



Citizenship

a guide for providers of
support

by Sam Sly and Bob Tindall



Citizen Network
FOR A WORLD WHERE EVERYONE MATTERS



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Introduction

Keys to Citizenship was the nationally acclaimed concept conceived by Simon Duffy and published as a guide to getting good support for people with learning disabilities in 2003. The principles were taken on by many working alongside people with learning disabilities and increasingly other groups of people have found that its principles apply equally to everyone. It was a book that helped people to improve people's lives. It was at the forefront of developing true citizenship for all.

In 2014 Simon Duffy and Wendy Perez published a revised and accessible version of *Keys to Citizenship* called *Citizenship for All*. Importantly the new model for Keys added a seventh key - Love.

The 7 Keys to Citizenship are:

1. **Purpose** – having goals, hopes and dreams and a structure for life and a plan to achieve this - having our own direction.
2. **Freedom** – having control and the ability to speak up and be heard and to be legally visible in society - taking charge of our own life.
3. **Money** – having enough money to live a good life and control over how that money is spent.
4. **Home** – having a place that belongs to us where we have control over everything that happens there and feel safe - a base for a good life.
5. **Help** – having good help that enhances our gifts, talents and skills and supports our standing, freedom, rights and responsibilities.
6. **Life** – making an active contribution to our communities - sharing our gifts - making a difference - learning with others - taking risks and having fun.
7. **Love** – having loving relationships - finding friendships - enjoying life, love and sex - being part of a family - respecting ourselves and the rights of others.

Sadly, more than ten years on, too many people with disabilities are still being abused, and are still not getting the chance to be full citizens enjoying great lives. We



strongly believe this is not acceptable. So in 2014 Simon Duffy, Wendy Perez, members of Cornwall People First, Gary Kent from New Key and Sam Sly came together to start thinking about how Keys to Citizenship could once again be pivotal to improving people's lives and gaining full citizenship. If like us you want to make a difference to the lives of the people you support then this guide will help you make those changes.

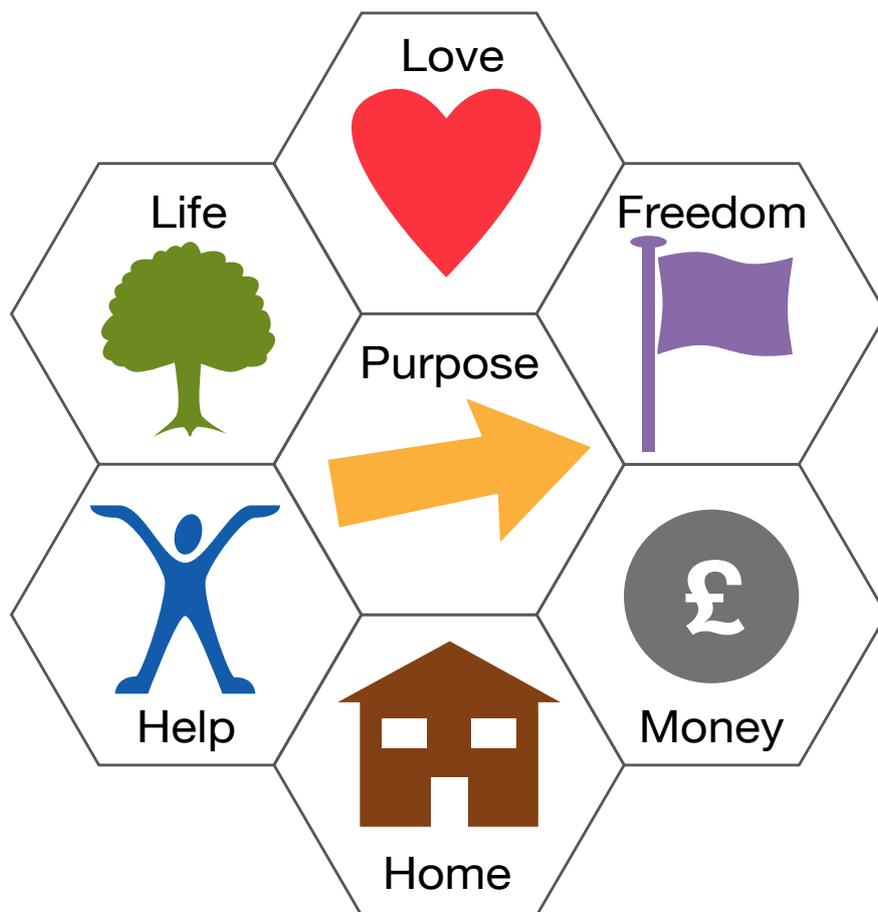


FIGURE 1. SEVEN KEYS TO CITIZENSHIP

Citizenship, and the acceptance it brings, is possibly **The Key** to truly belonging, being valued and getting the good things in life. In fact this is the key to building a good life for everyone. So with this belief it seems nonsensical not to be shaping services around these keys and helping people with disabilities achieve full citizenship.



Using the Keys

We believe the **7 Keys** provides a helpful guide and framework for what we all need in life. It can help anyone of us to find our own direction and meaning in life. It can also help people with disabilities and their families speak up about their rights and any help they need from others.

The **7 Keys** can also help build quality into any organisations that says it is providing services for people with disabilities, especially people with learning disabilities. Every organisation should be supporting people to be full citizens. These organisations may include:

- Commissioners of services for people with disabilities
- Providers of services for people with disabilities
- Training Organisations for professionals (social care workers, social workers and nurses)
- Training Organisations for people with disabilities
- Colleges and day services
- Support Organisations (community and residential care)
- Housing Organisations
- Regulatory Organisations (Care Quality Commission, Health & Social regulators)

In this document, we are going to call all these organisations Providers for the sake of simplicity. Providers can also get help with developing the use of the 7 Keys from organisations like Cornwall People First Quality Checker Team and others. You can find out more at www.citizen-network.org.



Taking Action

The **7 Keys** can help people to take action on three levels to bring about full citizenship:

- 1. Personal change** – We all need to think about what citizenship means for us. What can people with disabilities do to change things for themselves? And what can those helping people with disabilities do to help them gain confidence and knowledge to speak up and be heard?
- 2. Local change** – Personal change can lead to change in our local communities. How can people with disabilities be good local citizens? And how can those helping people with disabilities be of assistance so that they become valued members of the community?
- 3. Political change** – There are many things that are not fair in society. How can people with disabilities help change this on a political, legal and moral level and help build a better world? And how can those helping people with disabilities support this process?



What is Citizenship?

Citizenship means being equal AND different. Citizens are respected and valued for all their differences. Everybody doesn't need to be the same. We each make our own unique contribution to community life. It is being members of our community that makes us equal. Citizens have rights, including the duty to help others be citizens. Citizens are free, both to benefit from and contribute to society. We should be able to live our own life, our own way, but as part of a community. Citizenship is important because it means being treated with respect and dignity. Citizenship means being part of everyday life – not being stuck in a box. Not only can people with disabilities be full citizens – they can be the very best citizens there are.

If you have no disability or traits that others perceive as different then citizenship is a 'given'. However the importance of citizenship is often little understood and little appreciated. For those people in society with disabilities citizenship is something that can seem out of reach and unachievable. Citizenship is about how we can all be equal and different. We should all be equal as citizens and equal members of our community. As citizens we should be welcomed into the community for who we are; with all our gifts and differences. Citizenship is how we reconcile equality and difference through community.

Citizenship carries with it both rights and responsibilities, including the right to political participation, the right to be heard and to free speech. Also the right to work and live a life that makes sense to you and the right to respect and dignity. With rights also come responsibilities including following the laws, respecting others, contributing and being productive. People with disabilities, especially learning disabilities, are often not made aware that they have responsibilities in the communities they live in. Not only are people with disabilities rights ignored, but also their responsibilities. A double whammy.



