Changing Our Lives

Quality of Life Standards

Book 1: Living a full life, my home and employment

Making an ordinary life *possible.*

Changing Our Lives is a rights-based organisation. We work in partnership with disabled people and people with lived experience of mental health difficulties to find solutions to social injustice and health inequalities.

All of our work is rooted in the belief that no one is too disabled and that no one's mental health is too complex to lead an 'ordinary life'.

Our approach rests firmly on the social model of disability. As such, we don't believe people's lives should be limited or defined by labels or diagnoses, and we are committed to reframing how society views mental health and disability.

Our vision is of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights, resulting in them being in control of their own lives as equal citizens.

Quality of Life Standards, v4, January 2024

Introduction

The history of the Quality of Life Standards

The Quality of Life standards started their life in 2005 when a group of people with a learning disability came together to define for themselves what a good life looks like. They wanted to be in control of defining what 'good' looks like, rather than have regulatory bodies, commissioners and social workers make these decisions for them. Carrying out Quality of Life reviews, they used these standards to measure how support services, such as residential homes and supported living providers, unlocked a life for their peers.

As such, the Quality of Life standards reflect these ordinary aspirations. They are not a set of service standards. They do not reflect a model of service. They are standards which reflect an ordinary and equal life.

What an ordinary life looks like

The Quality of Life standards aim to raise people's expectations about what a an ordinary life looks like. An ordinary life, first coined by The King's Fund in their seminal report *An Ordinary Life* (1980), promoted the concept that people with a learning disability should live in ordinary houses, in ordinary streets and be part of ordinary communities.[1]

We often take for granted certain things such as having a partner, a good job, or living in our own home. These are ordinary and everyday things that make up our life. People with a learning disability are often faced with significant barriers which make these everyday, ordinary things very difficult to achieve. However, we know from experience that having the right level of good quality support that is appropriately resourced can enable all people with a learning disability to have ordinary life experiences.

Leading an ordinary life means people with a learning disability are seen as human beings first: as loving family members, rebellious teenagers, paid employees, community leaders, home owners and tenants, as neighbours, as friends and partners.

The standards apply to all people with a learning disability

These standards apply to all people with a learning disability, whatever their level of disability. This means that the standards do not apply only to those who are seen to be most able.

This is Book 1 of 3 of the Quality of Life Standards

Book 2: Communication, the way people work with me, being in control and *Book 3: My health and safety* and can be found on our website alongside this publication.

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[1] The King's Fund, 1980. *An Ordinary Life: Comprehensive locally based residential services for mentally handicapped people*, London: The King's Fund.

The rights of people with a learning disability are protected by law

Summarised here, the following laws underpin the Quality of Life standards. Further details regarding these laws can be found in the Appendix (pp.29-31).

The Equality Act (2010)

There is a duty to make reasonable adjustments if the person is placed at a substantial disadvantage because of their disability compared with people who are not disabled.

The Mental Capacity Act (2005)

Under the Mental Capacity Act (2005), support staff and professionals must let a person make decisions about their life, unless they are not able to.

The Care Act (2014)

Under the Care Act (2014), local authorities have to make sure that people who live in their areas: receive services that prevent their care needs from becoming more serious, or delay the impact of their needs; can get the information and advice they need to make good decisions about care and support; and have a range of provision of high quality, appropriate services to choose from.

The Accessible Information Standard

All health, social care services and other publicly funded services must meet the Accessible Information Standard to ensure disabled people and people with sensory impairments are given information they can understand.

The United Nations Convention on the Rights of People with Disabilities

Agrees to protect and promote the human rights of disabled people, including: enabling disabled people to live independently in the community, ensuring an inclusive education system, and ensuring that disabled people are protected from all forms of exploitation, discrimination, violence and abuse.

The Human Rights Act (1998)

The Human Rights Act (1998) sets out the fundamental rights and freedoms that everyone in the UK is entitled to. It incorporates the rights set out in the European Convention on Human Rights (ECHR) into British law.

