

Transition Matters

A guide to transition to adulthood
for families of young people
with learning disabilities

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This guide has been written by parents for parents. We wanted to write a guide because just like many other families who have Teenagers with learning disabilities/difficulties and/or other additional needs we struggled to find the information we needed through the transition to adulthood phase. Not only did we have no idea of what should be happening, who should be involved, what we needed to do in terms of planning or what would be available in terms of support for our children, we had no idea where to look for information and advice either. The process felt rather like trying to piece together a large, complicated jigsaw but, without the the picture on the box as a guide and with far too many blank pieces. This guide is our attempt to put some of the jigsaw pieces together and share with you what we have learned (so far) in the hope that your journey through this stage will be an easier one.

Finding the information for this guide has taken a huge amount of time and effort and only confirms to us how difficult it is for parents to find the information they need. We hope that the information we have provided will be a good starting point and be of benefit to you, your family and the professionals who work with you, but stress that it is only a starting point!

We have made every effort to make sure the information in this guide is correct. However, the factual content and contact details cannot be guaranteed. Information constantly changes and has done considerably, even during the time it has taken to write this guide. There may also be other details, organisations and

groups that we have not been aware of and so not included. If you are aware of any other organisations or services that we have overlooked please get in touch so we can incorporate them into future publications.

We must also stress that the inclusion of any organisation is not a recommendation from OxFSN and the information we have included was, to our knowledge, correct and up-to-date at the time of print (Sept 2009).

We have used the term "parents" throughout this guide and by this we mean anyone who has either a parental responsibility for, or who has a family member with learning disability.

How to use this guide

There is a huge amount of information in this guide and we could have included more. We don't expect that you will sit down and read it all in one go, but rather see it as a resource to dip in and out of, as and when you need it. We know we will not have covered every single issue or provided the answer to every individual family circumstance. As a family carer led organisation although we strive to provide the best possible advice and support to families of people with learning disabilities, we don't claim to have all the answers. We also take our lead from you, so please get in touch with us if you require more specific advice relating to you and your family and we will do our best to support you.

Acknowledgments

In developing this guide we have taken information from a number of sources, including existing (national and locally developed) guides and websites. The most useful by far was the **AMAZE transition handbook: Through the Next Maze**. Written by parents and carers from AMAZE, a Brighton based charity that offers information, advice and support to parents and carers who have a child or young person with Special Educational Needs. We are grateful to them for allowing us to reproduce some of the extracts contained in their excellent handbook.

We would like to express our thanks to the **Oxfordshire Learning Disability Partnership Board** who provided the funding for the Oxfordshire Family Support Network and the additional funding for the Transition Support Service, which enabled us to produce this guide.

We would also like to thank **Oxfordshire County Council**. Their encouragement, assistance and financial support has contributed considerably to the emergence of this new countywide resource.

Finally, we would like to say a big thank you to all the parents and professionals (too numerous to mention individually) who have given their time and expertise to help us develop this guide, their contributions have been invaluable.

This guide has been written primarily for families who have teenagers with learning disabilities, who attend either special or mainstream schools, and who have a statement of Special Educational Needs. However, some of the information contained in it may also apply to other young people who have additional learning needs and those with physical impairments (alone) and/or sensory impairments.

We are aware that not all children with a statement will be considered/or consider themselves to be disabled. Some will have learning difficulties and/or additional needs which mean they require extra support with learning. For these young people the school SENCO (Special Educational Needs Co-ordinator), your child's Connexions Personal Advisor and in some cases, the Special Education Needs Support Service (SENSS) will be the key people to help ensure that they/and you are aware of future options in education, training and work.

Whatever your child's impairment the need to plan for their transition to adulthood remains the same and the transition process which begins in Year 9 (the year the child turns 14) should be the same for all young people with a statement of special educational needs. However, it's important to note that some of the other topics addressed in this guide, such as supported living, day services, and issues about mental capacity and consent at age 18 or over are aimed at families who have teenagers who are severely disabled, as they are often subject to strict eligibility criteria.

In writing this guide we have attempted to consider as many needs as possible but recognise that there is a wide range of abilities/disabilities, difficulties and family circumstances. As parents ourselves we are only too aware that our children are individuals and that there is no "one size fits all". We are also aware that when you have a child who is severely disabled little, if any of the information available seems relevant. This guide is our attempt to remedy this. It is the first guide to transition in Oxfordshire written by parents for parents and we welcome your feedback, comments and constructive criticism to help us improve future publications.

Leaving school and moving into adulthood is an exciting time for most young people but for young people with learning disabilities and their families it can be a time of uncertainty and anxiety.

On reaching adolescence issues such as further education, relationships, sexuality, work, leaving home and personal choices become important. Most families would agree that the teenage years can be stressful for parents and teenagers alike and dealing with growing up, puberty, and increasing independence can be tricky. But, for our families, there are additional things to think about. Our children are dependent on many different services and agencies for support with lots of different aspects of their daily lives and because of this we have to think ahead and plan for the future in a way that other families don't. Planning for the future with young disabled people starts in the year they turn 14 years old and the process takes a number of years. This phase is commonly referred to as transition.

As parents/family carers, we are often unclear about what happens during transition, who should be doing what and when they should do it, and our role in the process. Many families worry about what choices exist in education, training, work and housing. What support will be available for my child/family member as they reach adulthood? The range of adult services can seem confusing and the whole process can seem complex with lots of new terms and systems to understand and navigate.

"After 19 years familiarising myself with one system, it's like starting all over again from scratch with the same worries and concerns" [parent]

Old issues like the lack of appropriate services and our child's vulnerability can become especially relevant again and you may have also heard stories about the lack of services from other parents/carers of older children.

"I have often heard transition described by other parents as like "standing on the edge of a cliff, about to fall into a black hole" I can now confirm this is exactly what it feels like" [parent]

According to the Government's Strategy Unit Report (Improving the Life Chances of Disabled People 2005)

"Planning for transition should be focussed on individual need" there should be "continuous service provision" and "access to a more transparent and appropriate menu of opportunity and choices."

However, the reality is transition to adulthood is often far from smooth for many young people and their families and the "menu" can feel rather limited in its choices.

It would also be misleading to say that there is a comprehensive support network of services available to young people and their carers during this time and beyond into adulthood. There are still many challenges ahead for services, local authorities and the Government to ensure that people with learning disabilities have the same life

chances as those without disabilities, but things do appear to be moving, albeit slowly, in the right direction.

The Oxfordshire Family Support Network is an organisation run *by* family carers of people with learning disabilities *for* family carers of people with learning disabilities. We believe that access to high-quality, timely information is essential at all times but is particularly critical during the transition process when families can often feel as “lost in the system” as they were when they first discovered their child had a disability.

“As parents we don’t know what we don’t know. It’s pretty scary not knowing what you don’t know, because you don’t know what to start looking for or where to start looking” [parent]

The aim of this guide is to provide an easy to follow route through transition, with some suggestions of where you might get further help and advice. We cannot vouch for any of the organisations or groups listed and strongly suggest that you check them out for yourself, but we hope it gives you an idea of what to start looking for and where to start looking.

Ultimately, this guide stems from the belief that all young people, even those deemed to have the most complex needs are capable of achieving a good quality of life. We also believe that armed with the right information, support and guidance families will meet this challenge head on (as they have every other challenge) and view transition to adulthood as a positive stage in theirs and their child’s life

“Just knowing what’s supposed to happen, when it’s supposed to happen, and who is there to help would be a good start” [parent]

Transition means change and in this context it refers to the change from being a child to becoming an adult. It’s primarily a term used by services to describe the transition from children to adult services but the term seems to have taken on a whole new life of it’s own and for those of us who have children with learning disabilities or other additional needs it’s now a term used to describe the period between when your child is 14 years old to around 25. If you have a son or daughter in this age group then they will be considered to be “in transition”

The transition process can seem complex, but put simply it is a process that should bring together the people who can ensure that young disabled people and their families can plan ahead for the future as they enter adult life. Many parents of children with learning disabilities may not want to think about the future. As parents we often take each day as it comes and face each new battle as it arrives but the transition process is a time to think about the future, explore the possibilities and start planning ahead.

Planning for transition starts in the year your child turns 14 (although, it can be sooner if it is considered that the young person will significantly benefit from a longer adjustment period to prepare them for their involvement at the Year 9 review). It also helps if families can start thinking about it sooner as all young people and their families should have time and the opportunity to not only prepare for the first review (before the day itself) but also to start thinking about what sort of life your family member would like.

Although the beginning of the transition process starts at school it’s important to recognise that it is not just about education. It is vital to understand that transition planning is **a continuous evolving process embracing the young person’s whole life.**

Promoting young people’s involvement in transition planning means enabling them to communicate and plan **with** them rather than for them. Thus the involvement of young people, their parents and their advocates in the process is central to a successful outcome.

When you first found out your child had a learning disability or difficulty you may have felt that you had to learn a whole new language. Over the years you've probably got used to the jargon that professionals use and have a pretty good understanding of who does what. When your child becomes an adult there are whole new systems to get used to and lots of new terms that you may be unfamiliar with. In this section we have produced a jargon buster to help explain some of them

Advocate	Someone who can help ensure that a person is listened to, and their rights, concerns and needs are acted upon
Appointee	Someone who acts on another persons behalf in all social security matters
Assessments	Different organisations use different assessments to look at the needs of the individual to decide if and how they can help
Care Manager	A health or social worker who acts as a lead worker for a person
Carers assessment	Carers are entitled to an assessment of their own needs as a carer. This is the responsibility of the Social Care Service
Circle of support	A group of people, who will support and help a person to say what they want and plan what they want to do
Community Care Assessment	An assessment under the NHS & Community Care Act 1990, used to find out what the needs of the individual are
Connexions Personal Advisor (PA)	A support service for all young people aged 13-19 and up to 25 for young people with learning difficulties and/or disabilities. They can offer the young person information, advice and practical help on things like education, employment, work-based learning, housing, health, transport, free time and benefits. Every school has access to a Connexions Personal Advisor
Court of Protection - Deputy	Someone who is appointed by the court to act on the behalf of a person who lacks the mental capacity to make their own decisions regarding financial and personal welfare issues – this is usually a family member

Direct Payment (DP)	Payments given by Social Care Services to disabled people who have been assessed as needing support
Disability Employment Advisor	(DEA) Based in Job Centre Plus, they can offer information, advice and practical help with looking for work and support in work
Health Action Plan (HAP)	Information about a persons health needs and how they can be met. The plan should belong to the person and be part of the transition plan
Health Facilitator	Someone who helps doctors and other health professionals to identify patients with learning disabilities to ensure that they have full access to health care. Also, someone who makes sure that individuals with learning disabilities have a personal Health Action Plan
Job Centre Plus	A place you can go to for help in finding work and get benefit advice
LAC (looked after children) Review	A statutory review meeting to ensure that the care and support needed is provided and kept up to date. They should be integrated with transition reviews
Learning and Skills Council (LSC)	Responsible for planning and funding education and training for everyone in England other than those in universities
Learning Support Coordinator	Every college has a learning support coordinator. They can explain more about college courses and discuss particular learning support needs
Looked after	Children or young people who are in the care of the local authority, whether by voluntary agreement or by court order
Parent Partnership Service	A statutory service responsible for providing information and advice to parents and carers of children with special educational needs (SEN)
Person centred approaches	A way of working with a person to find out what is important and meaningful to them as an individual

Person Centred Planning (PCP)	Putting the person at the centre of all plans for their future. Focusing on the persons needs and wishes and not the wishes of the service providers
Person Centred Review	A meeting that is held in a way that the young person feels comfortable with, to check and plan what is important to them both now and in the future
Personal Budget	The funding that a person is entitled to for their support and the person chooses how to spend it. This may come from a range of different sources
Personalisation	The Governments agenda for ensuring that people have a real choice and control over their lives and the services they need to support them
Self Advocacy	Speaking up for yourself, putting across your views
Self Directed Support (SDS)	A different way of organising social care, to ensure that all people can take as much control as possible of their own lives and their own support
SEN	Special Educational Needs
Specialist College	A college where young people can go as a boarder or day pupil if local colleges do not offer the support they need. Funding is needed from the Learning and Skills Council
Transition	The period between 14 –25 years, a term used by services to describe the change from being a teenager to becoming an adult
Transition Plan	A plan drawn up in Year 9 in school that brings together information from the young person, parents, school and other agencies and that looks at the needs and choices of the young person now and in the future
Transition Review meeting	A meeting to look at the transition plan and make any changes needed. This should start in Year 9 and happen every year the young person is at school
Valuing People	Valuing People is the government’s plan for making the lives of people with learning disabilities and their families better.

The transition process starts in Year 9, the year your child turn 14, so it makes sense that the school leads the process at this point, but there are a number of other agencies who may be providing support during this time.

Connexions	Connexions brings together the range of services and support that young people need. The service is delivered by Personal Advisors (PA) who are responsible for advocating on behalf of the young people to help them to get the services they might require.
Local Authority Children’s Services	<p>An essential function of the Education team is to make effective arrangements for children with SEN. They should do this by:</p> <ul style="list-style-type: none"> • Ensuring that young people’s needs are identified, assessed and quickly matched with appropriate provision • Providing support for schools • Co-ordinating provision to ensure that children benefit. • Develop close partnership with parents, schools, health, social services/social care and health/ children’s services and the voluntary sector. • Ensuring systems are in place for monitoring and accountability.
Special Educational Needs Coordinator (SENCO)	Under the Education Act 1996, the Headteacher and school Governors have legal responsibilities for young people with SEN. Each school has a teacher who is the designated SENCO and is responsible for co-ordinating support for children with SEN. The SENCO advises other teachers, liases with young people, parents/ carers and external agencies, contributes to in-service training of teachers and support staff and oversees SEN records. The SENCO is responsible for obtaining reports from school staff, parents/carers and all other relevant agencies. They are also responsible for organising the review meetings.

Social & Community Services (Social Services) Provide a range of care and support services for children, adults and families. Oxfordshire has a separate service for children with disabilities within the Children and Families Department. They are responsible for assessing the needs of children and young people with disabilities and co-ordinating the care and support services they and their families need. By the time the young person reaches 18, any relevant assessments should be made to ensure they continue to receive appropriate support as they move from children's to adults services. In Oxfordshire there are specialist transition social workers, who will provide this support and advice during this time. Changes after 18 may include moving to the adult learning disability team (or other specialist adult social care teams)

Health Health provision is usually shared between local health authorities, primary care trusts and NHS trusts. They have to agree, in consultation with the local authority, how to identify, assess and make provision for the health needs of children and young people with special educational needs (SEN).

Children and Adolescent Mental Health Service (CAMHS) This is a multi-disciplinary special mental health service for children up to the age of 18 who may be experiencing severe and/or complex emotional and behavioural problems.

Special Educational Needs Support Service (SENS) A pupil focused, integrated SEN support service. Managing and coordinating specialist teaching, support and provision to children and young people who have sensory impairments, communication and interaction difficulties and physical and complex difficulties.

Who else can help

Care manager/Social Worker Care Managers/Social workers assess the needs of the individuals and co-ordinate a package of support to meet these specific needs. Oxfordshire has specialist transition Care Manager/social workers who also provide appropriate support during this period

Local Authority Special Educational Needs Officer This is a designated officer within the local authority with responsibility for young people who have a statement of SEN. SEN officers have responsibility for writing and reviewing statements and ensuring that the needs outlined in the statement are met. The local authority continues to be responsible for young people with a statement who remain at school until the age of 19.

Educational Psychologist (EP) Educational psychologists are employed by the local authorities and work with schools and parents /carers to offer assessment and support in relation to a child's development and learning. They can offer personal support, group support and counselling. They are particularly involved in the statutory assessment process to determine whether a child requires a statement of SEN.

School Nurse School nurses can provide the link between families and other agencies and can inform the school of referral routes to other agencies offering support in specialist fields

Parent Partnership Service Is an impartial advice service providing advice and support to parents of children with Special Educational Needs (SEN)

The beginning of the transition process

For young people with a statement of Special Educational Needs the transition process starts in Year 9, the year the young person turns 14. The Head teacher of your child's school will write to invite you to the annual review (as they have every year since the statement has been in place). However, this review differs from previous annual reviews in that, as well as the statutory requirement to review your child's statement it will also include planning for transition to adulthood and drawing up a transition plan. For this reason the Year 9 Review meeting is also sometimes referred to as the "Transition review".

At this stage it is important that all the different agencies are made aware of the young person's needs and the role that they may be required to play as they approach adulthood. These should be your child's school, the Connexions Service, the Local Authority Special Educational Needs officer and the local Social Services department. The input of these agencies into this process will principally come through two major documents that will be produced at this time: **The Transition Plan**, which is produced as part of the Year 9 review, and the **Action Plan** produced by the Connexions service before the Year 9 review which should then be incorporated into the Transition Plan.

Who can attend the review?

- ✓ Parents and carers must be invited
- ✓ Your child's views must be sought and recorded
- ✓ If your child is likely to need social care as an adult Social Services must be invited to ensure that the young person's care needs are fully assessed
- ✓ Health professionals involved in the care of the young person should provide advice on the transition plan and where possible attend the meeting (if they can't attend they should send reports)
- ✓ The Connexions service has a obligation to attend the year 9 review
- ✓ A relevant teacher and a representative from the local authority must be invited
- ✓ The Head teacher can invite anyone else they think is appropriate
- ✓ If your child receives a service from the SEN Support Service (SENSS) it would be useful for their Advisory Teacher to attend
- ✓ Parents can invite people too. This could be an advocate or someone else who knows you or your child well.