What this means for providers

If you are paid to ensure that people with disabilities can lead full lives as citizens then these are some of the guiding principles you should stick to:

Principle	Why it's important
I am accountable to the person and their family.	Power is often presumed to be in the hands of paid professionals but this is not where it should be.
I can only serve them well if I have a relationship with them.	Relationships are crucial to understanding, learning and supporting people to lead better lives.
I am clear that the experts in knowing what disabled people want are people with disabilities themselves and those who are closest to them.	Professional support is littered with instances of professionals presuming they know best, but sadly this is rarely true.
Each person I serve is a source of learning and personal growth for me.	Expertise comes from learning together with people with disabilities and those closest to them.
I always want to improve on the support I am giving to people with disabilities.	As people with disabilities take on the rights and responsibilities of citizenship, they will create new challenges for themselves and for those who provide support professional support.
Citizenship applies in the same way to people with disabilities as it does to myself - engagement in real life on equal terms with everyone else.	It is too easy for people to exclude people with disabilities and to have low expectations of what they can achieve.
It's my job to challenge negative stories and assumptions about people with disabilities.	True professionalism requires in depth knowledge, empathy and courage.
Being skilled and being a professional is about acting like a real citizen and helping others to achieve citizenship.	Too often we hide behind professional roles, jargon and expertise and fail to connect to people and the real problems they face.
Learning and improving means taking risks and making mistakes.	Too often we won't move out of our comfort zones and we won't let others move and so we never learn to do things differently.

In the early 1970s, New Zealand's Prime Minister Norman Kirk laid out a political philosophy which still resonates today. People, he said, don't want much. They want:

“Someone to love, somewhere to live, somewhere to work and something to hope for.”

Basic Tasks for Providers

John O'Brien has been one of the most important thinkers and activists working with people with learning disabilities. Many years ago he described Five Basic Tasks that providers should carry out to make a positive difference in the lives of the people they support (O'Brien, 2011).

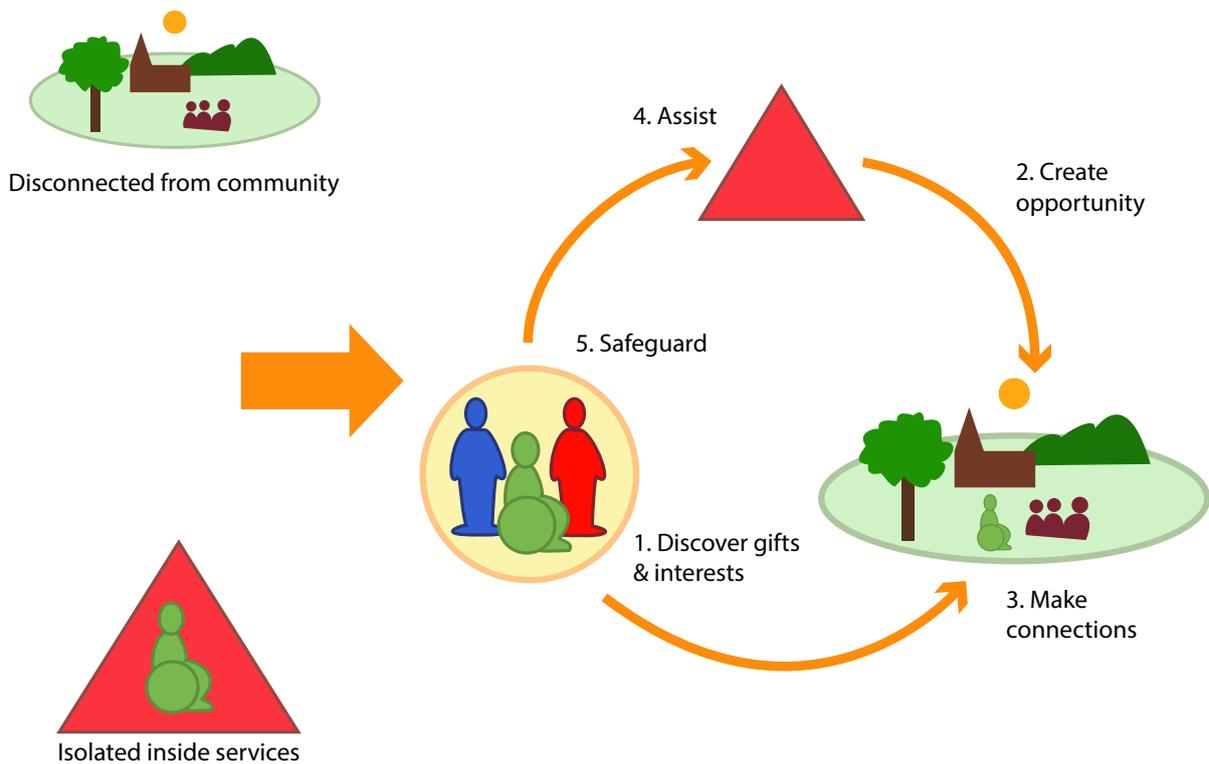


FIGURE 2. FIVE BASIC TASKS



These tasks cannot be reduced to bureaucratic routines by providers, for each is based on a relationship with a real person.

It is a provider's job to:

- 1. Discover Gifts & Interests** – We must find out and nurture what people care about and what they have to offer. Sometimes people have not been given the attention and time to discover and explore what their gifts and interests are.
- 2. Develop Community Opportunities** – Interests and gifts direct people to community settings where they can participate and connect to other people. Providers should develop these opportunities and this means working with other people in the community to help people find a productive and valued place.
- 3. Make Good Connections** – Good preparation and making any changes necessary for the person will help them make a success of these new community opportunities. Most importantly we need to create relationships with people who believe in us.
- 4. Provide Continuing Assistance** – Some people will need and continue to need help to participate successfully. The best help becomes 'invisible' support or comes 'in and out'. Support that is artful, facilitative, educational, and leaves space for the person to engage freely with others will also help people form real and lasting friendships.
- 5. Safeguarding** – In every situation, however well planned, things can still go wrong and problems may arise. Providers are most appreciated when they are open to identifying problems, positive and flexible in trying other ways and are committed to learning with people what support they need to have a good life.

These basic tasks stop people slipping into social exclusion and disconnection from their communities. They stop people from becoming stuck inside services.

These basic tasks were defined many years ago but are as relevant now as they were then.



Real Wealth

Pippa Murray also developed a concept called **Real Wealth** the resources that help individuals with learning disabilities and their families achieve a good life (Murray, 2010).

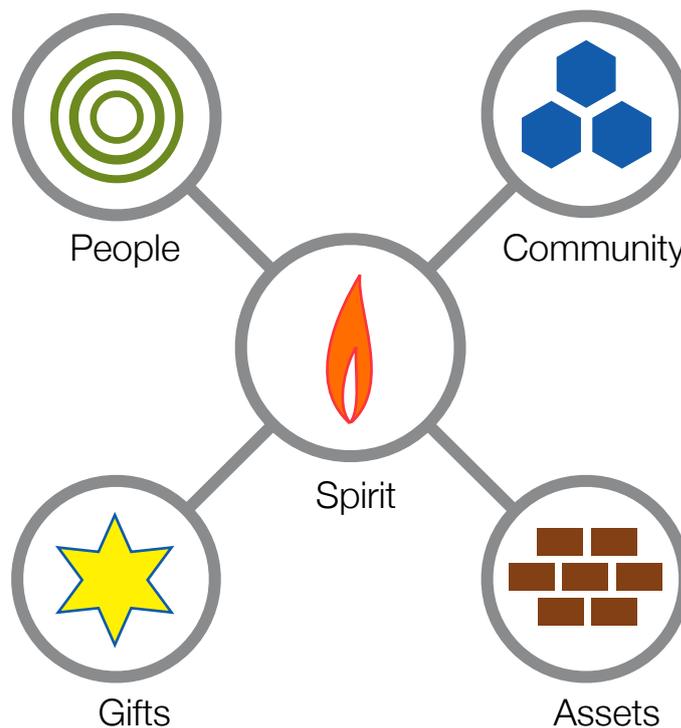


FIGURE 3. REAL WEALTH

We all have Real Wealth:

- 1. Strengths** – We all have strengths made up of our gifts, abilities and skills. Providers will be supporting some people who just need a bit more help to build, nurture and grow these strengths until they are admired by others.
- 2. Connections** – We all develop and rely on connections as citizens. They include our close family, our friends, work colleagues, peers, community networks and organisations. Some people will need help make and nurture these connections.



