

# **MOVING ON** *to adult life*

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The cd-rom has been designed to help you find your way around the resource pack.

- You can go back to the contents page from any point.
- Click on the arrow or item in the contents list to go to that section.
- Click on the web or email addresses in the text and you can go straight to that organisation.



***A resource pack written  
by families for families***



We hope you find this useful and enjoy using the cd-rom as well as using the book.

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# Moving on to Adult Life

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**Moving on to Adult Life**

# **PART 1: INTRODUCTION**



## Moving on to Adult Life

# PART 1: INTRODUCTION

This resource pack is intended to help young people who have additional support needs and their families to plan for the future. It was started by families in one place – Fife – but we soon realised that the approaches and ideas here are likely to be useful to families and workers in other places.

The pack has contact points where you can get more information. Some of these are useful for anyone living in the UK, and some are good international contacts. We've given references to places in Fife and other local projects as examples of the type of services and community resources that are useful. You will probably have equivalent places in your area – and if not, you can always start something like them (or even better) where you live.

The next section explains who we are and how we developed the pack. We then thought it might be useful to explain about Fife, and about the current arrangements for people with disabilities in Scotland. A lot of people helped us develop this pack and will be part of whatever happens next; this is at the end of this part of the pack.

## Who we are

We are parents who live in Fife. Some of our children have additional support needs, and they all have the usual problems of being a teenager. Some of us have a son or daughter who is now a young adult: we wanted to share our experience of finding our way through the processes and decisions that happened when our children were leaving school. Some of us wanted advice to help our teenager who has additional support needs and the rest of the family through the next few years. We decided to work together to develop a resource pack, which we thought could benefit many young people in Fife (initially) and their parents.

## Why we developed this pack

For most young people, growing up and making the decisions about what you are going to do as an adult is hard. It can be confusing and an emotional roller-coaster for young people and a time of worry for their parents. But it is a lot harder when the young person has additional needs. And having to cope with social care and health services, and the way that services are organised, makes it even harder. From the experience of families and young people with disabilities – everywhere, not just in Fife – children’s services and adult services don’t seem to talk to each other. Instead, we have to communicate with them both.

There are many forms and assessments for many different types of support. If you ask for the wrong thing, or don’t know about something, your child and the rest of the family can miss out. Once a decision is made, it seems that it is hard to change it – even though your circumstances might have changed, and you may have wanted to keep all your choices and options open. On top of all that, you are having to cope with your child’s disability, which usually means lots of time is taken up doing things which are easy for other families, and you are even more tired than other parents with teenagers.

We think it can all be easier and better for young people and their families. This pack brings together what we have learned, and what other people have learned. We hope that it will be useful for a lot of other families.

We also want our ideas and experience to be used when people are planning services and strategies. Over the next year or so there are going to be developments in Fife which we hope will lead to significant improvements in the choices and opportunities for people with disabilities and their families.

- ⇒ Local Area Co-ordinators are getting appointed as part of the implementation of the Same As You programme.
- ⇒ Local Authorities and the NHS are developing strategic plans which are intended to improve the quality of services for children and young people, and for people with disabilities, and the choices open to them.
- ⇒ In some areas staff are trying to improve the co-ordination between services that support children and the community care services for adults.
- ⇒ More advocacy projects are getting started.

Because services are developing over the next year, the detailed arrangements around which services are available in each local area and how to get access to them are likely to change. But families still need help in making choices and decisions now. So this pack concentrates on giving help to plan for the future. It tells you about some of the places where you can get more detailed information and who can help you. We don't expect that it will all be relevant to you right now, or that every family will need all of it. But we have tried to bring together the ideas and practical contacts that might be useful to you over the next few years.

We hope this pack will have real benefits for people, by helping them to have:

- more choice for young people, especially people who need extra support as they move away from schools and children's services
- better information and reassurance for their parents and families
- greater participation by young people in determining their own future, and influencing the decisions that are made about them
- easier access to the range of services which can give advice and offer opportunities.

We also hope it will help people who work in services and families to work together. This is a time when young people and their families have a lot of contact with both children's services and people who plan and run services for adults. This is the start of the young person's relationship with services and people who will support them through their adult lives.

We aren't saying that everything is easy, and that it will all work out exactly as the young people and their families want it to. We are saying that it is worth having dreams and starting off being ambitious, and taking the opportunities and help that you will find on the way.

## Our starting point is summed up here.

- ➡ Thinking about the future, and wanting the best for the people we love, is the natural thing to do.
  - ➡ It is natural for parents to worry about all their children as they move through to being adults, and especially about children who have additional support needs.
  - ➡ It is also natural for young people to be unreasonable, take risks, have huge ambitions and not spend too much time worrying about the consequences or practicalities.
  - ➡ We should all have high expectations for every young person – for what they can contribute and what they will achieve.
  - ➡ All of this is about people having a life, and how all sorts of services and other people can bring resources and supports to help make things happen.
- ➡ There are people in formal services – and in all sorts of ordinary, not-care-services organisations – who would like to work in different ways with you and your family, if you can explain what will be helpful.
  - ➡ It is OK to ask for what is out there.
  - ➡ It is also OK to ask for something different.
  - ➡ It helps when everyone involved – staff and professionals as well as the young people and their parents – know what each young person is like.
  - ➡ We all make the best decisions we can on the information we have at the time. When we get more information, or more experience, we might want to make changes to what we decided earlier. This doesn't mean we made a mistake earlier.

## About Fife

Fife is on the east side of Scotland. The population is about 350,000. There are a few big towns and lots of smaller towns and villages. Fife used to be an important coal mining area, but since the mines closed these areas have had economic problems. The north of Fife is more rural, and there are old fishing villages along the coast. St Andrew's is in Fife, with the University, beaches and golf courses. Fife has higher rates of unemployment than other parts of Scotland. Tourism is important, and there is a growing interest in protecting the environment across Fife – it is one of the priorities in Fife's Community Plan. Fife is just across the Forth from Edinburgh and across the Tay from Dundee – which has meant more competition for housing from people who work in the cities. Public transport is fine if you are going between the bigger places, but getting about can be difficult if you don't drive and you want to travel in other parts of Fife or in the evenings.

All of this gives some great opportunities for young people who want to live in Fife, and some practical problems.

## Other sources

Fife Council, NHS Fife, CVS Fife and other organisations have a shared website, Fife Direct. It has details about a wide range of services and activities in Fife, and links to other sources of information.

Web: [www.fifedirect.org.uk](http://www.fifedirect.org.uk)

## About policies in Scotland and other places

The families who put this pack together have young people who have learning difficulties. Many of the examples here are about young people with learning difficulties, although we think the ideas will be useful to young people with many different types of additional support needs.

In Scotland, the national policy for people with learning difficulties is *The Same As You*, which was published in 2000. There are also national policies for people with learning disabilities for Wales and for England.

Each local area in Scotland has to produce a Partnership in Practice agreement, setting out what services they provide and what their plans are. The 2004 PiP for Fife is on the local websites such as [www.fifedirect.org.uk](http://www.fifedirect.org.uk). Most other local plans will be on the Scottish Executive's website, as well as on their local ones.

*The Same As You* said that each area in Scotland should introduce Local Area Co-ordinators. We think this development will make life much easier for children and young people who have disabilities and for their families, once it is fully implemented. This approach was developed in Australia, where it has made a difference to the lives of thousands of people. A Local Area

Co-ordinator helps families find the supports they want, from services or from ordinary resources in the local community. Outside the Box has produced a short background note, with links to places which will give more information.

Councils are also expected to develop a Children's Plan. But one of the problems here is that these sometimes don't give much attention to children and young people with disabilities. The national policy is *For Scotland's Children*.

From October 2004, all services throughout the United Kingdom – ordinary everyday places like shops and swimming pools as well as health and social care services – have to make their services accessible to people with disabilities. The Disability Rights Commission has more information on this.

## Other sources

There is a section on policies for people with learning disabilities on the Scottish Executive's website. It has the Same As You and the reports from Working Groups, and the local Partnership in Practice agreements:

[www.scottishexecutive.gov.uk/Topics/Health/Care](http://www.scottishexecutive.gov.uk/Topics/Health/Care), and choose the learning disabilities option

Information on various aspects of policy in Scotland affecting children and young people is at [www.scottishexecutive.gov.uk/topics/People/Young-People](http://www.scottishexecutive.gov.uk/topics/People/Young-People)

The Welsh Mental Handicap Strategy is at [www.wales.gov.uk/subisocialpolicy/content/mentalhealth/contents-e.htm](http://www.wales.gov.uk/subisocialpolicy/content/mentalhealth/contents-e.htm)

The policy for England for people with learning disabilities is Valuing People. There is information at [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)

The background note on Local Area Co-ordination and links to other sources of information is at [www.otbds.org](http://www.otbds.org)

The Disability Rights Commission has information on the Disability Discrimination Act

Disability Rights Commission  
Helpline  
FREEPOST  
MID 02164  
Stratford upon Avon  
CV37 9BR

Tel: 08457 622633

Textphone: 08457 622644

Web: [www.drc.org.uk](http://www.drc.org.uk) and [www.drc.org.uk/scotland](http://www.drc.org.uk/scotland)

We hope that this pack will give people ideas about how wider policies can support young people who have disabilities or other additional support needs, and their families. We have made some suggestions on ways young people and families can contribute your experience in Scotland. We hope that people in other places can use similar routes. We also hope that people will continue to swap information and ideas about what makes things change for the better.



## People who helped to develop this pack

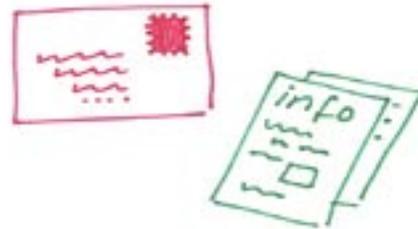
There are many people who gave us ideas and information, and the benefits of their experience – we are grateful to all of you. We also want to thank the people who encouraged us to put the pack together.

- ➡ Young people in Fife and their families who contributed ideas and gave us advice and comments as we worked on it.
- ➡ People with learning difficulties, other disabled people and families in other parts of Scotland told us about what they had found worked for them.
- ➡ Roseanne Fearon and other staff in the Fife Same As You project team, other staff in the many parts of Fife Council, NHS Fife and voluntary organisations in Fife gave us information.
- ➡ The Same As You team circulated an earlier version of the pack to families in Fife.
- ➡ Projects and organisations in other parts of Scotland and in other places gave us examples of the work they are doing – the ones that are featured in the pack and many more.
- ➡ Several of us had taken part in the Partners in Policymaking course run by SHS Trust, and many of the ideas and suggestions in this pack grew from what we learned through SHS.

- ➔ Eddie Bartnik, Al Etmanski, Michael Kendrick, John McKnight, John O'Brien, Jack Pearpoint and many other people gave us contacts and ideas.
- ➔ Al Etmanski, Julia Fitzpatrick, Jo Kennedy, Helen Sanderson and Helen Wilson let us use material from their books.
- ➔ Helen Wilson from Envision did the drawings.
- ➔ Anne Connor from Outside the Box put the pack together and made contact with other people and organisations.
- ➔ We got a grant from The Voluntary Action Fund to cover volunteers' expenses. We put in our own time and covered some expenses ourselves.

The pack reflects our experiences and our values. Where we have given stories, these are real experiences, though we have changed people's names if they preferred that. The views in it are ours.

We have tried to get the information as correct and up-to-date as we can: this is the information that was available to us at early April 2005. But services and information will change – hopefully for the better – so readers may still have to check out some of the details in the pack.



## What happens next

We want to develop a version of the pack which is accessible to young people and to people who have learning difficulties.

We want to make more contacts with people and organisations in Fife and other places who are doing ordinary things, to complement the services that are about disabilities - especially where this may lead to job opportunities and the chance for people to enjoy themselves as part of their communities.

We hope that these organisations will make it easy for young people with disabilities and their families to get up-to-date information about the services and supports which can help them have real choices.

We want to get in touch with other people who are working to give young people choices and opportunities to have a good life as part of their communities. We've included contacts for other information packs or training courses that we've heard of. Please tell us if you've been doing something in your area, and we'll do an update through Outside the Box.

We also hope that the ideas here will encourage more people in other places to put together a pack for their local area. If you want to use the material here to help you get started, contact Anne Connor at Outside the Box Development Support.



## How to contact us

We can be reached through

Outside the Box Development Support  
St Andrew's by the Green  
33 Turnbull St  
Glasgow G1 5PR

Tel: 0141 552 5592

Web: [www.otbds.org](http://www.otbds.org)

Email: [anne@otbds.org](mailto:anne@otbds.org)



**Moving on to Adult Life**

# **PART 2: WHAT A GOOD LIFE IS**



## Moving on to Adult Life

# PART 2:

## WHAT A GOOD LIFE IS

### What we want for all our children

“The one thing I want for all my children is that they are happy adults.”

*Mum who helped put this pack together*

When we first got together as a group of parents, we started from the position that we all want the best for all our children. But what do we mean by that? We found it helpful to try to think a bit more about what that might actually mean, and a helpful way to do this is to consider what being a happy adult means. Once you know what you are aiming for, it is easier to think about what types of supports – services as well as ordinary, everyday supports – can help this particular young person achieve her ambitions.

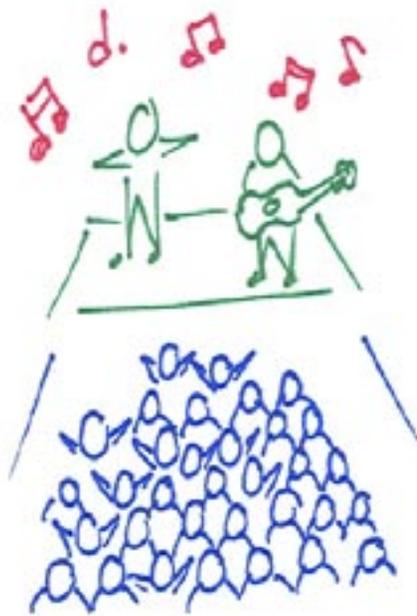
## What does being a happy adult mean?

### This is our list.

- ▶ Taking responsibility for our own life and choices.
- ▶ Having some stability and certainty in our life.
- ▶ Feeling happy.
- ▶ Being ok financially.
- ▶ Having as much education as I want and need.
- ▶ Being healthy and living healthily – ‘not just eating pot noodles’.
- ▶ Enjoying good emotional health.
- ▶ Having good experiences.
- ▶ Being able to do the things our parents couldn’t do when they were that age - ‘go on holiday with a bunch of other lads, travel’.
- ▶ Getting as many good experiences in life as possible.
- ▶ Having choices.
- ▶ Taking risks – ‘being less sensible than we [his parents] were, and than other people expect him to be’.
- ▶ Having friends, relationships.
- ▶ Being able to come back when we want to, gradually grow up and grow away – ‘I was about 30 before I stopped looking to my mum for advice on most things’.
- ▶ Having people in your life who love you and want to be with you - ‘people around them that will fill the space when we [his parents] are not there.’ ‘I hope they won’t be dependent on me.’

“It’s the same as for our other children. What this would mean in practice is different for every person.”





## What we suggest you do first

1. Make a list with this young person of what she thinks is a good life.

2. Ask her parents, brothers and sisters, friends and other people you respect to do their lists – what would they want for themselves, or any young person that age, as well as for this person?

3. Bring together the people who care about this young person and have a discussion about what is a good life for her.

- ➡ Bring all your lists together – what are the things that appear on all or most of the lists?
- ➡ Has someone seen something about her or for her that other people haven't noticed?
- ➡ What would each aspect look like in practice?
- ➡ What would the person be doing? Who would be with her? What would she be wearing? Where is it happening?

Plan to take your time to do this. Think about who is going to write down a summary of what you have talked about.

4. Allow yourselves some time – maybe a few days - to go away and reflect on people's thoughts and ideas. Then you can come back to your summary and think about some more questions.

- ➡ Is it all about disabilities and services?
- ➡ If so, how can it get more "ordinary"?
- ➡ How is it going to be achievable for this person?

There are other good examples of ways to think about life in books. Some of our ideas came from reading Al Etmanski's 'A Good Life', which has worksheets to help you think about things, as well as stories and examples of what has happened to real people. There are other useful books, CDs and videos available.

## Other sources

Al Etmanski: A Good Life: see [www.plan.ca](http://www.plan.ca)

There is a lot of useful material and ideas on the PLAN website.

PLAN has links with Philia, a network which is stimulating discussion across Canada about inclusive citizenship.

Web: [www.philia.ca](http://www.philia.ca)

There is also a lot of useful information through Inclusive Solutions

Web: [www.inclusion.com](http://www.inclusion.com)

Email: [inclusionpress@inclusion.com](mailto:inclusionpress@inclusion.com)

Some people we know have found Dave Hingsburger's books to be helpful. Dave sometimes does training in the UK with Paradigm.

Paradigm  
8 Brandon Street  
Birkenhead  
CH41 5HN

Tel: 0870 010 4933

Fax: 0870 010 4934

Web: [www.paradigm-uk.org](http://www.paradigm-uk.org)



## Story

David lives with his mum and dad. He has 2 older sisters – Kate and Sally – who now live away from home. Kate and Sally were back home at the holidays when David and his parents were talking about what would happen when David left school.

Kate and Sally thought there were going to be difficulties with this. One problem was that David didn't look like a 16 year old, and they were worried that other people might not treat him as if he was 16 and had his own ideas.

David was also not used to making decisions. For example, at their house everyone just ate whatever their mum decided to buy and cook, David's mum bought his clothes when she was in the shop anyway, and at weekends they had slipped into the pattern of David going with his mum and dad to the things they usually did.

Kate and Sally decided they needed to be bossy big sisters.

David was small, and a lot of his clothes were for children. The rest were just like his dad wore ('he looked 6 or 46, but never 16'). They cleared out their own wardrobes, and then did

David's and their mum's. They told their dad he was getting done next year. Then David, Sally and Kate went shopping, with Kate's boyfriend along for advice and help. While they were out they took David to places like coffee bars and restaurants. At every point, David was asked what he thought and what he wanted to do.

Over the next few months Sally and Kate kept phoning and emailing David. They asked him about what he was doing, and talking about what they would all do in the summer, or next year.

One night their mum got talking about how difficult it was for her to plan for David's future. When David was born he was very ill and his family were told he would probably die as a child. Since then, David had several major operations, and the problems were now sorted. But his mum remembered the times she thought David was going to die, and felt that even thinking about the future was tempting fate.

The family agreed that they were all going to think about the future for David, but really it was David who was making the decisions now. David's dad and one of his sisters would go to meetings with him if his mum felt she might get upset.

## Other sources

There are some good publications around growing up and planning for the future

The Transitions Information Network is an alliance of organizations and individuals who want to improve the experience of disabled young people moving to adulthood. There is useful material available on their website.

