

Thinking ahead ...

A handbook to help families and people with disabilities think about planning for the future and keeping control when circumstances change.

Logos

Acknowledgements

The direction, content and design for this handbook came from families of people with learning difficulties and people with learning difficulties who attended workshops. The stories and quotes in the booklet come from these groups and other families who have been willing to share their feelings and stories, although some names have been changed. Thanks to all who contributed in this way and who commented on drafts.

The handbook was commissioned by Common Knowledge and Quarriers Homelife project. Common Knowledge is a learning partnership which promotes inclusion for people with a learning difficulty in Glasgow. Quarriers is a Scottish care charity providing support to meet the diverse needs of individuals. The Homelife project supports people with learning difficulties to live in their own homes and to make the most of opportunities available in the community. Both organisations seek to empower families and individuals to have choices and control over their own lives.

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Introduction

First Thoughts

'There's a niggle at the back of my mind most of the time - but the more I don't do anything about it the harder it is to start. I know I should sort a Will out. I worry about where Laurence will live - this house would probably be too big. I've spent his whole life fighting for him to have chances and I've not had a lot of help... Sometimes I wonder if that's why I can't face it, it's sort of thinking the unthinkable - and I don't know if I can cope with how we'll feel.' Laura

This book has been written to help families of people with learning difficulties, especially parents and people with learning difficulties themselves, to worry less about the future, to hope and plan more. It is particularly designed for people who live in or around the Greater Glasgow area. However much of the information and approaches will be relevant wherever you live.

The book aims to:

- ◆ help families and people with learning difficulties think about why they should plan ahead;
- ◆ give people ideas and encouragement to plan for change
- ◆ provide information and signposts to help people get the information they need;
- ◆ help people to put things in place which will be the means of telling others essential information about who they are and what they want to happen
- ◆ provide some starting points to open up discussion about the future, with the person with a learning difficulty and with family members.

Why do you need to think ahead?

*"What'll I do
when you are far away
and I am blue
what'll I do." Irving Berlin*

Ninety percent of people with learning difficulties live in the family home, supported by family members. In many situations a family member aged over 65 years old is the most important carer and advocate in their son or daughter's life.

People get sick, people die, change happens.

Many people with learning difficulties have not had the opportunity to develop strong relationships beyond the immediate family and family members may feel lonely and unsupported in their concern for the future. Often care and support providers get called on to provide support when people are in crisis. Perhaps a parent who was the main carer has died or suddenly been taken in to hospital. In these situations, however well meaning, social work departments and care providers often do not have the information or background to know how best to help and as a result poor decisions may get made.

Preparation means more peace of mind

Some people worry about the future but don't always take action to make sure it's a positive future and that plans follow the direction they want to take.

You can plan for positive outcomes

Being included, among other things, means having your voice heard and being able to control what happens to you. For this to happen, you need to be prepared and to think about what you and other people need to know.

If you think ahead, it's easier to stay in control

The Top Tenthinking ahead priorities

These are some of the things families and people with learning difficulties highlight as their priorities in planning for the future.

- Good friends and relationships - people we can trust, feeling safe, protected and loved
- Finding ways of communicating, being understood
- Being in control, making our own decisions, being listened to
- Money: having enough and managing it
- Health - emotional as well as physical
- Dealing with death - practical and emotional
- Home - having and keeping a home of your choice
- Being part of the community - a job, shopping, activities, church
- Knowing our rights
- Freedom and choice

How to use this handbook

The book is arranged in a series of chapters, addressing some of these main elements in planning for the future. In each chapter you will find information, stories and ideas, and signposts for places you can visit or telephone to get more information.

You can dip in and out. The chapters are designed to be read in any order, and for readers to dip in and out rather than reading it from cover to cover. However we suggest that you read chapters 1 and 2 to get started in thinking about your own priorities.

You can use it as a directory. The final chapter provides, in alphabetical order, details of how to contact or find all the organisations mentioned in the signposts.

You can use it to record information or as a checklist. At the end of each chapter, there is space to record information, action points or thoughts and there are some questions to help with this process. These spaces are partly designed for you to record information in order to pass this on. Even if you do nothing else, consider recording some of the essential information prompted by the questions at the end of each chapter. Perhaps give this to someone you trust or store it in a clearly marked place. This will give others a starting point if this is needed in future.

You can use the stories or questions as a way of opening up discussion with the person with a learning difficulty and with other family member about the future.

People at the workshops gave advice on deciding how to approach planning for the future, and the same tips are useful for using this book.

- Make sure you and your family member are part of the process, but look for other people to help you.
- Prioritise: pick one or two topics and work on these. If you try to think about everything at once, it will all seem too much and you won't do anything.
- Stop saying 'if such and such happens..' and start saying 'when such and such happens..' It will help you to take practical steps.
- Don't make any assumptions - about someone else's fears or desires; about someone else's motivations.
- Get informed yourself, inform others what you want to happen or to change, follow it up or get people you trust to follow up promised actions.

Start as small as you like, but start thinking now!

Chapter 1 Getting Started

Everyone should plan ahead because

"You need to be prepared, if anything happened to your Mum and Dad. Speak to people now so you're prepared for the 'what ifs'. You want to stay in your own community, in your own house, with people who know you and you know them."

If a parent dies, in addition to facing all the emotions of loss or bereavement , many people with learning difficulties also fear that they will be removed from what is familiar and secure, that they will lose control. And their families have the same fear.

You can't plan for every eventuality. But in one way or another change is inevitable. People want to plan for keeping what is familiar where this is good, for making sure that they carry on having a good life even if a key family member is not present. They often also want to think about safety and about managing finances and assets.

"You need to think with the person about what they and you want. I'd been assuming that Jayne will look out for Laurence, without talking to either of them. It shouldn't be left to chance and Laurence might have other ideas! You can enjoy today better if you've thought about the future." Laura

You can't stop change, but you can prepare for it

Neil attended a day centre every day, over the last fifteen years. He got picked up by the bus and he knew the staff and the other people who attended very well.

Then the day centre closed. Nobody really spoke to Neil about what he would do instead. The social worker said he didn't really need to go to a day centre and he didn't need support in the community either. Suddenly Neil lost his friends and his routine. He was devastated and so was his mother, now in her seventies and in poor health. The problem wasn't that the centre closed - it was that somewhere along the line, Neil hadn't made ordinary friends and ordinary connections in his community.

One day he was picked up by the police. They found him following the bus route to the day centre, along a motorway. One policeman had a friend who used to work at the centre and he talked to her. Over the next year Susan helped Neil to join an art class. He met up with a friend from the centre and was invited to his house to watch videos - he is now a regular visitor. For something to do, his mum suggested he help her on the bus to her hospital appointments. He waited in the WRVS café and enjoyed having a cup of tea and chatting to the ladies behind the counter. After some months one of them jokingly said it was about time he helped them out - he took her literally and now has a job four hours a week.

Neil is getting a life and relationships with people that don't rely only on his Mum or on services.

Listen to your feelings

"It's hard to face up to the fact that you won't always be around. You allow yourself to think that tomorrow never comes or that the social work department will take care of things and it will be alright. No-one talks of the changes we need to make or supports us in making these and in fact I'm afraid to ask in case something gets taken away." Audrey

If planning for the future was just about organisation and finding out information, then people would just get on with it. But it isn't that simple.

If you have had years of protecting someone from an un-welcoming society it may be difficult for you or them to trust others. Part of the process in making plans for the future may be experiencing some emotional upheaval. People want to hang on to what they have, what is familiar. It's hard to let go and move on, even to something better, because it involves taking a risk.

Listen to your feelings, perhaps talk to a friend about them. Acknowledge your fears, prejudices and pre-conceptions: if these remain hidden, they will get in the way of making progress with practical plans. Sometimes when you speak about fears they either don't seem so bad or become more manageable. Work out what is getting in the way of thinking about the future.

Points to help you get started and to help you on the journey

- ◆ Take it one step at a time. Plans do not have to be perfect or finished. If you make part of the journey and then decide you are happy to stop there, then that's fine - some plan is better than no plan.
- ◆ There is no 'right' way to think ahead. Choose the approach that suits you.
- ◆ You don't have to do it all yourself. Recruit a planning buddy - someone to share the highs and lows, who has similar interests but who also opens your eyes to things you might otherwise miss, who will motivate you if you lose heart or energy. Make contact with other families or people with learning difficulties or friends who can support you and the person you care about.
- ◆ There are helpful people to talk to with expertise and experience, including other people or families who have already done some planning for the future. Use this handbook to think about the areas where it would help to have professional or personal help and the questions you want to ask. The signposts will point you in the right direction.
- ◆ Build your self confidence - no-one else knows as much as you do about yourself, your son or your daughter and your family. This is the most valuable information needed for thinking ahead.

Gina and Suzanne

"What made us start was that we got fed up waiting for others to do the planning or to do it with us. We thought we couldn't do it without the social worker or the college being involved. But Suzanne just never seemed to be the priority and we kept being put off.

College was great for her - she was away from home, she learned and developed, particularly about communicating with others, and she became more independent. We really feared that if she just came back and lived with us all that would be lost. The options being given to her were that she could come back and live with us, or she could live in a group home. We couldn't get anyone to listen and to plan for what she did want. Although I was calm on the outside, I was angry about being in this situation. So eventually we forced the pace.

We refused to believe that because she needs support, this meant she had no right to choose how or where she lived. So we decided that the first step in the plan had to be to get her own house - and in the end we knew a lot more about different housing options than anyone from the social work or education departments.

What helped us over the wall? Fear of what would happen if we did nothing; support from a solicitor and some independent professional advisors who believed we should be able to plan for a future which suited our circumstances and Suzanne's hopes and potential.

Signposts

If you would like to be put in touch with other people or families with similar concern to plan for the future, contact:

- Common Knowledge
- Equal Futures
- Your Area Learning Disability team
- West of Scotland Carers Forum
- Glasgow carers project for your area

Look in the Directory, Chapter 13, for further information and contact details.

Thinking about**getting started**

How do you feel about planning for the future?

If you are having trouble starting to think ahead, or are stuck, or need to review your plans, what might be getting in the way?

What could help you get started? Think about a friend or relative, support person or group that you could work with or who could help or even just listen.

Chapter 2

Where are you now, where have you been and where would you like to go?

'Don't stop thinking about tomorrow, it'll soon be here.

It'll be better than before...'

Fleetwood Mac

The best place to start planning for the future, is the present. Sometimes it is also useful to know about the past, because previous experiences influence the choices and decisions a person makes about the future.