Tips for parents

- **If you think there is a professional involved with your child who it would be important to invite, such as an Educational Psychologist, Speech and Language Therapist, or SENSS Advisory Teacher you should make sure the head teacher knows about this in good time to invite them to attend the meeting, or to ask them to write a report.**
- **Is there someone else you haven't thought of, like a friend, advocate or mentor, that you or your child would like at the meeting to support you?**
- **Inform the school beforehand, if you decide to take someone along with you.**
- **Reports should be circulated about two weeks before the meeting. If this doesn't happen you may need to ask the school to chase up the relevant professionals.**
- **Be aware, some of those attending this review meeting may have no previous knowledge of your child.**
- **The first review is a chance to ask about what each service represented can offer and what their role in the planning process will be.**
- **It's important to specify your child's strengths and weaknesses and be clear about what support they will need.**
- **It can be helpful to do some homework before the actual meeting so you have an idea of what options may be available.**

All young people with a statement of Special educational needs should have a Transition Plan

From Year 9 onwards, the aim of the annual review is not only to review the young person's statement, but also to update and review the Transition Plan. This should happen every year until they leave school.

The plan should bring together information from a range of people and agencies involved with your child. It should also make clear the type of support and provision needed to make sure the young person can make an effective transition into adult life. It's important to be aware that the transition plan is a continuous and evolving process, embracing the young person's whole life (not just education) and the plan can and should change and grow over time.

The Transition Plan should be about answering questions which concern the young person and their family such as...

- **What are their hopes and aims for the future?**
- **What skills do they need to develop to achieve these?**
- **Any care needs and practical help needed?**
- **How are the school helping the young person?**
- **Are there any health or welfare needs, requiring planning and support from health and social services?**
- **Can any other agency or organisation provide support?**

The school is responsible for putting the Transition Plan together, Connexions offer support to try and make sure that it is carried out. Once the transition plan has been drawn up it **must** be circulated to parents/carers and to all the other professionals involved

How can parents contribute?

Parents/carers have a vital role in collecting relevant information because you know all the important people and activities in your child's life. You also know what you may be able to do to help in the future and may be aware of some of the choices available.

It is helpful to make a checklist of everyone who has been working with your child and those who may have information that is important. Your views are very important and so it's helpful to think about your input as a parent/carer.

- How can you contribute to your child's personal, social and emotional development?
- Will your child's care needs change as they get older?
- How do you see your child's future?

You can also gather and have the right to bring along additional and independent evidence to the review meeting

How can the young person contribute?

"The views of the young people themselves should be sought and recorded in any assessments, reassessment or review from Year 9 onwards. Personal assistants, student counsellors, advocates or advisors, and teachers and other school staff, social workers or peer support may be needed to support the young person through the transition process"

(Special Educational Needs Code of Practice, Para.9.55)

It is important that young people are at the centre of the whole planning process and given the opportunity to share their views and share their concerns and ideas. They should be encouraged to attend the review meeting and contribute to it, and the transition plan.

Young people with communication difficulties or those with severe learning difficulties will need to be represented by a close family member, an advocate or a support worker. Some young people may not be able to verbalise or understand what the review or transition plan is about, but this doesn't mean that they cannot contribute. Doing reviews in a person centred way can help with this. We look at Person Centred planning and person centred reviews in the next chapter

Some useful projects/resources to help young people with transition planning:

Mencap's Trans-active

Trans-active is a project in which teenagers with and without severe learning disabilities work together. They use multimedia to explore and communicate choices they will have when they leave school. The project is about using and giving support, making plans, making friends and having fun. For further information visit web: www.trans-active.org.uk/index.htm

Moving on up

For young people from ethnic minority communities to find out about transition. This website is especially for young people with a learning disability and their supporters and families. Although it is especially for people from minority communities with a learning disability, any young person at transition stage may find it helpful. Visit web: www.movingonup.info/

Transition Pathway

The Transition Pathway is a resource pack which can be used by anybody who is involved in supporting a young person in transition to adult life. It gives information and guidance about transition and provides tools, using person-centred approaches, to help young people think about, plan and lead the lives they want. Visit web: www.transitionpathway.co.uk/tranpath.html

(And Person Centred Reviews)

“Person centred planning is about getting a life, not a service!”

So far in this guide we have talked about planning for the future and gathering information to support this planning. Person centred planning is a way of doing this that is useful for everyone, but particularly useful for those who are unable to express their own views, because of severe learning or communication difficulties. We believe that person centred planning should be at the core of transition planning for all young people with learning disabilities.

For people with learning disabilities it is useful to plan in a structured way, and person centred planning provides a number of styles that can help do this. Person centred planning is not just about services, or impairments, it is something that everyone can use to plan their lives.

Styles of person centred planning share common values and principles, and are used to answer two fundamental questions:

- **Who are you, and who are we in your life?**
- **What can we do together to achieve a better life for you now, and in the future?**

Person centred planning is a process of continual listening, and learning; focussed on what is important to someone now, and for the future; and acting upon this with their family and friends. It means that the person is at the centre of planning their life.

It is not simply a collection of new techniques for planning to replace any other plans. It is about seeing and thinking about people with impairments in the same way we think about ourselves and everyone else.

“When we did a person centred plan it was the first time I had heard anyone say anything nice and positive about my child ” [Parent]

Person Centred Planning is about

- ✓ Listening to and learning about what people want from their lives
- ✓ Helping people to think about what they want now and in the future
- ✓ Family, friends, professionals and services all working together with the person to make this happen
- ✓ A commitment to keep learning about the person

Person Centred Planning is not

- X The same as assessment and care planning
- X The same as reviews
- X Owned by services
- X Just a new type of meeting

Person Centred Reviews

Supporting families to prepare for the review

As family carers we all have different experiences of the review process and the review itself. The most common experience families’ share is that they feel that neither the young person nor themselves are listened to. Other family carers admitted to taking a more passive role that generally consisted of reading and listening to reports being read out by professionals. Yet families do have an important role to play therefore families should know what will happen at the meeting and be given time to prepare for it.

In person centred planning there are established ways of helping people to think about their life that can be used to prepare specifically for a person centred review. Where a person centred plan already exists, the review is a great opportunity to share this with other people and to think about:

- What people like and admire about the young person
- What is important to the young person now (from their perspective)
 - o Relationships with others and their interactions
 - o Things to do and things to have
 - o The rhythm and pace of their life
 - o Positive rituals and routines
 - o Things to avoid
- What is important to the young person for the future (from their perspective)

- What support the young person needs to stay healthy and safe
- What is working and not working for the young person, their family and other people
- Questions raised and unresolved issues
- Actions and implementing the plan.

If the young person does not have a person centred plan, a person centred review is a great opportunity to get one started.

Supporting other people to prepare for the review

Professionals will be used to preparing reports and attending review meetings. However, person centred review meetings are quite different from traditional review meetings. The review meeting process will need to be explained to them before hand so that they too can consider their contribution. This is not an opportunity for them to write reports under new headings. It is an opportunity for them to bring their knowledge and contribute to a shared understanding of the young person and his or her present and future life chances.

The success of the review meeting relies on everyone’s preparation and participation and the skill of the person facilitating the meeting. Before the meeting, the facilitator needs to learn how the young person will be supported to be at the centre of his/her review meeting and how he or she will be supported to contribute themselves.

A person centred review is powerful approach as it brings together people who have a willingness to participate in a way that supports positive and productive review outcomes for the young person.

Where to get further information about Person Centred Planning and Person Centred Reviews:

Families Leading Planning UK

A 'family-led' independent, national organisation based in Oxfordshire. Provides Person Centred Planning courses for people with learning disabilities and their families, with the aim of helping them to work towards a lifestyle of their choosing.

Telephone Barbara on: 07780 675197, or email barbara@familiesleadingplanning.co.uk

For further details visit the website at www.familiesleadingplanning.co.uk/index.htm

Helen Sanderson Associates:

Helen Sanderson Associates is a development training and consultancy team. They work with people to change their lives, organisations and communities through person centred thinking and planning.

For Further information visit web: www.helensandersonassociates.co.uk

The Circles Network

Circles Network is a national voluntary organisation based around the key principles of inclusion, person centred thinking skills and person centred Planning approaches. Provides unique personal support for people who are in danger of

becoming socially excluded, or who are currently suffering the consequences of prior segregation and discrimination.

Circles Network uses the tools of Person Centred Planning to facilitate inclusion in the community, principally through the setting up of Circles of support and through their individual projects for specific areas of need.

Circles Network also provides training for individuals, parents, carers, professionals and tailored in-house training for organisations.

For further information about what's happening in Oxfordshire please contact Emma Hope at emma.hope@circlesnetwork.org.uk. Or visit web: www.circlesnetwork.org.uk/

Valuing People

The Valuing People website has lots of useful information and links for families about Person Centred planning. A useful guide for families is available to download <http://valuingpeople.gov.uk/dynamic/valuingpeople138.jsp>

Valuing People web: www.valuingpeople.gov.uk

Inclusive Solutions:

Inclusive Solutions makes available cutting edge practical strategies and ideas for developing effective inclusion in mainstream classrooms, schools, early years settings and communities. Their website contains lots of information about person centred planning approaches and they provide training and advice... for more information visit web: www.inclusive-solutions.com

Tips for Parents:

- **Person Centred Planning is useful for everyone but particularly useful for those who can't express their views in a conventional way.**
- **Person Centred Planning may sound like a new fangled idea, but we have all probably been thinking in a person centred way throughout our child's childhood – we just get sucked into "services speak" and often start using their jargon too! Being person centred means thinking from the person's perspective "bringing it back to basics" - " see the person not their disability"- "lose the labels!"**
- **Friends and family and anyone else who knows your son or daughter can be involved in planning and it's a great way of learning about how others see them. It can also be lots of fun!**
- **Think! What does he/she want out of life and what steps can we take to get there – Dream! And then see how you can achieve that dream!**
- **Consider doing a person centred planning course to learn how to plan and learn from other parents who have used these methods. OxFSN can provide these courses.**
- **A person centred plan should inform a transition plan and any other plans made for or about the person, but it is owned by them. It can, and should be developed in a format that makes sense to the person themselves, e.g. a book with photo's, a DVD, or in easy words and pictures.**
- **Don't take our word for it, look around and see for yourself and do your own research.**

Options for Post 16 education will be discussed at your child's Year 9 review meeting, and the Connexions Personal Advisor should be able to tell you what these options are. We advise that you look around for yourself to see what provision will best meet your child's needs.

Young people with Learning disabilities in Oxfordshire have the option to...

- **Stay on at school** (if the school has a sixth form)
- Go to another **school** that offers post sixteen education
- Go to an **FE college**
- In approved cases, go to an **independent special school** or **college**, which may be residential
- Participate in **work-based learning**

A list of post 16 education providers with contact details, and their websites (if they have one) is below, to help get you started. A link to all Oxfordshire special schools and resource bases is available on the council website at

Oxfordshire Special schools offering post 16 education

Kingfisher school

Radley Road
Abingdon
OX14 3RR
Tel: 01235 555512
www.kingfisherschool.co.uk

Fitzwaryn School

Denchworth Road
Wantage
OX12 9ET
Tel: 01235 764504
www.fitzwaryn.oxon.sch.uk

Bardwell School

Hendon Place
Bicester
OX26 4RZ
Tel: 01869 242182
www.bardwell.oxon.digitalbrain.com

Iffley Mead School

Iffley Turn
Oxford
OX4 4DU
Tel: 01865 747606
www.iffley-mead.oxon.sch.uk

John Watson School

Littleworth Road
Wheatley
OX33 1NN
Tel: 01865 452725
www.johnwatson.oxon.sch.uk

Frank Wise School

Hornbeam Close
Broughton Road
Banbury
OX16 9RL
Tel: 01295 263520
www.frankwise.oxon.sch.uk

Northfield School

Knights Road
Blackbird Leys
Oxford
OX4 6DQ
Tel: 01865 771703
http://northfieldsschool.co.uk

Woodeaton Manor School

Woodeaton
Oxford
OX3 9TS
Tel: 01865 558 722
www.woodeaton.oxon.sch.uk

Mabel Pritchard School

St. Nicholas Road,
Oxford,
OX4 4PN
Tel: 01865 777878
www.mabel-prichard.oxon.sch.uk

Oxfordshire Hospital School

Windmill Road
Oxford
OX3 7BL
Tel: 01865 231584

The Moving on Plan (Section 139a Assessment)

This name for this assessment comes from a piece of legislation called the Learning and Skills Act (2000) It used to be called the section 140 Assessment and has now changed it's name to the Section 139a assessment (and may change again), so in this guide we've called it the moving on plan (because that's actually what it is!)

This assessment is done when it becomes clear that the young person with a statement of Special Educational Needs is likely to leave school and move on to further education or training. It involves the **Connexions Personal Advisor** gathering information about their future learning and support needs.

The information comes from your child's school and other professionals, involved with your child, such as social workers, educational psychologists and teachers, as well as parents/carers and should build upon the transition plan started in Year 9.

This assessment can then be shared with the new education provider to make sure the young person continues to get the right level and type of support they need. It can also help those responsible for post 16 education provision to plan how to meet the needs of future students.

For young people on School Action or School Action Plus a Moving on Plan (Section 139a assessment) could also be used to help ensure that the support needed in post 16 education is available.

Further/post 16 Education

Up until the age of 16, you will be used to the Local Authority having a responsibility for your child's education and most further education being funded by a different body called the Learning and Skills Council (LSC). However, from April 2010 the Local Authority will also be responsible for planning, funding, management and quality assurance of all post 16 education and training, except university courses. This also includes a duty to meet the needs of all disabled students.

Further education (FE) is the term used to refer to education for young people after 16.

Higher Education (HE) refers to courses at Higher National Diploma (HND) degree level or Higher.

The Connexions service has a major role in managing the transition from school to further education or work-based learning. Your child's Personal Advisor (PA) from Connexions has an important role to play, working with schools, young people and their

families to support and co-ordinate the transition planning process. They may also stay involved with the young person up to the age of 25

All young people are entitled to free full-time education until they reach 19. However, the routes they chose to take will vary depending on their individual preferences and abilities.

Once your child leaves school their statement of special educational needs will cease, unless they stay on at a local authority funded school for their sixth form. Arrangements for continued learning after school are less formal and will not be documented in a contract like a statement.

Oxfordshire colleges offering courses for learners with learning disabilities/difficulties

Abingdon & Witney College

Have courses for young people with learning disabilities called "The Steps programme" these are based on both of their sites in Abingdon and Witney.

To find out more about these courses visit their website @ www.abingdon-witney.ac.uk/courses-and-applying/the-steps-programme/the-steps-programme/

Or contact the college at the addresses and telephone numbers below

Abingdon Campus

Wooten Road, Abingdon
Oxfordshire OX14 1GG
01235 555585 (Switchboard)

Witney Campus

Holloway Road, Witney
Oxfordshire OX28 6NE
01933 703464

Oxford & Cherwell Valley College

Have full and part-time courses based at Oxford, Banbury and Blackbird Leys sites called "Foundation studies" These courses are for young people and adults with learning difficulties and /or disabilities ranging from profound and complex to moderate needs.

To find out more about Foundation Studies contact Elsbeth Tibbetts 01865 550385, etibbetts@ocvc.ac.uk
Visit web: www.ocva.ac.uk

Banbury Campus

Broughton Road, Banbury
Oxfordshire OX16 9QA
Tel: 01865 550550
Fax: 01865 551777
email: enquiries@ocvc.ac.uk

Blackbird Leys Campus

Cuddesdon Way, Oxford, OX4 6HN
Tel: 01865 550550
Fax: 01865 269299
email: enquiries@ocvc.ac.uk

Oxford City Centre Campus

Oxpens Road, Oxford
Oxfordshire OX1 1SA
Tel: 01865 550550
Fax: 01865 551386
email: enquiries@ocvc.ac.uk

Bicester Campus

Telford House, Telford Road
Bicester, Oxfordshire OX26 4LA
Tel: 01865 550550
Fax: 01865 551199
email: enquiries@ocvc.ac.uk

Henley College

Offers a variety of courses for learners with learning disabilities based on the college site called "Pathways". For further information visit the website @ www.henleycol.ac.uk/henleycollege/courses/pathways/main.html

Write: *The HENLEY College*, Deanfield Avenue, Henley-on-Thames, Oxon RG9 1UH.

Or telephone: 01491 634067

Oakley College

Is a specialist day college operating in partnership with Abingdon and Witney College of Further Education. Run by Macintyre Care they have a person centred approach to learning, the college supports students, aged 18-25, who have complex learning difficulties that place them on the autistic spectrum.

For more information, or if you would like to visit the college, please contact: 01844 338475 or email: oakley.college@macintyrecharity.org

Things to think about:

- What are the advantages of staying on at school as opposed to going to college and vice versa?
- What do each of the local FE (Further Education) colleges offer?
- What courses are available at the colleges and would they suit your child?
- Are these courses full time, and importantly, what does full time mean?
- What additional support arrangements will be provided?
- Is support provided outside of lessons?

- When should you apply for the course and will it definitely run?
- Will your child need transport and who will arrange it?
- What financial support is available and can you apply to the college to cover the costs of books and equipment?
- If the local schools or colleges don't seem appropriate and you want to consider an independent residential college, who will pay the fees and how will you find out more?

Courses and qualifications:

It's important to choose courses that are pitched at the right level for your child and your child's Connexions Personal Advisor, their teacher and the colleges will be able to help you with this. Colleges also have learner support advisors who will be able to offer advice about available courses for prospective students.

Support with learning

If your son or daughter is likely to require additional support to assist with learning then this can often be arranged on an individual basis but you should be aware that this may not be specified until the start of the academic year. Colleges can deliver individual tutorial programmes if agreed, and IT support can be put in place. Colleges can provide extra support if they decide it's necessary, such as in-class support and can buy in more specialist support such as a specialist teacher for hearing impaired students. We strongly recommend that you don't assume that the appropriate support will automatically be in place and so you will need to think about these needs well in advance of applying for courses.

