



Freedom

a guide to good
support

by Simon Duffy



The Centre for Welfare Reform



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Foreword

by Alicia Wood

Supported Living equals freedom - at least it should do...

When we were developing what we call Supported Living in the UK in the late nineties, we were trying to help people with learning disabilities escape from the institution of long stay hospitals, the institution of residential care and the institution of group homes and hostels. It was called Supported Living to make sense of a concept and to differentiate it from institutional models.

Supported Living is about people's freedom to determine what happens in their lives: where they live, who they live with and how they are supported. However, all too often now we see and hear evidence that the real meaning of Supported Living is misunderstood or distorted. We hear people's homes being called units or services and claimed by the organisations that house and support them as their own. We see people being made to share with people they don't choose to share with because it meets the needs of the commissioners. We see people with little choice over who supports them or how they are supported, and with no control over who steps through their front door. Supported Living has become an institution.

In 2013 H&SA wants to challenge you as our members to reflect on where you are at with Supported Living. Has it become a service model rather than a way of life? Do the people you house or support have freedom. No organisation is perfect; we are human beings working in human services and need human responses, rather than just service responses to enable people to have freedom in their lives. So many of the Supported Living services we work in have evolved from institutional service models or through old models of commissioning that don't allow for freedom.

Give *Freedom* to your managers and staff and ask them to reflect on how free the people are that you support. Get them to use the practical tips here in *Freedom* to make small changes that don't cost anything, but help people to lead free lives.



Preface

by Simon Cramp

Most people take freedom as a given. But for someone with a learning disability that is not always the case. This means that there are often more controls and fewer choices. People miss out on some of the most important things in life.

A lot has happened in my life. I have a learning disability; but I am passionate about politics and the rights of people with learning disabilities. I bought my first newspaper when I was fourteen years old – The Guardian. Often I went without my lunch to afford it and would rush out of school to go and buy it.

I have kept trying to contribute and to give something back to the community and to stick up for people like me and others who have even more severe disabilities. For many years people with learning disabilities and their allies have been campaigning for the right for people to have more control over their own lives. In response to this, in England the government published a consultation document, *Supported Decisions* and then a further paper, *Who Decides?*

In 2003 Parliament set up a Joint Committee in order to review the draft legislation on mental capacity (which at the time was called the Mental Incapacity Bill). I wrote to the committee, with the support of Mencap, and was then invited to speak to the committee at the Palace of Westminster.

It was a nerve-wracking experience; but I was able to argue that people should have a clear 'right to advocacy' and there should be better safeguards for people with severe disabilities. There were then some important changes made to the final legislation.

I was very proud that I was one of the first people with learning disabilities ever to speak to a committee in Westminster.



Then in 2005 I worked with Simon Duffy to publish an important paper on self-determination and individual budgets (Cramp and Duffy, 2005). We explained how it was possible for people with learning disabilities to control their lives, including any budget for their support.

I have been lucky. I was given the chance to exercise control and be in control of my own life. There have been many low points, and many plus points, but I was very lucky to have had good parents and the support of friends and family. But some people are not so lucky.

I hope and pray that one day everyone – whether or not they have a learning disability – will have freedom. Choice and control should be a given. We should not have to keep fighting for our freedom.



Summary

Freedom means being in control of your own life.

In the 7 Chapters below I will explore the following seven questions:

1. Why freedom is important to everyone
2. How everyone can be free, including people with learning disabilities
3. How we can help people be free
4. What kinds of partnership are needed to support freedom
5. How people can be both free and safe
6. How to help people control their own money
7. Why the best support helps people be full citizens



Introduction

I used to think that freedom was freedom of speech, freedom of the press, freedom of conscience. But freedom needs to include all of the lives of all of the people. Freedom is the right to sow what you want. It's the right to make boots or shoes, it's the right to bake bread from the grain you've sown and to sell it or not to sell it as you choose. The same goes for a locksmith or steelworker or an artist – freedom is the right to live and work as you wish and not as you're ordered to. But these days there's no freedom for anyone – whether you write books, whether you sow grain or whether you make boots.

From Everything Flows by Vasily Grossman

Freedom is important to everyone. But often we have a narrow view of freedom and we don't notice the different ways that it can be taken away.

If you live in a police state you may notice that you are not free to speak your mind. If you live in economic hardship you may find you are not free to live and work without becoming enslaved to others. But political and economic tyranny is not the only form of tyranny.

If you have a learning disability you may find that other people take away your freedom simply by treating you as someone who doesn't really count. What you say and what you do does not even matter. This tyranny is created by prejudice and it can be just as damaging and frightening as other forms of tyranny.

This handbook builds on work over the last 20 years or so; I have tried to write down some of the most important things I have learned as I have worked with people with learning disabilities and their families. Over these years I have often used other words to describe this goal: self-determination, autonomy, authority, citizenship, choice and control. But I increasingly think that **freedom** is the best word to use.



1. Freedom is important

This small book is about how to give the kind of thoughtful help that will make sure everybody can be in control of their own life. And to begin its important to understand why being free and in control is so important.

Freedom is an important part of all our lives, but it is something we often take for granted until we suddenly find we have lost it. If we lose control of our lives then we become very vulnerable. Many people with disabilities find that they are not in control of their own lives and this stops people making the most of their life and often leads to misery and abuse by others.

There seems to be a much greater risk that someone with a disability will not be free:

- Many people believe that people with disabilities are not really equal to other people, so they don't listen to them respectfully.
- People with disabilities are often swallowed up by institutions, services and other systems that pay little regard to individual choices, instead they are expected to fit into the system.
- Sometimes people with disabilities become so dependent on the assistance of other people it becomes hard for them to stand up for themselves, for fear of upsetting them.
- Sometimes people do need thoughtful help in order to take control, help to: listen, communicate, plan and decide – but sometimes other people just don't know how to give this vital support.

Freedom brings some major advantages to everyday life.

1.1 Freedom feels good

We like to be in control, it feels good. In fact we know that when people don't feel in control of their lives they are likely to feel sad or even depressed.



Living our own life means being the author of our own life, directing it, making our own decisions, taking our own risks.

It doesn't matter whether you have a disability or not, freedom is vital to our well-being.

This is a simple but vital point. If you ever wonder why it's important that you should help people with disabilities be in control just take a few moments to imagine what it would be like not to be able to be in control of your own life.

1.2 Freedom gives us important rights

Freedom also has lots of practical advantages. If you are not treated as someone who can make their own decisions then there are a lot of things that you are not allowed to do.

For example you may not be allowed to:

- Have a tenancy or own your own home
- Control your own money
- Get married or have sex
- Control how doctors treat you
- Enter into contracts
- Vote
- Hold legal offices and responsibilities
- Get a job

These things really matter not least because they affect how seriously other people treat you. But more importantly, they matter because having a good life can depend upon having the ability to do these practical things.



1.3 People take us more seriously when we are free

Freedom is also important because it means that what you say really counts and other people have to listen to what you say. If you have no control then people do not have to take what you say seriously.

Being listened to is important; only when people listen to you will you get what you want and need from them, and feeling that you are listened to is the basis of self-respect. Nothing undermines how we feel about ourselves more than how others treat what we say and do.

1.4 We can change things when we are free

Freedom lets us make our own decisions. Life requires decisions; even poor decisions are an important part of living. If we can't make decisions we are stuck and unable to control the direction of our life.

In general, we know what we like and don't like, we know the people we like and the kind of things we like to do. We can't magically get what we want, we need to work at it but we can try to change the direction of our lives if things don't seem to be going right.

