



Moving into Adulthood & Getting a Life

Getting Started

About these guides

The '**Moving into Adulthood and Getting a Life**' guides are a series of guides, written *by* and *for* families of young people with learning disabilities. However, some of the information contained in them may also be helpful for families of other disabled young people or those who have additional or special educational needs.

Each guide covers the many issues that families have to think and know about during the stage when their child is preparing for adulthood. This stage is often referred to by services as 'Transition'.

- **Getting started:** Where to start. 10 top tips, 'Jargon buster'.
An introduction to person centred thinking, planning and approaches. The start of the preparing for adulthood stage. The Year 9 review. Person centred thinking tools.
- **Education Matters:** Further education - Staying on at school or going to college. Residential colleges. Adult education and lifelong learning
- **Money Matters:** Benefit changes at 16. Managing money. Court of Protection
- **Social Care Matters:** Personalisation and choice and control. Personal budgets. 'Just enough support'
- **Finding the Right Support:** What support are you looking for? Finding support providers. Checking out support providers. Employing your own staff. Keeping safe
- **Becoming an Adult:** The Mental Capacity Act. Supported decision making
- **Health Matters:** Staying healthy and safe. Health action plans. Personal Health Budgets
- **Social Life, Having Fun, Friends and relationships:** Social life and having fun. Staying safe online. Growing up – sex and relationships. Circles of Support.
- **Finding a Job:** Work experience. Volunteering. Supported Employment.
- **Finding a Somewhere to Live:** Independent living. Supported living.

All of the guides stem from the belief that all young people, whatever their ability are capable of achieving a good quality of life as an adult.

As parents we know that our children are all different. They are unique individuals with their own gifts, talents, difficulties and challenges. The 'one size fits all' approach has never worked for young people and families like ours and so throughout these guides we have included information about how you can tailor the support your child needs and wants to live a good life. This approach is called **person centred planning** and everything in this series of guides centres around person centred thinking, planning and approaches.

Contents

- **Introduction**
- **10 top tips**
- **Where to start**
- **Person centred thinking, planning and approaches**
- **The start of the preparing for adulthood stage**
- **The Year 9 Review**
- **Person centred thinking tools:** The tools to help you plan -what are they and how are they used?
- **Further reading, useful resources & websites**

Introduction

Leaving school and becoming an adult can be an exciting time for young people but for young people with special educational needs/learning disabilities and their families it can be a time of uncertainty and anxiety. 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. For those of us who have children with learning disabilities there are also many other things to think about, new services, new terminology and jargon and different rules, guidance and legislation.

One of our biggest anxieties, as parents during this stage, is the fear of the unknown. Not knowing what options are available, who can help, what should happen and when it should happen and what our roles are in the process? For many of us school has been a source of support and guidance for many years, but what happens when they leave school?

We also worry about what support will be available for our children when they become an adult and there is also a huge concern about what our rights are as parents. What will my rights be and what rights will they have? How can I ensure that he/she will lead a full and happy life?

“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 look for or where to start looking” [parent]

Information at this time is crucial and The Code of Practice for SEN and Disability (2014) sets out guidance on how the needs of children and young people with SEN or disability should be met. Information is gathered in one place. It includes the information, advice and sources of support that parents, children and young people will find useful. This is called the **Local Offer**. Every Local Authority now has a duty to provide this information.

The Local Offer for Oxfordshire is available [here](#) or by Visiting Oxfordshire County Council website at www.oxfordshire.gov.uk

The new system (*as of September 2014*) also introduces a single plan called the **Education, Health and Care plan** or EHC plan for short. The EHC plan replaces the Statement of Special Educational Needs and it covers the period from birth to 25 years for those children and young people with more complex needs. Some young people who currently have a statement will have their needs met by additional funding without recourse to the statutory process. For example where they have special educational needs but don’t need additional support from health or social care services. Further information about EHC plans is available on the Local Offer.

This also covers the period referred to by services as ‘Transition’ and *should* mean that planning for the future is easier and the information gathered in the plan transports more seamlessly into adult services.

Where to start

We think the best way to start thinking about your child's life as an adult is to start thinking about them in the same way you think about your other children (*if you have them*) or anyone else their age. This way you will be looking for an "ordinary" life, even if making that happen requires additional support from others.

When we've held our workshops on 'transition' one of the first exercises we did was to get parents to think about their 'hopes and dreams' and 'fears and nightmares'

Try jotting down what these might be now.

The reason for doing this is that acknowledging your fears and nightmares, recognising what you don't want for your child helps you to move closer to and focus on what you do want **"the dream!"** For most of us the "dream" is pretty simple, i.e. our child having friends, being happy and fulfilled, living independently from us, getting a job, (*the same things we want for ourselves and other children if we have them*)

Many people with learning disabilities live lives that are focussed on staying healthy and safe – obviously these are very important issues –but this can mean that the ordinary things in life get overlooked, or squeezed into a corner.

Practical barriers and the limiting ideas of society often get in the way of people and families having the same opportunities as everyone else and having the opportunity to discover the possibility of dreams of a different future. We all have dreams but some people say that dreaming is pointless, it leads to unrealistic expectations and disappointment. However dreams are not promises; they are glimpses into the imagination and an additional view of what is important to people. Dreams contain small seeds that can be built into practical and possible outcomes and daily activities for our children. As families we often hear that our expectations need to be managed but, as an organisation by and for families of children and adults with learning disabilities we think expectations need to be raised! Our children can and should have the same life chances and opportunities as everyone else.

The reality is that for us, as families we've often been forced to focus on what our children can't do (*like when filling in Disability Living Allowance forms*) and, whilst it's important to think about all the things our children will need support and help with we also need to start thinking about all the things they *can* do, things they like doing and the things they want to do, whatever their ability. Those of us who have gone through this stage (*and survived to tell the tale*) have found this quite refreshing!