What if your child is currently living away from home?

If your child is living away from home, e.g. at a residential school or health unit, the residential school should arrange a transition review. This should be arranged in exactly the same way as described earlier in this guide. A representative from the local authority should also be fully involved in review meetings and plans and Connexions services should also be involved. If your child is **'looked after'** then plans for leaving care should run in parallel to the school transition planning. In Oxfordshire there are designated workers called **Leaving Care Personal Advisors**. If you would like to find out more about this role then visit the council website – www.oxfordshire.gov.uk (go to the children and families section and look under the heading "children in care")

If the plan is for your son or daughter to return to live in the county, it is important that there is proper planning so that they are well prepared for the changes. However, it can sometimes be difficult to keep your child involved in planning if they live a long way from home.

Make sure that you contact your child's **Special Educational Needs Officer and Transition Social Worker** to check who is going to attend meetings and do this well in advance of any proposed meeting. Be clear who will take on the different roles in the plan - for example, check if the school will support your son or daughter to visit colleges and adult health and social care services.

Tips for Parents

- **The Connexions Personal Advisor (PA) should automatically attend the annual review from Year 9 onwards. However, it is our understanding that PA's in mainstream school dedicate less hours to students than to those in special schools and so it's important that in your child's final year at school that you make sure the PA attends the transition review.**
- **Make sure that you talk to the PA about the Moving on Plan (Section 139a assessment) which they will be writing if your child is going on to college or training and make sure that you discuss what equipment or extra support your child may need. This will help them to write the assessment plan as fully as possible.**
- **If your child has had support from the Special Educational Needs Support Service (SENSS) their Advisory Teacher will be a key person in the transition process so make sure they are invited to the transition reviews.**
- **Ask whether the college has specialist support or if not, whether they will buy it in.**
- **Arrange for an individual meeting with the learning support co-ordinators at the college concerned to discuss how the needs of the young person will be met.**
- **It's a good idea to ask for written confirmation of the level of learning support available before the start of the course.**

Special Educational Needs Support Service (SENSS)

SENSS is a pupil-focused service which delivers a range of specialist services and provision for children and young people with identified special educational needs. SENSS offers a range of interventions, advice and support to; individual children/young people, parents, school staff and other supporting agencies who are associated with pupils identified as having:

- Hearing Impairment
- Visual Impairment
- Language & Communication Difficulties
- Specific Learning Difficulties or Dyslexia
- Autistic Spectrum Disorders
- Physical Disabilities
- Down's Syndrome and Complex Medical Needs

This support is provided for children/young people aged 0-19 attending schools and settings which are maintained by Oxfordshire County Council.

If appropriate the SENSS will offer/ provide:

- Individual teaching to pupil/groups of pupils.
- Placement in a specialist resource base for children unable to attend their local mainstream setting

- Advices and support to meet a child's identified Special Educational Needs.
- Assistance with the planning/advice on the use of additional support.
- Contributing to the organisation and delivering of specialist programmes.
- Support for the monitoring and evaluation of a child's progress, achievement and attainment.
- Where appropriate, and subject to agreement, provide additional systematic support through In-Service Training (INSET)
- Provide advice for pupils who have particular ICT needs because of their Special Educational Needs.

Referrals to this service are usually made through health or education settings/schools and vary depending on when the child's disability or difficulty is diagnosed, but can be from birth. There may well have been a long involvement with the child and family over a number of years and therefore they will be a key help in the transition process

This is a county wide service based in three localities across the county, North, City and South

For further information contact:

The Wheatley Centre, Littleworth Road, Wheatley, Oxford OX33 1PH
 Tel: (01865) 456702
 Fax: (01865) 456710
 Email: diane.floyd@oxfordshire.gov.uk

A word about residential colleges

Residential colleges can provide young people with the personal, social and practical skills they need to move on to more independent living. They can also be a “stepping-stone” to supported living by allowing the young person the opportunity to experience life away from their family home. Just like other young people without learning disabilities who go onto university it can often be the first time young people have to cope without their families and can be hugely beneficial in helping them make the transition to adulthood.

However, we have to be honest here and say that securing a place in a residential college is not easy. Residential college places are expensive (and we know that local authority funds are limited). Because of this those who fund a place need to agree that there is no other suitable local provision and that the courses available at the school or college will not meet the young persons needs. The learning and skills council (LSC) and from 2010 the Local Authority have to agree to this funding and there is a strict and increasingly tight criteria for this.

To meet the criteria you will need to show that residential provision is an essential part of the young person’s education and/or training needs. This can be for educational or medical reasons. You may also need to demonstrate that there is a need to develop essential life skills, such as communication, daily living, mobility and self-care in addition to educational learning, which local provision or a package of provision cannot meet and that these needs can only be met in a residential setting.

It’s also necessary to provide evidence that the local college/s have been consulted before a specialist college will be considered. “Local” means the college/s which the young person could reasonably be expected to travel to (often the closest from the local authority’s point of view). It is our understanding that it may be less likely that a place will be funded at a specialist college if the young person has already transferred to a local FE college, unless you have strong evidence and can prove that the college your child is currently attending is not meeting their needs.

In some cases joint funding with Social and Community Care Services or Health Care services may be sought for young people who are over 16.

After the age of 19 Adult Social Care services may contribute to the cost of the “accommodation” or “care” element of residential provision.

Tips for parents

- **Residential college places fill up very quickly so make sure you look around and do your research early. If this is an option you are thinking about mention it at your child’s Year 9 review meeting and start looking at suitable colleges from then.**
- **To pursue this option you will need to collect evidence that the young persons needs, as described in their statement (or other reports if they no longer have a statement) can no longer be met at a local FE sector college/school – i.e. your child’s current educational placement can no longer meet their learning needs.**

- **You should include the young person’s views (as far as possible) too, as it’s important to show that the young person wants to go to a residential college.**
- **Once you’ve made the decision about which college you would like your child to apply to, it is important that you work closely with your Connexions PA who can advise you on what evidence and reports you’ll need to gather to support your application for funding. They will then present the case for funding on your child’s behalf.**
- **If funding is turned down, you can ask your child’s PA to appeal for the decision to be reviewed. However at the time of writing, because of changes in the way that post 16 education is being funded, we have no idea what this appeal process will be. We have been informed that there will be a mechanism for appealing but that this is currently under discussion. We strongly suggest you speak to your child’s PA.**
- **Residential college courses vary from 1-3 years and current criteria states that funding for these courses depends on the progress made by the young person. However, for some young people, especially those with more severe/profound disabilities, “progress” can be hard to measure. It could be argued that sometimes maintaining skills is in itself progress.**

Adult Education

Lifelong learning opportunities should be available for everyone. We feel it is especially important for young people who have learning disabilities or difficulties who often learn at a slower rate and consequently need to take advantage of learning opportunities for longer. Local FE colleges such as those listed in this section have courses that run for learners beyond 19 and in some cases up to 25 years old. Unlike provision for 16-19 year olds these courses are not guaranteed to be full time and many families discover that after their child turns 19 the college provision is reduced. We suggest you speak to the colleges and find out what courses will be available to meet your son or daughters needs and for how many days. In the next section of this guide we will look at social care. It could be that a combination of social care provision and education could be provided to meet the young person’s needs.

The Disability Discrimination Act (1995) has made it unlawful for education providers such as schools, colleges, universities, and youth services to discriminate against disabled people by treating them less favourably in their admissions policies or the services provided and this also applies to providers of adult education.

Adult education is provided at a number of centres across the county. However, in saying this there is currently a distinct lack of adult education courses available to people who have more severe and complex disabilities. We recommend that you make contact and have a look to see if there is anything that may interest your son or daughter. Please be aware that there are charges for these courses. However, for people on low incomes and/or benefits there are concessions available.

Oxfordshire Adult Learning

Adult education courses are available to everyone and courses are available to appeal to a broad range of interests. A brochure is available from The Oxfordshire Adult Education service with details about how to apply if your family member has a learning disability or disability.

Courses include: Art & craft, music, dance and computer skills and all courses are subject to charges. However there are concessions for people on low incomes

To find out more visit web: www.oxfordshire.gov.uk click on education & learning on the links on the left hand side, click on adult learning, then learners with disabilities.

Or alternatively contact:
Tel: 01865 779584.

Other sources of independent support & advice

Parent Partnership Service

Offers impartial information, support, advice and training to parents to enable them to make informed decisions about their child's special educational needs. They also hold "talking points" – informal drop-in advice sessions every Wednesday at different locations around the county and send out an informative newsletter. To find out more about how the service can help you please visit the Oxfordshire County council website @ www.oxfordshire.gov.uk or e-mail: parentpartnership@oxfordshire.gov.uk or Tel: 01865 810516

IPSEA (Independent Panel for Special Education Advice)

IPSEA offers free and independent legal advice and support in England and Wales through, helplines, written information on website and in print, advice, support and representation (when needed) in appeals to the Special Educational Needs and Disability Tribunal and Disability Discrimination advice and training

Contact IPSEA, by visited their website @ www.ipsea.org.uk

Or by telephone: 0800 0184016 – for their advice line

During the Year 9 Review meeting at school, one of the things that should be looked at is whether your child is likely to require support from adult social care.

Under the Disabled Persons Act (1986) social services, health and education are required to cooperate and exchange information and to jointly assess the needs of the young person before they reach school leaving age. It also places a duty on the education department of the local authority to consult with Adult Social Care when a person with a statement reaches 14 years old. In Oxfordshire this is done through the multi-agency **School Leavers Panel** and involves education, social care and health services working together to consider possible support needs in adulthood.

In Oxfordshire there are specialist Transition Social Workers in both the Children with Disabilities team and the Learning Disability Teams (which is specifically for adults)

The details of all young people with a statement are presented at the school leavers panel. This occurs just before they enter Year 9.

Young people clearly requiring support once they reach 18 are then identified to the appropriate transition workers from the children's and disability teams and the appropriate adult transition workers. Over the next 4 years a transition plan and care plan for adult support should be developed.

For a small number of students there will be insufficient information to determine if the young person is eligible for support. These families

should be contacted by the adult social care team and informed of the service. They should then be advised to contact the team if they require support and offered an eligibility assessment. This will determine if they receive support from adult services or not. The adult service operates an **open referral system** and anyone can request an assessment either directly from the team or via the access or assessment teams.

Many families will have not had any contact with social services and consequently never received support from them. However, once a young person is over 18 years old they may be able to receive services that would be helpful to them (and to you, as their carer). If you have not been in receipt of services from the children's team it is useful to make contact with the adult social care team well before your child turns 18 to find out what support may be available.

Adult Community Care services...

"Community Care" is a term used in adult services and it refers to a range of help provided for people over the age of 18 who are considered to be vulnerable or who are disabled. Community Care Services are there to help people to live in their community as independently as possible.

Adult social care is responsible for arranging community care services or providing the funding to pay for a service. They have a legal duty to carry out an assessment to determine what support they can offer you and your family member.

Community Care Assessment

This assessment is the first step in getting community care services and what support will be available to your son or daughter depends on the outcome of the assessment.

[Support after 18 falls within the duties set out under the Community Care Act (1990) (*information about this act is available in the "Guidance & Legislation" chapter on page 76 of this guide*)]

Although there are limited resources available, the law states that the assessment should be "needs led" and, therefore, the resources of the local authority should not be taken into account while it is taking place.

Eligibility Criteria

The eligibility criteria for adult services is different from children's services and although you and your child may have been eligible for support while your child was at school you may find that when they become an adult this is no longer the case. Parents' experiences vary greatly and each person must be assessed according to their individual needs.

Oxfordshire's eligibility criteria are based on the Government's National Guidance. This is called Fair Access to Care (FAC's) and is used by all councils providing adult social care services. There are 4 bands that describe the seriousness of the risk to independence and other consequences if people's needs for community care services are not addressed and the likelihood of those risks happening. These are Critical, Substantial, Moderate and Low, but

although there are 4 bands it's important to know that in Oxfordshire eligible needs (like those in most other councils) are deemed to be those that fall into **critical or substantial only**. Oxfordshire's policy on Fair Access to Care (FAC's) is available to view on the council website at www.oxfordshire.gov.uk

For an explanation of what each band means in more detail visit the council website or download the policy guidance from the Department of Health at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653

To find out more about how to get support from the learning disability teams. Contact details are below:

Oxford and South Cherwell

Knights Court
21 Between Towns Rd,
Cowley, Oxford OX4 3LX
Tel: 01865 323357

North (and West)

Redlands Centre
Neithrop Ave, Banbury OX16 2NT
Tel: 01295 257727

South & Vale

Foxcombe Court, Wyndyke Furlong
Abingdon Business Park
Abingdon OX14 1DZ
Tel: 01235 375515

Oxford & Kidlington

Wadham Court
Edgeway Rd, Oxford OX3 0HD
Tel: 01865 721510

If your child is not eligible for the Learning Disability Team's services they may be eligible for other social services, such as the Physical Disabilities Team, the Sensory Impairment Team or the Mental Health Team. To find out more contact the County Council's Access team, which is the main point of contact for all Adult Social Care services in Oxfordshire.

Tel: 0845 050 7666. Staff should help you to contact the services you need. Hours are: Monday to Thursday, 8.30 am to 5pm; Friday, 8.30 am to 4pm.
E-Mail: access@oxfordshire.gov.uk

Emergency Help

Emergency help is also available to people who live in Oxfordshire or who are staying or visiting the county.

The team is available from 5pm-8.30am Monday-Thursday, 4pm-8.30am on Friday's and Bank Holidays.

Urgent advice is available by ringing the freephone number **0800 833408**. You will hear a pre-recorded message giving you the telephone number of the social worker on duty. The Emergency Duty Team is staffed by qualified social workers

Your Needs as a Carer

Parents can find it difficult to ask for help but it's important that as well as thinking about the needs of your son or daughter you should also consider your own needs as their carer. If your child regularly relies on you for care, you have the legal right to ask for an assessment of your own needs. This is done through a **Carers Assessment**.

Under the Carers Act legislation you cannot be refused this assessment if you ask for one and the local authority has a duty to inform you of your rights to an assessment. This can be done alongside the needs assessment for the person you care for **or done separately if you request it**.

Once your child has turned 18 if they have been assessed as having eligible needs you should automatically be asked if you would like a Carers Assessment. This should then be incorporated into the Community Care assessment your young person will receive. If you are the carer of a young person who does not have eligible needs you may still be able to obtain carers support via the carers' centres. (*Further information about the Carers Act can be found in the Guidance & Legislation chapter on page 76*)

Oxfordshire Carers Centres

Oxfordshire has 3 carer's centres that offer free, confidential advice, support, advocacy and information to anyone with a caring responsibility.

South & Vale Carers Centre

5 Lydalls Rd, Didcot OX11 7HX
Tel: 01235 510212
E-Mail: carers@cvcarers.org.uk

Oxford Carers Centre

174a Cowley Rd, Oxford OX4 1UE
Tel: 01865 205192
E-Mail: infor@carerscentre.co.uk

North & West Carers Centre

27 Horsefair, Banbury OX16 0AE
Tel: 08457 125526 (local rate)
01295 264545
E-Mail: carers@ccnwoxon.org.uk

A Word about Charging

All local authorities have the power to charge for their services. However, in children's services they rarely do. This all changes when your child becomes an adult and this can come as a bit of shock to parents.

The local authority operates a **Fairer Charging Scheme** and some services that may be charged for include:

- Sessions at day centres
- Transport
- Help with personal care
- Meals
- Supported living
- Relief to carers
- Laundry and home shopping services

The Fairer Charging Scheme relates to people who receive care or other services in their home or day care provided by Social and Community Services. It does not apply to people living in residential or nursing homes or who are receiving only residential respite services as these are covered by a separate charging scheme. For further information about charging and the Fairer Charging Scheme speak to your son or daughter's Care

Manager and/or visit the council website where you can view or download information about the scheme in more detail – [Go to Health and Social Care from the drop down menu on the left hand side. Click on learning disabilities, then "getting care services", then Care Charges]

Tips for parents

- **Don't assume that because your child has a statement of Special Educational Needs you will automatically get adult social care services. But do contact the Access team anyway to find out - and ask for a needs assessment.**
- **If your child has not had children's social care support, don't assume that they will be refused a service from adult care. Basically, don't assume anything, always ask.**
- **If a social worker has not been involved before or circumstances change so that you feel that you or the young person needs more help than in the past, contact the adult disability teams directly to ask for an assessment of needs.**
- **Once your child is 18 years old, there should be no assumption from social care services that you will continue to care for them at home and there is no legal onus on you to do so. Most people however still want to and do. In order to do this you should make sure that you get all the help you need to continue to provide care for your family member – so make sure you have a carers assessment which takes into account your need to work/learn and have leisure time.**

- **In Oxfordshire the Community Care Assessment is referred to as the "FACE" assessment by Care Managers – this name comes from the organisation who developed the assessment. It is in fact local "professional jargon" for a Community Care Assessment. This assessment is carried out by a Local Authority Care Manager**
- **Don't assume it's "you against them" – try to explain yourself clearly, and see their point of view. If you don't agree with the outcome of the assessment process, explain why this is to the Care Manager. Ask him/her what are the next steps you can take to address this issue in order to continue to move the process forward.**
- **Don't be afraid of suggesting something that has not (to your knowledge) been tried before. Some of the most creative ways of supporting people have come from parents. If you know why your idea might work, then others may see your point of view.**
- **Get as much solid information from other people in a similar position. Find out what is possible and how they went about getting what they did for their family member.**
- **Write down the correct name and job title of the people you speak to (although these do always change) and take their phone number.**
- **Don't rely solely on telephone conversations. If you think what you have been told verbally *seems* unreasonable then ask for a written explanation.**
- **Check and check again that all your child's needs have been considered and taken into account. Once a care package has been agreed its hard to negotiate for more money.**
- **Once a service has been agreed it can't be taken away without the person's needs being reassessed.**
- **Local authorities have certain "Powers" and "Duties" within the law. A Duty to provide a service – means it *must* be provided. A Power to provide a service – means it *may* be provided.**
- **If you ask for a Community Care assessment, social care services have a *duty* to assess a person's needs. A local authority cannot refuse to assess even if it thinks a person is probably not in need of services as such a decision can only follow the assessment itself.**

If your child has ongoing health issues or medical needs it is important to start to plan for the move from children's to adult's health care services, to ensure they continue to receive the support they need. Once your child becomes 18 they will no longer see the Paediatrician or other children's services, such as CAMHS (Child and Adolescent Mental Health Service) and will often move to more general health services. The age of transfer for many health authority services is 18, but this varies in different medical specialities. There may also be a period when your child is seeing adult services for some things and children's for others. So, it's a good idea to ask the individual services/specialities when the transfer to other teams will happen and this will help you plan ahead.