Contents

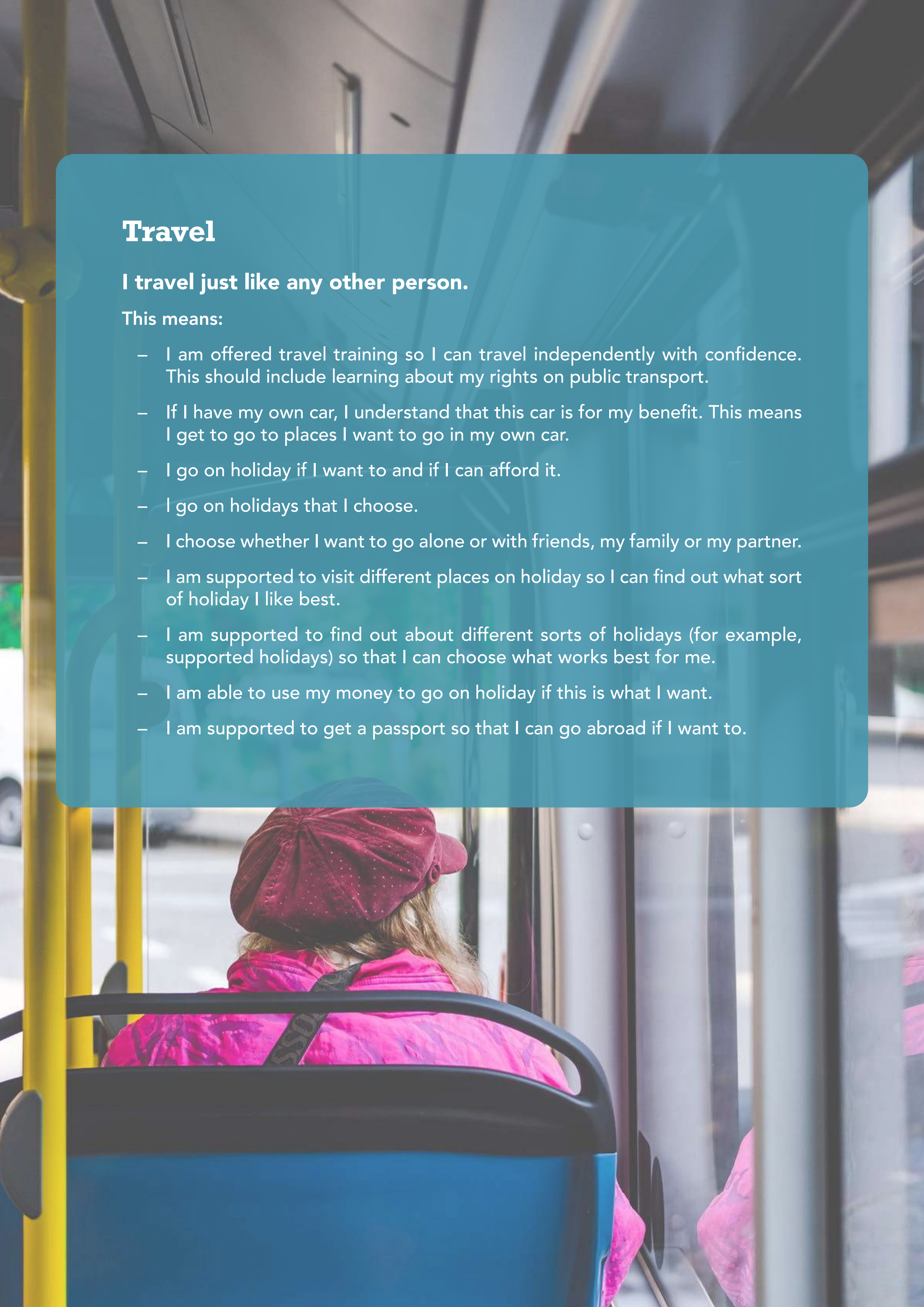
Section 1:
Living a full life

Being part of the local community

I am a valued member of the community.

This means:

- I get to know my local community and go to things that happen there, for example clubs, theatre, festivals, leisure or events.
- I find out about religious and cultural activities, events in my area and am supported to do things with people from my own cultural background, if that is what I want.
- I practise my religion, if I have one.
- I am supported to develop hobbies if I want to and learn about things that interest me.
- I go where everyone else goes, and do not always use ‘services’ that work with disabled people.
- I go out when I want to and not when my supporter, or the service that supports me, says I can go out. Staff’s working hours need to revolve around when I want to go out and do things. This might include going to pray at set times or going out to socialise late in the evening.
- I am supported to have good relationships with my neighbours.
- I contribute to my community using my skills and talents in ways that work for me.
- If I need them, my staff and I know where the Changing Places toilets are, so I can easily access the toilet when I am out in the local area.



Travel

I travel just like any other person.

This means:

- I am offered travel training so I can travel independently with confidence. This should include learning about my rights on public transport.
- If I have my own car, I understand that this car is for my benefit. This means I get to go to places I want to go in my own car.
- I go on holiday if I want to and if I can afford it.
- I go on holidays that I choose.
- I choose whether I want to go alone or with friends, my family or my partner.
- I am supported to visit different places on holiday so I can find out what sort of holiday I like best.
- I am supported to find out about different sorts of holidays (for example, supported holidays) so that I can choose what works best for me.
- I am able to use my money to go on holiday if this is what I want.
- I am supported to get a passport so that I can go abroad if I want to.

My family

I have my family involved in my life. I can choose which family members I want involved in my life.

This means:

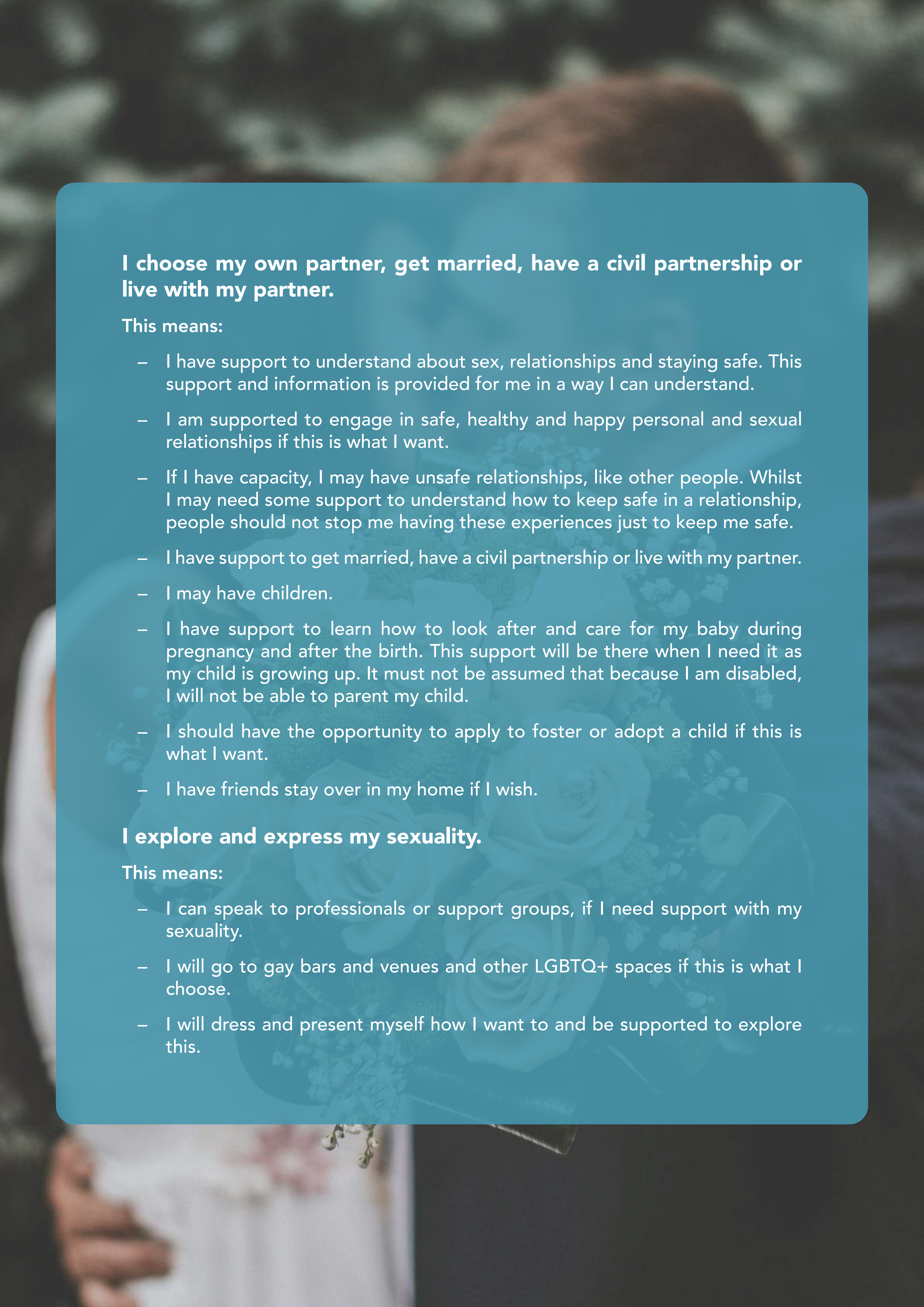
- I see my family if this is what I want. If I don’t want to see my family, my wishes are respected.
- I see my family where I choose to see them. This might be in a cafe or at the family home.
- If I am seeing my family in my home, I have private space to do this.
- My support staff and professionals keep my family up to date with things about me if this is what I want. They should check with me that this is what I want.
- I am supported to move out of the family home if this is what I want.
- I am supported to go to family functions, if this is what I want. For example, birthday parties, or funerals.