Transition Information Network  
c/o Campaign department,  
Scope  
6 Market Road  
London  
N7 9PW

Tel: 020 7619 7244  
Fax: 020 7619 7380  
Email: [bronia.kita@scope.org.uk](mailto:bronia.kita@scope.org.uk)  
Web: [www.myfuturechoices.org.uk](http://www.myfuturechoices.org.uk)

Transactive brings together young people with and without learning disabilities. There are sections of the website for teenagers and for parents and teachers:  
Web: [www.trans-active.org.uk](http://www.trans-active.org.uk)

Moving On Up is a multicultural website for young people with disabilities.  
Web: [www.movingonup.info](http://www.movingonup.info)

Growing Up – what young people liked is produced by BILD (British Institute for Learning Disabilities)

British Institute of Learning Disabilities  
Campion House  
Green Street  
Kidderminster  
Worcestershire  
DY10 1JL

Tel: 01562 723 010  
Fax: 01562 723 029  
E-mail: [enquiries@bild.org.uk](mailto:enquiries@bild.org.uk)  
Web: [www.bild.org.uk](http://www.bild.org.uk)

They also have the Plain Facts magazine.  
Phone 0117 923 8137 for free copies.

After 16 – what's new? is a resource by the Family Fund for young people.

Family Fund  
PO Box 50  
York  
YO1 9ZX

Tel: 0845 130 4542  
Web: [www.after16.org.uk](http://www.after16.org.uk)

Several projects have also produced packs and other material to help young people and their families make the transition from school to adult life. These may cover aspects which we have missed. Or you might find the contacts and suggestions there helpful in giving you ideas of what might be possible where you live.

The Edinburgh Development Group has had a project on transition.

Edinburgh Development Group  
John Cotton Business Centre  
Sunnyside  
Edinburgh  
EH7 SRA

Tel: 0131 476 0522

Web: [www.edg-sco.org](http://www.edg-sco.org)

PUSH has material for young people in accessible formats, as well as information for families.

PUSH, Perth and Kinross  
90 Tay Street  
Perth  
PH2 8NA

Tel: 01738 621929

Email: [enquires@pushinfo.org](mailto:enquires@pushinfo.org)

The Road Ahead brings together lots of material for young people, parents and staff who work with them.

There is a list of resources from many local projects at:

[www.scie.org.uk/publications/tra/resources/index.asp](http://www.scie.org.uk/publications/tra/resources/index.asp)

To order a copy of The Road Ahead call 020 7089 6840 or email [publications@scie.org.uk](mailto:publications@scie.org.uk).

## Questions to help everyone in the family keep well

Growing up is a stressful time for most young people, and for their parents. It helps if everyone keeps well, so they can all deal with whatever happens. It is also easier to make positive choices about the future when we are feeling well and in control of what is happening around us.

It can be difficult for everybody to live in ways that help them to stay well, particularly for families of young people who have additional support needs.

Research has shown that there are some things we all need to help keep us well.

- ⇒ People around us – whether we have family, friends, social contacts, and a sense of community.
- ⇒ Our own behaviour – what we eat, what we drink, taking exercise and so on.
- ⇒ The environment – where we live, housing that is good or poor and whether it suits our needs, whether we live next to fresh air or to pollution.

⇒ Income – for virtually every aspect of health and well-being, poorer people get unwell more often and take longer to recover than do people who are better off.

⇒ Access to health services.

For many families, the practical consequences of disability affect all of these ways to stay well.

Parents are likely to have fewer friends around them – if you can't get babysitters you don't go out so much; if you don't work there isn't the network of friends there; and some people have found that their extended families and friends drifted away or cut contact when there was a child who was 'different'. A disabled child's brothers and sisters may have found it harder to make and keep friends – maybe because other children weren't comfortable with someone who was different, or perhaps because their mum and dad had less time to provide the usual lifts and encouragement.

Often there is less money around because parents' job opportunities are restricted. Bringing up a child who has additional support needs can also involve costs that other families don't have to meet.

Parents of children with disabilities and other carers tend to take less care of themselves. They may just eat on-the-run, and not take enough exercise. Carers' mental health and well-being can also be overlooked. Using health services

may be a problem if visits to the GP or to a hospital need to be fitted in around the needs of the rest of the family. Parents can find that when they are themselves unwell, it can be difficult to get help to care for their child (or children) who has additional support needs. So what can you do to try to keep yourselves well?

## Our suggestions are:

- ➡ Think about what a good life means for you and for the other people in your family, as well as for the young person with additional support needs. Think too about things that you may have done and enjoyed at an earlier time in your life and that you might have forgotten about.
- ➡ Think about who and what supports you as a family. Talk to people who have known you for a long time and ask them about how they see you.
- ➡ Again, write these things down and give yourselves time to reflect, chat to other people, and add to your lists.
- ➡ Look for ways to build this in to what happens for the young person with the disability.
- ➡ If you think it will help, ask for advice and support for your needs, too.

This is our list of the things that keep us well.

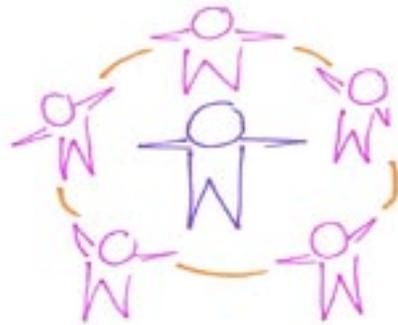
- ➡ Circles of Support for parents as well as for the young person with additional support needs.
- ➡ Time with friends and family, with our children.
- ➡ Being an ordinary family, doing things with all of us in ordinary places.
- ➡ Time with friends and family without the children.
- ➡ Friends.
- ➡ My job.
- ➡ Hobbies – painting, music, sewing.
- ➡ Gardening – ‘something to hack at when you are frustrated’, ‘getting close to the plants’.



- ➔ Meeting up with women friends and sharing a bottle of wine (or 2).
- ➔ Going to the cinema to see a grown up film.
- ➔ Getting out together – just the 2 of us – once in a while.
- ➔ Supermarkets that deliver the groceries to your door.
- ➔ Going for a swim or a walk.
- ➔ A friend who likes to stay in with 3 teenagers.
- ➔ A friend who helps with my ironing.
- ➔ More friends for the young person who has the disability.
- ➔ Opportunities for the children to do ordinary things with kids their own age with the support they need to do that
- ➔ Children who try to keep their rooms tidy and help with chores.

- ➔ Good flexible family support, rather than inflexible respite.
- ➔ GP being flexible about when I come for things like a cervical smear – working round when I can come.
- ➔ People who respect us, who help make me and my child feel that we are in charge of our lives.
- ➔ Everyone looking out for the ordinary things – friends, jobs, leisure.

Help from other people can make a difference. We probably all need to get better at inviting people to help, and finding out how we can help each other.



The sources of help and information that are likely to be available are:

- ➡ Local Area Co-ordinators
- ➡ Carers' Assessments through the local authority's Social Work Department
- ➡ Carers' support projects and organisations
- ➡ Local health and well-being projects and the services they provide.



## Other sources

Carers UK has information for family carers living in Scotland, England, Northern Ireland and Wales

Web: [www.carersuk.org](http://www.carersuk.org)

Carers Scotland can be reached at:  
91 Mitchell Street  
Glasgow  
G1 3LN

Tel: 0141 221 9141

Email: [info@carerscotland.org](mailto:info@carerscotland.org)

Princess Royal Trust for Carers

There are Carers' Centres linked to the PRTC all over the country. The website helps you identify the centres that are near you. There are also office bases.

Northern Office  
Suite 4, Oak House,  
High Street,  
Chorley  
PR7 1DW

Tel: 01257 234 070

Fax: 01257 234 105

Email: [infochorley@carers.org](mailto:infochorley@carers.org)

Web: [www.carers.org](http://www.carers.org)

London Office  
142 Minories  
London  
EC3N 1LB

Tel: 020 7480 7788

Fax: 020 7481 4729

For publications and PR email: [info@carers.org](mailto:info@carers.org)

For all other enquiries email: [help@carers.org](mailto:help@carers.org)

Glasgow Office  
Campbell House,  
215 West Campbell Street  
Glasgow  
G2 4TT

Tel: 0141 221 5066

Fax: 0141 221 4623

Email: [infoscotland@carers.org](mailto:infoscotland@carers.org)

The Family Fund provides information and practical advice for families of children and young people (aged up to 25) who have a disability. It also provides financial help for families who have low incomes (currently up to £23,000).

Family Fund  
PO Box 50  
York  
YO1 9ZX

Tel: 0845 130 4542

Web: [www.familyfund.org.uk](http://www.familyfund.org.uk)

There are country co-ordinators:

➡ Scotland: 01592 874541

➡ England 01223 842914

➡ Northern Ireland: 028 7035 5660

➡ Wales: 01792 361 498

**Moving on to Adult Life**

# **PART 3: MAKING CHOICES**



## Moving on to Adult Life

# PART 3: MAKING CHOICES

We all make choices about our lives – what we want to do, where we want to do it, who we want to be with and so on. Some of these choices may be things we agonise over, but often, even major decisions follow choices we aren't really conscious we have made. But this isn't the same for everybody, and so here we are contrasting the experiences that different people and families might have.



# How decisions get made

## What happens for most young people

**Process** There are a few key dates and stages for people who are applying for further education, but many of the key things in people's lives just happen. There isn't really a clear process. The various elements of your life inform each other – who you want to be with, where you will study, what you want to do, where you want to live, what your interests are. It can go on for a long time.

**Ideas** From the time you are small, people probably ask you what you want to do when you grow up. You see lots of people doing lots of different jobs. You think about where you would like to live, whether you want to settle down or travel, about having relationships. You've got ideas about things you might want to do and what you don't want to do. You might change your mind a hundred times, or you might be clear the whole way through about your future. But if you are like most people, you'll gradually narrow down your ideas about what you want your life to be like.

**Information** You'll get information from all sorts of places and people. For jobs, there will be the formal written material from the school guidance service and from places like Careers Scotland. Companies and industries produce publicity materials to help them to recruit

more staff. There is material from colleges and universities about opportunities for learning. You watch movies and read magazines. You ask your pals and their friends and families. Once you get interested in something, you can start checking it out – find someone who works in that line, check the internet, go to see the place.

**Options** There are lots of options, and most of the people who talk to you are encouraging you to widen your horizons – to consider things you may not have thought of. Sometimes you'll get advice and suggestions when someone thinks you are being too ambitious, or not ambitious enough, and they suggest something else.

**Choices** You've probably been making choices all your life, so when someone asks you to choose your subjects at school, or which college course you are going to apply for, you've had practise. Sometimes you make the choice and tell other people – at the time and in the way of your choosing.

**Discussion** You check out ideas with lots of people, discuss ideas with them. It mostly happens in a casual way. You decide how and when you bring something up with your mum or dad.

**Decisions** You make the decision about what you are going to do. Sometimes, it doesn't work out that way – you don't get the job

you apply for, the college turns you down, a friendship breaks up. So you check out other options, try something else.

**Getting confidence, practicing** Some people postpone the decision, or the start of the next stage of their life, by having a gap year. There are opportunities to try things out – you gradually move away from home by sharing a flat but still popping round to your mum’s.

**Persistence** You may find you need to stick at it, when things don’t work out at first, e.g. spending a long time looking for a flat, making lots of applications for jobs. Doing other things in the meantime can help.

**Changing your mind** Sometimes you start something, and it doesn’t work out. You drop out of college. You leave your flat and go back to your mum’s or stay with a friend. You try new things. And then you may go back and pick up something that wasn’t right before. There are plenty of opportunities for second, and third, and more chances.

## **What is it like for young people who have additional support needs?**

In our experience, the way in which a young person with a disability gets to make choices is much more limited. We know that some families have good experiences – which show how it can be done. The section on meetings, at the end of this part of the pack, explains why so many people find it difficult and can have poor experiences. It also gives ideas on how things can be better.

**Process** There is a set process for young people who have additional support needs. This is the one that happens in Scotland at the moment; some details may be different where you live, but we expect that there will be similar features.

- ➔ You will probably have had a Record of Needs through school. In Fife and some other places, the Education Department uses a different format, which the Department and some parents think gives more flexibility, but which may not have the same legal status. (Under the new Additional Support with Learning Act the Record of Needs will get replaced by a Co-ordinated Support Plan – the scope of this is slightly different.)
- ➔ The Future Needs Assessment happens when you are aged 14.
- ➔ There is a review at age 15 and another review when you are 16.
- ➔ When you are 17 you start on your transition plan. (There is some more information about transition plans below). A formal Care Assessment is also prepared at about this time. This is for social work and other specialist services, and you have access to these services when you leave school.

## Example

A typical pattern for a young person who has been in a special school, or for someone who has a learning difficulty, is that at 18 he will spend 5 days a week at college, for life/work skills, with supports from the adult services and college staff.

At 20, there will be a further decision about what happens next. The young person will leave college. Future options are usually either work or day time services provided through the Social Work Department.

In other areas, the plan is for everyone to have a mix of college, work and leisure from the outset, and then review it after a year or so.

**Information** The information tends to be provided by staff who work in your school or other services. Frequently, it is only about 'special' placements or services. Staff may be keen to help you do something different, but they may not have much experience of (or information about) the alternatives.

**Assessment** The starting point is assessments by people who are expert in disability. Assessments may be done in school, but should include meetings with the young person at home. Staff often have heavy caseloads which mean they don't have time to get to know you, and may even put in a report without having met you. The focus is usually on what it is thought that you – or people who have the same disability or condition - can't do. There isn't much attention paid to what you can do, or what you might want to try.

**Discussion or meeting** The Future Needs Assessments and reviews are usually held in an office or at the school, during office hours. Your parents will be invited, but you may not have been invited. There will be several professionals there, whom your parents may not have met before. The discussion usually starts off with the assessments and proposals. Often the only suggestions are the established routes, such as special college placements, services run by the local authority or from a voluntary organisation providing care for people with that disability, or more sheltered

work settings. The suggestion is often based on the funding options and is based around the usual budgets for care, even when there are other sources of funding which might be available for other things. The suggestions tend to emphasise looking after you and responding to your needs and the things you cannot do. No other options are put forward.

Sometimes staff and parents know of other ways of handling the discussions to make them more creative and inclusive – and there are suggestions to help with this later in this pack.

**Decisions** Decisions are effectively made by your parents rather than by you. Your parents may accept what is proposed, partly because they are told by experts this is what is best, and partly because they don't know what else to ask for. Once a decision is made, it tends to be hard to change it. It also sets the course for what happens in other areas of your life.

We think that there are too many differences between these scenarios. We have summarised some key points into two columns, and we think that our aim should be to get as many as possible of the ideas and processes from what happens to most people – the left column – into the experience for young people with additional needs – the right column:

### **What it is like for most young people**

Lots of practice in making choices and decisions throughout childhood  
Ideas come from friends, school, family, marketing, other places

Information is aimed at the young person, and comes from lots of sources

Options are around what this person wants to do, widening choices

Choices are made by the young person with advice, and these can change over time

Discussion is with friends, as well as parents and school

The young person makes the decisions

Lots of ways to get confidence

You can change your mind

### **What it is like for many young people who have additional support needs**

Few opportunities to have choices or make decisions

Information is aimed at parents, through the school and specialist services

Assessment is by people who may not have met the person, based around what 'people like him' need

Options are for specialist services only, based on disability and what the person can't do

Discussion happens in meetings, and involve professionals and parents

Decisions are usually made by parents

You get one option to try, it feels hard to change your mind

## Legal capacity - Who is able to make decisions?

This is the position in Scotland. We think it is important for families to have information about what the position is where they live.

Until someone is 16 they are legally a child. However, there are situations where the young person's views have a big influence. More information is available from the Scottish Child Law Centre and from the local law centres or projects that exist in a few places, such as the Fife Children's Rights Project and Govan Law Centre.

On his 16th birthday, a person becomes an adult, and his parents can't make decisions for him any more. This applies to all sorts of things – consent to medical treatment, entering into contracts and managing money, making decisions about what we do and who we do it with, and taking responsibility for our actions.

The Adults with Incapacity (Scotland) Act, 2000 sets the rules for other people making decisions for someone who is not able to manage their own affairs. It provides various ways of intervening – taking decisions or actions – on behalf of an adult. This can be around property and financial affairs, or personal welfare matters. The Act says that people with disabilities should be supported to have as much control over their lives as possible. It also

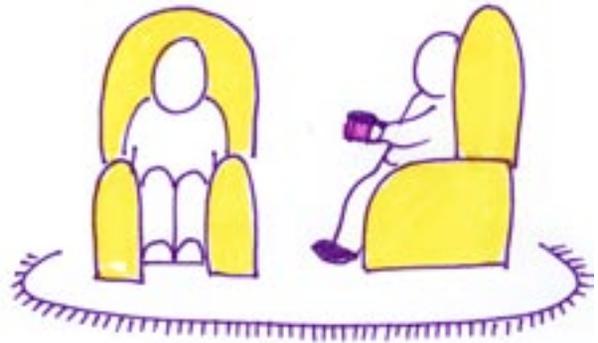
recognises that someone's ability to understand something and make a decision or take action can vary from situation to situation – it says other people can only make the minimum intervention for that particular purpose.

Parents can take out Guardianship orders for their son or daughter. There are also arrangements for someone else to do this. The Act encourages situations where several people share the work and provide support and monitoring for each other. All intervention orders and guardianship orders are registered with the Public Guardian. The Public Guardian supervises the exercise of powers over money and property, while the local social work department supervises welfare guardians.

You can get more information about the Adults with Incapacity Act and forms of intervention from the Scottish Executive, and from the Office of the Public Guardian. Fife Council has also produced a short guide to the Act, and your local Council may also have information.

When you are checking out what happens to a young person and their legal rights, you might also want to get some information about other legal aspects of planning for the future, such as wills and putting money in trusts. In many places, there will be some local lawyers who have some expertise on this and understand the issues. Families in some places have swapped information about local banks and lawyers whom they have found helpful.

In Scotland, there are a couple of voluntary organisations which provide information. Equal Futures is developing services based on the model used over the past 15 years in Canada by PLAN, so puts the technical information in the context of friendships and the other types of support someone will need.



## Other sources

### Legal rights

Scottish Executive Justice Department  
Civil Law Division  
Floor 2 West (Rear)  
St Andrew's House  
Regent Road  
Edinburgh  
EH1 3DG

Tel: 0131 244 2193

Web: [www.scotland.gov.uk/topics/justice/civil](http://www.scotland.gov.uk/topics/justice/civil),  
and navigate to Adults with incapacity.

The Office of the Public Guardian  
Hadrian House  
Callendar Business Park  
Callendar Road  
Falkirk  
FK1 1XR

Tel: 01324 678 300

[www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

Scottish Child Law Centre  
54, East Crosscauseway  
Edinburgh  
EH8 9HD

Tel: 0131 667 6333

Freephone for under 18s: 0800 328 8970

Fife Council has a guide to the Adults with  
Incapacity Act. Contact:

Arthur Martin, Team Leader  
Fife Council  
Social Work  
St David's Centre  
Albany Park  
St Andrews  
KY16 8BP

Tel: 01334 412615

Email: [arthur.martin@fife.gov.uk](mailto:arthur.martin@fife.gov.uk)

### Information about wills and trusts

Enable  
6th Floor  
7, Buchanan Street  
Glasgow  
G1 3HL

Tel: 0141 226 4541

Fax: 0141 204 4398

Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)

Web: [www.enable.org.uk](http://www.enable.org.uk)

Equal Futures supports people to develop  
networks of people who will be a source of  
long-term support. It also provides families  
with information to plan for the future. At the  
time we were writing this pack, Equal Futures  
was planning to appoint a development  
worker.

