Prepared for the future?

Information to prepare families when a young person with a learning disability is leaving school or college



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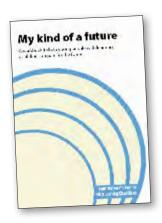


Background

Leaving school or college and setting out on adult life is an exciting time for young people and their families. It also has its challenges and even more so if the young person has a learning disability. Through using this booklet we hope that families may find the process less daunting.



The Foundation for People with Learning Disabilities has done a lot of work in recent years to support young people and their families at this stage of their lives. In the first phase of the What Kind of a Future? project it talked with ten young people who have Down's syndrome and their families to find out what has enabled them to achieve fulfilling lives on leaving school. It produced a booklet in 2007, What Kind of a Future? for families and young people to look at together to get ideas about what the young person might do in their adult life.



In the second phase of the project we worked with young people with Down's syndrome because of the terms of the legacy that funded it. However, the project and these booklets are relevant to a lot of other young people. Based on what participants have told us about what is helpful to them, we have written this booklet specifically for parents, brothers and sisters and other family members who wish to help the young person to lead a fulfilling life on leaving school. We use guotes from some of the families who took part in the project and some examples from the Foundation's work. We also write about different aspects of UK Government policies about the transition from full time education to adult life, so that families can be informed about what they should expect. This booklet can either be read straight through or by using relevant sections as they are needed.



This booklet is accompanied by a workbook called My Kind of a Future. This easy read workbook helps young people to think through the issues they face as they leave school or college. These are available from the Foundation's website at: http://www.learningdisabilities.org.uk/publications/what-kind-of-future/

Introduction



Parents, siblings and other relatives want the young person with learning disabilities in their family to have a fulfilling life as an adult, but sometimes finding out how to achieve this and what is available can be hard. This is where this booklet comes in. Sometimes professionals use jargon or technical language. We have put definitions of some of the terms they may use in boxes.

School has often provided a predictable and secure environment and there can be uncertainty about what the future holds. Some parents have fitted their own paid work around school hours and they wonder how they will be able to manage in the future.

we've come towards the end of the educational system it's all drying up, it's the time when you need the input the most and it's not there, there's been nothing now from college in terms of transitional planning really, apart from that I did have this meeting with the social worker at Easter but that was it, you know.

There has been a big shift in recent years in the way things are done. In the past, following an assessment of what the young person needed they might have been offered a place in a service such as a day centre. They would have slotted into what was available. Now young peoples' futures should be based on their individual needs and preferences.

Across the UK over recent years there have been policy documents that share similar values such as social inclusion and person centred approaches. Young people should be supported to think about whether they want to go to college, have a job, volunteer, go to a centre, participate in local sport, leisure and other community activities, where they want to live and about their health care. Practices vary across the four countries.

In England a 5 year strategy document, *Valuing People* was published in 2001. This has been followed by the three year strategy, Valuing People Now (2009).

In Scotland The Same as You? was published in 2000.

In Wales Fulfilling the Promises in Wales (2001) was followed up by a Statement of Policy and Practice for Adults with a Learning Disability in 2007.

In Northern Ireland, the independent Bamford review of services for people with learning disabilities and mental health problems included a specific report relating to people with learning disabilities, called *Equal Lives* (2005).

Parents and other family members may wonder what input they will have in planning for the future, now that the young person is becoming an adult. Recently there has been legislation about making decisions (Adults with Incapacity Act Scotland 2000 and the Mental Capacity Act 2005). Where a young person may be assessed as unable ('lacking capacity') to make a particular decision, such as where to live, then a decision must be made for their benefit in Scotland and in their 'best interests' in other parts of the UK. Family and friends must be consulted.

Making Decisions: A guide for families, friends and other unpaid carers www.publicguardian.gov.uk/docs/opg-602-0409.pdf

An Introduction to the Adults with Incapacity Act www.enable.org.uk/docs/An_Introduction_to_the_Adults_with_Incapacity_Act_ (Aug_2010).pdf

Whether the young person has capacity or not for a particular decision, families will be involved in thinking with the young person about their future, as they would with other young people in their family.

The young person may also be eligible for additional benefits when they reach sixteen. You may want to check with the local benefits office or ring the Benefits helpline.

Benefits helpline: telephone 0800 882200

Section 1: Getting the support that is needed



Personalisation

Personalisation means that every person who needs support, whether for health, social care, leisure, transport, education or employment is to be empowered to shape their own lives and the services they receive. Personalisation includes person centred planning and the opportunity for self directed support (see page 10). A cross-Government document, *Putting People First* (2007) is about personalisation.

In this section we look at the process by which the young person should be supported to make plans about all aspects of their lives, how friends and family can help and how these plans can be implemented and kept under regular review.

Person centred planning

Person centred planning is a way of planning all aspects of the young person's life. The young person is at the centre of the planning. With support, they need to decide how they want to make their plans, who they would like to help, how they want to record them and who they need to help to make the plans happen. Person centred plans need to be revisited regularly as a person's life changes. Health action planning is an important part of person centred planning.

Person centred planning is not an assessment. It should be about making things happen. It is increasingly widely used across the UK. To do this it is important to involve others and always the young person should be at the centre. The way the young person likes to communicate should always be respected.

So it's about what Neil wants to do rather than just what's on offer.

The key questions to think about in person centred planning

Who are the important people in a person's life?

These are the people the young person wants to be involved in developing their person centred plan and who can help them make things happen. These are the committed people in the young person's life: family, friends and professionals who know and care about them.

What are the person's strengths (or gifts)?

Finding out what the young person is really good at and what other people see as their gifts can help people think about the kinds of employment, educational courses, career paths, activities or future housing options they may wish to pursue.

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

What are the supports the person may need to make things happen to get the future they want?

People will need to identify key areas in which support is needed and to talk about how they can get that support.

What do we need to do?