We've started by giving you our 10 top tips. You will find the information the tips refer to in either this guide or one of the others in the series. We've tried to break the information down into 'bite size' chunks because we are well aware how overwhelming it can feel at this stage in your child's life. Even though you may feel that some of the guides don't relate to your child we do recommend that you work your way through them all at a pace that suits you.

10 Top Tips: For Preparing for Adulthood

1



Don't Panic – take small steps. The whole thing can be pretty overwhelming so look at the things you need to know now and 'park' the rest for later.

2



The best place to start is to learn about **person centred planning**. Even better do a course and learn to think and plan in a person centred way – we found this particularly useful for our kids as they don't use words to speak but it's equally useful for *everyone* else. It also helped us to see them as individuals in their own right and see things from their perspective and this really helped.

3



Think about what your son or daughter likes doing, what they'd like to do not where they will go i.e. **think about getting a life not a service**. It's hard to imagine when your child is at school that there is a life outside educational institutions and sometimes I think we are looking to swap one institution for another when what we should be looking for is an 'ordinary life'

4



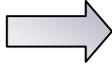
Know your children's rights (and yours) - It's a bit of a mantra of ours but knowledge really is power. It sometimes feel as though you need a Degree in social and health care to understand the complicated system of adult social care, but Community Care Lawyer, Luke Clements has written [ten top tips](#) to adult social care for carers, which is a pretty good place to start. Find out about the **Mental Capacity Act** and learn about what **benefits** they may be entitled to in their own right.

5



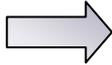
Do your research. Talk to lots of other parents and talk to lots of different provider organisations to get a feel for what they may be able to offer but go armed with what you and they would like. With a personal budget you need to think of yourself and your child as 'consumers' - the market place is growing so shop around. There is lots of information and useful websites out there to so look around for some positive stories to give you inspiration. Look outside the traditional services, be creative and don't be afraid to dream

6



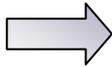
Be prepared to **'drive' the process yourself** if the school isn't. The process starts with schools but always keep the bigger picture in mind - remember you're planning for the whole of their life not just college.

7



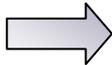
Don't rely on individual professionals to have all the answers – In our experience, whilst they may have the knowledge in their particular area of expertise they often don't have the required overview you'll need at this stage (very few people will). *Also, if they tell you something you think sounds wrong or unfair then check it out because it just might be.*

8



Don't scare yourself listening to other parent's bad experiences. This was their experience - it doesn't have to be yours. Stay positive and look for the positive stories to give you inspiration.

9



As families of children and young people with additional needs we often become so enconced in 'service land' we start to use the same jargon and 'service speak' as the professionals who work with us. **Think about the language you use – keep it real** – would you talk about your other kids or yourself this way? See [service speak: the language barrier](http://abitmissing.wordpress.com/2012/05/04/service-speak-the-language-barrier/)
<http://abitmissing.wordpress.com/2012/05/04/service-speak-the-language-barrier/>

10



The following advice was given to us by another parent... "when times get tough and you don't think you're getting anywhere you have to have **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 let's find another way".

Jargon Buster

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 Social and Health Care Services
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
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 and can be more than one person
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
Education, Health & Care Plan (EHCP)	A single plan, replacing the Statement of Special Educational Needs (SEN)
Health Action Plan (HAP)	Information about what is needed to keep a person healthy, includes a person's health needs and how they can be met. Should be part of a person centred 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 Support Coordinator	Every college has a learning support coordinator. They can explain more about college courses and discuss particular learning support needs

Local Offer	A new parent focussed access point for information about education, health and care services available for children and young people aged 0-25 with special educational needs
Looked after	Children or young people who are in the care of the local authority, whether by voluntary agreement or by court order
SENDIASS – Special Educational Needs & Disabilities Information Advice & Support Service (formally the Parent Partnership Service – but may well change its name again)	A statutory service responsible for providing information and advice to parents and carers of children with special educational needs (SEN) and disabilities
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 a 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.
Personal Health Budget	An amount of money to support a person’s identified health and wellbeing needs, planned and agreed between the person and their local NHS team
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 Support	Replaced school action & school action plus
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.
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	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

Person centred thinking, planning & approaches

You will hear these terms a lot throughout this series of guides. We can't emphasise enough how strongly we advise that you learn about person centred planning. New systems, processes and policies and guidance will come and go throughout our children's lives but the need to view our child as a unique individual remains and person centred planning enables us to do this.

"Throughout the whole transition process, it's the only thing that has ever made any sense" (Parent)

We've provided quite a lot of information here but there is a whole lot more on the web. Oxfordshire Family Support Network (OxFSN) will be running some courses too – so please join our database and we can send you information as and when these happen. info@oxfsn.org.uk

What is person centred planning?

This is a way of planning that works for **everyone** but is particularly helpful for children and adults with learning disabilities as it helps us to plan in a more meaningful and structured way with them. For people who have more severe or profound disabilities this approach is vital as it helps us to understand the detail in their lives and what makes them 'tick' as individuals. It brings together the people who know them best to work together to ensure they achieve the best outcomes.

The tools used help us identify what matters to the individual, what's important to and for them and how best to support them even if they can't communicate these things vocally. They also give us clear and simple methods of checking back and reflecting on what works and doesn't work, so we can retain the good stuff and lose the bad!

Most importantly for families this way of planning actively involves us. It draws on the in depth knowledge we have of our child and includes the perspectives of other family members, friends and people who know them best.

Not only does an understanding of person centred planning help to make sense of the new Education Health and Care plan (All about me section) as part of the SEND (Special Educational Needs and Disabilities) reforms. They are approaches for life.