If we are at the mercy of other people's decisions then we rely on them to work out what is the right direction for our life. Given that it is sometimes quite difficult to know what is the right thing to do in one's own life, making decisions for someone else is extremely risky.

Too many people with disabilities find that their lives are stuck in a rut – a rut shaped by other people's needs and expectations. Too many people find they cannot control their own life.

1.5 Freedom is at the heart of citizenship

Citizenship means living together in a community where we see each other as equal, different and free. Citizenship lets us live together in a way that is mutually respectful and accepting of difference.

Part of that respect comes from seeing each other as free and independent – in control of our own life – connected, part of the community, but also free to make our own unique contribution.

There are 7 keys that bring citizenship to life (see Figure 1):

1. **Purpose** – having our own direction, our own way of living
2. **Freedom** – following our own path, making decisions
3. **Money** – having enough to pursue our own path, to be independent and free
4. **Home** – having a place of our own, a place where we belong
5. **Help** – having other people to help us out
6. **Life** – giving back, getting involved and making a difference in our own way
7. **Love** – building on existing and supporting new relationships

Freedom is a critical key to citizenship without it there is a real danger that people with learning disabilities will not be treated as full citizens.

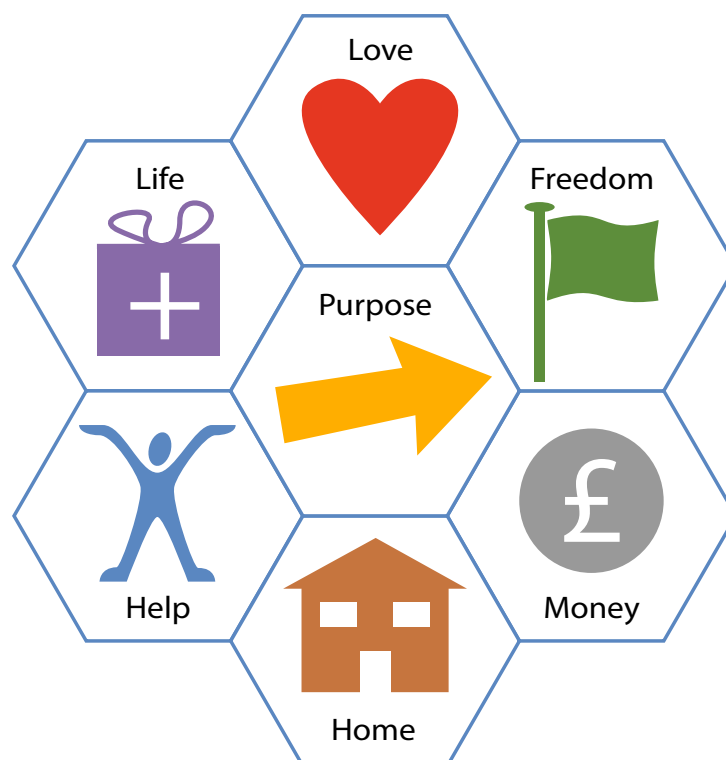


FIGURE 1 KEYS TO CITIZENSHIP



2. Everyone can be free

It doesn't matter how profound or complex your disabilities, you can still be in control of your own life, you can still be free. Sometimes people just need some assistance to be free, and this needs to be done thoughtfully and with care.

It is important to remember the 7 Principles for Freedom:

1. **Capacity** – you must start by assuming I have the ability to be in control
2. **Specific** – even if I cannot make some decisions I may still be able to make others
3. **Selection** – if I need a representative I should be able to pick them
4. **Suitable** – any representative should be right for me and my needs
5. **Best Interest** – any representative must look after my best interests
6. **Involvement** – I always have the right to be involved in any decisions
7. **Review** – all arrangements must be reviewed and improved over time

We often forget that most of us need help and assistance to be in control; some people just need extra support.

Freedom is not something that is private, it is social, it is something we make happen by the way we live together.

Barriers to freedom can be:

- **Prejudice** – Simply the appearance of having a disability can lead some people to stop treating you seriously, they stop listening and take control.



- **Experience** – We learn to be in control by being in control. When people are systematically deprived of the opportunity to make decisions and choices then it is harder to begin.
- **Judgement** – We often need help and guidance to make decisions because we lack any of the necessary information, so sometimes people need time, information or assistance to make an informed decision.
- **Communication** – Some people have communication difficulties and we need to listen really carefully, possibly using special languages, tools or systems to make communication possible.
- **Allies** – Sometimes we do need other people to make some decisions for us – but they should be people who know us and love us.

If we work together – we can overcome these barriers. Following the 7 Principles for Freedom will help you support people to be free and in control of their own lives.

2.1 Capacity

You must always start with the assumption that the other person can make their own decisions.

Too often we don't even give people the chance to make their own decisions. Taking reasonable risks is a necessary part of ordinary life; it is not acceptable to remove someone's ability to take the same kind of risks that other people take for granted.

There are two circumstances when you may need to limit someone's control, or to find another way of making decisions:

1. If the person does not genuinely understand the options or choices they face, no matter how well these are explained to them, or
2. If letting the person exercise choice will place them or others at a significant risk of harm.

It is important to remember that you should **only** be limiting people's right to make decisions for reasons of health or safety grounds if the person is likely to make choices which will place them or others at a **significant** risk of harm.



2.2 Specific Capacity

You must never assume that because someone cannot make a particular decision that this means they lack capacity to make other decisions.

Sometimes people will agree that a person cannot make a particular decision, perhaps an especially complicated decision, but will carelessly slip into assuming that the person 'lacks capacity' to make all sorts of different decisions. But capacity is not like that.

You only have the right to limit someone's ability to be in control in very special circumstances and around particular kinds of decisions – where there is a recognised problem about the person making a decision.

2.3 Selection

You must support the individual to select someone who will help them to make decisions, or act as their representative for a particular decision where a representative is needed.

You must give the right to individuals to make decisions about who will represent their interests on the questions that they cannot answer themselves. If someone knows enough to know that themselves and that some decisions are best left to someone else that they trust, then their selection should be **respected**.

The only reasons not to do this would be:

- If events made it impossible for the representative to make the necessary decisions, or
- If there was good evidence that the representative had or would be likely to abuse any authority that they had.

People may also have different representatives for different questions. This is only natural, the person helping to make decisions about housing is not necessarily the right person to help make decisions about health. Ideally people should also be able to change their minds, and experience will teach them if other people's judgements can be trusted.



2.4 Suitable Person

If the person cannot select a representative for themselves then you will need to help find the most suitable person for the particular decision.

Ideally a good representative will:

- Have a good knowledge of the person's preferences in a particular area (e.g. if someone had to do shopping for you, then you would like them to know what food you like to eat).
- Have a good knowledge of the available options (e.g. if someone was going to make decisions about what kind of support you were to receive you would like them to know about all the available options).
- Be available at the right times and the right places (e.g. someone selecting food needs to be doing the shopping with or for you, or needs to be able to write the shopping list; someone who did not live near you would most likely make a bad representative for regular shopping decisions).
- Not have conflicts of interest (e.g. if a decision was to be made about where you were to go on holiday it would be a conflict of interest if the person you were going to pay to come with you made that decision by themselves).
- Be available for as long as necessary (e.g. if someone was likely to move away or be unable to maintain their role as a representative then they would not make a good long-term representative).

Few people may be willing to take on such a role and you may need to find the best person on balance – there may be no ideal person.

