Changing Our Lives

Quality of Life Standards

Book 2: Communication, the way people work with me, being in control

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 2 of 3 of the Quality of Life Standards

Book 1: Living a full life, my home and employment and *Book 3: My health and safety* 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.31-33).

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 4: Communication

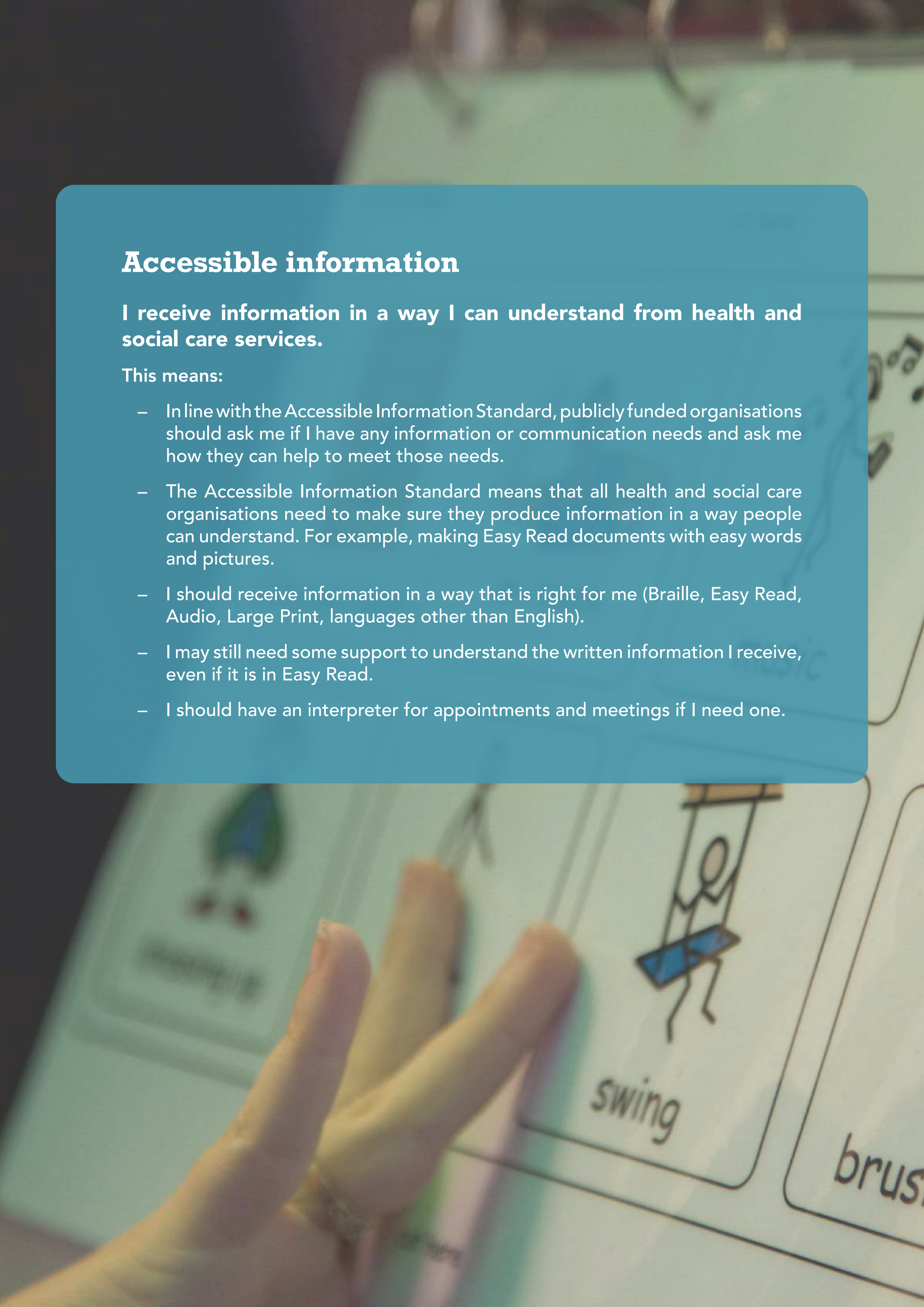
Expressing myself

I have support to express myself.