When people think about the future, concerns range from questions about the big issues, to questions about small details.

- ◆ "Who will know what I like to eat?"
- ◆ "People wouldn't know how often I have to take my medication?"
- ◆ "Where would I stay?"

If you are a family member of someone with a disability, you may be the main holder and transmitter of information about them and your family. You may be the main person who supports them with understanding and being understood. This means that if or when you are not there to provide this, there is a gap to fill. So it is worth thinking now about what information you can transfer and about different ways of doing this.

Putting together some background information

Look at the questions at the end of this chapter. They will prompt you on the type of information which it is useful to collect. This can be as detailed as you think necessary - but a few details will be better than no information at all.

Collecting and collating this information can be a good way of involving other people, especially the person with a disability and family members, in the process of thinking ahead.

Create an information bank

- ◆ Build up a file which holds documents such as the birth certificate, passport, National Insurance number, NHS card, health information, benefits notices, bank books or statements, tenancy or support agreements and so on.
- ◆ Make up a diary - start with background details of family, next of kin, addresses and contact details for friends, essential health and medication details. A diary can record what people do with their day, the music they like, favourite foods, what they enjoy and what they dislike. The 'thinking about...' sheet at the end of the chapter includes some questions to help build up this kind of personal profile.

- ◆ You can gather the information in writing. If you are not comfortable with this, let someone else ask you the questions and write down your answers - you can check afterwards that you are happy with what they have written down.
- ◆ Try to involve the disabled person and other family members or friends in compiling the information. You and other family members could make a tape - either audio or video - where you record your conversation about the various questions. Home video can let you show film to illustrate some of the information e.g. family members, houses. You could use graphics or drawing, pictures or photographs.

Sharing and storing information

The whole point about compiling the information is to share it, to involve others in knowing about the person's past and present and invite them to be part of that person's future. At the very least, store the information in a safe place and tell at least two key people, whom you trust, where it is.

Another approach is to split the information up, and ask people to be involved in different aspects of the person's life. These should be people that you trust to be involved and who will treat the information with respect and care. Sometimes it helps to have a co-ordinator who knows who else is involved.

Person centred planning

One way of thinking ahead is a tool called *Person centred planning*. This is a way of understanding who a person is; what would give them a life which is meaningful and to which they can contribute; and who can help them to achieve this. It is a tool offered by some services, as a way of planning for the future, achieving positive change and finding better ways of listening to people and responding to them.

Signpost: *Help with person centred planning*

It is important that people helping you with person centred planning are experienced and trained to a high standard. The following organisations may be able to provide person centred planning or able to refer you to people with the right expertise.

- Scottish Human Services Trust
- Family Futures
- Quarriers Homelife project
- Diversity Matters
- Contact your Area Learning Disability team for advice.

Look in the Directory, Chapter 13, for contact details.

David, Jean and Jonathan

We kept being told David had to be controlled and sometimes almost forgot our own knowledge of why he might be behaving like this. Person centred planning helped us to see we were looking at it back to front. When we turned it round the other way and thought about how his world needed to be for David to be in control, then it all became much clearer.

We put together screeds of information about his life and what made him happy. When we did this, some things became obvious, particularly that David needed to have his own space and to live near his family and to be with people who would help him to channel his enthusiasms. We had to think about what he wanted and about what could go wrong.

In the end our plan didn't seem that ambitious, but it would never have happened if we hadn't pushed and if we hadn't had help, even just moral support from people who believed in our dream. We worked out who could help us. It wasn't easy. We were both ill at different points and thought it was all going to fall apart. My daughters helped with keeping things going and along the way we met people who offered information and contacts which then led us to think about new possibilities.

We're starting to feel easier now - that we don't *need* to be at the centre of David's support. He's got his sisters, his support team, his work in the forestry group which he loves. He's a member of the local church and now he doesn't always need a support worker to be there with him. Two of the church members have got to know him and they walk back up the road with him. David doesn't always like people in the house, but he likes Mary and Jo to go in for a coffee after church.

Getting organised

- ◆ Start with a recap of where you and your family member are now. It brings everyone up to date and it helps you to think about priorities.
- ◆ Use the 'thinking about...' sheets aim to help you gather information, involving others where possible.
- ◆ Think about how you want to store factual information and documents and with whom you want to share these. It will help you with planning and coping with change if a number of trusted people can access important information.
- ◆ Don't just file information away. Review and update it on a regular basis.

The rest of this handbook looks at key aspects of building a good life and planning to sustain this. Don't be put off starting to think ahead, for fear that you won't have time, energy or motivation to finish. A bit of a plan is better than none and other people can help or carry on if you have to stop.

"To accomplish great things, we must not only act, but also dream, not only plan, but also believe." Anatole France

Thinking about**Sharing your past and present; sharing your dreams for the future**

Here are some questions to think about and suggestions for information which it is useful to record and share.

Start with a dream

- ◆ Why are you thinking ahead? What are you planning for?
- ◆ Dream a little - describe the life your family member wants to be leading in the future. Perhaps describe a day in that life - what would be happening?

You and your family

- ◆ Describe yourself and your family; the people your family member is close to.
- ◆ What information would you like to pass on, or be passed on, about yourself and the family history? For example, information about great grandparents, family talents or enduring interests, significant events.
- ◆ Tell someone about 'remember when...' moments or events which are particularly important to you and your family and you would like someone to be able to share or to talk about with your family member?

Friends, supporters and advisors

Think about these questions with the person whose future you are thinking about.

- ◆ Who helps or supports the person now with making important decisions in their life? What about the past?
- ◆ What would the person need help or support with if you were not there?
- ◆ Who would the person like to support them with different aspects of their life in the future?
- ◆ Make a note of any professionals or services you have found helpful (or not) in the past or are using now, ideally with contact details e.g. support providers, your GP, other health service professionals, social workers, advocates, solicitor.

Where you live

- ◆ Where has the person lived before and where do they live now? What have they liked or not liked about these places and about where they live now?

- ◆ Does the person want or need to think about where to live in the future? What initial thoughts and dreams do you or they have about this?

Living your life

- ◆ How does the person spend time during the day and evening and what are their favourite bits? Is there anything the person used to do which they don't do any more, but would like to?
- ◆ Would the person like to try something new? What might they like to do?
- ◆ Does the person have a job? Would they like one? What would their ideal job be?
- ◆ Would it help you or the person you are planning with to get advice or support about making best use of money in the future?
- ◆ Does the person have any impairments or conditions that affect how they live your life or that it helps others to be aware of? Think about the past - is there any personal or family health history or information which should be shared for the future?

Future planning

- ◆ Write down any legal details which you have put in place and which it is important for others to know, for example, solicitor, executors for your Will, power of attorney, any guardianship arrangement, details of Trusts and trustees.
- ◆ Have you and your family talked about ideas for the future? If you have, write down what you would like to happen and the action you would like key people, such as trustees, to take.

Chapter 3 A matter of life and death

*If I should go before the rest of you
Break not a flower nor inscribe a stone.
Nor when I'm gone speak in a Sunday voice,
But be the usual selves that I have known.*

*Weep if you must,
Parting is hell.
But life goes on,
So sing as well.*

Joyce Grenfell

Some parents will have to cope with the death of their son or daughter. Most children, usually in adulthood, will have to deal with the death of their parents. Death is part of life but most people would rather not think about it. When it comes to the people we love, the dread of death and of the pain of bereavement can be so great our mind simply closes down. But if people don't think about it and make no preparations, make no Will and leave no instructions, then it can leave a confusing and difficult mess for those left behind.

This chapter gives a few practical suggestions for helping people to think about death and for helping those who may be providing support after a death. The 'thinking about' pages may help you to provide information to others about how you or your family member can be supported.

Making it easier for others

It is not easy to think about your own death or funeral. However it can help those left behind if they have answers to some practical questions. For example, some people have religious beliefs that mean it is easy to decide whether they would want to be buried or cremated. Other do not, so leaving an instruction can help. If you haven't made a Will, make this a priority (see chapter 5). You can write down your wishes and tell someone where your instructions are kept or talk to your family so they know your views.

Some people worry about the cost of a funeral. You can take out a funeral savings plan or you can make arrangements in your Will for funeral expenses to be met from the money left in your estate. The benefit system can also help in some situations. If this concerns you, speak to a solicitor, financial or benefits advisor about this.

Signposts - practical steps in preparing for death

To find a solicitor to make a Will :

- look in the Yellow Pages under 'Solicitors' and 'Wills'
- get a recommendation from friends or family
- contact the Law Society for information on suitable lawyers.

To make funeral plans or discuss funeral savings or insurance schemes:

- contact the Financial Services Authority for details of registered advisors or brokers.
- look in the Yellow Pages under 'Financial advisors' or 'Funeral Directors'.

Look in the Directory, Chapter 13, for organisation contact details.

Support with understanding and emotions

"Don't assume the person won't be able to understand or will get upset. One day Stephen's Gran was talking about who she was leaving money to and later he asked 'Mum, what will happen to your money when you die?' It was a good practical question and we talked about how it would be split up between him and his brother and sister." Gail.

Family members worry about how a son or daughter will cope with the emotions of loss and grief; and with loneliness where family members have been very close. How will people be helped to express their feelings and to be understood?

At times of pain and grief everybody needs a circle of supportive friends and family, people who know you well and know how to comfort you. If a person's circle is not very big, then those who know them less well need readily available information which can act as a prompt.

Here are some ideas:

Helping someone prepare for bereavement and to understand death

- ◆ Discuss past experiences of death and relate them to the present situation.
- ◆ Give people information about the rituals and choices that surround death. Being included in the rituals and symbols around a death helps people to understand and accept that people die and to prepare for the future.
- ◆ Help people find and keep mementoes of someone who is dying or has died.
- ◆ Think about whether viewing the body would help the person to understand.

Supporting loss and grief

- ◆ Write down or pass on information which others can use to remind the person of the one who has died e.g. familiar items; details of places they went together or activities they did together. Make sure that family members, friends and support staff know what the person finds reassuring and comforting, including spiritual or religious beliefs.
- ◆ Sometimes it helps to talk to or be with someone else who has experienced death, possibly from outside the close family e.g. CRUSE Bereavement Care.

Trevor's Dad

Trevor knew something was wrong with his Dad - in fact it's part of the reason we couldn't have him at home anymore - but I'm not sure how much he understood. There were some funny moments because by then John often didn't remember our names. Trevor never got upset or bored repeating back his name. It was a game for them..

