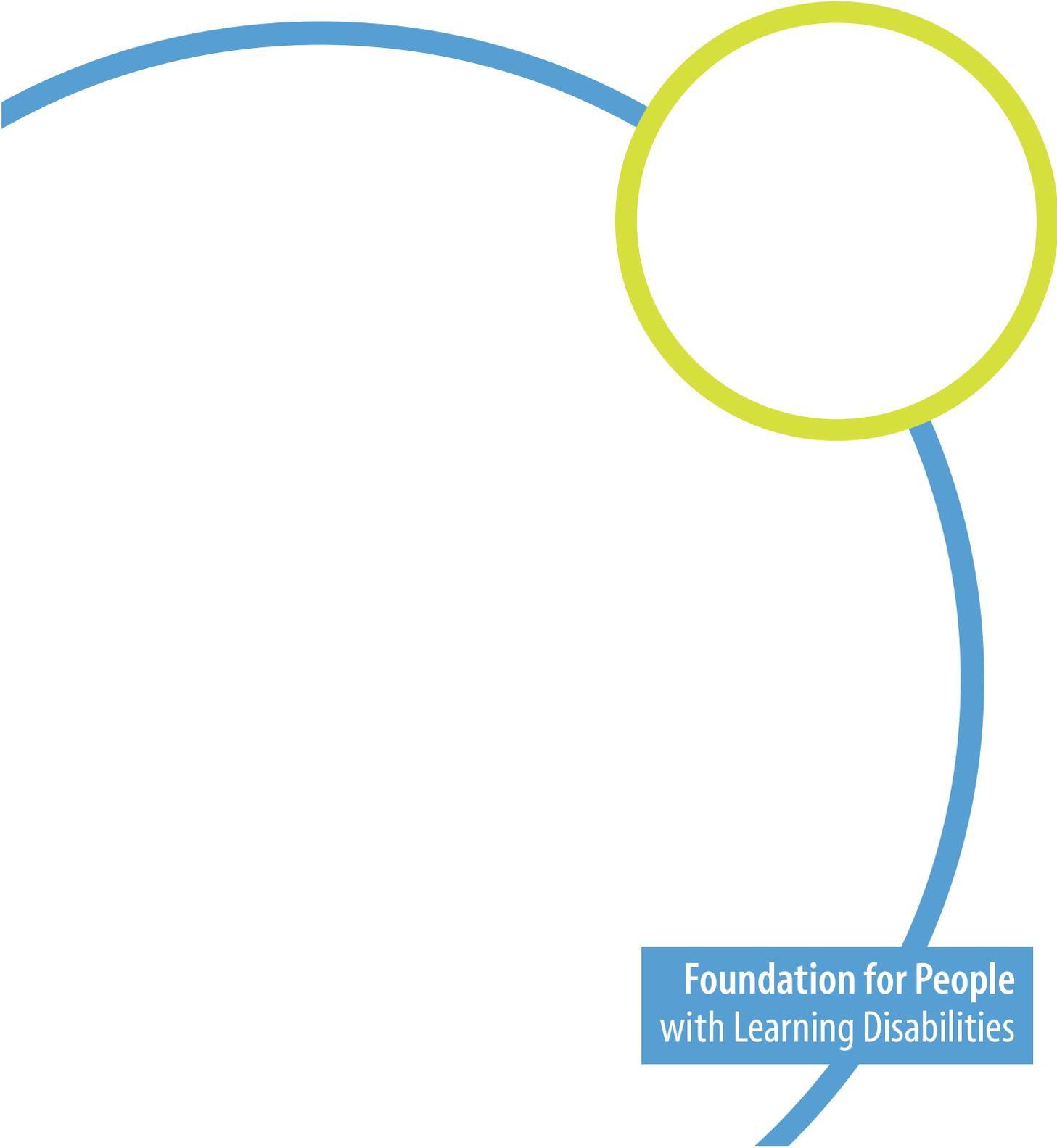


What kind of a future?

Supporting young people with Down's syndrome
to lead full lives after they leave school



Foundation for People
with Learning Disabilities

Acknowledgements

Our thanks to the ten young people and their families for talking to us and allowing us to tell their stories and to use their photos. We could not have written the booklet without them.

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Pictures courtesy of the young people and their families as well as Photosymbols.



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Introduction

The What kind of a future? project

The Foundation for People with Learning Disabilities was fortunate to receive a legacy to improve the lives of people with Down's syndrome. We looked at recent research and talked to people with Down's syndrome, their family members and professionals. We heard that one of their greatest concerns was what happens to young people when they leave school. They may not have enough to do during the week and they may find it difficult to keep in touch with their friends.

We also heard that some young people do lead full lives. We talked to ten young people and their families to find out what had enabled them to bring about the changes they wanted. We made sure we talked to young people who need lots of support as well as to young people who need very little.

This booklet

We have written this booklet based on their stories. We hope that it will empower other young people, their families and friends. We want to emphasise that it is not always easy to bring about changes. These often took a long time for the young people we talked to.

This booklet is for young people and their families, friends and supporters to read and talk about together. We do not think you will want to read and talk about it all at once. You may want to read and make plans about one or two areas at a time. It is written in plain English and there is an easy read summary. At the end of each section there are ideas for young people and information about some easy read websites and booklets. There is a final section on useful addresses and information for families.

It is not easy to bring about lots of changes all at the same time! We think that person centred planning is a good place to start.

'If you did this (person centred planning) with every person... it would be a fantastic thing to do.'

-a father of one of the participants

The next steps

The project is continuing. We are going to help three groups of young people and their friends and families in three different places to make plans and bring changes to their lives. They will use this booklet. We will learn what has helped them. We would love to hear about your experiences in the next year too.

We will then publish lots more information. The information for young people will be easy read. There will be publications for families and professionals. We are working closely with organisations that support young people with Down's syndrome.

This booklet and publications in the future will be useful for other young people with learning disabilities as well as young people with Down's syndrome.

To find out more about the What kind of a future? project please visit www.learningdisabilities.org.uk or contact Jill Davies at:

jdavies@fpld.org.uk

0207 803 1141

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Sea Containers House
20 Upper Ground
London
SE1 9QB

Easy read summary



• • • • • We met ten young people with Down's syndrome.



• • • • • They have lots of activities and hobbies.