"Person centred planning gave my son a voice. It helped us to see him as the unique individual he is and helped us lose the labels he'd been given throughout his childhood. It helped us plan for his future and working this way continues to ensure he lives the life he wants to lead" (parent)

There are five key principles of Person Centred Planning:

1. The person is at the centre
2. Family members and friends are partners in planning
3. The plan reflects what is important to the person now (and for the future) their capacities and what support they require

4. The plan helps build the person's place in the community and helps the community to welcome them. It is not just about services, and reflects what is possible, not just what is available.
5. The plan results in ongoing listening, learning, and further action. Putting the plan into action helps the person to achieve what they want out of life.

Person centred planning is about	Person centred planning is not
✓ Listening and learning about what people want from their lives	✗ The same as assessment and care planning
✓ Helping people to think about what they want now and in the future	✗ The same as reviews
✓ Family, friends, professionals and services all working together with the person to make this happen	✗ Owned by services
✓ A commitment to keep learning about the person	✗ Just a new type of meeting

Essential Lifestyle plans

Essential Lifestyle Planning is a guided process for learning how someone wants to live and developing a plan to help make it happen.

An essential lifestyle plan is useful for anyone where it is helpful to:

- Discover what is important to a person in everyday life: and
- Identify what support the person requires and any issues of health and safety (from the perspective of the person)
- Describe what you have learned in a way that is easily understood by those who will enable the person to get what is important to them.

"Our quality of life everyday is determined by the presence or absence of things that are important to us - our choices, our routines." Michael Smull

Essential lifestyle planning is a flexible process that can be used in combination with other person centred planning techniques.

Fundamentally, an essential lifestyle plan identifies and separates what is important to someone, from what others see as important for them. Good plans reflect both the perceptions of the person themselves and those who know and care about her or him. Developing plans that really reflect how people want to live requires the perspectives of those who know and love the person: listening to what they like and admire about the person; and their stories and good days and bad. Learning how people want to live is just the beginning, a plan provides the framework of our on-going learning.

You can find out more about Essential Lifestyle planning and see some examples of plans here <http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-planning/essential-lifestyle-planning-.aspx>

Person Centred Thinking

Person centred thinking is a set of values, skills and tools that help with getting to know someone, find out what is important to them and how they want to live their life. It challenges the idea that people with similar needs all want or need the same thing and looks deeper and in more detail about what makes individuals 'tick'.

Parents have a key role in helping others to understand the detail in their child's lives. We suggest you start with thinking about your son or daughter and gather some key information to help with planning.

- What do others like and admire about the person?
- What is important to them
- What is important for them (to keep them healthy and safe)
- How do they communicate with others?
- How do others communicate with them?
- Do they have any significant routines or rituals?
- What places do they like to go to?
- Who are the important people in their life?
- What are their gifts, qualities and skills?
- What would a good day look like?
- What would a bad day look like?
- What would the perfect week look like?

What about people with more severe or profound disabilities?

One of the concerns we frequently hear comes from parents who have a son or daughter with severe or profound learning disabilities. They tell us that they can't see how this approach could work for their children – and that it seems geared towards those more able to communicate their wishes and needs.

"How can this possibly work for my daughter when she can't speak and doesn't understand what we are asking her?"

Just because people don't use words to communicate it doesn't mean they don't have anything to say. People communicate in different ways and we and others can get to know them really well, by learning what they are communicating (by making sounds, vocalisation, gesture, body language and/or their behaviour) we can get a good picture of what a person likes. What they like to eat, whether they like a busy or quiet environment and what sort of music, if any, makes them smile. We can learn a lot about their likes and dislikes and what's important to them when we listen to what they are telling us through these methods. For example:

- Lucy rubs her chin and side of her face gently against her shoulder when she wears her soft pink fleecy top. This is telling us that she likes wearing this fleece and enjoys the feel of it against her skin. We know it's important for Lucy to have sensory experiences like this because she finds it comforting. Now when we go clothes shopping we hold the fabric against her face to see if she likes the texture. This means Lucy is making choices.

Sometimes people's behaviour can be misunderstood, seen as challenging and down to the fact they have a learning disability when actually, more often than not they are simply trying to tell us something.

- Aidan is refusing to wear anything over his head (t-shirt, jumper, top) he pulls it off straight away and pushes us away. This is not his usual behaviour but staff supporting him are concerned because he can't go out (and he loves going out) Aidan is taken to the doctor for a check up and it turns out he has a rather nasty ear infection. Aidan was telling us something was hurting him. This was his way of communicating it to us because he can't verbalise it. Aidan now has this written down in his communication chart so if he does this again staff now know to take him to the doctors straight away (*an example of a communication chart can be found on page 25 of this guide*)

What about dreams and aspirations for those with profound and multiple learning disabilities?

At this stage in your child's life you'll be asked what would your child like to do in the future, what are their aspirations?

For people with profound and multiple learning disabilities and/or people unable to understand what the future means and unable to communicate this, we can only 'best guess' - what we (*those of us who know them best*) think would make a good life for them. They may not have dreams or aspirations of their own but we can still plan, based on what we know is important to them.

A good place to start is to think about what a **perfect week** would look like for your son or daughter. If they could have the best week ever what would that entail? Who would be there, where would they go? What would they do? Try to think big and not just stick to what is currently practical or achievable. This is a great way of identifying people's dreams and aspirations!

	Mornings	Afternoons	Evenings
Mon			
Tues			
Wed			
Thurs			
Fri			
Sat			
Sun			

You can also use the good day/ bad day tool – see page 22.

You could ask:

'If you had a magic wand and were going to create a really good day for the person - what would happen? What would they be doing? Who else would be there?'

And then ask a similar question about a bad day:

'What would you do if you wanted to ruin someone's day?'

This teases out what is important *to* and *for* a person and it can then be used to make changes by asking 'What would it take for you to have more good days and fewer bad days?'

Using these approaches with children and adults who have more complex needs (and don't use words to speak) is essential. It captures the tiny details in a person's life that need to be known by others supporting them. As parents we are the experts on our children. We know those details because we've got to know them throughout our child's life, but if these details are not captured and written down and understood by others who support our children life can become very unhappy. The key is that person centred planning is done in conjunction with family and friends and everyone who knows the person best and this is what makes it so much more powerful.