I think in the background Trevor's support workers were probably talking to him about people dying. But when it happened it was a shock. We had known for weeks it was only a matter of time, but it was still a shock. I think I might have shut Trevor out, but I'd got to know Lynne, one of his support workers. When I phoned his flat, she suggested bringing Trevor round so he could be with his sisters and me. At first I said no, I had enough to deal with. But she said she would come too and she thought it was important that Trevor was there.

She took on the job of telling Trevor that his Dad had passed away and she was brilliant. When they got here, John was still in the bedroom. We just sat for a while, holding hands and nobody said anything. Later, after the undertaker had been I got out John's envelope. I knew he had written down all the hymns he wanted and even the readings for the funeral service. What I didn't know until then was that he had chosen one of the hymns with Trevor. It helped us all that he was so organised.

The day of the funeral, Trevor came with his flatmate and Lynne. He knew lots of the relatives but a few of them had the cheek to tell me they thought I shouldn't have 'allowed' him to come. I was quite rude to one of them. How could you not include your son in his father's funeral?

Signposts: Understanding death and dying

Common Knowledge has an e-learning and interactive resource for adults with learning difficulties, What happens when someone dies? This helps an individual to both understand their own death and that of others.

These organisations have useful publications:

British Institute of Learning Disabilities: A series of booklets by Fiona Cathcart, Understanding death and dying, is designed to help people with learning disabilities, and those caring for them to understand their own feelings about death and dying.

Down's Syndrome Scotland: A book and cassette called Let's talk about death and funerals.

For information, advice or support:

- *CRUSE Bereavement Care* (page x)
- Beyond Indigo
- COPE - Caring Over People's Emotions (page x)

Look in the Directory, Chapter 13, for organisation contact details.

Thinking about.....**matters of life and death**

Practical arrangements

- ◆ Write down any arrangements you have made for your funeral or instructions you have left. Write down where people can find this information or who they should contact.
- ◆ If you haven't made arrangements, think about simply writing a note with any important points you would want followed in the event of your death e.g. burial or cremation. Give a copy of this to someone you know will be contacted in the event of your death or tell them where it can be found later.
- ◆ Have you made a Will? Write down where your Will can be found?

Spiritual matters

- ◆ Do you or your family member have important spiritual or religious beliefs which others need to know about? Think about how you make sure others know what these are.

Help with support and understanding

Think about recording any information which would help others to support you (your family member) in dealing with the death of someone close to them. For example:

- ◆ Has anyone in the person's life already died? Is there anything others should be aware of in terms of the person's experience of preparing for and dealing with this loss? What helped and what was difficult?

- ◆ What does the person find reassuring or comforting?

Think about asking a family member or close friend to be the person who will make sure your family member is supported in understanding and grieving your death. Give them copies of any information you have now recorded or gathered together or tell them where they can find it when needed.

Chapter 4

Trusting relationships, making and communicating decisions

Peter and Janice

"I would like to have a girlfriend and maybe to get married and I'd like us to live in this house, or maybe in our own house. I'm not sure if my Mum would like that though. And because I'm blind I would need help - how else would I know if she was nice looking!"

"I swing between fears and hopes for him. He would love to have a girlfriend. I would love that for him, but I am also nervous about it - which possibly stands in the way of it happening. Who will help him find that kind of relationship and then guide him? He'll talk to me about most things. But he's 30 and I'm his mother. There are some things a boy shouldn't have talk to his mother about."

Many people with learning difficulties have had most of their lives being defined by what they cannot do. They, and their family, are told they are 'incapable' of communicating or living in their own home or making decisions. Families become accustomed to challenging such pre-conceptions and pushing for the right to have choices and opportunities. So they worry about what will happen when they are not there. Who will carry on standing up for the person? Who will know the person well enough to listen to, understand and respond to their needs and to their potential?

In this section you will find information about:

- ◆ building networks of trusting relationships
- ◆ communicating and being listened to.
- ◆ making decisions and staying in control

Making connections - building networks of trusting relationships

"When I was in Buchanan Street last week, I was astonished to bump into my daughter with a girl I'd never met before. They were arm in arm and laughing and from the shopping bags, it was clear Vicki had been indulging her passion for fashion. It turned out she was my son's latest girlfriend. Isn't that great? A few years ago, I don't think she knew anyone that we hadn't introduced her to."
Robin

Relationships with others keep you safe and valued - friends, family and neighbours who are in your life because they want to be there, not because they are paid to be there. These are the people who help you lead the life you want to lead, who watch out for you, protect and comfort you. Legal mechanisms for decision making can play a part in this. But no matter how much legal provision anyone makes for their son or daughter, it is a network of strong relationships, which continue when you are not there, which ensure the person is listened to and cared for.

Many people with learning difficulties have not had much opportunity to develop some of these relationships. Help may be needed to make contacts and to keep relationships going. Family members, friends and paid staff or service providers can help with this, as can voluntary groups and organisations, such as those suggested in the signposts.

Circles of support

People may have a circle of friends and relations whose commitment to them goes beyond a casual friendship. Some people have had the idea of forming this into a 'Circle of Support'. Building a circle is a way of bringing people together who care about the person with learning difficulties to help them make decisions and, if necessary, to campaign for change. Members of the circle are invited to join by the person or by someone close to them. They are usually friends, family members, members of the community and sometimes service providers. They make a commitment to be part of this person's life and to help them fulfil their needs and aspirations. A circle is usually between 6 and 8 people.

Signposts for information about circles or networks of support

You can find more information about circles of support and similar ideas or projects from:

- Equal Futures
- Circles Network
- Values into Action

Look in the Directory, Chapter 13, for organisation contact details.

Lindsay's circle

Lindsay's circle of support first met in June 2000. Since then it has supported her to make important decisions about her life and given her the confidence to try out new things. She decided to stop going to a Skills Centre and now works as a volunteer at a local coffee shop one morning each week. Another morning she helps with photocopying at the local primary school. She had always wanted to try gliding. Through a member of the circle she was introduced to a local gliding club. Lindsay loves her weekly 'walk on air' and has recently completed her 40th flight.

Lindsay talked to her circle friends about moving to her own home. They helped her to decide how and where she wanted to live. Through direct payments (page b) she is able to employ a team of personal assistants.

Lindsay's circle is made up of her parents, other family and friends, who meet every six weeks to focus on what is happening in her life, to look for new opportunities and to set goals to work towards.

Alex, Lindsay's Dad, was pretty sceptical at first. Would these people really stay involved in Lindsay's life? What could they provide that her parents weren't doing already? Three years on he feels very differently 'I see how it has enriched her life and widened her horizons. It's also wonderful to see her share her sense of fun and adventure. It is difficult for parents not to be over protective and, with the best of intentions, to influence decisions. The circle has helped her to make her own, independent, choices and helped us to support these. We are a very close family and it hasn't taken anything away from that. It has helped us to know that others care too."

There were 80 people at Lindsay's 30th birthday party last week. She was the only person who knew everyone.

Making yourself understood and being heard

"Becca mostly uses noises and things like smiling to let people know how she is feeling. No-one knows her better than me - after all we've had 35 years of communicating with each other. Do you know I lay awake the other night thinking about how someone else will know she wants her hair washed?" Kay

Just because someone can't speak doesn't mean they have nothing to say. Everyone, no matter how disabled, is always communicating. However it can take time and close knowledge of the person to learn how to listen and to understand what is being said. Some people find it difficult to listen - assumptions get made that a person is not capable of communicating or that she will be happy with the decision made by others. People may need help to challenge these assumptions.

Even the law now says that if people want to be involved in decisions made with or for someone who cannot make that decision for herself, then they have to take the time to get to know the person, or they have to listen to others who are willing to take the time.

There are all sorts of ways of communicating which can either replace or add to language, for example body language, noises, signs or behaviours. Where this is the case, often parents or immediate family or carers are the communication channel between their son or daughter and others. Thinking about recording some of these ways so that if you are not around, others have some help to start listening and understanding.

Stephen

If you ask Stephen something like "have you cleaned your teeth?" or "did you see Linda this afternoon?", he answers "been". "Been" is his shorthand answer to many questions..

He uses Makaton, which he has used since he was 3 and also some BSL, which I taught him because Makaton wasn't enough for everything he wanted to communicate. When he was younger he made a video of himself signing. I

called out words and Stephen made the sign - he used to take it to give to new teachers or support workers and it helped them to understand.

We wrote all these communications down as part of a support plan. When Stephen first meets someone he tells them, please don't pretend to understand, just ask. "I know if they are pretending and I don't like it."

Signposts - support with communication

- Scottish Centre of Technology for Communication Impaired (Glasgow)
- Local speech therapist, who can refer to specialist expertise if appropriate
- Dyspraxic Association
- **Deafblind Scotland**

Contact details for these organisations can be found in Chapter 13.

Making decisions - staying in control

Everybody needs people who support them and having people around your family member that you trust, and that they trust, to stand up for them is one of the most effective ways of making sure they stay in control of their life.

In some situations, particularly those involving disagreements about the future or decisions to be made, it can help to have an independent **advocate** who will speak with and for their partner.

An advocate can help make sure that choices and rights are respected. There are different types of advocacy, but generally an advocate supports people in decision-making in everyday life. An advocate can help someone speak up for themselves by offering information and support and speak for someone who is unable to speak for themselves.

There are services which offer a professional and independent advocacy service. One type of advocacy is called 'citizen's advocacy'. This provides a trained advocate who is a member of the local community.

An advocate does not have any legal powers. If you need to mount a legal challenge about someone's capacity to make their own decisions or about a proposed action then certain solicitors specialise in this.

Signposts for information about advocacy or advocacy services

- Equal Say
- Partners in Advocacy
- People First
- The Advocacy Project

Chapter 13 has contact details for these organisations.

Capacity to make and communicate decisions

The ***Adults with Incapacity (Scotland) Act 2000*** is designed to help those adults who some times are not capable of making decisions

Capacity is defined in many different ways but the law says that it means:

- ◆ being able to make a decision or choice
- ◆ being able to communicate that decision
- ◆ being able to understand a decision
- ◆ being able to remember a decision (to retain understanding for long enough to make a decision).

A person can have capacity to make some sorts of decisions but not others. Wherever possible the law requires that others maximise the ability of the individual to act for themselves and support them to make and communicate decisions.

The Act introduces new forms of 'proxy' decision-making, that is when the court will make a decision or will appoint someone to make decisions for a person's welfare or finances. The terms you will hear for this are 'intervention orders' and 'guardians'.