3. **Access** – The more we can access our community the richer we are. Lack of information or skills to access key resources means that some people will need physical and emotional help to access the wider community.
4. **Assets** – Income, property, savings, benefits and entitlements are what adds to the wealth that helps people have a good life. People need help to find work, to maximise their income, understand what they can spend it on and use their monetary wealth to help increase their real wealth.
5. **Spirit** – The most important thing is our attitude to life or spirit. We become stronger when we recognise that we all have some forms of real wealth and work to build, use and share our wealth.

Above all providers must work in a way that helps people feel stronger, more confident and optimistic - they must believe in people.

With belief we can help people to achieve their goals using their **Real Wealth**. Where necessary a provider may need to strengthen people in their gifts, connections, access or assets.

It is by focusing on people's **Real Wealth** that we also help them to be free from dependency on paid services.

True Citizenship

True Citizenship is a guide to exploring the meaning of citizenship from the inside-out written by Civitas Vera. It offers a framework of values to live by and explores how those values can be used by individuals, families, professionals, services and commissioners in order that all of us can be better citizens. At the heart of the book is the framework for citizenship, which is rooted in a commitment to seven values:

1. Support and care
2. Respect
3. Integrity
4. For future generations
5. Freedom of heart and mind
6. Hope and courage
7. Productive living and working



It gives a framework by which citizens can think together about the quality of their own citizenship. It may inspire action - but it will be action that will be rooted in authenticity, personal control and moral awareness. It emphasises that citizenship is all about doing with, collective action and collective strength and this can only start from within.

For service providers and the professionals who work in them it is very important that we take seriously our own citizenship. Especially our own commitment to these important values in our lives and work.

The Good Things in Life

Wolfensberger believed that people with learning disabilities are often devalued and discriminated against by society (Thomas and Wolfensberger, 1999). They are not seen as full citizens they are often treated badly and subjected to systematic, sometimes life-long, negative experiences such as:

1. Being perceived and treated as 'deviant', due to being seen in a negative way as different – negative traits.
2. Being rejected by the community, society, and even family and services.
3. Being cast into negative social roles, some of which can be severely negative, such as 'subhuman', 'menace', and a 'burden on society'.
4. Being kept at social and physical distance from others through segregation.
5. Having negative images (including language) attached to them.
6. Being an object of abuse, violence, brutalisation and even death.

By being cast into these roles, and experiencing these things, people with learning disabilities are denied the good things in life that valued citizens' experience:

- Being part of a family or small intimate group
- Having a transcendental (inspiring) belief system
- Having the absence of imminent threats of extreme privation (hardship)
- To be viewed as a human and treated with respect
- To be treated justly
- Friends
- Work, especially meaningful work



- Opportunities and expectations to discover and develop skills, abilities, gifts and talents
- To be dealt with honestly
- To be treated as an individual
- Having access to the 'sites of everyday life'
- Being able to contribute, and having ones contributions recognised as valuable

The ideas of Wolf Wolfensberger have been very powerful and influential in helping people with leading disabilities become citizens. The **7 Keys** is, in many ways an accessible and positive model, which builds on the earlier work of important thinkers like Wolfensberger.



Key 1 – Purpose

Purpose means citizens having lives that are meaningful and that have a sense of purpose. Sometimes we find ourselves living a life without meaning. This often happens when other people take control, exploit us or boss us around. We can lose our sense of purpose or we may have never been given the chance to find it. We then don't believe in ourselves – we forget we have talents, skills and gifts. We can waste our time, our talents and our money. We may think that no one cares about us. We become isolated, unable to join in with things. We lose hope and we can stop believing that things can get better.

We can find our sense of purpose through:

- **Our Gifts** – having faith in our unique gifts and finding ways to share them.
- **Our Resources** – making the best of everything we've got to offer.
- **People** – finding the people who believe in us and who can help us find our way.
- **Our Community** – finding meaning by joining in with things that matter to us.
- **Hope** – following our dreams and not playing safe – life is for living!

Having purpose (goals, hopes and dreams and a plan to get there) in life is important for everyone as it helps a person gain a sense of self-understanding and individuality. It's the 'spark' in a person. Purpose also gives structure to life. Life is more satisfying and rewarding when there is an aim to existence and other people see the person as useful and their life as meaningful.

Our purpose in life will often stem from the unique gifts, talents and skills that we all have. People with disabilities have often been treated as if they do not have anything to give, which is fundamentally wrong. Everyone has something to offer others, and should be given the help they might need to identify these gifts, talents and skills and share them with others.

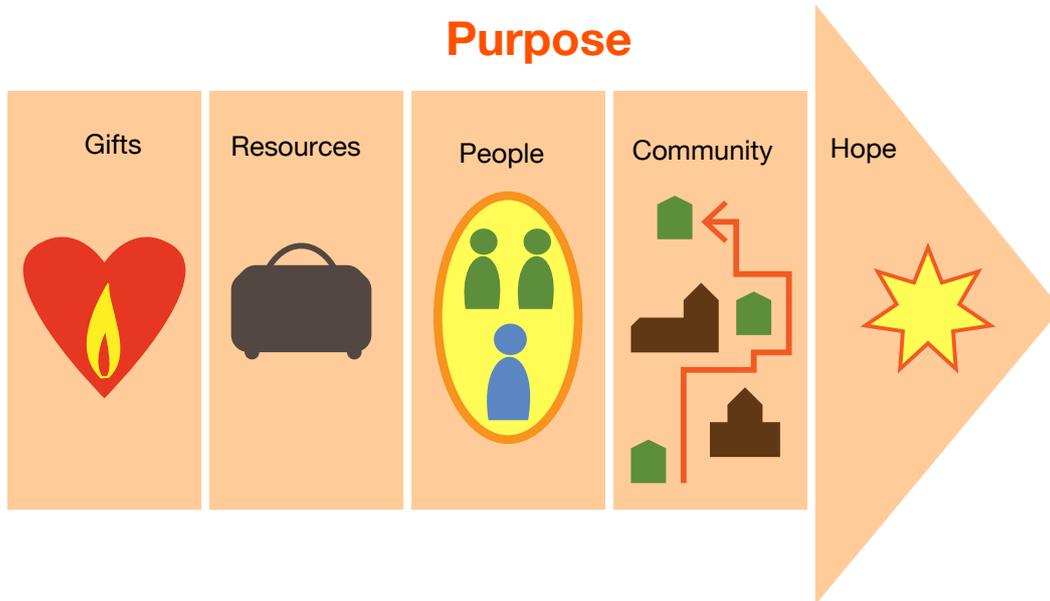


FIGURE 3. PURPOSE

Also without purpose, things just don't happen! Plans don't have to be set in stone, and people don't have to have lots of goals, but full citizens will have found a lifestyle that offers satisfaction, personal fulfilment and roots them in their community. People often get as much out of the journey towards a goal as they do from achieving it.

Planning with purpose

Planning should always build on positives (the hopes, dreams, gifts, skills and talents of a person). Also during planning it is very useful for the person and their family to tell their 'story', as these details will help those working with the person understand who they are and what they have experienced in the past. All too often these stories are lost and with it the wealth of learning from what worked and what did not work in the past. It also helps those working alongside people know why they do the things they do and who they and their families really are.



“Don’t judge me, you can’t handle half of what I’ve dealt with. There is a reason I do the things I do, there’s a reason I am who I am.”

[Anonymous proverb.]