We know from talking to families that they have, more often than not, thought this way but somewhere along the line they got lost – frustrated that others didn't appear to see their child the same way they did. Person centred planning is often something they grasp straight away because of this.

Here's what some families have said about person centred planning:

When we were planning for Sarah's move into a new home we held a person centred planning meeting. We invited her sisters, her auntie, her Grandma as well as some of the staff who had supported her at her school and short break centre. Everyone had something to contribute about who her favourite people were. What a good day looked like, what activities she liked doing and where we all thought she'd like to live and who with. Sarah can't tell us what she wants but by working together we came up with some great ideas about what would make a good life for her. That was 5 years ago. Sarah now lives a great life in her own home with full time support. She lives with people that we are convinced if she could have told us, they would be the people she'd have chosen. We can only ever 'best guess' with people like Sarah and even though I know Sarah really well I don't think doing it on my own would have given us such rich information to plan for her move. It felt like Sarah was truly at the centre of the decisions being made about her then. That we were making those decisions with her as well as for her. We continue to use this way of working to ensure she always is. (Parent)

I thought I knew my son so well but until we started planning with him. We were helped by a person who was very skilled in getting John's family and his supporters to share their experiences and stories about John. We began to look at John's movements (eye, hand, facial, feet, body, etc.) as ways he was communicating.

This changed our whole way of thinking about what John was capable of doing now and in his future. He no longer is going to a day centre, which we found out was making him very anxious and upset. He is now getting support from home to go and do the things he enjoys with the people he enjoys

doing things with. We are still learning about John, as we will for the rest of his life. But through regular planning meetings with the people who care and work for John we see a different future. We recognised that John needs to establish relationships with people he shares interests with rather than it being just based on family relationships and support workers. We are starting to look into expanding John's social networks and giving him more opportunities to experience different things. We learn something every time John experiences something new and then we build on this.
(parent)

When does the preparing for adulthood stage start?

It's never too early to start thinking about the future but preparing for adulthood officially starts when your child is in Year 9 (the year they turn 14) Although, planning can start sooner if it's considered that the young person will significantly benefit from a longer adjustment period.

This stage in our children's life is commonly referred to by services as 'Transition' Transition simply means change and in this context it refers to the change from being a child to becoming an adult. It's used to describe the period from when your child is 14 years old to 25 years old so if you have a son or daughter in this age group they will be considered to be "in transition"

The Year 9 Review

The Education Health and Care plan (EHC Plan) will be reviewed annually and in Year 9 the review has an additional focus of preparing for adulthood. The SEND Code of Practice 2014 states:

'All reviews taking place from year 9 at the latest and onwards must include a focus on preparing for adulthood, including employment, independent living and participation in society. This transition planning must be built into the EHC plan and where relevant should include effective planning for young people moving from children's to adult care and health services. It is particularly important in these reviews to seek and to record the views, wishes and feelings of the child or young person. The review meeting organiser should invite representatives of post-16 institutions to these review meetings, particularly where the child or young person has expressed a desire to attend a particular institution. Review meetings taking place in year 9 should have a particular focus on considering options and choices for the next phase of education.' [SEND Code of Practice 2014]

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/342440/SEND_Code_of_Practice_approved_by_Parliament_29.07.14.pdf

Although the review will take place in school it's important to remember that this is a time to be thinking about the whole of the young person's life and not just education.

Who should attend the review?

- Your son or daughter – they may also want a friend or an advocate with them
- You – and you can take along other family members, a friend or advocate too
- School staff who work with your son or daughter
- If your child is likely to need adult social care services the transition social worker should attend
- Anybody else who works with your son or daughter, including therapists

The school should tell you who they have invited and you can request that other people that you think need to be there are also invited.

Top tip:

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.

Top tip:

Is there someone else you haven't thought of, like other family members, 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.

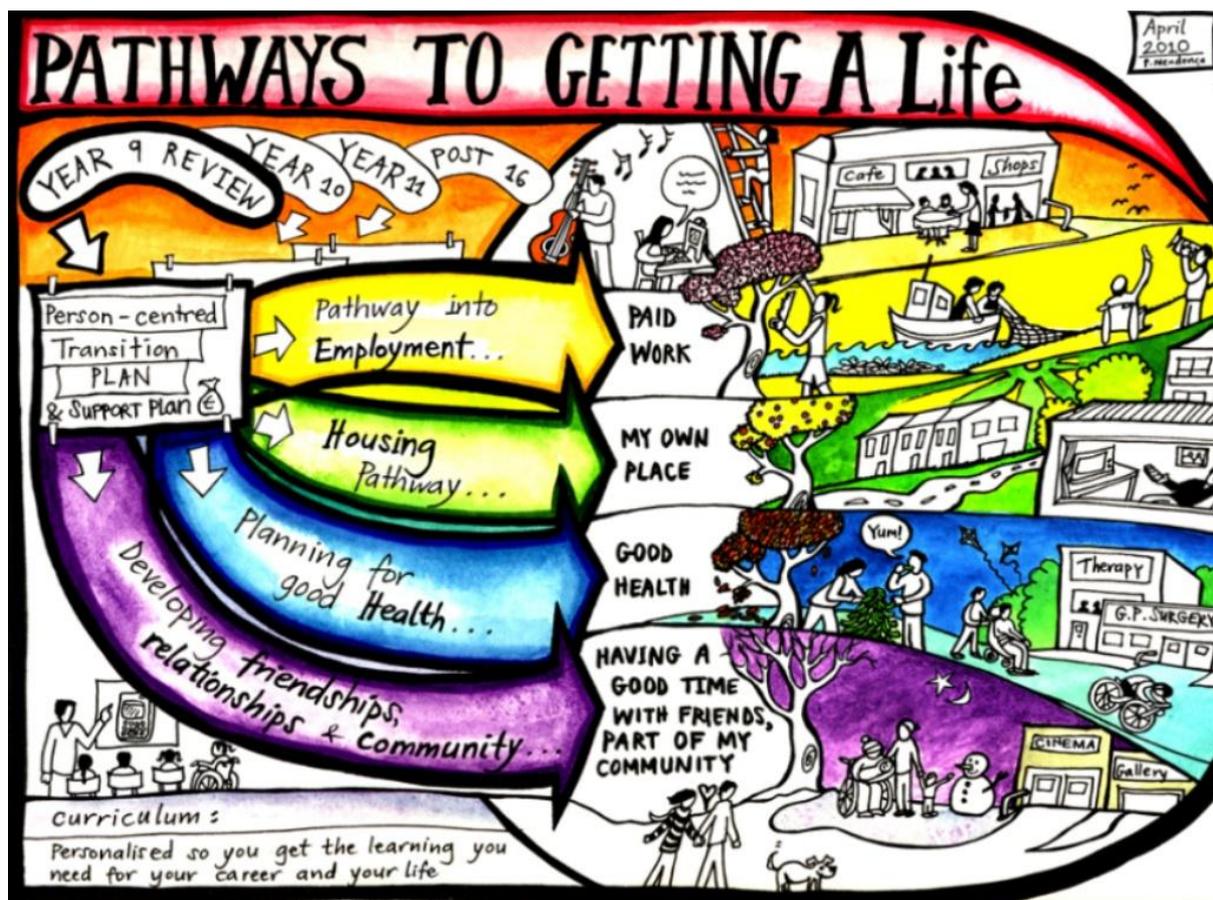
Is there anything I need to do before the meeting?