There are some situations where it can be useful for a person to have a guardian. However it should not be a substitute for wider trusting relationships and working out clear ways in which the person with a learning difficulty can be represented or supported in decision making.

Signposts for information and advice about capacity and decision making

- Legal Services Agency
- ENABLE
- Law Society - for advice on solicitors specialising in this area
- Public Guardian's Office

Chapter 13 has contact details for these organisations.

Independent Living Trusts

Where a person is not able to manage money or property a new idea to help with decision making is to set up an 'independent living trust'. The word 'independent' means being helped to make independent choices; it does not mean living alone. An Independent Living Trust is a legally constituted body, like any other Trust (see page ?). The difference is that all the trustees are people who know the person and are committed to enabling them to be in control of decisions. Trustees are selected from members of the person's circle or network of support. In other types of Trust, the trustees tend to make the

decision for the person not with them and sometimes trustees are chosen who have little or no knowledge of the individual who is to benefit from the Trust.

Signposts for information about Independent Living Trusts

Values into Action and Community Living publish a useful book, Independent Living Trusts by Andrew Holman & Catherine Bewley

Other useful organisations are:

- Circles Network
- Inland Revenue in Scotland
- ENABLE for sample trust deeds.

Chapter 13 has contact details for these organisations.

What is needed to make any of this happen?

- ◆ Some courage - you need to ASK people to become involved, invite them in. Potential supporters are often there under your nose, but you may not have thought about them in that way. People want to make a contribution to the life of someone they care about. In turn the person who needs support is also giving to others and contributing to the life of their community.
- ◆ Trusting relationships need investment and commitment - without it they lose their vitality and strength and sometimes they struggle to survive. It can help to have someone whose role within the circle is to co-ordinate it and make sure it keeps going and gets renewed as members' lives change.
- ◆ Staying in control means recognising that sometimes you need to share the responsibility or you become too tired; sometimes you have to trust the expertise or the care of others. Get advice, get independent and second opinions, find out about advocacy services.
- ◆ Know that your family member has a right to take risks, to make mistakes, to say 'no', to make their own choices.

There is a lot to think about in this chapter. Use the 'Thinking about...' sheets to start focusing your own ideas on what to do next.

Thinking about - **Communicating and making decisions**

Extending someone's circle of support

- ◆ Who are the most important people in your family member's life? Who supports them with making important decisions about their life?
- ◆ Think about ways you could help your family member to extend their circle. What people could you or they speak to and invite to join?
- ◆ Do you want to find out more about national or local organisations which could give you more information, advice or support with building a circle?

Communication

- ◆ If you think others might have difficulty understanding what your family member wants to communicate, work with them to write some guidance for others or make a tape. For example:

How does the person show people that they are...?

Happy, Sad, Angry, Tired, Hungry, In pain, Worried, Excited and so on

What should people do to make the person feel better if they are ...?

Sad, In pain, and so on.

What should people do to show the person they are sharing their emotions when they are:

Happy, Excited, Pleased and so on.

Support with making decisions

- ◆ What areas of life does your family member need support in making decisions? Health? Thinking about where to live? Deciding how to spend or save money? Deciding how to spend the day? Choosing friends?

Perhaps make a table with the areas of decision making and write down who supports the person now and how. Think about other ways they could be supported.

- ◆ Think about whether you want to find out more about any of the ideas in this chapter - decide who to contact and when.

Chapter 5

Safeguarding the future

"I should have made a Will years ago. I think the reason I didn't was because I couldn't see how it could work to be fair to them all and protect Paul. The solicitor was so matter of fact, he helped take the emotion out of it even though I could see he did understand my turmoil. He made suggestions for doing things in a way I hadn't even thought of. He also made me realise that although I think I don't have any money, I've got about 5 insurance policies, including an endowment policy for the house, so if I died tomorrow it would all add up." Linda

Making a Will

Here are some facts about Wills.

- ◆ A Will is just a written record. It is a way of making sure that after your death your wishes about the distribution of money and property (your 'estate') will be carried out.
- ◆ If you do not leave a Will, the law lays down certain rules about how your Estate must be divided. Sometimes this can be disastrous for your family and your 'estate' may not end up where you wanted it to go. If you own a house or a flat it is especially important that you leave a Will.
- ◆ In your Will, it is usual to appoint one or two Executors. The executor is responsible for making sure your wishes get carried out, so this is a position of responsibility and trust.
- ◆ Making a Will is usually quite simple and it need not cost a lot. You can telephone solicitors to get quotes. If you have a low income and few savings, you can qualify for Legal Aid to help with the costs. Some solicitors will offer a free Will advice and preparation service in return for a donation to charity.
- ◆ It is possible to prepare your own Will or to complete a ready made form. However it is important that you get proper advice. To get this advice, you need to see a solicitor.
- ◆ You can change your Will at any time and in any case, it is a good idea to look at your Will every three or four years.

There are some questions to help you think about your Will before you go to see a solicitor in the thinking about sheet.

Estate Planning

If your assets add up to a significant amount of money, and if you own a property, then it is even more important that you see a solicitor about making a Will. A solicitor with expertise will help you to minimise the inheritance tax

burden. He or she should also advise you on how to sort out your affairs so that it has minimal effect on your family member's benefit entitlement.

An independent financial advisor (IFA), a bank, insurance company or a building society could also help with inheritance tax planning.

Signpost: Finding a solicitor to make a Will or think about Estate Planning

- The Law Society of Scotland can advise you of solicitors in your area, including those who specialise in Wills, Trusts and estate planning.
- Look in the Yellow Pages under 'Solicitors'
- Contact your local Citizen's Advice Bureau, addresses in the Yellow pages or ordinary telephone book.
- Ask your friends for a recommendation
- Carers and family support groups may also be able to advise.

Chapter 13 has contact details for some of these organisations.

Trusts

A trust is a legal body, set up using a document called a 'Trust Deed'), to hold assets for the benefit of one or more people, called the beneficiaries. There are usually three or four trustees who administer the trust, invest money and make payments to the intended beneficiaries of the trust. A trust can be set up at any time, for example an Independent Living Trust as described in Chapter 4, or a person's Will can set out the terms of a trust which comes into existence upon their death.

In the past trusts have generally been set up to handle money, but a trust deed can also give the trustees powers and responsibilities in relation to the welfare of a person. There are different types of trust and the one which is best will depend upon the individual's circumstances.

Choice of trustees

Choice of trustees is important. An issue for older people who only have one child, is that there may be a dearth of younger people who genuinely care about the person. Relatives may now be far flung and all of their 'circle' is made up of professional care or service providers.

If this is your situation, please read Chapter 4. It may be that thinking about a Trust is better left until after some time has been spent trying to build up a wider circle of support. This will make choice of trustees easier in the future. In the meantime ENABLE operates a corporate trustee service which can be helpful in this situation.

Signposts for more information or advice about Trusts

- ENABLE
- Legal Services Agency
- Equal Futures
- The Law Society in Scotland for advice on suitable solicitors
- Ownership Options in Scotland and ENABLE can advise about trusts and property ownership and may be able to put you in contact with other families who have gone down this road.
- Look at the signposts in Chapter 4 for more information on Independent Living Trusts.

Sylvia, Alister & Kirsten - Setting up a Discretionary Trust.

Some years ago, we decided it was time to put in place some safeguards for the future of Kirsten. We used a solicitor to draw up our Wills and with the guidance of Enable he also set up a Trust Deed.

We looked around to find suitable people who would be trustees. We have a small family and it was difficult to find people who might survive us. However we approached a close family friend who had known Kirsten for a number of years and also Kirsten's cousin who is ten years older than her and very active in her life. At that time, we also arranged that ENABLE would provide a corporate Trustee. We put a great deal of thought into this because the trustees are the main people who would have a say, after our deaths, in relation to spending and investing the money left for Kirsten's benefit.

Armed with more information and confidence, we are now revisiting these ideas. We have realised that our long term family friend hasn't seen or been in touch with Kirsten for a number of years and although we know she would always do her best by her, she would not necessarily know her well enough to make the right decisions. We realise that there are choices to be made. Now we believe that all the trustees should be people who actively know our daughter, people who will go the extra mile if and when necessary, who could and would speak up for her at the right time.

Because of these factors our intention is to have a new Trust Deed prepared with new trustees appointed. Kirsten's cousin, now older and more aware of the responsibilities is still happy to remain as a Trustee.

We are keen on the idea of setting up a lifetime network (circle) of support. We intend to link this in with the setting up of a new Trust Deed. Our intention is to invite at least one of the new network members to become a Trustee for Kirsten. We believe that this will be a better safeguard for Kirsten's future, where more people will be involved in helping her to make decisions.

Safeguarding the future

This and the previous chapter have covered a lot of questions about steps you can take to safeguard the future of your disabled relative. Everybody's situation is different and there can be unseen dangers in the very legal systems you may be considering to safeguard the future. It can help to have advice for a sympathetic solicitor or a voluntary organisation with relevant expertise or from other families who are also thinking about the future.

Do I need a Will? Yes. If you haven't already made a Will, make an appointment with a solicitor now. Don't leave it too late.

Do I need to set up a Trust? It depends on how much money or property you have and the financial circumstances of those who would inherit. It also depends on the ability of your family member, with support, to make decisions and handle money or property.

How do I help my son or daughter to stay in control? Know what they and you want, have a support network, think about approaches for supporting decision making. If you feel uncomfortable with an advisor, such as a solicitor, or that he or she is not listening to you or understanding you, use the signposts to find another one.

Thinking about - **Wills and Trusts**

If you have made a Will, think about.....

- ◆ Telling a family member or close friend the name of your solicitor and the executors.
- ◆ When did you last review your Will? If it is more than 3 years ago, then think about whether it needs reviewed.

If you have not made a Will....

Before you go to see a solicitor, think about:

- What possessions you have, such as property, money or jewellery?
- Who do you want to pass these on to - family, friends, charity?
- Do you want your family member to be able to continue to live in your home, even if they do not inherit it outright?
- Do you want to give everything to one person or to split your possessions among a number of people?
- Is there anything else you want to include in a Will, for example your funeral arrangements, small bequests.
- Who will you appoint as Executors? You only need one executor, but it can be a good idea to have two (in case one is not available) or to put down your solicitor's firm as an additional executor.

Estate Planning

- ◆ Is your family member in receipt of means tested benefits? Think about your assets and how much they might inherit. Would this affect their benefit entitlement? Does this matter to you or them?
- ◆ Might your assets add up to more than £234,000? If so, think about speaking to a tax and inheritance planner.