Contact: [info@ef.org.uk](mailto:info@ef.org.uk)

## These are our suggestions on how to get as much choice as possible

- ➔ The person is at the heart of everything
- ➔ You need a goal
- ➔ Practical things make a good life happen
- ➔ You need to learn to live with risk
- ➔ Keep reminding everyone who this young person is





### **The person is at the heart of everything**

- ➡ Check what the young person wants, not just what her parents want, or think she wants.
- ➡ Draw in other people who are in the young person's life, such as extended family, neighbours, and friends.

We think this is why it matters for younger children to get people around them – to give them opportunities to make friendships, try new things, and have a wider range of experiences.

This can be at school, where people spend their leisure time and spending time with neighbours and friends on their own.

*“We feel we have to actively work to maintain friendships, whereas for most young people this happens more easily”. Mum who helped put this pack together.*

But parents can get tired, and may not think to make the effort if they expect that services will be able to look after their child as he grows up.

Things that can help children have more people in their lives include circles of friends and education that is really inclusive.

The ideas and approaches around person-centred planning have helped people, and also their families and staff who work in services, to think about how to help make the person be at the centre. Other ideas and tools which many people have found helpful are getting circles of people to share activities and support someone to have choices and to be part of their community.

There are sources of more information on circles of support, person-centred planning and inclusive education in Part 5 of this pack. When we were putting together this pack, the Same As You Project Team in Fife was organising training in person-centred planning for staff who work in services to support people with learning disabilities. Some families and people with learning disabilities have also been part of the training. If you are interested in finding out whether this is available in your area, we suggest you contact the local authority or organisations which provide person-centred services. And if it isn't happening, you might want to suggest it.

## Other sources

Circles of Support and friendships

Al Etmanski: A Good Life: see [www.plan.ca](http://www.plan.ca)

There is a lot of useful material and ideas on the PLAN website.

Jo Kennedy, Helen Sanderson and Helen Wilson: Friendship and Community  
Published by North West Training and Development Team  
Adamson House  
Pomona Strand  
Old Trafford  
Manchester  
M16 0BA

Tel: 0161 877 7499

Circles Around Dundee  
Number 10  
10 Constitution Road  
Dundee  
DD11 1LL

Tel: 01382 305 726

Web: [www.circlesarounddundee.org.uk](http://www.circlesarounddundee.org.uk)

Circles Network  
Potford's Dam Farm  
Coventry Road  
Cawston  
Rugby  
Warwickshire  
CV 23 9JP

Tel: 01788 816 671

Email: [information.circles@btconnect.com](mailto:information.circles@btconnect.com)

Web: [www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)

### Person-centred planning

There are many people and organisations in Scotland which will give you information about person-centred planning, facilitate plans and provide training for families and for staff.

Inclusion and Person Centred Planning, by Edinburgh Development Group, People First and City of Edinburgh Social Work Department, is a booklet for people with disabilities and families. It is available from:

Edinburgh Development Group  
John Cotton Business Centre  
Sunnyside  
Edinburgh  
EH7 SRA

Tel: 0131 476 0522

Web: [www.edg-sco.org](http://www.edg-sco.org)

Helen Wilson  
Envision  
88 Montpelier Park  
Edinburgh  
EH10 4NG

Tel: 0131 466 4006  
Email: [helen@envision-uk.org](mailto:helen@envision-uk.org)  
Web: [www.envision-uk.org](http://www.envision-uk.org)

SHS Trust  
5b Washington Place  
Washington Lane  
Edinburgh  
EH11 2HA

Tel: 0131 538 7717  
Email: [admin@shstrust.org.uk](mailto:admin@shstrust.org.uk)  
Web: [www.shstrust.org.uk](http://www.shstrust.org.uk)

Altrum is a network of organisations which work in person-centred ways. An initial point of contact for the members is

Rebecca Allan  
Neighbourhood Networks  
Unit 10  
First Floor  
Festival Business Centre  
150 Brand St  
Glasgow  
G51 1DH

Tel: 0141 314 0027  
Email: [rebeccaallan@neighbourhoodnetworks.org](mailto:rebeccaallan@neighbourhoodnetworks.org)

## **Inclusive education**

The Equity Group is a member led, not for profit organisation which is working to develop sustainable inclusive education structures for all children in Scotland with additional support needs, irrespective of their disability, race, creed or gender. They aim to enable children with additional support needs to reach their full potential through having access to an appropriate education. They support children and families to achieve the education and support they need, and to work with professionals to develop sound inclusive educational practice.

Contact: Eileen Prior  
Equity in Education  
76 High Street  
Peebles  
EH45 8SW

Tel 01721 729326  
Email: [eileen@equityineducation.org](mailto:eileen@equityineducation.org)  
Web: [www.equityineducation.org](http://www.equityineducation.org)

A book which describes families' experiences on inclusive education is:

Ceri Mollard: Why it's worth it

Published by SHS Trust  
5b Washington Court  
Washington Lane  
Edinburgh  
EH11 2HA

Tel: 0131 538 7717

Email: [admin@shstrust.org.uk](mailto:admin@shstrust.org.uk)

Web: [www.shstrust.org.uk](http://www.shstrust.org.uk)

## Story

Lauren's family has had a caravan at one of the sites beside the Fife coast for years. They spend a lot of time there at the holidays and try to go most weekends during the summer. Other people do the same.

Josephine has known Lauren since she was a teenager and Lauren was a little girl. She enjoyed being with Lauren as Lauren is good company on walks and doing things around the site. As Lauren became a teenager, she and Josephine talked about clothes and hair and music and boys – all the usual stuff. They sometimes go out for the evening together now.

When Lauren's mum was invited to the formal planning meetings about Lauren's future, Josephine was one of the people she talked to, as she reckoned Josephine would know aspects of Lauren that her parents and school would miss. Josephine is happy to contribute to the discussions and ideas about what Lauren might want to do in the future, because that's what you do for friends.

## Story

Jenny went to a special school and she had no friends of her own in her local area. Her family has moved around, so she doesn't have a big family nearby either. Her mum built up a circle of people to help her and Jenny plan for the future.

The people in the circle have brought their connections with the local community. They have contributed ideas about what Jenny could try and people she could meet to get more information or have a go at something. They have also taken on an advocacy role in formal meetings, so Jenny and her mum have someone with them for support.

## Story

Gillian is a young, trendy 17 year old. She is bouncy and bubbly with a strong will and is quite able to say what she wants. But she sometimes lets her mum do the talking, and sometimes it is hard to work out what it is that Gillian wants and what are her mum's ideas.

The staff at Gillian's school suggested she and her mum get in touch with the local citizen advocacy project.

Donna got to know Gillian and they spent time together over the summer. Gillian talked to Donna about what she wanted to do when she left school, in between all the other things that young women talk about.

When Gillian had her next big meeting with the school and her mum, she talked over with Donna what she wanted to say. Sometimes Donna comes with Gillian to meetings, especially if Gillian is feeling nervous, and sometimes Gillian goes on her own.

But this is just part of their relationship.

Gillian and Donna are now very close. Donna is a hairdresser and where Gillian used to get the hairdresser come and do her hair in the house (this arrangement was easier than going out to a hairdresser due to her physical disability), she now goes to the trendiest salon in town and has her advocate turn her hair pink, spiky and all sorts of other styles!

Gillian and Donna still visit their local pub and have a laugh together. Donna knows Gillian's family well and they too are delighted with the relationship.

There is no ending to this story – Donna is definitely there for Gillian and Gillian will definitely turn to Donna when she needs to.

## You need a goal

“The goal is to have a life.”

*Mum who helped to put this pack together*

Sometimes, school and other experiences won't have prepared a young person for having choices. These are our suggestions to help someone get used to having choices.

- ➡ Be open, flexible. Don't set a rigid plan too soon.
- ➡ Find ways to make choices in small things, and then making choices in big things will feel easier.

You also need to keep revisiting the goal.

- ➡ It's ok to adapt it as you all learn and get more ideas.
- ➡ Keep remembering the long-term aims as well as the day-to-day ones.

## Story

Jenny and her mum didn't think that the formal services which were offered were right for Jenny. But they weren't sure what Jenny did want to do. Many young people take a gap year at the age of about 18, between school and college – and that is what Jenny did.

With help from her circle of friends, Jenny and her mum tried all sorts of leisure activities – partly to get a sense of whether work associated with that thing might be an option, and partly just to have some fun. There wasn't much money around, so free activities and short courses were useful.

They learned that some places are accessible to someone with a learning difficulty and others aren't. People's attitudes vary a lot – there are some people who are very welcoming and encouraging, even if others aren't.

One of the places they went to was a local art gallery. This was something new for Jenny, and she loved it. Jenny is now working at the gallery an afternoon each week, with support from support workers she employs using Direct Payments. She also enjoys painting and other crafts at home and in other places.

“Jenny is now having a great time in the life she didn't know she wanted.”

What we've learned is:

- ➡ Expect that some things won't work out
- ➡ Take time and patience to try new things
- ➡ Be open to new ideas
- ➡ Create choices
- ➡ And enjoy the process

The message we want to get over to young people, and to their families, is that you have the right to make a choice, and the right to try more than one thing.

There are various ways you can try out choices, and be in control of what support you get.

One is to find services that provide the supports you want. If these aren't right at first, discuss with the staff whether there is scope to make changes, or involve other services.

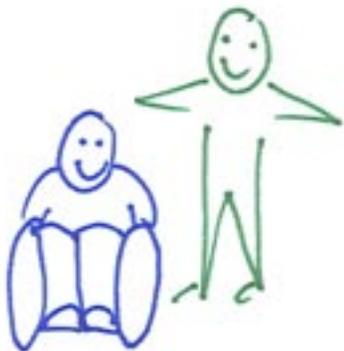
Another is to get 'self-directed support' – where an organisation provides the flexible support someone wants, and the person and their family gets the opportunity to choose their own staff, but the staff are employed by the organisation and the funding is all managed by the Social Work Department. Some people have found that this is a good way of trying out what works for them. It may also be quicker to organise than support under Direct Payments, as you don't have to get the money side sorted first.

Once someone is getting services, if these would cost more than £200 a week they can get Independent Living Allowance. After 6 months, you can ask to have this increased. The extra income can be used to get the additional supports which formal organisations don't usually provide.

A Direct Payment lets someone employ their own staff to give them the support they want. This is the arrangement that gives the person the most control and choice. Although you can start with care funded through Direct Payments, you could use one of the other arrangements (described above) to find out what works for you, and then switch to Direct Payments after a year or so. There is more information on Direct Payments in Part 4, and you can discuss with the Social Work Department what the current arrangements and options are in your area.

But the starting point for all of this is to be clear what kind of life the person wants, then work out what this looks like in practice, and what types of practical support will help this to happen.

As well as thinking about services, keep involving friends, family and other people in making choices for the young person. And keep listening to what he wants, as his ideas will change as gets to try out things – realising one choice leads on to lots more.



### **Practical things make a good life happen**

“The 3 things I’ve found are essential are money, transport, and doing it from your own doorstep.” *Mum who helped to put this pack together.*

Money is useful because it lets you try things out. You can even use it for a gap year. Money may be tighter for families with a child with additional support needs than for other families, because typically they have less income and higher expenses. Things that help here are:

- ➡ Direct Payments.
- ➡ Making sure you are getting all the income and benefits you are entitled to (see the money section in Part 4 of this pack).
- ➡ Asking about grants that are open to any young person, as some of these are also a way of getting extra assistance for young people with disabilities.

Look out for all sorts of opportunities. Test these against your values, and what you expect – do they respect the person? Would you be happy with your other children using this place? Don’t just ask whether they have special facilities or equipment.

In our experience, what you need are:

- ➡ Opportunities and scope to try things out
- ➡ Support and encouragement for the parents and family, as well as for the young person
- ➡ A circle of people around him – and keep renewing it to make sure it evolves as his circumstances and preferences change.

You also need good information about what is possible. We’ve found it useful to get information and advice from a couple of places – the social worker or care manager, the people who specialise in arrangements like Direct Payments and Independent Living Fund, and local Welfare Rights or Money Advice projects. That way, if it is a time when the rules are changing, or if you are checking out an arrangement that is different from the usual ones, you are more likely to get up to date advice.



## Story

Jill was checking out how to get the type of support and services that would let her son, Callum, have the life he wanted. The social worker was helpful about coming up with services that would be flexible and give a good quality of support. Her advice was that Direct Payments wouldn't suit and would take too long to get organised.

Just before Callum was due to leave school, the social worker said that maybe Direct Payments and Independent Living Fund would work better after all. But the problem was that the applications couldn't be processed in time for Callum getting the services in a few weeks.

In the 6 months or so since Jill and Callum had started planning what would happen when Callum left school, the Council had changed the ways Direct Payments were handled. But the social worker hadn't realised this, because she wasn't dealing with this every day.

After some discussions and phone calls the arrangements got sorted. Callum began getting support from personal assistants employed by a voluntary organisation, as planned, and there was no delay. But Jill had to get things like a bank account organised in much more of a rush than she would have liked. She had a few weeks when she was really worried that Callum would have no support for several months.

## You need to learn to live with risks

Practical things also help you deal with the risks. Most of the things we do in our lives involve some risk, and parents worry a lot about the risks for all our children. What we do is take steps to minimise the likelihood of the bad things happening at all, and to minimise the harm that will come to people if anything does go wrong. So we teach young people to be careful, to stay with people they know when they are in unfamiliar places, to have a phone to reach someone if they get lost, and so on. It is just the same for our children who have some additional needs.

It is useful to think about real situations, and list out what our worries are. Then write down

- ➡ How likely is this to happen?
- ➡ What are the consequences or impacts if something does go wrong?

You can then concentrate on putting safety nets in place for real risks.

- ➡ What makes the things that are likely to go wrong less likely to go wrong?
- ➡ If they would only be a bit embarrassing and no-one comes to any real harm, do they matter anyway?
- ➡ How can you prevent things happening if they would involve more harm?

These are a few things we have learned from our experience and other people's.

- ➡ It's best to say what your worries are and then start looking at how to deal with them.
- ➡ There are risks of long-term harm to people in not taking any risks, or being so careful that you don't have a life – no friends, no self-confidence, not being able to recognise or assess the risks in the unexpected situations that will come up.
- ➡ One of the best ways of protecting a young person is to have a range of different types of people in their life who care about them - who will look out for them and do something if they think there is a risk. There is more about this in Part 4 of this pack.
- ➡ Another way is to get them in regular contact with ordinary people who aren't part of the family or formal services – as friends, as the people who see them going about every day.
- ➡ If you think other people aren't taking some risks seriously, or aren't explaining what practical arrangements are going to be in place to help the person get the balance between having a good life and managing the risks, then say so.

There is a good example in the book *Friendship and Community* of thinking about the things that can happen in a particular situation and how to reduce the risks and keep the benefits. There are also other good books which discuss risks, and how to approach these in a constructive way, such as those by Dave Hingsburger.

## Other sources

Enable has produced a booklet for people with learning difficulties – *Are you being bullied?* It has practical suggestions about what people and their families can do, and more contact points. Copies are available from:

Information service  
ENABLE  
National Office  
6th floor  
7 Buchanan Street  
Glasgow  
G1 3HL

Tel: 0141 226 4541  
Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)  
Web: [www.enable.org.uk](http://www.enable.org.uk)

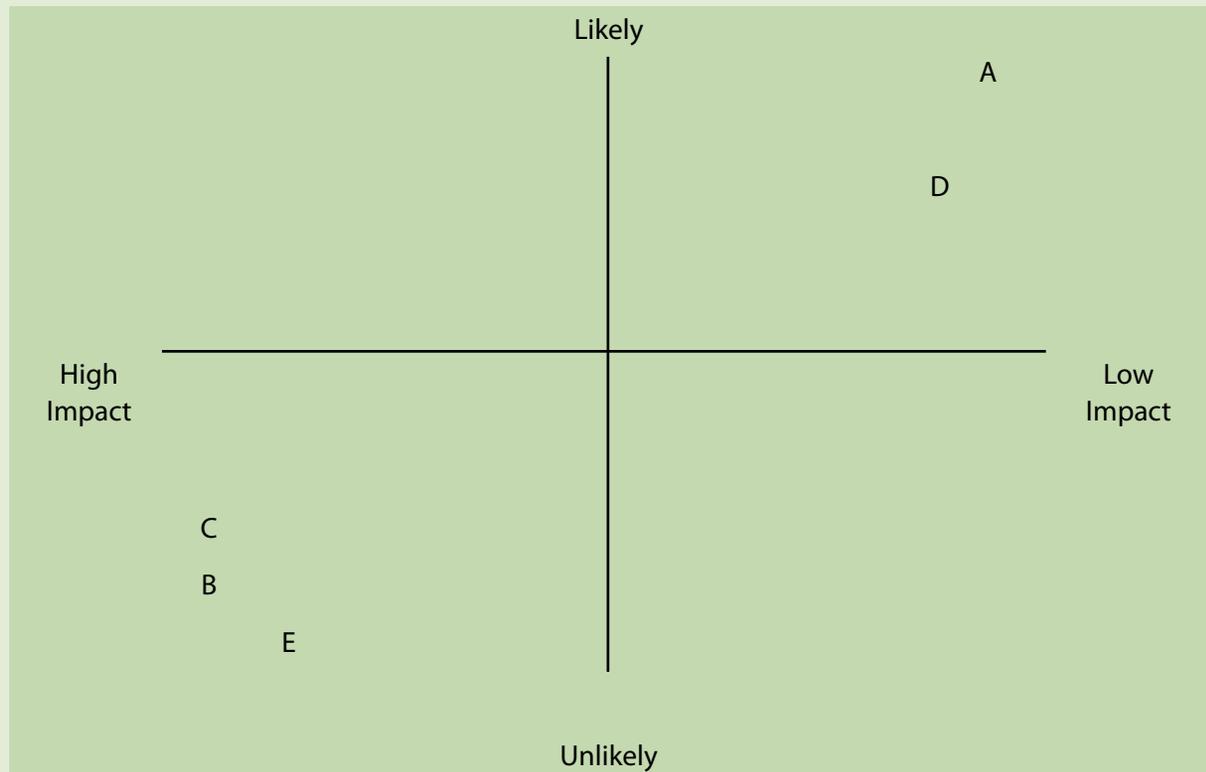
Dave Hingsburger's books might be helpful in discussing various risks. Dave sometimes does training in the UK with Paradigm.

Paradigm  
8 Brandon Street  
Birkenhead  
CH41 5HN

Tel: 0870 010 4933  
Fax: 0870 010 4934  
Web: [www.paradigm-uk.org](http://www.paradigm-uk.org)

This is an example of a framework to help someone's family and support workers assess and minimise risks.