My friends and relationships

I have support to see my friends and make new friends.

This means:

- I keep in contact with friends, seeing them at my home, their home and other places in the community.
- I am supported to keep in touch with them using the telephone, social media or video calls. I have access to Wi-Fi and the internet to help me stay connected with people. I have support to stay safe online.
- I see my friends in private. I don't have staff listening in on my friendship. This includes phone calls and video calls with both my family and friends.
- I go to places and meet new friends. I am supported to make new friendships in my local community, with my neighbours, amongst like minded people. It should not be assumed that I only want friendships with other disabled people.
- I have friends stay over in my home if I wish.



I choose my own partner, get married, have a civil partnership or live with my partner.

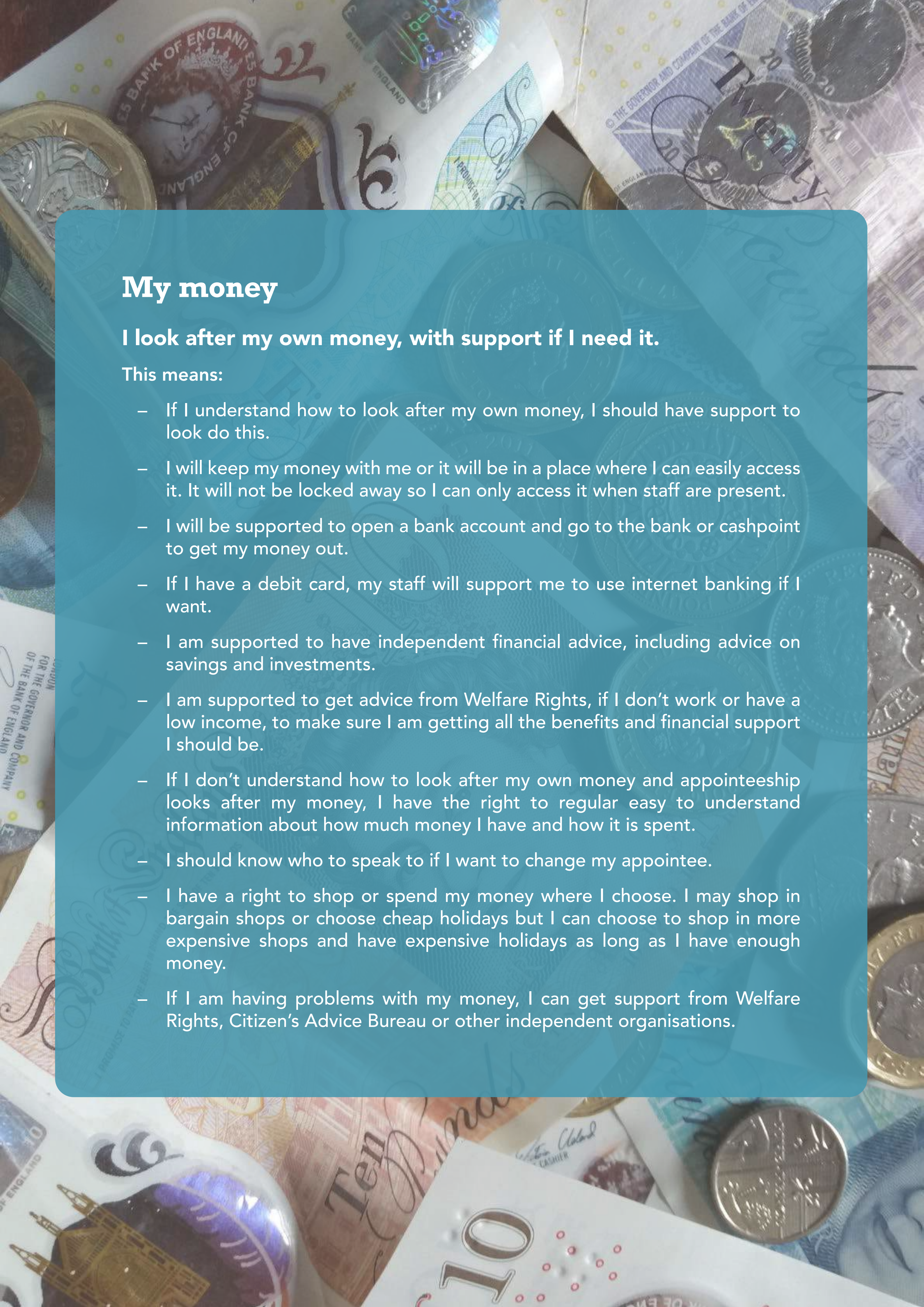
This means:

- I have support to understand about sex, relationships and staying safe. This support and information is provided for me in a way I can understand.
- I am supported to engage in safe, healthy and happy personal and sexual relationships if this is what I want.
- If I have capacity, I may have unsafe relationships, like other people. Whilst I may need some support to understand how to keep safe in a relationship, people should not stop me having these experiences just to keep me safe.
- I have support to get married, have a civil partnership or live with my partner.
- I may have children.
- I have support to learn how to look after and care for my baby during pregnancy and after the birth. This support will be there when I need it as my child is growing up. It must not be assumed that because I am disabled, I will not be able to parent my child.
- I should have the opportunity to apply to foster or adopt a child if this is what I want.
- I have friends stay over in my home if I wish.

I explore and express my sexuality.

This means:

- I can speak to professionals or support groups, if I need support with my sexuality.
- I will go to gay bars and venues and other LGBTQ+ spaces if this is what I choose.
- I will dress and present myself how I want to and be supported to explore this.



My money

I look after my own money, with support if I need it.

This means:

- If I understand how to look after my own money, I should have support to look do this.
- I will keep my money with me or it will be in a place where I can easily access it. It will not be locked away so I can only access it when staff are present.
- I will be supported to open a bank account and go to the bank or cashpoint to get my money out.
- If I have a debit card, my staff will support me to use internet banking if I want.
- I am supported to have independent financial advice, including advice on savings and investments.
- I am supported to get advice from Welfare Rights, if I don't work or have a low income, to make sure I am getting all the benefits and financial support I should be.
- If I don't understand how to look after my own money and appointeeship looks after my money, I have the right to regular easy to understand information about how much money I have and how it is spent.
- I should know who to speak to if I want to change my appointee.
- I have a right to shop or spend my money where I choose. I may shop in bargain shops or choose cheap holidays but I can choose to shop in more expensive shops and have expensive holidays as long as I have enough money.
- If I am having problems with my money, I can get support from Welfare Rights, Citizen's Advice Bureau or other independent organisations.

My education

I reach my full potential in all areas of my life by learning new skills and knowledge and having new experiences, that lead to personal growth.