At the Transition review meeting it is important that if your child is likely to have ongoing health needs you make sure that Health is represented and involved in the schools transition planning process. Health professionals involved should be invited to attend the review. If they can't attend they should provide advice in writing.

Health Action Plans

Good health is important to everyone and we all have the same right to NHS services. However, people with learning disabilities often need to be helped to lead healthy lives and stay healthy and even if your family member does not have specific health needs related to their disability maintaining good health is important.

"Valuing People" says that people with learning disabilities should get the chance to have a Health Action Plan. They should have help to get the services they need from the NHS.

A Health Action Plan is a personal plan about what a person with learning disabilities can do to be healthy. It lists any help people might need to do those things. It helps to make sure people get the services and support they need to be healthy. You can start making a health action plan in different ways. Someone at your family doctors surgery can help or you can make sure a health action plan is incorporated into the transition plan or your son or daughter's person centred plan.

Tips for parents:

- **Health Action Plans should contain all the information that is important to the health and well-being of the person. I.e. basic issues such as, how they like to be supported with cleaning teeth, washing and bathing, eating, taking medication... as well as their emotional well-being. If they become anxious -what causes this, how does this present itself and how do they communicate their anxiety? And how do they need reassuring?. As parents you will know your child better than anyone and can play a key part in making sure all this information is shared and incorporated into their plan.**
- **People with learning disabilities can tell us in different ways when they are feeling unwell or in pain. A person may stop enjoying their leisure activities; their behaviour may change; they may have problems sleeping or eating. Families do know and understand when something is wrong and must be listened to. It is critical that any information about how the person communicates they are in pain or discomfort is incorporated into the Health Action plan.**
- **It's important to make sure that you include key information about the your wider family's medical history, e.g. diabetes, thyroid problems, heart conditions, or certain cancers as this may help doctors to keep an eye on potential health problems for the future.**
- **Further information about Health Action plans can be found on the Valuing People website @ www.valuingpeople.gov.uk in the resources section.**

When your child reaches **16** they may be able to claim benefits in their own right. However, you need to be aware that if they do you will lose any benefits you receive for them as your dependent (e.g. child benefit)

As parents of disabled children you may be used to getting extra money to help you to meet some of the additional costs of caring for your disabled children. These benefits often become part of the household budget and so it's not surprising that many of us worry about benefit changes and how they might impact on the household. If your son or daughter is living at home, and especially if your family claims income related benefits, such as Child Tax Credits it's important to get specialist benefits advice to work out what makes the most financial sense for your household at this time.

A young person can claim benefits in their own right even if they need someone else to manage their money for them and act on their behalf. Most parents will have been claiming Disability Living Allowance (DLA) for their children and awards for DLA are usually reviewed 6 months before the young person reaches 16. Claiming DLA as an adult can be the first time young people have to think about their ability to manage their own money and in reality most disabled young people don't feel ready to take on this responsibility and ask their parents to look after their money for them. Some young people will never be able to manage their own finances and in both these situations parents take on the role of "Benefits Appointee"

What is an Appointee?

An Appointee is someone who acts on the young person's behalf in all social security matters, not just Disability Living Allowance. This includes telling the Department for Work and Pensions (DWP) about any changes in their circumstances, banking any benefit money and using the money for the benefit of the person. (Just like you've done always as a parent really, only now you have an official title!)

Before an Appointee is agreed, the DWP should arrange to visit both the disabled young person and whoever is making the application on their behalf (often the parent). They then have to agree that the young person is unable to act on their own behalf. If you don't get a letter from the DWP to ask whether you will be your child's appointee make sure you ring them a couple of months before they turn 16

Through our work at the Family Support Network we regularly meet parents who have not applied for the benefits their son or daughter could be entitled too. This could mean that the young person misses out on having their own money that could enable them to pay for their own social life and any additional support they may need. There can be a number of reasons for this, but the most common by far is that they didn't know they could apply for them.

We have included some of the major benefits in this guide and details about where else to get more information, but can't stress enough how important it is that you **obtain specialist advice before your child turns 16 in order that they don't miss out on any entitlements at this time.**

There are several benefits a young person may be able to get such as:

Disability Living Allowance (DLA)

Many Parents will already (*we hope!*) be claiming DLA for their children: similar rules apply about how decisions are made about awards for adults and the benefit rates remain same. A big difference is that your teenager's need for care and supervision only need be greater than another adult's as a result of illness or disability. For the claim for adult DLA a different form is used than the one you will be used to.

Awards for DLA are usually reviewed 6 months before the child reaches 16 years of age, so claiming DLA as an adult is often the first time young people have to think about their ability to manage significant amounts of money. Many disabled people don't feel ready to take on this responsibility and some are unable to manage their own finances. In these circumstances parents take on the role of "Appointee" If your child is able to manage their own money it makes sense for them to claim DLA for themselves as an adult at 16

- DLA isn't taxed and income from DLA is not taken into account if you or your child claim other benefits.

Employment and Support Allowance (ESA)

On the 27th of October 2008 a new benefit called the Employment and Support Allowance (ESA) replaced both Incapacity Benefit and Income Support for people who are incapable of work.

ESA has two types of payment. There is the Contributory ESA. Special rules allow young people to receive this despite having paid no national insurance contributions. There will also be income related ESA which is means tested. Some young people will get both forms of ESA, others will only qualify for one or the other.

Young people in full-time mainstream education, aged under 19 who do not get DLA are unable to claim ESA at all. Other students may be able to apply.

To find out whether your son or daughter is eligible for this benefit contact your local job Centre Plus, visit the Department for Work and Pensions (DWP) website at web: www.dwp.gov.uk or telephone the benefits advice line on 0800 055 6688

Education Maintenance Allowance (EMA)

An EMA is a weekly payment worth up to £30 for students who are aged 16 or over and are planning to continue in further education. This is available to all students providing they meet a certain criteria:

You can get EMA if:

- ✓ You are aged 16
- ✓ Your household income is £30,000 or below

- ✓ You are on further education courses in school sixth forms, sixth form colleges and FE colleges or starting non employed training, Entry to Employment (e2e) and Programme led pathways to Apprenticeships (PLP) For more information, call EMA Helpline on 0801 016219 or visit www.direct.gov.uk/ema

Independent Living Fund (ILF)

This is designed to help disabled people, over the age of 16 and under 66, to live independently at home or in the community. The payments can be used to employ people for personal and domestic care such as bathing, shopping or household tasks.

As with all benefits there are certain criteria that must be met. To find out more about this talk to a benefits advisor or your care manager (if you have one)... or the Transition social work team.

Or visit the ILF Website @ www.ilf.org.uk

Where to get advice and further information

The Carers Centres

can offer advice about benefits and The Citizens Advice Bureau (CAB) can also be very helpful. To find your local CAB office you can look in the yellow pages or visit web: www.citizensadvice.org.uk

Direct Gov

The official Government Website for citizens, contains lots of useful information about benefits for disabled people. Visit web: www.direct.gov.uk

Barton Advice Centre (BAC)

Barton Advice Centre (BAC) is an independent community advice and information centre, providing services to individuals who live locally in Barton, Headington and Risinghurst and throughout Oxfordshire. BAC provides specialist advice on welfare benefits, debt and general advice on a wide range of other issues. They also offer assistance to fill claim forms, negotiate with the Department for Work and Pensions or other outside agencies like fuel, water board, banks, creditors and housing.

BAC is part of a network of advice centres in the City that includes The Agnes Smith Advice Centre, Donnington and Rose Hill Advice Centre, Oxford Citizens Advice Centre and the Chinese Advice Centre.

Donnington & Rose Hill Advice Centre

The Cabin, The Oval
Rose Hill, Oxford OX4 4SF
Phone 01865 438634
Fax 01865 438643

Agnes Smith Advice Centre

96 Blackbird Leys Road
Blackbird Leys
Oxford OX4 6HS
Phone 01865 770206
Fax 01865 771585

Oxford Citizens' Advice Bureau

95 St Aldate's
Oxford OX1 1DA
Phone 0870 2200608
Fax 01865 202715

Contact a Family

Produce a number of useful guides. E.g. Preparing for Adult Life and Transition & Money when your child reaches 16 years of age. They also have specialist benefit advice workers. The guides can be downloaded free from their website at www.cafamily.org.uk or by contacting the free parents helpline on 0808 808 3555

The National Autistic Society (NAS)

Provides information factsheets about benefit entitlements - available to download from web: www.nas.org.uk

Job Centre Plus

Information on website about what benefits disabled people and their carers may be entitled to. Most major towns have a Job Centre Plus - to find the nearest to you

Visit web: www.jobcentreplus.gov.uk or telephone: 0800 055 6688.

Department for Work and Pensions (DWP)

The DWP is a government department and the website has lots of useful information about what benefits are available for disabled people and their carers and where to go for further help and advice
Visit web: www.dwp.gov.uk

Tips for Parents

- **Benefits are real minefield. Knowing what benefits affect other benefits and the impact of any paid employment on benefits can be really complicated. We therefore recommend that you always seek individual, specialist advice.**
- **Disability Living Allowance (DLA) can be the passport to other sources of financial help and other benefits available at 16. If you are not currently claiming DLA for your child then now is a good time to look into it.**
- **If your child is already in receipt of DLA then it's important that you check they are on the right level (OxFSN can help with this or put you in touch with someone else who can advise you)**
- **All children are meant to become less financially dependent on their parents when they become adults and this is the same for young people with learning disabilities. Make sure that they are receiving everything they are entitled to.**
- **It is also important that you are aware that at the point that your family member is receiving benefits that these are seen by adult services as their own income and not the families.**
- **It is a good idea to think about setting up a separate account for your son or daughters benefits (if you haven't already done so)**

What happens at 18?

Once your child turns 18 years old they are legally considered to be an adult. You may have already noticed some changes in the way they are treated by agencies involved in their lives, such as, letters addressed to them, rather than you. For families with young people with learning disabilities this can be a worrying time and so in this section we will address what this will mean for you and your family member and what your roles and responsibilities will be **if your child is unable to make decisions for themselves.**

"It seemed strange that when my son turned 18 he was suddenly an adult, and yet nothing had changed. For him, age really is just a number and he needs the same care and support as he always has" [parent]

If your son or daughter has learning disabilities you may want to continue to make/or help them to make decisions about their lives, their health and well being, just as you have throughout their childhood. However, once they turn 18 they are legally considered to be an adult in their own right with all the rights and responsibilities being an adult brings. You, as their parent are no longer assumed to be responsible for them or acting on their behalf and there are major issues about consent. The basic concept here is that once a person becomes an adult **the law assumes that they have the capacity to make their own decisions, unless it is proven otherwise.**

Some issues that may arise could be...

- In order to get a Direct Payment to pay for services a person needs to have a bank account in their own name.
- In order to have a bank account in their own name the person needs to be able to sign their name and understand what they are signing
- Consent to health treatment or medical procedures

The Mental Capacity Act

Came into full force in October 2007. It aims to protect people who cannot make decisions for themselves due to a learning disability or mental health problem. The Act states that everyone should be treated as able to make their own decisions unless it is shown that they can't.

The Act has been welcomed as a way of protecting people who lack capacity from financial abuse and as a way of addressing wider issues of health and welfare. However, it does have implications for carers that you need to be aware of.

Mental Capacity Act 2005 for England and Wales

provides a framework to empower and protect people who may lack capacity to make some decisions for themselves. It makes it clear who can take decisions in which situations, and how they should go about this. It also allows people to plan ahead for a time when they may lack capacity.

It will cover major decisions about someone's property and affairs, healthcare treatment and where the person lives, as well as everyday decisions about personal care (such as what the person eats), where the person lacks capacity to make those decisions themselves.

Key Principles

There are five key principles in the Act:

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise
- A person must be given all practicable help before anyone treats them as not being able to make their own decisions
- Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
- Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests
- Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms

You can view a full copy of the Mental Capacity Act 2005 on the Office of Public Sector website @ www.opsi.gov.uk

If your son or daughter has a severe learning disability (and you believe that they cannot manage their own affairs) then you will need to contact the **Office of the Public Guardian** and apply to **The Court of Protection** in order for you to become their Deputy and make decisions on their behalf.

The Office of the Public Guardian

The Office of the Public Guardian (OPG) protects people who lack the mental capacity to make decisions for themselves.

It does this through regulating and supervising court-appointed deputies, and by registering Lasting Powers of Attorney (LPA) and Enduring Powers of Attorney (EPA).

In some cases, where there are suspicions that an attorney or deputy might not be acting in the best interests of the person they represent, the OPG will work with other organisations to ensure that any allegations of abuse are fully investigated and acted on.

The OPG also provides information on mental capacity to the public and can provide contacts with other organisations working in the field of mental capacity. More information about the Office of the Public Guardian, the Court of Protection and Lasting Powers of Attorney can be found on the Office of the Public Guardian website.

See Web: www.publicguardian.gov.uk

The Court of Protection

The Court of Protection deals with all issues relating to people who lack capacity to make specific decisions, for example concerning financial or serious healthcare matters. It will look at cases where the person's carer and healthcare worker or social worker disagree on what are the person's best interests.

The Court of Protection has specially trained judges to deal with decisions relating to personal welfare, as well as property and financial affairs.

See Web: www.publicguardian.gov.uk

Having **Lasting Powers of Attorney** differs from being a Court Appointed Deputy through the Court of Protection, in that, your son or daughter needs to have the mental capacity to understand and be able to give their consent for you to make decisions on their behalf.

Lasting Powers of Attorney

Lasting Powers of Attorney (LPAs) replace Enduring Powers of Attorney (EPAs). LPAs will give vulnerable people greater choice and control over their future and enable people to choose someone they trust to look after their affairs if necessary.

The new LPAs cover personal welfare as well as finance and property decisions. As they can only be used after they have been registered with the Public Guardian, they will be under more scrutiny and ensure that any decisions made on behalf of people lacking capacity are in their best interests.

To find out more visit web: www.publicguardian.gov.uk

Now, this all sounds really complicated and official and actually we know from experience that it is. However, like everything else to do with raising a disabled child you can get advice and help with this (if you know where to look) and we recommend that you do. The helpline at The Office of the Public Guardian is very helpful and your child's Care Manager should also be able to help and advise you.

Where to get further help and advice

Mencap

produce a number of useful guides and these are also free to download from their website. These include guides to:

- **Consent and decision making:** Financial matters for people with a learning disability aged 18 or over
- **Capacity and housing tenancies:** Explaining what a housing tenancy is, issues of capacity and the law surrounding housing tenancy and how it might apply to a person with a learning disability.
- **Bank accounts Factsheet:** An introduction to bank accounts for people with a learning disability
- **An introduction to The Mental Capacity Act**
- **The Mental Capacity Act:** frequently asked questions

For further information visit the Mencap website @ www.mencap.org.uk and click on the resources link at the top of the page, then under subject, click on law and rights.

Independent Mental Capacity Advocate (IMCA)

The Mental Capacity Act set up the Independent Mental Capacity Advocate (IMCA) service. The service helps vulnerable people who cannot make some or all important decisions about their lives.

The IMCA service will mean that certain people who lack capacity - this may include people with dementia, Alzheimer's disease, brain injury or a very severe learning disability - will be helped to make difficult decisions such as medical treatment choices or where they live. It is aimed at people who do not have relatives or friends to speak for them.

For further information visit the Department of Health (DOH) website @ www.doh.gov.uk, if you put IMCA into you browser this site should appear

Tips for Parents

- **As always, it's a good idea to talk to other parents who have gone through the same process.**
- **You can seek independent, professional legal advice, but beware, this can be costly.**
- **You also need to be aware that it costs £400 to apply for Court of Protection, but this can be paid for with the young person's personal budget or their own benefits.**
- **When applying to the Court of Protection it's a good idea to include other family members as deputy's in the application, such as siblings, even if they are younger, as this will save you applying again and having to pay again in the future.**
- **If you set up a bank account for your son or daughter before they turn 18, when they are still considered a "minor" you do not need to use the Court of Protection process. However once they turn 18 you cannot set up a bank account without becoming their deputy.**

For most young people, social life takes off when they enter adulthood and they become increasingly independent. But for young people with learning disabilities making friends, meeting up and going out and about can be more difficult than it is for other teenagers. This may be due to difficulties with communication, getting around, being able to travel independently or due to their particular impairment. Many of our children need support to engage in social activities, leisure opportunities, and generally just have fun with friends.

"Like other teenagers, when my daughter turned sixteen, her friends were everything to her and her social life took off in a big way. Her disabled brother loved going out and being with his friends too, but when he reached the same age it looked as though his social life was going to stop all together"
[parent]

In this section we show you some of the opportunities available for young people who may need support and supervision with social activities. This is not a complete list, but will give you an idea of what there is and where else to start looking and get information. The Learning Disability Partnership Board has its own website called "Easy Words" which contains over 200 links to local and national organisations and groups, including a section on "living a full life" to check this out visit:
www.EasyWords.co.uk

Anjali

Anjali Dance Company is a professional contemporary dance company, and is one of the first of its kind in the world. All of Anjali's dancers have learning disabilities. The company produces and tours performances and undertakes educational and outreach work. Anjali aims to show that disability is no barrier to creativity.