There are two parts to planning to support a person well and in a person centred way:

1. The ‘what’ or Life Plan answers questions like:

- What should the whole service look like including paid and unpaid help?
- What housing?
- Who can help?
- What will the person will do with their time?
- What are the person’s hopes and dreams?
- What strengths and resilience does the person and their family bring to the plan?
- What other community strength can be drawn on?

2. The ‘how’ or Support Plan or Working Policy asks:

- How will the person and family make things happen?
- How will we, and others help the person?
- What other community strength can be drawn on?
- What is important to and for the person?
- What is the important detail to supporting this person well?

Both of these parts must be done in partnership with the person and the people that know them well and who the person wants to involve.

The Support Plan should be detailed enough that any new worker could rely solely on the information to work safely and constructively with the person in getting them a life that makes sense to them.

For plans to be meaningful and accessible to the person they may not necessarily be paper-based. Multi-media approaches (video, photos, audio, computer generated etc.)



are more meaningful for some people. Plans that sit in drawers or on shelves and which are never used or only used to ‘review services’ are worse than useless.

Life is for living and taking risks is an important part of life. We all take risks on a daily basis and it is how we learn. It is exactly the same for people with disabilities. Being risk-averse can stifle experiences, restrict learning and fulfilment and ultimately make people vulnerable. As Wendy Perez puts it:

“Why is there always a question when people with learning difficulties want to do something; but when other people do it no questions are asked?”

This doesn’t mean we shouldn’t consider the risks involved in new experiences, but this should be done in a positive ‘can do’ way looking at what the person wants to achieve and what they will achieve by doing something new, and working within the law when people lack the capacity to make decisions for themselves. We can learn from what might have gone wrong in the past, and from what strengths and resources the person has that will help them keep safe. There may be people in their lives who can form a network of support to help a person achieve what they want to do. It is particularly important that risk taking is seen as a means to achievement and not a process to be stifled in order to conform to over-restrictive professional cultures, where they exist.

People have to have hope to live; hope for a good future. Hope comes from those dreams and goals both short-term and longer-term that make us get up in the morning and make us strive for better things.



Key 2 – Freedom

Citizens are born free, but sometimes that freedom is lost. People with disabilities, especially people who don't communicate with words, often find that other people take control of their lives.

We can lose our freedom and end up with:

- **No control** – other people making our decisions for us
- **No confidence** – we don't feel we can say what we want
- **No ideas** – we don't know our options, we just accept what we're given
- **No communication** – people don't know how to communicate with us, so don't ask us
- **No decisions** – nothing gets done, things just keep going round in circles and we waste our lives

To gain our freedom we need:

- **Control** – remember we have the right to be in control of our life
- **Voice** – to learn to speak our minds and get help to speak out
- **Options** – get good advice, get information and find out all options
- **To be listened to** – we need people to listen, to really understand what we are saying
- **To make decisions** – if we can't do this for ourselves we need a good representative or support with decisions

Freedom enables people to be legally visible in our society; to be really listened to and to make those important decisions in life that all citizens have to make. Freedom brings control which means people are seen to be able to speak up for themselves and taken seriously and able to act for themselves.

Freedom is about making your own decisions. To make decisions people need information that they understand. Some people need help to speak up and make



decisions and this help should come from the right people - the people that care about that person and have their best interests at heart. Time needs to be spent getting to know a person and the way they communicate.

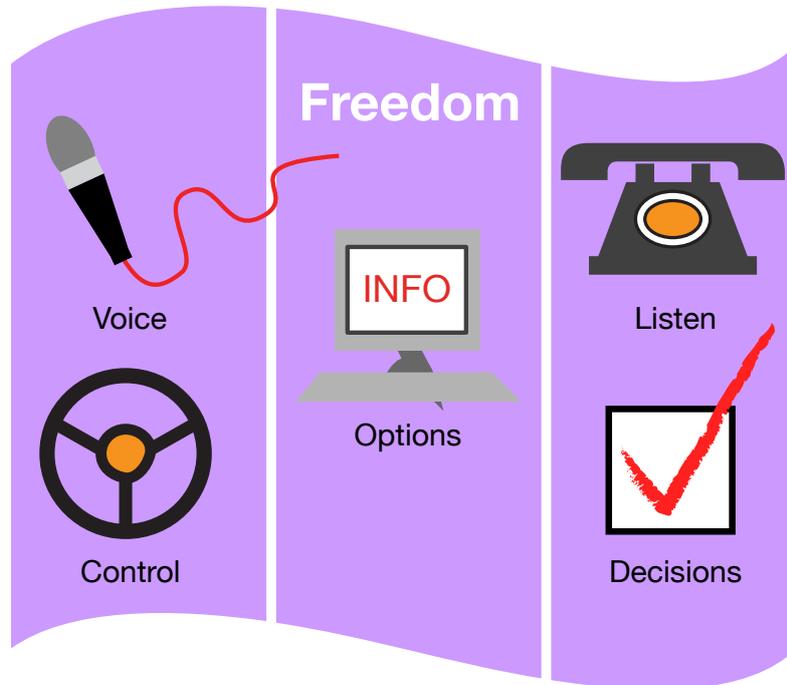


FIGURE 4. FREEDOM

Communication

People aren't listened to, heard or able to make decisions if their means of communication are not fully understood and any communication aids are not in place to maximise inclusion and choice.

In England the Mental Capacity Act (2005) requires that decisions be made by the person or as close to the person as possible. It is essential to ensure people have every chance of communication so that they can be understood and supported. You cannot decide someone lacks capacity to make decisions for themselves unless you've made every effort to help someone communicate for themselves.



Advice and information for decision-making

People can't make decisions if they don't know what options they have and for this to happen people need advice and information in ways they understand.

Everyone can make some decisions about some things in their lives. Everyone equally will seek advice or ask others for help to make decisions at times. Some people will rely on those they trust and who know them well, or know their situation, to make decisions on their behalf. Sharing decision-making usually involves inviting someone the person trusts, is knowledgeable about them or their circumstances to help them and act in their best interests.

Sometimes people will make decisions that other people think are wrong or that don't result in good things happening, but that is also how people learn. An unwise decision is not necessarily a wrong decision and a person's decision should be respected. Seeking help with decision-making doesn't make a person any more or less of a citizen. Bad things will happen when other people make decisions about people with disabilities without them and not taking into consideration their skills and talents, because they do not see them as true citizens.

The Mental Capacity Act (2005) should be one of the most exciting and potentially life changing pieces of legislation for people with disabilities and can have far reaching implications on how people are supported with decision-making. The Act confirms in legislation that it should be assumed that an adult (aged 16 or over) has full capacity to make decisions for themselves (the right to autonomy) unless it can be shown that they lack capacity to make a decision at a time the decision is required. The Act also puts the onus on those helping people in decision-making to take all practicable steps to inform and support a person to make a decision, before concluding that a person lacks capacity, and undertaking a capacity assessment.



This is an exhilarating challenge for those paid to help people who must:

- Always assume capacity
- Become excellent at providing decision-making information in ways that people understand
- Increase decision-making opportunities
- Assess and put into place plans to build on a person's decision-making skills
- Be person-centred in all decision-making processes
- Record processes and outcomes

Speaking up

People with disabilities may find it hard to speak up confidently for a range of reasons:

- low self-esteem
- they haven't been listened to before
- they need communication aids
- they are not confident in being assertive
- other people taking control and many other reasons.

This is where advocacy, and especially self-advocacy, groups run by and for people with disabilities are important. One person's voice may not be as strong or as powerful as a group of people with the same life experiences.

There are now some powerful national self-advocacy groups such as [Learning Disability England](#) and the [National Forums](#) for people with learning disabilities and families and many areas of the Country have their own People First and Self Advocacy groups.



Key 3 – Money

Citizens need money and at least enough money to allow us to live with dignity and security. Too many people, especially disabled people find themselves living in poverty.