Trusts

- ◆ Think about getting information and advice about setting up a Trust.
- ◆ Who are your trustees or who might you ask to become a trustee? Note down the details of the trustees. Are these people who know your family member well?
- ◆ Although it will not be legally binding, you can write a 'Letter of Intent' to the trustees and this would be taken into account by a court if there was any disagreement among the trustees. This sets out your priorities for their actions. What would these be?

Chapter 6

Support for living

'There is no person so independent in the world they don't need anybody. We all need support, but with that support we don't want somebody coming in and taking over our lives.' Michael J Kennedy¹

" It has two meanings for me. At the moment we both need support to think about the future and to think about change and we aren't sure where we can get this. In the future, if I'm not around, Jamie will need support that I provide just now, with things like helping him dress, making sure he eats properly, calming him down if he gets agitated. This is what worries me - who will provide this?" Rosie.

This chapter includes information on:

- ◆ sources of advice to plan for support
- ◆ different ways in which support can be provided.

First things first - support with what?

Everyone needs support, with different areas of our life, and in different ways at different times. This could be about:

- ◆ personal assistance with everyday tasks like washing, dressing, eating, getting around
- ◆ emotional matters like dealing with bereavement, managing a crisis
- ◆ technical and practical matters, such as fixing things around the house; finding another home; filling in forms; managing money; planning for the future
- ◆ growing and learning as a person, fulfilling potential and making a contribution, support to get a job
- ◆ maintaining and developing social networks
- ◆ staying healthy and well
- ◆ being represented positively - by people who see you as a worthwhile person and speak well of you.

The first thing to do is to try and work out what support you or your family member wants or needs. You might like to get some help with this, for example Chapter 2 explains how person centred planning can help. Use the questions in the 'thinking about' sheets at the end of the chapter to think about support in more detail.

¹ Kennedy M cited in Racino et al. (1993). Housing, Support and Community: Choices and Strategies for Adults with Learning Disabilities.

Glasgow Learning Disability Partnership Area Learning Disability Teams

The Glasgow Learning Disability Partnership is a partnership between Glasgow City Council Social Services and Greater Glasgow Primary Care NHS Trust.

There are 9 *Area Learning Disability teams* in Glasgow. Each team has a co-ordinator and a number of *care managers*. The care manager is responsible for making sure effective services are co-ordinated for each person with a learning difficulty in Glasgow.

If you live in Glasgow and want help with planning for the future or planning for change; if you want to discuss support and care requirements; if you need advice on anything to do with learning difficulties; contact your Area Learning Disability Team (pages v).

Local area co-ordinators

In the wider Greater Glasgow area, some *Local Area Co-ordinators* work within the community to assist people with disabilities and their families and carers to plan, select and receive the support and services they need. They get to know people personally, building relationships, supporting networks and making connections within the community. They are co-ordinators rather than service providers.

Where can people get support?

Once you have worked out the different kinds of support you need, the next step is to work out where to find this support. Everyone needs support and in some situations you are entitled to receive it. A disabled person has a right to assessment for community care services.

Support for living

Often one of the first sources of care and support comes from family members. Concern for the future arises where this is the only source of support. Building up other sources of support - paid or unpaid - is an important aspect of thinking ahead.

The Glasgow Learning Disability partnership, and most local authority social work departments, work with a number of organisations that are experienced in providing support for people, whether this is in their own homes, sharing with other people or living with family. In Glasgow there are over 25 different providers. However in some other areas there may only be a few.

Ask to be put in touch with several providers so you can compare the different types of service provided and decide which will suit the person best. Even if the you or your family member does not need a service now, it can help your thought processes and planning to know the range of services and providers which are available.

Signposts for information about support

- Contact your Area Learning Disability team or local area co-ordinator for a list of support providers
- Look at the Glasgow Learning Disability Partnership website www.IXSEED.com

Support with daytime activities and employment

People want meaningful lives. For most people this means having opportunities to do something interesting during the day, to have new experiences and meet new people. Many people want to have a job and earn real money. Some people need support to find a job and may need continuing support while working. People with learning difficulties in Glasgow are being supported to make more choices about what they do during the day and lots of people are choosing to get a job.

Signposts for support with daytime activities and employment

- Contact the Employment Adviser, OPUS employment team, part of Glasgow Learning Disability Partnership.
- Glasgow Supported Employment Project (part of ENABLE)
- Contact your Area Learning Disability team to talk about other day opportunities
- Common Knowledge

Chapter 13 has contact details for these organisations.

Support for families and carers

As a parent, relative or friend who cares for and supports a person with learning difficulties, it is important that this contribution is recognised and that you get support for this role. You may also need support with making a transition from being the person who is the key carer in your family member's life, to one who listens, advises and supports others to take on this role. **Right to carer's assessment - ask the SWD.**

Signpost: Information, advice or support for families and carers

- Glasgow Carers: Glasgow City Council social work department offers support to carers through a number of area based carers projects - see page v for contact details.
- Carers Scotland
- Princess Royal Trust for Carers - Scotland
- West of Scotland Carers Forum
- Equal Futures
- PAMIS

Chapter 13 has contact details for these organisations.

How can support be arranged?

How support is arranged or managed depends to a large extent on whether it needs to be paid for and who pays for it.

In some situations, such as being disabled or a carer, the Council's social work department is obliged to assess the person's need for care or support **and the carer's needs**. In Glasgow this responsibility is carried out by the **Area Learning Disability Teams**. They must then either provide services to meet your assessed needs, or arrange or enable services to be provided. The Council might provide the service itself or it may contract with an **independent or a voluntary organisation** to provide this.

If you are offered a service, you should also be offered a **Direct Payment**. A Direct Payment can be made instead of a community care service if a person consents and is able to manage the payment, with or without assistance. The person is then able to purchase his or her own services and tailor these to their own needs and situations. For example they might decide to employ their own personal assistants.

It is possible to use a mixture of Direct Payments and arranged services. If the person decides to manage their own services, these can still be bought from established service providers. There are also agencies which can help with the legal processes and administration involved in **employing staff**.

Many voluntary organisations run support, information or advice schemes which extend beyond the area of personal care. They may be able to assist with transport, befriending schemes to help meet other people, advocacy work (see page x) , community activities and specialist advice.

Signposts for thinking about support arrangements

- Area Learning Disability Team or Local Area Co-ordinator
- Direct Payments Scotland
- Centre for Independent Living in Glasgow (for advice about employing personal assistants)
- Scottish Personal Assistants Employment Network (SPAEN)
- Look in the Yellow Pages under 'voluntary organisations' or 'charities' for list of specialist voluntary organisations, or contact Glasgow Council for Voluntary Services
- Neighbourhood networks
- Care Commission, Glasgow Office
- Befriending Network Scotland

Chapter 13 has contact details for these organisations.

The Johnston family

When Stephen was 15 he got a social worker for a Future Needs Assessment. We got a newly qualified social worker who was dead keen and he really listened. As a result of this we got a Home Support Worker.

Then there were cut backs, and Stephen lost the home support. I insisted that the department record that Stephen had an assessed need for this and that it was unmet. Well we didn't hear anything and then when he was 18, Stephen got a letter saying 'we're bringing out a pilot scheme for Direct payments, are you interested?' To cut a long story short we eventually got an up to date community care assessment and care plan. Before the person came to assess his need for personal assistance, we worked out a timetable for what support he needed. We did it in 2 hour slots and we put down where Stephen wanted me to continue providing his support. Then we added up how many hours support he needed to employ someone to assist him.

At the beginning there was no-one to help us with the process or with employing people. It was very difficult to get and keep staff because it was such a low hourly rate. It was only later that we found out that direct payments can be used to employ personal assistants through an agency and that the hourly rate is different for this. So now we have commissioned a care provider and the support workers have to be able to help him with every aspect of his life, from having a shave to getting a job.

The involvement of other people in Stephen's life is good for him although there were teething problems. But we find it gives us much more flexibility and more control than if social work was arranging a whole service.

My big fear now is: what if they come along and take the support away? However I was reassured at a review meeting, when social work said to Stephen that this time next year he has to have thought about what he wants to do with his life. He has to start thinking ahead.

Thinking about**getting the right support**

- Make out a daily and a weekly timetable, breaking the day up into 2 hour time slots and write down who supports you now and with what aspects of your life? This is a useful process if you are going to approach the Social Work department or a care provider about helping to provide or pay for support. Think about giving this list to someone who can help you find a replacement if one of your supporters is no longer able to be there.

- Does this list tell you that you rely heavily on one or two people? If so, think about who you would like to support you in future with some of these areas of your life and how you would like to be supported.

- If you want to start putting different support systems in place now, do you need more information on your rights or on support providers or ways of controlling the service you receive? Think about making some phone calls to one or two of the agencies on the signposts.

- Getting support to make sure you are getting a good quality of support service is also important - make sure this is on your list.

Chapter 7

Home is where we start from

Christopher

Until Chris was 21 years old he lived at home with his parents, Lilian and David, and Lilian provided most of the support. Then Lilian died quite suddenly. The family struggled to come to terms with her death. Chris took his grief and anger about his mother's death out on his father and his health deteriorated. David has a full time job and he simply could not cope

The social work department thought it would be best if Chris moved into a group home, where support staff could be on hand 24 hours a day. So he moved into a house with 8 people in it, on the other side of Glasgow. This didn't work out and Chris was eventually asked to leave. He was admitted to hospital for assessment.

A group of people worked with his family and with Chris to think about where and how he wanted to live and to be supported. Everyone agreed he needed to have support, during the day and overnight, and he didn't want to live with strangers. He wanted privacy, to cut the grass, and to eat dinner in front of the TV. He wanted to be able to see his family easily.

It was decided that the ideal was a 2 or 3 bedroom house, with a small garden, within a short bus ride to his Dad's house. The next step was to find out if this ideal existed and was affordable. If not, could any compromises be made? This seemed a better way to stay in control than to work backwards from the limited options which had previously been discussed.

Living in the right type of home in the right place isn't enough for a good life, but it is an essential foundation. If 'home' does not meet a person's emotional as well as physical needs, it can affect ability to play a part in family life, to sustain employment, to make connections and relationships and to be physically and emotionally healthy.

This chapter will look at:

- ◆ Personal housing planning
- ◆ Finding out about different housing options
- ◆ Housing rights

First steps in thinking about housing

"The main advice I would give, to professionals, and to families, is to **listen** to people and not to assume that persons with difficulties lack understanding or that they want a different lifestyle or life than they would." Veronica

Personal housing plans

Most people get to choose where they live, who they live with and who comes into their home to support or help them. This does not mean that everyone lives in their ideal home - money and availability and timing issues all mean that compromises get made.

