/ find difficult are. . .
Things that scare/upset me are. . .	Foods I don’t like are. . .
I also don’t like. . .	Other things that make me unhappy. . .

My routine – typical day

Time	Activity	What I do
	Get up	
	Morning	
	Lunch	
	Afternoon	
	Dinner	
	Evening	
	Bed	

My routine – typical week

Day	Morning	Afternoon	Evening
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Food and drink

Special dietary requirements – e.g. allergies etc.

Special feeding requirements – e.g. feeding assistance required, how I am fed etc.

My health needs

This section could include equipment used and what its used for, medication history, how I manage and control pain, support needed at night etc.

	What are my needs?
Medication	
Pain management	
Mobility	
Respiratory	
Behaviour	
Sleep/night routine	

Any other information

Appendix 4

Adapting your home

Why you might need to adapt a property

If you are caring for a disabled child or young person at home, you may need support and advice to do this. Some very practical support and even changes in your own home can make life a little easier and sometimes safer. Having the right equipment can also enhance your child's ability to become more independent and help family life.

You will know what will help make your home a place where you can continue to provide the care and support your child needs. This might be some small practical changes or major adaptations. The types of work that you might want to undertake include:

- Widening doors and installing ramps.
- Providing or improving access to rooms and facilities – for example, by installing a stair lift or providing a downstairs bathroom.
- Improving or providing a heating system that is suitable for your needs.
- Adapting heating or lighting controls to make them easier to use.
- Improving access to and movement around the home to enable you to care for your child and others living at your property.

The Joseph Rowntree Foundation has made a short film on the housing issues affecting children/young people with a disability and their families and it can be found at: http://www.jrf.org.uk/work/film-housing-matters.

How do you go about making this happen?

Begin by making a plan! Write down or record all the things that you think might help you all at home. An occupational therapist could look at your circumstances and can recommend the type of adaptation(s) needed.

You might also want to look at the section in this publication that sets out some of the ways you might need to adapt your house.

You may be able to get help from a Home Improvement Agency with arranging for adaptation work to be carried out. They are not-for-profit organisations, which are often managed locally by councils or housing associations. They can:

- Give free advice about what work needs to be done.
- Offer support to tenants who want to adapt their homes.
- Arrange to have small adaptations and equipment installed.
- Organise larger adaptation work.
- Sort out finances.
- Find a surveyor, architect or builder.
- Keep an eye on how the work is progressing.

Foundations is the national co-ordinating body for Home Improvement Agencies in England.

For information about local agencies in England, contact: Foundations
Tel: 01457 891 909
Web: http://www.foundations.uk.com.

How can the adaptations be paid for?

Having made your plan and sought some advice, you will need to think about how much all this will cost, where the money might come from and if you can really afford everything in your plan.

Some families need help to pay for all adaptations and it is important to understand what financial support there may be and some of the limitations with this.

Social Services obligations to adults are specified in the Chronically Sick and Disabled Persons Act 1970. Social Services obligations to children appear in a number of Acts, but central is the 1989 Children's Act. Research suggests Social Services seldom use their powers under this Act to fund adaptations for children and their families, so the provisions are outlined here.

Section 17 of the Children's Act places 'a duty on every local authority [i.e. Social Services] to safeguard and promote the welfare of children in need and promote the upbringing of such children by their families'. A child is someone under the age of 18 and is in need if 'he is disabled'. The Act requires local authorities to offer services that give disabled children 'the opportunity to lead lives which are as normal as possible'. Services can be provided to the family or any member of the family if the purpose is to safeguard or promote the child's welfare. Services can include (exceptionally) giving cash.

Help from Social Services may be means tested, but no charge can be levied on a family in receipt of Income Support or Family Credit. A new means test will not be applied where the person with a disability is a dependent, up until their 19th birthday.

Grants are also administered by the Local Housing Authority (District Council/ Borough). They are available to shared owners, outright owners, landlords and tenants:

- Home Repair Assistance – for smaller repairs and adaptations.
- Disabled Facilities Grant – to adapt property.

Home repair assistance

Home repair assistance is discretionary – the authority is not obliged to give a grant. There is no formal means test, but this does not stop an authority introducing its own way of rationing resources to help ensure those most in need get assistance. This grant is primarily aimed at helping older people stay put in their own homes rather than move, but it is worth enquiring.