Denise has been going to various pubs and social places, and has found that the local Goth club suits her – there is loud music, people shouting, people wear flamboyant clothes and most people enjoy talking to Denise. The situation here is when Denise goes to the Goth club without her support worker for the first time but with a friend she has met there.



## Risks

- A: Denise gets too friendly and annoys people.**
- B: She gets separated from her friend and has to find her way back home on her own.**
- C: She goes home with someone else and ends up in a vulnerable situation.**
- D: She doesn't enjoy it.**
- E: She drinks too much or takes drugs.**

Risk A is quite likely to happen but unlikely to have much impact. Denise is a very friendly person and likely to talk to complete strangers. However, people normally make it clear to Denise when she is bothering them, and she doesn't mind and just talks to someone else. The team decided they didn't have to plan for that.

Risk B is unlikely to happen but could have a very high impact. Her team decided to stress to Denise's friend how important it was that she stayed with her and brought her home at the end of the night. They also gave Denise a mobile phone with the 'on call' number programmed in so that she could phone if anything happened. They also programmed in a taxi number.

Risk C was unlikely to happen but again could have a very high impact. The team decided to talk to Denise about their concerns and to her friend to try to ensure that they came home together at the end of the night. Denise and her support worker have on-going discussions about personal safety and sexual health.

Risk D was possible but unlikely to have a high impact. If Denise wasn't enjoying herself she was quite capable of leaving. Because she had the mobile phone she could ring 'on call' or a taxi if she wanted to leave before her friend.

Risk E was unlikely to happen but could have a high impact. Denise never drinks too much. She normally only has a couple of beers before reverting to coke. The team discussed the possibility that someone might spike her drink but didn't think it very likely. Nevertheless they told Denise to mind out.

Denise thought her team were worrying about nothing but they felt better having discussed the possibilities and done as much as they could to protect her from unnecessary risks while supporting her freedom to live life as she chooses.

Quoted with permission, from Jo Kennedy, Helen Sanderson and Helen Wilson: *Friendship and Community*, pp 72-73.

## Story

When David was 16 his older sister took him with her when she went to be a volunteer cleaning the beach. Sally had done this for several years and had liked having something that got her away from the rest of her family for a bit. David liked being a helper at the beach and talked about going after Sally went back to college. The question was, how could he get there?

The first suggestion was that his mum or dad would take him, but that would miss the point (or at least part of it). David and Sally talked about which people who were volunteers at the beach would be good for giving David a lift. David knew who he liked and who he didn't like. They both thought that the man with the green jumper was the first choice, and they had a few back-ups.

They talked it over at home. The family had known the man with the jumper – James – by sight for a long time. He had been a volunteer at the beach for years, he lived fairly near them and his children had been at the same school as them. They thought about checking up on him, but decided to trust David's and Sally's instincts and what they already knew. Instead, the priority was talking to David about what to do if anyone ever did anything that he didn't like or frightened him.

Sally explained the situation to James, and he said he would be pleased to give David a lift. He also suggested coming in to meet their parents. For the next few weeks James collected David and Sally and brought them home, and then it was just David.

The arrangement has worked well. David and James don't do other things together. They just go as volunteers to help keep the beach nice.

Each time they meet, James asks David how his week went. David's parents feel that James is now one of the other people who watch out for David and would act if he thought anything was wrong.

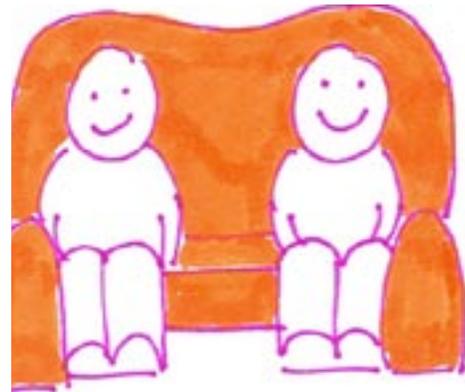
## Keep reminding everyone who this young person is

The people who will be involved in helping plan for this young person's future may see him only in places where he isn't comfortable, and they may not have time to get to know him. Try to make sure that either the young person, or you, has a chance to share his ideas and hopes with them so that they can understand what makes him tick. There are lots of ways to do this.

- ➡ Talk to the other people who are involved in the decisions early, and try to keep the dialogue open.
- ➡ Bring photographs of him doing things he enjoys.
- ➡ Bring his account of what he wants his life to be – drawings, pictures from magazines, tape or video recordings.
- ➡ Ask for the assessment meetings or planning meetings to be in a time and in a place that suits him – where he feels comfortable, his best time of day.
- ➡ Get the people he wants to be there.
- ➡ If people can't come, bring their stories of him, their experience of what interests and excites him.
- ➡ If he has particular needs that you think might be overlooked, bring along information about what these are, and why they are particularly important. Some of the ideas in Part 4 of this pack might help

you describe what he needs and what a good support for him might look like.

Find someone who will help all of you – the young person and his parents - to prepare what you want to say. It could be a friend, or another family who have done this before, or one of the advice or advocacy projects. You might find it helpful to have someone who supports the young person and someone else to support the parents.



## Why many people find meetings difficult

From our experiences, other people's experiences, and all that we've read and heard about how people communicate and make decisions, we think there are several reasons why so many young people and their parents – and many professionals – find formal meetings difficult. The ideas and suggestions throughout this pack are meant to help avoid or reduce the difficulties.

## What the meetings are about

These meetings cover 3 different ways of thinking – making assessments of what this person can do and what support they need, and considering the practical situations they will be dealing with; exploring ideas and options; and making decisions about which option to follow. There are several ways things can go wrong.

- ⇒ The assessment stage happens without the young person and all the other people who know him contributing their experiences of what he can do and what he might want to do.
- ⇒ People have few ideas, and are not expecting that there could be lots of ideas and choices for this young person, so that stage gets more or less skipped.
- ⇒ There is a single meeting to explore ideas and make the decisions - so no-one has time to reflect, or get some more information.
- ⇒ The professionals come to a meeting which they think is to confirm a decision based on the information already gathered, while the parents come expecting it to be the start of thinking about their child's future - because they don't know about what has already been put together.

These are our suggestions on questions to ask, and you will think of more.

- Is everyone coming to the meeting clear about what stage in the process this discussion is – making assessments, exploring ideas or making decisions?
- Is this the right stage to be at? Would it be useful to spend a bit longer finding out about this person and exploring his and other people's ideas?
- Does everyone know who everyone else is, and what they are contributing?
- Have we got enough information to make a good decision?
- Do we know what to do if we later think of something better?

## **Taking account of people's feelings**

Everyone might want the best for this young person, but there can be a big difference in the significance of these meetings for the parents and for the staff who are there.

For a mum, her child's future – his quality of life and opportunities for years to come – is dependent on what happens. This is likely to come on top of lots of rejections and disappointments because this young man is disabled. And the practical consequences of being the parent of a young person with a disability means she is more likely to be tired and under stress.

For a busy professional, this is another case in a heavy workload. But professionals also bring their feelings to meetings. For example, a social worker might be worried about how she is working with all the other services which are involved. Or she may feel frustrated that she isn't able to offer the young person more choices.

There are lots of ways in which the communication can go wrong.

- ➡ As a parent, you get angry when you think someone is not treating your child – or you as the parent – with respect.
- ➡ The memories of previous times you have had difficult relationships with some of the people at the meeting – for example, when trying to get access to services – get in the way.
- ➡ It feels as if previous arguments with the people there or the organisations they represent are being held against you – so this young person is being punished as a consequence.
- ➡ It feels as if the people at the meeting are more concerned with setting a precedent or with the overall policies, than with what is best for this young person.
- ➡ Someone gets defensive about a position because they are worried about what other professionals will think of them – so they are not able to explore other ideas.
- ➡ When any of us feels very upset, we can't really hear what other people are saying.

These are our suggestions of what can help.

- ➡ Where and when the meeting happens can make a big difference – a place where the young person and his parents feel more comfortable, but also a place where staff won't get interrupted, where everyone feels more relaxed.
- ➡ Have someone with you if it is a formal meeting – to help you listen to all that is happening and to help calm or encourage you if you need it.
- ➡ Most people – parents and professionals – say it feels different and more constructive when the young person is there. If he can't be there, have another person who knows and likes him. And if he is there, it can be useful to have someone to advocate for him who isn't his mum or dad.
- ➡ Take time out at the meeting if it getting confrontational or if you want to pause and think.
- ➡ Suggest a delay before the next stage – such as meeting again in a month – if you want to get more information, or to help keep options and choices open.

## Story

Whenever David had to go to a meeting, or something important was happening, one of his sisters came to the meeting with him. It couldn't always be the same person, as it depended on things like exams and getting time off work. So David and his family always had a planning session before the meeting and a "report back" session after it, so that David's mum and dad and his other sister knew what was happening. This helped them think through the questions they wanted to ask and be clear what they wanted.

Advocacy projects will have more information and advice.

People First have produced material for people with learning difficulties on assessments – for example, Oi! It's my assessment, and Helping you get the services you want.

The ideas around person-centred planning will help.

SHS Trust produced a set of checklists to help people feel more comfortable at formal planning and consultation meetings. Some of the ideas in these can also be useful when planning for meetings about someone's future.

## Other sources

The Scottish Independent Advocacy Alliance has information on local advocacy project across Scotland.

138-140 Slateford Road  
Edinburgh  
EH14 1LR

Tel: 0131 455 8183  
Email: [enquiry@siaa.org.uk](mailto:enquiry@siaa.org.uk)  
Web: [www.siaa.org.uk](http://www.siaa.org.uk)

People First supports people with learning difficulties to speak up for themselves, and is a route for collective advocacy.

People First Scotland  
77-79 Easter Road  
Edinburgh  
EH7 5PW

Tel: 0131 478 7707  
Email: [P1st@aol.com](mailto:P1st@aol.com)

People First  
3rd Floor  
299 Kentish Town Road  
London  
NW5 2TJ

Tel: 020 7485 6660  
Web: [www.peoplefirstltd.com](http://www.peoplefirstltd.com)

National Young People's Self Advocacy Groups  
ENABLE  
National Office  
6th Floor  
7 Buchanan Street  
Glasgow  
G1 3HL

Tel: 0141 226 4541  
Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)  
Web: [www.enable.org.uk](http://www.enable.org.uk)

Meetings checklists are available from SHS Trust:  
5 b Washington Court  
Washington Lane  
Edinburgh  
EH11 2HA

Tel: 0131 538 7717  
Email: [admin@shstrust.org.uk](mailto:admin@shstrust.org.uk)  
Web: [www.shstrust.org.uk](http://www.shstrust.org.uk)

**Moving on to Adult Life**

# **PART 4 : ASPECTS OF THE PERSON'S LIFE**



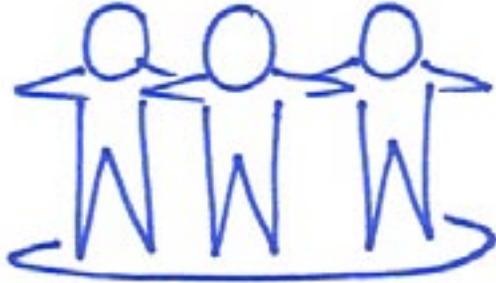
## Moving on to Adult Life

# PART 4: ASPECTS OF THE PERSON'S LIFE

There are very many aspects of a good life, and in this part of the pack we have described some of the things that we think are important. These include things such as having and keeping friends, enjoying a social life, contributing to your community through your work or in other ways, and living in the home of your choosing. But coping with these different things in life can sometimes feel overwhelming – not least because you can't usually deal with them one at a time, ticking them off before moving on to the next one.

We hope that you will find the ideas here useful in themselves. They build on the suggestions in the earlier parts of the pack, so refer back to what you thought about what makes a good life, and do remember about the things that help you to stay well. As you are making plans, it might help you to refer back to the table in Part 3. Where we were thinking about how decisions are made – and check out whether what is happening is happening in the way that you want it to.

Above all, though, remember that we are all allowed to try new things out, to change our minds, and that we all need to take things a step at a time.



## Getting friends

We think that getting friends has to be the starting point. All the other aspects of anyone's life are easier when you have friends – people to give you encouragement and advice, to go to places with you, and to spend time with you, just enjoying each other's company.

Most people make friends with the children they play with near their home, or children at school, and often both. Some people have friends in their extended family – such as cousins as well as brothers and sisters. Later, we make friends through work and social activities such as hobbies. We all meet lots of people, but only a few of these will become our close friends, and this pattern continues through our lives. One of the things we learn when we are wee is how to work out when someone wants

to stay as an acquaintance rather than become a close friend. We also learn how to cope with offering friendship and it being rejected.

In the book *A Good Life*, Al Etmanski describes how a child who has a disability may not have had the chance to meet lots of other children and find those special lasting friends. And some children will find the social interactions difficult because of their disabilities.

There can be particular problems for young people who have been away from the community in which they now live – for example, because they went to a special school and have fewer friends in the local area, or because they have moved into that area.

But it can be hard for parents to help teenagers find friends.

“He’s 15. He doesn’t want his mum hanging about, seeing that he is ok.”

“How do you start doing anything when you are so tired?”

*Mums who helped put this pack together.*

These are our suggestions:

- ➡ Think about where to find people who share this young person's interests.
- ➡ Look for people who have a similar outlook, temperament.
- ➡ Be prepared to meet lots of people, and the people who will welcome and include the person will find her.
- ➡ Use money from Direct Payments or Independent Living Fund for people to support the person to go to the kinds of places where she might make friends.
- ➡ Think about places and activities that are good for 'people meeting' rather than just 'people watching'.
- ➡ Remember the friends that the person already has, for example from school. Think about how they will be able to keep in touch.

*"Where's the kind of place you would meet yourself?" Mum who helped put this pack together.*

## Story

Jenny's and her mum Debbie's experience was that the circle of people who wanted to stand by them could support and encourage Jenny to find friendships, even though it couldn't facilitate real friendships.

People in the circle went with Jenny to various activities, such as pop concerts. They let her begin to do grown up things without her mum being the only person with her. They introduced her to people who wanted to spend time with her and get to know her. Most of these contacts have settled into the background. But some of the people Jenny met while she was out with the people in her circle have become real friends.

These are Debbie's comments:

*"At the beginning they aren't natural friendships – but try arranged friendships. They probably won't stick, but one might. Even if it doesn't stick, it buys time. The person will gain confidence and experience, and be in places where the real friendships can happen."*

## Story

Mary's and Louise's mums were friends, and the families lived near each other. Mary and Louise didn't have much contact with each other when they were growing up: Mary went to a special school while Louise went to the local one, and Louise was several years older than Mary.

Mary is now in her late teens and Louise is in her early 20s. Louise works in a shop. Whenever Mary and her mum were in the shop, Mary's mum would stop and chat for a few minutes. Over the next few months the conversations moved to being between Mary and Louise. Now Louise takes Mary to various social events where they are mixing with Louise's other friends.

## Story

Support services can also help people make friends.

Michelle loves swimming and goes to the local pool with her support worker, Tracy. Michelle is a really chatty person, despite not using words. Tracy helps people be comfortable with Michelle by showing them how Tracy and Michelle talk to each other.

Michelle and Tracy go to the pool at the same times each week, and the other women who are regulars have got to know them. They stop and have a chat with Michelle, and have helped out with practical things.

From Friendship and Community by Jo Kennedy, Helen Sanderson and Helen Wilson



## Other sources

A good starting point is *A Good Life*,  
by Al Etmanski  
Web: [www.plan.ca](http://www.plan.ca)

There is a lot of useful material and ideas on the  
PLAN website.

PLAN has links with Philia, a network which is  
stimulating discussion across Canada about  
inclusive citizenship.

Web: [www.philia.ca](http://www.philia.ca)

*Friendship and Community*, which was written  
by Jo Kennedy, Helen Sanderson and Helen  
Wilson, has a lot of good ideas and practical  
advice for people who live with their families  
and for people who have been using services  
for a while.

It is published by North West Training and  
Development Team  
Adamson House, Pomona Strand  
Old Trafford  
Manchester  
M16 0BA

Tel: 0161 877 7499  
Email: [sue.canavan@nwttdt.com](mailto:sue.canavan@nwttdt.com)

Circles Around Dundee  
Number 10  
10 Constitution Road  
Dundee  
DD11 1LL

Tel: 01382 305 726  
Web: [www.circlesarounddundee.org.uk](http://www.circlesarounddundee.org.uk)

Circles Network  
Potford's Dam Farm  
Coventry Road  
Cawston  
Rugby  
Warwickshire  
CV 23 9JP

Tel: 01788 816 671  
Email: [information.circles@btconnect.com](mailto:information.circles@btconnect.com)  
Web: [www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)

## Having a social life

What we mean by a social life is hobbies, leisure activities, going on holiday, having and enjoying interests such as music. These are some of the things that people do where they enjoy themselves. Most of them also involve mixing with other people – they are the kinds of things you do with your friends, and where you meet new friends.



These are our suggestions:

- ➔ Social activities should be about what interests that person – not ‘what disabled people do’.
- ➔ Don’t forget to encourage someone to try new things, to see if they like it.
- ➔ Aim for inclusion, for being involved in what other people do.
- ➔ Think about things that other teenagers do, and what is going to help him grow into activities that young adults do.
- ➔ Use Direct Payments and other flexible forms of support to help make social activities happen.
- ➔ Think about combinations of services and activities – such as using special transport to get the young person to an ordinary place, if that is what he needs.
- ➔ Think about what other sources of support and practical help there are around you – people in your community, ordinary clubs and activities – who might be willing to help if they are invited.
- ➔ Start with people and places you know and trust, and build from there.

## Story

One thing can lead to another... These events happened over about a year.

David went to a couple of football matches with his sister's boyfriend. He liked them, but preferred when it was a smaller game and the crowd wasn't so big.

They then went to an ice hockey match, which David loved even more than the football.

David joined the beginners' skating class at the ice rink where the ice hockey is played. He has made friends there and goes for coffee with them after the class.

He now lets his dad come with him to the ice hockey games where David is the expert and the host.

There are a lot of good sources of information about leisure facilities in Fife, and there may be similar information in your area:

- ➡ Kingdom of Fife Tourist Board
- ➡ Fife Council Leisure and Recreation services
- ➡ Community Education
- ➡ Fife Independent Disability Network is developing a guide to accessible leisure activities throughout Fife.

From October 2004 there are more legal obligations on people who provide services to make sure these are also available to disabled people. If you need information about access to buildings and services by disabled people, contact the Disability Rights Commission, or your local disability or inclusion networks.



## Getting a job



For most young people the main decision around life after school will be what job they do. But for many disabled children employment isn't really considered as a possibility. Their teachers and often their parents start from with the assumption that work will be beyond their abilities, or that it will be too stressful. Some families may also be anxious that if the person gets a job, they won't be entitled to welfare benefits and the income – their's and perhaps the family's too – will be less.

These are our suggestions.