• • • • • Some have a paid job or volunteer.



• • • • • Some go to college.



• • • • • Some live in their own home.



• • • • • They keep in touch with their friends.



• • • • • Some had a person centred plan.



• • • • • Some had a circle of support.

Direct Payment



• • • • Some get support by using direct payments.



• • • • Some need more support than others in their lives.



We hope their stories will give you ideas and help you to plan what you would like to do. You may like to read this booklet with a friend or a member of your family and to talk about your plans with them.

You may want to read about different topics at different times. It can take a long time to bring about changes in your life. It is not always easy.

The ten young people



Aaron is 19. He lives with his family in Scotland. He left school when he was sixteen. He has direct payments. He has personal assistants to support him for 52 hours a week, he is registered blind. He does lots of different things. He delivers the local free paper and saves the money for his holidays. He works as a volunteer in a local restaurant putting glasses in the dishwasher, bottles in the bin and clearing the tables for a couple of hours a week. His favourite activity is playing the samba drums with a group. He also does go-karting and swimming. He goes to the local amusement arcade and to the pub with his personal assistant. At home he likes chilling out in his pyjamas. He enjoys watching music shows on the television.



Adam is 23 and lives with his parents and brother Jack, in Kent. He has a paid job with the local learning disability team three mornings a week. He does the post, photocopying and shredding papers. He goes to college. He does computing, typing, money and life skills. He enjoys gymnastics, snooker, visiting the library and going to the local Down's syndrome group. He is a member of his church. He keeps in touch with his friends and fiancée by texting and by phone. His person centred planning coordinator has been a great help to him. He has achieved his dream of having a job. Now he would like to have a place of his own.



Andrew lives near Glasgow with his family. He is 20. He loves gymnastics. He goes to a gymnastics club on two evenings and on Saturdays. On a Saturday, he is there most of the day as he is also a co-instructor in the sessions with younger children. He has won a lot of medals, including some at the Special Olympics. He has a heart condition, but gymnastics keeps him fit. He goes to college and is doing a transition course three days per week. This course will help him with his life as a young adult. He goes to a resource centre on one day. In the next two years he will do a college course called Careerwise. This course will help him to prepare to get a job. He sees his best friend at gymnastics, at college and at a social club every other Friday. He also keeps in touch on the phone. He and his family are planning for him to have short breaks so that he will get used to being away from his home.



Chris is 24. He shares a house with his friend in Norfolk. They have help for thirty hours a week. On Tuesdays he has work experience. He helps with cooking in a community centre. On other days he goes to a day centre where he learns lots of things like gardening and about using computers. His girlfriend, Katy, is there some days. His evenings and Saturday mornings are often busy - he goes to drama and dance groups and runs a disco on a Wednesday. He likes to go out on a Sunday with his housemate and their supporter. They have to do the housework too! They have been on holiday to Center Parcs with their friends and their support workers.



Christopher is 26 and lives with his parents in Essex. They are a big family. They meet up regularly and have a great time. Christopher is well known in his local community. He likes parties, pubs, night clubs, barbecues and visiting friends. He has been a best man at a wedding. Christopher needs to take oxygen with him wherever he goes because of his heart condition. He has travelled widely and has been as far as India. He likes clothes and bought a designer jacket in Paris. He goes to a small day centre five days a week, where there is a farm. Two days a week one of the support workers from the centre goes with him to college. He does cooking, dance, drama and music. Each month he goes away with an organisation that arranges short breaks. He uses direct payments to pay for a lot of his support.



Gethin is 21. He lives with his mum, dad and brothers in South Wales. He is good friends with his cousin next door and sees him most days. Sometimes he goes out with him or with his brothers. He has direct payments and for three hours each week he goes out with his personal assistant. Usually this is on a Monday. He plays football on Saturday mornings with family and friends and goes to the gym and pub on Wednesday evenings. He loves music, sometimes goes to gigs where his cousin's group is playing, enjoys the computer and Tae Kwon Do. He had a work placement in a pub and is now doing work experience in Morrisons. He would like to have a job in a pub and eventually to have his own house.



Karen spent some time at a residential college, which helped her to be independent. She is 28 and has been living in her own flat in London, ten minutes walk from her family home, since 2004. She has direct payments. She interviewed her own staff and has four support workers help her during the week. She has to do housework and shopping. She goes to college and chooses the courses she wants to do each year. She is doing art, music and massage. Each week she goes to the local sports centre to keep fit, using weights, trampolining and going to classes. She uses buses, the underground and taxis. She goes to clubs on four evenings. She spends most Sundays at home with her family. She goes to church if she is not attending the Down 2 Earth group which meets monthly. She enjoys the cinema and playing football with her college friends.



Katy is 26 and shares a house in Norfolk with a friend. They have support workers with them all the time. Katy goes to two centres during the week. At one centre she learns skills like using money, travelling on buses, cooking and gardening, which will help her get into work in the future. She sees her boyfriend, Chris, on two days, when she is at this centre. At the other centre, she does cooking, sewing and art. In the evenings she likes watching DVDs and listening to music. On Wednesdays she goes out to a Gateway club. She has to do the housework and shopping. Some Saturdays she goes to a drama group where she sees Chris. She spends part of the weekend at her family's home. On Sundays, she goes to church where she takes the collection and in the evening she enjoys a jazz club.



Paul is 28 and lives with his family in London. He had a person centred plan and a circle of support to help him decide what he wanted to do. He wanted a job. In fact he has two - one in a pub and the other in a warehouse. He has had help from a supported employment agency. He has also earned money as a photographer. He learned about photography at college. He has direct payments and has a personal assistant, Amin, who helps him to keep in contact with his friends and to make new friends. He goes out with Paul in the week. Paul likes going to the pub, swimming, football and going to the gym. Paul and his family will be going to Amin's wedding in India soon. At weekends he chills out or goes out with his family. Sometimes he stays over at his friend's house or his friend stays over at his house.



Sara lives in Cardiff with her family. She is 24. She 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. Sometimes she has to stay away over night. She goes to a dance studio on Wednesday evenings and Saturdays all day. She does tap, ballet and jazz. She also goes to several drama groups and takes part in shows. When she has time, she likes shopping with her sister, Bethan, or going to the health club with her mum. She loves being with family and keeping in touch with close friends. She enjoys eating out, going to the cinema and bowling. At home she relaxes by listening to music and watching Eastenders, Coronation Street and Neighbours. She has a person centred plan. Her motto is 'Down's syndrome, so what?'