This means:

- I am supported to reach my potential as independently as possible, so that I can have an active life.
- I am supported to prepare for being an adult and having adult responsibilities.
- I am supported to access informal as well as formal educational opportunities. For example, this may include visiting art galleries and museums going to the theatre and concerts to help me develop my interests, hobbies and passions.

I have an education that prepares me for paid employment.

This means:

- I have people around me who believe I can work with the right support.
- I have careers advice and information from a specialist employment support service from the age of 14.
- My school curriculum prepares me for the world of work, not a lifetime in services.
- I have Saturday jobs and other tasters, so that I can find out what sort of work I want to do in the future, from the age of 14.
- I have support to understand the steps I need to take to get the job that I want.
- I have support to understand what my rights are if I have a job.

I understand what I will gain from any education I take part in.

This means:

- I get skills and qualifications that I can use to get myself a job and a career.
- I am not left in the same dead-end college course year after year, making no progress.
- I access education at any stage of my life and should be supported to do this if this is what I want.I have support to understand what my rights are if I have a job.

Section 2:
My home

This section covers where I live if I am not living with my family and I need support in my home.

These are some of the types of home I may have:

Supported Living

- I may live in my own home with a tenancy agreement. This may be with the council, with a housing association or privately rented. This is called supported living. This means I pay rent for my home. I choose the staff who come in to support me. It's their job to support me to be as independent as I am able in my own home.

Extra care housing

- Extra care housing enables people to live independently with some support. Sometimes you can live on the same site as other people who need some support. You can socialise with these people if you want to. There are staff who come in to see you to support you to be independent.

Shared Lives

- Shared Lives is the name that is sometimes used for when people are living in a family that is not their own family. The person could live there for some of the time or most of the time. It might also be called shared care.

Residential home

- If I live in a residential home, I live with other people. I have my own bedroom and I share the other space in the house, like the living room and bathroom with other people. There are staff to support me in the residential home.

Nursing home

- If I live in a nursing home, I will need to have some support from a nurse. Some people live in their own home and have a nurse go in and support them. If I live in a nursing home, my nursing needs will be great enough for me not to be able to be supported in my own home.

Home Ownership

- I may own my own home. Whichever type of place I live in, it is my home. People might be paid to support me in my home, but it's my home.

Where I live

I live in a home that I have chosen.

This means:

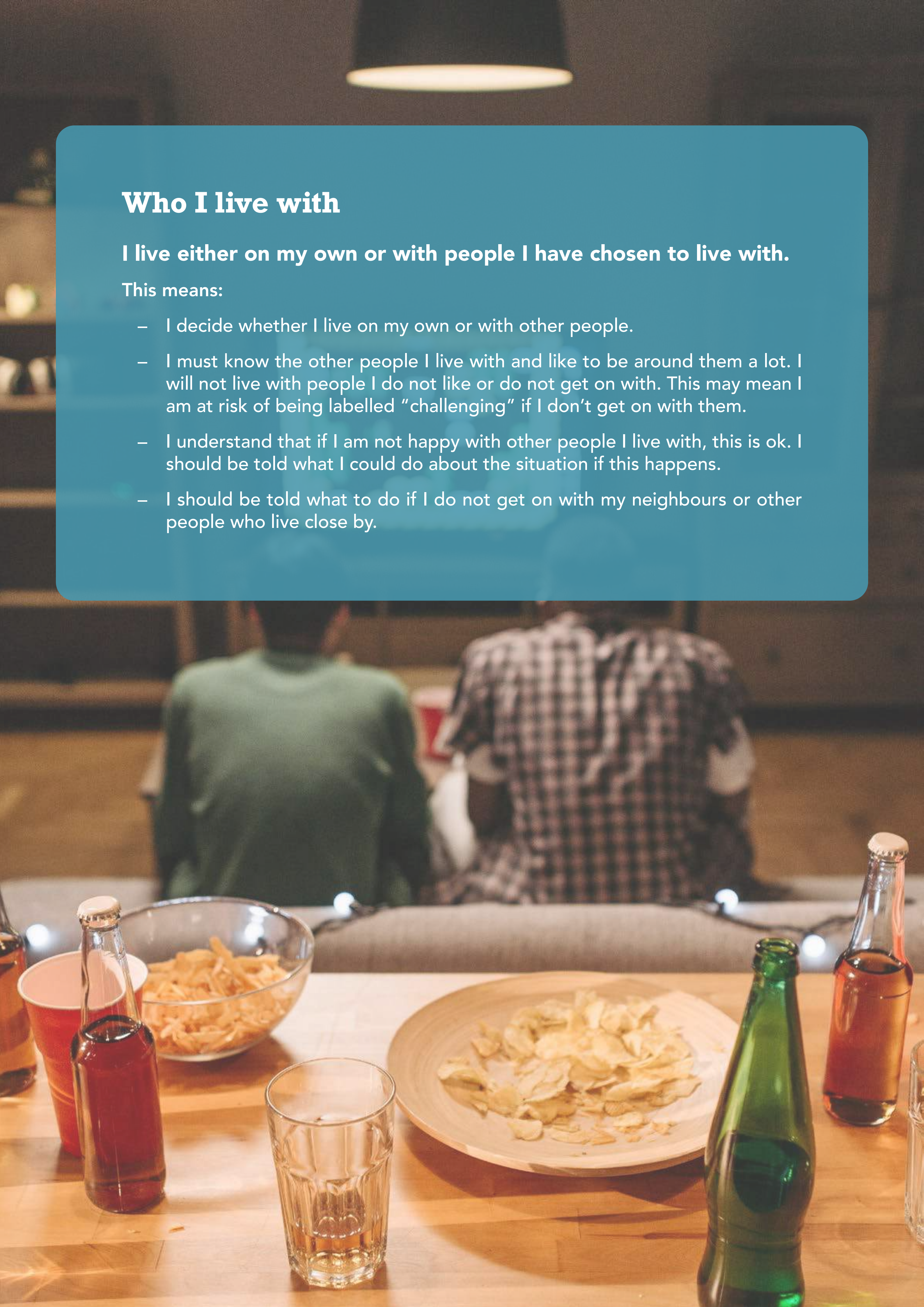
- It should be my decision if I want to live in my own home even if my family disapprove. I should have support from professionals including an advocate to make this happen.
- People in my life should believe that I can live in my own home with the right support if I need it.
- I choose what sort of home I live in.
- I am told about all of the different types of housing options available to me. I will have support to know what my rights and responsibilities are for different housing options.
- I am supported to choose which area I live in and think about any issues affecting this. For example, if I am African-Caribbean, I may choose to live in an area with other people from African-Caribbean communities.
- I am told which housing options will give me more independence and how they will give me more independence.
- I am supported how to find one of these places to live in an area I want to live in.
- I am supported to apply for council housing if this is what I want. I will have support to find out how to get on the housing register.
- I am supported to think about how I might be able to buy my home or part of my home. I will have support to find out how this could happen.
- All of this information is given to me in an easy to understand way.
- My home is my home, so if staff come to support me they should knock on my front door so I can open it myself.
- If I have support from staff in my own home I can ask them to leave if I want a break, if it is safe for me to be alone.
- If I want a pet, I should be supported to choose a home where pets are allowed.
- If I want to move house, I should have support to do this and this should not affect the level of support I receive.