2.5 Best Interest

As a representative your duty is to act in the person's best interests; to look at things from their point of view and to make the decision that they think the person would make if they were to do so themselves.

Good decisions will:

- Help the person achieve their goals and preferences
- Respect the person's individual personality



- Help build the person's relationships with other people
- Increase the person's skills and capacities
- Develop the person's status within the community
- Keep the person and others healthy and safe
- Not be based on the prejudices of the representative

While it is not possible for decisions to perfectly reflect these outcomes there should be some accountability for any decisions made. If a representative constantly failed to make decisions that reflected these factors, in a balanced way, then they should not continue in this role.

2.6 Involvement

The individual always has the right to be involved in any decisions made, even if they are using a representative.

Even if someone has a representative for a particular decision this does not mean the individual cannot be involved or consulted in making that decision.

2.7 Review

It is vital that any arrangements for making decisions are regularly reviewed. This should include ensuring the individual has the right to select a new representative. People change, their capacities change, their interests change and their relationships with others change.

It is important to note that the Law has an important role in these matters and different countries have slightly different laws. Sometimes it might be useful or necessary to make use of any legal mechanisms. For example, in different countries people use: trusts, guardians, attorneys, agents, living wills and many other systems for protecting their interests and making critical decisions.

Freedom is a human right. It does not stop being a right just because someone has a disability. Instead we simply need to think about how to make that human right real. The 7 Principles for Freedom help us do that. Everybody can be free.



3. Helping people be free

If you want to support someone with learning disabilities there are many practical things you can do. But it is important to remember that everybody is different. Finding the best way to help people maximize their control is central to providing good support.

Before you consider taking control away from people or using some kind of representation it is vital to do everything possible to support people to stay in control in the first place.

3.1 Don't make a problem when there isn't one

Sometimes the best advice is to do nothing, just give people the chance to make their own decisions.

Don't start worrying about the issue of capacity unnecessarily. This is such simple advice that it may seem redundant, but it is important to realise that most people with learning disabilities can get by without complex systems and without requiring any representation.

Instead people may just need really practical help to make good decisions: enough time to think things through, help to break down problems so that options are clear, good and clear information about the options and encouragement to make decisions.

These are the building blocks of good support.

Ann's story

Ann lived in a large residential home. She had lived there many years and thought it a great improvement on the hospital where she was forced to live before. But Ann had started to think that maybe it was time for her to move on, to find a place of her own. In fact her supporters agreed and they were eager that she make the move.

The problem was that Ann kept changing her mind. Some days she thought it was a good thing to move. Sometimes she thought it was a bad thing. Her supporters even got a little frustrated: 'The problem with Ann is she can't make up her own mind.' So the supporters asked an independent person to come and plan with her to 'help her make her mind up.'

The first thing the independent person did was spend a little time with Ann to learn a little bit more about how she lived. One thing that struck him was that Ann was a great shopper, she often went into town and hunted for bargains with her friend Mary. But her supporters were describing her as someone who couldn't make up her mind, so that seemed odd.

The facilitator suggested to Ann that she get together with people she liked and trusted to think about all the different things she could do. So this what they did. The facilitator took away all the words and pictures from the day and then drew them up as a shopping catalogue. Ann was then able to look at and think about all her choices, in her own time.

Six months later Ann decided. She and her friend Mary were going to live in a flat together. This was not what people were expecting, but Ann and Mary were determined. They persuaded their supporters and they persuaded the social worker and in a few months they had their own flat where they lived together enjoying a new level of freedom and responsibility, together.

Ann (and Mary) had made a decision, but at their own pace and with the information they needed.



3.2 Help people to become self-advocates

Sometimes the most powerful way of taking more control of your own life is to become a self-advocate.

People with disabilities repeatedly report that the most powerful way of becoming a self-confident self-advocate is to meet with other people who share similar experiences and to grow in confidence though taking charge together.

There are many groups of people who offer support to their members to learn new skills, express themselves more effectively and to assert themselves. For example People First is a movement that helps people find or set up a local group.

3.3 Communicate clearly

Increasingly organisations like People First are creating effective books, videos, CDs, computer programs and other sources of information that are made more accessible by the use of clear writing, pictures, video and symbols. Communication is always possible, it just takes three things: signs, listening and language.

Signs – people use these, and many other means, to communicate:

- Spoken words
- Pictures
- Photographs
- Sounds
- Art
- Eye movement
- Special communication equipment
- Behaviour – even getting angry
- Written words
- Symbols
- Body movement
- Hand signs and gestures
- Computer

Even the most minimal form of expression can convey meaning. Everything someone can control can be used as a means of expression.



Listening – having a means of expression is only useful if someone else is willing to look for meaning in your signs and behaviour.

This is not a skill; it is an attitude. It is the attitude of being interested in what someone might be saying. It is the attitude of believing in the person. We might say it is a form of love - positive, respectful attention.

For people who struggle to communicate it is important to find people who really want to listen. Often these people will be close family or friends or people who spend a lot of time with the person and who have this positive attitude.

Language – a system of communication

The way a person expresses themselves is connected to what is meant. For example:

This expression...	in this language	means...
waving your hand giving someone a hug	in body language	'hello' or 'goodbye' 'I really like you'
a red traffic light	in UK Highway Code	'stop'
--- ...---	in Morse Code	'help!'
moving your hand away from your mouth	in British Sign Language	'thank you'
saying 'merci'	in French	'thank you'

For someone who has difficulty communicating and who does not use any of the pre-existing systems of communication then it will be necessary to create a new language or communication system – just for them.

One useful way of gathering that information is provided by developing a communication chart like the one below. If you have paid attention to someone who does not use a standard language you will still be able to identify: signs or behaviours



that seem meaningful, what you think is meant, when and where this happens and what you should do when this happens.

When this is happening...	and Sam does this...	we think it means this...	and we should do this...
Sam is doing something	hums	Sam is happy	Encourage and praise Sam
Sam is eating	throws the food	Sam does not like the food	Find food Sam likes
Sam is at home	tugs at your hair	Sam likes you	Give Sam an affectionate cuddle
Sam is at home	grabs at his trousers	Sam needs the toilet	Help Sam go to the toilet

However it is very important to remember when you are doing this that:

- We sometimes communicate differently with different people
- We might want people to respond in different ways
- We can change how we communicate in different settings
- The same bit of behaviour might mean something different in a different setting

3.4. Organise yourselves to listen

It is important that everyone is organised to really listen and communicate with the person they are supporting. You must ensure:

- Everybody is trained in the person's system of communication.
- Support is provided by people who listen and are trusted by the person.
- Decisions can be made quickly so that the person's life is not tied up

Nothing is more frustrating than communicating what you want only to find that people don't understand or can't act on what you need.



4. Partnerships for freedom

Sometimes it will require many different people to come together to make sure the person has freedom.

Human beings all need many different relationships with many different people; if we are fortunate enough to be supporting someone with disabilities we must take care not to damage this vital network of relationships.

Sometimes the best approach for achieving freedom is to act in partnership with someone else. This means you are not in the position of being wholly responsible yourself; instead you are a partner with someone else.

4.1 Families

Families often provide the backbone of support and advocacy for people with disabilities. At their best families will promote people's independence, and will also stick up for them when things are difficult.

Sometimes families struggle. They will have shared experiences of discrimination and disadvantage with the person with a disability; they may feel bad, ashamed or angry at the way others treat them. It is vital that families are respected, listened to and supported to make a positive contribution. Families will usually be around long after paid workers have gone on to different jobs.