Any work could be eligible. This includes:

- Adaptations such as adding a downstairs toilet
- Improving energy efficiency
- Improving security – adding a door entry system.
- Minor works grants are limited to £3,000, major works up to £15,000.

Disabled facilities grant

Grants are available to provide facilities and adaptations to help disabled children to live as independently and in as much comfort as possible. The grants are available whether you are a home owner, tenant of a housing association or private tenant. In order to qualify your child must be disabled under the terms of the Housing Grants, Construction and Regeneration Act 1996.

A person is disabled if:

- Their sight, hearing or speech is substantially impaired.
- They have a mental disorder or impairment of any kind.
- They are physically substantially disabled by illness, injury, impairment present since birth, or otherwise.

You will also be eligible for a Disabled Facilities Grant if your child is registered disabled under the terms of the National Assistance Act 1948. The maximum grant is £30,000 in England and may be different in Wales. There should be no means testing for families of disabled children under 19 and the grant will not affect any benefits that you receive.

The Disabled Facilities Grant is a mandatory grant (that means it must be given) in specific circumstances. It must be given if you are disabled and do not have access to your home and to the basic amenities within it, provided that you qualify on income grounds. The council will also have to agree that the works are reasonable, practicable and the works are necessary and appropriate for the disabled child.

Examples of the types of work covered by a mandatory grant that may support your child include:

- Making it easier to get into and out of your home.
- Making access easier to the living room, bedroom, kitchen and bathroom.
- Providing suitable bathroom and kitchen facilities that they can use independently.
- Making your home safe for your child and other people living with you adapting heating or lighting controls to make them easier for your child to use.
- Improving the heating system in your home.

The local authority housing department is responsible for deciding whether you will get a grant. They will consult with the Social Services department to decide what adaptations are 'necessary and appropriate'. This will normally mean an assessment by an occupational therapist from Social Services.

Local authority housing budgets are limited and these grants can be substantial; as a result there can be lengthy delays in getting a Disabled Facilities Grant. You do have certain rights to assistance that mean you should not have to wait an unreasonable amount of time. The law says that you should not have to wait more than six months after you apply for a grant to hear whether you will get one. Although the council may try to delay your application until after an assessment by Social Services (usually by an occupational therapist), they are not allowed to refuse you permission to make a formal application if you request this. After it is approved the council may delay payment of a Disabled Facilities Grant for up to 12 months at most unless there are 'exceptional circumstances'.

Social Services departments have a duty to provide certain services to disabled people. This duty is a result of the Chronically Sick and Disabled Persons (CSDP) Act 1970. A council has to provide services to meet the needs of disabled people, including:

- Provision of practical assistance within the home.
- Provision of disability aids and equipment.
- Assistance with adaptations to the home.

This means that, if you need adaptations and are having difficulty getting a Disabled Facilities Grant, Social Services may still have a duty to assist your child. They may do this by funding the work or 'topping' up whatever grant is provided to a disabled person who cannot afford the part of the work the means test says they should meet.

You will usually be asked to sign a certificate stating that the disabled occupant will live in the property for at least five years after the works are completed, or a shorter period if there are health or other special reasons.

You should not have any work carried out on the property until your council approves the application. If the work is urgent, you should contact the council to discuss this. You will also need to ensure that you get separately any planning or building approval needed. Application forms are given by your local authority housing or health department. They will start with an assessment by an occupational therapist.

Aids and adaptations

There has always been specialist equipment for sale or loan that will help support your child at home. The good news is that these aids are becoming less 'specialist' and therefore not as expensive, and certainly more available. Sometimes the very obvious things can help the most – large digit phones, epilepsy monitors, kitchen cupboard locks and so on. However, increasingly technology is helping provide some really useful products and you may be interested to find out more.

Social Services are the normal source for minor aids and equipment. To get expensive, permanent alterations, people are referred to the local authority housing department. Social Services occupational therapists play a crucial role in:

- Providing advice on aids and adaptations.
- Assessing needs.
- Supporting applications for a Disabled Facilities Grant.

The local authority may make a charge for the provision of aids and equipment – authorities' practices differ.