Who I live with

I live either on my own or with people I have chosen to live with.

This means:

- I decide whether I live on my own or with other people.
- I must know the other people I live with and like to be around them a lot. I will not live with people I do not like or do not get on with. This may mean I am at risk of being labelled "challenging" if I don't get on with them.
- I understand that if I am not happy with other people I live with, this is ok. I should be told what I could do about the situation if this happens.
- I should be told what to do if I do not get on with my neighbours or other people who live close by.

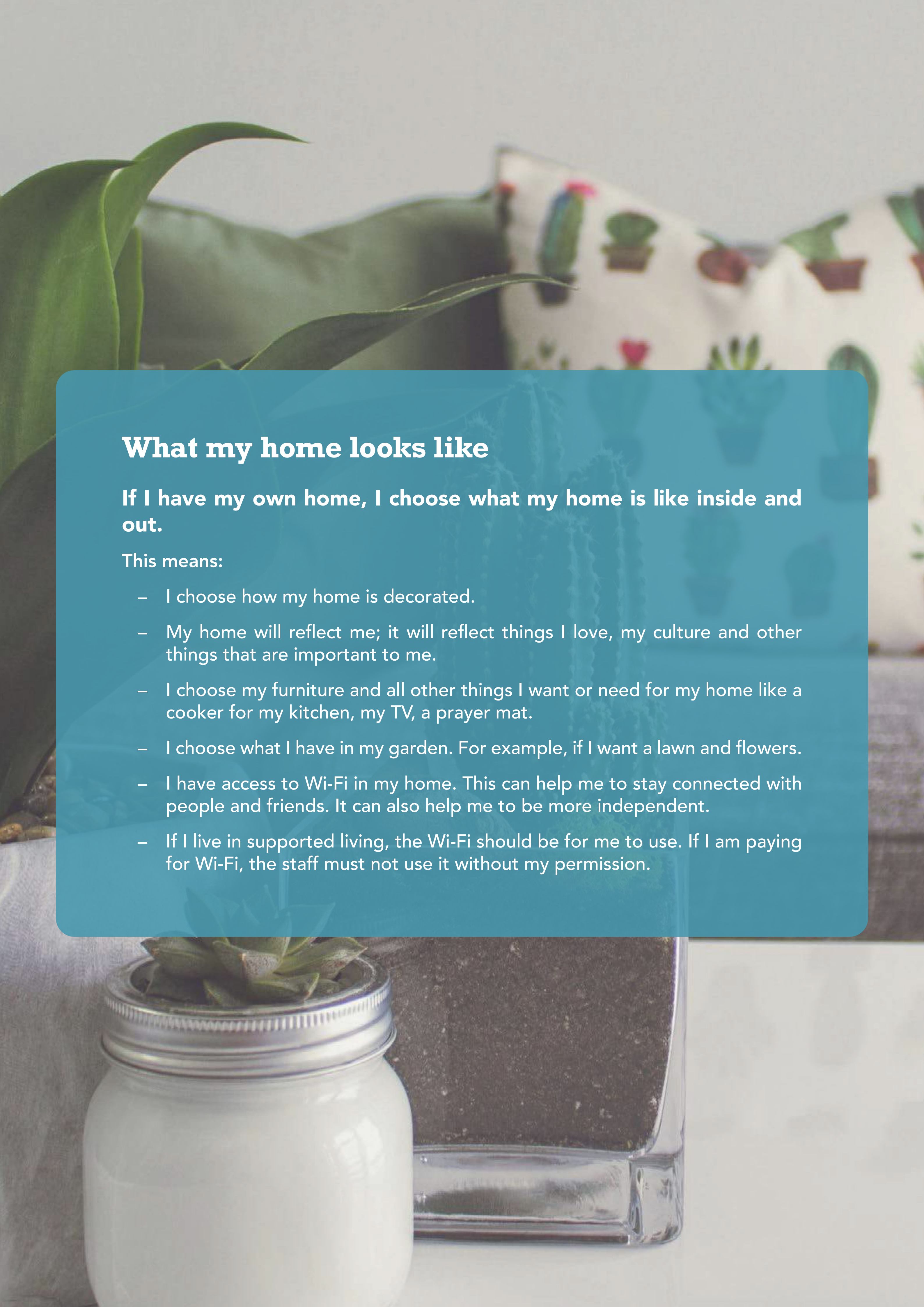


Tenancy agreement

If I live in supported living, I should have a tenancy agreement.

This means:

- I have a copy of my tenancy agreement.
- I am supported to understand my responsibilities under this tenancy agreement. This tenancy agreement will be in easy read. It will be explained to me in a way I understand.
- My tenancy rights are not affected by who supports me. If my support needs change, this will not threaten where I live.
- Any support staff I may have do not take over a part of my home and use it as their office. I decide what happens in each part of my home. I can access each part of my home. In some circumstances, for example if I need 24 hour care, there may be a bedroom in my home in which a paid carer sleeps. This room may also be a place that the carer stores any work records.
- Any agency that supports me does not install a telephone line in my home or keep any files or paper work they own in my home. They do not use the Wi-Fi if this is my Wi-Fi.
- I have my own key and I know how to use it. This is important because some people do not have their own key, or they are given a key and they are not supported to use it. Just because one of the agencies supporting me may have a spare key, they cannot come into my home unless I say they can.
- If I have problems with my tenancy I can get support from Welfare Rights, Citizen’s Advice Bureau or an advocate.