Families should not be patronised or disregarded. Often paid supporters and family members come into conflict over things which are quite trivial or which can be sorted out by honest conversations. An approach that is powerful and simple is to ensure that you start by understanding about all the things you do agree on – before you worry about the small number of things that you may disagree about.

This is called focusing on the mountain – not the molehill see Figure 2.

Michael's story

Michael is a young man who lives in a big city. He has a learning disability and a strong personality, and he's often got himself in trouble in his local community. But he is also a loving and positive person with a great family.

As Michael grew up his family began to ask for some help so that Michael could attend school, college and become more independent. Unfortunately the only help on offer was a temporary place in a residential home. After Michael attended the first of these homes he escaped home. So the second place was offered further from home. Again Michael escaped home. The next home was even further away, but again Michael escaped home.

This wasn't really what Michael's family wanted for him anyway. They wanted him to become more independent, but close to home. But there seemed to be no way of making this happen. Eventually Mum heard about a local voluntary organisation that might be able to help her.

Finally Mum and the manager from the voluntary organisation persuaded the local council to do something a bit different. Instead of giving money to different homes they suggested that the council gave money to the voluntary organisation.

The organisation then helped the family move to a different house, one in which they could create a separate flat for Michael. The family were given funding to employ two part time support workers to help Michael attend college and have a fuller social life. They also recruited an advocate to spend regular time with Michael and to find out what he wanted.

None of this would have happened without the grit and determination of his mother who persisted in believing that something better was possible for Michael and was prepared to fight to make it happen.



Focus on the mountain not the molehill

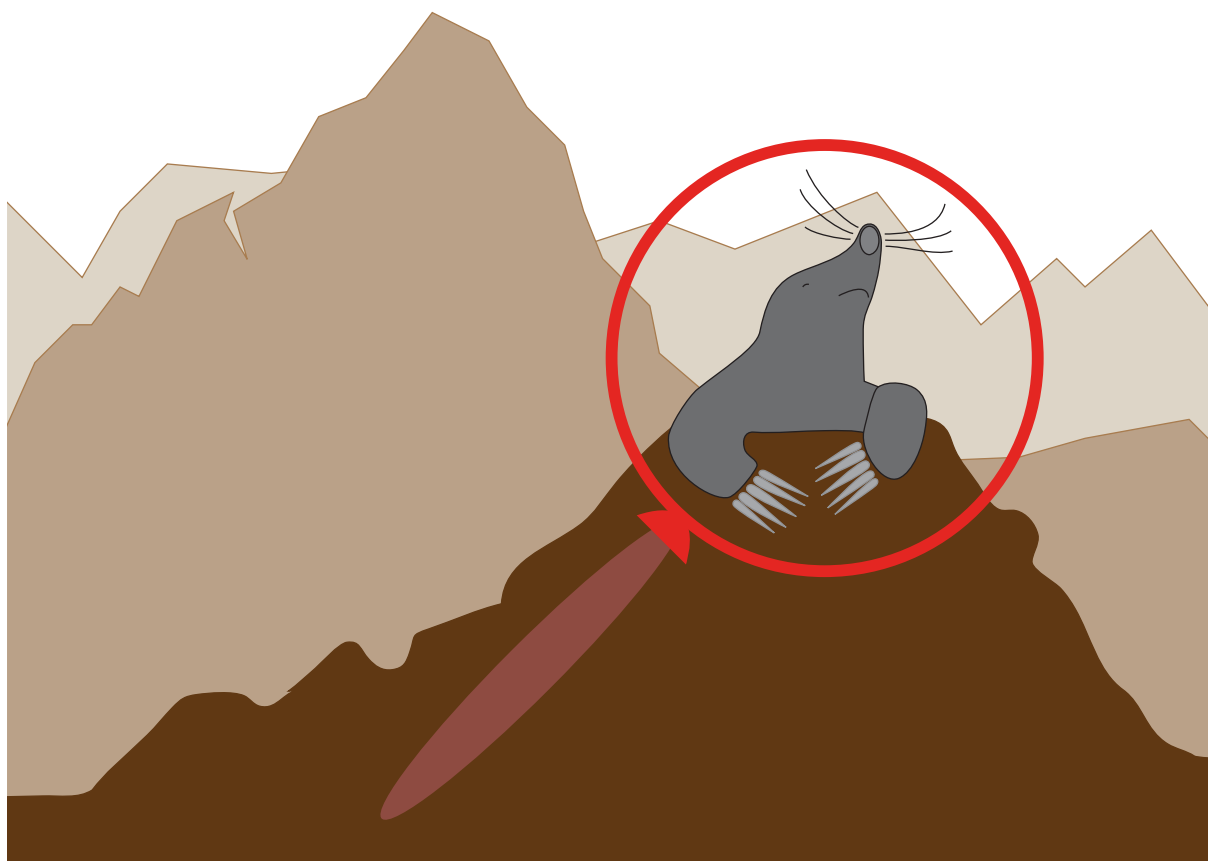


FIGURE 2 FOCUS ON THE MOUNTAIN NOT THE MOLEHILL

On rare occasions there will be families who present a real risk to the person. The person may not want to see their family, there may be a history of abuse, violence or sexual assault. In this instance your role will be to work with others to ensure that the person is safe from harm.

4.2 Partnerships

Often people with disabilities find it useful to enter into partnerships with other people who might seem to have greater capacity to make certain decisions. In this way the person with a disability can retain control – but share responsibility.



There are many examples of this kind of partnership, for example:

- **Co-employing staff** – it is possible for support staff to be employed by the person and a partner person or organisation
- **Shared ownership** – people can buy their home along with another person or organisation
- **Joint bank accounts** – people can share a bank account with someone else they trust
- **Temporary powers of attorney** – sometimes people can ask someone else to make a decision for them – but just on a temporary basis

Such arrangements need to be entered into thoughtfully, but they can provide a useful and practical way of opening up more freedom to people with learning disabilities.

4.3 Circles

One of the most powerful ways of getting help with decisions is to gather together a group of friends, neighbours, supporters or other people you trust. This is often referred to as a 'circle of support' or 'circle'.

This can be a great way of getting help because:

- You can get advice from several different people rather than just relying on one person
- The circle can develop a team spirit and its members can support each other
- It can be fun and social
- It is voluntary and people leave their power and position outside the meetings



4.4 Trusts

Sometimes these circles can go further and become legal Trusts. A Trust is a very useful thing: people come together and commit to act in the person's interests, they write down the rules they will work by ('the Trust deeds') and then they get themselves registered.

The Trust will then be treated by the law as if it were a 'person'. But a very special person – a person specially designed to act in the interests of the person with disabilities.

A Trust is not the same as a guardian. Trusts do not take over responsibility for the person's life. Instead the Trust is like an extra person who has been artificially created just for the purpose of doing things for the person.

Trusts can be used to:

- Manage support services to individuals with disabilities
- Hold ownership of a home or other property
- Oversee the private funds of the person with a disability
- Borrow funding for a mortgage

Another good thing about a Trust is that it can provide a vehicle for decisions to be made into the future without one person having to take all the responsibility. This is particularly important for Mums and Dads who know that their son or daughter is likely to live much longer than them. If they make all the decisions for their son or daughter then when they die they will have no clear way of handing that responsibility over to anybody else. If a Trust is set up other family members can be invited to join the Trust and can take more responsibility over time.