It's a good idea to think about the meeting beforehand and to write down any thoughts and questions you might want to ask. You should also think about the people you would like to attend and let the school know well in advance.

It's important that all aspects of a young person's life are considered not just your immediate concerns around schooling. Talk to your son or daughter about their ideas for the future and write down what you know about things they like doing at school (and outside of it) what interests and hobbies do they have?

Here are some other things to think about –

- Health care needs
- What skills do they need to develop to help them in the future
- Travel training and transport
- Getting a place at college
- Getting a job
- Where they live
- Anything else that is a concern to you or your son or daughter now and in the future



The 'Getting a life pathways' are a series of pathways developed to help you think about the key areas that need to be considered at this stage of your child's life. The pathway above is an overview. Further pathways on each of the areas – Employment, Housing, Health and Friendships, relationships and community can be found here

<http://www.gettingalife.org.uk/index.html>

Further information about further education and training is available in the Local Offer on Oxfordshire County Council's website: <https://www.oxfordshire.gov.uk/cms/content/further-education-and-training-children-and-young-people-sen>

If you have a son or daughter with complex health needs this excellent guide called '**Moving on Well**' has been developed by Winchester and Eastleigh NHS trust has some useful advice and guidance that can be used to help you think and plan for the future.

http://www.preparingforadulthood.org.uk/media/267901/moving_on_well_pack.pdf

How will my son or daughter prepare for the meeting?

Supporting the child or young person to prepare is essential to ensure a better result. There are two main areas that the school should consider. Thinking about what to share at the meeting and how the meeting should go.

Careful consideration should be given to how the child or young person communicates. You need to think and discuss how they will be able contribute as fully as possible. You and the school staff

will already be skilled in this, for example by using drawings, pictures, photographs, symbols or objects. School could use a variety of media such as a book, a film, showing everyone the things they like doing, a slide show with photographs or a poster or something they have made that they are proud of.

Some children may be reluctant or be unable to contribute to the whole review process and some may only be able to manage a small part of it. This should be their choice. The school should explain the process to them and why the review needs to take place to help them to feel confident and happy about what will happen. You can do this too

The focus should be on how they feel about themselves, about school and their learning as well as what they would like to do in the future and what they need to do to achieve this. You should do everything you can to ensure they are included.

Where the meeting takes place is important and so you will need to think about and discuss where it will be held. You will also need to think about who they wish to invite, for example they may wish to invite their best friend or additional members of their family.

Person Centred Reviews

Ideally the review should be a **person centred review**. We do know however, that not all schools are running reviews in this way. In these circumstances you may want to think about some of the questions we have listed in this guide before the review itself. Jot down the information you have gathered using the templates provided and take it with you to the review. **Although we feel that a person centred review process is the best way to hold a review it's the questions that are asked and the conversations that happen as a result that are the most important.**

Preparing for the review

As family carers we all have different experiences of school reviews. The most common experience that families' have shared is that they feel that neither the young person nor themselves feel 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 or appreciate about the young person
- What is important to the young person now (from their perspective)
- Relationships with others and their interactions
- Things to do and things to have
- The rhythm and pace of their life
- Positive rituals and routines
- 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.

Further information on person centred reviews can be found here

<http://www.helensandersonassociates.co.uk/media/42199/yr9pcreviews.pdf>

Person centred reviews animate from Helen Sanderson Associates

<https://www.youtube.com/watch?v=YpRz-YEwkP8>

This animate has been developed for all people using services who should have an annual review.

Person Centred Thinking Tools

These are the tools we can use to help us think and plan. They are simple but effective tools that can help us with planning, organising and reviewing a person's life. We have listed the person centred thinking tools with a small explanation about what they are and why they are useful. Throughout each guide in this series we have provided further examples so you can see how they can be used in practice.

All the templates for the person centred thinking tools are available on the Think and Plan website developed by Dimensions UK and Helen Sanderson Associates. www.thinkandplan.com to make it easier you can register on the site and fill in the templates online and save or download as a PDF to print off

One Page Profile

One page profile

Photo Each one page profile has a current photo of the person.	Appreciations This section lists the positive qualities, strengths and talents of the person. It can also be called 'like and admire'.
What's important to the person This is a bullet list of what really matters to the person from their perspective (even if others do not agree). It is detailed and specific. This section needs to have enough detail so that someone who does not know the person can understand what matters to them. It could include: <ul style="list-style-type: none">• Who the important people are in the person's life, and when and how they spend time together.• Important activities and hobbies, and when, where and how often these take place.• Any routines that are important to the person.	How to support the person This is a list of how to support the person, and what is helpful and what is not. The information in this section includes what people need to know, and what people need to do.