This is also called Action Planning. This is a way to ensure that those things the person wants to happen to make a positive future actually happen. This would include identifying the people who are responsible for implementing the plan with the young person.

fyou did this with every person of that age it would be a fantastic thing to do.

Sammy's dream is to go to Las Vegas with a friend. She is now planning to go away for a weekend in the UK with a friend and their older sisters will accompany them. If this goes well, the next goal is to save up her money and go to Europe.



Gethin's dream was to have a bank-card so that he could draw money from the cash machine. An action plan was drawn up and a new account was opened so that he could withdraw up to £10.00 per week and he was given help to memorise his pin number (PIN).

Circle of support

A circle of support is sometimes called a circle of friends. It is a group of people who meet together regularly to help somebody achieve what they would like to do in their life. It might be, for example, about a job or somewhere to live or a leisure activity or a holiday. The person is in charge and decides who they want to invite, what they talk about and where the circle should meet.

Some young people have found that a circle of support or circle of friends can be really useful in getting the kind of life they want to lead. The young person assembles round them the people they know well and some of the people who may be able to support them in the future. It can include family, friends and professionals. They participate in person centred planning, which is an ongoing process as the lives of the young people develop and their aspirations change.



Amanda's circle

We wanted to help our daughter as much as we could so in 1990 formed a small circle of friends... We worked together to make sure Amanda could get further education and we contacted the local speech and language therapist to support us develop a communication system with our daughter who does not use spoken language. With the help of some thick card, Velcro and photographs we were able to support Amanda to make some choices in her life.

Some years ago Amanda was successful in getting an increase in the Independent Living Fund money. Having a person centred plan really helped this... Today our daughter has personal support at a small daytime service that has helped her so much. She goes out most evenings and has more people in her life who are closer to her own age.

Over the years some people have left the circle, but others have joined. We thought about the future and drew out a PATH... We are looking into shared ownership at the moment...

^{- (}From C Burke Building Community through Circles of Friends p56 Foundation for People with Learning Disabilities)

The circle can be a powerful group, not only in providing support in making plans, but also in enabling the young person to have a circle of friends and to build up a social life. The young person will want to be part of their community.

See: www.circlesnetwork.org.uk

Advocacy

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

Independent or citizen advocacy is about speaking up for someone who has difficulty in getting their voice heard. It is about spending time with them and getting to know their wishes and then supporting them to bring about the changes they desire in their lives. It is about putting the person in control of their lives.

Transition planning

England and Wales

Ideally, person centred planning should be at the heart of the planning during transition to adult life. In England and Wales Year Nine, at 14 plus, the young person with a statement of educational needs will have a review, organised by the school. It should involve family, friends and professionals from different agencies who may be helping the young person. The process of planning for the future has been laid down in law. A key member in England will be the **Connexions** adviser. In Wales, the representative from Careers Wales has the responsibility for overseeing training, learning and employment. It is good practice for the young person to have a key worker



or lead professional to ensure the process is co-ordinated and effective. The Welsh Assembly Government are currently in the process of drawing up national guidance for transition for disabled young people.

Connexions in England is responsible for giving advice to young people from the age of 13 to 19 and to 25 if the young person has learning difficulties. Since 2008, the Connexions service is under the local authority.

It is good practice to have such reviews with those young people who do not have statements who nonetheless have additional needs. The review meetings are about planning for their future and should include meeting health needs.

This should lead to a **Transition Plan**. It is now good practice that the plan should be person centred so that the young person will be the focus and have choice and control over their future. They will be likely to need a facilitator for the meeting and sometimes parents have been facilitators or co-facilitators if they and the young person wish that, especially where the young person has high support needs and is unable to communicate their wishes in words. It is helpful if the plan is in a format that will be useful to the young person, for example in plain English, with pictures or photos or even using video. It will be reviewed each year until the young person leaves full time education. From 2012, in England, those with statements of educational needs will have to have person centred transition planning.

At 16, and the last review before the end of compulsory education, the young person should have an assessment and report about further education and training needs. This is called a section 140 assessment. It should fit in with the overall planning for the future.

Social care is the provision of services that offer personal care and support to disabled and other vulnerable people to help them achieve independence and to contribute to their communities. It could be personal care such as washing and dressing if these are needed, support in everyday life such as shopping, or support for opportunities to engage in their communities, for example to participate in daytime activities outside the home.

If the young person is going to need social care, they will usually transfer to the adult social care team at eighteen. A social worker should attend the Year Nine Review if they already have support from children's services. Otherwise the adult social care team must be informed. The young person will need a community care assessment and plan. In Wales there is a unified care assessment and care management process.

The young person will have to meet the eligibility criteria for their local authority. The Government introduced guidance called Fair Access to Care.

Fair Access to Care was introduced in 2003 to provide a framework for deciding about eligibility for care. It has four bands or levels of need. These are about risks to independence. The levels are critical, substantial, moderate and low. There will be different levels of provision according to need. There are variations between local authorities about the level of need they will support. Some local authorities are only providing support where the need is considered to be critical. This means that many young people with Down's syndrome may not get support from the social care team.

We hope in the future there will be greater equity across the country and young people with moderate learning disabilities will be able to have more support or a direct payment/ budget from the social care team if they need it. At the time of writing the Government is consulting about the provision and funding of adult social care.

For more information see Contact a Family's guides below, available from their website or by calling their free helpline on 0808 808 3555

Preparing for Adult Life and Transition- England and Wales: www.cafamily.org.uk/pdfs/preparing_for_adult_life_web.pdf

Northern Ireland

In Northern Ireland there is a similar transition process to England and Wales. There needs to be close liaison between the Education and Library Boards (ELBs), the Health and Social Care Trusts and the Careers service to ensure that the young person is able to gain the future that they would like.

An interdepartmental group: Departments of Education, Health Social Services and Public Safety, and Employment and Learning (DE/DHSSPS/DEL) has looked at the issue of transition from school and what needs to be done to develop an improved transition process.