A Trust can also include non-family members in order to achieve an outside perspective. By inviting a family friend, a trusted professional or another person with disabilities to join the Trust, the Trust is more likely to be able to get a really good understanding.



4.5 Representatives

As we discussed above, when outlining the 7 Principles for Freedom (see page 13), sometimes it's necessary for people to have a representative who can act on their behalf.

Representatives can come in many different forms:

- **Family members** – someone from the family
- **Peer advocates** – someone else with a disability
- **Citizen advocates** – a community volunteer who will act on the person's behalf
- **Professional advocates** – a professional paid advocate
- **Legal guardians or attorneys** – someone appointed by the courts
- **Social worker or nurse** – often appointed by the government
- **Public body** – government or another public body can take a representative role
- **Organisation or service provider** – an organisation that will represent the person
- **Legal advocate** – a lawyer or someone able to act in the legal system

All can have a positive role to play in different circumstances – and all could be irrelevant or damaging in the wrong circumstance. It is vital to follow the 7 Principles for Freedom when organizing any system of representation (see page 13).

Sometimes people think that the best advocate is going to be independent. But often the more independent someone is the less likely that they will know what the person really wants. Independent advocates can be useful when there are difficult decisions to be made – but they are not a solution for most problems.



4.6 Decision-making Agreements

When people have significant disabilities and have many different people in their lives to help make decisions, then it may be worth drawing up a decision-making agreement which sets out:

1. Key decision that needs to be made
2. How the person will be involved
3. Who makes the final decision

Life is for living and important decisions need to be made so that people can get on and live in the right way for them. It's important not to spend too much time debating, arguing and thinking. That's why it's really useful to be clear about who does what, as set out in the table below.

Important decisions in my life	How I must be involved	Who makes final decision
Setting my household budget and claiming benefits	I want my Mum to talk to me about my benefits and my budget - my supporters will need to know from my Mum what is in the budget	Mum
Buying food at the shops	My supporters should help me make a shopping list - at the shops I will pick and choose everything	Me
Recruiting new staff	All staff will be recruited according to a specification drawn up with me and I will meet everybody before they are employed to make sure they're okay	Mum



5. Safe and free

It is part of our responsibility to ourselves and to each other not to do things which are dangerous or which put other people at risk.

Sometimes, not always, there is a problem when what people want and choose to do, is dangerous – to themselves or to others. As discussed above, in the 7 Principles for Freedom, this is the most important reason for limiting someone’s choice and control and for asking other people to make decisions on their behalf (see page 13).

However taking control away from someone must never be done lightly. We must think carefully about the risks and what can be done to reduce them before we have a right to stop people making their own decisions. One of the things that makes good support complex and interesting is that we cannot be simple-minded. It requires skill and imagination to support someone well.

5.1 Freedom is essential

We all develop and grow by taking risks, doing new things and by failing from time to time. We all have a right to fail. This might seem strange – but we can only achieve things if we also know what it is like to fail. Without risk and failure there is no achievement, no growth and no learning and this freedom is essential to human development.

Some of the greatest dangers in life are:

- Damage to relationships and personal reputations
- Damage to or loss of property
- Physical, sexual, emotional or financial abuse
- Trauma and mental health problems
- Illness and the abuse of drugs or alcohol
- Physical harm and injury, including violence to others
- Death



Of course almost anything we do – in the wrong circumstances – can lead to one of these dangers. We all live with some risk every moment of every day. But sometimes the risk of harm will be too great.

As a general rule, we might say people are free to make their own decisions; however we may also have a responsibility to stop them if what they decide to do has a HIGH risk of causing SIGNIFICANT harm to themselves or others.

5.2 Not everything is our business

The 7 Principles for Freedom (see page 13) mean that sometimes, some of us, may need someone to make decisions for us. But this does not give everybody the right to interfere in our lives.

Instead we must take care to ensure that people are getting the right representation from the right people. Not only is this important morally it is also important practically – if everybody feels they can interfere then things can quickly get in a muddle where nobody takes responsibility.

As a supporter it is important to clarify where your own responsibilities or duties lie.

It can be useful to remember that responsibilities come in three forms:

1. **Things I must do** – my positive duties
2. **Things I must not do** – my negative duties
3. **Things I am free to do** – things I can decide or interpret flexibly

The thinker Charles Handy pictures our duties as an inverted donut: a solid middle of things we must do, surrounded by an open ring of things where we are free (see Figure 3).



FIGURE 3 DUTIES DONUT

In practice this means we must be clear about where our duties lie:

1. Is this a situation where I have a duty to act or interfere to keep someone safe?
2. Is this none of my business and I have a duty not to interfere?
3. Is this one of those areas where I am free to act as I choose?

If the answer to these questions is not obvious then you need to talk to other people, especially to the person you support, your employer and your team mates, to make sure you are clear.

5.3 We can help people reduce the risk of harm

The best way of responding to any choice that does seem risky is to find a way of letting people do what they want – by making it safer. This may require some creative thinking.



a) Imagine different things that you can do to reduce the risk of harm:

There may be a wide number of responses that might reduce the risk of harm and it is important that those responses are not limited to the first thought that you have. It is best to work with others to identify a range of possible responses and then to decide on the best response in the light of those options.

These may include:

- Changing the physical environment
- Helping the individual make new choices and explore different opportunities
- Supporting the individual in a different way
- Providing training for supporters

b) Selecting the best option

Choosing the best option may involve thinking about several different factors:

- Will it actually work – will it reduce the risk of harm?
- Will it promote the dignity of the individual?
- Will it be sensible and affordable?
- Will it not lead to other negative risks or behaviours?
- Is it the least restrictive option available?

It is often necessary to balance a number of these factors when reaching your decision about what best to do. Wherever possible this should be done by more than one person and in consultation with the person with a disability.

Sometimes, especially where people's needs are complex or people have behaviours that challenge, it will be important to develop consistent policies and ways of working and to document these.



5.4 Taking control away can be risky

Although we may sometimes be justified in taking away choice and control this must not be done without good reason and not before proper and careful planning.

Remember it is dangerous to treat people disrespectfully. The right to make choices and take risks is not only an essential freedom, it is something that people really value.

When you take away control there are two major risks: the person will become depressed and will lose belief in themselves, or the person will become angry and distressed.

Marks' story gives one example of how thoughtless control of somebody who just wanted to be more independent became very dangerous indeed.

Mark's story

Mark, who had autism and a learning disability, lived in a group home, but his violent outbursts had led to the police being called to his home and there was concern that he may have to go and live in a secure unit or prison. To forestall this possibility the social work department asked for some independent advice on Mark's behaviour.

The independent advisor discovered that Mark's violent outbursts were connected to the regime within the group home which set a series of restrictive rules, that applied specifically to Mark and which were justified for reasons of public safety. For example, Mark was not allowed to go out on to the street alone to purchase an ice cream when the ice cream van arrived, while his housemates could.

Mark's behaviour seemed to be becoming more risky as he reacted to policies which aimed to promote public safety and limit the liabilities of the organisation, and what made Mark's situation particularly striking was that the restrictions on Mark's movement made by the group home only applied in that environment.

When Mark spent the weekend with his mother she had developed a carefully designed and step-by-step programme to encourage Mark's independence (but she was frightened

of telling anyone of her very thoughtful approach in case the social work department thought it was 'wrong' and stopped Mark from staying with her).