Chapter 2 describes person centred planning. Personal housing planning develops this further to help people think and plan for a home to meet their needs and aspirations, to decide what is essential and what would be nice, but not necessary.

The 'thinking about..' pages will help you, with your family member, to start thinking about what they want and need from 'home'. Depending on the situation, you might want to get help with thinking about the plan. This could involve asking for advice about certain issues, such as housing benefits or advice on aids and adaptations.

Signpost - help with personal housing planning

- Area Learning Disability Teams
- Glasgow Disabled Persons Housing Service
- Social work department occupational therapists should be able to advise on aids, adaptations and grants (although there may be a lengthy waiting list).

Chapter 13 has contact details for these organisations

The art of the possible

Veronica, Ian, Helen, Andrew and Richard are adults in their 30's, who wanted to have their own homes but also to live as neighbours so they could provide mutual support. They all lived in the family home, supported by parents or siblings and had discussions at their day centre about what would happen if parents or family members were no longer around.

Over the period of discussion, the group visited many places to get ideas and drew up their own personal housing plans - two people needed houses suitable for wheelchairs, one person had mobility problems. They were clear that they didn't want a group home to share - they all wanted their own flats - but they also wanted readily available companionship and to be able to help one another at short notice.

They also thought they might need some paid staff to support them. They approached the local social work department to talk about the support they would need in their own homes and they asked a local housing association to help. Over the next few years the group worked with social work, an architect, the housing association and their families to design their own homes in a larger housing development. Family members are regular visitors and some still provide active support.

The five tenants have now lived here for 5 years and inspired others to think about and plan for their future.

" We did compromise, but we understood why and we kept the things that were most important. We chose to be neighbours so we can look out for each other and help each other. Now we've got to know our other neighbours too."

Housing options

- You can live with your family.
- You can live by yourself or with friends or with supporters.
- You can rent from the local authority or a housing association or a private landlord or from a member of your family.
- You can buy or inherit a house.
- You can live in a house owned by a Trust
- You can live in a group home or in residential care

People with learning difficulties should have the same housing choices and opportunities as anyone else. This includes the choice to buy a home. However when people have support needs, sometimes they are told that this limits the choices they can have. This is not always true.

There are pros and cons to all of the above options, and these will depend on each person's unique situation. Think about the person's personal housing plan and what is most important for them and talk to some housing advisors.

In some situations, housing and support are linked and this affects housing rights. For example, if someone's support needs change, they may be asked to move. Having a circle of support, which is separate from paid support staff, is very important to ensure that the needs and interests of the person with a disability are uppermost in any discussions (see Chapter 4) .

Signpost - where to find out more about your housing choices

- Glasgow Housing Association - local neighbourhood offices
- Glasgow Disabled Person's Housing Service
- Glasgow Learning Disability Partnership: Area Learning Disability Teams
- Ownership Options in Scotland
- Association of Residential Care Scotland
- Look in the Yellow Pages under 'Housing Associations', 'Accommodation', 'Estate Agents', 'Letting agents'
- Glasgow Solicitors Property Centre
- Scottish Federation of Housing Associations

Chapter 13 has contact details for these organisations.

Housing rights

There are several pieces of legislation which are linked when considering housing rights. For example the Social Work Department is obliged to carry out a housing assessment as part of a community care assessment under community care legislation and to help their client to get suitable housing, or arrange for aids and adaptations. Even if the Council cannot assist directly with housing, it is still obliged to offer advice and assistance to find housing or to adapt the person's current home. This is particularly so if the person is homeless or about to become homeless.

Because the legislation can be complicated, if you think you or your family member are not being treated properly, get advice from one of the signposted organisations.

Signpost - housing rights advice

- Glasgow disabled persons housing service
- Shelter housing advice centre
- Legal Services Agency
- Local law centres such as Castlemilk, Drumchapel or Govan law centres
- Positive Action in Housing (for issues of race equality)
- Citizen's Advice Bureau
- Disability Rights Commission Helpline
- Glasgow Homelessness Network

Chapter 13 has contact details for these organisations.

"Do I have the right to stay in the family home?"

This is a frequently asked question and the answer depends on whether the family home is owned or rented.

If you are a tenant living in social rented housing, then, in most cases, your family member will have a right to stay in the house if you die. As a tenant you also have a right to pass on the tenancy to someone else who lives in the house, with the agreement of the landlord. Sometimes councils or housing associations may raise questions of capacity (page), and suggest that a person cannot hold a tenancy because they cannot understand the obligations of a tenancy. If this happens, then you should seek help, perhaps from an advocate or independent housing adviser or take legal advice.

If you **own** the house, then you need to make legal provision through your Will. There are several ways of enabling a person to stay in the family home, including **setting up a Trust**, and arranging for your home to be left in Trust (chapter 5).

Hettie and Martin

Hettie is 68 and lives with 32 year old Martin in a council house which has been adapted to meet Martin's needs. Martin has mobility and learning difficulties. As Hettie has got older and less mobile herself, she fears that if she dies or is moved into residential care, then Martin will be forced to leave the house.

The Council told her that Martin could not succeed to the tenancy and that Hettie could not assign (give) the tenancy to him because, they said, Martin would not be able to understand a tenancy agreement. The council lawyers who said this had never met Martin. Hettie then decided she would try to buy the house, so she could leave it to Martin in her Will. However Hettie had very little money, had never owned a house before, and was worried about how she or Martin could afford the upkeep of the house if anything happened to her.

Martin had an advocate, Maria, who thought the Council must be wrong about Martin's right to inherit the tenancy. She sought advice from a Shelter housing advice centre. They advised Hettie that if she remained the tenant and died, because Martin had been living in the house for so long, and there was no-one else living there, then Martin would have a right to stay in the house. The Council would have to prove in court that Martin was unable to understand a tenancy even with support. They also advised that Hettie could challenge the Council's decision to deny her the right to assign the tenancy to Martin.

Hettie has decided to do this, with support from Maria. She has also started building a network of people around Martin - his sister, Maria, a niece and grand-niece - who will support him to have his rights recognised and to keep the house when Hettie can no longer do this.

The housing and support jigsaw

Everyone is unique, everyone's personal housing plan is slightly different. For many people, housing is only one part of a jigsaw. Thinking ahead about how you can be supported to live where you want to live is just as important.

- Think about your needs and aspirations before you think about what you can afford and what is available - sometimes dreams do come true.
- Some people have devised whole new options that no-one had thought about before. If necessary, see if you can combine elements of different options to find something that suits your particular circumstances.
- Use the resources and professional expertise which are available, but take recommendations - some advice services are better than others.
- Find supporters and build networks - getting the right home is only the first step. People need trusting relationships and networks of support to make sure it is more than bricks and mortar -that it becomes a safe base for a life well lived.

Thinking about**where you will live**

Where do you want to live?

- ◆ What have you liked or not liked about where you lived before and where you live now?
- ◆ Where would your ideal home be? Think about what you would need nearby, so you can discover the type of location you would most like to live in.

Who do you want to live with?

- ◆ Do you want to live in your own home, perhaps with support? Would you like to share with someone else, or with a number of people?

What will your home look and feel like?

- ◆ 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 property you need.
- ◆ What else do you need from your home, for example furniture layout, colours, how much noise you can generate or tolerate.

What can you afford or might you be able to afford in the future?

- ◆ Think about the money you might need to get a new home, and then to set it up and live in it. Do you need advice about housing benefits or getting grants?

The next steps

- ◆ Think about contacting some of the signposted organisations for help to work out your options or get more information?
- ◆ Think about storing or sharing information on: your housing needs and dreams; the places you have lived and where you were happy or unhappy.

Suzanne and Gina

We planned where Suzanne would live and put her name on the Council's housing list and quite a few housing associations. But it seemed to be catch 22. Even if Suzanne had been offered the perfect house, the social work department didn't seem willing to provide the support she would need. Then when they agreed that she should be supported in her own house, we thought they would work with the housing department to come up with a suitable house. But it didn't happen.

It was hugely frustrating. But we had heard that some disabled people had been able to buy their own home and thought that if this was possible, it would be the solution.

We found a lovely flat at a reasonable price. We had worked out that we could release some capital from our home to help her with the price of a deposit and a Bank had agreed in principle to give her a mortgage. Suzanne is on Income Support and she can get help with the mortgage interest costs as part of her Income Support, which gets paid direct to the lender. When we die, she will inherit enough money to repay the capital.

Suzanne chose the house and wanted to live there. But she does not have a great understanding of money, so it seemed a good idea for her to appoint me as her Power of Attorney so I could deal with the more complex matters. However our own solicitor, who had never even met Suzanne, decided he wasn't willing to act for her. I made the mistake of saying she had learning difficulties. Then we found another solicitor, who was more enlightened, who agreed to act for her

We had some sleepless nights. However it has been worth it. Suzanne has a great support team. She has a job at the hairdresser's down the road. She owns her own home. She is part of the community she lives in. She is settled and secure. Now we're working on making sure she stays that way.

Chapter 8 Money matters

That money talks

I won't deny.

I heard it once.

It said 'Goodbye.' Richard Armour

Disabled people have lower incomes than the general population, two thirds rely on state benefits. People worry about having enough money and about being supported to manage this money, making sure they are not exploited.

This chapter will help you think about:

- ◆ having enough money, now and in the future
- ◆ managing money - paying the bills, debts
- ◆ making the most of it - financial planning, investing and saving.

The signposts suggest organisations which provide money, benefits or financial advice. Use the 'Thinking about...' sheets to record financial information which it may be useful to pass on to others and to think about what support may be needed. You may find it helpful to read Chapter 5 if you want to think about money you may leave on your death.

Having enough money, now and in the future - where will it come from?

Broad priorities for money are very similar from one person to the next, even if some have more to spend than others.

- ◆ The basics - food, housing costs, utilities such as gas, electricity and the telephone, clothes, transport, anything to do with your health, support.
- ◆ A life - entertainment, hobbies, holidays.
- ◆ Planning for the future - savings, insurance, new furniture.

If you don't have enough money, sometimes the last category falls by the wayside. However whether your money mostly comes from benefits or you have thousands of pounds to manage and invest, most people can benefit from having a financial health check and advice.