The role of Social Services is to supply aids. If fitting is required, for example of a grab rail, then Social Services may pay for this to be done by a local contractor. The items commonly provided by Social Services include:

- Grab rails, stair rails, bath rails and toilet frames.
- Wooden ramps and steps, bed and chair raisers.
- Simple door entry systems and t elephone extensions.

The ultimate legal duty to provide equipment and adaptations that disabled people are assessed as needing lies with Social Services (Section 2 of the Chronically Sick and Disabled Persons Act). Social Services may therefore be approached for help with any kind of aid or adaptation where this is not provided by the Housing Authority for some reason.

In England, families can receive some aids and equipment from their local authority for free. They must cost £1,000 or less; examples include equipment for daily living, such as a shower, chair or minor adaptations. You first need to contact a social worker to discuss the kind of help you think would benefit you and your family. You can also speak to your GP.

Social fund – Community Care Grants

The Social Fund is the only way to get help from the Benefits Agency for one-off lump sum expenses. The Social Fund is administered by the Benefits Agency, which has a Social Fund Officer. Awards are discretionary, but a key purpose of the Social Fund is to make Community Care Grants and Social Fund Loans. The aim is to improve living conditions for people with disabilities and includes children at home with their families.

Availability of grants varies because local offices of the Benefits Agency are given a fixed amount to spend under this heading and may simply run out of money part way through the year or keep grants quite small to spread the available cash further. Less than £1,000 is common, though there is no standard amount.

Things that have been paid for from the Social Fund include:

- Removal expenses.
- Furniture.
- Equipment like a washing machine or cooker.

The Social Fund can also provide loans of up to £1,000 to help spread the cost of buying large items. The loan has to be repaid by a deduction from benefits within 18 months. Apply for a grant or loan by getting form SF300 from the local Benefits Agency office.

VAT relief

Disabled people do not have to pay VAT on the cost of some building work involved in adaptations to their homes. If an adaptation qualifies for VAT relief, the work preparing for the adaptation and the work to tidy up afterwards are also free from VAT.

Council Tax reduction

If you adapt your home so that a disabled child can live there, you may be eligible for a one-band reduction on your Council Tax. Information on how Disabled Facilities Grants are assessed and eligibility can be found at:
http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/DG_4000642.

There are several grant making organisations that may be able to assist some families. A good place to search for these organisations is online and families can find information on all benefits and grants available to them from both statutory and voluntary organisations in the UK.

The following website contains some of this information:

Turn2us

Web: http://www.turn2us.org.uk.

Things to think about

If you and your family think that you need to adapt your property, you might want to think about some of the following:

- Have you thought about how long the adaptation might take? It is usually a lengthy process and the needs of your child and your family may change. Consider this whilst you are planning and talking to the occupational therapist, who will be able to advise you.
- Who should you involve in the planning and design of any adaptations? This could include all members of your family, even if they are not currently living at your house, support staff or personal assistants, occupational therapists, nurses and other health professionals.
- Will you be able to manage the on-going maintenance and repairs of the adaptations?
- If you are physically involved in the personal care of your relative, will the adaptations make this easier for you and other supporters? Check that everything will work for you and that any risks to health and safety have been thought about.

More Information

More information can be obtained from:

- www.disabilityalliance.org/f49.htm.
- www.cafamily.org.uk/pdfs/AidsUpdate.pdf.
- www.housingoptions.org.uk.

Appendix 5

Design and changes to your property

Having made the decision that your family will need to adapt your property to better support the needs of your child/children, the next thing you will need to think about is what exactly it is you would want to change at your property. Clearly this is based on the very individual needs of your family, but in order to help you think this through here are some of the ways people change their property. You could start by making a list of things that you think you will need. Then check the list below and add to your own ideas. You will then be ready to talk to your occupational therapist or builder about what you really need in your home.

Buildings:

- Fully accessible for wheelchair users.
- Drive in shower, ideally en-suite to bedroom.
- In some cases a bath rather than a shower may need to be provided according to individual needs and this may need to be a specialist/tilting bath or similar.
- Floor or wall coverings should differentiate between areas and usage.
- Automatic water and gas shut off systems linked to suitable sensors.
- Where radiators are installed as opposed to under floor heating they should be covered in order to avoid injury to anyone prone to falling.