From January 2010 there will be changes to the way education is planned and delivered. Currently, ELBs are responsible for ensuring provision for children with special educational needs. The role of ELBs will be undertaken by a new body, the Education and Skills Authority (ESA).

Preparing for Adult Life and Transition- Northern Ireland www.cafamily.org.uk/pdfs/transition_ni.pdf

Scotland

In Scotland there are duties laid down on education authorities and schools about timescales for planning. There are also requirements for the young person to have all the information they need and for education authorities to seek and take into account the views of the young person and their family. Once the young person is 16 they gain additional rights and have the right to advocacy. Families should still be involved.

12 months before the young person with additional needs leaves school, education authorities must have received information from agencies that may support the young person, so that their education can be tailored to their future needs in the final school year. Planning will therefore need to start earlier than this. These agencies might be:

- A local authority
- An NHS Board
- Careers Scotland
- An FE College.

Six months before the young person leaves school the information about what support the young person will need must be passed on to the relevant agencies, for example social care needs to the social work department.

If a young person has a co-ordinated support plan (CSP) for learning, then the co-ordinator will take the lead in organising the planning. Otherwise there are no standard procedures for how the planning takes place, apart from adhering to the timescales and ensuring that the young person and their family have information and are fully consulted.

Up to the age of 18 the community care needs of the young person are assessed under the Children (Scotland) Act, although there is a transfer to adult services at 16. After that local authorities are required to assess the young person's social care needs under community care legislation and any plans should complement the transition plan.

This information is taken from Contact a Family's guide *Preparing for Adult Life* and *Transition – Scotland*.

For more detailed information please see the full guide, available at: www.cafamily.org.uk/pdfs/transitionScot.pdf or by calling their free helpline on Tel: 0808 808 3555

Down's Syndrome Scotland fact sheet *Leaving School* is available at: www.dsscotland.org.uk

We know from the What Kind of a Future? project and other research that this transition process can be very worrying to families and that it does not always work as well as it should. The Government in England has put money into the Transition Support Programme, in recognition that more work was needed to improve and co-ordinate services for disabled young people into adult life. The programme aims to raise the standards of transition in all local areas. The English government is also piloting good practice in a project called Getting a Life. There are nine demonstration sites where young people will be supported through the transition process to identify effective ways of bringing about the changes they want. The sites are Herefordshire, Norfolk, North Tyneside, Richmond, Oldham and Manchester, South East Strategic Transition Group with Kent and Medway, Somerset and ROC (Robert Owen Communities) with Torbay. The learning from these sites will benefit other young people. It is important to press for the young person to get the best possible plans.

See:

www.transitionsupportprogramme.org.uk www.gettingalife.org.uk

Self directed support

In **self directed support** the support the person has is controlled by them. It involves:

- having better access to information
- advice and guidance
- self assessment by the person with as much help as they need
- a personal budget/direct payment if they are eligible
- having control over the way the money is spent
- having the help that is needed in organising the support.

Now, however young people get their support, their wishes should be central. More recently a small number of young people have been getting a **direct payment**, a **personal budget**, or an **individual budget** so that they can organise their support as they want it.

Now a local authority must offer a young person the choice of a direct payment if they are eligible for help with social care.

A personal budget is a term used to describe an up front, transparent allocation of social care resources to individuals. It could be managed by a council or another organisation on behalf of an individual, be paid as a cash sum (a direct payment) to the individual, or as a mixture of both - it is for the individual to choose. (From Carers at the Heart of 21st Century Families and Communities)

Local authorities vary in how far they have gone down the road towards personal budgets and you will need to ask about this. They must offer a young person the choice of a direct payment if they are eligible for help with social care.

Most people who need social care can get a *direct payment*. It is a different way of getting support. A direct payment is money given to the young person by the local authority. They use it to buy the support they need. They are given the money instead of a service. The person agrees with their social worker or care manager how they will spend the money. They have a special bank account. They can get help to organise this. Sometimes family carers get a direct payment - see page 26.

Individual budgets were piloted in thirteen authorities.

With an *individual budget* a person knows how much they have to spend on many aspects of their lives, not just social care. Direct payments may be a part of an individual budget. An individual budget may include money from the Independent Living Fund (ILF), housing benefit, Access to Work, etc. If a person wishes to do so, they can also take up a direct service knowing how much it will cost - and how much of the individual budget it will use - and for this no actual money will change hands.

www.in-control.org.uk

I'd like to preach direct payments from the rooftops.

We knew it (direct payment) was the best way to buy the flexible support we wanted for him.

Different parts of the UK vary in how far they have gone down the road towards self directed support. Many people like the idea. Some people are put off by the fact that they may have to deal with money and engaging staff. This is not necessarily so.

You and the young person should be able to get help with this through local brokerage agencies or local centres for independent living. You could:

- ask the young person's social worker or care manager about this
- look at the directory of support on the National Centre for Independent Living website: www.ncil.org.uk/categoryid21.html
- In Control's Shop4Support website: www.shop4support.com

We decided to go to an agency... saved us a lot of hassle.

Family and friends often give a young person a lot of support and it is important that families in particular are not expected to give more help than they can realistically offer.

As a family, we've always had to do things ourselves. Well not we've had to, but we just naturally get on and do. (Sister)

You get to turn 60 and you think you should be sitting back but now I'm taking a more active part again because care agencies aren't delivering. (Parent)

Getting in Control: People with learning disabilities, their families, individual budgets and self-directed support.

See: www.hft.org.uk

If people prefer, they can still have services and support organised by their local authority (or health and social care trust in Northern Ireland). Sometimes if they are receiving services such as short term breaks or a day service they have to pay towards the service from their benefits or their own money. This varies across different authorities.

Planning for the future: A checklist for families

- Have you sat down with the young person to begin talking about what they will do after leaving school?
- Have you looked at the booklet What Kind of a Future? with the young person as a way of thinking about different aspects of life as a young adult?