Person centred planning

Many of the young people we talked to have done a person centred plan. This helped them to decide what they wanted to do.

Person centred planning is a way of planning all aspects of your life. You are at the centre of the planning. With support you need to decide how you want to make your plans, who you would like to help you, how you want to record them and who you need to help you make your plans happen.



A person centred planning coordinator helped **Adam** and his family. They met together to talk about the future. They put down all their ideas on a big sheet of paper. They talked about Adam's gifts. He is especially good at gymnastics. He does gymnastics in his leisure time. He decided he wanted a job. He now works in the office at his local learning disability team. His next aim is to get a flat.

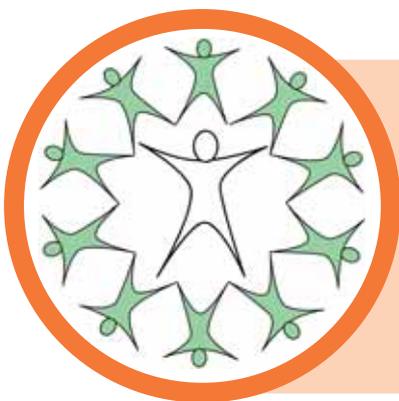
Aaron had some person centred planning meetings before he left school. His mum, his teachers, his support assistant, someone from college, a careers officer and sometimes a social worker were there. Aaron came along for part of the meeting but if he did not want to sit there he would leave. They talked together about what Aaron was good at. They made an Essential Lifestyle Planning Book. Aaron's mum and his psychologist made a CD-Rom with Aaron, which showed what he enjoyed and what he wanted to do.

Essential Life Style Planning is one kind of person centred planning. It means discovering what is important to a person in everyday life, how they would wish to be kept safe and healthy and what support they need to do what they want to do.

Paul met several years ago with his person centred planning facilitator. They talked about what he had done at college and what he had done since college like working at a supermarket. They made a PATH. Paul wanted to work in a pub and to see more of his friends. Because he needed others to help him he set up a circle of support. He invited the circle to meet with him in his home. In his circle were some people he had worked with in a gardening project, his mum and dad, sisters and some of their friends. They talked more about what he was good at, what he wanted to do and how they would make this happen. He now has two part-time jobs. He also has direct payments. Amin is his personal assistant and supports him to keep up with his friends and to make new ones. Paul no longer has regular circle meetings because he is quite settled however he may need their support in the future.

PATH stands for **Planning Alternative Tomorrows with Hope**. If you have a PATH you meet with others to talk about your dreams, what would need to happen to achieve your dreams, what is going on at the time in your life, what would be the next steps and who needs to help.

When she was a volunteer **Sara** met a PCP coordinator who suggested she should have a person centred plan and do a PATH. Sara set up a circle of support in her house. Her circle included her friend from across the road, two college tutors, someone who had worked in her school, her Godparents, some family friends, her parents, sister and grandma. They helped her to plan all the things she wanted to do. Although she has not yet achieved her dream to be on the stage in the West End Theatre every night, she has been on the stage in the Millenium Centre in Cardiff. The circle does not meet regularly at the moment, as she has a job and a full social life and lots of hobbies, but the people in it are still there to help her.



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. That person is in charge and decides who they want to invite, what they talk about and where it should be held.

Getting a person centred plan

If you are in England you should have a review and begin your transition planning in year 9 in school. In some areas they are using person centred approaches. You could ask that your review includes a person centred plan. In Wales too you will start planning for the future in year 9. A careers adviser from Careers Wales will get involved. In Northern Ireland a transition planning coordinator may attend your planning meetings. In Scotland you can do a person centred plan as part of your Future Needs Assessment.



You can do a person centred plan at any time. You will need to do it again from time to time as your life changes.

A person centred plan can help you to get the life you would like to lead. Here are some things you may wish to do:

- Find out if your local authority has a person centred planning coordinator or facilitator who could help you.
- Think if you would like to do a PATH or an Essential Lifestyle Plan or find another way to think about what you are good at, your gifts, what you enjoy, what your dreams are and who could help you to achieve your dreams.
- Remember your person centred plan includes all the things you do in your life including what you need to keep you healthy.
- Think about whether you would like to have a circle of support, who you would invite and where you would meet. Make sure everyone is comfortable in your meetings, including yourself and that everyone enjoys themselves.
- Think about how you would like to record your ideas. Would you like to draw or write on big pieces of paper? Do you want to use photos? Do you want to make a book?
- Make sure that people sign up to your plan and do the things that they say they will do.
- If you want to use services or to have a direct payment, ask a Connexions worker or a social worker or care manager if they can help, as they will need to be involved.



More information for young people about person centred planning

- You can download *My Personal Planning Book* by the Foundation for People with Learning Disabilities at www.learningdisabilities.org.uk
- There is a workbook, *Listen to Me*, which you can get off the Valuing People website www.valuingpeople.gov.uk/dynamic/valuingpeople137.jsp
- You can download a paper called *What is Person Centred Planning* at www.helensandersonassociates.co.uk/reading_room.htm
- There is a website designed, planned and run by people with learning disabilities to help others stay in control of their lives. www.handsoffmyplan.co.uk
- See the Trans-Active website for help with making plans www.trans-active.org.uk/teenz/index.htm

Circles of support

Circles Network

www.circlesnetwork.org.uk

Potford's Dam Farm
Coventry Road
Cawston
Rugby
CV23 9JP
0178 881 6671

Advocacy

People First

www.peoplefirstltd.com

4th Floor, Hampton House
20 Albert Embankment
Vauxhall
London
SE1 7TJ
020 7820 6655
general@peoplefirstltd.com

Direct payments

Many of the young people we talked to use direct payments. This helps them to get the support they need to do the things that are important to them. Some get direct payments to pay for support for them during the week instead of using a day service or going to college. Others use it to pay for staff to support them to live in their own home or to have a social life. Some people do not want a direct payment and prefer to use the services and support provided by their local authority.

Direct Payment



A direct payment is money given to you by your local council social services department. It is a different way of getting support. You use it to buy the support you need. Your local council social services department gives you the money instead of a service. You agree with your social worker or care manager how you will spend the money. You have a special bank account. Most people who would use social services could get a direct payment.