- ➔ Start from the point that an ordinary job will be possible, sooner or later, if the person has the right support.
- ➔ Think about what this person might want to do, be interested in – his hobbies, what excites him - rather than what options are available to someone with his disability. The questions in A Good Life and some of the ideas in Part 3 of this pack - Making Choices - should help.
- ➔ Get the ordinary Careers Service people involved in any discussions in school about what his future might be.
- ➔ Check the advice from places like Careers Scotland and Business Gateway for options such as becoming self-employed.
- ➔ Check out the possible types of support around employment that are available from services. But also remember the natural supports that people find once they are settled in a workplace, with people they've got to know.
- ➔ Encourage this young person to try lots of things. Look for opportunities to do all the usual things that other young people do, such as Saturday and holiday jobs.
- ➔ Think about unpaid work, if that is where he will find a meaningful contribution. For example, the story about Jenny in Part 3 of this pack showed how finding a hobby led to finding a job. She also learned new

things and got confidence while she was an unpaid helper and participant.

- ➔ Don't just rely on special jobs through special schemes, or jobs which are advertised. If there is something else you think he might want to try, ask.
- ➔ Ask friends, your family, neighbours. Do they know anyone who could help by giving him an opportunity to try something? Can they help him get some work experience? This is how lots of people get jobs.
- ➔ Don't be discouraged if the first jobs don't work out. Lots of young people move in and out of jobs before they find what is right, so why should it be different for a young person who has a disability?
- ➔ Get advice about the money side. Ask for a jobs/benefits analysis.
- ➔ The rules about benefits and tax can change, and it may become easier for disabled people to get into work and to make changes if the first arrangement doesn't suit them. So make sure that there is someone in this young person's life who will help him check out the possibilities and get information from time to time.

There is a section on people to stand by you later in this part of the pack that should help you with this.



### Extracts from Al Etmanski: A Good Life:

Imagine meaningful activity for your friends and relatives with a disability in a different way. Let's make the focus meaningful work, not paid work. Let's not confuse work with paid employment.

Essentially, work serves three different functions:

One, we receive a salary; we get paid.

Two, we receive personal satisfaction, deep pleasure and fulfilment.

Three, we make a contribution to our community.

For many of our relatives the financial function of work will be critical and important. They will want to earn a living. For others this will be less so. What will be true in both situations is the value of pursuing work that brings meaning, fulfilment, purpose and satisfaction to their lives. In fact, many of us are confronting the same dilemma. Witness the growth of the 'simple living' movement. (pp 161-2)

- ➡ What contributions does your loved one make to the family?
- ➡ What are the three activities your friend or family member does best? What are the 3 skills they would most like to learn?
- ➡ What are their passions? What gives them greatest joy or pleasure?
- ➡ What kind of job (paid or voluntary) might be associated with their passions?
- ➡ What product or service would they enjoy selling?
- ➡ If they could start a business, what would it be?

(Some of the questions to help you explore possibilities from worksheet 9 of A Good Life.)

quoted with permission



**Example:** What this looks like for someone

Aaron likes:

roller coasters, chips, slush puppies, lights, swimming, roundabouts or anything that twirls him round, caravan holidays, seaside – standing in waves, music, car and bus journeys, sausages, train rides, amusement arcades, car racing games

Aaron is:

Tidy – likes order

Good at helping with cleaning and learning these skills at work experience

Taking things to people

He is getting better at talking to people, and loves the activity around a crowd.

We think the ideal job for Aaron would be:

Working at a holiday camp, cleaning caravans and enjoying all the activities on site when he is not working and enjoying seaside experiences, with support. He may need to live in a caravan to be near at hand.

*Lesley, Aaron's Mum*

## Story

Gary likes being around people but not having to say too much. He likes to keep his surroundings tidy, and he likes to have something to do.

He got bored being at home over the holidays from school and then college, so his uncle suggested he come over to his firm, which delivers goods to local businesses.

Gary enjoyed going out in the van and meeting people, and helping with the boxes. His favourite job was sweeping up. He got much more confident as he got to know the other people who worked there.

One of the warehouses Gary used to visit was looking for someone to keep the warehouse tidy. Gary's uncle helped him write a letter explaining all the things he was good at and what would help him do a good job.

Gary went with his uncle to meet the manager and they talked about how Gary could do the job. Gary got the job at the warehouse.

## Story

Lorna decided she wanted to try several things, to find out what sort of job she liked.

When they moved to a new area, Lorna's friend's cousin used her contacts to help them find a good hairdresser, since this was one of their priorities. After a few months, Lorna asked if she could get a part-time job at the hairdresser's. That was her first job, and the women there helped her learn about having a job.

Once she had more confidence, Lorna got several other jobs, including one in a tea room.

Lorna also started doing more of the cooking at home for her and Elizabeth (her flatmate), and really liked it.

She has now decided to go to college to learn more about cooking. Her aim is to make cakes and sell them to tearooms.

## Story

While she still lived with her mum and dad, Elizabeth met the staff at the supported employment project. The people at the project helped her find a job.

The first place wasn't ideal, as although the office was accessible for a wheelchair she still found it awkward to get around and couldn't be independent. Elizabeth tried hard to do this job, and when it didn't work her confidence was shaken.

The employment project helped her find a similar job in another building, where it is much easier for her to get around on her own. She also got lots of encouragement and help with practical things from her family and support worker, so the new job got off to a good start.

Resources and information within Fife include:

- ➡ the Fife Employability Team – who now have a resource pack
- ➡ FEAT (Fife Enterprise and Training)
- ➡ Business Gateway for help to set up your own business.

There will be similar sources of information and advice in your area. Some will focus on the employment needs of people with disabilities. But also check out the places that support anyone who is looking for work, or who may want to start a business or become self-employed.

## Other sources

Fife EmployAbility Team

Contact: Callum MacGregor  
Fife Council  
Social Work Department  
Kingdom House  
Kingdom Avenue  
Glenrothes  
KY7 5LY

Tel: 01592 414 957  
Textphone: 01592 416 418  
Email: [Fife.Employability@fife.gov.uk](mailto:Fife.Employability@fife.gov.uk) or [callum.macgregor@fife.gov.uk](mailto:callum.macgregor@fife.gov.uk)

Business Gateway, for starting new businesses  
Tel: 0845 609 6611

Working Families provides information on many aspects of flexible working – for parents and carers, for people with disabilities, and for people who want to work flexible hours. It has fact sheets and advice for employers, and does training and consultancy.

Web: [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)

The Prince's Trust helps young people who want to start up in business and gives support through the early period.

Prince's Trust  
Prince's Scottish Youth Business Trust  
Mercantile Chambers  
6th Floor  
53 Bothwell Street  
Glasgow  
G2 6TS

Web: [www.psybt.org.uk](http://www.psybt.org.uk)

## Continuing to learn

Continuing to learn is important for everyone, but we think it is especially important for young people who are disabled. It takes some people longer to learn how to do some things, so the learning around day-to-day skills continues after the person has left school. Learning helps people to get work – it builds both the skills to do a job and the confidence to give it a go. And taking part in courses and evening classes and the like is the way lots of us make more friends.

There are several colleges which have courses designed for young people who



have disabilities. Colleges also have support arrangements to let disabled students access the ordinary courses that they provide.

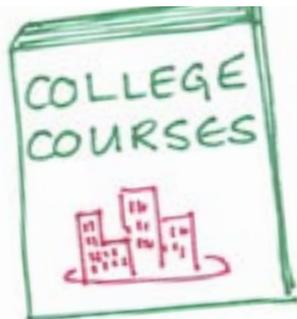
Learning isn't just around work or study. It is also community education, evening classes and opportunities provided by lots of local organisations. For example, Learning Locally in Fife links 53 learning centres in Fife. They cover a range of subjects, including computer skills, office skills and customer care.

But you are not limited to local provision. For example, we've heard from young people in Dumfries and Galloway – in the south-west of Scotland – who have gone to the college in Carlisle - near by, but in England – because the courses there suit them better.

Good sources of information are the careers advisers attached to schools – ordinary ones, as well as specialist schools, colleges and community education staff.

These are our suggestions.

- As with everything else, we think it helps to start with this young person, his interests and enthusiasm, what he brings and needs. Don't start with the label or disability.
- Ask other young people and their families what they found helpful.
- Check if using Direct Payments or some other way of getting support tailored to this young person may give him a much wider range of options around learning.
- Explain what he and you think will work for him, and see if people can think of ways of meeting this.
- Ask the place he is interested in what support they can provide to help him beyond the usual supports for all students.
- If the first place you approach can't provide what this young person needs, go to others.



## Other sources

Learndirect Scotland has details of the learning centres across Scotland:

Tel: 0808 100 1855

Fairbridge provides support to young people aged 13-25 in urban areas who are not in education or work and who have been identified as being at risk of dropping out. It provides support to young people and challenging activities which enable people to learn and gain confidence.

Fairbridge  
73 Ferry Road  
Edinburgh  
EH6 4AQ

Tel: 0131 554 2568

Web: [www.fairbridge.org.uk](http://www.fairbridge.org.uk)

## Making a contribution



“Community connectedness says I don’t care about your deficiencies, I insist on your contribution.” *John McKnight*

There are many ways in which we can make a contribution. One is through paid work. Others are the unpaid things we do – volunteering, being a member of an association or community group. We contribute as a citizen by voting, by asking questions and by contributing our views. We contribute by being someone’s friend or neighbour. We contribute just by being part of a community and being with other people.

We benefit by gaining in confidence, and mixing with other people. The rest of the community benefits from our ideas and experience, and from the personal qualities we bring to our connections.

These are some of the practical things families can do to help make sure the young person is able to contribute his gifts.

- ➔ Make sure the young person is included on the electoral register, so he will be able to vote when he is 18. Contact the Electoral Registration Officer at the local authority.
- ➔ Check out opportunities such as volunteering. These can be a way to try out new things and learn skills, which may lead to friends and new interests, and may even lead to a job.
- ➔ Join local community groups where people share their hobbies and interests. For example, if someone likes being outdoors, there are many organisations which are looking for people to help with environmental projects.
- ➔ Find out about the collective advocacy groups which bring together disabled people, or are tackling other issues which affect this person or he cares about.

## Story

My name is Ann Marie and I live in East Kilbride. I am a volunteer for Art-Ability which helps people with a disability and people that need encouragement like me, to take part in an art class. I wanted to volunteer in the office but couldn't because of space and time so I spoke to Craig and asked him if I could become a volunteer in the art classes.

I help people to paint and draw and I help to set up and tidy up. I enjoy helping others and meeting people and I get a chance to paint my own pictures when there is time. I think volunteering helps you meet other people and helps disabled people and the Art-Ability team.

Here is an example of one of my own pictures. It is called 'summer' and it was used for the Art-Ability brochure.



## Story

David is a volunteer who helps keep the local beach clean.

He also helps promote fair trade. When David's sisters were clearing out their wardrobes they made several trips to the local Oxfam shop, and David heard all about fair trade products. David thinks this is a good idea. The people at the Oxfam shop asked David if he wanted to help. It doesn't suit him to come to the shop, but he goes with one of the women when she has a stall at local churches or markets at weekends. David helps set up the stall, gives out leaflets and tells people about fair trade.

Don't just think about conventional, organised ways to make a contribution. For example, We Are What We Do has brought together great suggestions about many creative ways people can contribute to making life better for everyone. The website is good fun, and there are lots of ways people of all ages can be involved in it, as well as contributing to their community. The book, Change the World for a Fiver, is available from We Are What We Do and from bookshops.

John McKnight and his colleagues at NorthWestern University in Chicago have been looking at how communities work, and how people contribute. The Asset-Based Community Development programme has given us many ideas and helped us understand why making a contribution is so important. They have produced many useful reports and practical tools, which help identify the assets and strengths of individuals and small groups, as well as of communities.

In Scotland there are organisations which are working to promote participation and to promote diversity and inclusion. We've given some contacts here, as examples and to get you started. You will find others in your area.

## Other sources

The Voluntary Action Fund (formerly the Unemployed Voluntary Action Fund) has a report on volunteering opportunities for disabled people and what would help make volunteering projects more inclusive:

Everyone Included, All Equal, No Arguments

The Voluntary Action Fund  
Comely Bank house  
80 New Row  
Dunfermline  
KY12 7EJ

Tel: 01383 620 780  
Web: [www.voluntaryactionfund.org.uk](http://www.voluntaryactionfund.org.uk)

Councils of Voluntary Service usually have information about volunteering opportunities in their area – or will be able to give you a contact.

ProjectScotland is a new organisation developing full time volunteering for 16-25 year olds. It will be up and running by summer 2005, and aims to be inclusive. It will be working with partner organisations in the public, private and voluntary sectors which will provide placements for young people.

ProjectScotland  
Tel: 0131 226 0700  
Email: [info@projectscotland.co.uk](mailto:info@projectscotland.co.uk)

Lead Scotland supports disabled adults into learning. It uses volunteers to work with people, and the volunteers include disabled people.

The office for the East of Scotland is at:  
Lead Scotland  
Queen Margaret University College  
Clerwood Terrace  
Edinburgh  
EH12 0BR

Tel: 0131 317 3439  
Email: [enquiries@lead.org.uk](mailto:enquiries@lead.org.uk)  
Web: [www.lead.org.uk](http://www.lead.org.uk)

We Are What We Do  
15-17 Lincoln's Inn Fields  
London  
WC2A 3ED

Tel: 020 7396 5330  
Email: [sara@wearewhatwedo.org](mailto:sara@wearewhatwedo.org)  
Web: [www.wearewhatwedo.org](http://www.wearewhatwedo.org)

The Asset-Based Community Development Institute of Northwestern University has information about their programmes and publications on their website. This includes articles and examples of tools used in working with communities and organisations. The list of their publications is at:  
[www.northwestern.edu/ipr/abcd/abcdtopics.html](http://www.northwestern.edu/ipr/abcd/abcdtopics.html)

A good starting point is Building Communities from the Inside Out: A path toward finding and mobilizing a community's assets, by John P. Kretzman and John L. McKnight. The book captures over 3,000 people's stories about what others have done to make their communities better. You can order the book from the Institute and through bookshops.

The introduction to the book is at [www.northwestern.edu/ipr/publications/](http://www.northwestern.edu/ipr/publications/) and navigate via "books" to these authors

Mapping Community Capacity: [www.northwestern.edu/ipr/publications/papers/mcc.pdf](http://www.northwestern.edu/ipr/publications/papers/mcc.pdf)

The ABCD Capacity Inventory in Building Communities from the Inside Out is at [www.northwestern.edu/ipr/abcd/abcdci.html](http://www.northwestern.edu/ipr/abcd/abcdci.html) and [www.northwestern.edu/ipr/abcd/cihowto.html](http://www.northwestern.edu/ipr/abcd/cihowto.html)

Philia is stimulating discussion across Canada about inclusive citizenship.

Web: [www.philia.ca](http://www.philia.ca)

The Forum on Discrimination brings together people and organisations across Scotland with an interest in any aspect of discrimination. It is linked to the Scottish Civic Forum. It shares information and raises issues with policy makers.

Forum on Discrimination  
Scottish Civic Forum  
Fòram Catharra Na H-Alba  
16 Jackson's Entry  
Holyrood Road  
Edinburgh  
EH8 8PJ

Tel: 0131 524 9392

Fax: 0870 051 1192

Web: [www.forumondiscrimination.org.uk](http://www.forumondiscrimination.org.uk)

## Where you live



Most young people with disabilities stay at home with their parents, and may expect to stay there for the next few years at least. But they may want to start thinking early on about longer-term options and becoming more independent.

‘Disabled people can need

- ➡ a special type of house, or
- ➡ a special type of support, or
- ➡ both a special house and support, or
- ➡ a special approach – sensitive or flexible – to meeting their needs, but an ordinary house and ordinary support.’

(Fife local housing strategy, 2003-08)

These are our suggestions.

- ➡ It is easier to think about where someone wants to live, and then about the type of house and the type of support they might want, once it’s clearer what type of life they want and what they want to do.
- ➡ Think about what type of support this person wants, and then look at which support services can provide this.
- ➡ Start planning early, as it can take a while to get the right house in the right place, especially if someone needs a special type of house.
- ➡ Think of a house and support for someone as a way of helping them have the type of life they want, rather than letting the house determine everything else.

Possibilities for support include:

- ➔ Sharing a flat with someone – one of the ways in which friends are important.
- ➔ Support providers helping someone live on their own and providing people to stay with them. This can be organised through a support service or by the person employing people through use of Direct Payments or Independent Living Fund.
- ➔ Living alone with a lower level of support, say from people visiting each day or so. Again, this can be organised by a service provided through the Council or by the person employing someone using Direct Payments.
- ➔ Living with a lodger who provides care in exchange for a reduction in rent, or living rent-free.



Many people assume that someone with a disability will rent their home – and that works well for lots of people. But there are other options.

For some people, their ideal choice will be to stay in the family home – for example, if you know all the people round about you and it is already suited to your needs. We know of some families where everyone talked it over and decided the best option was for the person who was disabled to stay in the house they had grown up in and for their mum and dad to move to a house that gave them what they now wanted. If this is the choice for you, think about how to make this a secure place for as much as the person's adulthood as they want. This might involve checking out about wills and trusts – see the section in Part 3 of this pack, Making Choices.

Another option is to buy your home. Ownership Options in Scotland is an organisation which provides information about ways for disabled people to become home owners. There is information on their website and available from their office. They will also run courses and workshops/surgeries if people in a local area or an organisation want to organise this.

There is also the private rented sector - there are some good landlords around. This can be a way of trying out living more independently without making a long term commitment. It can be easier to do it at a time when it suits the person, as opposed to the time a house in the social rented sector happens to be available. You also may have more choice about area and type of house or flat, than the housing association or the Council can offer.

A group of families in Edinburgh commissioned a report to explore all the possible ways of getting housing for a young man or woman who had a learning difficulty and was living at home with parents. Although the specific suggestions are about Edinburgh, many of the ideas would also apply to people living in Fife or anywhere else, and it may give you options to start considering and following up.

It includes a set of questions (reproduced below) to help you work out what the ideal housing options are for this person. There is also a useful set of appendices with information about technical aspects of housing and buying homes or taking on a tenancy, and the report has contact details.

Neighbourhood Networks is based on the idea of supporting a small network of up to nine people living within a neighbourhood. People live in their own home in the community and within reasonable travelling distance from each other. Support is offered by a local worker and focuses on ensuring that all members of the network contribute to supporting each other on a neighbourly basis.

Neighbourhood Networks has several projects across Scotland. It is based on the Key Ring model, which has operated in England for several years.

## Story

Lorna and Elizabeth have been best friends since they were 5 years old. They each stayed at home with their mum after they left school, but always talked about sharing a flat. Lorna's mum wasn't well, and several people suggested to Lorna that it might be better if she moved to a house on her own or with other people. Lorna said that she was going to share a flat with Elizabeth. They told their mums (who both cried).

It was over a year before Lorna and Elizabeth moved into their flat. These are some of the people who helped make it happen.