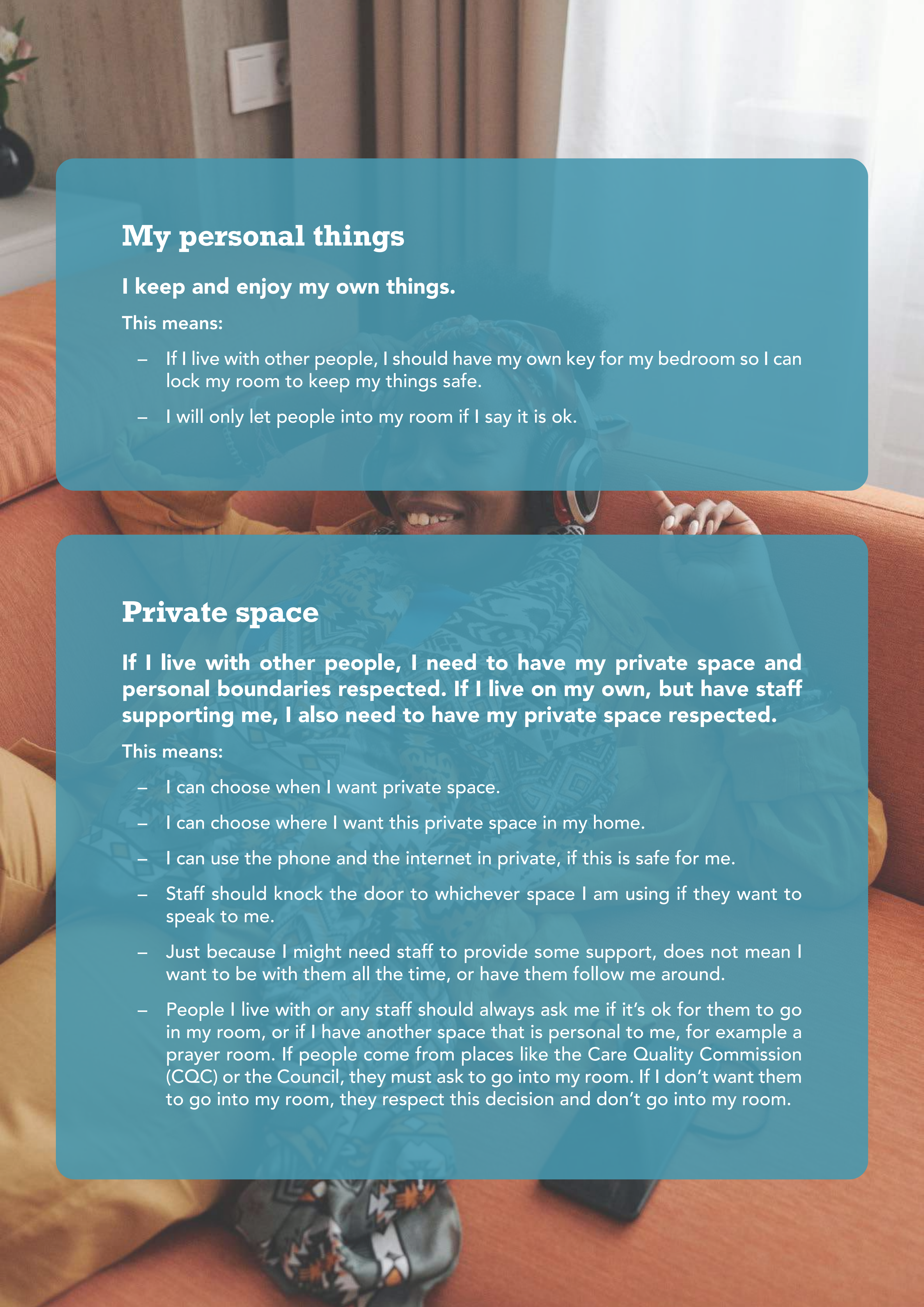


What my home looks like

If I have my own home, I choose what my home is like inside and out.

This means:

- I choose how my home is decorated.
- My home will reflect me; it will reflect things I love, my culture and other things that are important to me.
- I choose my furniture and all other things I want or need for my home like a cooker for my kitchen, my TV, a prayer mat.
- I choose what I have in my garden. For example, if I want a lawn and flowers.
- I have access to Wi-Fi in my home. This can help me to stay connected with people and friends. It can also help me to be more independent.
- If I live in supported living, the Wi-Fi should be for me to use. If I am paying for Wi-Fi, the staff must not use it without my permission.



My personal things

I keep and enjoy my own things.

This means:

- If I live with other people, I should have my own key for my bedroom so I can lock my room to keep my things safe.
- I will only let people into my room if I say it is ok.

Private space

If I live with other people, I need to have my private space and personal boundaries respected. If I live on my own, but have staff supporting me, I also need to have my private space respected.

This means:

- I can choose when I want private space.
- I can choose where I want this private space in my home.
- I can use the phone and the internet in private, if this is safe for me.
- Staff should knock the door to whichever space I am using if they want to speak to me.
- Just because I might need staff to provide some support, does not mean I want to be with them all the time, or have them follow me around.
- People I live with or any staff should always ask me if it's ok for them to go in my room, or if I have another space that is personal to me, for example a prayer room. If people come from places like the Care Quality Commission (CQC) or the Council, they must ask to go into my room. If I don't want them to go into my room, they respect this decision and don't go into my room.

Being independent in my home

I have support in my own home to be as independent as possible. This includes making my own choices about my daily living and what happens in my home.

Here are some of the choices that I will be in control of:

- I have support, if I need it, to shop for my own food.
- I choose what I eat and drink and when I want to eat and drink.
- I have support to prepare my own food.
- I have support to pay my bills.
- I have support to organise my own repairs if something needs fixing in my home.
- I choose what time I get up and go to bed.
- I choose what I wear, shop for my own clothes and support to do my own laundry.
- I choose what happens in my home, including who comes to my home and who does not come.

There are lots of other choices I make in my day to day living that I also have control of that are not included here.

Using telecare to support my independence

I access telecare to make me more independent. Telecare is technology which can be used to keep me safe or support me to be more independent.

Examples of telecare:

- An alarm which hangs around my neck. I can press this alarm if I am in difficulty and people come to help me.
- Alarms which go off if I fall, to tell someone to come and help me.
- A pillbox that reminds me when I need to take my medicine and gives it to me.
- A smoke alarm that lets people know to come and help me if something catches fire.
- A flood detector that switches off the water if I forget to.