Aaron lives with his family and uses his direct payment to have support 52 hours a week. His personal assistants help him to do the things he wants to do. He likes going to the cinema, to the pub and go karting, for example. They also support him in his jobs.

An agency employs his personal assistants. The agency tells him and his mum how much money needs to be paid from his bank account to the agency each month. They have agreed that his mum organises for the money to be paid. She is called his appointee.

Paul also lives with his family and has direct payments to have a personal assistant 15 hours a week. He supports Paul for some of the time in his work and for some of the time in his leisure activities and for keeping in touch with friends.

Paul uses an agency. Paul and his family wrote the advert and person specification for the job and interviewed people in the agency's offices. They advertised the job in colleges, universities and youth clubs in their local area. Paul and his family write down the hours the personal assistant has worked each month. The agency works out how much is needed to pay his personal assistant and Paul writes the cheque.

Christopher lives with his family. He has lots of health needs. He needs support all the time. He uses the money from his direct payments to have support for some of the time at home, to pay to go to a small day service, to go out and about in his community and to pay for a carer to go with him to evening classes. He goes away on breaks for a few days each month and uses his direct payment for this too.

Christopher and his mum choose the staff. They pay some money each month to an agency to pay the staff.

Karen lives in a flat on her own. She uses direct payments to have support to live independently. She has a team of four personal assistants. She has a personal assistant sleeping over and has support for some hours most days. She also uses an agency.

Getting direct payments

When you leave school or college, some of you will need extra help to make the most of your life. If you get or have been assessed by your local authority social services as needing a care service you may be able to get a direct payment. Not everyone wants a direct payment as they may prefer to have services provided by their local authority.

Here are some things to do, if you think you would like a direct payment:

- Talk to your friends and family about what you would like to do and why you want a direct payment.
- Find out more about direct payments by talking to friends who have them already.
- Ask your social worker about whether you can have a direct payment. If you do not have a social worker contact social services and ask if someone can talk to you about getting a direct payment.
- If you are able to have a direct payment, the social worker will tell you how much you can have and you will agree how you will spend the money. You will have a special bank account.
- If you are able to have a direct payment, decide whether you and your family wants to deal with the money and pay the personal assistants or carers or whether you would like an agency to do that for you. (You can still appoint your own staff if you like).





More information for young people on direct payments

You can download *An Easy Guide to Direct Payments: Giving you the choice and control* from the Department of Health website www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/Directpayments/index.htm

You can order hard copies from

DH publications

PO Box 777

London

SE1 6XH

0870 155 5455

You can download *An Easy Guide to Direct Payments in Scotland: Giving you choice and control over your social work services* from the Scottish Consortium for Learning Disability website

www.sclد.org.uk/data/file/file_78_An_easy_guide_to_direct_payments.pdf

You can order hard copies from

The Scottish Consortium for Learning Disability

Adelphi Centre Room 16

2 Commercial Road

Glasgow 5 OPQ

0141 418 5420

adminstrator@sclد.org.uk

In some areas you can have individual budgets. A social worker or care manager will look with you at all the money you have, which will include benefits, direct payments and any services you use. They will agree with you how you want to organise all your support. This approach is called In Control.

This DVD is for families, *Getting in Control: People with learning disabilities, their families, individual budgets and self-directed support*. You can order it from:

HFT, Merchants House

Wapping Rd

Bristol BS1 4RW

0117 930 2600

Learning new skills and going to college

Many young people we talked to are learning new skills. Often this is at a college.

Young people do courses to help them have skills for everyday living and to get a job. Sometimes they do special courses for young disabled people. Sometimes they do courses that are for everyone.

Andrew is doing a transition course at college in the day time. He does reading, writing and number work and some courses on living skills. He also does tasters, seeing what other courses he might like to do. This will give him ideas about what he wants to do when he leaves college. Over the next two years Andrew will be doing a course called Careerwise that will help him prepare to get a job. He will spend two days a week at college and two days on a work placement.



Adam is doing computing and typing in a class in a morning and a class in an evening. He did some tasters in plumbing, car mechanics and electrics when he was at college.

Christopher is doing a cookery course at college in the evening.

Sara went to the local college to study business studies and child care skills.

Several young people enjoy doing courses in art, music and drama.

Karen chooses new courses each year. At the moment she is doing art, music and massage courses in two colleges. Other years she has done photography, gone to a woman's group and done computing. When she was younger she went to a residential college to learn to live independently and she now lives on her own.

Paul chose to do a photography course and he can now earn some extra money from taking photos for people that he and his family know.

If you would like to go to college:

- Get information from your local colleges and adult education centres about what is available. Find out about open days and go on visits.
- Talk to the Connexions or Careers Service about what you might like to do at college.
- Talk to your family and friends about what you might like to do and how much of the week you would like to spend at college.
- Decide whether you would like to do a special course to help you have skills to live more independently or to give you skills to get a job. It might be possible to do both!

- Decide whether you would like courses such as drama, music and art.
- A few people might want to go to a residential college. It can be hard to get the money to do this, but you could talk about this when you have meetings to make plans for leaving school.



More information for young people on learning new skills and going to college

- Look at the website of **Moving On Up!**
www.movingonup.info/en/learning-working
- Skill: National Bureau for Students with Disabilities has two useful information sheets for students:

Applying to Further Education;
Funding for Disabled Students in Further Education.

You may like to read these with a family member, friend or supporter.

You can download copies at www.skill.org.uk/info/infosheets/

Or you can contact

Skill: National Bureau for Students with Disabilities

Head Office
Chapter House
18-20 Crucifix Lane
London SE1 3JW
0207 450 0620
Fax: 020 7450 0650
skill@skill.org.uk

Information:
0800 328 5050

Getting a job

Four young people we talked to have paid jobs. **Sara** and **Paul** got help from supported employment agencies and job coaches.

In **supported employment** you spend some time with a job coach and maybe others who are close to you talking about what you enjoy, what your skills are and what kind of job you would like. Then it is time to look for a job, to do any training before you start the job, and to plan for your first day. The job coach will help you learn on the job and then he or she will spend less and less time with you as you feel more confident. He or she will stay in touch with you to make sure everything is OK.