State benefits

Most people with learning difficulties get some of their money from benefits, such as income support, housing benefit and disability living allowance. Laws governing the eligibility for these benefits change regularly as does the amount that people may receive. The signposts direct you to organisations that can offer up-to-date information about benefits and it may be worth getting a 'benefits check' to make sure you and your family member are getting everything to which you are entitled.

Wages or Earnings and Working Tax credits

Being employed is not just about making money. It also helps people to feel valued and to have a place in the community. People may need support to take up employment (see Chapter 6) or to make sure they get paid a proper wage or to think about the effect of taking up a job on their benefit entitlement.

Signpost - money and welfare benefits advice

- Glasgow Disability Benefits Centre
- Citizens' Advice Bureaux
- For employment advice - Opus employment, Glasgow Learning Disability Partnership
- Local law centres e.g. Drumchapel, Castlemilk, Govan, East End, Sunnyslaw, Milton, Ladymuir
- Maryhill Representation Unit
- Welfare rights, welfare benefits or disability advice services are based in most local authority social work services departments: Contact your local council social work office or local area learning disability team.

You will find contact details for all these organisations in Chapter 13.

Paying for support

Chapter 6 gives information about different ways of organising care and support, including the possibility of employing your own staff. Depending on your preference and choice, it is possible to control the money for some or all of your support. There are two main sources of money for this:

- the Independent Living Fund
- Direct payments.

The signposts suggest organisations which can give you more information about these.

Signposts

- Centre for Independent Living in Glasgow
- Independent Living Fund
- Direct Payments Scotland
- Area Learning Disability Teams

You will find contact details for these organisations in Chapter 13.

Inheritances and Trusts

"My Gran told me that she was going to leave her money to my brother and sister, but she wouldn't leave me anything. She said it was because I get benefits and it wouldn't be fair to me if I lost them because of her. Mum told me a lot of people think that and they're wrong." Stephen

Some people have substantial money from an inheritance or a gift. If someone's main income is from benefits then it is worth getting good advice about the best way of leaving or giving money so that it does not affect entitlement to state benefits. One approach is to leave money in a Trust. (See chapter 5 for more information and signposts about Wills and Trusts).

Kenneth

Kenneth owns his own home which he shares with a supportive flatmate and he has three other support workers. He sees a lot of his family who live about 10 miles away.

Ken gets money from Income Support, with disability and severe disability premiums and disability living allowance (high rates) for care and mobility. He also gets Income Support for Mortgage Interest. He has a job at Asda two mornings a week, and he gets £20 a week for this. All of this money gets paid into Ken's own bank account. He cannot sign his name but he has a stamp which the bank gave him and he is a well known customer when he goes into the local branch to take out money.

Debbie helps her brother to manage his money and his mortgage. Day to day his support flatmate and the other support workers are involved - helping Ken with his weekly shop and so on. They have a system for recording the money and keeping receipts. They have found this is really important - they did have a problem with one member of staff which was quickly found out because several people are involved in helping with the money management.

Ken gets a direct payment from the Social Work Department to pay for the support he needs. This goes into a separate bank account. His mother, Jenny, initially managed all the direct payment money, but it was getting too much for her. Now they employ an accountant to deal with the staff wages and they keep receipts for other things, passing these monthly to the accountant. Jenny is the main contact for this at the moment.

When Ken bought the house, the family knew that in the future it would need maintenance and Ken might struggle to afford this. His parents have some small insurance policies due to mature. They are not as valuable as they once hoped. However they have worked out the best way to reinvest these, minimise tax, and help Ken with some of the expected future house maintenance costs.

Managing money - paying the bills

When someone has lived in the family home all of their life, it is not surprising that they may not know how to budget for the cost of living and running a home. Families worry about who will support their son or daughter with this.

Budgeting is a skill - some people are good at it, some people are not. Think about people who may help your son and daughter in future with managing

money. See if they would be willing to be involved sooner - even in a small way.

Money advice centres (see signpost) can be a great help with checking people are getting all the benefits to which they are entitled. They can also help with ideas for managing money and with advice about budgeting and about loans and debts.

Making the most of your money - saving and investing

Thinking about managing financial funding for the future is a complicated area. You might need advice about:

- Benefits
- Saving
- Estate planning
- Home insurance
- Future care insurance
- Life assurance
- Health care plans

Get independent financial advice and find someone who understands the type of financial provision you may be trying to make and why.

Signposts for financial advice and planning

- High street banks or building societies
- Independent Financial advisors - names in the Yellow Pages or contact IFA Promotion www.ifap.org.uk
- Money Management National Register of fee based advisors
- Financial Services Authority, which has a series of leaflets on savings and investments, financial planning and advice, mortgages and pensions.

Contact details for some of these can be found in Chapter 13.

The 'thinking about ...' sheet is designed to help you think about the financial information it is useful to record and share with a trusted person. Think about building up relationships with professionals who can give expert advice, and with honest and competent supporters to help with day to day management.

Thinking about - **money planning**

Note down some of details about your family member's money or financial situation:

National Insurance Number?

What state benefits are received?

Check the books or letters from the Department of Work and Pensions and write down what they are called and how much is paid.

Does the person have any Wages or earnings? Write down the details, including the name of the employer?

Does the person have a bank account?

Write down the name and address of the bank and the account details.

Does the person have separate savings or investments?

Write down the details.

Who helps with managing this money now?

Is this help as a DWP appointee?

Who will help to manage this money in the future and make decisions?

Write down the names of the people involved and what they help with, for example, a support worker may help with budgeting, but someone else as the DWP appointee.

Professional advisors

Do you need to plan how you will leave money or property? Have you seen a solicitor or financial advisor about this?

Do you have a financial advisor or accountant?

Will your family member with a disability inherit money through your Will?

Who will help them to make the best use of this money and to make decisions?

Chapter 9

Health and wellbeing

People who analyse trends in the health of the population tell us there are 5 factors which determine our state of health. These influence how often a person is sick and how long the person will live.

1. Our individual behaviour - what we eat, how much we drink, whether we smoke and so on.
2. Social relationships - whether we have contact with family, friends and the state of those relationships.
3. Our physical environment - where we live, what is in the air.
4. Our economic status - employment, poverty, links to the other factors.
5. And lastly, access to medical care

Of these 5 factors, research has shown that access to medical care is the least significant in determining our health.

John McKnight: Communities and Health, Partners in Change 2001

Other chapters have talked about social networks and supportive relationships (chapter 4) where you live (chapter 7, and about economic status (chapters 4 and 8). This chapter looks at rights to access health services and thinks about what other people may need to know in order to support your family member to stay well.

Planning for a healthy life

David

David lived in a big house with residential staff. He shared a room with another young man and tension developed between them. As well as this, he wasn't being cared for physically. He started losing weight. His skin was breaking down and he was in a terrible state. We complained but nothing seemed to change. Then he got moved to his own room - but it was tiny and dark, in a basement and it looked out on a brick wall. If his behaviour was difficult they put him to bed in this basement. We said " Why do you do that? No wonder he is difficult. Get his boots on and take him to the hills for a walk and space"

Then we got a call to say he he'd been admitted to the mental health hospital, a secure ward. The hospital said "he's a manic depressive, he's got mood swings, he needs the drugs to even out the mood swings." I doubt that very much. I think he was just very badly misunderstood...

He came home with us, joined a work group laying paths and planting trees. We found a local agency to provide carers . David grew happier, he put on weight and his skin healed because he was getting clean clothes and washed properly. (adapted from 'Home Truths: disabled people's stories and strategies for accessing home ownership.')

Eating well, sleeping well, getting enough exercise, having interesting and stimulating things to do. These are some of the basic elements affecting health, energy levels and self esteem. Emotional and physical health and wellbeing are closely linked.

Research has shown that the more people who are involved in your life, the more likely it is that changes in your looks or mood or behaviour will be noticed. It is these changes that generally indicate if you are not well - either mentally or physically. People need support with different aspects of their health - people who will notice when you are physically run down or "not yourself". Some people may need help to communicate pain or discomfort and to challenge assumptions which may be made by health professionals.

It is important to have regular check ups, health screening and to be health conscious. It is just as important to have people around who will prompt your family member to take action or will intervene if necessary (see chapters 4 and 6) The 'thinking about ...' sheet is intended to help you to pass on background information on health issues to the people providing this type of support.

Signposts for more information about health issues

A number of organisations produce useful information, often in illustrated or cassette form. Contact:

- Mencap: for a series of illustrated books Your good health
- British Institute of Learning Disabilities: for a wide range of publications on access to health services and specific health conditions such as cancer.
- Your Area Learning Disability Team should signpost you to local health centres and projects with relevant information or services.
- Royal College of Psychiatrists: Books beyond words, dealing with difficult issues which may be faced by people with learning difficulties.
- Health promotion section of your local Health Board

Chapter 13 has contact details for these organisations.

Access to health services

GP and NHS hospital services are free to everyone. You may have to pay for other health services such as eye tests, dentistry or prescribed medicines. If you are on income support or aged over 60 then you should not be charged.

Your rights to access health services are covered by a string of laws. It is not necessary for you to know what these are in detail as long as you remember your fundamental right to be treated as an equal citizen (chapter 10). Some other points are worth remembering, because some doctors, nurses and dentists are not as good as they should be at communicating with their patients.

People have a legal right to:

- ◆ have access to NHS services on the same terms as anyone else. No-one should not be denied treatment or have treatment delayed because they have a learning difficulty.
- ◆ to be registered with a GP, to get information on the GP and other health services in your area and to be referred by a GP for further treatment if this is needed.
- ◆ to accept or refuse treatment. You have to be asked if you agree to having medical treatment. You can say no. You cannot be forced to have treatment which you do not want or have not properly understood. The Adults with Incapacity Act has a whole section, Part Five, about medical treatment and decision making where someone may not be able to understand or communicate.
- ◆ to see and get a copy of your medical records.
- ◆ to make a complaint. You can complain to your local NHS Board or Trust or GP or dental practice.

Who and what else can help?

Other people and organisations can help either with continual involvement in your family member's health and wellbeing or with advice in particular situations.

These include:

- ◆ Your family and friends, who may need background information.
- ◆ Your GP - a good GP and Health Centre are invaluable as sources of information and referrals to other services
- ◆ Other health care professionals - the practice nurse, physiotherapist, dentist.
- ◆ Voluntary organisations which specialise in health issues or in particular conditions

Signposts - finding out about health services and support groups

- Glasgow Learning Disability Partnership - Area Learning Disability Teams
- Greater Glasgow Health Board
- NHS Helpline 0800 22 44 88
- Care Commission Glasgow office
- Look in the Yellow pages under 'Health services and authorities' and 'Health Centres' or under the specific service e.g. Dentists, Chiropodists.
- Local libraries are a good source of local information or voluntary organisations, and health related support groups
- Ask at your local health centre, or telephone the local health care co-operative (LHCC).