Anjali have classes for adults, children and young people.

ANJALI OPEN CLASSES

Dance class for creative people aged 16 plus who enjoy music and dance. Dancers with or without learning disabilities are always welcome. This class offers fun and friendship and it also provides training for potential new dance company members. Wednesdays, 4.30pm - 6.00pm, £3.50 per session.

The Mill Arts Centre, Banbury, Oxfordshire. -Anjali have just started a **NEW OPEN CLASS** in **OXFORD** for people with learning disabilities aged 16 plus at John Bunyan Baptist Church, Crowell Road, Cowley, **Oxford** OX4 3LN. Tuesdays, 5.00pm - 6.30pm, £3.50 per session.

(For further information about regular classes, please call 01295 251909 or by contact them by e-mail) info@anjali.co.uk or visit web: www.anjali.co.uk

Buddies & Wider Horizons

The Chiltern Centre is an independent company and registered charity. Established in 2004 in response to the needs of local families. The Centre was originally setup to provide essential short break services for children and young people with learning and/or physical disabilities. Today the Centre offers a full spectrum of , including provision for those with complex health and medical needs. They also run youth groups - see below

Buddies meets fortnightly during term time, with occasional social outings in the holidays and caters for young people between 12 and 21 years; The young people then move on to the or become a Buddies helper in some cases.

The Wider Horizons Group offers a monthly programme (arranged together with the members of the group) of recreational and leisure opportunities such as meals out, cinema trips, weekend breaks and in-house activities to young adults, aged 18 - 25, with a learning disability who live with their parents/carers.

For further information visit web: www.chilterncentre.co.uk

Or Tel: 01491 575575

or e-mail: chiltern@chilterncentre.demon.co.uk

Guideposts Trust

Is a charity that provides support for people with Alzheimers, learning disabilities and mental health issues. They provide a number of services in Oxfordshire including....

Friendship scheme

Guideposts has developed Friendship Schemes for people with learning disabilities in Oxfordshire, East Hertfordshire and Gloucestershire. The service links volunteers with people who have learning disabilities, enabling them to go out socially and enjoy the 'same kind' of leisure activities as anyone else and which, otherwise, would not be possible. Volunteers are matched with people who have similar interests and hobbies, to form a friendship and enjoy activities. These include going to the pub for a drink, shopping, outings to London, watching live music, playing snooker and pool, going swimming and much more. Guideposts also currently run 2 evening youth & social groups and one on Saturdays as well as providing day services for young adults, 3 days per week.

LISTEN (Leisure integrated sports to enjoy now) runs on Wednesdays evenings from 7.30 - 9.30pm throughout the year. The age group is 13- 18 years

OX18+ runs on Thursday evenings 7pm - 9.30pm throughout the year and as the name suggest for over 18's only (no upper age limit but the average is 18 - 35)

Lap runs on Saturdays 10- 3pm throughout the year - age group over 18 yrs no upper age limit.

For more information visit web: www.guidepoststrust.org.uk

Or Tel: 01993 899980

KEEN (Kids Enjoy Exercise Now)

Offers activities for children and young adults with special needs aged 5-30. They offer sports sessions, drama and craft workshops and an over 18's social club. Get in touch to find out more by Tel: 01865 794 198. write to: South Oxford Community Centre, Lake Street, Oxford, OX1 4RD. E-Mail: keen@herald.ox.ac.uk Or visit their website @ www.keenoxford.org

Mencap local groups & Oxford Mencap

Mencap have 4 local societies in Oxfordshire. These are: Oxford & District Mencap, South West Oxfordshire Mencap (SWOM), South Oxfordshire Mencap and Witney & District Mencap. Details of all these groups and the local leisure clubs and activities they run can be found on the Mencap website @ www.mencap.org.uk by clicking on the local groups link.

Oxford Mencap

Oxford Mencap provides support and recreational activities for children and adults with learning difficulties in the **Oxford area.**

The 7 o'clock club

The 7 o'clock club is a youth/social club for adults with a learning disability. The club meets on Wednesday evenings between 7-9 pm at Bullingdon Community Centre Peatmoors, Headington Oxford. The ages of club members range from 14 to 79, the majority being in their twenties or thirties. About 60 members attend each week to play bridge, listen to music or just

socialise with their friends. They can also take part in extra activities, including trips to the theatre, walks, swimming etc. Transport is provided for Wednesday evenings and outings.

Hill End Holidays

Each year in the glorious Oxfordshire countryside Oxford Mencap organises three weeks summer holidays for people with learning disabilities.

For further information visit web: www.oxfordmencap.org

Or Tel: 01865 557 489

My Life My Choice

Is a Self-Advocacy group run by people with learning difficulties for people with learning difficulties. They run several groups around the county and send out regular newsletters telling everyone what they are doing.

To find out more visit their website @ http://www.mylifemychoice.org.uk

Or telephone: 01865 204214, or write to: My Life My Choice, the Jam Factory, 27 Park End Street, Oxford, OX1 1HU

Oxford City Casuals

Is a football club for young people with learning disabilities/difficulties. They currently have 80 members (aged from 16 years old) For further information Tel: 08500 338611

OXS RAD: The integrated sports centre

Aims to offer sports, recreational and leisure activities that are accessible to all. OXS RAD has over 800 members all of whom use the centre for various activities. By becoming a member you are entitled to use facilities at a small cost per activity.

Provides lots of activities - including swimming, trampolining, archery, a sensory room, art & singing and a fitness suite.

For further details please visit web: www.oxsrاد.org.uk

E-mail: info@oxsrاد.org

Or Tel: 01865 308383

Stingray Nightclub

The Stingray club nights are run by My Life My Choice and are specifically for people with learning disabilities. To find out more about when and where these club nights take place visit the My Life My Choice website @ www.mylifemychoice.org.uk Or e-mail: stingrayarts@yahoo.com

Soundabout

Soundabout is a charity working with people with profound and multiple learning disabilities and based at Thomley Barn near to Oxford. Their focus is using music as a tool for communication.

They run events on Saturdays for families with children aged up to 16 years old with complex disabilities; also for young people aged 16 to 25 years old with complex disabilities and their carers; and also for young people aged 16 to 25 years with autism. Soundabout also run a themed sensory festival with sessions for schools groups and adult groups once a term and these are during the week.

For further information Tel: 01844 338898 or visit web: www.soundabout.org.uk

Tips for Parents:

- **Check out your local sports/leisure centres – activities are available to everyone.**
- **Contact some of the supported living and day care providers (listed in this guide), they will have a good idea of what activities are out there for people with learning disabilities and it may be that even if you son or daughter isn't being supported by them, they could join in some of the activities.**

Parents can find it uncomfortable talking to their children about growing up, puberty and sex. This can be even more difficult when your child has learning disabilities or difficulties and is often a subject area that many parents of young people find difficult to think about. Some families are reluctant to see their children as sexual and there may also be greater fears about exploitation, abuse and pregnancy making some parents unwilling or unable to tackle the many issues surrounding sex and relationships. It is an important part of growing older, however, and we felt it was essential to include it in this guide. We have not included a huge amount of detail, but discuss some key issues to think about and useful resources for you to explore yourself.

Puberty

Young people with learning disabilities go through the same physical process as any other children. Although puberty may be early for some and delayed for others it is a biological and emotional process that will happen (even though some parents wish it wouldn't!)

All young people need to have an understanding of how their body will change and develop during puberty. Young people with learning disabilities need to be helped to understand that the feelings and desires they may experience are completely natural and normal. Not knowing and understanding these changes can be frightening and bewildering for them. Young people without learning disabilities often

discuss these issues with friends but our children may not have the same ability to communicate their feelings and/or the social networks that can facilitate this kind of "social norm". So, as difficult as this issue may be for parents it's important that it's not avoided. Avoiding the issue will not make your child's sexual development, feelings and desires go away but ignoring it may cause them confusion and fear.

Puberty usually starts between 9 and 13 years old for girls and 10 and 15 in boys, so it may be that by the time you are reading this guide your child or children may have already started the bodily changes that occur through puberty. However, you may not have begun to talk to them about sex and relationships and so we will address this in the next section of this chapter

Every young person is different and as a parent you will already have a good idea about their individual ability to understand and retain information. It will be up to you to pitch this information at the right level for your child. Your child's school teachers will also be able to help. Remember that although this may be the first time you've gone through this, teachers will have seen it all before and helped other young people and their families through this time. There are also a number of useful resources to help you talk to your child with learning disabilities about the changes that boys and girls go through as part of puberty, which include menstruation, personal care and personal hygiene

Talking together about growing up: a workbook for parents of children with learning disabilities by Lorna Scott and Lesley Kerr is available from the Family Planning Association.

Me and Us

Me-and-Us produces educational resources and provides training on Sex and Relationships Education (SRE) and Personal, Social and Health Education (PSHE) Although aimed at professional these resources may also be useful for parents. Training resources can be ordered from the website through the online store. www.me-and-us.com

Growing up Sex & Relationships

is a guide written by Contact a Family for families of children with physical disabilities or mild – moderate learning disabilities. There is also another guide for the young people themselves. Both can be downloaded free of charge from the Contact a Family website at www.cafamily.org.uk or by contacting the free parents helpline on 0808 8083555

The Family Planning Association (FPA)

Have a number of useful guides available to buy for young people with learning disabilities and their families.

• **Talking together about growing up:** Offers support to parents/carers of children with learning disabilities who are approaching or who are around the age of puberty. The easy-to-follow style is suitable for young people who may not be able to read.

• **Talking together about sex and relationships:** A practical resource for schools and parents working with young people with learning disabilities. Uses illustrated stories and activities for use in the classroom to explore a range of situations that young people with learning disabilities face as they grow up. Also has pages for parents/carers so that home and school can work in partnership.

• **Talking together about contraception:** This two-book pack supports young people with learning disabilities who wish to access contraception. *Book one* contains a guide on the methods of contraception available. *Book two* has been written for young people and has clear pictures, easy-to-read stories and picture posters.

• **All about us:** NEW CD-ROM aims to assist the personal development and knowledge of people with learning disabilities around sex, sexuality and relationships. The resource provides a self-study learning tool that can be used by someone with learning disabilities on their own, or with support, to introduce key issues. It will complement the delivery of sex and relationships education in the home, school, and other learning environments.

For further information visit web: www.fpa.org.uk

In Oxfordshire there have been several courses for parents run by Autism Family Support for all parents of young people. These are specifically for those on the autistic

spectrum but may be useful for other parents of young people with learning disabilities too. To find out more about these courses please contact Autism Family Support at Tel/Fax: 01844 338696 or e-mail: info@autism-fs.org.uk

Sex and relationships

“It’s important to recognise that young people with learning disabilities are sexual beings like everyone else and have the same rights and needs for good sex education and sexual health care and the same opportunities for sexual expression and socialising as their non-disabled peers. Parents play a key role in teaching their children about sex and relationships, helping them cope with the emotional and physical aspects of growing up and preparing them for the challenges and responsibilities that sexual maturity brings.

Disability often affects many different aspects of sexual development. For example, a lack of privacy and independence in daily living can mean that young disabled people can miss out on early sexual experiences such as kissing or flirting. Many other things stop disabled people achieving sexual and emotional fulfilment, including cultural prejudices, professional and parental attitudes, lack of social opportunities and the lack of appropriate services.”

[Through the Next Maze: Planning for life after school, AMAZE, Brighton 2008]

Although nationally there is a lack of appropriate services we are very lucky in Oxfordshire to have a multi-

organisation project called Mates n Dates that supports people with a learning disability to make friends and have relationships. They recognise that whilst people with a learning disability want to be the same as everyone else, including having their own friends and maybe a partner, they often find it difficult to find the opportunity to do this and may also need protection from exploitation and abuse (we talk more about what you can do to protect your child from abuse later in this chapter)

Research by local clinical psychologists has found that many adults with learning disabilities in Oxfordshire can feel lonely and can find it difficult to make meaningful friendships and relationships due to social barriers they face. Mates n’ Dates can support them to make new friends and start relationships, in the hope that they will be able to form their own group of friends, to spend time with.

Mates n’ Dates

This multi-organisation project is led by Guideposts Trust in partnership with other organisations – The Ridgeway Partnership, Mencap, Styleacre, Kingwood.

For further information contact: Nicola Oddy Mates and Dates Co-ordinator email: matesndates@guidepoststrust.org.uk

Tel: 01993 899987 or visit web: www.matesndates.org.uk

Guideposts Trust, Independent Living Centre, North Field Farm Lane, Witney, Oxon. OX38 1UD

Masturbation

Discovering your own body is a natural part of growing up but for parents of young people with learning disabilities it’s often a difficult subject to talk about, or deal with. Some things are just meant to be private but some young people with learning disabilities don’t understand the difference between public and private and let’s face it, it’s one thing knowing and accepting it’s natural and inevitable, but quite another actually witnessing them doing it!

Every child needs to be given the opportunity and privacy to explore their own bodies and it’s important to remember that masturbation is a natural expression of sexuality. Some children and young people masturbate because it helps them to feel warm, relaxed and because it feels good. It’s important therefore that they are helped and supported to understand that what they are doing is natural and not wrong, but also that it is only right on their own in a private place such as their bedroom or the bathroom. Again, it’s a good idea to talk to professionals who support your child, either at school or other settings who should be able to help you.

Protecting your child from abuse:

Disabled children and young people may be more vulnerable to abuse. Their need for sex education and an understanding of appropriate “touch” is essential because:

- They may rely on intimate care and assistance with using the toilet, getting dressed etc. This care may be provided by a number of different staff in a number of different settings

- They may have less understanding about “personal” and “private” parts of the body
- They may have less understanding about “personal” and “private” parts of the body due to frequent medical examinations where they need to undress or be undressed.
- They may have communication difficulties which affect their ability to speak about abuse or understand that they are being abused
- Children and young people with learning disabilities can often be “compliant” and are used to doing what they are told without questioning what they are being asked to do

“The best way to protect your child from abuse is to have an open and loving relationship with them based on honesty. You can reassure your child that there is nothing so awful or embarrassing that they couldn’t talk to you about it. Try to make sure that your child understands as much as they can about love and sex and the difference between wanting to touch and kiss someone and being made to do something that feels wrong or scary. Discuss with them openly (if they are able to understand) how they might handle a situation where they feel uncomfortable, rehearse and role-play – practice shouting “No” and calling for help. Be open about discussing who a child or young person might turn to if they are frightening or worried – you as their parents, a teacher, policeman, taxi or bus driver, a lifeguard, depending on where they are at the time”

[Through the Next Maze: Planning for life after school, AMAZE, Brighton, 2008]

The worry of abuse is never far from the minds of parents of children with learning disabilities but whereas it's important to recognise the risks it's equally important that you don't overestimate them and overprotect your child as a result. It's thankfully relatively rare for children to experience abuse or assault from strangers. However in saying this we know only too well that it does happen as recent scandals in residential care homes have shown.

For parents of children with severe learning disabilities who may also have communication difficulties it's important to be **vigilant**, understand and watch out for changes in behaviour or emotions. All settings that look after children and/or young people with disabilities should log any accidents that happen so make sure you get suitable explanations for any injuries of unexplained bruises etc. Also question any provider of services for your child about "open door" policies for parents. It's important that wherever your son or daughter is you can just "pop in" without announcing your visit (personally, we'd be suspicious of anywhere that didn't allow this!)

For further information about keeping your family member safe from abuse and where to get help if you have any concerns visit web: www.oxonsafeguardingadults.org.uk

"More people with learning disabilities should be able to commission their own services to live independently and have real choice about the way they live their lives."

[Valuing People Now: A new 3-year strategy for people with learning disabilities]

As you can see in the above quote Valuing People talks about people with learning disabilities "commissioning" their own services. At OxFSN we like to think of it more as "designing their own support and deciding how they want to live". Self directed support is a way to do this and is the new way social care is being made available to people who need support and assistance with daily living. It will soon be the only way that social care is provided to adults in Oxfordshire.

Self directed support is for adults aged 18 and over who need (and are eligible for) social care and support services. It is the process by which the individual has choice and control over the support they need to live their life as independently as possible. Some people can manage their support on their own. Others may need help - from family or friends or people who are paid to help.

If your child was eligible for social care services from children's services you may have been offered a Direct Payment (DP) instead of direct services from the local authority. Self directed support works on the same principle in that it gives the person their own money to buy in support in a more flexible way. This is known as an **"Individual or Personal budget"**

Once an assessment has taken place and the person's needs have been clearly identified and discussed with you, (and where appropriate the cared for person) you will need to make a support plan. This is a document that describes the support you/they think they need to meet their social care and support needs. Your son or daughter's care manager can give you a template support plan to help you get started, or you and/or the young person can make your own plan. Once the support plan is in place social care services will give you an indication of how much money will be available to pay for the identified care and support needs. This is done through something called a Resource Allocation System (RAS). The support plan must be agreed by the care manager and an assessment panel before any of the money can be released.

The role of the carer in self directed support remains crucial. As a carer, you might find yourself helping the person you care for design and plan their own support, because you know what their preferences are. However, there is help available to help you do this. In Oxfordshire there are a number of agencies that have set themselves up as Support Brokers. Put simply, this means that you can focus on the needs and wishes of the person you care for, while the support broker provides practical help identifying suitable ways of meeting needs and fulfilling wishes. Self directed support puts self-determination and dignity at the centre of all decisions made about someone's care arrangements. It also aims to develop better and more links with the person's local community.