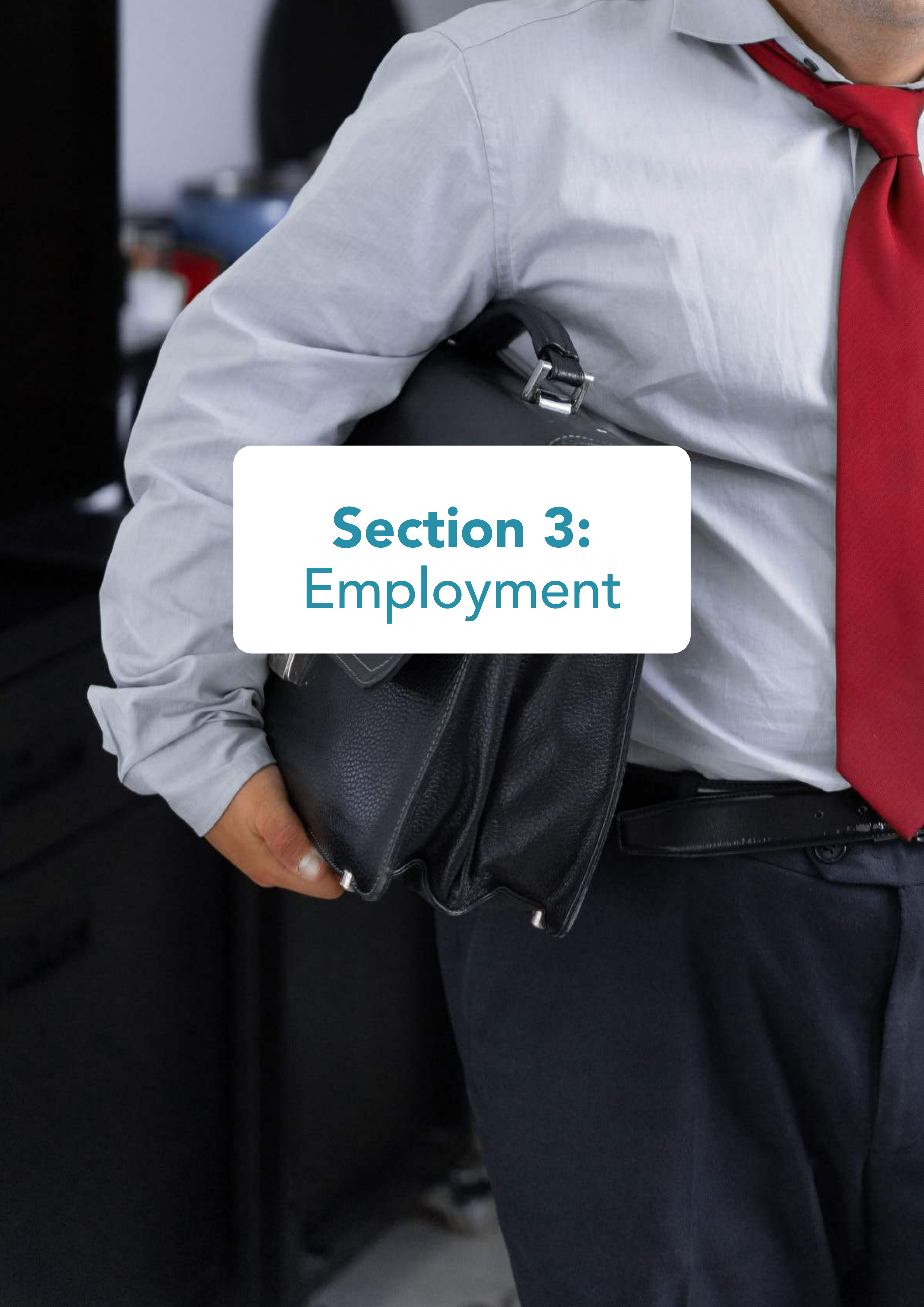
A social worker or other professionals will support me to find out about telecare and how it could be useful in my life.

An accessible home

I live in a home that is accessible. If it is not accessible this means there are some places in my home I can't get to. It might also mean there are some things in my home I can't do.

This means:

- My home has adaptations if I need things to make it more accessible. For example, if I need a ramp, handrail, loop system, lower kitchen units or a fire alarm system with flashing lights.



Section 3:
Employment

Support into paid employment

I am supported to have paid employment. Just because I am disabled does not mean I can't work. I will receive support to help me get a job in a person centred way.

This means:

- People in my life believe that I can work and help me to achieve this.
- Having the chance to have work experience and careers advice while I am still at school.
- Having access to a supported employment service that is located in an accessible building in the community.
- Being treated as an individual with my own views and wishes.
- Listening to what I say.
- Not making assumptions about what I can and can't do.
- Challenging other people's views that may not help me get a job or an apprenticeship, such as employers and other staff who support me.
- Having information and advice that I can understand, including a benefits assessment.
- Making sure that any concerns people have who support and are close to me, are understood, and dealt with. This may include my family.
- I am supported to understand my rights to reasonable adjustments in getting a job and whilst in employment.
- I am supported to progress in my employment and have a career if this is what I want.

Having fulfilling employment

I want the chance to get a job that I want to do, and will be good at.

This means:

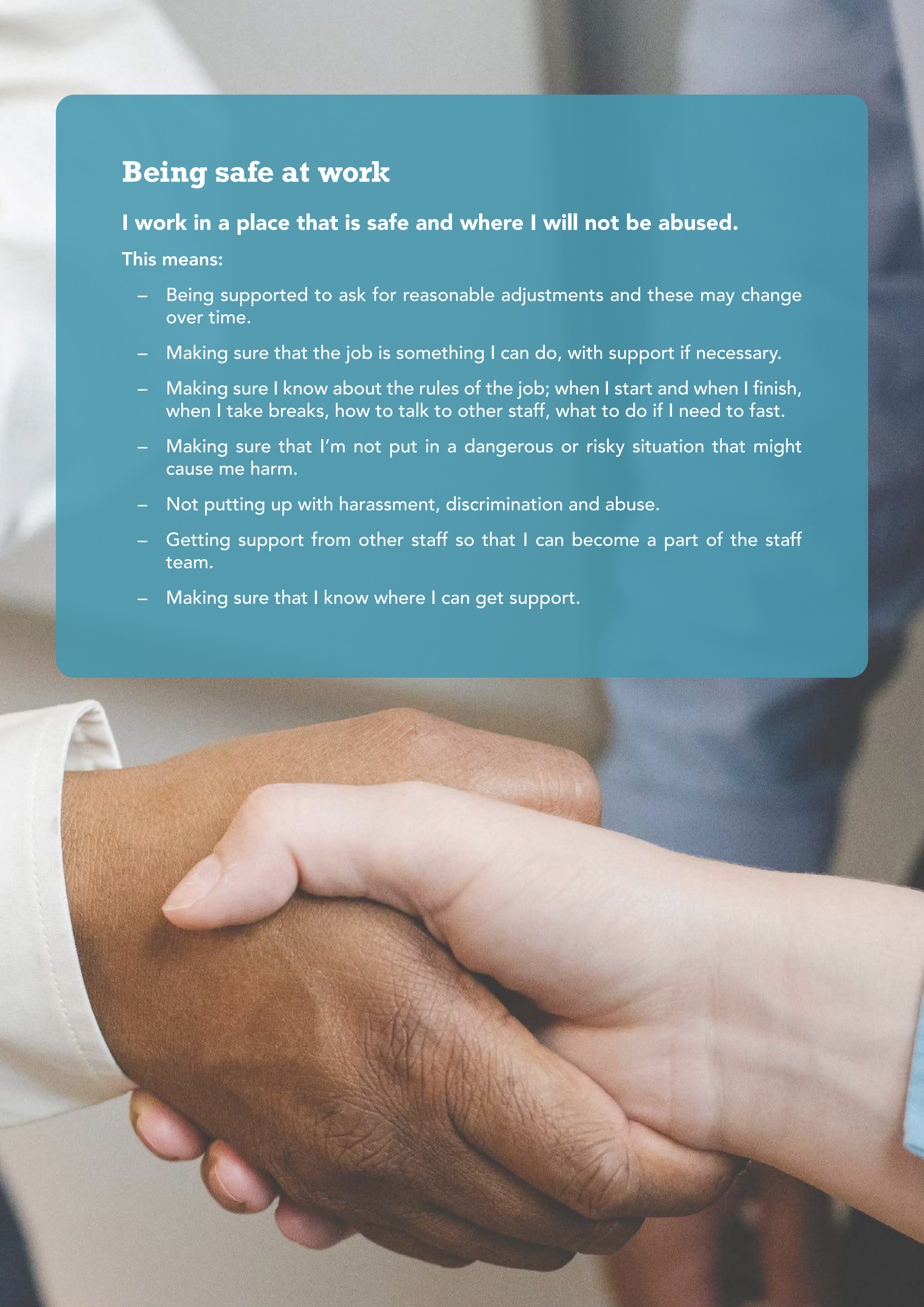
- Getting to know me, to identify what job I might be good at, based on my experiences, my skills, my abilities, interests and talent.
- Making sure I'm supported to make informed and realistic choices about work and future career opportunities.
- Helping me understand the impact of having a job on my life. What I will need to sort out myself, and what I'll need help with.
- Arranging short work trials or tasters to help me decide what sort of job I want to do.
- To agree the level of support I may need to get a job. This might be staff support, or the use of equipment; such as a mobile phone.
- Helping me to think about work throughout my life. Just because I tried working once and it didn't work out for me does not mean I never want to work again.
- Being treated as an individual with my own views and wishes.
- Listening to what I say.
- Not making assumptions about what I can and cannot do.