Chapter 13 has contact details for some of these organisations.

Thinking about - **Your health and wellbeing**

- ◆ Does your family member have any impairments or long term conditions that affect how you live your life or that it helps others to be aware of.

- ◆ Is there any family health or genetic history which it may help others to be aware of e.g. glaucoma, breast cancer?

- ◆ Make a note the name of the person's GP and any other medical advisors that they see regularly, screening or treatments that they receive or should receive.

- ◆ Perhaps note down any steps the person takes (or should take!) to help them stay well e.g. cutting down on smoking or being careful about weight.

- ◆ Do any situations tend to make the person unwell? e.g. being in enclosed spaces

- ◆ When your family member is unwell or in pain, are there particular ways in which they communicate this? How might someone know? For example, some people get very agitated before they have an epileptic seizure.

Think about picking someone in your support circle with whom you would be comfortable sharing this information. Ask if they will hold this information for you and support your family member with communicating it and ensuring they receive the services they need.

Chapter 10

Knowing your rights

Within each of the earlier chapters there has been reference to rights or entitlements, such as rights to access health services or to stay in the family home. There are two ways of thinking about rights:

1. there are rights that are supported by legislation and this chapter will tell you about a few important Acts which are meant to protect your rights
2. the other rights could be called 'rights of citizenship' or of social justice. These may be less clear and are about rights to equal choices and common experience.

Human Rights

The Human Rights Act 1998 recognises basic human rights. Important ones for disabled people are:

- Article 2: the right to life.
- Article 3: prohibition of torture and inhuman or degrading treatment.
- Article 5: right to liberty and security
- Article 8: right to respect for private and family life
- Article 14: prohibition of discrimination (in access to the other rights)

This means people have the right to dignity and privacy. For example, if you have to use a commode in a living room, because of unsuitable housing, then this can be interpreted as lacking in respect for your privacy and family life. Public and private sector agencies and the people who work in them do not always understand or apply these principles as fully as they should.

From the time Robbie was seven, his parents found it more and more difficult to look after him at home. So he went away to a children's home and went to the school which was attached to the home. When he moved up to secondary school, he did not like the classroom and kept trying to leave. The teacher would not let him and Robbie hit out at her, which caused her to fall and hit her head. Robbie was twelve years old.

Robbie is now 52. He has lived in several different residential care homes and each time, staff at the new home have been given a file which tells them what happened when he was 12. He has carried a reputation for being difficult with him for 40 years, although he has never hurt anyone deliberately.

Robbie has a right to access the information on his file and to be told what information is passed from one agency to another. That is covered by the **Data Protection Act 1998**. His right as a citizen is to share the experience of most adults, whose childhood mistakes generally get forgotten over time.

The Disability Discrimination Act

Under the Disability Discrimination Act it is unlawful for service providers to treat disabled people less favourably for a reason related to their disability. Providers also have an active duty to change policy, procedures and practices that make it difficult for disabled people to use a service. Reasonable steps have to be taken to remove or reduce physical barriers.

The problem with the law is that it is quite vague in some places and does not force services to have to change things. If services do not change policy and procedures, then you may have to make a complaint. The Disability Rights Commission may be able to advise or even help you to take a case to court if necessary.

Adults with Incapacity Act 2000

This Act introduces new definitions of incapacity, and new legal mechanisms for taking decisions for someone who is not able to make their own decisions (see chapter 4). Most importantly it emphasises that any intervention has to be the least restrictive of the person's freedom and anyone acting for a disabled person has to encourage the person to exercise whatever skills or capacity they have.

The Disability Discrimination Act states that someone who is defined as incapable can be treated differently to other people but not without good reason. This means that a person with learning difficulties should not be asked to satisfy a higher level of understanding than would be imposed on a non disabled person.

"They say Linda can't have the flat because she can't understand the tenancy agreement. But no wonder - it's 30 pages long and full of legal jargon. I doubt anyone understands it, let alone someone with learning difficulties. I don't think they are being reasonable. "

Community care legislation

There are a number of important pieces of legislation that set out the local authorities' obligations to provide services to people assessed as having 'community care needs'.

The way all of this legislation links together can be quite complicated - so knowing your rights is not always easy. However the local authority does have obligations towards people who are 'disabled' or 'vulnerable' - to make sure they are housed, protected and cared for. Most people also now have the right to a direct payment instead of services, so that they can arrange their own services (see chapter 6 and 8)

Other legislation and regulations

Almost every aspect of life which previous chapters have covered, has legislation and regulations attached to it. Housing legislation, social security legislation and health legislation can have a big impact on a person's life - opening up choices. Sometimes you will be told by staff in advice agencies and by service providers that 'you can't do that' or 'we can't do that'. And sometimes this is true. But sometimes it is not true - the person has misinterpreted the law or the rules or does not know about other laws or rules which would allow you to move forward.

So if you don't get the answer you want, get a second opinion.

The right to be yourself, to have a choice and to say 'No'

Just because someone has a learning difficulty does not mean that others should be allowed to make decisions for them. Just because someone needs support does not mean that they should take whatever they are offered.

People have a right to say 'no' to options presented to them and to ask for something different if they think that will suit their needs better.

Irene, Bill and Peter

Irene and Bill have always been Peter's main carers. For the last few years Peter has also had support workers, paid for by the social work department and the Independent Living Fund. However Irene is there for Peter on four mornings a week, three afternoons and every night. She is normally up at least once during the night to help him go to or come back from the bathroom.

Although Irene has a carer's assessment which says she needs respite, she has never taken this up because the only option given was for Peter to go into a respite 'bed' in a local residential care home. This was not acceptable to them. Irene and Bill did not want to go away, or stay at home, if the consequence of this was that Peter would have his whole life upset.

Last year brought a period of stressful family illness. The social work department again offered 5 days in the residential care home. Irene found out how much the home would charge for the week. It was £2000. She put it to the social work department that they could make her a direct payment of less than this, she could then arrange for extra support for Peter at home while they went away. The Social Work Department refused. Irene contacted her local councillor and her MSP to help her challenge the council's decision. Eventually she was advised that if she arranged the additional support at home, the Social Work Department would meet these costs.

What should you do if you think your rights are being refused or breached?

Get advice. The duties of the local authority and rights of disabled people under either the Human Rights or Disability Discrimination Act are often vague and untested. Words like 'reasonable' are used in legislation and are interpreted in many different ways.

A professional **advocate** (chapter 4) or independent advice agency may be able to help you to have your rights respected. If you think your rights under the Disability Discrimination Act are being ignored, contact the Disability Rights Commission.

Sometimes the involvement of a lawyer can help everyone to clarify what the law is and come to an agreement. Depending on the aspect of a law you want to challenge you may get Legal Aid to meet all or part of the costs.

Signposts for advice about rights

- Disability Rights Commission
- Centre for independent living in Glasgow
- Legal Services Agency
- Your local law centre (look up Yellow Pages under 'law centres')
- Scottish Consortium for Learning Disabilities
- ENABLE legal service
- Citizen's Advice Bureaux

Contact details for these organisations can be found in Chapter 13.

"It is a funny thing about life; if you refuse to accept anything but the best, you very often get it." Somerset Maugham

Chapter 11

How far have you come?

*'The best laid plans o' mice and men
Gang aft agley...'* Robert Burns

Time for review

"My nightmares are going to a day centre; living on my own; travelling by myself; having no pals; having pals who live far away. At first I could only think of nightmares. But then I thought about dreams. I want to work, but only 4 days a week because I get tired; I want to live at home but have lots of friends and be near family; I want to do a parachute jump. I'm doing a parachute jump next week." Stephen

Chapter 1 stated obvious facts: people die, people get sick, things change. It could have added: people change their minds, people fall in love, people have experiences which alter their plans, other people put barriers in the way, other people offer suggestions you didn't know were possible.

If you have used the 'thinking about' sheets as part of the process thinking ahead, then you can keep using them as a way of asking yourself 'how are we doing?' For example, you may have decided to contact an organisation about person centred planning or to see a solicitor about a Will. Review your progress every six months or so, involving others, friends or family, if this is helpful.

If you used the 'thinking about...' sheets as starting points for recording information, store this in a safe place or with people you trust. Think about reviewing and update the information perhaps every two to three years. If people have moved on, then you may need to find new people to hold the information.

This handbook cannot be a comprehensive guide to thinking ahead about every possible aspect of your family member's life. Inevitably we may have missed out something which may be very important to you. If this is the case, then use the approach here to think ahead.

- What information do you have and can you give to others as a background?
- Who do you need to tell?
- Are you happy with how things are and you want to make sure it stays that way?
- Or do you dream of something different?
- Tell people and get support and allies to have the future you want.

Making space to think ahead and to review your thoughts

Everybody needs space to think and to think ahead - something which can be hard to find. Make a date with yourself. Find a comfortable space. Invite people who are close to you to join you in thinking ahead.

Sometimes people put off thinking or planning ahead because the issues seem so big. It's hard to think ahead about 'money' or 'death'. Take it one step at a time. Building supportive relationships outside his family will help Stephen (quoted above) achieve his dream of a job. It's also part of the bigger 'thinking ahead' picture of a good life for Stephen which is not completely dependent on his mother, brother and sister.

"Independence for Stephen is going out in the morning with his support worker and being able to tell him what he wants to do with the day. Not that long ago, I would have written a note to tell the support worker what needed to be done. I'm trying to push Stephen to make his own decisions and take responsibility for his actions. I'm telling him I'm not doing everything anymore. Stephen and his supporters have to start doing the thinking ahead instead of always looking to me. It's not easy for any of us - but it's happening, we're getting there." Gail

'The future belongs to those who believe in their dreams.' Eleanor Roosevelt

Thinking about **reviewing your thoughts and plans**

How far have you come?

- What progress have you made?
- Who is advising and supporting you?
- Do you need to change anything you are doing in order to make better progress?
- Have you written down some of the essential information suggested in the thinking about sheets and given it to trusted people?

Are you stuck or having difficulty getting started again?

- Do you need to get more information about a subject? If so, where can you get this from?
- Do you need some specialist advice?
- Has your thinking changed a lot in the past few months? Would it be better to take some steps back before going forward again?

Are your friends and supporters or motivators still with you?

People move on or away. Do you need to find some new people to share the tasks? Can you get anyone to help with this?