 See: http://www.learningdisabilities.org.uk/publications/what-kind-of-future/
- Do you think it is a good idea to talk with the young person about setting up a circle of support?
- Who at school or college is the staff member responsible for helping the young person think about the future?
- Does the young person have a key worker or lead professional to help to coordinate the transition process and to make sure good plans are made?
- How can you make sure the meetings to talk with the young person about their future are conducted in a way that focus on the young person or are meaningful for them?
- Is there a local advocacy organisation? (The public library or adult social care team should be able to help you.) Would the young person like support from such an organisation?
- Who is your contact in adult social care if you think that the young person might be eligible? Is there a person centred planning co-ordinator or a transition worker or a transition team?
- Is the young person going to have a health action plan or health plan?
- Has the young person been able to consider all aspects of their lives: for example, education, employment, leisure, community activities and where they will live?
- Have you considered with the young person whether they would like to direct their own support? Has the young person been offered a direct payment? Is your local authority offering personal or individual budgets?

Section 2: Different opportunities

What about college?

For many young people, college will be the next step after school. Others will prefer to go straight into work and maybe have training on the job or to have other daytime activities.

We knew he was leaving at 16 because he wasn't enjoying school and we knew that (direct payments) was the best way to buy flexible support for him...

Where young people are going to college, there are often link courses to ensure a smooth transition. Some colleges offer taster sessions to pupils the year before they leave school so they become familiar with the college and get a better idea of what courses they would like to study. Sometimes transferring to a specific college course is almost seen as automatic and it is important for the young person and yourselves to visit and to explore the various options.

There was a college that everybody goes to and I was yet again an annoying person... When I went and saw it and said "no", and it's such a low expectation the local college that I just had to change it.

Often there are college courses specifically for young people with learning disabilities that are a preparation for adult life looking at both employment and everyday living skills.

Andrew went to college three days a week. He had two years in a Steps course. He was on a transitions course that enabled him to do tasters of different courses available within the college as well as core skills such as reading, writing, numbers and social skills. He was planning to go on Careerwise a two year course preparing him for work.

Courses in independent living skills may include the use of money and travel training. Both these areas cause a lot of concern for parents.

He could so very easily be taken advantage of with money.

My heart's in my mouth sometimes 'cos I think once he realises that Assembly travel card can take him anywhere in Wales, it will be like, oh where is John tonight?

Sometimes young people prefer to participate in mainstream courses.

Every September she (Karen) gets the prospectuses for the different colleges and chooses what courses she wants to do... She is doing art, she is doing music, she is doing massage... she is doing drama and... something called a woman's group.

Colleges can get funding to support students in their learning if they are assessed as needing extra help. If they need help with personal care, this has to come from adult social care. Some people use direct payments to employ a personal assistant to support them to go to college.

Long college vacations, particularly in the summer, can be a problem for families. Sometimes a young person can use direct payments to get support to do leisure activities at these times.

Paying for FE courses

Young people under the age of 19 in England, Wales and Northern Ireland get their further education free. Between 19 and 25, it will depend on their benefits. In Scotland it is free up to the age of 25 as long as residency requirements are fulfilled.

Specialist colleges

Another alternative for further education is to seek a placement at a specialist residential college. This may be the most appropriate option if the young person has complex needs that cannot be met at a local level. You will need to talk with the Connexions specialist officer in England or the specialist careers adviser about making an application for funding. In England the Learning and Skills Council (LSC) will oversee funding until 2010. Then the LSC will close and the local authority will be responsible for placing young people and funding will come from the Young People's Learning Agency (YPLA).

It is important to consider the arguments for and against. These colleges may increase the skills and independence of the young person on the one hand, but take them out of their own community for a while on the other.

We thought the things he'd gained in the community, it was better to strengthen those.

The Association of National Specialist Colleges provides information: www.natspec.org.uk

SKILL, the National Bureau for Students with Disabilities has information sheets on further education: www.skill.org.uk

Please note SKILL no longer exists but information and resources are still available on their website.

Checklist on further education



Have you talked with the young person about whether they would like to do further training or go to an FE college or whether they would prefer to do other things?

Do you know what courses are available locally? Is there a college open day or an opportunity to visit?

Would the young person want to go to a specialist residential college? What would they hope to gain from this?

What about employment?



I think (he) always said 'I want to go to work because mum and dad go to work: His sisters go to work, and it's just something he naturally thought "I'll do that as well..."

The Governments across the UK are placing great emphasis on getting people into work, including people with learning disabilities. It is an aim of Valuing People Now and the other policy documents and the focus is particularly on young people, including young people with high support needs.

Currently it is estimated that only about 10% of people with a learning disability known to services have a job and then it is often part-time. Therefore in the past parents may not have thought of work as an option, but increasingly this option will be explored during transition planning.

NIACE booklet, Moving into Work: www.niace.org.uk

Daniel works 18 hours a week for an organisation which uses his experience as a person with a learning disability.

Neil has tried a number of part-time jobs, including pub work, carpentry and work in a shop warehouse. He has used his direct payment to employ someone to help him settle into these jobs.

It is likely that schools and colleges will be giving more encouragement to students to think about work. There will be more courses



preparing young people for employment. Like other young people in Years 10 or 11, your young relative should be offered work experience. Possible future employment should be discussed in the meetings about the transition plan.

He... worked for two hours in total in the youth hostel... he would go round the bakers at lunch time to get a sausage roll.

He did a graphics company with... sort of computer images... and putting them on cars ... and he really enjoyed that cos it was out and about with a gang of boys... in a van.

The Government set up a new specialist disability programme, Workchoice in 2010, to replace previous employment schemes, Work Preparation and Job Introduction schemes. More money has been put into the Government's Access to Work programme. This enables disabled people to get additional help with equipment, adapting the workplace or a support worker.