When we lack the money we need we become:

- **Poor** – we might not even have enough to live on which will affect our physical and mental wellbeing
- **Trapped** – in a cycle of poverty where it can then feel risky to try and earn money or save it
- **Dependent** – we may have to put up with the things people choose for us
- **Abused** – other people can take advantage of us; using our money as if it were theirs, or treating us badly because we can't join in
- **Fearful** – we can feel we've got nothing to fall back on, no safety net whatsoever

To get the money we need:

- **Rights** – we should have an entitlement to enough money to live on
- **Earn** – we may be able to find work to earn more money
- **Use** – we should be able to use our money flexibly, to get the best out of it
- **Manage** – we may need to help to manage our money well
- **Save** – we all need savings, something to fall back on in a crisis

“Money makes the world go round” the saying goes – and there is truth in that statement. Money gives status and control to people. Control over money gives us a means to fulfil our life plans and gives other people an incentive to act in a person's interests. Money is power.

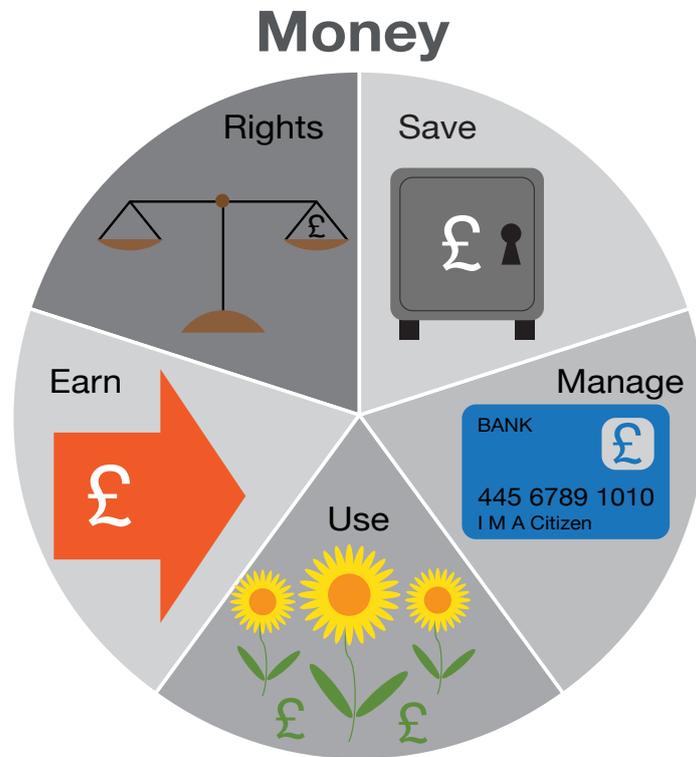


FIGURE 5. MONEY

Without being able to grow and control our income (for example, by working), a person is left powerless. Only receiving the help that another people has decided they need. People are seen as ‘needy’. Simon Duffy calls this the **Professional Gift Model** of organising social care where the person is totally at the mercy of those that have been given power and control over their money (Duffy, 1996) This does not enhance citizenship

The prevalent model for the delivery of many public services, including health care, education and social care, is the **Professional Gift Model**. People find themselves at the receiving-end of a chain of power and control that starts when we pay our taxes. Taxes go to the government (both central and local) and the community leaves to the government the job of working out how to take care of people who are deemed needy.



The government in turn transfers that funding to various professional bodies (Social Service Departments, providers of care, the NHS) so that they can take care of disabled people. Finally those needy people are assessed by professionals to establish what kind of professional care is appropriate; this care is then provided by other professionals who are paid for by the first group. At no stage does the person have a say on how their money is spent.

In fact the current situation is far worse than this. The control of disabled people by professionals is not always benign; and powerlessness can combine with segregation to rob people of their citizenship twice over. Even today, when there is lots of information about why institutional services work badly, these segregated services continue to be the standard service provided to disabled people.

The reason for this is not that disabled people demand segregated services. Instead, like all systems, the present system tends to serve its own interests; not the interests of disabled people but the interests of the professionals who earn their living within it. The services people receive are much more likely to be based upon what is already available rather than what people really need. The kind of service that is available is exactly the kind of standardised and segregated care that is poorest at meeting people's needs and it holds people back from citizenship.

Changing these institutional services into better services that people can control and use to live their own lives, takes time and energy and demands that the staff in those services have to make changes to their work practices and even their forms of employment. But the existing services naturally resist making such changes and so funding remains locked into old-fashioned forms of care. So, the professional's free gift turns out to be a gift that mostly suits the interests of the giver, not a carefully tailored present that suits the individual disabled person.

This may seem too strong: there are many good professionals continually battling to offer people what they really need and to help people take up their rightful place as citizens. But the system is stacked against them, because power and control is in all the wrong places. People are not in control of their own lives.

Things don't need to be this way. There is nothing natural about organising social care around the **Professional Gift Model**. Instead a system is needed where disabled people actually have real power and responsibility and where the relationships

between the disabled person, professional groups and government are much more balanced. Simon Duffy calls this the **Citizenship Model** (Duffy, 1996).

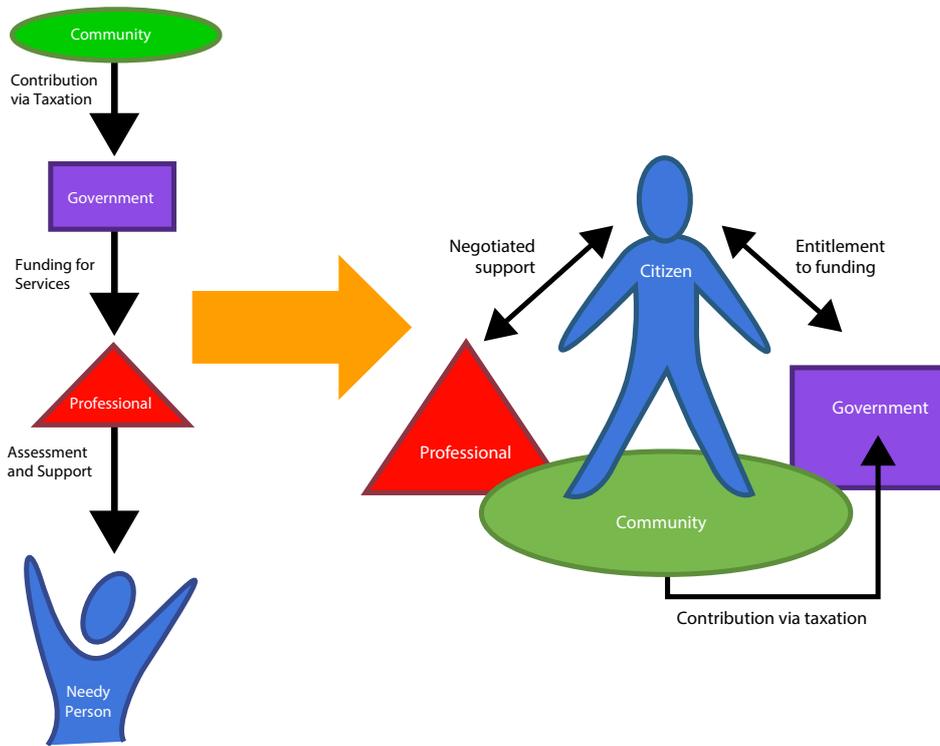


FIGURE 6. SHIFT TO CITIZENSHIP MODEL

In which:

- The citizen is in control of their life, and any support they need to lead that life.
- The citizen leads their life as part of a community of family, friends and fellow citizens
- Where necessary additional support is provided by the state through an entitlement, whose rules and responsibilities are fair, open and appropriate.
- The citizen can shape any extra support they need by using their resources to negotiate additional support from within, or from outside, their community
- Professional services are available and agreed on the basis of an equal relationship between the citizen and the professional.