When Mark was at the day centre he would often leave early, before the bus arrived to pick him up and take him home (for he was bored at the day centre). Mark would then walk several miles across town to get to his group home, with no support or escort. The day centre staff had no responsibility for him once he'd left; the group home staff had no responsibility until he got home. It was only when he was at 'home' that the tight restrictions began.

This story shows the poor quality thinking that follows from a partial focus on one risk ('what might happen if we let Mark out on to the local streets') without really understanding the impact that the restriction actually has on the whole of Mark's life. In fact it seemed, in this case, that the service provider had lost a sense of perspective – they had failed to understand Mark as a whole human being and by focusing on one insignificant risk they had created some very serious risks for Mark.

5.5 Sometimes it is necessary to take control away

Taking away control is only justified in the most extreme circumstances, and after careful consideration. However it is important to remember that those circumstances can occur.

Providing good support is never simple, but thinking things through, honestly, with other people, is the best guarantee we can have that we are doing the right thing.



Karen's story

Karen is a woman with a moderate learning disability. In her twenties Karen began to drink, mixed with a rough crowd and began to get involved in prostitution. Although she was supported by a service provider the service provider did not seem to be able to alter Karen's behaviour, which became more and more extreme. Eventually, drunk one night, she was hit by a car. She acquired a brain injury and was placed in an institution while she recovered.

Karen was desperate to leave the institution; within the institution she was unable to drink and her behaviour was very controlled. A new service provider was asked to work with Karen to help her move out of the institution and initially, when Karen moved into a flat of her own things went very well. However, after some time Karen chose to buy herself alcohol. Very quickly her behaviour spiralled out of control again.

The service provider was determined not to repeat the mistakes of the past. Together with the social worker the provider met with Karen's family and began to identify every strategy that they thought might deal with Karen's drinking problem. They identified more than 10 possible strategies, but they then had to eliminate every strategy that past experience suggested would not be effective. In the end only one strategy seemed likely to be successful – to ban Karen from drinking alcohol.

This strategy is extreme, however it was very successful. When Karen purchased alcohol the organisation's Director came to her house and poured the alcohol down the sink. Once Karen realised her behaviour would not be tolerated she stopped trying to drink. Moreover she seemed to feel that the firmness with which she was being treated actually demonstrated the commitment of the service provider to stick with her and to not allow her life to descend into chaos.





6. Freedom and support

In the past people with disabilities have found that when they needed help then they had to give up their freedom. This is unnecessary and wrong; freedom should not be the price of help.

To support someone properly is to support them to do what they want to do. The best support is support that helps someone achieve their own goals, helps someone be free.

The history of people with disabilities over the last 200 hundred years is very negative. Mostly people have been treated very badly. For much of this time people have either been left without assistance or have been forced to live in institutions or care homes and day centres. Since the 1960s people with disabilities have shown that they can get support and still be free. But this requires some changes in how systems work.

Freedom has been undermined by care at almost every point. People have not been able to choose: how they live – job, lifestyle or career, where they live – home, neighbourhood or country, who they live with – family, flatmates or partners and why they live – goals, dreams or interests.

If people need help then they can still be free; but this help must be organised so that it is directed by the person. This is sometimes called self-directed support.

6.1 Freedom and other rights

Systems work in different ways and in many countries society does not really provide enough help for everyone to achieve active citizenship, or the way in which help is provided is not good enough.

Some countries recognise that having a disability means that you will need the right amount of support so that you can be an active citizen. This is a matter of human rights – it is not just about kindness or charity.



The UN's Declaration of Human Rights sets out the fundamental human rights that every society should protect and live up to.

Key Elements of the Declaration of Human Rights

Article 1

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 22

Everyone, as a member of society, has the right to social security and is entitled to realisation, through national effort and international co-operation and in accordance with the organisation and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 25

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control...

Article 27

Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits...

In the *Convention of the Human Rights of Persons with Disabilities* the United Nations went further in outlining what all countries are expected to achieve to enable people with disabilities to live as full citizens.



The purpose of the UN Convention is described as follows:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

So, however good or bad your local systems are, it is important to remember that what they should achieve is a way of making human rights be **real rights and entitlements**. If these systems don't give enough support or if they give support in a way that undermines freedom and dignity then they are failing to respect human rights.

6.2 Controlling the budget

If people are entitled to help and assistance because of a disability then it is often useful to get that assistance in the form of a budget that they can manage and control.

The reason why money is important is that money can be used flexibly to find the right kind of help to let you live your life. Money is useful because it can be used for: employing staff, paying a service provider, equipment, changes to your home, training or therapy, paying memberships and fees or expenses.

In a good system of self-directed support people should be free to find the best way of getting the support they need and should be able to change their support to suit them and their life.

Of course this does not mean you can buy everything you need in life or that money is the answer to every problem. But usually it is helpful, especially if the money can be used flexibly.



6.3 The right system of control

Not everybody wants to control a budget themselves. In a good system of self-directed support there will be several possible ways of managing your money.

Deciding how best to manage a budget can be determined using the 7 Principles for Freedom (see page 13) and in practice there are at least six different ways that people can control their money (see Figure 4):

1. Control it yourself
2. Use a representative, for example a trusted family member
3. Set up a trust to manage it
4. Pay an intermediary organisation to manage it
5. Pay a service provider to manage it
6. Let a government worker manage it

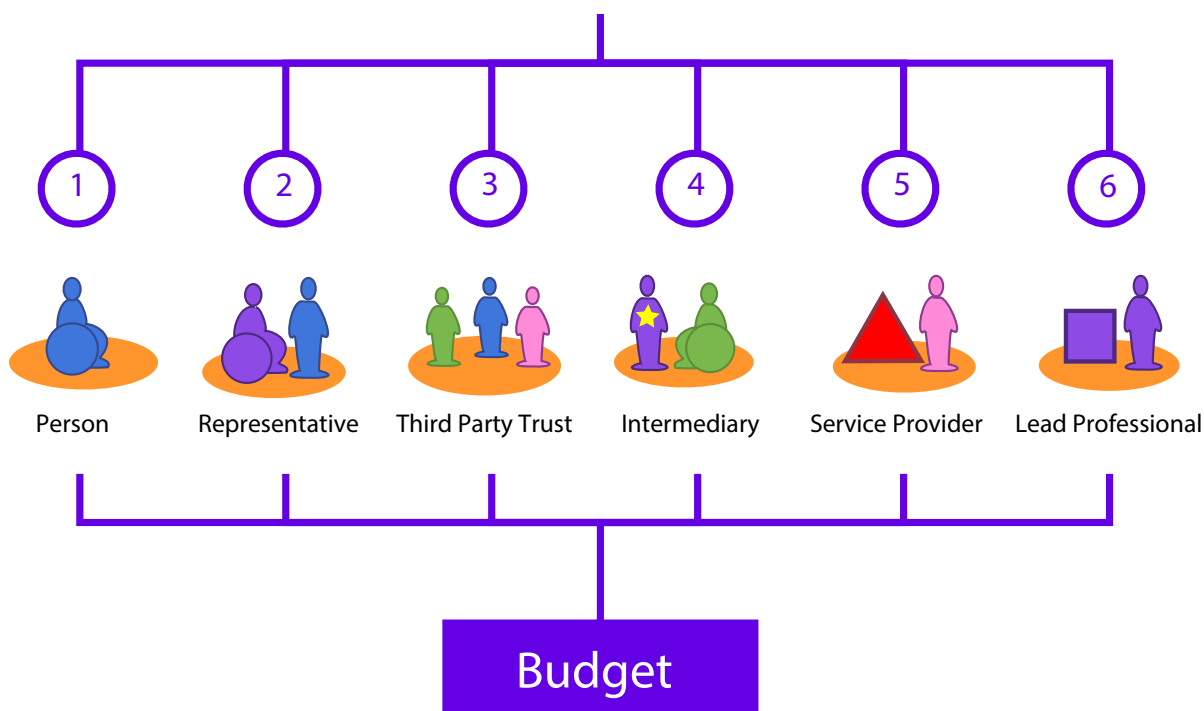


FIGURE 4 SIX DIFFERENT SYSTEMS OF CONTROL



The 7 Principles for Freedom suggest that we should start with the assumption that people will manage their budget themselves. However there is nothing wrong with any of the other options and each person must work out what is the best system for themselves.