The Government now realises that some people will need ongoing support – and maybe for all the time they are in the workplace and so it may be possible to use individual budgets or direct payments for this support if this is what is needed.

Jobcentre Plus and the Disability Employment Adviser (DEA) in England, Careers Scotland, Careers Wales, and the Careers service in Northern Ireland should be able to help with getting a job. There may also be local agencies, such as supported employment agencies run either by a voluntary body (for example Mencap Pathway and the Enable employment service in Scotland) or the local authority, that can offer advice and support.

There are different models for employment:

- Employment on the open market
- Employment on the open market with some additional support through a Government scheme
- Supported employment a way of ensuring that a person with learning disabilities has the support to have the job that meets both their skills and the requirements of the employer (see below)
- Sheltered employment working in a factory or enterprise that is subsidised The Government now encourages jobs in open employment and is less keen on sheltered employment
- Social enterprises or social firms businesses employing disabled people supported by staff with business skills are available in some areas. These sometimes also offer training
- Self employment a small number of people with learning disabilities have been supported to set up their own businesses.

See: www.learningdisabilities.org.uk/in-business

The stages to supported employment

A job coach will get to know the person and do a vocational profile with them, exploring their interests and skills.

Together they will decide on possible kinds of jobs and then talk to potential employers (job search).

Once a job has been identified - and it may be carved out specifically to meet the person's skills - the job coach will do a job analysis so that specific training can be provided both before taking up work and on the job.

Gradually the job coach may reduce support once the person is established in their role, but if a person has high support needs they may need ongoing support.

We approached the supported employment agency... and talked to them about things that he enjoyed doing and we talked about how could he... realise all the things that he enjoys doing and match it up to work... He actually collects glasses and empties the ashtrays, takes the empty stuff to the bar and I think he has now started to bottle up as well...



Some firms may have a buddy system and then another employee will support them.

Hanifa has a circle of support at work; here she describes how it supports her:

Thave a circle of support at work. It is a good time to talk things through with my colleagues and to know there are people to support me if I need help. The circle meets every two months over lunch. Each circle member passes work to me from their team. For example, Sarah gives me mail outs and sponsorship packs to send out. Gillian gives me events work to do.

I plan the agenda and chair each meeting and we usually discuss what has happened during the past two months. It is a good opportunity to find out more about my colleagues, for example, Sarah showed us photos from her travels in the last meeting.

Having a circle of support means that if my some of my colleagues are not in the office there are others I can turn to if I need help.

Having a circle at work has also had an impact on my social life. I have been to football matches, gone shopping and stayed over at a colleague's house.

Some people get work using their unique skills as a person with a learning disability, possibly with the local authority, or other government agencies or in voluntary organisations.

1 know there is a scheme... where people with learning disabilities work for social services doing interviews...

Sara works four days a week for Mencap as Partners in Politics Officer. She goes to schools and colleges doing presentations and training students in having their say about what they want.

Checklist for families about employment

Have you talked to the young person about the possibility of getting a job?

Does the curriculum in the school or college help the student to think about work and to get the skills they need?

Does the young person have the opportunity to get work experience?

Have you been able to make sure that the possibility of employment is fully explored in the transition planning?

Have you been able to explore the range of options for employment with the young person?

Has the young person had interview practice?

Have you talked about options other than employment?

Other activities in the daytime, evenings and weekends

There will be many young people who do not have a job, or do not want a job, and will want other things to do. Even those who do have a job are likely to work part-time, at least initially, and will want other activities during the week. It is also important for young people to maintain their friendship networks and to make new friends.

In the past many people with learning disabilities would have attended a day centre. Day service modernisation has led to the closure of some centres and it is less likely that this option will be offered, particularly to young people. We know that this has caused great concern to some parents as centres offered a certainty that the young person would be occupied for a given number of hours each week.

Where time in a day centre is offered you may like to explore:

- the kind of activities that are available
- the opportunities to engage in the community
- the opportunities to try out new things
- whether it is possible to use the centre as a stepping stone to employment for example.

He goes to a day centre which is very small... they've got a farm... they have a sauna there, aromatherapy... perhaps trying a bit of gardening.

Some young people may choose to continue to take courses at college after completing their full-time education. Volunteering is a choice that many young people may make. It provides useful experience that may in time lead to a job.

Nicola attends college but also has a weekly paper round. She likes getting paid and found it has boosted her confidence and is keeping her fit.

There may be drop in centres, daytime activities for young disabled people, sports, leisure and social clubs that the young person can go along to. Some young people belong to their local faith community.

Tuesday (evenings) they go to theatre group... Wednesdays they help run the Wednesday club... Thursdays they go to a dance group and Friday they are actually in...

Mondays are free days but he tends to go down to either the snooker club with his PA or they go to football if the weather is nice.

Where the young person meets the eligibility criteria for the local authority they should get support for day time activities. It may alternatively be possible to get direct payments and employ a personal assistant to enable the young person to do the things they choose.

He goes go-karting... with his PA.

At the moment there is a real worry that it is often going to fall to the family to ensure that the young person has a fulfilling life - or indeed that in some cases the young person has someone to look after them for part or all of the day, with the consequent implications for the parent's own employment and income.

You have the right to have a carer's assessment (see section 5). It is helpful to be clear about expectations that the young person should be able to lead a life more like any other young person - and not always to be reliant on the family for almost everything.

Friendships



Often it is hard for the young person to keep in touch with friends from school or college and they may need help with this.

He has direct payments and has a personal assistant... who helps him to keep in contact with his friends and to make new friends.

Young people may also be forming long term relationships or becoming engaged.

He has a fiancée. He has been going out with her for three years. He rings her on a Tuesday evening. He sees her at weekends.

Hugh and Jenny live some miles apart. Their relationship really is on the phone and when they see each other at a day centre. They are going on holiday to Center Parcs with their two housemates and their carers will go along too. It's difficult isn't it cos all their meetings are what I call supervised.