Specifically for wheelchair users:

- Corridors minimum 900mm wide, 1200mm where a 90° turn is necessary and 1500mm wide where a 180° turn is necessary.
- Internal doorways to give minimum 775mm clear opening width and to have level thresholds.
- Provision for storage and re-charging of battery operated wheelchair.
- Minimum turning space inside entrance 1200 x 1500mm.
- Rooms all on one level or accessible by wheelchair accessible lift. Where a lift is required, this must comply with BS5900 (1991).
- Bedrooms, living rooms and dining rooms with adequate space for wheelchair users to turn through 180° with furniture in place, i.e. turning circle 1500mm or ellipse 1800mm x 1400mm.

Bathroom

- Space should be allowed to accommodate carers around the WC and shower.
- Flush floor shower to be provided with shower screen fixed to the floor.
- Space for a shower seat in the wet room.
- Doors to open outwards to allow access in case of emergency.
- Walls capable of taking additional handrails/wall fittings in future.
- Emergency lighting facilities.
- Extractor fans should be quiet – ideally silent in operation.
- Coat hooks and towel rail clear of water delivery.
- Hot water temperature should not exceed 43° centigrade at the point of delivery for showers and basins.
- Temperature controls at point of water delivery to be soft touch where possible and user friendly.
- WC to be close coupled with tamper proof operation.
- Adjustable height mirror.

Bedroom

- Space around the bed for moving whilst providing support or care to your child.
- Suitable flooring for comfort and cleaning as well as movement in wheelchair.
- Space to store personal equipment.
- Appropriate storage for medicines and personal care items.
- Lighting, sensory and comfort all need to be considered. Using assistive technology with some of the gadgets really could help.

External

- The external environment should generally provide a secure, enclosed area with lockable gates.
- Raised flower beds; also consider a sensory garden.
- Sufficient parking for care staff, visitors and potentially a Motability vehicle.
- Laundry drying area.
- Bin store including any specialist disposal needs, e.g. incontinence, medical waste.
- Level or gently sloping route to all external entrances, and to external facilities such as storage, parking, garden and clothes drying area.
- Paths slip-resistant and smooth, minimum width 1200mm.
- Path gateways to provide minimum 850mm clear opening width.
- Good cover at point of transfer from vehicle to wheelchair.

General

Using different colours and textures on walls and floors may help children with impaired sight to know where they are. Non-reflective surfaces are generally to be preferred and for some individuals can be very important. This implies, for example, specifying matt finishes on painted surfaces and choosing kitchen units and work surfaces that are not glossy.

Skirting boards should be the same colour as walls so they do not appear to be a step. In specifying kitchen fittings and white goods, consider how each family member may use the equipment safely and practically. So for example, a washing machine or drier is easier for someone in a wheelchair to load if it is raised slightly. Hand rails should be a different colour from the wall. They also need to be of a size and shape that is easy to grip.

These are very general ideas and there are organisations that can provide further advice specific to your situation.

Things to think about

Before you go ahead with the design of your adaptations there are several things you might want to think about with your family as these changes will affect you all. It is likely to be a lengthy process and there will be a period of disruption for you all, however good your builders are!

- Will the changes work for all members of the family? If the bathroom is changed to a wet room, how will other family members adjust if they are used to a bath?
- Think about the really practical support your child/your relative will need. Are you creating enough space to deliver this in your home? For example, space around the kitchen/bathroom.
- Build into the design whatever technology you think you can. Things are changing so quickly that gadgets and equipment will become more and more useful so you need to be ready to use them.
- Many grants require you to live in your house for five years after completion of the work.
- Are all your family members ready for the disruption that the building work will cause? Have you got some extra help or somewhere to go whilst this is happening?

Organisations that can advise on property design and changes include:

- www.cafamily.org.uk/pdfs/AidsUpdate.pdf
- www.housingoptions.org.uk
- www.cae.org.uk/guidance.html
- www.thecbf.org.uk

Appendix 6

Aids, adaptations and assistive technology

Assistive technology (AT) refers to any system or device that enables an individual to perform a task that they would otherwise be unable to do, or would need additional support to carry out. AT promotes independence, choice and control for children and helps those supporting them. AT can range from simple tools such as a specialised spoon for feeding to more technical equipment such as satellite navigation to help find a certain place. AT can help with a wide range of tasks and living situations.