6.4 Support that fits you

It is not just a matter of having enough money and controlling that money, self-directed support also means that you can use that money flexibly and that it is really treated as your own.

In many places personal control is reduced by systems that are disrespectful or inflexible, for example:

- People are made to live by written plans
- People are told to keep receipts and other detailed financial records
- If people save any money they find it is clawed back
- Rules and regulations limit what people can spend their own money on
- People can only use institutional services

This is not good self-directed support and it contradicts people's rights. A good system is flexible and works to help people meet their needs and achieve their goals.

Good self-directed support is:

- **Innovative** – people are inventive and flexible with their own money
- **Enterprising** – people form businesses, get jobs
- **Community-building** – people join and help build stronger communities
- **Collective** – people work with peers, share experiences and learn together
- **Pro-family** – families are stronger, development and less fragile
- **Personalised** – support is designed around the individual

7. Supporting citizenship

A good way of thinking about help is to see it as something we do to help each other be full citizens. This means respecting our right to freedom, but it also means supporting people to exercise that freedom in ways that build citizenship.

Working to help citizens means we need to master the five basic tasks of good support. The five basic tasks help create a bridge from exclusion to inclusion in full citizenship (see Figure 5).

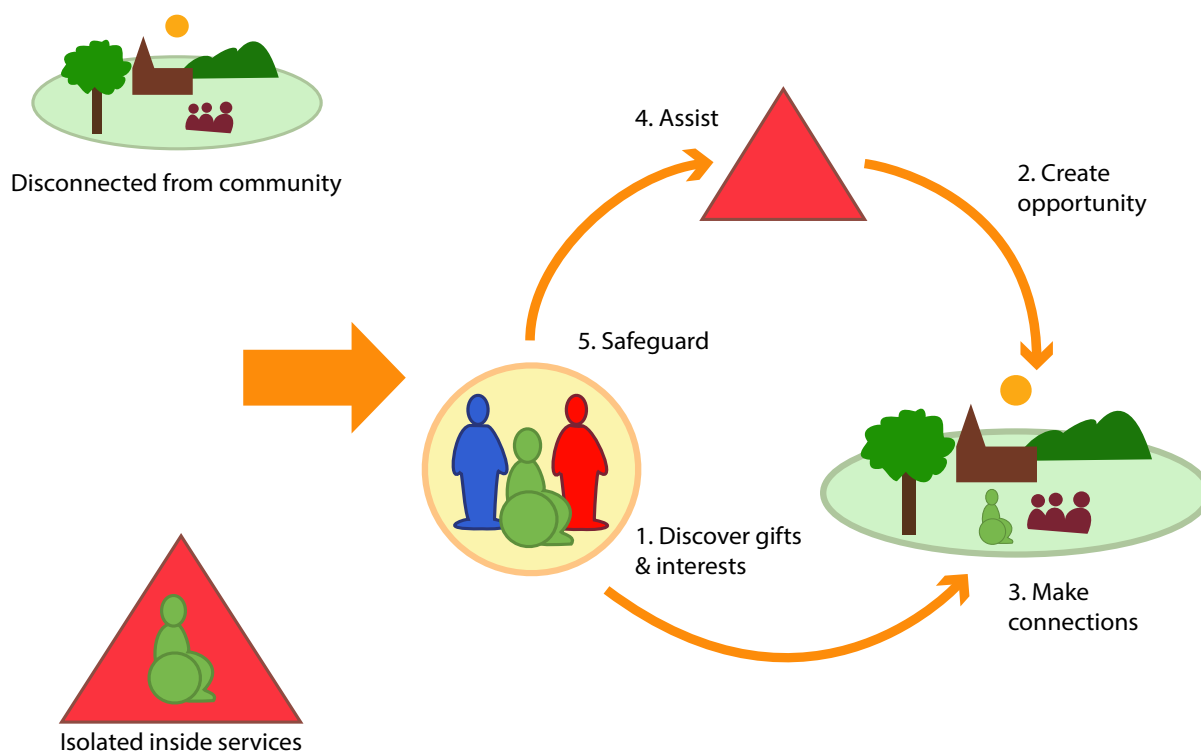


FIGURE 5 FIVE BASIC TASKS

The best supporters know that they are not the centre of things. Instead they work to help the person with disabilities take control of their own life, as an active member of the community – as a full citizen.



The five basic tasks were developed by John O'Brien in 1986. They continue to be a powerful and useful way of thinking about good support. They are relevant because too many people with disabilities remain socially isolated and dependent upon services. They don't take up their proper place as full and valued citizens.

The five basic tasks are described from the perspective of the service provider; but the point is to move services into the background, and to only provide the minimum assistance necessary to build the relationship between people with disabilities and their communities.

If you want to be provide the best possible support then you will need to keep working to become skilled in each of the five basic tasks. There is always more to learn.

These tasks are basic because there is no getting around them. Without each task there is always a risk that the person with a disability will slip into social isolation. Services for people with disabilities are not safe.

Too often services:

- disregard people's gifts, talents and preferences
- cut people off from ordinary experiences
- isolate people from the full range of human relationships
- leave people unskilled and dependent
- encourage abuse and danger

The service system for people with disabilities cannot be trusted to just take care of people. It must be challenged and any supporter must learn the skills necessary to avoid the severe risks that are created by bad and institutional support.

Not all people with disabilities will even need every kind of support. If people come to service providers with a strong social network of family and friends, used to being an active member of their community, then they will be more confident about negotiating the right help and assistance from service providers.

These tasks are each a distinct kind of support. They are done individually, with people and their allies – not to them.



7.1 Discover interests and gifts

Meaningful engagement and contribution grows from what people care about and what they have to offer. Discovery can be as simple as stating what everyone who knows the person knows about them. But some people have experienced so little attention to their capacities and so few opportunities for exploration and development that they will benefit from a thoughtful and imaginative discovery process.

When people use person-centred planning this is what they are doing – discovering people’s interests, gifts and capacities.

Pippa Murray also describes this as using our real wealth and this offers us a useful way of remembering that we all have many different things that we can build upon:

- **Gifts** – we each have our own strengths, gifts and abilities – even our own needs are a kind of gift because they create the possibility of meaningful connection with other human beings.
- **People** – we each have our own relationships, people who are important to us, people we love and people who love us.
- **Community** – our community is a source of wealth to us if it offers up chances to meet, connect and contribute.
- **Assets** – money, time, energy are all things we can use to our advantage and which can help us build a positive life.
- **Spirit** – our attitude towards ourself and the world is at the heart of making the best of our real wealth

Each of us has many kinds of real wealth – but sometimes we don’t notice or we lose faith in our ability to make the best of things. So the first basic task of good support is to help identify and appreciate the individual’s real wealth in all its forms (see Figure 6).