(Names have been changed)

See:

www.movingonup.info

Short term breaks

We have agreed going into respite... I think he will like it... hopefully it will be a preparation for him being away from us.

Transition planning should include planning for short term breaks if they are important to the young person and their family. Adult social care teams and possibly health trusts if the young person has complex needs should have several options. Health and social care trusts would be able to help in Northern Ireland. It is important that the breaks meet the needs of the young person and the family. The young person should have a chance to make new friends and have opportunities for activities they enjoy, while the family recharges its batteries.

There are several possible ways to get a break:

- the young person may visit another family, couple or individual
- the person offering the break may come to the young person's home
- there may be a residential unit where the young person can go for a break
- you may be able to use direct payments to get a break
- there may be a local befriending scheme
- there are places that offer holidays.

Breaks away from home are a useful way of preparing for the time when the young person leaves home. Nonetheless some parents report that they do not have access to breaks or that they are far too rare. The Government (in England) has given councils and the NHS more money for short term breaks.

Section 3: Moving from the family home



Where the young person is going to live should be part of the discussion in transition planning. Many young people will want to continue to live with their families, but others may have ambitions to live more independently.

His older brother and sisters had left home and he was going to do the same.

Young people are often advised to go on the housing register as it makes the local authority aware of the level of need in the area. In the past many young people would have been offered a place in residential care when leaving the family home. For some this is still their chosen option. Others opt for supported living.

In *supported living* the young person will have their own tenancy alone or with others, or own the house/flat. Support will be organised separately from the accommodation. Support may be organised by social services or Supporting People. Or the young person may employ their own staff or get them through an agency.

In residential care, the accommodation and care go together. In all other options they are separate. There should be a wide range of choices:

- Residential care where the person lives with others and has staffing often for 24 hours a day. Benefits and allowances pay for housing, food, care etc and each resident has a small personal allowance. The way to access residential care is through adult social care.
- Supported housing a house with staffing provided according to the needs of the tenants. They share the bills with the other residents. They usually access this through adult social care, or sometimes through the housing register.
- Floating support support ranging from a few hours a week to several hours a day, wherever the young person lives. This may be obtained through Supporting People.
- Shared ownership where they own part and rent part from a housing association and then need to organise support. They may achieve this directly with the housing association or through the housing register.
- Renting from the council or Northern Ireland Housing Executive or a housing association for this the young person has to go onto the housing register.

- Renting privately there are some implications for housing benefit that need to be looked into. They can go through an estate agent, the housing register or a housing association.
- Extra care housing or cluster flats where there are tenants who also have some extra support. A tenancy is usually accessed through adult social care, but sometimes through the housing register.
- Adult placements and supported lodgings here the young person either lives with a family or has their own room and possibly some support. This is accessed through adult social care.

The housing association owns the place... the rent is paid to them out of housing benefit... there's two regular carers and I think there's one or two reserves... They always try to send someone who the girls have seen before...

She owns a quarter and she pays rent on the three quarters she rents.

Some young people like to live alone. Others prefer to share. The importance of living with people that the young person chooses is now more widely recognised, although it does not always happen.

If someone goes into residential care, the home is responsible for providing the staffing. Although families will want to remain involved, they will not be called upon to give support. In supported living, families may wish to offer some support and may welcome this opportunity. Direct payments can also be used additionally for support. It is important to ensure the arrangements about the care of the young person are right for everyone.

See:

www.housingoptions.org.uk www.dimensions-uk.org for Lost in Transition? A home of my own.

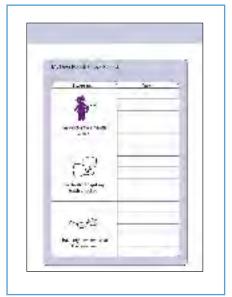
Checklist of things to consider about housing



If living away from the family home in young adulthood is being considered, it is important to establish whether the young person wants to live alone or with others. Sometimes there is an assumption that living alone with support is what a young person will aspire to. Some people value this – but others may find this a very lonely option.

The various options will need to be looked at. There is likely to be greater choice and independence in supported living and many young people appreciate this. Residential care currently may offer more security in staffing.

Section 4: Health



The move to adult health services can be unsettling. It is important that there is a health transition plan or health action plan that complements the other plans (such as a person centred plan) that the young person is being supported to make during the transition stage.

Health plans or health action plans should cover all aspects of health, both health promotion and health problems: for example, diet, dentistry, physiotherapy, speech and language therapy, mental health and well being, hearing and sight problems, etc.

Often, as well as going to the GP for run-of-themill health problems, the young person may

have seen a paediatrician or attended a child development centre. Between sixteen and eighteen, more usually at eighteen, the young person will be expected to access other adult health services, although the GP should provide some continuity. GPs are now expected to do annual health checks on most young people with learning disabilities from the age of eighteen under something called the Directed Enhanced Service (DES).

There has been a lot of concern over recent years about the quality of health care for some people with learning disabilities. Generally a young adult will attend mainstream health services. If they have complex physical or emotional difficulties, they may have access to additional support from specialist learning disability services.

The Government in England is going to pilot personal health budgets which may help some people to get more responsive services; and so these are something to look out for in the future.

To promote good health, diet and exercise continue to be important and there are some useful easy read resources to encourage this. The young person's emotional well being is likely to be enhanced by a good social life and that is not always easy to achieve (see section 2).

He was unfit, he'd had pneumonia and been in hospital and then when he came home he was very debilitated and just sat in front of the telly... I was beginning to panic that his heart had been affected and so we went to see the doctor and he said, no - things are just as stable heart wise but he's unfit. Let's try to find something and a friend just suggested this (gymnastics).

Checklist on health

In the transition process



Does the plan include the full range of services and supports the young person might need: for example dentistry, eye care, communication, mobility, mental health, postural care?