- ➡ The support workers who worked with Lorna and Elizabeth got together with them, and they all decided who would help Elizabeth and Lorna on things they wanted to do together to plan for the flat.
- ➡ Initially, they met up in Lorna's house, but that got to be hard for Lorna and her mum. So Elizabeth's aunt suggested they meet at her house, and they could invite their mums when they wanted to.
- ➡ An advocacy project helped them write to Housing Associations, and later helped get some problems about the tenancy sorted.
- ➡ Lots of people started looking for houses for them: family friends and relatives as well as support workers and the Housing Associations. People went with them to look at flats, and kept encouraging them when it seemed to be taking a long time to find the right place.
- ➡ People in the Social Work Department helped by sorting out the money side, and made sure there would be more support for Elizabeth and Lorna for 6 months or so after they moved into the flat.
- ➡ When they got the flat, Elizabeth's family helped with decorating and making some adjustments. Lots of people bought them things for the flat.
- ➡ One of Elizabeth's cousins lived in the area. She helped them get settled in by

showing them local shops, popping round and keeping in touch with the rest of the families so they knew Lorna and Elizabeth really were doing all right.

Places where you can get more information about what is available in Fife are:

- ➡ The Local Area Co-ordinators
- ➡ The Housing Department
- ➡ The Social Work Department has information about the range of organisations they have approved to provide housing and related support.

There will be similar sources of information in other local areas.

## Other sources

The Homepoint service provided by Communities Scotland also has a lot of useful information:

Web: [www.homepoint.communitiesscotland.gov.uk/homepoint](http://www.homepoint.communitiesscotland.gov.uk/homepoint)

Ownership Options provides advice and support to disabled people who are interested in owning, rather than renting, their home.

Ownership Options in Scotland  
10 Sunnyside  
John Cotton Centre  
Edinburgh  
EH7 5RA

Tel: 0131 661 3400

Email: [info@oois.org.uk](mailto:info@oois.org.uk)

Web: [www.oois.org.uk](http://www.oois.org.uk) site is for people who advise disabled people.

The site at [www.housingoptions.info](http://www.housingoptions.info) is aimed at individuals.

Mainstream housing options for people with learning difficulties in Edinburgh, by Julia Fitzpatrick (2002). Written for Parent Pressure, available from FAiR

FAiR (Family Advice and Information Resource)  
25/27 West Nicholson St,  
Edinburgh  
EH8 9DB

Tel: 0131 662 1962

Email: [fair@fairadvice.org.uk](mailto:fair@fairadvice.org.uk)

KeyRing  
National Office  
3rd Floor, Impact Centre  
12-18 Hoxton Street  
London  
N1 6NG

Tel 020 7749 9411

Fax 020 7749 9415

Email: [enquiries@keyring.org](mailto:enquiries@keyring.org)

Neighbourhood Networks  
Unit 10  
First Floor  
Festival Business Centre  
150 Brand St  
Glasgow  
G51 1DH

Tel: 0141 314 0027

Email: [rebeccaallan@neighbourhoodnetworks.org](mailto:rebeccaallan@neighbourhoodnetworks.org)



**Extract from Mainstream Housing options,  
written by Julia Fitzpatrick for Parent  
Pressure**

## **PERSONAL HOUSING PLANNING**

The starting point for a personal housing plan is just to think through a number of questions about who you want to live with or near, how and where you want to live, what your house needs to look like in order to meet your needs, and what you can afford. Because it is personal, each person or family may have extra information they want to add.

### **1. Where are you starting from?**

Before you put lots of effort into thinking about or researching what options are available, it helps to think about where you live now, and about where you have lived in the past. This can help to build up a picture of what aspects you want to change and what you would like to continue. For example you might like the size of your living room but note that the bathroom is too small to be adapted for your needs, or the house is too far from amenities.

-  What do you like about where you live now or where you have lived before?
-  What do you not like? What isn't suitable for you? Why?
-  What needs to change?

## 2. Who do you want to live with?

- ➡ How many people will live in the house as their main home?
- ➡ Will people from different age groups be living in the house e.g. children?
- ➡ Do you want to share with anyone?
- ➡ Will you need room or space for people to support you? Think about when and what kind of support you might need and if this will affect the size or type of house.

## 3. Where do you want to live?

- ➡ Think about what you do or would like to do (or have to do) on a daily, weekly or monthly basis.
- ➡ Think about your friends and family and how often you would like to see them.
- ➡ Think about what kind of area makes you feel at home and why.
- ➡ Think practically about how you or your friends or family will travel to and from where you live

For example, you might like to walk to a local shop but be happy to get on a bus to work. Some people want to be able to see their family every day; others will want to meet up only occasionally. It might be very important to you to stay in a local area where you are familiar with the people or you might like the idea of getting to know somewhere new.

## 4. What will your home look and feel like?

Do you or your family have particular needs which will affect the type of house which will be suitable for you? For example, you might use a wheelchair which means you need to have level or ramped access to your home.

What sort of space or design or aids or adaptations might help you to do things in the house or be supported to do them? For example, if there was a kitchen surface that you could sit at, would this mean you could help with making meals, but if the kitchen is very small then you can't do this?

Do you need help with some things which might affect the size or type of house you need? For example, if you need help with bathing or going to the toilet, you may need a bigger bathroom so there is room for someone else to help.

Think through what elements of a property would be essential for you, and what would you like to have but could live without. For example, you might need at least 2 bedrooms - one would not be enough in your situation. However while you would like a garden, you could manage without one as long as you felt the house was quite private and no-one would disturb you.

## 5. What can you afford?

-  Where does your money come from at the moment and how much do you have?
-  Do you have to pay any money for care and support?
-  What do you spend your money on now, would this change if you were to move?
-  Think about what you would need money for to get a new home, and then to set it up and live in it. Try to estimate how much you might spend.
-  If you moved, would you or could you get help with any of the costs? Where from and how much?

## 6. Any other points which might affect your plan?

- ⇒ Are there likely to be questions about legal capacity to make decisions?
- ⇒ Are there local care or housing policies or initiatives which could help you, or which might stand in your way?
- ⇒ Think about people who can help you work out your options or get more information?

Depending on your situation, you might want to get help with thinking about these questions. It could involve discussions and meetings with families, care commissioners, and support providers. It may also be useful to seek specialist or professional assistance to clarify certain areas e.g. welfare benefits entitlements; occupational therapy advice on aids and adaptations options.

## Description of basic housing requirements

Once you have carried out this detailed planning, you are ready to be quite clear about what you are looking for and why, and have an idea about what you can compromise on. You don't need any technical or specialist knowledge to do this but your description will probably also include information on adaptations which you would need and any design features. This can provide a useful summary for a person or family and for anybody working with him or her then to consider some preliminary housing options.

## How would you use this information?

- ➡ Match against existing and potential housing options and work out preferred routes.
- ➡ Support funding submissions for capital and revenue grants.
- ➡ Provide the basis for applications to rented housing providers, or discussions with them.
- ➡ Provide a starting point for assessing house layout plans or housing offers.
- ➡ Provide an initial brief to an architect.
- ➡ Provide a summary of requirements to estate agents or new housing developers for property matching purposes.

It is worth spending time on the process of drawing up the preliminary information and on thinking through where a requirement is essential or desirable e.g. range of locations, and how much scope for negotiation there is around preferences. This will help others who are working with you to be clear about the parameters. However, bear in mind that personal housing planning is not a science, it is a process. In the course of thinking about and finding housing, people revisit and change their plan. This can be because a new opportunity is presented or because experience of searching helps people to

become clearer about what is negotiable and what is not.

Disabled people or their families who have access to the internet can work through out a detailed personal housing plan questionnaire and access information about options on [www.housingoptions.info](http://www.housingoptions.info).

Extract from Julia Fitzpatrick's report for Parent Pressure, quoted with permission.

## Keeping well



Keeping well involves lots of things.

It starts with access to health services, including primary care. If the young person is staying at home, or nearby, then he will probably stay registered with the GP (family doctor) who has known him since he was a child. But if someone is moving into a new area, or is moving to their own flat some distance away, you may want to check out the local practices.

People with disabilities may need some extra help to keep well, so check out what is available to help someone maintain good health and prevent or identify serious illnesses. This might be advice around diet, exercise and so on. It will also include care on women's health/men's health issues.

This young person may also need access to specialist services that support people with particular conditions and disabilities.

These are our suggestions.

- ➡ The GP is the starting point for access to health services. So cultivate a good relationship with your GP.
  - ➡ Discuss when and how this young person's parents are going to be involved in his care, and make sure that your GP and other health professionals know whether there is a guardianship order or not.
  - ➡ The person's health needs may have a bearing on other aspects of his life. If you are worried about something, or feel that there is a risk for the person, think about this in the context of what a good life is for him. Use this as the starting point to have discussions aimed at finding a way of balancing risks and opportunities for him.
  - ➡ Make a list of any health worries for this person when everyone is at the stage of planning for the future.
- ➡ Also make a list of any health problems that are in his family – parents, grandparents, his brothers and sisters - so this can go into his files, in case people need to know this later. Think about who will keep this type of information updated.
  - ➡ Many families find that the attitudes of health care staff are as important as their skills. If you have concerns about the quality of care, talk it over with your GP or someone whom you trust.
  - ➡ Advocacy projects may be a good way of helping to ensure that someone has access to good health care.
  - ➡ A citizen advocacy project or a circle of friends may also help make sure the person stays well.

## Story

Since he left school David has started being physically more active. He is down at the beach as a volunteer for several hours most weeks and he has started doing some sports. He now has fewer digestive problems and is sleeping better.

Mencap published 'Treat Me Right' in 2004. This report describes the experiences of people with learning disabilities when using health services. The Mencap website also has examples of really useful material and links to other sources of information on health matters for people with learning disabilities, and for staff who work in the NHS.

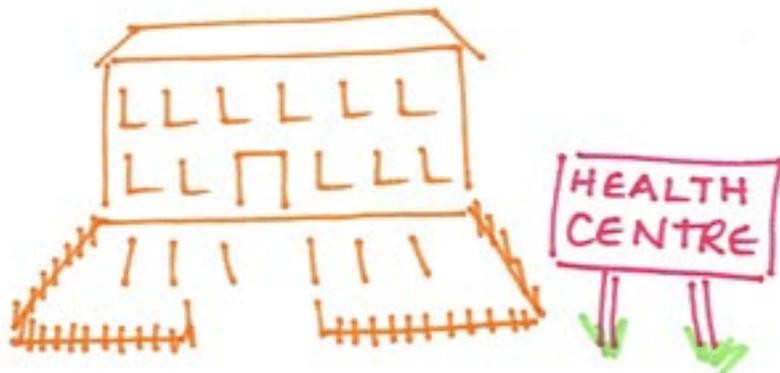
Another useful source of information on health for people with learning disabilities, their families, and for staff who are treating or supporting people with learning disabilities is The Health Challenge Bulletin, published by the Scottish Consortium for Learning Disability in 2004.

## Other sources

The Mencap report is at: [www.mencap.org.uk](http://www.mencap.org.uk)

Scottish Consortium for Learning Disability  
Adelphi Centre Room 16  
12 Commercial Road  
Glasgow  
G5 0PQ

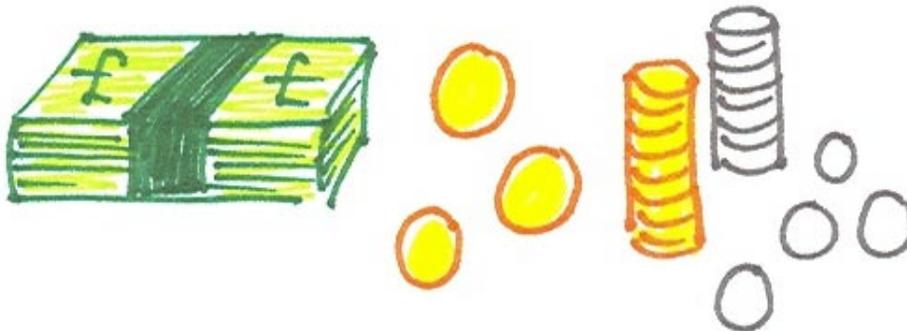
Tel: 0141 418 5420  
Web: [www.sclld.org.uk](http://www.sclld.org.uk)



# Money

Planning for the future should include planning for the money that someone will have. The sources of money for someone with a disability will usually be a combination of:

- ➔ welfare benefits
- ➔ Direct Payments or Independent Living Fund
- ➔ earned income
- ➔ income from trust funds, for example when someone inherits money, or from a settlement after an accident, and
- ➔ one-off grants or loans from schemes to help young people, or to help people do certain things.



The person needs to get information and advice on the benefits and other payments that they might be entitled to. The rules on benefits change, so it is worth updating this from time to time – for example, on how much earned income someone can have before particular benefits are affected. In Fife, the Direct Payments Team is a good source of information on Direct Payments and on the Independent Living Fund, and there is likely to be a similar source of information in your area.

There are some good publications about Direct Payments which young people and parents will find useful.

Living it up: guide by disabled young people on Direct Payments and Personal Assistants  
A magazine-style report, and details of a video version, is at:  
<http://www.bris.ac.uk/Depts/NorahFry/transition/livingitup1.pdf>

A video about Direct Payments is available from Values Into Action. Contact them at:  
[www.viauk.org](http://www.viauk.org)

Direct Payments Scotland has a lot of helpful information, and a Helpline.

People First Swindon produced a guide to direct payments for people with learning difficulties for the Department of Health in August 2004. It's title is 'An easy guide to direct payments: giving you the choice and control' – order number 33291. Copies are available from Department of Health Publications.

The Scottish Consortium for Learning Disability published Frequently Asked Questions in 2002.

The Department of Work and Pensions has a lot of information on benefits and on matters around employment.

The Family Fund provides information and practical advice for families of children and young people (aged up to 25) who have a disability. It also provides financial help for families who have low incomes (currently up to £23,000).

Families may also want to get advice on financial matters – for example, if someone wants to give money to this person or leave him money in their will. You can get advice from lawyers, accountants and other professionals. The report on housing options for Parent Pressure in Edinburgh identified some solicitors who had a particular interest and expertise around how the law and other systems affect people with disabilities, and families may want to swap this sort of information about people in your area who are especially helpful.

A recent report by FAiR describes how hard it can be for people with disabilities to get access to bank accounts and other financial services. But it also has a lot of good practical suggestions.

Another good source of ideas is a leaflet called 'It's your money – banks can help', which was developed in partnership with People First Swindon and is published by the Employers' Forum on Disability. It is an accessible guide to how bank accounts work and has many practical suggestions.



## Other sources

The Direct Payments Team in Fife has produced a good booklet, with detailed information and examples to show how Direct Payments works. There may be a team near you which has similar information.

Fife Direct Payments Support Service  
Talbot Cottage  
Station Road  
Leven  
KY8 4QU

Tel: 01333 592656  
Email: [denise.boyd@smtp5.fife.gov.uk](mailto:denise.boyd@smtp5.fife.gov.uk)

Direct Payments Scotland  
27 Beaverhall Road  
Edinburgh  
EH7 4JE

Tel: 0131 558 5200  
Minicom: 0131 558 5202  
Web: [www.dpscotland.org.uk](http://www.dpscotland.org.uk)  
Helpline: 0131 558 3450

Norah Fry Research Centre  
3 Priory Road,  
Bristol  
BS8 1TX

Tel: 0117 946 6553

Department of Health Publications

Tel: 08701 555 455  
Minicom: 08700 102 870  
Email: [dh@prolog.uk.com](mailto:dh@prolog.uk.com)

Scottish Consortium for Learning Disability  
Adelphi Centre Room 16  
12 Commercial Road  
Glasgow  
G5 0PQ

Tel: 0141 418 5420  
Email: [administrator@sclد.org.uk](mailto:administrator@sclد.org.uk)  
Web: [www.sclد.org.uk](http://www.sclد.org.uk)

Department of Works and Pensions

There is information about benefits from the Department of Work and Pensions. The website has information about the range of benefits available.

You can get general information about the work of the Department for Work and Pensions from the Public Enquiry Office.

Opening hours: Monday-Friday 9.00am-5.00pm

Tel: 020 7712 2171  
Web: [www.dwp.gov.uk](http://www.dwp.gov.uk)

You can also write to the Public Enquiry Office at:

Department for Work and Pensions  
Room 112  
The Adelphi  
1-11 John Adam Street  
London  
WC2N 6HT

The general office cannot deal with enquiries about an individual person's claim or entitlement. You will get this from the local offices.

Family Fund  
PO Box 50  
York  
YO1 9ZX

Tel: 0845 130 4542  
Web: [www.familyfund.org.uk](http://www.familyfund.org.uk)

It's your money – banks can help (2002)  
published by

The Employers' Forum on Disability  
Nutmeg House  
60 Gainsford St  
London SE 1 2NY

Tel: 020 7340 3020

Email: [efd@employers-forum.co.uk](mailto:efd@employers-forum.co.uk)

Web: [www.employers-forum.co.uk](http://www.employers-forum.co.uk)

Banking on Change (2004), by Margaret Hurcome. There is a full report and easy read summary.

FAiR (Family Advice and Information Resource)  
25/27 West Nicholson St  
Edinburgh  
EH8 9DB

Tel: 0131 662 1962

Email: [fair@fairadvice.org.uk](mailto:fair@fairadvice.org.uk)

The report is available on Outside the Box  
website: [www.otbds.org](http://www.otbds.org)

## People who will help you and stand by you



There are lots of people who will stand by someone, and be a support to them in good times and bad. These people may come from different parts of someone's life, and from different periods in the person's life. But we think that you can think of them as coming from three main groups of people. Our advice is that it is good to have people in each of these groups, as their skills and experiences and interests tend to complement each other.

Firstly, there are people who work for services, whose job is to try to help make the system work for each person. At the time of putting this pack together there are 2 Local Area Co-ordinators in Fife, and we hope that soon there will be a Local Area Co-ordinator for people in every area. Local Area Co-ordination is a way of linking with disabled people and families, and helping them get the support they need from services and from ordinary resources within their communities.

There is more information about Local Area Co-ordination on the Outside the Box website: [www.otbds.org](http://www.otbds.org)

Other contacts are the social workers who do assessments.

Within health services, there are some teams who aim to co-ordinate services – as well as the person's GP.

## Example

This is the experience of the families who helped to put this pack together.

Sometimes you really need someone who can help you through the system.

One problem which several of us experienced is that you need to be getting services in order to get services – receipt of services is equated with level of need. For example, you need to be getting £200 worth of services in order to apply for Independent Living Fund, which would then let you have alternatives to conventional services. But we thought the conventional services weren't helpful for our families – so it looked as if we would end up not being able to get anything.

It is worth talking to a social worker or a Local Area Co-ordinator about this type of situation. It turned out that what counts as services and how need is assessed may be more flexible than it first appears.

Secondly, there are independent sources of advocacy or information.

Broadly, there are 3 types of advocacy projects which are all independent of the organisations which provide services.