AT is a general description for a range of applications of (predominantly) electronic equipment used to monitor or enable people. It can:

- Help manage or eliminate a wide range of risks to the individual (e.g. falling) or to the property (e.g. fire, smoke, flood alert).
- Promote independence by assisting people to overcome a sensory or physical or sometimes mental impairment.
- Do some tasks better or more reliably than the human equivalent.
- Help deliver greater privacy or dignity in certain circumstances.
- Tunstall provide the illustration on page 61 of where AT could be used around your home. This will vary according to your own situation and the needs of your child.

Gadgets	**How you can use them**
	This fall alarm is usually worn on a belt or waistband and can tell you if your child falls or calls for help.
	This flood detector can tell if taps have been left on and there might be a flood. It sets off an alarm or tells someone who can help.
	This mobile phone is for people who find it difficult to use ordinary mobile phones. It has three buttons to call three different numbers and, if the red button is pressed twice, it calls emergency services. The phone can also remind you about things like the time to leave work, to get up, or to catch a bus.
	There are lots of gadgets and programmes that can make using a computer easier, especially for people who do not read and write.

The key message is that AT can have a role in supporting people to live more safely, securely, and as independently as possible. The illustration on page 61 gives examples of a wide range of equipment you could have in your home, but not everything will be appropriate for your family situation. The table on page 60 gives a brief explanation of some of the equipment you could use.

Some applications can simply do a monitoring job, possibly more reliably and less intrusively than the equivalent person. As an example, someone who may be incontinent at night may need a family member to check their bed periodically through the night. An enuresis alarm will do the job more reliably, only triggering an alarm when there is a problem.

There are examples of people who had been unable to communicate using computer based devices who can now use touch screens and special software programmes to build up a network of friends, to write and communicate; examples of families finding one simple bit of AT like an automatic water shut off valve, enabling the whole family to cope and manage behaviours that had previously led to regular house flooding.

Where can you get more information?

- Organisations such as Assist UK provide a wide network of locally situated Disabled Living Centres. Each centre has permanent exhibitions of products and equipment for people to try. It also has professional staff who can advise on what equipment may be the most appropriate for someone's particular needs.

- The Disabled Living Foundation has factsheets on how to choose play equipment, mobility equipment and living aids for your child.

- The British Red Cross has a volunteer-led medical equipment service that provides wheelchair hire and short-term loans of equipment across the UK.

- The charity Independence at Home provides grants for disabled people and those with a long-term illness. Grants can be made for adaptations, equipment or other things to help people manage at home if they are not funded by local or national government.

- A simple introduction to AT, what it can do, and likely costs with some examples of how people with a learning disability have used AT is 'Gadgets, Gizmos and Gaining Independence': www.housingoptions.org.uk/general_information/gi_publications_docs/AT_Report.pdf.

- Tunstall Ltd are the market leaders in telecare. They have produced a guide to the application of their products for people with learning disabilities: www.tunstall.co.uk/guides.

- The Disabled Living Foundation has a very helpful website with advice, case studies and a comprehensive list of products www.living.org.uk.

- Assistive technology websites supply both ideas for equipment that you might find useful (which you can buy anywhere) and products for purchase:

    - **Tunstall**
      www.tunstallgroup.com

    - **BT**
      www.bt.com/homemonitoring

    - **Attendo**
      www.attendo.se

    - **Jontek**
      www.jontek.com

    - **Tynetec**
      www.tynetec.co.uk

    - **Vivatec**
      www.vivatec.co.uk

    - **Initial**
      www.iess.co.uk

    - **Docobo**
      www.docobo.co.uk

    - **Nestor**
      www.primecare.uk.net

Foundation for People
with Learning Disabilities

Colechurch House
1 London Bridge Walk
London
SE1 2SX

Telephone:
020 7803 1100
Email:
info@fpld.org.uk
Website:
www.learningdisability.org.uk

Registered charity number
England 801130
Scotland SC039714

changing
lives