If you attend appointments with the young person

Have you checked whether appointments can be arranged at a time that is least likely to cause distress?

Do health professionals communicate with the young person in a way that is appropriate for them and in a way that they like?

Do health professionals treat you, as a family carer, as an equal partner in health care?

If the young person is an inpatient in an acute hospital

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

Health promotion

Are there any ways you could encourage the physical and mental health of the young person: for example, encouraging exercise and a good diet?

Section 5: Getting support in your caring role



get as much support as possible.

As we have said, as a family carer you will play a large part in supporting the young person through the transition process and as a young adult. It is important to get support for yourself. Over recent years the Government has recognised that family carers are very valuable to our society and has offered some help. Although there is a long way to go before families get the support they really need, it is useful to know what is available and to make sure you

A carer's assessment

Carers have the right to have an assessment of their own needs and local authorities must inform carers about this, as a result of Carers Acts in 1995, 2001 and 2004, the Carers and Direct Payments Act (Northern Ireland) in 2002 and the Community Care and Health Act (Scotland) in 2002. Local authorities have been given the *power* to provide services following an assessment, although there is no *duty* that they must provide the service that someone is assessed as needing. They must also consider whether the carer works or wishes to work and whether the carer is pursuing or wishes to pursue education, training or leisure activities. They can enlist the help of housing, health and education to support carers' needs. Family carers can have direct payments.

Sometimes family carers say that their concern is to get the best support for the young person and that will satisfy them. They may say that it is not worth having an assessment as it does not necessarily lead to getting help for themselves in their caring role. However, sometimes a carer's assessment can also lead to a better service for the person they care for.

To get a carer's assessment you need to contact your local authority or Health and Social Services Trust in Northern Ireland. Before your assessment, you need to be thinking about the impact of caring on your life:

- Does it affect your sleep or your health?
- Are you able to work if you want to?
- Do you have time for other members of the family, activities or for yourself?
- It will be helpful to talk about the kind of needs the person you care for has but they of course will be able to have their own assessment.

This is about your needs to enable you to continue caring. You may have to pay for some services depending on the local policy for charging.

The carers allowance

If you are caring for someone over sixteen for 35 hours a week who has the Disability Living Allowance at the middle or higher rate for personal care, you may be eligible for the Carers Allowance, which is currently £53.90 a week. You must not be in full-time education or earning over £100 a week after certain deductions. These include income tax, national insurance and part of your pension contributions. You are also allowed up to half what remains for paying for care for your relative.

Carers' organisations are trying to persuade the government to increase the carers' allowance as it is not large.

Catherine's Story



Catherine's mother said:
"After we found out about direct
payments we contacted a social worker,
who came to see us and carried out
a carer's assessment first and then a
needs assessment on Catherine. She
then took our case to panel and we
were awarded a direct payment of six
hours a week. The social worker gave
us information about an agency that
supports people on direct payments.

We needed someone to be flexible - to work evenings and weekends as the direct payment was for Catherine's social needs. We found a 'buddy' as Catherine calls her - a young woman of a similar age and who drives. Catherine interviewed her and liked her straight away. The agency helped us with advert, the contract, wages and holiday entitlements. Catherine and her 'buddy' have nights in where they paint nails, watch DVDs, go on the Nintendo Wii, or just watch the soaps!! They go out for meals, go bowling, go line dancing, go to the pub, go shopping and now the weather is getting better, they have been to the park. The nice thing is that Catherine also now knows her buddy's family and friends and they meet together at the pub sometimes and she's been to a family party.

The benefit for Catherine is that she has someone her own age to go out with, has made new friends, has a break from us and can do what she wants to do - it has given her more confidence in decision making. The benefit for us is that we have time together as a couple or if I'm at work and my husband wants to go out, there is someone for Catherine and much as we love her, it gives us a break."

Government plans for more help for carers

A New Deal for Carers (2007) and a ten year Carers Strategy (2008) set out plans to help carers. These include:

- A telephone helpline launched in Spring 2009: 0808 808 7777
- A training programme, Caring with Confidence, enabling family carers to get information and helping them to advocate for their families, either through group learning or distance learning
- More money for emergency cover and short breaks
- More support for getting back into work
- Pilot for GPs to do annual health checks with carers.

The Government is saying that by 2018 carers should be able to have a life of their own alongside their caring role, have the support they need and be seen as experts. For many family carers that may seem a long way off.

I've got a job to go back to on September 3rd for four days a week... and I have got to have that morning off or some time that morning to see if I can get him on the courses...that's why I am a bit stressed at the moment...

In Northern Ireland there is a strategy entitled *Caring for Carers: Recognising,* valuing and supporting the caring role (2006).

Working with professionals

Caring with Confidence has a useful session examining how family carers can best work with professionals to achieve the care that their family member wants. In our research, many family carers spoke enthusiastically about a professional who made so much difference to the life of the person they care for. At other times they have been disappointed.

Thad an excellent social worker two years ago, but... I don't know whether she disappeared with ill health problems... this one that came in at Easter is supposed to be permanent but I've great difficulty in reaching her...

When there are difficulties

When there are difficulties and things go wrong, it is best to see if they can be resolved through meetings and discussions. It is helpful to keep a record in writing if there are problems. Local authorities and Health and Social Services Trusts in Northern Ireland have complaints procedures, which you can ask about. If you have a complaint about a care home, care service or agency, you would contact:

- The Care Quality Commission in England (also covers health services)
- The Regulation and Quality Improvement Authority (RQIA) In Northern Ireland
- The Scottish Commission for the Regulation of Care in Scotland
- The Care and Social Services Inspectorate in Wales.

People with learning disabilities and their family carers have rights with respect to the way they are treated by public bodies as a result of the Human Rights Act (1998). For example if someone's serious health condition was neglected because of their caring role, this could be an infringement of their right to life.