Sara works 30 hours a week as Partners in Politics officer at Mencap. She goes round schools and colleges in Wales, providing training sessions. These are about how important it is for everyone to have their say in politics. This is a great job for her as she likes meeting people and doing presentations. She heard about the job from a friend, found out about it and applied. At her interview she had to do a presentation.

Previously she has had several jobs paid and unpaid. These helped her to find out what she liked doing. When she was at college she did work experience in an office and with small children in a nursery. After college she and her family got in touch with Careers Wales. Through Careers Wales she got help from a supported employment agency. She then did some work experience at a drama and arts centre. Her first paid job was as a receptionist in a special school. She saw an advert in a local paper. She was on her own quite a lot and found this a bit lonely so she left. She then did work experience at another special school, one day a week in the office and one day a week as a class room assistant. She learnt a lot from being with the children and that has helped her in her job now.

Paul had work experience stacking shelves in a supermarket when at school but didn't like it. He had paid work with a carpet fitter carrying things for him. After he left college he worked on a gardening project for 18 months.

He and his family then got in touch with a supported employment agency and they talked about the things Paul would like to do. He wanted to work in a pub. His circle of support also helped him to plan what he would like to do. Paul started some work tasters to see what he liked best. He now has two paid jobs. Two mornings a week he works in the warehouse of a shop, taking clothes out of boxes and putting them on rails.

One afternoon he works for a few hours in a pub, collecting glasses and putting bottles on shelves. A job coach has helped him to learn the jobs.

Adam did work experience in a library while he was at school. This made him realise that he would like a job. He did several taster courses while he was at college. He got help from a local supported employment agency. He heard about the job in the office of the local learning disability team from them. He had to have an interview.



For over two years since leaving college he has worked there part-time. He does the post, photocopying and shredding.

Aaron has a job delivering the local free paper on Tuesdays and Wednesdays. His personal assistant helps him. He gets paid for this. He also does voluntary work at a local restaurant for a few hours one day a week.



Getting a job

You may have decided that you would like to have a job, for example, when you did your person centred plan.

If you would like to have a job here are some things you might do:

- Talk to friends, family and others who know you well about the kind of job you might like.
- Do courses at college or other centres which might help you to get the skills you would need.
- Talk to people who are helping you make plans. These might be your social worker, if you have one, or in England your Connexions adviser.
- Make contact with Job Centre Plus and ask to talk to the Disability Employment Adviser. In Scotland you can make contact with an adviser in Careers Scotland and in Wales with an adviser from Careers Wales. In Northern Ireland you can get advice from the Careers service.

- Ask if there are any supported employment agencies in your area that could help you.
- Try to get some work experience. School or college should be able to give you advice.
- See if you can practice doing an interview with a friend or family member or member of staff.
- Talk to a supported employment agency or the local Benefits agency about how earning a wage will affect your benefits.



More information for young people on getting a job

- Look at the website of Moving on up!
www.movingonup.info/en/learning-working
- Employment Opportunities give information, advice and support for finding a job. They also offer training courses to help you get ready to apply for a job. Employment Opportunities have lots of offices in the UK. To find out which one is near to you call 020 7448 5420. Visit the Employment Opportunities website www.opportunities.org.uk
- You can download *Education and Employment for People with Learning Difficulties* at www.learningdisabilities.org.uk
- You can get some booklets from the Valuing People Support Team
I can get a job: A step by step guide about how to get a job
I want to work: A guide to benefits and work
You can work it out!: Supporting you into work

You can download them at
www.valuingpeople.gov.uk/dynamic/valuingpeople120.jsp
or you can get your own copy by emailing or asking a friend or a member of your family to email valuing.people.info@dh.gsi.gov.uk

Other activities

The young people we talked to lead busy lives.

Katy uses two day services. At one she does swimming, cooking and gardening. At the other she does cooking, art, sewing and learns about using computers.

On Wednesday evenings she goes to the local Gateway club. She goes to a drama club every fortnight on a Saturday morning. On a Sunday she goes to church where she takes the collection and in the evening she goes to a jazz club with her dad.

She enjoys relaxing in her home which she shares with her friend. She likes reading magazines and watching DVDs and videos. Her favourites are musicals.

Gethin plays football on Saturday morning with his friends and family. He goes to the gym with his dad. He enjoys the martial art, Tae Kwon Do and belongs to a club. He goes bowling once a month with the local Down's syndrome group. One evening he often goes out with his personal assistant. They may travel into town and go bowling or for a meal.

His cousin has a band and he loves going to gigs. He likes meeting his friends in the local pub. At home he likes watching TV and DVDs and being on his computer.



Day services

Several other young people spend part of the week at a day service.

Chris goes to a day service four days a week and is learning skills like gardening and cooking.

Christopher attends a small day service three days a week. There is a farm and gardening. There is a sauna, reflexology and aromatherapy.

Andrew goes to a day service one day a week, where he goes swimming and plays snooker.



Sport

Many of the young people do sport. **Andrew** has won medals for gymnastics at the Special Olympics.

Adam does gymnastics too. He likes snooker.

Each week **Karen** goes to the local sports centre to keep fit, using weights, trampolining and going to classes. She plays football on Sundays with friends from college.

Sara belongs to a health club and goes swimming.

Paul goes to the gym with Amin. He enjoys playing football with friends.



Drama, dance and music

Sara spends a lot of her week outside work doing drama and dance. She belongs to two drama groups and appears in shows.

Aaron belongs to a samba drumming group.

Chris belongs to two drama groups and a dance group. **Andrew, Katy** and **Paul** go to a drama club too.

Social clubs

Several young people belong to clubs for disabled people.

Andrew goes to a club for young people with learning disabilities once a fortnight. **Chris** helps to run the Wednesday club where they have a disco. **Karen** goes to the Down 2 Earth group once a month which is run by the Down's Syndrome Association.



Out and about

The young people talked about lots of things they do in their local communities. **Andrew** and **Christopher** enjoy going out to the local pub. **Aaron** sometimes goes to the pub or goes out with his personal assistant.

Paul sometimes goes clubbing with his sister and **Christopher** goes clubbing with his mum and with his personal assistants. **Chris** likes going clubbing too.

Some said they like going out for a meal. Some go to the cinema or theatre. **Sara** and **Katy** love going to musicals.