Person centred planning can start with a one page profile. A simple one page of information all about the child or young person

One-page profiles are a simple and versatile tool that captures key information about the person. Information is structured under standard headings that enable everyone to understand what is important to the person and how best to support them.

For more information and examples of one page profiles visit web:

<http://www.helensandersonassociates.co.uk/media/38428/onepageprofilesinschools.pdf>

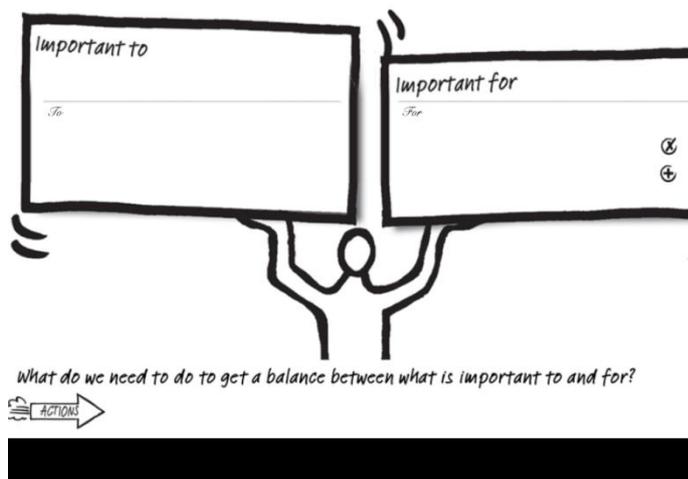
Top Tip

Think about having different one page profiles for different situations. E.g. how best to support them when visiting the G.P, going swimming or going out shopping etc.

Try doing your own one page profile so the people supporting your son or daughter know how best to support you in your relationship with him/her. Here is a link to one Gail did in her blog <http://abitmissing.wordpress.com/2013/01/29/one-page-profiles-getting-to-know-me/>

Important to/ important for

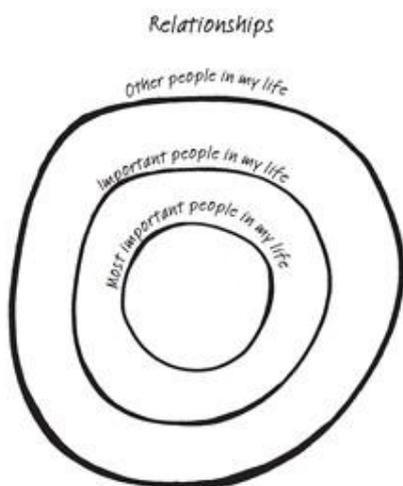
PERSON CENTRED THINKING | COMMUNITY CONNECTIONS | ONE PAGE PROFILES | PERSON CENTRED REVIEWS | SUPPORT PLANNING



A fundamental person centred thinking skill is to be able to separate what is important to someone from what is important for them. **Important to** is what really matters to the person from their perspective. This should include only what people are saying with their words or behaviour, the things that really matter, things that make them feel happy or content, fulfilled and things that they look forward to and enjoy.

Important for is about the help and support a person needs to stay healthy, safe and well. While this is clearly essential, families and professionals often put the main focus on important for and sometimes fail to ensure that there is equal balance between the two. If we only focus on keeping people healthy and safe we may ignore the things that are important to them and life can become very unhappy and frustrating. Equally if we only focus on what is important to people then it becomes all choice and no responsibility. The so getting the balance right is key.

Relationship Circle



A Relationship Circle is a tool to help map who are the important people in a person's life. Who is the closest to them, family and friends, who do they enjoy spending time with and who are the people who share the same interests.

People with learning disabilities often need help in staying in touch with friends and a relationship circle can help to identify who those people are as well as looking at where there are gaps, i.e. do they have more paid staff in their circle but very few friends? A relationship circle can also help to identify who can help with developing a person centred plan.

"When my son left his special school I realised that he was leaving behind lots of people who were important to him. Unlike his sisters he couldn't pick up the phone and call them, email or text them

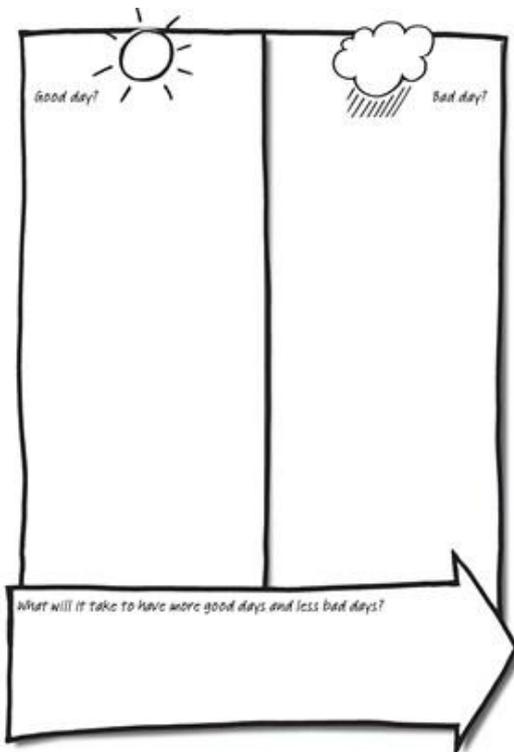
himself. While their social life and friendship group was getting bigger and changing, his circle of friends was getting smaller. We couldn't explain to him why he didn't see these people anymore but by mapping who was important to him it made it easier for us to ensure he maintained these friendships. Seeing how happy he is when he meets up with old friends now makes the effort of doing this totally worthwhile" (parent)

Good day/Bad day

is a person-centred thinking tool that simply asks the person to describe what a typical day is like, starting with when they wake up and continuing until they go to bed. Then you can ask for the same detailed information about what an especially good day is like and a particularly bad day. This tells you what needs to be present for them in their day-to-day life and what needs to be absent.