Self directed support is new to Oxfordshire, and while in principle it seems like a good idea, it's still early days and we watch with interest to see how it develops and how it affects you as family carers and those you care for.

To find out more please visit the Taking Control Oxfordshire website @ www.takingcontroloxon.org.uk This contains all the information you need to get started, links to support brokers and contact details for adult social care. You could also talk to your child's social worker/ care manager if they have one. If they don't and you are currently not in touch with social services please contact the Access Team

Tel: 0845 050 7666
Fax: 01865 783111

Out of hours emergency number:
0800 833408 (freephone)

Email: Access@oxfordshire.gov.uk

Some Useful websites/contacts for further information:

Valuing People

This is the website for the Valuing People Support Team (more about Valuing people in the Legislation and Guidance chapter of this guide on page? www.valuingpeople.gov.uk

Contact by e-mail
valuing.people.info@doh.gsi.gov.uk

In Control

In Control is an organisation helping people get real choice and control. It is supporting some local authorities to deliver Self-Directed Support.

www.in-control.org.uk
email admin@in-control.org.uk
Telephone: In Control Support Line
0156 482 1650. Fax: 0156 482 4260

For Advice about Direct Payments visit the Direct Gov website @ www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10016128

Direct Payment Support Service

For local advice about Direct payments the Oxfordshire Direct Payment Support Service is a user led organisation funded by Oxfordshire County Council. They offer free independent and impartial advice to people who are interested in learning more about all aspects of Direct Payments as well as providing on going support and advice to Direct Payment users.

For further information visit: www.oxfordshire.gov.uk from the drop down menu on the left hand side click on Social and Health care, go to "learning disabilities", then "getting care services" the Direct Payments section is on this page.

A4e

Offers support to people who want to retain control of their own support through either a Direct Payment or an individual budget. The website also contains lots of information about Direct Payments.

For more information visit the A4e website @ <http://dpssc.a4e.co.uk/default.aspx>

Tips for parents:

- **Think "person centred" – what do they want? How do they want to live? What would be a good life for them?**
- **Talk to other parents who have been through this process – OxFSN will be able to help with this**
- **Individual budgets are meant to provide people with learning disabilities and their families with flexibility – think "outside the box", don't stick with traditional ideas. Start with a vision, what is your/their goal? And then look at how you might get there!**
- **Get an idea of what services are available. Visit/contact lots of different care providers and day services. With an individual budget you are a customer after all! Your son or daughter is buying services – put you consumer head on! It's a good idea to do this before you put together the support plan so you have an idea of how much these services cost.**
- **The local authority has contracts with a number of Brokers who can help you through this process – details of these are available on the In Control Oxfordshire website.**

In the not so distant past parents of children with learning disabilities had very limited options of where their children lived when they became adults. People with learning disabilities had no choice in this either and the options were to either stay in the family home or move into institutional type care homes or long stay hospitals. Thankfully, things have now changed, and, whilst the majority of people with learning disabilities still live at home with their families, an increasing number are living in their own homes, with support.

Housing with support is often called Supported Living or Independent Living. What both of these terms mean is that a person has their own home and support is put in place to help them live independently. This could mean that they are supported for a few hours a week, everyday, overnight or 24 hours a day. The support should be carefully planned to meet their individual needs to enable them to live independently.

The principles behind Supported living are that a person is supported to live the way they want to.

- Housing and support is built around the person rather than fitting them into a service
- The person chooses who they want to live with (if anyone!)
- They choose where they live
- They choose who supports them and how they are supported

In supported living, people are supported to take control of their own lives and anyone regardless of their abilities can be supported to live in

their own home with the right support. However, it would be misleading to say that supported living is easily available to everyone. Most people with learning disabilities are completely dependent on the state to fund their support and as with everything else, funding is major issue and there are eligibility criteria to be considered for this kind of support. But, if this is something you would like to consider it's worth looking into it to see what the options there are for your son or daughter.

The following organisations currently provide supported living services in Oxfordshire (there may be others). They are commonly referred to as "care providers" and the support they provide can range from a few hours support a week to 24-hour support depending on assessed need. Some of these services also provide day services and these will be looked at in the next chapter of this guide

Advance Housing and Support

Advance provides support in core and cluster units of accommodation, either provided by Advance Housing or other landlords, throughout Central and Southern England. These are typically individual flats with some communal areas. The accent is on moving away from traditional Group Home practices towards lifetime homes which incorporate greater individual choice of individually tailored flexible support packages.

For further information
Tel: 01993 700331 or
visit web: www.advanceuk.org

Dimensions

Supports people with learning difficulties and/or autism throughout West Berkshire, Reading & South Oxfordshire. For further information visit web: www.dimensions-uk.org/
Write: 9 - 10 Commerce Park, Brunel Road, Theale RG7 4AB
or Tel: 0118 929 7900

HFT

Runs services in North & South Oxfordshire

In North Oxfordshire HFT currently supports people who rent or part own their own homes in the area. Types of support vary depending on the needs of the individuals and range from help with personal care and daily tasks to getting and keeping a job.

In South Oxfordshire at Milton Heights, near Dicot, and Abingdon.

There are seven houses and four flats at Milton Heights. These provide

accommodation for groups of between three and nine people. They also support people to live in their own homes in the community and currently these are in Abingdon

For Further Information about HFT visit web: www.hft.org.uk

HFT North Oxfordshire

Unit 1, Lower Ground Floor Office, Borough House, Marlborough Road, Banbury, Oxfordshire, OX16 5TH.
Tel: 01295 267906
E-mail: hftnorthoxon@hft.org.uk

HFT South Oxfordshire & Berkshire

Potash Lane, Milton Heights, Abingdon, Oxfordshire, OX14 4DR.
Tel: 01235 831686. E-mail: hftsouthoxonandberks@hft.org.uk

Mencap Personal Support

Provide a number of services in Oxfordshire, including supporting people (over 18, with a learning disability) to live in their own homes with support. For further information contact Simon Evans
Email: simon.evans@mencap.org.uk
Tel: 07943 844544

Mencap

1st Floor, 213 Barns Road, Oxford, Oxon. OX4 3UT
Tel: 01865 770994

Oxfordshire Social & Community Services

For information about the services provided by Oxfordshire Community services visit web: www.oxfordshire.gov.uk or telephone Cathy Brown on 07711 117398

Real Life Options

Real Life Options is a specialist service provider, providing support for people with learning disabilities and high support needs. They offer a range of specialist services and a variety of service models, that can offer flexible support, choice and freedom to find a constructive way forward. For further information Tel: 01865 309662 - Or visit web: www.reallifeoptions.org

Ridgeway Partnership

(formally, Oxfordshire Learning Disability NHS Trust)

Is a specialist organisation providing a range of health care and social support services for people who have a learning disability and for their families/ carers. Most of the people

who use their services are adults who have moderate to severe learning disabilities. They also support adults with milder disabilities, along with a small specialist service for children.

For further information visit web: www.oldt.nhs.uk
 Write: Ridgeway Partnership (OLDT), Slade House, Horspath Driftway Headington, Oxford, OX3 7JH
 Tel: 01865 747455 or
 E-Mail: enquiries@ridgeway.nhs.uk

Style Acre

Is based in South Oxfordshire, and supports people with a wide range of learning disabilities, including autistic spectrum disorders, mental health problems and physical or sensory needs. Style Acre support people to live in their own homes, with friends or with family. Services are designed around the needs and wishes of the individual and range from a few hours of support per week to 24-hour support. For further information visit web: www.styleacre.org.uk
 Write: Evenlode House, Howbery Park, Crowmarsh Gifford, Wallingford, Oxon OX10 8BA.
 Telephone no: 01491 838760.
 E: mail: info@styleacre.org.uk

The Kingwood Trust

The Kingwood Trust provides supported living, runs registered group homes and provides outreach support in family homes. Provides services specifically for people with Autism.
 For further information visit web: www.kingwood.org.uk
 Write: 2 Chalfont Court, Chalfont Close, Lower Earley, Reading, Berks RG6 5SY.
 Tel: 0118 931 0143

United Response

United Response is a charity working across England and in Wales supporting people with learning disabilities, mental health needs or physical disabilities. The services they provide depend on each person they work with. They can provide 24-hour support for people with complex needs.

For further information visit web: www.unitedresponse.org.uk
 Write: United Response, 113-123 Upper Richmond Road, London SW15 2TL
 Tel: 0208 246 5200

Voyage

Voyage provide a range of care and support solutions for people with a variety of specialist needs. These currently include Learning Disability, Autistic Spectrum Disorders, Physical Disabilities, Acquired Brain Injuries, Neurological Impairments and Mental Health.

For further information visit web: <http://www.voyagecare.com>

From our own experience and from what parents have told us through our transition workshops, some of the best ways of informing people about supported living is to give them real life examples and so in the next section we look at two positive parent stories, explaining how they have gone about organising supported living for their children in Oxfordshire.

Gemma & Katy's Story



This is a story about my daughter, Gemma and her friend, Katy. They are now both 30 and 29 respectively and have profound and complex learning difficulties. Neither Gemma nor Katy has any spoken language and Gemma uses a wheelchair. Katy is fed through a tube in her tummy and was very underweight.

Katy's mother, Wendy, and I have been friends since Gemma and Katy started special school in the 1980s when we both did the obligatory stint on the school PTA as you do! Over recent years those who understood the problems we faced constantly encouraged us 'to look to the future' particularly in terms of residential care. Rather reluctantly and with great trepidation, when Gemma and Katy were about 17, we began to investigate various residential options and it was then we realised what little was on offer, how far away they were and how totally unlike their own homes they felt. Fortunately this is not a universal experience and I accept that everybody has different wishes and aspirations, but for us it was an extremely depressing time.

It was at this point that we decided to write **our** vision for our daughters' future happiness. We wanted Gemma and Katy to live together in their own home locally with 24-hour support and we thought they would want this too. This vision formed the basis of a

comprehensive 'booklet' (it would now be a person centred plan!) detailing exactly the level of support they needed and how we wished it to be provided and this we presented to our local Social Services Department. Then we waited..... surprisingly our ideas were well received.

We had two main objectives: 1) to find a suitable home and arrange for its purchase and 2) to obtain the funding for 24 hour support hopefully using direct payments. (Direct Payments is discussed elsewhere in this guide) Gemma and Katy also get money from the Independent Living Fund (ILF) because of their significant health needs. They themselves also have to contribute from their benefits.

We were soon introduced to a specialist local Housing Association (Advance Housing) who suggested a Do It Yourself Shared Ownership (DIYSO) scheme This was a part rent/part buy arrangement - the mortgage interest paid by Income Support and the rent by Housing Benefit. Our first obstacle was Housing Corporation rules and to meet these it was suggested that each girl bought her own small house. So.....we were looking for two, small, adjoining, semi-detached bungalows for sale together, which seemed like looking for a needle in a haystack - or rather two needles! But someone must have been smiling on Gemma and Katy because, within weeks, we heard of another housing association who was about to build several semi-detached bungalows with level access, wide doors and in a perfect location. An agreement was negotiated between us and the two housing associations so that this scheme could be offered to Gemma and Katy.

Over the next few months we redesigned the inside of the property and even managed to persuade the Court of Protection to provide us with the authority to help Gemma and Katy have their own mortgages. Then, devastatingly, the local council refused Gemma and Katy permission to purchase. This was a huge blow but after several more uncertain months spent lobbying county councilors and seeking support from our MP and many others, Gemma and Katy were finally allowed to **rent**, but **not buy**, the properties. So the first objective had been accomplished, if not quite in the way we had planned.

We then considered the support and at first we wondered if we should employ staff directly. This route was fraught with difficulties as we felt we would be faced with more work and responsibility forever! Social Services had already refused Gemma and Katy Direct Payments so, as an alternative, it was agreed that we would set up a legal Trust to enable money to be deposited for their support - now we were getting somewhere!

The next task was to send out a support specification. We short-listed, interviewed and appointed a service provider, having negotiated and agreed the maximum annual cost with the Local Authority. Whilst the staff team would be employed by the service provider, Wendy and I were clear that recruitment, like most decisions, should be the result of partnership between us all. Thus the staff team was recruited and all was proceeding smoothly until one week before the support was to start, Social Services declared our Trust to

be illegal! We refused to agree to their alternative suggestion that they pay our service provider direct. We knew that, if this were the case, we would lose all influence in the style of support. We asked them to reconsider direct payments. As you can imagine, what followed was a very difficult time of tense negotiation. This way of living was innovative and exciting – surely it could not founder at this late stage. After a month spent collecting reports from various people about Gemma and Katy's abilities to make choices, Social Services finally agreed that they **did** meet the criteria for direct payments and eventually, 2½ years after the original 'vision', they moved in.

We parents, along with several other committed people, act as circles of support for Gemma and Katy. This ensures that their wishes remain central to any decisions made and that the direct payments are used to best advantage on their behalf.

Ten (can it really be ten?) years on Gemma and Katy are very much enjoying their independence and this is just of flavour of some of the things they do. Having had their maximum time at college (there is a real lack of choice and provision for ongoing learning for people who have complex learning difficulties) they now plan activities from their home. They go swimming, sailing, trampolining, to the theatre and have holidays and parties to name but a few. The team we employed together is superb and truly person-centred and Gemma and Katy's lives have continued to grow as the team has got to know them really well.

We have called their home "Two Hoots" and they now have 8 superb

staff, including a team leader, who together form a very cohesive team. I still do shifts very occasionally when needed, and have found this not only enjoyable but also a chance to work alongside the team. Of course they still visit their family homes from time to time, which allows us to make the best and most flexible use of their finances. It is also easy for us to resolve problems quickly rather than waiting for a care manager to find time to intervene.

You might be tempted to ask 'what is the difference and what are the benefits of doing it as we did? The answer would be simple: its about shifting control and giving the choice to the individual. Gemma and Katy, through the families and the circles of support, have the power to say how they would like to live and to change things if they are not working. They are customers, not just service users. I can't say it has been easy – nothing good was ever easy but the outcome is so positive I wouldn't consider doing it any other way.

In conclusion helping Gemma and Katy to live independently was the best thing we could have done and we have no regrets. The total seesaw of emotions and problems we encountered over the years has been very draining but it has all been worthwhile. I continue to be very closely involved and it is wonderful to be able to visit my daughter whenever I want and feel completely at ease and welcome. I am absolutely confident that our daughters are having the best life that they could possibly lead surrounded by people who care about them as individuals – and with the sort of partnership we all enjoy, I feel sure it can only get better.

I glibly said we have no regrets but sadly there is just one. Katy's mum, my dearest friend, tragically died in 2002. When she was ill the only person she wasn't worried about was her daughter. Katy had her life and her circle of support which includes me. Nothing needed to change for her – how different it would have been had we not planned this move. How sad would it have been for Katy to lose not only her mum but probably her home too.

When I first wrote this story several years ago, Direct Payments were new and now we are slowly moving on towards Self Directed Services and Individual Budgets. Hopefully, this will be a real step forward and will make what we did more achievable for other families. Of course there will be lots of learning (and probably hurdles) along the way but I believe it will still be a better way of designing services for people. It should be fairer, more flexible, quicker and easier – but of course only time will tell.

Jan Roast (2009)

Jan's Tips for parents

- **Whose vision?** - If we were designing the vision now we would make sure it was truly our daughters' 'vision' not ours. We would write a person centred plan right at the outset. Luckily we believe it was their vision too and time has endorsed that view.
- **Person Centred Planning** - Being person centred is really important. Person Centred thinking was vital when we learned that we could only rent the property – we came to the view that it was of no consequence to our daughters whether they bought or rented and this helped overcome our huge disappointment at the decision.

- **Partnership** - Working in partnership is key. Real partnership between us and the care provider and also between the two families has proved a crucial factor in the success of this style of working.
- **Resolve and persistence** - Never give up – there is always a way if you stay strong and focussed. 'No' mustn't mean no – it just means lets find another way.
- **Value the Team** - Be sure to value the people who support our loved ones. I believe if I truly value them there is a good chance that they will value and help our daughters to become citizens in their local community.
- **Circle of Support** - A circle of support which often includes their supporters is really beneficial when trying to make sure that their lives continue to reflect their wishes. Decisions made jointly usually turn out to be good decisions.
- **Keep the vision alive** - Remember to keep the vision alive – its never done, just work in progress and reflection, it could soon stagnate and become no different to more conventional homes in the past. However, this is something I do willingly as, I feel sure, would most parents. Getting the right amount of money will always be a challenge but that's the same for everyone. Of course, it is never enough to design a set up such as this and then expect it to run like clockwork.

Guy's Story



As parents of a child with severe learning disabilities we had always had it in our plans that Guy would live independently from us when he was older.

From when he was around 13 years old we started to think about what we envisaged his life looking like when he became an adult, but of course at that time we had little idea of what opportunities would be available to him and whether any of this would be possible. We were also, at that time, thinking along traditional ideas. I.e. fitting him into existing services, like residential care, rather than looking at how services could fit to his needs.

At 16, after a battle for his post 16 education we secured him a place at MacIntyre school, a residential special school based at Wingrave, Buckinghamshire. We hadn't wanted him to live away from home this early but none of the local colleges could meet his needs. Oxfordshire was in the very early stages of developing post 16 provision in special schools at this time and none of that could meet his needs either. Once there, we informed his social worker that we didn't expect him to come home and live with us after he finished his 3 year course, in fact the words I used were "You do realise he's not coming home at 19 don't you?" this may sound harsh, but we knew that for Guy coming home, after getting used to living away from us would be completely detrimental to him. This then also gave us three years to plan what we wanted his future life to look like. We had our vision at this time, but no idea how to go about it!