Some like shopping, especially for clothes, CDs or DVDs. Sara likes going clothes shopping with her best friend or her mum or her sister. **Christopher** has a Burton's card to buy his clothes.

Aaron likes going go karting or to the local amusement arcade.

Adam enjoys going to the library. **Karen** and **Adam** go to their local churches.

Paul's hobby is photography and he has earned money taking photos on special occasions.

At home

Young people described how they like to chill out at home. They watch television. Soaps and Friends seemed to be the favourites.

Often they watch videos or DVDs or listen to music. Several have video games.

They enjoy being with their families. They talked about family occasions, parties and barbecues. **Aaron** likes going out with his family in the car at weekends.

Those who live independently have to do the housework and go shopping.

Things you might do if you want to have more activities

- Talk with your family and or friends about the things you are interested in. You might like to set up a circle of support. You might want to look again at your person centred plan.
- Go to the local library to find out about local clubs and activities.



- Ask your social worker if he or she knows about local activities you would be interested in. If you do not have a social worker, contact your local social services office to find out about any local activities.
- If you need support, you might want to see if you could have direct payments to pay for a personal assistant. You could ask your social worker or care manager. If you do not have a social worker or care manager, again contact your local social services office.



More information for young people on other activities

- Find out from your local Down's syndrome group or local Mencap about activities that they know about in your area. If you do not know how to contact your local groups, ask the national offices.
- **Beautiful Octopus**, a popular nightclub run by people with learning disabilities (Heart n Soul).
www.heartnsoul.co.uk
 The Albany Theatre
 Douglas Way
 Deptford
 London
 SE8 4AG
 020 8694 1692
- **Stars in the Sky**, a dating/friendship service run by people with learning disabilities based in London.
www.starsinthesky.co.uk
 First Floor Cara House
 341A Seven Sisters Road (Eade Road)
 Tottenham
 London
 N15 6RD
 020 8 809 4442
info@starsinthesky.co.uk

Friends, relationships and keeping in touch

Friends were important to all the young people we talked to. Often they made their friends at school, college, work, day centre or at the clubs they go to. Sometimes it was hard to keep in touch with friends, especially after they had moved on.

Andrew meets up with friends at his gymnastics club and at the social club he goes to once a fortnight. He has known one good friend since primary school. They go to the same college, gym and social club. They phone one another. It is hard to keep in touch with some friends because they live a long way away.



Paul has a personal assistant, through his direct payment. He helps him to keep in touch with the friends he made on the gardening project he used to go to. He also supports Paul to make new friends. He and his best friend enjoy meeting up for a meal. Sometimes his friend comes to stay at his house or he goes to his friend's house. Paul uses the phone or his mobile to get in touch with his friend.

Sara has made a lot of friends through her dance and theatre groups. She keeps in touch by phone or by texting. She met best friend at college. They like going bowling and shopping. Sara says, 'we have always been there for one another so that is good.'

Adam has a fiancée. They met when they were at college. They talk to each other on the phone and may meet up in the week and at weekends. They are going on holiday with their families to the Isle of Wight. He also meets an old school friend once a week for lunch.

Making and keeping friends

It can be hard to make friends and to keep in touch with friends. Many of the young people had help from their families.

Here are some things you can do:

- Join a club or activity where you may make new friends.
- You may want to see if you can have a direct payment to pay for a personal assistant who can help you to keep in touch with old friends and make new ones.
- You may want to set up a circle of support.
- Contact your social worker or your social services department to find out if they have schemes to help people make friends.
- Find the best way for keeping in touch with friends for you.
 - You may need help from your family or support staff.
 - You may want help with using the phone or a mobile.
 - Not everyone likes texting, but you may want to learn about this from a friend or family member.



Travel

Some young people we talked to travel independently. Others go with family or carers. It is easier to travel on buses in the towns. Often there are fewer buses in the country areas.

Christopher is a great traveller. He goes with his carers or family by taxi, on the train or buses. He particularly enjoys flying.

Adam did a course at college about independent travel. He goes on the train, underground, bus or by car. He takes the bus to work. He has a Freedom Pass. He enjoys planning routes and can help his family if they are not sure how to get to a place.

Andrew goes to his day centre in his mum's car. He goes in a minibus to college. His parents or the parents of friends take him to his gymnastics club. He is learning to travel on buses with a group. He would find it easier if he lived on a bus route where he could travel directly into a town.

To travel more independently:

- If you are travelling independently let your carers know where you are going and when you will return.
- See if you can do a travel course in college or at a day centre.
- If you have a job you may be able to get help to learn how to travel from a supported employment agency.
- You may want to ask a family member or friend to help you practise new journeys.
- Ask a friend or family member to help you to see if you can get the Disability Living Allowance mobility component.



Living in your own home

Three young people we talked to live away from their families. They come back to see their families often.

Katy lives in a house in Norfolk with another young woman. Her housemate needed someone to share her house with her. Her social worker arranged for her to meet Katy and they got on well. The house belongs to a housing association. Their social workers have arranged for them to have support all the time.

Chris went to college after he left school. He lived there during the week. When he left college, he said, 'I am not coming home.' He wanted to live independently like his brother and sisters. He rents his house from his cousin's boyfriend. He asked his friend to share the house with him. Their social workers have arranged for them to have support for 30 hours a week.

Karen went to residential college when she was younger and so she got used to living away from home. She has been living in her own flat in a block of flats in London since 2004. She owns part of the flat and a housing association owns the rest. She pays rent to the housing association. She uses direct payments to pay for the support she needs.

Some young people spend time away from their family. This helps them to find out how they feel when they are away from their family home. **Christopher** goes away each month for a few days with his carers. An organisation helps him to arrange these breaks.

Sara sometimes stays away overnight because of her work.

Gethin goes to stay with another family one weekend each month.

Several young people told us they would like to live independently in the future.



Planning to have your own home

If you think you would like to live independently here are some things you can do:

- It is a good idea to get used to spending some time away from home to find out how you feel. Your social worker may be able to help you to arrange short breaks away from home. If you do not have a social worker you can ask social services to send someone to talk to you about this.
- You need to talk with your family and find out more about all the different ways you can live independently.
- You need to think about whether you would want to live on your own or with friends. You might want to ask your friends if they are interested.
- You need to think about the kind of support you would need.
- Make sure you have day activities in place first, as you can get lonely being alone with nothing to do.