-  Collective advocacy, where people who share a common interest come together to support each other. They make the case for changes that will benefit one or more individuals within the group, or for changes that will benefit everyone.
-  Citizen advocacy, where one person volunteers to get to know and stand alongside someone who has few other friends or is especially vulnerable. Each citizen advocate works with only one person, and is usually involved with them for many years.
-  Professional or individual advocacy, where a person – paid or a volunteer – supports someone to say what they want on a particular issue. The advocate will usually be working with several people at any one time, and their involvement with each individual is usually over a short period.

These are the current advocacy projects in Fife, and there might be a similar range in other places.

- ➔ Dunfermline Advocacy, which is a citizen advocacy project for adults and children with learning difficulties in Dunfermline and the surrounding town. Two new citizen advocacy projects are being developed for other parts of Fife.
- ➔ People First, which is a collective advocacy project for people who have learning difficulties. There are 2 groups, one in Leven and one in Glenrothes.
- ➔ Fife Children's Rights Project, which provides advocacy for children who are vulnerable, including children who are looked after or away at school, and children with disabilities.
- ➔ A local group linked to a national young person's self advocacy group.
- ➔ The Fife Carers' Centre advocates for carers and for people with additional needs.
- ➔ Fife Independent Disability Network.

Some people find it helpful to be in contact with other women, or other people from black and minority ethnic communities. People First have produced 2 books – ‘Women First’ and ‘Black People First’.

There are also a lot of national groups which provide information, advice and some self-help networks for people who have particular illnesses or conditions. Voluntary Health Scotland can provide information on these projects. Carers’ Centres also have information on self-help and support groups for families, and there are likely to be similar sources of information in your area.

And last, but definitely not least, the third group of people who can stand by someone who has some additional needs are friends, family, neighbours – people in their community. Some of the advantages they bring include their own varied experiences and contacts on a huge range of matters, not just about social care or disability services. Also, it is our view that the more people who are around someone and who care about him as a person, the less likely it is that anyone will harm that person.

There are lots of good ideas on how to build up a formal network of friends in Al Etmanski’s A Good Life. And some of the books listed in other parts of the pack will give you ideas and show the benefits of someone being included in their community.

Some of the people among friends and family might take on formal roles as guardians, if the person needs this type of extra help around making decisions. Again, the information section has contact details and there are more suggestions in Part 3 of this pack - Making Choices.

## Stories

Lorna had several part-time jobs: some were paid and some were voluntary. There was one job which started out fine, but after a while Lorna thought she was being messed around. Her colleagues at another job noticed she was worried, and asked if she was OK. She told them what was happening, and they agreed that it wasn't right. They helped her work out what she was going to say to her boss at the other place. One person offered to come with her if she wanted.

When Lorna and Elizabeth moved into their new flat, one of their presents didn't work properly. They went to a local advice centre to find out what they could do. The man there didn't have much practice of giving information to people with learning difficulties, but kept trying until he had written down what they were to do in a combination of words and pictures that they were all happy with. Afterwards, Lorna and Elizabeth got their support worker to go in and tell the advice centre about where to get more information on easy read and about Change Bank pictures.

Lorna's mum had to go into hospital for a big operation. The hospital was hard to get to by bus, especially at night, and Lorna was worried about visiting. Elizabeth, Lorna's friend, has a big family with lots of brothers and cousins. They helped take Lorna up to the hospital to visit her mum whenever she wanted. Elizabeth's mum stayed with Lorna and Elizabeth for a while, so she could be around for things like shopping and they could do whatever Lorna and her mum wanted.

At one point her mum was very ill, and Lorna wanted to be with her mum to talk to the doctors about what was going to happen. Elizabeth's mum and the support worker suggested Lorna get in touch with the local advocacy project, so there was someone to help her and someone to help her mum.

## Story

Elaine lives at home with her mum, dad and brother. She likes going to the day centre where she goes horse riding, bowling, ice skating and other centre based activities.

Elaine does not lead the life of an ordinary 20 year old. Her life runs to a tight time table consisting of medication, feeding, physiotherapy and home care services. The number of health and local authority run services that she requires on a daily basis mean that her social life outside of 9 – 5 Monday to Friday day centre hours is non-existent.

Elaine wanted a citizen advocate of her own age so that she would have someone she could call a friend, rely on and to stand up to the authorities sometimes so that they would pay for the type of flexible service that she is looking for. Elaine's brother also has a disability and all her life she has been treated as one of 2 people with complex needs, receiving services into the home that are for her and her brother to share. At the age of 20, Elaine wants to now start being treated like an individual with needs and wants.

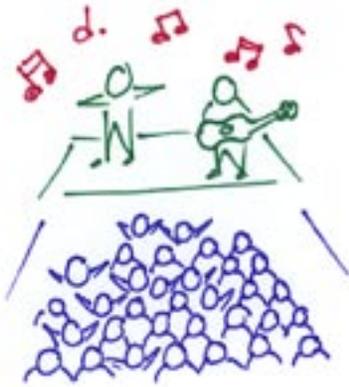
It took 9 months to find the right person to be Elaine's citizen advocate. The project worker was searching for a very particular kind of young woman.

- ⇒ Someone who is bright and cheerful while being able to deal with silence as Elaine has no speech.
- ⇒ A young woman who was going to commit to taking a long time to get to know Elaine because of the level of her physical disability and lack of verbal communication.
- ⇒ Someone who would be willing to learn some particular medical/care interventions that are required to help Elaine e.g. if she had a seizure or required suction.
- ⇒ Someone who would be accepted by Elaine's family and the professionals involved in her care.

Elaine now has a wonderful young woman in her life. Beth fits the bill in all of the above criteria. Beth has been visiting Elaine now every fortnight for over a year.

Beth is now at the stage of attending meetings on Elaine's behalf. She is consistently putting over Elaine's point of view by sharing her experiences with the relevant people, fighting for a more flexible care routine for Elaine and asking for some services which Elaine is missing out on.

Beth is also encouraging the relevant professionals to give Elaine the flexibility in her home care service so that the 2 of them will be able to share the experience of Elaine's first ever night out, away from family or paid carers – something that most young adults take for granted.



## Other sources

National Young People's Self Advocacy Groups  
ENABLE

National office  
6th floor  
7 Buchanan Street  
Glasgow  
G1 3HL

Tel: 0141 226 4541  
Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)  
Web: [www.enable.org.uk](http://www.enable.org.uk)

The Scottish Independent Advocacy Alliance  
has information on local advocacy projects

138-140 Slateford Road  
Edinburgh  
EH 14 1LR

Tel: 0131 455 8183  
Email: [enquiry@siaa.org.uk](mailto:enquiry@siaa.org.uk)  
Web: [www.siaa.org.uk](http://www.siaa.org.uk)

The Advocacy Safeguards Agency has  
produced a Map of Independent Advocacy in  
Scotland, which has contact details for projects.

1-2 St Andrew Square  
Edinburgh  
EH2 2BD

Tel: 0131 534 9380  
Fax: 0131 524 9381  
Email: [asainfo@advocacysafeguards.org](mailto:asainfo@advocacysafeguards.org)  
Web: [www.advocacysafeguards.org](http://www.advocacysafeguards.org)

People First is the collective advocacy and  
self-advocacy organisation run by people with  
learning difficulties.

People First Scotland  
77-79 Easter Road  
Edinburgh  
EH7 5PW

Tel: 0131 478 7707  
Email: [P1stScot@aol.com](mailto:P1stScot@aol.com)

People First  
3rd floor  
299 Kentish Road  
London  
NW5 2TJ

Tel: 020 7485 6660  
Web: [www.peoplefirstltd.com](http://www.peoplefirstltd.com)

Voluntary Health Scotland  
11 Waterloo Place  
Edinburgh  
EH1 3BG

Tel: 0131 557 6845  
fax: 0131 557 5207  
Web: [www.vhsscotland.org.uk](http://www.vhsscotland.org.uk)



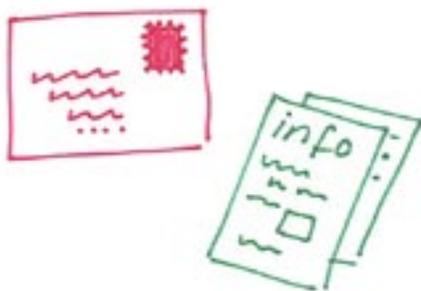
## Moving on to Adult Life

# **PART 5: FURTHER INFORMATION, CONTACT DETAILS FOR ORGANISATIONS, AND PUBLICATIONS**



## Moving on to Adult Life

# PART 5: FURTHER INFORMATION, CONTACT DETAILS FOR ORGANISATIONS, AND PUBLICATIONS



## What this part of the pack covers

This part of the pack brings together information about resources and information from various places. We've included a lot from Fife as examples of the kind of resources that are useful, and because the details of what happens there may give you ideas or questions to ask around the resources in your area.

We have included information about national policies, and then a directory of organisations, and a short section on publications and websites that may be useful to you. Some organisations have been listed more than once, to make it as easy as possible to find them.

We know there are lots of local services run by people with disabilities, families, voluntary organisations, the NHS and local authorities. We hope you will start adding to our list, so we have left lots of spaces for you to do this. And tell us about the services in your area which are good at helping young people and their families to have a good life.

## Overview of resources in Fife

Fife Council, NHS Fife and other organisations have a shared website:

Web: [www.fifedirect.org.uk](http://www.fifedirect.org.uk)

Fife Council can be contacted at:

Fife House  
North St  
Glenrothes  
KY7 5LT

Tel: 01592 414 141

Email: [fife.council@fife.gov.uk](mailto:fife.council@fife.gov.uk)

It isn't always easy to know who to contact within the Council. A good starting point is usually the social work offices. There is a leaflet explaining what they do and how to contact the teams. To obtain a copy or copies, contact:

Tel: 01592 413 200

The Post 16 Group co-ordinates Fife Council services for people as they move from education and children's services to the community care services. The Children and Families teams and the Community Care teams at the Social Work Department will have more information about the services and how they link together, and are the first contact point. Staff in health services will also have information.



You may want to check out what support is available for young people who are still aged under 16, and for the rest of the family.

Information about the Fife Children's Services Plan is available from:

Fife Council  
Fife House  
North St  
Glenrothes  
KY7 5LT

Tel: 01592 414 141  
Email: [fife.council@fife.gov.uk](mailto:fife.council@fife.gov.uk)

The Child Health Plan describes all the health care support for children and their families, and can be obtained from:

Dr Lesley McDonald  
Director of Public Health  
Cameron House  
Cameron Bridge

Tel: 01592 712 472

There are plans which describe how services will develop for people who make more use of social care and health services.

The Community Care Plan and plans for people with particular disabilities are available from:

Fife Council  
Fife House  
North St  
Glenrothes  
KY7 5LT

Tel: 01592 414 141  
Email: [fife.council@fife.gov.uk](mailto:fife.council@fife.gov.uk)

The Fife Health Plan and the Health Promotion Plan are available from:

Fife NHS Board  
Haig House  
Cameron Hospital  
Leven  
KY8 5RA

Tel: 01592 712 812

## **Other useful contact information for Fife**

At the time we were writing this pack some social work services in Fife were being reorganised. If the contacts have changed, ask at the main office: 01582 414 141

Social Work contacts for carers' assessments are at:

Enquiries and Information Team  
South Street  
Glenrothes  
KY7 5NL

Tel: 01592 415 252

Guide to the Adults with Incapacity Act:

Fife Council  
Social Work  
St David's Centre  
Albany Park  
St Andrews  
KY16 8BP

Contact name: Arthur Martin, Team Leader

Tel: 01334 412 615

Email: [arthur.martin@fife.gov.uk](mailto:arthur.martin@fife.gov.uk)

Citizen Advocacy - Central Fife projects  
The Broom Community Flat  
Balmaisie Centre  
Linwood Drive  
Leven  
Fife  
KY8 5AE

Tel: 01333 592 573

Citizen Advocacy - North East Fife project  
Pitteuchar Resource Centre  
211, Tantallon Avenue  
Pitteuchar  
Glenrothes  
Fife  
KY7 4QA

Contact name: Alan Stewart

Tel: 01592 412 033

Email: [Allan.Stewart@fife.gov.uk](mailto:Allan.Stewart@fife.gov.uk)

Dunfermline Advocacy Initiative  
2, Halbeth Road  
Dunfermline  
KY12 7QX

Tel: 01383 624 382

Fax: 01383 724 486

Email: [advocacy.initiative@btinternet.com](mailto:advocacy.initiative@btinternet.com)

Web: [dunfermlineadvocacyinitiative.btinternet.co.uk](http://dunfermlineadvocacyinitiative.btinternet.co.uk)

Fife Children's Rights Service  
West Bridge Street  
Kirkcaldy  
KY1 1TE

Tel: 01592 265 294

Email: [Fife.Childrens.Rights.Service@barnardos.org.uk](mailto:Fife.Childrens.Rights.Service@barnardos.org.uk)

Fife Direct Payments Support Service  
Talbot Cottage  
Station Road  
Leven  
KY8 4QU

Tel: 01333 592 656

Email: [denise.boyd@smtp5.fife.gov.uk](mailto:denise.boyd@smtp5.fife.gov.uk)

Fife Disabled Persons' Housing Service  
Viewforth Centre  
Viewforth St  
Kirkcaldy  
KY1 3DH

Contact names: Harry Ferrier and Ian Fricker

Tel: 01592 418 350

Fife EmployAbility Team

Fife Council  
Social Work Department  
Kingdom House  
Kingdom Avenue  
Glenrothes  
KY7 5LY

Contact name: Callum McGregor

Tel: 01592 414 957

Textphone: 01592 416 418

Email: [Fife.Employability@fife.gov.uk](mailto:Fife.Employability@fife.gov.uk) or [callum.macgregor@fife.gov.uk](mailto:callum.macgregor@fife.gov.uk)

Fife NHS Health Promotion Department  
Haig House  
Leven  
KY8 5RA

Tel: 01592 712 812

Fife Postural Management Clinic  
SAY Project  
Q10, Flemington Road  
Glenrothes  
KY7 5QF

Contact names: Joyce McDonald, Occupational  
Therapist and  
Moira Dewar, Physiotherapist

Tel: 01592 415 185 (Joyce McDonald)  
Fax: 01592 414 273  
Email: [Joyce.McDonald@smtp5.fife.gov.uk](mailto:Joyce.McDonald@smtp5.fife.gov.uk)

Fife Supporting People Team  
SAY Project  
Q10, Flemington Road  
Glenrothes  
KY5 5QF

Tel: 01592 414 272

People First in Fife has an office base at  
Lynebank Hospital

Tel: 01383 623 623

## National policies

There is a section on policies for people with learning disabilities on the Scottish Executive's website. It has the Same As You and the reports from Working Groups, and the local Partnership in Practice agreements:

Web: [www.scottishexecutive.gov.uk/Topics/Health/Care](http://www.scottishexecutive.gov.uk/Topics/Health/Care)  
and choose the Learning Disabilities option.

Information on various aspects of policy in Scotland affecting children and young people is at:

Web: [www.scottishexecutive.gov.uk/topics/People/Young-People](http://www.scottishexecutive.gov.uk/topics/People/Young-People)

The Welsh Mental Handicap Strategy is at:

Web: [www.wales.gov.uk/subisocialpolicy/content/mentalhealth/contents-e.htm](http://www.wales.gov.uk/subisocialpolicy/content/mentalhealth/contents-e.htm)

The policy for England for people with learning disabilities is Valuing People. There is information at:

Web: [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)

The background note on Local Area Co-ordination and links to other sources of information are at:

Web: [www.otbds.org](http://www.otbds.org)

The Disability Rights Commission has information on the Disability Discrimination Act:

Disability Rights Commission  
Helpline  
FREEPOST  
MID 02164  
Stratford upon Avon  
CV37 9BR

Tel: 08457 622 633

Textphone: 08457 622 644

Web: [www.drc.org.uk](http://www.drc.org.uk) and [www.drc.org.uk/scotland](http://www.drc.org.uk/scotland)

# Directory of organisations

## A

Scottish Independent Advocacy Alliance  
138-140 Slateford Road  
Edinburgh  
EH14 1LR

Tel: 0131 455 8183  
Email: [enquiry@siaa.org.uk](mailto:enquiry@siaa.org.uk)  
Web: [www.siaa.org.uk](http://www.siaa.org.uk)

Advocacy Safeguards Agency  
1-2 St Andrew Square  
Edinburgh  
EH2 2BD

Tel: 0131 534 9380  
Fax: 0131 524 9381  
Email: [asainfo@advocacysafeguards.org](mailto:asainfo@advocacysafeguards.org)  
Web: [www.advocacysafeguards.org](http://www.advocacysafeguards.org)

Altrum

Contact: Rebecca Allan  
Neighbourhood Networks  
Unit 10 First Floor  
Festival Business Centre  
150 Brand St  
Glasgow  
G51 1DH

Tel: 0141 314 0027  
Email: [rebeccaallan@neighbourhoodnetworks.org](mailto:rebeccaallan@neighbourhoodnetworks.org)

Art-Ability

Tel: 01355 249 402  
Email: [artability@aol.com](mailto:artability@aol.com)

## B

British Institute of Learning Disabilities  
Campion House  
Green Street  
Kidderminster  
Worcestershire  
DY10 1JL

Tel: 01562 723 010  
Fax: 01562 723 029  
E-mail: [enquiries@bild.org.uk](mailto:enquiries@bild.org.uk)  
Web: [www.bild.org.uk](http://www.bild.org.uk)

Business Gateway

Tel: 0845 609 6611

## C

Carers Scotland  
91 Mitchell Street  
Glasgow  
G13LN  
  
Tel: 0141 221 9141  
Email: [info@carerscotland.org](mailto:info@carerscotland.org)  
Web: [www.carerscotland.org](http://www.carerscotland.org)

Carers UK

Web: [www.carersuk.org](http://www.carersuk.org)

Scottish Child Law Centre  
54 East Causewayside  
Edinburgh  
EH8 9HD

Tel: 0131 667 6333  
Freephone: 0800 328 8970 (For under 18s)

Circles Around Dundee  
Number 10  
10 Constitution Road  
Dundee  
DD11 1LL

Tel: 01382 305 726  
Web: [www.circlesarounddundee.org.uk](http://www.circlesarounddundee.org.uk)

Circles Network  
Potford's Dam Farm  
Coventry Road  
Cawston  
Rugby  
Warwickshire  
CV 23 9JP

Tel: 01788 816 671  
Email: [information.circles@btconnect.com](mailto:information.circles@btconnect.com)  
Web: [www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)

Scottish Consortium for Learning Disability  
Adelphi Centre Room 16  
12 Commercial Road  
Glasgow  
G5 0PQ

Tel: 0141 418 5420  
Web: [www.sclid.org.uk](http://www.sclid.org.uk)

## D

Department for Work and Pensions  
Public Enquiry Office  
Room 112  
The Adelphi  
1-11, John Adam Street  
London  
WC2N 6HT

Tel: 020 7712 2171  
Web: [www.dwp.gov.uk](http://www.dwp.gov.uk)

Direct Payments Scotland  
27 Beaverhall Road  
Edinburgh  
EH7 4JE

Tel: 0131 558 5200  
Minicom: 0131 558 5202  
Helpline: 0131 558 3450  
Web: [www.dpscotland.org.uk](http://www.dpscotland.org.uk)