Being safe at work

I work in a place that is safe and where I will not be abused.

This means:

- Being supported to ask for reasonable adjustments and these may change over time.
- Making sure that the job is something I can do, with support if necessary.
- Making sure I know about the rules of the job; when I start and when I finish, when I take breaks, how to talk to other staff, what to do if I need to fast.
- Making sure that I'm not put in a dangerous or risky situation that might cause me harm.
- Not putting up with harassment, discrimination and abuse.
- Getting support from other staff so that I can become a part of the staff team.
- Making sure that I know where I can get support.



Having support in employment

I will have support when I start my job.

This means:

- Making sure that I have the chance to choose the job I want and make my own decisions.
- Having a plan that will help me to start a job. This may include support from my family, friends and staff.
- Having a job coach who will make sure I know what to do, at my own pace.
- This will include how I get to and from work at the right time, and may include travel training.
- Making sure that my job will help me become more independent.
- Helping me understand how having a job will change my life. For example, meeting new people, and having new friends.

I will have support as I progress in my job.

This means:

- Giving me support to understand what I have to do, and explaining things in a simple way.
- Breaking hard tasks into easy to understand parts.
- Giving me support to do tasks and then helping me to become independent of staff support.
- Making sure that any training provided by the employer is useful and understandable.
- Helping me develop work routines that will help me in my job.
- Ensuring that I'm able to develop and continue good relationships with other staff where I work.
- Giving me support if I need it to learn new skills and talents when my job changes or I'm asked to do something different.
- Having help and support if anything goes wrong at work or if I'm not able to do a task.

Appendix:
Legal background

The following laws underpin the aforementioned standards and protect the rights of people with a learning disability:

The Equality Act (2010)

Under the Equality Act (2010) there is a duty to make reasonable adjustments if an individual is placed at a substantial disadvantage because of their disability, when compared to their non-disabled peers. Support staff and other professionals in a person's life, for example a social worker, must make reasonable adjustments for them. This might mean changing the way things are normally done so it is easier for the person to access, changing physical features, and providing them with extra aids and services if necessary.

The Care Act (2014)

The Care Act (2014) imposes a general duty to promote the wellbeing of the individual. Under the Care Act, local authorities have to make sure that people who live in their areas:

- Receive services that prevent their care needs from becoming more serious, or delay the impact of their needs
- Can get the information and advice they need to make good decisions about care and support
- Have a range of provision of high quality, appropriate services to choose from

Disabled people are entitled to a Care Act assessment where a social worker will talk to them, their family, friends, carer or advocate to find out about their situation and how they are managing everyday activities. This could include managing personal care, getting out and about and being part of the community or household tasks.

The Care Acts says local authorities need to provide comprehensive information and advice about care and support services in their local area.

Under the Care Act (2014) individuals have a right to a personal budget if they need support from social care.

Under the Care Act (2014), individuals have a right to an advocate if a social care needs assessment, carers assessment, care planning, care review or safeguarding investigation is taking place, and they would have substantial difficulty being involved and have no appropriate, able and willing family member or friend to support them.

The Human Rights Act (1998)

The Human Rights Act 1998 sets out the fundamental rights and freedoms that everyone in the UK is entitled to. It incorporates the rights set out in the European Convention on Human Rights (ECHR) into British law. Each right in the act is referred to as a separate article, for example Article 8, *Right to respect for private and family life*. Staff in the NHS, local councils and services must respect, protect and fulfil people's human rights.

The Mental Capacity Act (2005)

Under the Mental Capacity Act (2005), support staff and other professionals in a person's life must let the individual make decisions about their own life, unless they are not able to. The individual should not have to prove that they can make their own decisions. Staff and professionals must not assume that because a person has a learning disability or is autistic that they cannot make decisions about their own life even if what the individual wants is not what staff and professionals think is best. Staff and professionals must support the person to make decisions before thinking whether or not they can make decisions for themselves.

The Accessible Information Standard

All health services, social care services and other publicly funded services must meet the Accessible Information Standard to ensure disabled people and people with sensory impairments are given information they can understand.

There are 5 steps to the standard:

1. **Identify:** The service need to assess what additional support someone might need if they are disabled, and what extra information or communication methods might be required.
2. **Record:** The service must record identified needs clearly.
3. **Flag:** The service needs to make sure people's communication needs are in their paper and/or electronic records, where staff can access this information quickly.
4. **Share:** If needed services must share details of people's information and communication needs with other health and social care services.
5. **Meet:** The service must make sure that people receive information that they can access and understand.

The United Nations Convention on the Rights of People with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is an international treaty that sets out Disabled People's human rights. The UK ratified the CRPD in 2009. This means the UK Government has agreed to do what the Convention says and make changes to ensure that the rights in the Convention are respected in practice.

Rights under the CRPD include civil and political rights, like the right to life, liberty and security of the person, freedom from torture or inhuman and degrading treatment, equal recognition before the before the law, freedom from discrimination, and freedom from exploitation, violence and abuse. The CRPD also protects economic, social and cultural rights, like the right to live independently and be included in the community, the right to education, health, habilitation and rehabilitation, and the right to participate in cultural life, recreation, leisure and support.

Disabled people who experience a violation of their human rights by a state body can make individual complaints to the Committee on the Rights of Persons with Disabilities. If the claim is upheld, the Committee can request that the government make things right.

Making an ordinary life *possible*.

Acknowledgements:

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Design: Katie Seymour.

First published: January 2024.

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