More information for young people on living in your own home

- Housing Options has an easy read website and you can also ask them to send you information. You can get free advice on the phone.

Housing Options

Stanelaw House

Sutton Lane

Sutton

Witney

OX29 5RY

www.housingoptions.org.uk

0845 456 1497

You can also look at the Moving On Up website

www.movingonup.info/en/housing/

Money

The young people we talked to often said using money was difficult, although a couple of young people had good money skills.

Chris and his friend take money out from the Post Office each Friday. They keep it safely at home. They decide how they are going to spend it. They need money for food, travel, clothes, presents and leisure. They have cards for their gas, electricity, water and TV and pay money towards these each week. For example they take the card for electricity to the local Post Office and pay a sum towards their electricity costs. Chris also can use a bank card and draw money from a cash point machine (can also be called a 'hole in the wall').



Originally his mum helped him to budget. Then his carer helped him, but now he can do it himself.

Gethin likes to spend his money on holidays and DVDs. He can draw £10 a week with his card from the cash point machine. Someone who works in a bank, who is in his circle of support suggested that he arranged to get his money this way.

Adam did a college course to help him understand money. He has two bank accounts, but no bank card. He goes to the bank with his mum each week to get money out.

Karen goes with her family to get money from the cash point machine. Her dad helps her with paying the bills. She writes down everything she spends so that she knows what she has left.

Here are some things you could do to help you with money:

- You could see if there is a course at a college or centre to help you understand about money.
- You can arrange with the bank that you can get your money in small amounts if you wish.
- An easy way of remembering PIN numbers is to use numbers of familiar things (eg. addresses, dates)
- You can ask family and friends to help you with your money, so that you get used to buying things in a cafe or a shop. It is important that you only ask people you trust.





More information for young people on money

- You can look at the **Moving On Up!** website www.movingonup.info/en/money-benefits/
- You need to make sure you are getting the benefits that you should have.
- You may be able to have the Disability Living Allowance, Income Support or Incapacity Benefit or money from the Independent Living Fund or other benefits. You can ask a family member or friend to help you find out. You can ring the **Benefits Inquiry Line** 0800 882200.

We hope this booklet will give you, your family and friends **lots of ideas** about things you might do in your life. You may want to **ask your family** or friends to help you to look at the **websites** or contact the organisations on pages 36-42.

Of course it is not always easy to **achieve your plans** and it can take time. Sometimes you may want or need to **change** your plans. That is of course OK too.

It is best to **plan** one or two things at a time. Sometimes they will be small things like a **holiday**. At other times they will be big things like a **new place** to live.

Useful addresses and information for families

Addresses for general information

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

Graham House

Knockbracken Healthcare Park

Saintfield Road

Belfast

BT8 8BH

0289 066 5260

Wales office

Suite 1

206 Whitchurch Road

Heath

Cardiff

CF14 3NB

0292 052 2511

Down's Syndrome Scotland

www.dsscotland.org.uk

158/160 Balgreen Road

Edinburgh

EH11 3AU

0131 313 4225

info@dsscotland.org.uk

Mencap

www.mencap.org.uk

National Office

123 Golden Lane

London

EC1Y 0RT

0207 454 0454

information@mencap.org.uk

Northern Ireland office

Segal House

4 Annadale Avenue

Belfast

BT7 3JH

0289 069 1351

mencapni@mencap.org.uk

Wales office

31 Lambourne Crescent,

Cardiff Business Park,

Llanishen, Cardiff

CF14 5GF

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

www.askmencap.info

Enable

www.enable.org.uk

6th Floor,
7 Buchanan Street,
Glasgow
G1 3HL
0141 226 4541
enable@enable.org.uk

Contact a Family

www.cafamily.org.uk

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

Down's Heart Group

www.dhg.org.uk

PO Box 4260
Dunstable
Beds
LU6 2ZT
0845 166 8061
info@dhg.org.uk

For information on a range of issues

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

There are many great links from this site and it is a good place to start looking for information.

For information on transition

Transition Information Network

www.transitioninfonyetwork.org.uk

Trans-Active (run by Mencap)

www.trans-active.org.uk/adult/index.htm

Planning our Futures

Young people's perspectives.

www.transitioninfonyetwork.org.uk/filestore/TIN_188_136870.pdf

All Change – Transition into adult life

A resource for young people with learning difficulties, family carers and professionals.

Produced by HFT and available from Pavilion Publishing:

www.pavpub.com

0870 161 3505

Making Choices about Leaving School

Skill information Booklet

www.skill.org.uk/page.aspx?c=10&p=106

Person Centred Planning and Advocacy

Valuing People Support Team

Basic information and links to a variety of person centred resources,
www.valuingpeople.gov.uk/dynamic/valuingpeople135.jsp

Families Leading Planning

Information for families and individuals interested in person centred planning
www.familiesleadingplanning.co.uk

Person Centred Planning: Making it work in the UK

by Barbara McIntosh
www.learningdisabilities.org.uk

Person Centred Planning: Key features and approaches

by Helen Sanderson
www.paradigm-uk.org/pdf/Articles/helensandersonpaper.pdf

Circles Network

<http://www.circlesnetwork.org.uk/>

Potford's Dam Farm
Coventry Road
Cawston
Rugby
CV23 9JP
0178 881 6671

Circles of Support – Building Inclusive Communities

Video and book set available from Circles Network

Creating the Possible

DVD available from Circles Network

In Scotland **Equal Futures** supports people with learning disabilities and their families in planning for their futures and setting up lifelong circles of support.

www.equalfutures.org.uk/

Building Community through Circles of Friends: A practical guide

to making inclusion a reality for people with learning disabilities

by Christine Burke

Available from the Foundation for People with Learning Disabilities 0207 803 1100,
www.learningdisabilities.org.uk

Circles of Support

by Hazel Morgan

A briefing for the National Family Carer Network. Hard copies currently available from naomi.shannon@hft.org.uk

The National Family Carer Network

www.familycarers.org.uk

The Home Farm Trust

Merchants House

Wapping Rd

Bristol

BS1 4RW

0117 930 2600

Advocacy Resource Exchange (ARX)

Helps people find advocacy services.

www.advocacyresource.net

0845 122 8633

helpline@advocacyresource.net

Direct payments

There is information about direct payments and self-directed support with useful links on the Valuing People website www.valuingpeople.org.uk