Personal Budgets

The best way for a person to have control over the way they are supported and how they are supported is for them to have a personal (social care, educational, health) budget or for them to choose to have their money held by someone else in an individual service fund. Once a person has their own budget they can be much more creative about the support they receive. People should be made aware of their entitlement to these methods of payment and to facilitate take up. Personal budgets enable people to be in control of their money and employ or get other forms of help that is flexible, responsive and enables a good life. Personal budgets are sometimes misused and abused by those administering them through the criteria and bureaucratic red tape that they are tied up in. For information on Personal Budgets in England visit [NHS Choices](#) or [Think Local Act Personal](#).



Key 4 – Home

Citizens belong. They have their own place, a home where they are safe and secure, in a community that is right for them. Many disabled people find themselves living with their families too long, or are stuck in care homes.

Not every home is a real home:

- **No privacy** – we might not be free to do our own thing, get grumpy or let off steam
- **Wrong place** – we can end up in the wrong community, not where we want to live; miles away from the people we love
- **Shut off** – we can be locked in, not able to invite people in or share our home
- **Wrong people** – we can end up living with people we don't like or who abuse us
- **No rights** – we can find ourselves with no real housing rights, at others mercy

A real home is:

- **Private** – home is where we can unwind, do our own thing with no worries
- **Belong** – somewhere that works for our whole life and roots us in a community where we can demonstrate citizenship
- **Invite** – we should be able to invite our neighbours, friends and family round and tell them when to leave too
- **Safe** – we should be able to live with people we like and never have to live in fear
- **Secure** – we should have strong rights and not fear that we will easily lose our home

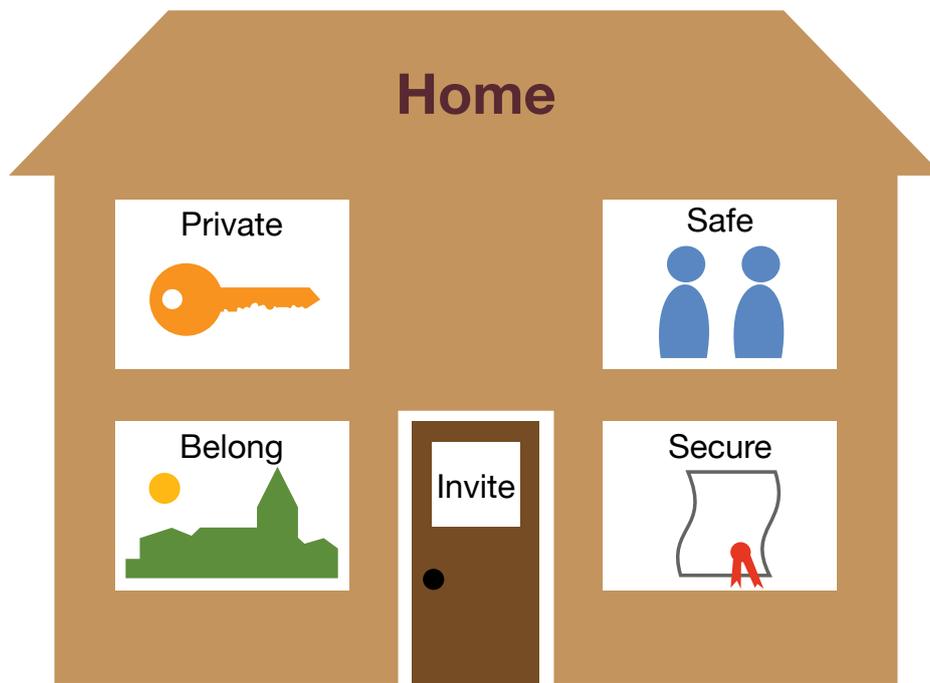


FIGURE 7. HOME

“Home is where the heart is” as the saying goes, and how true that is. A home roots a person in their community and is a base for life. It gives status, community presence and is a financial asset that is often handed down to a person’s nearest and dearest when they die. This is culturally important to many people.

A home of your own helps promote citizenship. At home people can be themselves and express their personalities through how they decorate and furnish it. People should feel at ease and be able to relax and have a private life within their home.

Home is the place to bring children up, or invite family round and make happy life long memories. People should be comfortable and settled and do all they want to do in privacy.

Most importantly home should feel safe because the people living there are people who have chosen to be together; usually because they love and respect one another, so are not scared of violence and abuse occurring. A home should protect and shelter; our society has laws that make entry by others very difficult without legal powers.



Unfortunately home for people with disabilities is often something quite different. Home is even talked about differently; valued citizens live at home, people with disabilities often live in a home. Home for people with disabilities may be called a 'bed', a 'ward', a 'unit', a 'placement', and people aren't people anymore they become 'residents'. There is often no ownership, no belonging, no safety, no security and it is somewhere people are put together with people they did not choose, but who were grouped together because they have similar devalued characteristics.

To top all that, if disabled people do anything others (usually professionals) don't like they can be removed, lose their home and become home-less. It is a paradox that we use the term 'home' for a care home when everybody knows that 'to go into a home' means to give up having a home - to become homeless.

Housing options are often not planned for early enough in a person's life and so, if legal representation is needed, and not available locally when that person wants to move, it can hold the process up. It is worth thinking about future housing needs as early as possible. It is important to start early and help people increase their decision-making skills and take control over where they want to live. For some people who may lack capacity to buy or rent a home, then it may be useful to put in place a Court of Protection Deputy,

In our society most people own their own home. Although as inequality increases people on low incomes are increasingly have to rent. But whether you rent or buy we all have a need for good quality housing and the legal right to remain for as long as we want in our home. A lack of capacity to make the decision to buy or rent a house must not prevent a person owning or renting their own home. There are excellent ways of people part-owning their own homes (Shared Ownership) and the basics that need to be understood to agree to a mortgage or tenancy are often not as complex as is imagined. For further information on Shared Ownership and Tenancy in England visit [Learning Disability England](#), [My Safe Home](#) or [Advance](#). A tenant should be a 'real' tenant with a 'real' tenancy that gives them the same rights and responsibilities as other citizens (NDTi, 2015).

Sharing a house is valued in our society in certain situations; sharing with others you love, respect and want to be with, or for short times when for example young people go to University or are saving for a home of their own. It is also valued to live with



your family whilst you grow up, but not to remain at the family home into adulthood if you don't want.

People should choose who they live with, if they share, and be in control of what happens within their home. Equally people should get any help they need in their home from who they choose, without this affecting their tenancy or rights to stay where they are if things change for them. This power and control is often restricted or non-existent for people with disabilities especially in shared houses.

A person's home is their sanctuary where their possessions and privacy should be respected by those visiting or helping within it. Every home should look, feel, smell and be valued as a home - a special and valuable space for each of us.



Key 5 – Help

Citizens need help. Everyone needs help. Help is good. But many disabled people are made to be too dependent on those who help them. They get help at the price of freedom. This is bad help.

Bad help means:

1. **Controlling** – sometimes people don't really help us to do what is important to us
2. **Dependent** – sometimes we are left weaker and more reliant on others
3. **Segregated** – sometimes we get cut out of ordinary life
4. **Wrong** – sometimes there's no fit and the person offering help is just wrong for us
5. **Abuse** – some people can even abuse their power over us

Good help leaves us stronger:

1. **Support** – good help gives us what we need to achieve our own plans
2. **Teach** – good help keeps us learning and making the best of our abilities
3. **Connect** – good help links us to other people and builds bridges into the community
4. **Respect** – good help is respectful, it is given in a spirit of equality and mutual benefit
5. **Champion** – good help means having someone to look out for us
6. **Independence** – good help leads to be more independent and helps us have the ability to do and to think for ourselves

For many people with disabilities the majority of help they receive will be paid help. Help of a quality that supports a person develop, based on their strengths, gifts and talents contributes enormously to them being seen positively by others fellow citizens. The aim of paid help should always be to help people increase their resilience



and skills and find their own freely given, loving relationships, that will support them and stay with them for the long term replacing paid help.