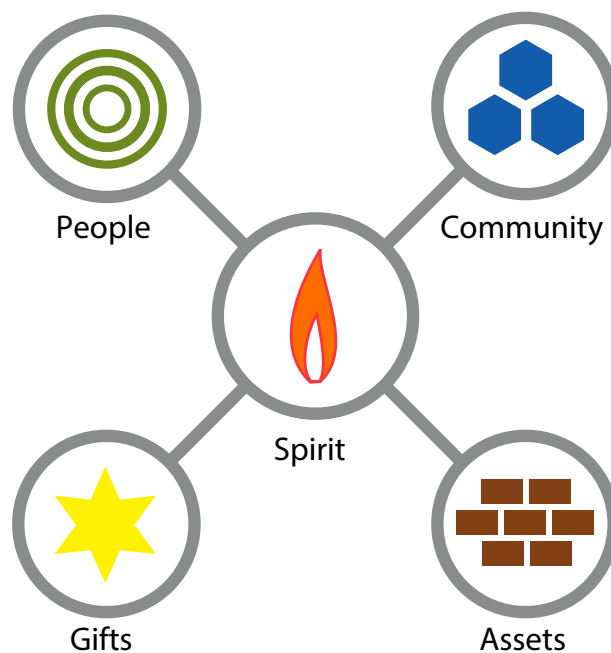


FIGURE 6 REAL WEALTH

7.2 Develop community opportunities

If we know what people like or where people's gifts lie then we must start to ask where those gifts can be best used. For example, if somebody likes music then we need to explore where music-lovers go. If somebody is interested in the police, then maybe this opens up a job opportunity. If somebody likes taking care of animals perhaps they can use this interest to help other people. There are countless opportunities for building on people's gifts if we are prepared to look for them:

1. Finding out about our communities – sitting and waiting for the community to come to you won't work – you need to find out about it and explore what it has to offer
2. Shaping opportunities – sometimes the community needs help to understand how a person with a disability can take a positive role – sometimes this means changing how things work so that people can be included

Opportunities will go to waste unless we help people spot them and take advantage of them.



7.3 Make good connections

If we can join in with communities then we get the chance to build new relationships or deepen older relationships.

But sometimes this requires effort and skill:

- **Taking the risk** – inviting people in, starting a conversation, trying out something new can feel difficult and requires courage.
- **Building on connections** – most new connections build on old connections. Finding out who you already know who can help build a bridge is often a powerful strategy.
- **Natural support** – support is often part of what we are doing together: supporting a colleague, helping a fellow church member, assisting a neighbour are natural forms of support. We need to expect and support people to use natural support.
- **Peer support** – support from other people we share experiences with is very important and often helps people become more confident in their own qualities.

One of the most important challenges for a supporter is to know how to get out of the way – to not interfere with growing friendships by over-shadowing people, demanding attention or undermining people's confidence.

7.4 Provide assistance and training

Some people will require continuing individually tailored personal assistance to join in and sometimes people will need training or support to learn new skills to do more themselves.

It may be particularly useful to use the technique called Training in Systematic Instruction – TSI – which is a way of breaking down tasks into small parts which people find easier to learn without having to do everything, all at once, for themselves.



7.5 Safeguard

No matter how carefully things are planned things will also go wrong. So you will need to help people plan in ways that keep them safe, but also be able to work with the person and their community to solve any problems that occur from time to time.

Good support is a natural part of living together as citizens – with mutual respect – but it can also demand the highest levels of care and attention. And done well it is immensely rewarding.



Final thoughts

Freedom is one of the most basic and fundamental human rights. It is a right that society often fails to recognise for people with disabilities. So we must become freedom fighters.

This involves a great deal of thought and care:

- **We must fight for freedom socially** – challenging oppressive laws and bad policies
- **We must fight for freedom individually** – working to create the best solutions for the people we help or the people we love
- **We must fight for freedom personally** – thinking more deeply about what we are doing and why we do it and questioning the prejudices that still persist

All of this takes action, the courage to do something new and reaching out to work with others. We cannot fight for freedom on our own. Freedom is something we build together.



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A note about language:

I have used the term people with disabilities rather than the term disabled people (although this is preferred in the UK) because this book is aimed at an international audience where the term disabled people is not understood in the same way as it is in the UK. I have also used the term learning disability instead of intellectual disability, developmental disability, learning difficulty or cognitive impairment.



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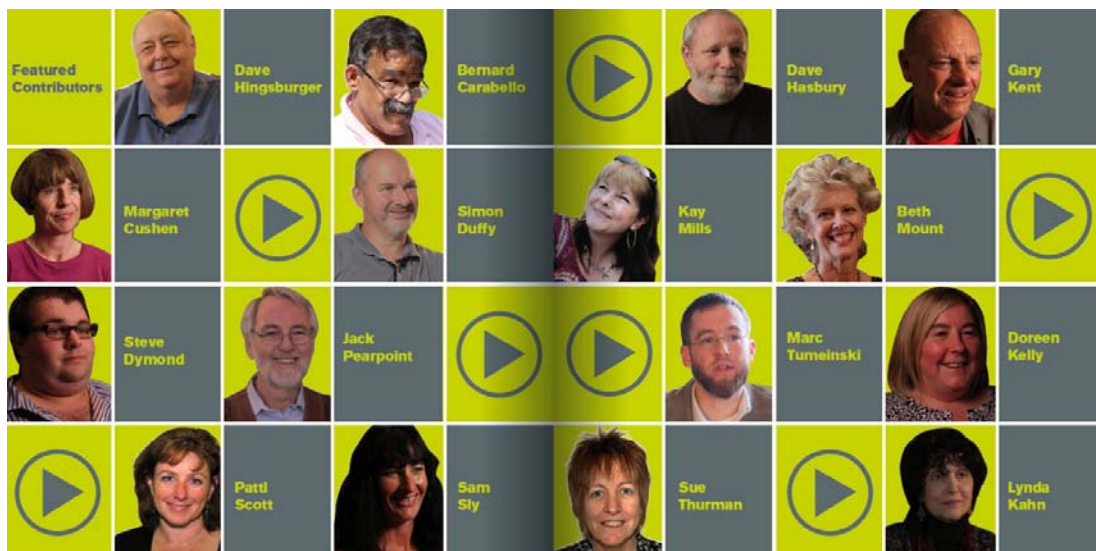
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About us

This webpage tells you briefly about The Housing and Support Alliance - what it believes and what it does.

The H&SA wants to create more choice and control for people with learning disabilities over where they live and how they are supported.

It is a national charity and membership organisation working with people with learning disabilities, families, advocacy organisations, housing and support providers and commissioners.

What we believe

We believe that people with learning disabilities should:

- live ordinary lives in their community
- have the same rights as everyone else - to make choices and to control what happens in their lives.

Good housing and support is the foundation of an equal and ordinary life. We believe people should make real choices about:

- where they live - not be placed in services
- how they get support - not be fitted into a one-size-fits-all package
- who they live with - not have to share with people just because they have a learning disability.

We believe that:

- communities are important to people and people are important to communities - we do not segregate people from communities unless the law says we must
- family, friends and relationships matter - we know this is the most important part of peoples lives.

What we do

H&SA:

- offers free independent advice, information and resources on housing, support, funding and rights
- campaigns for better housing, support and rights for people with learning disabilities
- hosts conferences and events
- offers training and consultancy services
- commissions and conducts research
- identifies and shares good practice.



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