In reality, the conversation is likely to meander. Some people cannot describe a good day or a bad day, but can tell you about the last week in great detail, so that you can gently ask which bits of the day were good and which not so good. If the person has not had good days for some time, they may be able to tell you about a good day from their past.

When the person cannot tell you directly themselves, then family or support staff can help.



You could ask:

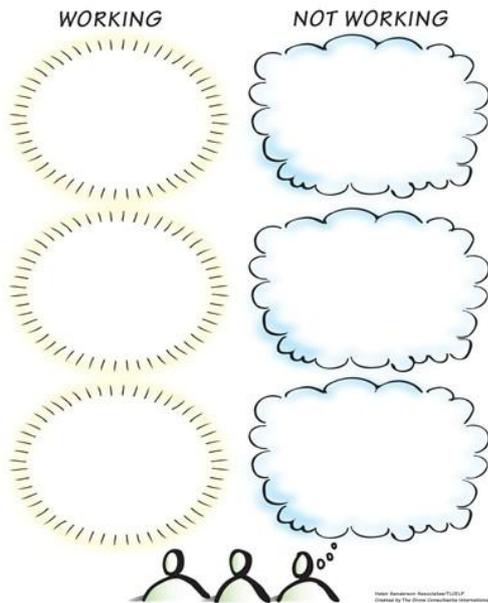
'If you had a magic wand and were going to create a really good day for the person - what would happen? What would they be doing? Who else would be there?'

And then ask a similar question about a bad day:

'What would you do if you wanted to ruin someone's day?'

This teases out what is important *to* and *for* a person and it can then be used to make changes by asking 'What would it take for you to have more good days and fewer bad days?'

Working/not working

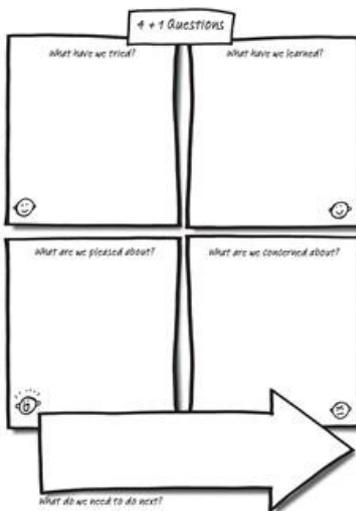


This tool is used to find out what's working, what's going well in a person's life from their perspective and what's not working, not going well in their lives.

It should also be used to see what's working and not working from the perspective of others too, eg. Family, school or support staff

Actions should be agreed to build on what is working and change what is not.

Four + 1 questions



This is another tool that is used to reflect and look at what is working and not working for a person. The questions:

- What have we tried?
- What have we learned?
- What are we pleased about
- What are we concerned about

The answers to these questions lead to the +1, which is - What do we need to do next?

These questions are great to use in meetings and reviews, or to reflect on a particular area of someone's life when they face a particular situation or challenge.

Learning log:

Learning log				
Date	What did the person do?	Who was there?	What did you learn about what worked well?	What did you learn about what didn't work?
What does THIS mean we need to keep doing or do differently?				

Learning logs are an opportunity for reflection. Recording what works makes it more likely that the activity or event will happen again. They are most useful when people are trying out new things, or being supported by new staff. It is crucial that the learning logs are reviewed regularly, and together people figure out what they are learning about the person and the support they provide. This results in doing things differently. The information from the learning log has to be used in the same way as the 'working/not working' information is used.

- Those things that are working need to be maintained. These can be added to information on 'how best to support the person'
- Those things that are not working need acting on to change them.

Communication Charts

The communication chart is a simple but powerful way to record how someone communicates with his or her behaviour. While it is a critical tool to have when people do not communicate with words, it is also important to use when communication with behaviour is clearer than the communication with words, or when what people say and what they mean are different.

This tool helps:

- As a way to help us to focus on people's communication whether they use words to speak or not.
- To identify and clarify communication whenever what the person does communicate with their actions is different from what they say.
- It works by giving a snapshot of how someone communicates.

Matthew's Communication Chart

What is happening	Matthew does this	We think it means	And we should
Anytime	clapping	Matthew wants something, could be a drink, food or the channel on the TV changed.	Ask him what he wants and take his hand and ask him to show you
Anytime	Hits out	He doesn't want to do something. He could be feeling unwell.	Tell him not to hit you but think about what it is you're asking him to do. If it's something he's usually happy to do then arrange a visit to the GP. He could be unwell
Anytime	Blows "raspberries"	Matthew is playing a game, he thinks this is funny. He's not being rude	Blow a raspberry back. This makes him laugh
Anytime	Strokes his head	He's upset about something and comforting himself	Offer him reassurance or comfort by chatting to him or looking at a magazine, book or his Ipad

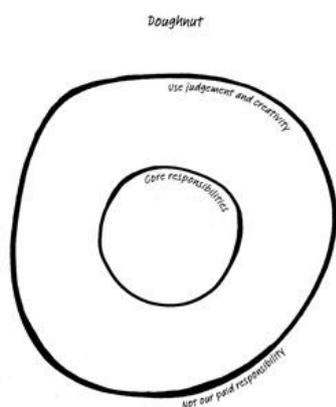
Matching Support

Getting a good match between the person supporting and the person being supported - whether paid or unpaid - is **crucial**. The Matching tool is a simple way to record what is needed to give a person the best match between those who use services and those who provide them.

The 'matching tool' has four columns. The first is the support that the person wants and needs, then the skills required to support them, followed by personality characteristics and then shared common interests. The most important part of this, is the box where personality characteristics are recorded.