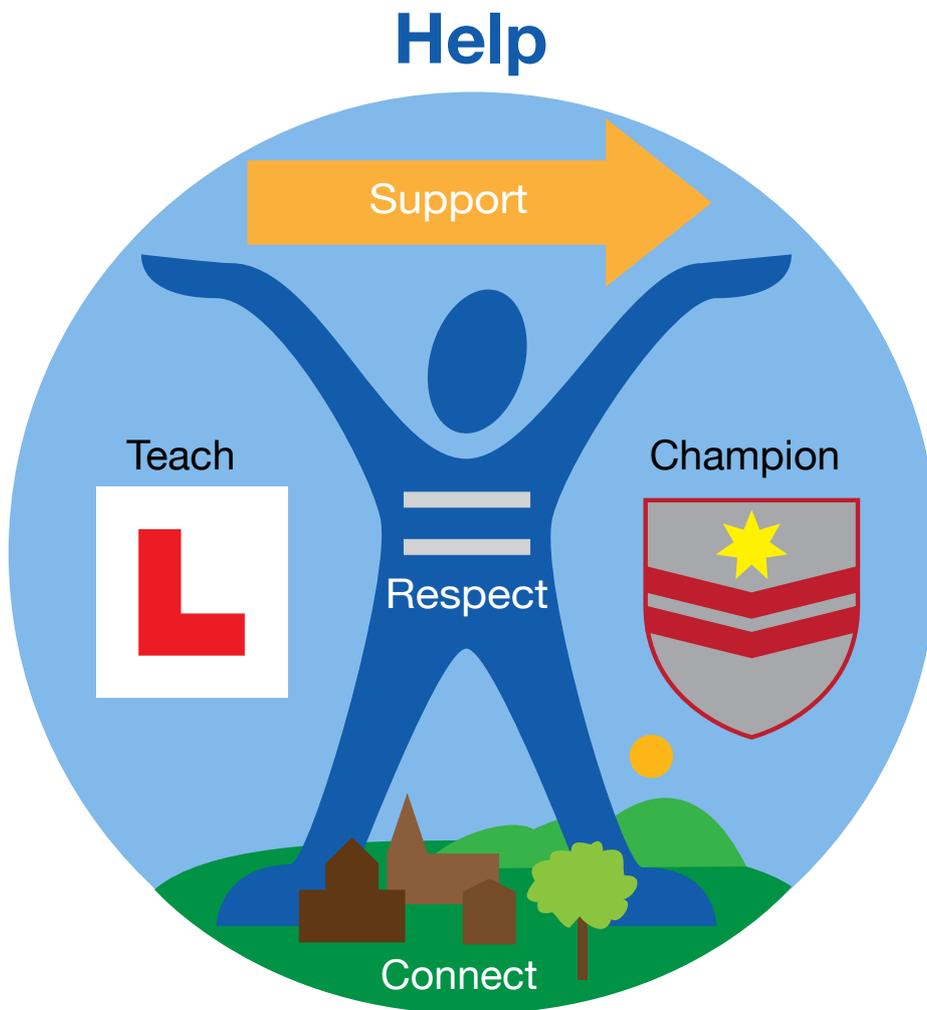


FIGURE 8. HELP

The reality is that paid help is a job; and helpers may leave because they can't handle the challenges of the job or they want to make progress in their careers. They can also be sick, they can have families and they have their own lives, which will in reality always come first. All these things can and do have significant negative impacts on the people with disabilities.

Truly involving people and families in recruiting and retaining their paid help is very important as this gives them the power and control over who and how they are



supported and paid helpers should always be reminded what their job is; which is to do themselves out of a job through making people more independent as well as helping develop relationships based on the person's skills, gifts and talents that will be long lasting and rewarding.

Help should be respectful, championing, mentoring and educating. Help is mutual and formed of give and take; everyone gets something out of the act. Everyone in society needs and receives help at different times, and this is a positive thing as our interdependency contributes to being a citizen. Help is good and all people should be confident in receiving it whether they have a disability or not. Interdependency is part of citizenship. Poor and inappropriate help can put the freedoms, social standing, rights and responsibilities of a person with disabilities at risk and at worst can lead to wasted lives and death.



Key 6 – Life

Citizenship is about making a difference. We do this by getting involved and helping make our community a better place. Many disabled people are excluded from community life.

No community means no life and being:

- 1. Bored** – we end up bored, living without purpose
- 2. Not valued** – nobody finds out what we have to offer because we were not part of it
- 3. False** – some of us end up in services that are just strange copies of ordinary lives
- 4. Lonely** – without community we make no friends and we can lose the friends we have
- 5. Disconnected** – without connections we are weaker and our options are limited

Community is where life is. We should be able to:

- 1. Join** – we will find lots more going on in our community if we look
- 2. Work** – our community needs us, there are always plenty of things we can do to help
- 3. Have fun** – find the places where we are happy, we can laugh and relax, have fun
- 4. Be together** – being part of the community is how we meet other people and make friends
- 5. Be Powerful** – together we can achieve so much more than on our own

Life is about having fun, experiencing highs and lows and getting together with other people in many different situations. It is about taking risks, and joining in. We are most successful and get the most out of life when we focus what we do in life on our gifts, talents, hobbies and interests as these are the things that lead us to connect with others we will form positive and lasting relationships with.

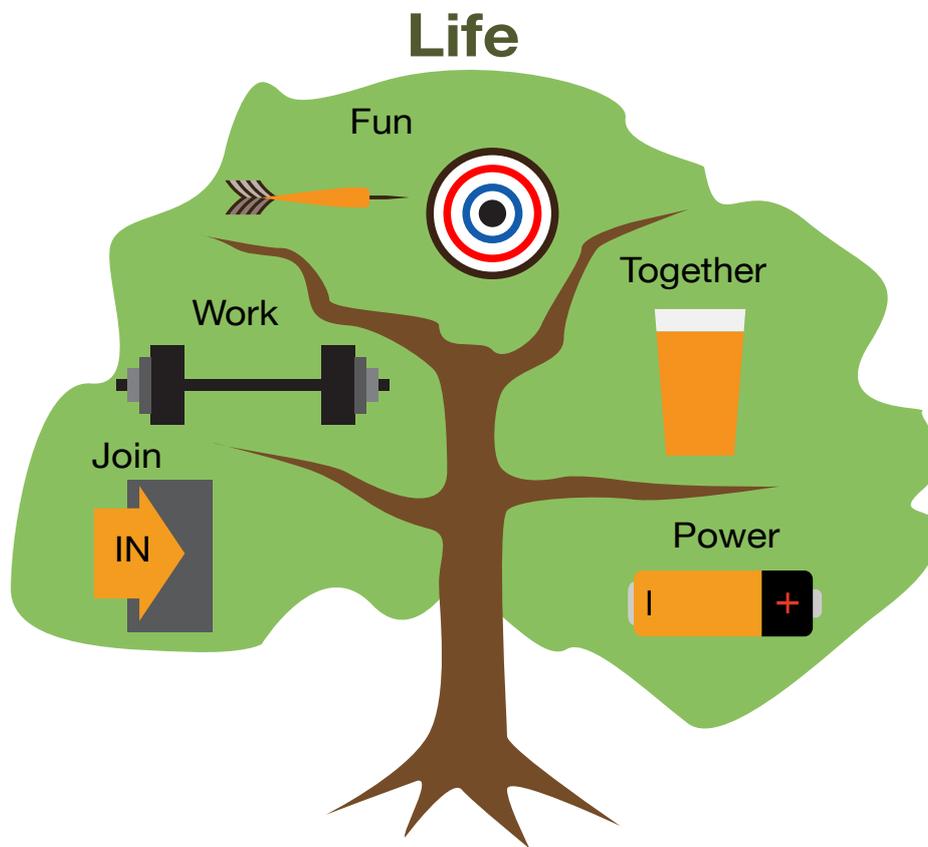


FIGURE 9. LIFE

Work is an important part of life for many reasons; it gives us status, respect, it pays the bills, it connects us with other people and enhances our skills and self-worth. Work comes in many different forms from being a parent to full time paid work. Each as important as the next. People with disabilities want to work and can work and this is a key part of citizenship.