The Employers' Forum on Disability  
Nutmeg House  
60 Gainsford St  
London  
SE1 2NY

Tel: 020 7340 3020  
Email: [efd@employers-forum.co.uk](mailto:efd@employers-forum.co.uk)  
Web: [www.employers-forum.co.uk](http://www.employers-forum.co.uk)

Disability Rights Commission  
Helpline  
FREEPOST  
MID 02164  
Stratford upon Avon  
CV37 9BR

Tel: 08457 622 633  
Textphone: 08457 622 644  
Web: [www.drc.org.uk](http://www.drc.org.uk) and [www.drc.org.uk/scotland](http://www.drc.org.uk/scotland)

Forum on Discrimination  
Scottish Civic Forum  
Fòram Catharra Na H-Alba  
16 Jackson's Entry  
Holyrood Road  
Edinburgh  
EH8 8PJ

Tel: 0131 524 9392  
Fax: 0870 051 1192  
Web: [www.forumondiscrimination.org.uk](http://www.forumondiscrimination.org.uk)

## E

Edinburgh Development Group  
John Cotton Business Centre  
Sunnyside  
Edinburgh  
EH7 5RA

Tel: 0131 476 0522  
Web: [www.edg-sco.org](http://www.edg-sco.org)

The Employers' Forum on Disability  
Nutmeg House  
60 Gainsford St  
London  
SE1 2NY

Tel: 020 7340 3020  
Email: [efd@employers-forum.co.uk](mailto:efd@employers-forum.co.uk)

ENABLE  
National Office  
6th Floor  
7 Buchanan Street  
Glasgow G1 3HL

Tel: 0141 226 4541  
Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)  
Web: [www.enable.org.uk](http://www.enable.org.uk)

Envision  
88 Montpelier Park  
Edinburgh  
EH10 4NG

Contact name: Helen Wilson

Tel: 0131 466 4006  
Email: [helen@envision-uk.org](mailto:helen@envision-uk.org)  
Web: [www.envision-uk.org](http://www.envision-uk.org) (From Summer 2005)

Equal Futures

Email: [info@ef.org.uk](mailto:info@ef.org.uk)

Equity in Education  
76 High Street  
Peebles  
EH45 8SW

Contact name: Eileen Prior

Tel 01721 729 326  
Email: [erica@equityineducation.org](mailto:erica@equityineducation.org) or  
[Eileen@equityineducation.org](mailto:Eileen@equityineducation.org)  
Website: [www.equityineducation.org](http://www.equityineducation.org)

## F

FAiR (Family Advice and Information Resource)  
25/27, West Nicholson St  
Edinburgh  
EH8 9DB

Tel: 0131 662 1962  
Email: [fair@fairadvice.org.uk](mailto:fair@fairadvice.org.uk)

Fairbridge  
73 Ferry Road  
Edinburgh  
EH6 4AQ

Tel: 0131 554 2568  
Web: [www.fairbridge.org.uk](http://www.fairbridge.org.uk)

Family Fund  
PO Box 50  
York  
YO1 9ZX

Tel: 0845 130 4542  
Web: [www.familyfund.org.uk](http://www.familyfund.org.uk)

Scotland  
Tel: 01592 874 541

England  
Tel: 01223 842 914

Northern Ireland  
Tel: 028 7035 5660

Wales  
Tel: 01792 361 498

Forum on Discrimination  
Scottish Civic Forum  
Fòram Catharra Na H-Alba  
16 Jackson's Entry  
Holyrood Road  
Edinburgh  
EH8 8PJ

Tel: 0131 524 9392  
Fax: 0870 051 1192  
Web: [www.forumondiscrimination.org.uk](http://www.forumondiscrimination.org.uk)

## H

The Homepoint Service (provided by  
Communities Scotland)

Web: [www.homepoint.communitiesscotland.gov.uk/homepoint](http://www.homepoint.communitiesscotland.gov.uk/homepoint)

## I

Inclusion Distribution  
29, Heron Drive  
Pontoon  
Stockport  
SK12 1QR

Inclusive Solutions

Email: [inclusionpress@inclusion.com](mailto:inclusionpress@inclusion.com)  
Web: [www.inclusion.com](http://www.inclusion.com)

Scottish Independent Advocacy Alliance  
138-140 Slateford Road  
Edinburgh  
EH14 1LR

Tel: 0131 455 8183  
Email: [enquiry@siaa.org.uk](mailto:enquiry@siaa.org.uk)  
Web: [www.siaa.org.uk](http://www.siaa.org.uk)

## J

Scottish Executive Justice Department  
Civil Law Division  
Floor 2 West (Rear)  
St Andrew's House  
Regent Road  
Edinburgh  
EH1 3DG

Tel: 0131 244 2193  
Web: [www.scotland.gov.uk/Topics/Justice/Civil](http://www.scotland.gov.uk/Topics/Justice/Civil)  
and navigate to Adults with Incapacity

## K

KeyRing  
National Office  
3rd Floor, Impact Centre  
12-18 Hoxton Street  
London  
N1 6NG

Tel 020 7749 9411  
Fax 020 7749 9415  
Email: [enquiries@keyring.org](mailto:enquiries@keyring.org)

## L

Lead Scotland  
Queen Margaret University College  
Clerwood Terrace  
Edinburgh  
EH12 0BR  
(This is the East of Scotland contact address)

Tel: 0131 317 3439  
Email: [enquiries@lead.org.uk](mailto:enquiries@lead.org.uk)  
Web: [www.lead.org.uk](http://www.lead.org.uk)

Learndirect Scotland

Tel: 0808 100 1855

## M

Mencap

Web: [www.mencap.org.uk](http://www.mencap.org.uk)

Moving On Up

Web: [www.movingonup.info](http://www.movingonup.info)

## N

### National Young People's Self Advocacy Groups

ENABLE

National Office

6th Floor

7 Buchanan Street

Glasgow

G1 3HL

Tel: 0141 226 4541

Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)

Web: [www.enable.org.uk](http://www.enable.org.uk)

### Neighbourhood Networks

Unit 10, First Floor

Festival Business Centre

150 Brand St

Glasgow

G51 1DH

Tel: 0141 314 0027

Email: [rebeccaallan@neighbourhoodnetworks.org](mailto:rebeccaallan@neighbourhoodnetworks.org)

### Norah Fry Research Centre

3, Priory Road

Bristol

BS8 1TX

Tel: 01179 466 553

## O

### Outside the Box Development Support

St Andrew's by the Green

33 Turnbull Street

G1 5PR

Tel: 0141 552 5992

Fax: 0141 6625

Email: [info@otbds.org](mailto:info@otbds.org)

Web: [www.otbds.org](http://www.otbds.org)

### Ownership Options in Scotland

Unit 20, The John Cotton Centre

10 Sunnyside

Edinburgh

EH7 5RA

Tel: 0131 661 3400

Email: [info@oois.org.uk](mailto:info@oois.org.uk)

Web: [www.oois.org.uk](http://www.oois.org.uk) (For people who advise disabled people)

Web: [www.housingoptions.info](http://www.housingoptions.info) (For individuals)

## P

Paradigm  
8 Brandon Street  
Birkenhead  
CH41 5HN

Tel: 0870 010 4933  
Fax: 0870 010 4934  
Web: [www.paradigm-uk.org](http://www.paradigm-uk.org)

People First  
3rd Floor  
299 Kentish Road  
London  
NW5 2TJ

Tel: 020 7485 6660  
Web: [www.peoplefirstltd.com](http://www.peoplefirstltd.com)

People First Scotland  
77-79 Easter Road  
Edinburgh  
EH7 5PW

Tel: 0131 478 7707  
Email: [P1stScot@aol.com](mailto:P1stScot@aol.com)

Princess Royal Trust for Carers

Web: [www.carers.org](http://www.carers.org)

Glasgow Office  
Campbell House  
215 West Campbell Street  
Glasgow G2 4TT

Tel: 0141 221 5066  
Fax: 0141 221 4623  
Email: [infoscotland@carers.org](mailto:infoscotland@carers.org)

London Office  
142 Minories,  
London  
EC3N 1LB

Tel: 020 7480 7788  
Fax: 020 7481 4729  
Email: [info@carers.org](mailto:info@carers.org) (For publications and PR)  
Email: [help@carers.org](mailto:help@carers.org) (For all other enquiries)

Northern Office  
Suite 4 Oak House  
High Street  
Chorley  
PR7 1DW

Tel: 01257 234 070

Fax: 01257 234 105

Email: [infochorley@carers.org](mailto:infochorley@carers.org)

Prince's Trust

Prince's Scottish Youth Business Trust  
Mercantile Chambers  
6th Floor  
53 Bothwell Street  
Glasgow G2 6TS

Web: [www.psybt.org.uk](http://www.psybt.org.uk)

ProjectScotland

Tel: 0131 226 0700

Email: [info@projectscotland.co.uk](mailto:info@projectscotland.co.uk)

The Office of the Public Guardian  
Hadrian House  
Callendar Business Park  
Callendar Road  
Falkirk  
FK1 1XR

Tel: 01324 678 300

Web: [www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

PUSH, Perth and Kinross  
90 Tay Street  
Perth  
PH2 8NP

Tel: 01738 621 929

Email: [enquires@pushinfo.org](mailto:enquires@pushinfo.org)

## S

Scottish Child Law Centre  
54 East Causewayside  
Edinburgh  
EH8 9HD

Tel: 0131 667 6333  
Freephone: 0800 328 8970 (For under 18s)

Scottish Consortium for Learning Disability  
Adelphi Centre Room 16  
12 Commercial Road  
Glasgow  
G5 0PQ

Tel: 0141 418 5420  
Web: [www.sclid.org.uk](http://www.sclid.org.uk)

Scottish Executive Justice Department  
Civil Law Division  
Floor 2 West (Rear)  
St Andrew's House  
Regent Road  
Edinburgh  
EH1 3DG

Tel: 0131 244 2193  
Web: [www.scotland.gov.uk/Topics/Justice/Civil](http://www.scotland.gov.uk/Topics/Justice/Civil)  
and navigate to Adults with Incapacity

Scottish Independent Advocacy Alliance  
138-140 Slateford Road  
Edinburgh  
EH14 1LR

Tel: 0131 455 8183  
Email: [enquiry@siaa.org.uk](mailto:enquiry@siaa.org.uk)  
Web: [www.siaa.org.uk](http://www.siaa.org.uk)

SHS Trust  
5b Washington Place  
Washington Lane  
Edinburgh  
EH11 2HA

Tel: 0131 538 7717  
Email: [admin@shstrust.org.uk](mailto:admin@shstrust.org.uk)  
Web: [www.shstrust.org.uk](http://www.shstrust.org.uk)

Social Care Institute for Excellence  
Goldings House  
2 Hay's Lane  
London  
SE1 2HB

Tel: 020 7089 6840  
Textphone: 020 7089 6893  
Fax: 020 7089 6841  
Email: [info@scie.org.uk](mailto:info@scie.org.uk)  
Web: [www.scie.org.uk](http://www.scie.org.uk)

## T

Transactive

Web: [www.trans-active.org.uk](http://www.trans-active.org.uk)

Transition Information Network  
c/o Campaign Department  
Scope  
6 Market Road  
London  
N7 9PW

Tel: 020 7619 7244

Fax: 020 7619 7380

Email: [bronia.kita@scope.org.uk](mailto:bronia.kita@scope.org.uk)

Web: [www.myfuturechoices.org.uk](http://www.myfuturechoices.org.uk)

## V

The Voluntary Action Fund  
Comely Bank House  
80 New Row  
Dunfermline  
KY12 7EJ

Tel: 01383 620 780

Web: [www.voluntaryactionfund.org.uk](http://www.voluntaryactionfund.org.uk)

Voluntary Health Scotland  
11 Waterloo Place  
Edinburgh  
EH13 3BG

Tel: 0131 557 6845

Web: [www.vhscotland.org.uk](http://www.vhscotland.org.uk)

## W

We Are What We Do  
15-17 Lincoln's Inn Fields  
London  
WC2A 3ED

Tel: 020 7396 5330  
Email: [sara@wearewhatwedo.org](mailto:sara@wearewhatwedo.org)  
Web: [www.wearewhatwedo.org](http://www.wearewhatwedo.org)

Department for Work and Pensions  
Public Enquiry Office  
Room 112  
The Adelphi  
1-11 John Adam Street  
London  
WC2N 6HT

Tel: 020 7712 2171  
Web: [www.dwp.gov.uk](http://www.dwp.gov.uk)

Working Families

Web: [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)

## Y

National Young People's Self Advocacy Groups  
ENABLE  
National Office  
6th Floor  
7 Buchanan Street  
Glasgow G1 3HL

Tel: 0141 226 4541  
Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)  
Web: [www.enable.org.uk](http://www.enable.org.uk)



## Publications and web-based information:

A Good Life, by Al Etmanski

Web: [www.plan.ca](http://www.plan.ca)

Are you being bullied? and other publications from Enable can be ordered via the Information Service:

ENABLE  
National Office  
6th Floor  
7 Buchanan Street  
Glasgow  
G1 3HL

Tel: 0141 226 4541  
Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)  
Web: [www.enable.org.uk](http://www.enable.org.uk)

The ABCD Capacity Inventory in Building Communities from the Inside Out is at:

[www.northwestern.edu/ipr/abcd/abcdci.html](http://www.northwestern.edu/ipr/abcd/abcdci.html)  
and [www.northwestern.edu/ipr/abcd/cihowto.html](http://www.northwestern.edu/ipr/abcd/cihowto.html)

The Asset Based Community Development Institute of Northwestern University: publications list:

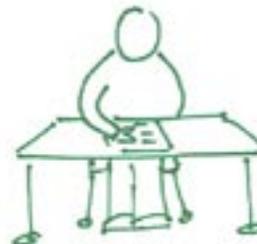
[www.northwestern.edu/ipr/abcd/abcdtopics.html](http://www.northwestern.edu/ipr/abcd/abcdtopics.html)

Banking on Change (2004), by Margaret Hurcome. There is a full report and easy read summary:

FAiR (Family Advice and Information Resource)  
25/27 West Nicholson St  
Edinburgh  
EH8 9DB

Tel: 0131 662 1962  
Email: [fair@fairadvice.org.uk](mailto:fair@fairadvice.org.uk)

The report is also available on the Outside the Box website: [www.otbds.org](http://www.otbds.org)



Building Communities from the Inside Out:  
A path toward finding and mobilizing a  
community's assets, by John P. Kretzman and  
John L. McKnight. The introduction to the book  
is at:

[www.northwestern.edu/ipr/publications/](http://www.northwestern.edu/ipr/publications/) and  
navigate via "books" to the authors named  
above.

A video about Direct Payments is available from  
Values Into Action:

[www.viauk.org](http://www.viauk.org)

Friendship and Community, by Jo Kennedy,  
Helen Sanderson and Helen Wilson:

North West Training and Development Team  
Adamson House  
Pomona Strand  
Old Trafford  
Manchester  
M16 0BA

Tel: 0161 877 7499

Everyone included, all equal, no arguments, a  
report by and available from:

The Voluntary Action Fund  
Comely Bank House  
80 New Row  
Dunfermline  
KY12 7EJ

Tel: 01383 620 780

Web: [www.voluntaryactionfund.org.uk](http://www.voluntaryactionfund.org.uk)

Growing Up is produced by BILD and is  
available from:

British Institute of Learning Disabilities  
Campion House  
Green Street  
Kidderminster  
Worcestershire  
DY10 1JL

Tel: 01562 723 010

Fax: 01562 723 029

E-mail: [enquiries@bild.org.uk](mailto:enquiries@bild.org.uk)

Web: [www.bild.org.uk](http://www.bild.org.uk)

The Health Challenge Bulletin is produced by and available from:

Scottish Consortium for Learning Disability  
Adelphi Centre Room 16  
12 Commercial Road  
Glasgow  
G5 0PQ

Tel: 0141 418 5420  
Web: [www.sclcd.org.uk](http://www.sclcd.org.uk)

Inclusion and person-centred planning, by Edinburgh Development Group, People First, and City of Edinburgh Social Work:

Edinburgh Development Group  
John Cotton Business Centre  
Sunnyside  
Edinburgh  
EH7 5RA

Tel: 0131 476 0522  
Web: [www.edg-sco.org](http://www.edg-sco.org)

Inclusive citizenship contacts and ideas are brought together by Philia:

Web: [www.philia.ca](http://www.philia.ca)

It's your money – banks can help (2002):

The Employers' Forum on Disability  
Nutmeg House  
60 Gainsford St  
London  
SE1 2NY

Tel: 020 7340 3020  
Email: [efd@employers-forum.co.uk](mailto:efd@employers-forum.co.uk)  
Web: [www.employers-forum.co.uk](http://www.employers-forum.co.uk)

Living it up: guide by disabled young people on Direct Payments and Personal Assistants. A magazine-style report, and details of a video version, is at:

<http://www.bris.ac.uk/Depts/NorahFry/transition/livingitup1.pdf>

or contact:

Norah Fry Research Centre  
3 Priory Road  
Bristol  
BS8 1TX

Tel: 01179 466 553

Mainstream housing options for people with learning difficulties in Edinburgh, by Julia Fitzpatrick (2002). Written for Parent Pressure, available from:

FAiR (Family Advice and Information Resource)  
25/27 West Nicholson St  
Edinburgh  
EH8 9DB

Tel: 0131 662 1962  
Email: [fair@fairadvice.org.uk](mailto:fair@fairadvice.org.uk)

Mapping Community Capacity:

[www.northwestern.edu/ipr/publications/papers/mcc.pdf](http://www.northwestern.edu/ipr/publications/papers/mcc.pdf)

Meetings checklists are available from:

SHS Trust  
5b Washington Court  
Washington Lane  
Edinburgh  
EH11 2HA

Tel: 0131 538 7717  
Email: [admin@shstrust.org.uk](mailto:admin@shstrust.org.uk)  
Web: [www.shstrust.org.uk](http://www.shstrust.org.uk)

Mencap

Web: [www.mencap.org.uk](http://www.mencap.org.uk)

Moving On Up

Web: [www.movingonup.info](http://www.movingonup.info)

The Road Ahead is available by contacting:

Tel: 020 7089 6840  
Email: [publications@scie.org.uk](mailto:publications@scie.org.uk)  
Web: [www.scie.org.uk](http://www.scie.org.uk)

A list of resources from many local projects is available at:

[www.scie.org.uk/publications/tra/resources/index.asp](http://www.scie.org.uk/publications/tra/resources/index.asp)

Transactive

Web: [www.trans-active.org.uk](http://www.trans-active.org.uk)

Why it's worth it, by Ceri Mollard:

SHS Trust  
5b Washington Court  
Washington Lane  
Edinburgh  
EH11 2HA

Tel: 0131 538 7717  
Email: [admin@shstrust.org.uk](mailto:admin@shstrust.org.uk)  
Web: [www.shstrust.org.uk](http://www.shstrust.org.uk)

Working Families

Web: [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)