We were really fortunate that MacIntyre school have a project called "**My Way**" This is a project that supports the young people and their families to have a successful transition from the school to supported living. The My Way Co-ordinator has been really hands on and helped us all through the process of finding local providers, developing his person centred plan and identifying people Guy could live with. As well as all the transition arrangements for his leaving school

Guy already lived with a lovely young lady called Olivia at MacIntyre. Olivia and Guy had been friends since they were 3, and used to spend respite weekends together at Hernes House in Oxford. Olivia's parents and ourselves had often talked when they were younger about them living together as adults. They get on so well and were due to leave the school at the same time and so it seemed logical that they would move on together. Being completely person centred about this, we were convinced that if Guy could tell us, then Olivia would be the person he'd most like to live with. Everyone else who knew him agreed. The next step would be identifying others. Guy and Olivia both like a busy household and we felt that 3 or 4 young people would be a better option for them and also more cost effective for the Local Authority.

Ellie was another lovely young lady whom Guy had known since he started the nursery at John Watson school, they had been in the same class all the way through their primary and secondary education. Ellie's parents were also looking for supported living options and so again, it seemed logical that we as

their parents worked together. MacIntyre's My Way Co-ordinator also, at this time, organised an event to bring together a number of different providers of supported living and young people and their parents who were all looking into this possibility. This provided us with the opportunity to talk to the different providers and see if any of the other young people would be good matches. Between us we visited different care providers to get a feeling of what was out there and kept in touch with what we had discovered. We had already decided to go down the individual budget route as we knew this was soon going to be only way to do things and there didn't seem any point going any other way. We also liked the idea of retaining some control over where our children lived and still playing a major role in their lives.

While all this was going on a local housing provider who works closely with one of the care providers we had been considering, found a fantastic property in Didcot, that was part renovated. It was a large house and would be ideal - but only cost effective for them if 4 people lived together. The Chief Executive of the care provider organisation contacted us and asked what we thought. They told us they could only go ahead and purchase the property once we all agreed that Guy, Olivia and Ellie would live there and on the proviso that we found a fourth person. It seemed too good a opportunity to miss, so we agreed, as long as we had a say in who that 4th person would be and that we wouldn't be rushed into making that decision. Guy, Olivia and Ellie are all vulnerable young people and so we were keen to ensure that the mix would work.

The My Way co-ordinator worked with the learning disability team care manager to seek out other young people who were looking for supported living and arranged for us to meet with them. We did this at Thomely Activity centre. As this was not immediately successful we went back to the care manager and suggested looking for someone older. Age wasn't really an issue and we felt it more important to get the right person.

Enter Nicky – Nicky is 36 and has been living at home with her parents throughout her life. She was already being supported by the same organisation. Although older and more able than the other three, Nicky seemed a perfect match... and Nicky and her parents were all keen to join our little group - so now we had our 4 housemates.

At time of writing, Nicky has just moved into their home in Didcot. Ellie will join her in a couple of weeks and Guy and Olivia soon afterwards. It's been a long drawn out process and we've had a massive amount of support from the care provider, My Way and the learning disability team's care manager. We have been involved every step of the way from the very beginning. We were all, including the young people themselves, involved in short-listing prospective staff and two of the parents were on the interview panels. We've had a say in everything including the colour schemes on their walls, carpets and flooring. We meet regularly, once a month and keep in touch with progress via e-mail. The Care provider has been brilliant in negotiating funding with social care, working with us to determine how

much support they need and how their days will look. They are arranging everything in minute detail in a completely person centred way. They have also helped us with all the forms to fill in such as housing benefit, ILF and others.

I'm keen to stress here that Guy will not be living in a "group home" a "care home" or "in residential care". He's moving into his own home as a tenant - with support that he is purchasing with his own personal budget. He's sharing a house with three people whom he's chosen (in his own way) to live with.

The way we approached this was first with a vision of what we wanted Guy's life to look like and then identified the steps we'd need to take to get there. We found like-minded parents who were at the same stage, who shared our vision and who pooled ideas. This allowed us to work together, learn from each other and share the journey. We've had to make a few compromises along the way, but then that's what life is like for all of us.

I've always wanted the same for Guy as I wanted for his sisters, that is, to be happy, healthy, have friends and to live independently in their own homes with people they want to live with and this has never seemed an unreasonable aspiration to me. Although it's early days and there's bound to be some teething problems, I'm confident that we are finally achieving our goal. We are also aware that things will change over time, needs will inevitably change and that this is an evolving and continuous process. This is not the end of Guy's story...it's just the beginning!

Gail Hanrahan (2009)

Housing

The big difference between traditional "residential care" and supported living is that in supported living housing and support are deliberately funded separately. This means that the person has greater control over their housing and support and they can change their support without losing their home. Finding housing in Oxfordshire can be tricky and so below we have listed some organisations who can help with this and provide you with further advice.

Advance Housing

Advance Housing looks after new houses, housing repairs, maintenance and shared ownership. They are a landlord to 1,800 people and are one of the country's leading providers of accommodation services for people with learning disabilities or mental health problems

For more information visit web: www.advanceuk.org
Tel: 01993 709221
E-mail: housing@advanceuk.org

Bromford Support

Bromford is a leading provider of affordable and supported housing throughout most of central England.

For further information
Tel: 01902 378653 or visit web:
www.bromfordgroup.co.uk

Catalyst Communities Housing Association

Provide more than 11,000 affordable homes in outer-west London and the Thames Valley, including homes for rent, shared ownership homes, sheltered schemes and supported housing. For further information
Tel: 01865 712244 or visit web:
www.chg.org.uk/catalystcommunities

Charter Community Housing

Charter Community Housing (CCH) provides homes for people in housing need on low incomes. For further information Tel: 0845 009 2500 or visit web: www.cchousing.co.uk

Cottsway

Is a registered social landlord operating in West Oxfordshire. For further information
Tel: 0800 8766 366 or visit web:
<http://cottsway.co.uk>

Golden Lane Housing

For further information Tel: 0845 604 0046 or visit web: www.mencap.org.uk/page.asp?id=10641

Hold Ltd

HOLD was formed in 1990 to provide opportunities for people with learning disabilities leaving long stay hospital. They have been providing a variety of services to disabled people in Oxfordshire since 1990.

For further information Tel: 01865 308888 or visit web: www.hold.org.uk

Housing Options

Housing Options is an independent advice and information service for people with learning disabilities. The aim is to assist people with learning disabilities achieve greater control over aspects of their life and to provide more housing and support choices - more options for individuals, parents, social services, care agencies. Housing Options exists to help people obtain the best option for their circumstances and this includes independent supported living and home ownership for people with learning disabilities. It does this by providing practical help, advice and information. It can be a gateway to accessing different types of social housing.

Housing Options is a national advice service (based in Witney) and can provide advice on rented housing and home ownership options. It also offers a consultancy service to individuals, parents and any organisation involved in providing a service to people with learning disabilities.

For further information visit web: www.housingoptions.org.uk
Tel: 0845 456 1497 E-Mail: enquiries@housingoptions.org.uk

Oxford Citizens Housing Association (OCHA)

Oxford Citizens was established in 1866 to provide affordable housing for people living in Oxford and its suburbs. Today they describe themselves as "a diverse and progressive organisation, providing high quality homes and services to over 3,000 households in six local authority areas". These include general rented, supported and sheltered homes, as well as shared ownership properties for people taking their first step on the property ladder.

For further information tel:01865 773000 or visit web: www.ocha.org.uk

SOHA Housing

SOHA is a not for profit housing association which provides homes for people who prefer to rent, or cannot afford to own or rent a home in the private sector. For further information Tel: 01235 515900 or visit web: www.soha.co.uk

The Vale Housing Association

Housing association based in the Vale of White Horse. For further information Tel: 01235 536001 or visit web: www.vale-housing.co.uk

Tips for Parents:

- **Talk to other families of people with learning disabilities who are supported to live in their own homes. The parents who have shared their stories in this guide have indicated that they would be happy to share what they have learned with others.**
- **Start with your vision of what you want to achieve and then work out the steps you'll need to take to get there.**
- **Visit lots of different care providers and ask lots of questions about how the support is provided and how much help they offer you. Most providers will let you arrange visits to the homes of some of the people they support (with their permission of course) this can give you a better idea of how this is actually working for individuals. Ask if it's possible to meet their parents or carers too.**
- **Housing is a real problem in Oxfordshire and very expensive. Although you can put your son or daughter's name down on the local council's housing list at 16 this doesn't mean that the local authority will agree to fund their support. It's therefore important that you discuss this with your son or daughter's Care Manager.**
- **If this is an option you are considering then talk to the Care Manager to find out if there are other families in the same position. Working together with other families can be really helpful, (as demonstrated in the real life stories in this guide).**

Whether your son or daughter is still living at home with you or has moved into their own home, one of things that parents often worry about is "what will they be doing when they no longer have school or college to fill their day?"

The opportunity to continue to learn new skills and retain the skills they have developed is crucial for people with learning disabilities. Like most people, they too want to be occupied during the day, retain friendships and make new ones, try new things and continue to do the things they like.

In this section we will look at some of the daytime opportunities provided by different services in Oxfordshire. In recent years day services have moved away from the idea that people with learning disabilities *just* go to a "day centre" to include more community based activities. Although services are based at centres around the county many have become more individualised and person centred in their approach to providing support for people to live their own lives and helping them to do the things they want to do.

They can help with...

- Information and advice
- Making plans
- Meeting friends and new people
- Getting a job (voluntary or paid)
- Staying healthy
- Learning new skills and trying new things

Oxfordshire County Council has day service providers based at 14 different day centres around the county. As noted in the last chapter some of the care providers also provide day services too. We recommend that you look around your local area and see what opportunities are available to best meet the needs of your son or daughter.

Didcot

139 Kynaston Road
Didcot OX11 8HB
Tel: 01235 813343
Fax: 01235 813343

Wallingford Day Services

High Street
Wallingford OX10 0DB
Tel: 01491 837139

Market Place Day Service

20-21 Market Place
Abingdon OX14 3HA
Tel: 01235 537743

Charlton Day Services

Charlton Village Road
Wantage OX12 7HG
Tel: 01235 769261

Oxford Day Services, (City)

Albion House, Albion Place
Oxford OX1 1QX
Tel: 07920 084512
Tel: 01865 241311

Cowley

Unit 7 Bobby Fryers Close
Cowley, Oxford OX4 6ZN

Kidlington

Ron Groves House, Oxford Road
Kidlington OX5 2BP
Tel: 07920 084511
Tel: 01865 377662

Henley

Old Trinity School, Greys Hill
Henley RG9 1SJ
Tel: 01491 576026
Fax: 01491 576026

Charlton Day Services

Charlton Village Road
Wantage OX12 7HG
Tel: 01235 769261

Oxford Day Services (Headington)

All Saints Church Hall
New High Street, Headington
Oxford OX3 7AI
Tel: 07920 084512
Tel: 01865 761666

St Johns Day Service

St Johns Church, Dupuis Centre
25 South Bar, Banbury OX16 9AE
Tel: 01295 272621
Fax: 01295 278560

Greenwood Day Service

Greenwood Resource Centre
Off Warwick Road
Banbury OX16 7BA
Tel: 01295 272306
Fax: 01295 272306

West Oxford

Moorland Centre, Dark Lane
Witney OX28 5LE
Tel: 07920 084511
Tel: 01993 703661

The Garth Day Service

The Garth, Launton Road
Bicester OX25 6JB
Tel: 01869 323471

Redlands Day Service

Neithrop Avenue
Banbury OX16 2NT
Tel: 07826 950506
Tel: 01295 272306

Advance Housing & Support Ltd

Provides a number of day-time opportunities for people with learning disabilities.

For further information
Tel: 01993 700331
email: support@advanceuk.org
or visit web: www.advanceuk.org

Dimensions

Supports people with learning difficulties and/or autism throughout West Berkshire, Reading & South Oxfordshire.

For further information visit web:
www.dimensions-uk.org/
Write: 9-10 Commerce Park
Brunel Road, Theale RG7 4AB
or Tel: 0118 929 7900

HFT

Provide a range of daytime opportunities and activities. The Day Resource Centre at Milton Heights offers activities such as: computers, cooking, photography and pottery. People are also supported in a range of activities including: hiking, drama, swimming, therapeutic dance and the gym. A number of people also attend courses at the local college. The daytime opportunities service has been re-designed to enable people to work in smaller groups and exercise individual choice.

To find out more visit web:
http://www.hft.org.uk/p/78/81/HFT_Central_region.html

Or Tel: 01235 831686

Or E-Mail:
hftsouthoxonandberks@hft.org.uk

Macintyre

Provides a number of different services, flexible to the needs of young people who have severe learning disabilities – in particularly Autistic Spectrum Disorders.

For further information
Tel: 01908 230100
or visit web:
www.macintyrecharity.org

Ridgeway Partnership

(formally Oxfordshire Learning Disability NHS Trust (OLDT))

Provide a number of services for people with learning disabilities including short breaks (respite care). One of their services is called VISION and offers day-time, evening and weekend support to help people enjoy a variety of activities in the community, including leisure, volunteering and work. VISION mostly works with people who live at home with their families.

To find out more visit web:
www.oldt.nhs.uk
or Tel: 01865 747455

Style-Acre

Run services at Turnstyle based at Crowmarsh Gifford, nr Wallingford. They provide leisure, education and work-related activities. The majority of their courses and recreational activities are run in local community facilities including leisure and community centres. The following information is taken from their website

"This ensures that people have the opportunity to meet other people and to be informed about other services

and activities near to where they live. Support can be provided on a 1:1 basis or in small groups according to the individual needs and preferences of everyone we are here to help".

To find out more visit web:
www.styleacre.org.uk
or Tel: 01235 519875
or E-Mail: info@styleacre.org.uk

Tips for parents:

- **Talk to other parents who have sons or daughters that use day services**
- **Think! Day services not just day centres - better still think! Things to do during the day**
- **As with other support, think flexibly and person centred. Start with what the person likes doing and look at how this can be achieved. It may be that your young person wants to do something that is not currently available, but there may be others who want to do the same. Maybe you could get together, pool budgets and employ people directly to deliver it – just a thought!**
- **We have listed some of the care providers organisations and charities who we know provide day time opportunities but it's worth contacting others to find out what could be available and do your own research**
- **Think about transport, how will they get there? – ask the question**

"It didn't cross my mind that he might get a job, but now I'm starting to think it just might be possible" [Parent]

Many young people with learning disabilities or difficulties, just like other young people, would like to have meaningful employment.

As part of the transition planning process young people should be asked about their hopes for the future and this could include getting a job. The Connexions Personal Advisor should offer information and an action plan about ways of finding a job. College should also have prepared young people for employment in an area they are interested in. Young people should also have the opportunity to undertake some work experience in school.

We appreciate that for some young people work will not be possible, but if this is something that your son or daughter would like to do there are a number of organisations in Oxfordshire who may be able to help and advise you.

Abletypes

Provide a mailing, word processing and database handling service. The majority of the staff have a disability. For more information visit web: www.abletypes.co.uk or Tel: 01865 244114

HFT

Will soon be providing an opportunity for people with learning disabilities to undertake an NVQ in catering on their site at Milton Heights near Didcot

For Further information contact Emma Pithers @ emma.pithers@hft.org.uk or Tel: 01235 831686

Mencap Employment

Provide a supported employment service for people with learning disabilities in Oxfordshire, through a contract with Oxfordshire County Council. Contact the service manager on Tel: 01865 770994 or e-mail carole.coppin@mencap.org.uk

Nextstep

An adults careers service for people over 20, providing information and advice and guidance on learning and work. For more information visit web: www.nextstepsoutheast.org.uk

The Area Manager for Oxfordshire, Milton Keynes and Buckinghamshire is currently Teresa Smith who can be contacted at Teresa.smith@vtplc.com or Tel: 01908 023808

Oxfordshire Employment Service

An employment service for people with all disabilities and is part of Oxfordshire County Council. For further information visit web: www.oes-oxon.org.uk Tel: 01865 791606 or E-mail: Barry Parsons (Manager) @ Barry.parsons@oxfordshire.gov.uk

County Print Finishers, which is a supported business doing print finishing. The majority of the employees have a disability and it provides training as well as employment. To find out more visit web: www.countyprintfinishers.org.uk the telephone number is the same as above.

Pathway Workshop

Makes garden furniture etc. provides employment and training opportunities for people with disabilities at their workshop. To find out more visit web: www.pathway-workshop.co.uk or Tel: 01865 714111

Restore

Provides services, including employment for people with mental health issues. To find out more visit web: www.restore.org.uk or Tel: 01865 455821

Right Employment

Right Employment is a supported employment service for people who have a learning disability and who live in Oxfordshire.

They provide an individualised service to anyone with a learning disability over the age of 16 and support them through the whole process of finding employment, from initial information and advice to sustained employment.

They support people to find full time or part time work. Some people may only wish to work for a few hours a week, particularly if they have not worked before. Their staff work alongside people with learning disabilities within their place of work to help them learn their job, gradually withdrawing support as the person becomes more competent.

For further information visit web: www.rightemployment.org E-mail: rightemployment@tiscali.co.uk or Telephone: 01865 408347 or 01608 646668

Volunteering

Work doesn't always have to be paid work and lots of people whether they have learning disabilities or not, do voluntary work. This is a good way of gaining new skills and can also be a good preparation for paid employment.

Vox Inc –

VOX is part of the Millennium Volunteer Award scheme. They specialise in working with young volunteers 16-24 who either have a Learning Disability or who want to volunteer for people who have a Learning Disability.

VOX inc is also starting up a Budding scheme for young people with learning difficulties or disabilities. The aim is to match volunteers up with people who would like a buddy in order to make friends, participate in activities more readily and expand on their interests.

For further information visit web: www.voxinc.org.uk or Tel: 01865 403296

Tips for parents

- **Think about the benefits your young person receives and how paid work can impact on them – get specialist advice or ask the work providers for information and advice**
- **Look into volunteering opportunities too – ask your Connexions PA, care manager or care provider about this or contact VOX Inc (listed above) to find out more**

There have been a number of Government policies and guidance in recent years that say transition to adulthood should be easier for young people and their families. Transition should be person-centred and emphasise full quality of life and user participation.