This means:

- I use the communication that works best for me.
- I may use words, Makaton, an electronic communication device, objects of reference, sensory communication, intensive interaction, a communication board or other ways to communicate.
  - **Makaton** uses speech with signs (gestures) and symbols (pictures) to help people communicate.
  - **A communication board** is a device that displays photos, symbols, or illustrations to help people with limited language skills express themselves. The user can gesture, point to, or blink at images to communicate with others.
  - **Intensive Interaction** is used with people with profound and multiple learning disabilities to develop positive communication. It involves the communication partner altering their communication behaviour to suit the person, taking the lead of the person with learning disabilities and responding to things they do and using observation to judge how well the interaction is going.
  - **An electronic communication device** is programmed with a few images or symbols and some sounds which are understood by the person using it. For example, when the person wants a drink, they learn to push the image or symbol which represents drink.
  - **Objects of Reference** are objects used to represent a person, activity or event. When used over time, people learn that the object represents a certain thing or activity. For example, an individual can pick up the car keys and this means they want to go for a drive.
  - **Sensory communication** includes facial expressions, pointing and speech, gaze, vocalisations, gestures and body movements.
- All forms of communication should be equally valued and listened to.
- The way I behave must also be viewed as communication.

- I may have a Communication Passport. This is one way of telling people how I communicate. I could have a book or a digital passport (on an app or tablet). It is like my voice and should not be ignored, filed away or forgotten. It must be updated regularly.
- It is my Communication Passport. I should be involved in creating it. I should have my own copy.
- It should talk about how I communicate and how I want people to communicate with me. It should include information about how to give me written information. It should include information about how to connect with me as a person NOT just how to recognise my functional needs.
- If I have staff they will be trained to communicate with me. This means they might be trained to use Makaton, PECS (Picture Exchange Communication System), objects of reference, talking mats, pictures, electronic communicators, intensive interaction or other ways of communicating.
- Electronic communicators should be in my first language. Speech and Language Therapy can help with this.
- People should connect with me, whether or not I use words to communicate. I should not be left with no one interacting with me or acknowledging me. If I use a spoken language that is not English I will have some staff on my team who speak the same language.
- If I need them, I will have Speech and Language Therapy working with me.