Skills needed	Support needed and wanted
Personality characteristics needed	Shared common interests

The Doughnut



Once you know the best person or people to provide support, the next task is to clarify their roles and responsibilities.

- The first ring is the inner core, which consists of the core responsibilities of staff or people providing support.
- The next ring is areas where staff need to exercise their own judgement and be creative. These are areas where people must make decisions, problem solve and creatively think about possibilities and potential.
- The final ring is areas beyond the scope of the staff member's role and responsibilities. All roles have limits and boundaries, some of which are formally in place, and some of these are informal, for example family preferences or respect for cultural differences.

You need to know what is important to and for someone, before you begin to use the doughnut tool to clarify the roles of supporters in specific situations.

Using the doughnut ring is a great way to explain it to people, but hard to use in practice, so we use the same headings in columns.

Decision making agreements

The Decision making agreement is a way to reflect how decisions are made

When supporting someone in their decision-making, here are some important questions to ask:

- Do I fully understand what is important to the person and their communication?
- Am I the best person to support this decision-making?
- Is the information that I have and am giving the person relevant to the decision?
- Am I presenting it in a way that the person can understand?
- I am giving the information in the right place and time?
- Have I given the person the best chance to make the decision themselves?

Decision making agreement		
Important decisions in my life	How I must be involved	Who makes the final decision

Clare's Decision Making Agreement				
You want to	Talk to and work out	By when	Make sure	Who has final say
Go to Oxford	Mum, Dad, Sarah. Tell us: <ul style="list-style-type: none"> • Who you are going with • How to keep in touch • When you plan to be back • How you are getting home 	At least the day before and not as we are all going to bed	You have money and your phone and keep your phone switched on	Mum, Dad or Sarah
Stay at Ellie's house	Ellie, Paul and Sue and Mum and Dad. If Mum is away then Dad and Sarah	At least 2 days before	You have clean clothes, phone and money	Paul and Sue and Mum and Dad

This tool helps:

- To think about how much power and control people have in their lives.
- To clarify how decisions are made.
- To increase choice and control people have in their lives.

It works by helping us to think about decision making and increasing the number and significance of the decisions people make.

Presence to contribution

Sometimes we can be present in a place or at an activity without actually connecting with people or contributing and taking part. i.e. being there but not actually being included. We want our young people to be active in their own community and connect to the people within it.

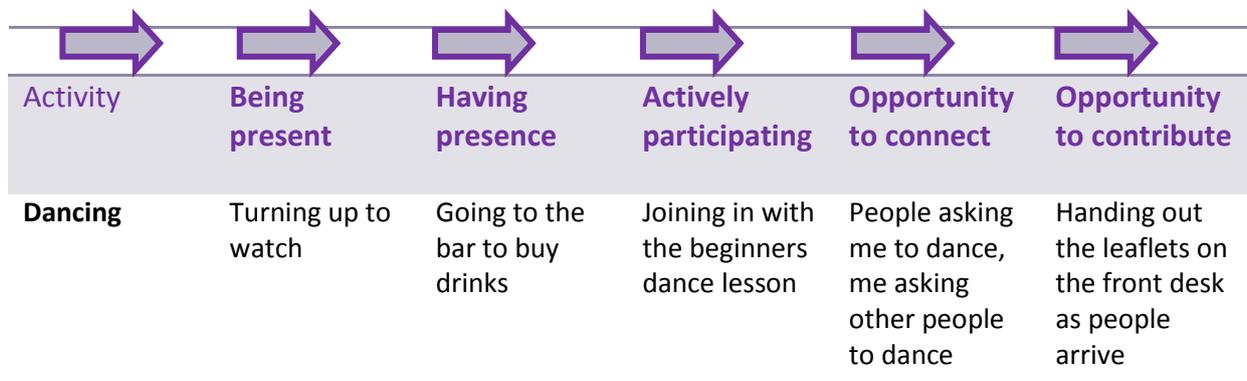
Presence to Contribution is a person-centred thinking tool that can help by asking people to think about the activities or interests they have in their community and how these could be developed further. This helps people work out what it would take to go from simply turning up to an activity and being present, to being fully involved and making a contribution.

This tool helps:

- To think with people about what they do on a day to day basis and the opportunities these present for getting involved, meeting new people, and making connections and contributions.
- As a way of looking at where people are now, thinking about possibilities and planning actions.

It works by helping us to think about how we can see current activities as opportunities for participation and contribution. For example:

Presence to contribution



Now you have the tools you can make a start gathering all the information that will help with planning for your child's future. Based on the information you have gathered start thinking about what kind of things they would like to do when they are older. If you can, ask your child what they want to do. You can also think about sharing the templates with other family members, friends and others who know your child well too.

Further reading, useful resources and websites

Helen Sanderson Associates – www.helensandersonassociates.co.uk

Personalising Education - <http://www.personalisingeducation.org/>

Oxfordshire Family Support network – www.oxfsn.org.uk

Oxfordshire Family Support Network's You Tube Channel (with videos from our 'Nothing About Me Without Me' training for professionals 2012) -

<https://www.youtube.com/channel/UCOvqbs2WU16XFi19pBJ874w>

Think and Plan – www.thinkandplan.com

Dimensions UK – person centred thinking - e-learning course - <http://www.dimensions-uk.org/about-us/person-centred/>

Preparing for Adulthood - <http://www.preparingforadulthood.org.uk/>

The Transition Information Network - <http://www.transitioninfonetwork.org.uk/>

Communication Matters- www.communicationmatters.org.uk

Oxfordshire Total Communication - <http://www.oxtc.co.uk/index.shtml>

Inclusive Solutions - www.inclusive-solutions.com/pcplanning.asp

The Foundation for People with Learning Disabilities - www.learningdisabilities.org.uk

Inclusion online - www.inclusiononline.co.uk

Getting a life - Pathways - <http://www.gettingalife.org.uk/>