As a result of the Disability Discrimination Acts 1995 and 2005 disabled people, but not family carers, have rights in the areas of education, employment, access to goods, facilities and service, including large private clubs and transport and owning or renting property. Public bodies are required to promote equality of opportunity. Recently the Coleman Judgement acknowledged that carers can experience discrimination by association. An Equality Bill will bring together previous legislation, further tackle discrimination and extend rights to carers.

The Equality and Human Rights Commission has helplines across the mainland. www.equalityhumanrights.com

See: www.equalityni.org www.nihrc.org

In Northern Ireland there is Section 75 of the Northern Ireland Act 1998 which says that public bodies should have due regard to promoting equality of opportunity between specified groups including people with dependents and disabled people.

Obviously going to court would be a last resort, but you could ask questions if you felt that rights were being infringed. Complaining formally should be an unusual occurrence, but it is important to ensure that poor or even criminal practice does not go unchallenged.

Influencing policy

Sometimes family carers want to get involved in influencing policy, nationally and locally. The Government in England is increasingly recognising that the voice

of family carers needs to be heard. In England, Learning Disability Partnership Boards have family carer representatives. They can meet other representatives through regional networks and representatives go to a National Valuing Families Forum. Many organisations in England supporting families with an adult member with a learning disability are linked through the National Family Carer Network which provides information and gives these families a voice.

There are courses that may be helpful to family carers:

- Caring with Confidence
- Partners in Policy Making courses for parents of disabled children and disabled adults
- Sharing the Challenge courses for parents of disabled adults developed from Partners in Policy Making courses
- Family Leadership courses run by the Foundation for People with Learning Disabilities.

See

http://www.nhs.uk/CarersDirect/carers-learning-online/Pages/Welcome.aspx www.partnersinpolicymaking.co.uk

There are of course problems for many family carers in getting involved because of their caring role.

Tused to get asked to go to a lot of these things but I just found the conflict with trying to work as well, and it was so time consuming...I found the kids were being neglected, you know, my own kids, I was having to sort of say Mum's out another evening. I just couldn't sort of do all of it so I purposely shut my ears now if anything like that comes up.

(Parent)

Wherever possible, it is important for the voice of family carers to be listened to. They need to be heard in a way that fits in with their lives and truly reflects the various and different experiences of families.

Concluding remarks



Families have told us the following are important during transition:

- knowing how the system works
- making sure the planning is focused on the wishes of the young person and not focused on slotting into what is available
- making sure that the different agencies communicate, have high expectations and work together creatively
- getting the adult social care team on board early
- having information about opportunities early; knowing about things like Access to Work and self directed support
- having more than one meeting on transition planning: follow up meetings are important
- thinking about other options after school; not just college
- for the young people to have their confidence built up as they move into adult life
- for young people to be prepared for greater independence
- for young people to be prepared for the possibility of work through getting advice, interview practice, work experience and volunteering.

We hope that this booklet will help to address these issues for families and enable them to support the young person to get the best possible life as a young adult.

Resource list: Useful addresses and websites

Foundation for People with Learning Disabilities

www.learningdisabilities.org.uk

Sea Containers House 20 Upper Ground London SE1 9QB Tel: 0207 803 1100 fpld@fpld.org.uk

Down's Syndrome Association

www.downs-syndrome.org.uk

National office

Langdon Down Centre 2a Langdon Park Teddington TW11 9PS Helpline: 0845 230 0372 info@downs-syndrome.org.uk

Northern Ireland office

Unit 2 Marlborough House 348 Lisburn Road Belfast BT9 6GH Tel: 0289 066 5260

Wales office

Suite 1 206 Whitchurch Road Heath Cardiff CF14 3NB Tel: 0292 052 2511

Down's Syndrome Scotland

www.dsscotland.org.uk

158/160 Balgreen Road Edinburgh EH11 3AU Tel: 0131 313 4225 info@dsscotland.org.uk

Enable

www.enable.org.uk

2nd Floor, 146 Argyle Street, Glasgow G2 8BL Tel: 0141 226 4541 enable@enable.org.uk

Contact a Family

www.cafamily.org.uk

209-211 City Road London EC1V 1JN Tel: 0207 608 8700 info@cafamily.org.uk

Mencap

www.mencap.org.uk

National office

123 Golden Lane London EC1Y ORT Tel: 0207 454 0454 information@mencap.org.uk

Northern Ireland office

Segal House 4 Annadale Avenue Belfast BT7 3JH Tel: 0289 069 1351 mencapni@mencap.org.uk

Wales office

31 Lambourne Crescent, Cardiff Business Park, Llanishen, Cardiff CF14 5GF Tel: 0292 074 7588 information.wales@mencap.org. uk

The Mencap Helpline

The Learning Disability Helpline Mencap 4 Swan Courtyard Coventry Road Birmingham B26 1BU

Freephone: 0808 808 1111 Minicom: 0808 808 8181 http://www.mencap.org.uk/ page.asp?id=2236

Down's Heart Group

www.dhg.org.uk

PO Box 4260 Dunstable Beds LU6 2ZT Tel: 0844 288 4800 info@dhg.org.uk

Down Syndrome Education International

www.dseinternational.org

The Sarah Duffen Centre

Belmont Street Southsea PO5 1NA enquiries@downsed.org Tel: 0239 285 5330

Transition Information Network

www.transitioninfonetwork.org.

Council for Disabled Children

8 Wakley Street London EC1V 7QE

Tel: 0207 843 6006

About the Foundation for People with Learning Disabilities

We promote the rights, quality of life and opportunities of people with learning disabilities and their families. We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information

www.learningdisabilities.org.uk

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation.

Foundation for People with Learning Disabilities

Sea Containers House 20 Upper Ground London SE1 9QB United Kingdon

Telephone 020 7803 1100 Fax 020 7803 1111

Email fpld@fpld.org.uk Website www.learningdisabilities.org.uk

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