The main message in all these policies is that people with learning disabilities should have the same opportunities as everyone else and the right to live their lives as everyone else does. In this section we have included some of the most relevant pieces of legislation and policy guidance for your information

Guidance

Valuing People: A new strategy for learning disability for the 21st century

Valuing People is the government's plan for making the lives of people with learning disabilities, their families and carers better. It was written in 2001, and it was the first White Paper for people with learning disabilities for 30 years. It covers England.

It is based on people having:

- their rights as citizens
- inclusion in local communities
- choice in daily life
- real chances to be independent

For further information visit the valuing people website www.valuingpeople.gov.uk

Valuing People Now: A new three year strategy for people with learning disabilities (2008)

The vision remains as set out in *Valuing People*³ in 2001: that all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens. Valuing people now goes further than Valuing people in that it also includes those who have historically been most isolated within our society, including those with complex needs and people from black and ethnic minorities with learning disabilities.

To find out more visit: www.dh.gov.uk

Aiming High for Disabled Children: Better support for families (2007)

Launched in May 2007, AHDC is the transformation programme for disabled children's services. It concentrates on 5 main areas...Short Breaks (formally know as respite care), childcare, transition support, palliative care, and parent participation, meaning that there is now a requirement to involve parents and carers in the development and delivery of services.

Following a review into disabled children's services it was found that more needed to be done to co-ordinate services for disabled young people in transition to adult life, and to ensure young people and families can access high quality information at

key points. To address this, the Aiming high for Disabled Children programme (AHDC) announced £19m over the CSR period (2008-2011) to develop a Transition Support Programme (TSP).

To find out more visit: www.everychildmatters.gov.uk/socialcare/ahdc/

And the Transition Support Team website at: www.transitionsupportprogramme.org.uk/

Improving the Life Chances for Disabled People (2005)

Has a section on transition which highlights 3 outcomes which will ensure that as young people enter adulthood they are able to participate and be included

The 3 outcomes are:

- Planning for transition on individual need
- Continuous service provision
- Access to a more transparent and appropriate menus of opportunities and choice

For further information visit web: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4101751

Removing Barriers to Achievement: The Government's strategy for SEN (2004)

Makes a commitment to work across Government to improve the quality of transition planning, setting national standards for health and social care through the children's National

Service Framework and to work with the Connexions Service and the Learning and Skills Council (LSC) to expand educational, training and work opportunities

Our health, our care, our say: A new direction for community services (2006)

Provides the Governments vision for improving and modernising community care services.

For further information and to download a copy visit web: www.dh.gov.uk

The SEN Code of Practice (November 2001)

Describes the responsibilities of the Connexions service and the role of social services and health. It also says that there should be one agreed document to cover a young persons transition into adulthood.

The Code sets out guidance on policies and procedures aimed at enabling pupils with special educational needs to reach their full potential, to be included fully in their school communities and make a successful transition to adulthood.

For further information visit web: <http://www.teachernet.gov.uk/wholeschool/sen/sencodeintro/>

Or you can order from the publication centre: telephone 0845 6022260 or email dcsf@prolog.uk.com, quoting the DCSF reference number. DCSF 581/2001

Putting People First: A shared vision and commitment to the transformation of adult social care (2008)

Guidance to local authorities, based on the values that older people, people with chronic conditions, disabled people and people with mental health

problems have the best possible quality of life and the equality of independent living is fundamental to a socially just society.

For more information and to download a copy visit web: www.dh.gov.uk

Useful Legislation:

The NHS & Community Care Act (1990)

The above Act came into force on 1st of April 1993 and provides the legal framework for entitlement of assessment of need for community care services and for decisions regarding provision of such services

The duty to assess is based on a very low threshold "If it appears...that a person may be in need". It is therefore not necessary for a request to be made for the need to be assessed.

A local authority cannot refuse to assess if it thinks a person is probably not in need of services, as such a decision can only follow the assessment itself

Where there is a request for an assessment the local authority MUST assess

The local authority may provide urgent services pending completion of any assessment. They must have good reasons not to provide urgent services when requested. If they fail to under sub-section 5, there decision may be challenged through the court by obtaining an injunction

Carers & Disabled Children Act (2000)

Under the Carers and Disabled Children Act 2000, carers aged 16 and over, who provide regular care for someone aged 18 or over have the right to an assessment of their needs as a carer.

If there is more than one carer providing regular care in your household, you are both entitled to an assessment.

Very occasionally, a 16 – or 17 year-old who cares for someone for a while may be entitled to an assessment

The Carers (equal opportunities) Act (2005)

The act came into force in April 2005 and ensures that carers are able to take up opportunities that people without caring responsibilities often take for granted

It builds on existing legislation and support for carers by

- Placing a duty on councils to ensure that all carers know they are entitled to an assessment of their needs
- Placing a duty on councils to consider a carers outside interests when carrying out an assessment.

- Promoting better joint working between councils and the health service to ensure support for carers is delivered in a coherent manner

The Disability Discrimination Act (1995)

The Disability Discrimination Act (DDA) came into law in 1995. It sets out a range of requirements which aim to prevent disabled people being treated less favourably because of their disability or reasons related to it.

A person is disabled under the DDA if:

"He or she has a physical or mental impairment that has a substantial and long-term effect on his or her ability to carry out normal day-to-day activities"

The DDA aims to end discrimination against disabled people. To do this it protects disabled people in:

- Employment
- Access to goods, facilities and services
- Management, buying or renting of property
- Education
- Access to public transport

Under the DDA it is unlawful to discriminate against disabled people during their employment or when they apply. Employers must also make reasonable adjustments where required, to make/ keep jobs accessible (for example, by supplying additional support)

The DDA also makes sure that businesses and organisations make **reasonable adjustments** to the way they provide their services and to their premises if physical barriers exist. It is also unlawful for these "service providers" to treat disabled people less favourably than other people because of their disability or a reason related to it.

Similar rules for schools, colleges and universities also make sure that they do not discriminate and make reasonable adjustments to their premises if these put disabled people at a substantial disadvantage. However, applicants must also be academically able to participate and achieve through the programme.

The Direct Gov. website for further information @ www.direct.gov.uk

The Children (Leaving Care) Act 2000

The main purpose of the Children (Leaving Care) Act 2000 is to improve the life chances of young people living in and leaving local authority care. Its main aims are: to delay young people's discharge from care until they are prepared and ready to leave; to improve the assessment, preparation and planning for leaving care; to provide better personal support for young people after leaving care; and to improve the financial arrangements for care leavers.

The aim of this guide is to provide you with some of the information you may need to help you through the transition process. It is not meant to be a stand-alone document and OxFSN has also set up a Transition Support Service providing a rolling programme of workshops in special schools. The aim of these workshops is to provide you with "bite size" chunks of information at each stage of the transition process. They will also provide you with the opportunity to meet other parents or family carers who are going through the same process and to learn together and from each other.

To find out when and where these workshops will take place please get in touch with us (*contact details below*) Your child does not have to attend any particular special school to attend the workshops there, as we want to be as flexible as possible for busy parents. If your child is at a "mainstream school" you are welcome attend workshops at a special school near you.

We have based this service on what family carers have told us they need and would value greatly your continued feedback on how we can improve what we are currently doing.

OxFSN -Transition Support Service

Provides information and independent advice, support and guidance on all issues relating to transition to adulthood for family carers of young people with learning disabilities.

To get in touch contact: **Gail Hanrahan** – Transition Support Service Co-ordinator at gail@oxfsn.co.uk
Or telephone: 07726 347395
To find out more about OxFSN visit our website @ www.oxfsn.co.uk

There are also a number of other sources of support and information and the following is a list of local and national organisations, groups and charities that may be able to offer help and advice.

Oxfordshire Learning Disability Partnership Board

Every local authority area has a Learning Disability Partnership Board. They were set up as a direct result of Valuing People to ensure that the objectives set out Valuing People are carried out locally. Oxfordshire's partnership board meets 6 times a year and is made up of professionals involved in services for people with learning disabilities, people with learning difficulties/disabilities themselves and family carers. Meetings are closed to the public but there are 5 places available for people who would like to go along and take part. If you wish to do this, then please get in touch (contact details below)

The Partnership Board has its own website called Easy Words. It contains lots of information about the work it does, including the minutes from meetings and a links page with over 200 links to other useful websites and organisations. There is also a monthly newsletter with events and activities happening in Oxfordshire.

Visit the website to find out more www.EasyWords.co.uk
Or Contact **Eddy McDowall** (Valuing People Manager) Tel: 07786 227972
E-mail: partnership.board@ridgeway.nhs.uk

Autism Family Support

Is a support service for people whose son/daughter or family member is on the autistic spectrum. They have a number of services and can:

- Offer you support if you have a family member who has just been diagnosed with an autistic spectrum disorder
- Give you information about autism and services in Oxfordshire & its borders
- Give you contact details of support groups
- Add your details to our database, so that you are kept informed of talks, training and developments in your area
- Show you resources which might be helpful Put you in contact with other parents

Other Services Offered

NAS Befriending Scheme- Trained volunteers who befriend a child or young person with autism or their family. This is a very popular scheme with befrienders linked to children and young people across Oxfordshire.

Youth Groups for young people with Asperger syndrome- semi-structured youth groups held in Oxford for people with Asperger syndrome, aged 10-21 years from across Oxfordshire

'Oxford Aspies' group- A monthly social group for people aged over 16 with Asperger syndrome.

Family Information Pack- free to parents who have just received a diagnosis for their son or daughter, individuals or families who are new to the area

Access to information programmes- for parent/carers of newly diagnosed sons/daughters

Database- to ensure that information about new developments, conferences reaches families and organisations

For further information
Tel: 01844 338696
E-Mail: info@autism-fs.org.uk
Or visit web @ www.autism-fs.org.uk

OCVA – Oxfordshire Community and Voluntary Action

OCVA is the main umbrella organisation for the voluntary and community sector in Oxfordshire. Their mission is to enable a diverse voluntary and community sector to flourish. They provide advice, information and training, act as advocates and representatives, and build partnerships.

Their website contains lists of all the local voluntary sector groups with links to other websites

For further information visit web: www.oxnet.org.uk

Or write: The Old Court House
Floyds Row, St Aldates
Oxford OX1 1SS
Tel: 01865 251946
Fax: 01865 204138

The Transition Information Network

Have a website for disabled young people in transition to adulthood, their families and people who work with them and is a source of information and good practice. Provides information through the website. A magazine "My Future Choices" and through an e-newsletter and seminars.

For further information please visit their website at:

Contact a Family

Is a national charity providing information, advice and support to families of disabled children, whatever their disability or health condition, from birth to 19. Their website is full of useful information, including free downloadable factsheets and podcasts. There is also a free parents helpline: **Tel: 0808 808 3555** to find out more visit web: www.cafamily.org

Total Communication

Oxfordshire Total Communication is a not-for-profit independent organisation that has evolved out of a need for information and resources about communicating with people with a learning disability in Oxfordshire. Promoting accessible communication and providing the tools necessary for support workers and others who live and work with people with a learning disability.

For further information visit web: www.oxtc.co.uk or telephone: **01865 228057**

Mencap – learning disability Helpline

The Learning Disability Helpline is an advice and information service for people with a learning disability, their families and carers.

4 Swan Courtyard
Coventry Road
Birmingham B26 1BU
Telephone: **0808 808 1111**
Email: help@mencap.org.uk
Typetalk: 18001 0808 808 1111

Mencap also have lots of useful guides on a variety of issues to find out more visit web: www.mencap.org

Progress

Progress magazine is a very useful transition guide, produced 3 times per year, for young people aged 13-25 who have special needs. It is available to view online. For further information visit web: www.progressmagazine.co.uk

Having your say & getting involved

As we stated in the introduction to this guide, there is still much to be done to improve the life chances of people with learning disabilities and their family carers. The following organisations enable parents and carers to have a say and get involved. Both these forums exist to promote the interests of carers and make sure their views are heard by voluntary, professional and statutory organisations with the aim of improving services.

Oxfordshire Carers Forum (All Carers)

Campaign to improve Carers' Quality of Life.

Arrange networking with all appropriate people and organisations.

Raise awareness of Carers' needs with public, professionals, statutory bodies and politicians.

Ensure that through consultation, services are developed to meet Carers' needs.

Raise funds to continue the Forum's work

Support Carers as their independent voice in Oxfordshire

For further information visit web: www.oxoncarersforum.org.uk or Tel: **01235 547180**

Oxfordshire Family Voices

(for parent carers of disabled children)

Aims to:

- Have a collective voice around issues that affect parents and carers of disabled children and young people
- Take issues forward to key policy makers
- To work in partnership with key policy makers
- To raise awareness of unmet needs
- To raise awareness of issues faced by disabled children and young people and their families in Oxfordshire
- Share experience, Knowledge and skills
- Give feedback on existing services
- To develop and maintain mutual respect between parents/carers and practitioners

For further information E-mail: oxfordshirefamilyvoices@googlemail.com

or telephone: **07906 389925**

& questions to ask: Checklist

- ✓ Talk to your child about what they would like to do when they leave school or, if you can't ask them, start thinking about what *you* think they would like to do
- ✓ Think about your child's strengths and the things they enjoy doing. Has your child got a school record of achievement? Can it help you to think about their strengths and the future?
- ✓ What have other young people from your child's school gone on to do?
- ✓ Are you thinking about residential college? Find out what's available and who will pay for this
- ✓ If your child would like to consider employment as an option then contact Connexions or find out about local supported employment schemes (and any other options)
- ✓ Get to know your local authority as early as possible, even if you don't currently receive a service from them. Introduce yourself to both children and adult social care teams and find out what services may be available
- ✓ If your child has specialist health needs then consider what continued help from health services they may need as they reach adulthood
- ✓ If your child would like to continue their education after school, visit local colleges to see what courses are available and what support your child will receive
- ✓ Contact the local authority about Direct Payments or individual budgets if you would like to consider using them
- ✓ What social and leisure opportunities does your son or daughter enjoy?
- ✓ What help will they need to be able to take part in these activities?
- ✓ Ask social services (or other agencies listed in this guide) for a review of any benefits you and your child may be getting. Some benefits are affected by college or employment
- ✓ Have you considered where your child will live when they leave school/college? Will they stay in the family home or will they move to more independent living?
- ✓ If your child will continue to remain at home would you wish to have short breaks? How many days would you need and how frequent would these be?
- ✓ Find out what other organisations (including voluntary organisations) are operating in your area and see what support they can offer.
- ✓ Find out what local daytime activities are available? What type of provision would suit your child?
- ✓ What about transport?
- ✓ Does your child need any specialist equipment? If so find out who will provide and maintain it?

"Formate alternative te ketij publikimi ofrohen me kerkese. Kjo perfshin dhe gjuhe te tjera, me shkronja te medhaja, shkronja per te verberit, kasete degjimi, disk kompjuteri ose email."

Albanian

आपनि यदि अनुरोध করেন তাহলে এই পুস্তিকাটি বিকল্প ছাঁদে, যেমন, অন্য কোনও ভাষায়, বড় হরফে, ব্রেইলে, অডিও-ক্যাসেটে, কমপিউটারের ডিস্কে বা ইমেলের মাধ্যমে পেতে পারেন।

Bengali

"本刊物備有其他的格式可供索取。這些包括有其他語言版，大字版，盲人用版，錄音帶版，電腦磁碟版或電子郵件版。"

Chinese

प्रार्थना करने पर यह प्रकाशन दूसरे रूपों में प्राप्त किया जा सकता है। जिस में सम्मिलित है, दूसरी भाषाओं में, बड़े छापे में, ब्रेअल, सुनने की टेप पर, कम्प्यूटर की डिस्क पर या ई-मेल द्वारा।

Hindi

"ਇਹ ਪੁਸਤਕ ਬੇਨਤੀ ਕਰਨ ਤੇ ਹੋਰ ਰੂਪਾਂ ਵਿਚ ਵੀ ਉਪਲਬਧ ਹੈ। ਜਿਵੇਂ ਕਿ ਹੋਰ ਭਾਸ਼ਾਵਾਂ ਵਿਚ, ਵੱਡੇ ਛਾਪੇ ਤੇ, ਬ੍ਰੇਲ ਵਿਚ, ਸੁਣਨ ਵਾਲੀ ਟੇਪ ਤੇ, ਕੰਪਿਊਟਰ ਡਿਸਕ ਜਾਂ ਈ ਮੇਲ ਤੇ।"

Punjabi

"اس اشاعت کو متبادل اشکال میں درخواست کرنے پر حاصل کیا جاسکتا ہے۔ اس میں دوسری زبانیں، بڑا پرنٹ، بریل (جسے اندھے چھو کر پڑھ سکیں)، آڈیو کیسٹ، کمپیوٹر ڈسک یا ای میل شامل ہیں۔"

Urdu

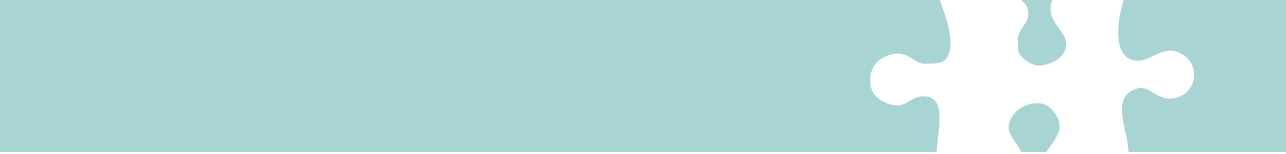
Alternative versions of this document are available on request. These include other languages, Braille, audio-cassette, computer disk or email.

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