Breaks away and holidays are important in keeping people motivated, having new experiences and making new friends. Most of us nowadays holiday abroad and therefore having a passport and being able to plan regular breaks away from home is part of getting a life.

An extremely important political right for all citizens is to vote. This means being registered and getting the information that the person understands and getting



any help they might need to cast their vote. Without political power people with disabilities will continue to be ‘done to’ instead of being in control.

Being active in and contributing to a community is an important component to building a safe, rewarding, inclusive life. A person’s neighbours and key local people are an important part of their everyday life and positive relationships help develop citizenship. A person with disabilities’ gifts and talents are the building blocks for helping them contribute and become valued.

To have a full life does not mean a person has to become mayor of their town or be voted citizen of the year (Although this could be a goal!). However, being known, being a ‘local’, a neighbour, making a positive contribution, being seen, working, and using local leisure and learning facilities with other citizens is vitally important for overcoming prejudice and for making lasting and valued friendships and relationships.

Providers have often overlooked the contribution, love and gifts that a person with disabilities has to offer; instead providers put much more effort into the personal care. This may be because those people helping them don’t know where to start, or how to connect people to community opportunities or because they don’t understand their role. It is only through community life that people with disabilities will be able to make those connections that will enable them to achieve a good life, be less reliant on paid support and be safer in their community.



Key 7 – Love

The most important thing in the world is love. Love exists even when citizenship is missing, but true citizenship strengthens the force of love in the world. Disabled people can love and be loved just like everyone else. But sometimes the world makes it harder.

It is hard to live a life without love, you can become:

1. Abused – we can be abused, made to have sex or be hurt in other ways
2. Broken – we can lose our families and miss out on the chance to have children
3. Lonely – we can have no real friends, even when we are surrounded by other people
4. Missing out – we can miss out on sex and the chance to be someone's lover
5. Closed in – we can be closed in, un-willing to love, frightened of giving to the world

Love is always possible:

1. Self-respect – we mustn't let other people hurt, use or abuse us
2. Family – we can be part of a family, we have the right to have our own family
3. Friends – we can find real friends, people who value us for who we really are
4. Lovers – we are full human beings who should be able to have affection and sex
5. Giving – we can give love to the world and to other people

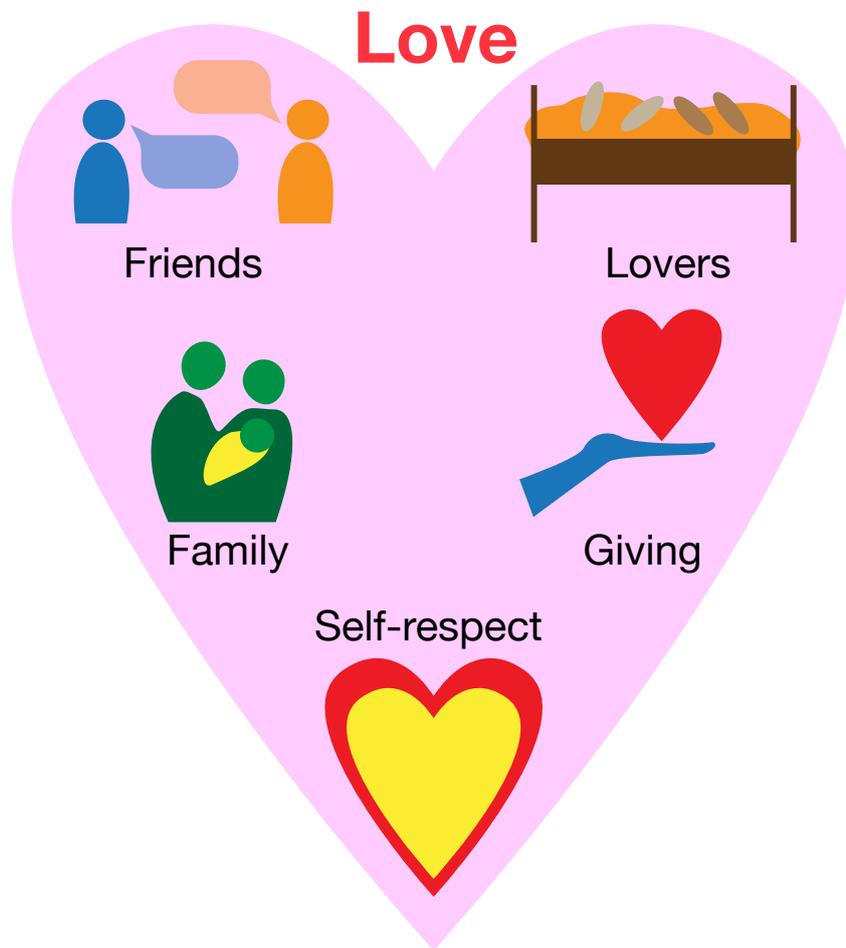


FIGURE 10. LOVE

Love is the foundation of life, without love people die. Loneliness is proven to kill people. Love is the connector key without which citizenship has no meaning. Love gives you permission to be vulnerable at the same time as being a protecting factor against abuse.

Love comes in many forms, all as important as the next. C S Lewis talks about two different kinds of love (Lewis, 1960). ‘Need-love’; like that of a child for a parent, and ‘gift-love’; the love we give to one another through humanity. Love is important to everyone and most people’s hopes and dreams are to find love through family, friends, relationships, sex and children. It is only through giving and receiving love and kindness, and feeling the range of emotions (from true love to heart break) that



people become alive. Love as a citizen is also about being responsible for others and respecting people's differences.

All types of love need nurturing and developing, and people with disabilities and especially learning disabilities will often not have learned how to do this because their lives so far have been lives of isolation, segregation, discrimination and congregation. People's relationships are a reflection of how they think about themselves or how others have made them feel. People with disabilities may have been badly treated, feel they are not sexually attractive or see themselves as asexual. They may have been discriminated against and may not seek positive relationships because they do not respect or trust others. People with disabilities may need support to feel good about themselves and develop and nurture loving relationships.

Lewis talks of four loves, which may be a useful way as providers to think about how you can help the people you support develop and nurture love:

- 1. Affection** – the love for those who are 'family' or who get together through chance. This is a love without coercion, love that descends discrimination and is without condition. It may be described as natural love, and love born out of familiarity however, the vulnerability of affection is that it appears to be ready-made and it therefore expected and is extremely hurtful and destructive if it is not there.
- 2. Friendship** – the love that is developed as a strong bond due to common interests, activities, histories, traits and characteristics. Friendships are freely-chosen and can be life-long or last as long as an activity or interest does. People may have a wide circle of acquaintances but much fewer true friendships. Choosing friends and going on to form lasting relationships may need support, as if people have not had chances to in the past they cannot always differentiate between kind, honest people and people who may take advantage of them.



- 3. Romance** – the strong sense and feelings that come with ‘being in love’ through attraction, desire and longing for a connection of body and mind. This love is very powerful and can sometimes grow out of friendship but not always and people sometimes get confused about this especially if they have had little experience of friendships. Most people want to experience sexual relationships which may lead to commitment and a family or may not. Having sexual experiences, lasting or not and of the person’s preference, and being seen as loveable and desirable by others is very important to people.
- 4. Gift-love** – love for others through their connection as people with humanity and giving without expectation of love in return. This is the love that binds communities together and those who give love in this way are often viewed highly by others.



Introducing Citizen Network



As we publish this important guide from Sam Sly and Bob Tindall we are also launching an international cooperative to bring people together to advance citizenship for all.

Around the world people are proving that everyone can be a citizen - no matter their race, gender, sexual orientation or disability.

Everyone has a valuable contribution to make, and a decent community is one that welcomes and supports that contribution.

Now is the time to build on this wealth of international experience. Let's work together, organise ourselves, learn and become a powerful force for change.

Join in • find allies • share ideas • get help

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