For information about direct payments from the Department of Health visit www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/Directpayments/index.htm

Particularly useful for downloading is *A guide to receiving direct payments from your local council: A route to independent living*

Hard copies can also be ordered from DH publications
PO Box 777
London
SE1 6XH
0870 155 5455
dh@prolog.uk.com

The Care Services Improvement Partnership (CSIP)

Information about individual budgets www.individualbudgets.csip.org.uk

In Control

Lots of information.
www.in-control.org.uk

Self Directed Services Network

www.sdsnetwork.org

Useful advice and information about your local area can be obtained from

National Centre for Independent Living

www.ncil.org.uk

250 Kennington Lane
London
SE11 5RD
0207 587 1633

Self-directed support: Direct payments, individual budgets and In Control

By Hazel Morgan

A briefing for The National Family Carer Network. Hard copies currently available from naomi.shannon@hft.org.uk

The National Family Carer Network

www.familycarers.org.uk

The Home Farm Trust
Merchants House
Wapping Rd
Bristol
BS1 4RW
0117 930 2600

Education

Applying to Further Education; Funding for Disabled Students in Further Education

Information sheets available from Skill.

<http://www.skill.org.uk/page.aspx?c=10&p=106>

Skill Scotland

0131 475 2348
<http://www.skill.org.uk/page.aspx?c=21&p=109>

The Learning and Skills Council

Helpline 0870 900 6800
info@lsc.gov.uk

For information about adult learning also contact Information Team, NIACE (National Institute of Adult Continuing Education)

NIACE

www.niace.org.uk

Renaissance House
20 Princess Road West
Leicester

LE1 6TP

Tel: 0116 204 4200/1

Fax: 0116 285 4514

Minicom: 0116 255 6049

enquiries@niace.org.uk

Employment

To find a supported employment agency, or wider employment support organisations, contact **BASE** in England on www.afse.org.uk or in Wales www.ldw.org.uk or in Northern Ireland www.niuse.org.uk or in Scotland www.suse.org.uk

Moving into Work

A fact sheet for families, can be downloaded from www.niace.org.uk/research/HDE/Documents/Parents.pdf (There is also a fact sheet for people with learning difficulties).

Employment Opportunities

A voluntary organisation that helps people with disabilities into employment
www.opportunities.org.uk

Job Centre Plus

Make contact with Job Centre Plus and ask to talk to the Disability Employment Adviser. In Scotland you can make contact with an adviser in Careers Scotland and in

Wales with an adviser from Careers Wales. In Northern Ireland you can get advice from the Careers service.

Ask about government schemes that may help you get a job.

Ask if there are any supported employment agencies in your area that could help you.

Activities

Drake Music Project

Enables disabled people to discover their musical ability. It has regional offices in London, Bristol and Manchester.
www.drakemusicproject.org

Good Access Guide

Directory of accessible leisure pursuits.
www.goodaccessguide.co.uk

What's On Guide on the internet.

www.whats-on-guide.co.uk

National Disability Arts Forum

Aims to create equal opportunity for disabled people in all arts. It provides advice about access, participation and inclusion.

NDAF

www.ndaf.org

59 Lime Street
Ouseburn Valley
Newcastle
NE1 2PQ

0845 260 1166

ndaf@ndaf.org.uk

Clubs

For information about **Gateway** clubs
www.askmencap.info
or telephone the Mencap helpline
0808 808 1111

Travel

To find out about the **Disability Living Allowance mobility component**, ask at your local Job Centre Plus, Social Security Office or ring the Benefit Inquiry Line
0800 882200

The website is
www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10011731

If you receive the Higher Rate Mobility Component of the Disability Living Allowance then you can use that to obtain a car through **Motability**
www.motabilityonline.co.uk

A Department of Transport Report: Travel Training Schemes

A review of travel training schemes in England has some useful information and websites.

www.dft.gov.uk/pgr/inclusion/tts/ttsreview

Your local authority publishes a transport policy each year for young people who are 16-19 and in full time education.

It sets out how you can get help with costs and gives information about transport services in your area. www.moneytolearn.direct.gov.uk/transportcosts/

Living away from home

Housing Options

Has useful advice on its website and you can also ask them to send you information. You can get free advice on the phone.

www.housingoptions.org.uk

Stanelaw House

Sutton Lane

Sutton

Witney

OX29 5RY

0845 456 1497

Money and benefits

Young people may be able to claim some of the following benefits at the age of 16.

- Disability Living Allowance (DLA)
- Incapacity Benefit
- Working Tax Credit
- Income Support
- The Social Fund
- Housing Benefit
- Council Tax Benefit
- Jobseekers Allowance
- Health Benefits
- Independent Living Fund

(The government is planning to replace incapacity benefit and other incapacity for work benefits with an employment and support allowance in November 2008.)

For information on the **Independent Living Fund** call 0845 601 8815 or visit www.ilf.org.uk

The Down's Syndrome Association has leaflets on benefits, including one on benefits at 16. It can be downloaded at www.downs-syndrome.org.uk/pdfs/Benefits%20at%2016%20April%202007-new.pdf

Or ring 0845 230 0372
or email info@downs-syndrome.org.uk

Mencap has a series of useful leaflets on money
www.askmencap.info
Phone the Mencap helpline 0808 808 1111,
or email help@mencap.org.uk

ARC

Has produced easy read information on Chip and Pin and banking for people with a learning disability.
Call ARC on 0124 654 1662

Dosh Financial Advocacy

Helps people with learning disabilities to be more independent and have more control over their money.
www.doshfinancialadvocacy.com
0845 880 0347

Barclays

Has made a booklet called *It's your money*. It is written for people with a learning disability who may find banking services difficult to understand. To get a free copy of the booklet call 0800 400 100.

Partners in Policymaking

Leadership courses for disabled adults and parents of disabled children: these enable participants to find out more about how they can influence services and also make informed decisions about the help they need for themselves or their children.
www.partnersinpolicymaking.co.uk



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

If you would like to find out more about our work, please contact us:

Foundation for People with Learning Disabilities

Sea Containers House
20 Upper Ground
London SE1 9QB
020 7803 1100

www.learningdisabilities.org.uk

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, registered charity number 801130.

**Foundation for People
with Learning Disabilities**