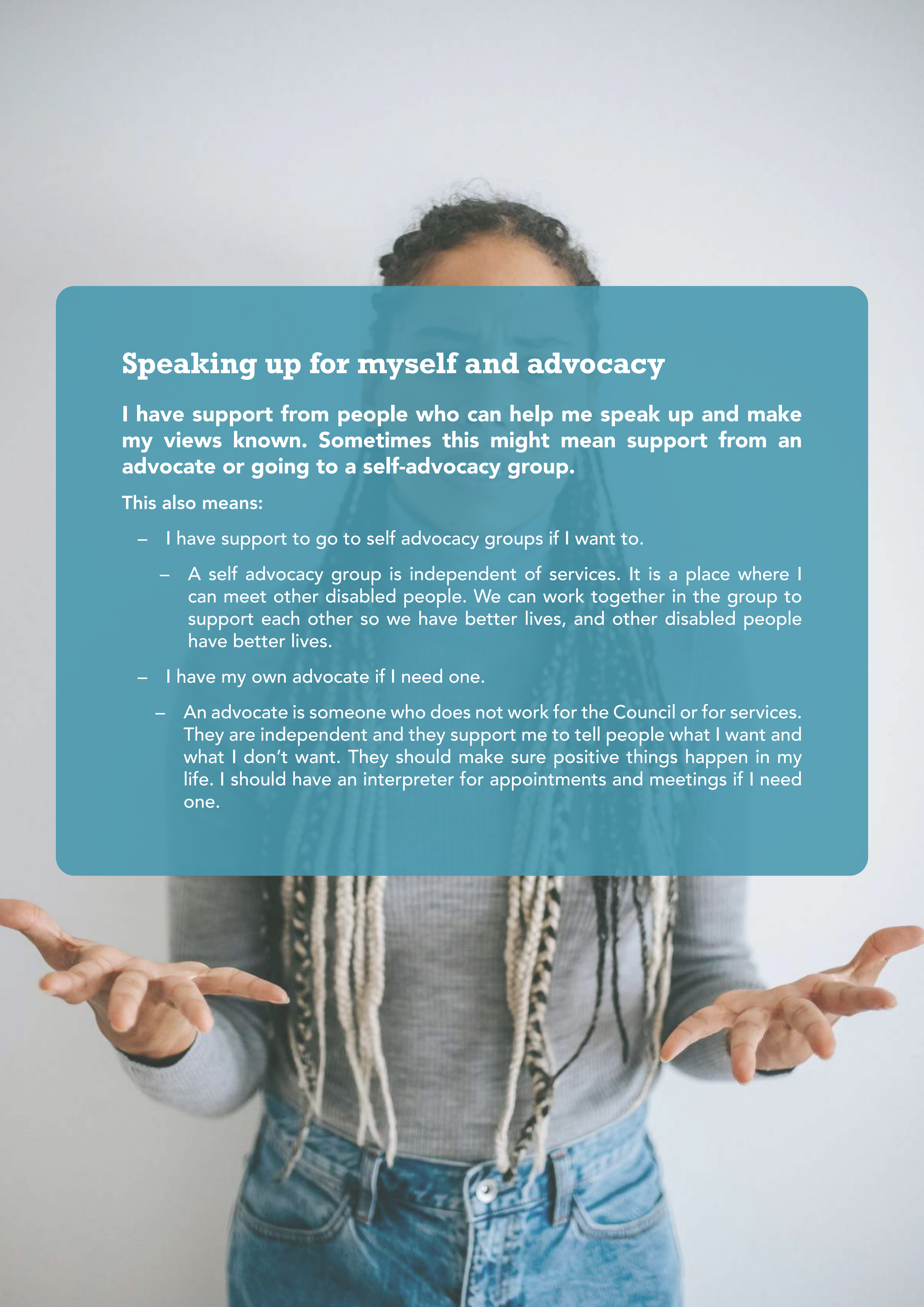


Accessible information

I receive information in a way I can understand from health and social care services.

This means:

- In line with the Accessible Information Standard, publicly funded organisations should ask me if I have any information or communication needs and ask me how they can help to meet those needs.
- The Accessible Information Standard means that all health and social care organisations need to make sure they produce information in a way people can understand. For example, making Easy Read documents with easy words and pictures.
- I should receive information in a way that is right for me (Braille, Easy Read, Audio, Large Print, languages other than English).
- I may still need some support to understand the written information I receive, even if it is in Easy Read.
- I should have an interpreter for appointments and meetings if I need one.



Speaking up for myself and advocacy

I have support from people who can help me speak up and make my views known. Sometimes this might mean support from an advocate or going to a self-advocacy group.

This also means:

- I have support to go to self advocacy groups if I want to.
  - A self advocacy group is independent of services. It is a place where I can meet other disabled people. We can work together in the group to support each other so we have better lives, and other disabled people have better lives.
- I have my own advocate if I need one.
  - An advocate is someone who does not work for the Council or for services. They are independent and they support me to tell people what I want and what I don't want. They should make sure positive things happen in my life. I should have an interpreter for appointments and meetings if I need one.

There are different types of advocacy. Some types of advocacy you can have by Law. This is called statutory advocacy and it is available everywhere. Statutory advocacy includes:

Independent Mental Capacity Advocate (IMCA)

- You have the right to an IMCA if you cannot make decisions for yourself, do not have any friends or family who can help you make decisions, and you need support with a decision about where you will live or about serious medical treatment.

Independent Mental Health Advocacy (IMHA)

- You have the right to an IMHA if you are sectioned under the Mental Health Act.

Care Act Advocacy

- You have a right to a Care Act advocate if you would need support to be involved in social care assessments or reviews, and safeguarding processes and you have no family or friends who can help.

NHS Complaints Advocacy

- You have a right to an NHS Complaints advocate to support you to complain about the treatment or care that you or a friend or family member have received from an NHS service. This support is available at every stage of the complaints process.

There are other types of advocacy that do not have to be provided by Law but are still very important. This is non-statutory advocacy and there are different services available in different areas. Non-statutory advocacy can be:

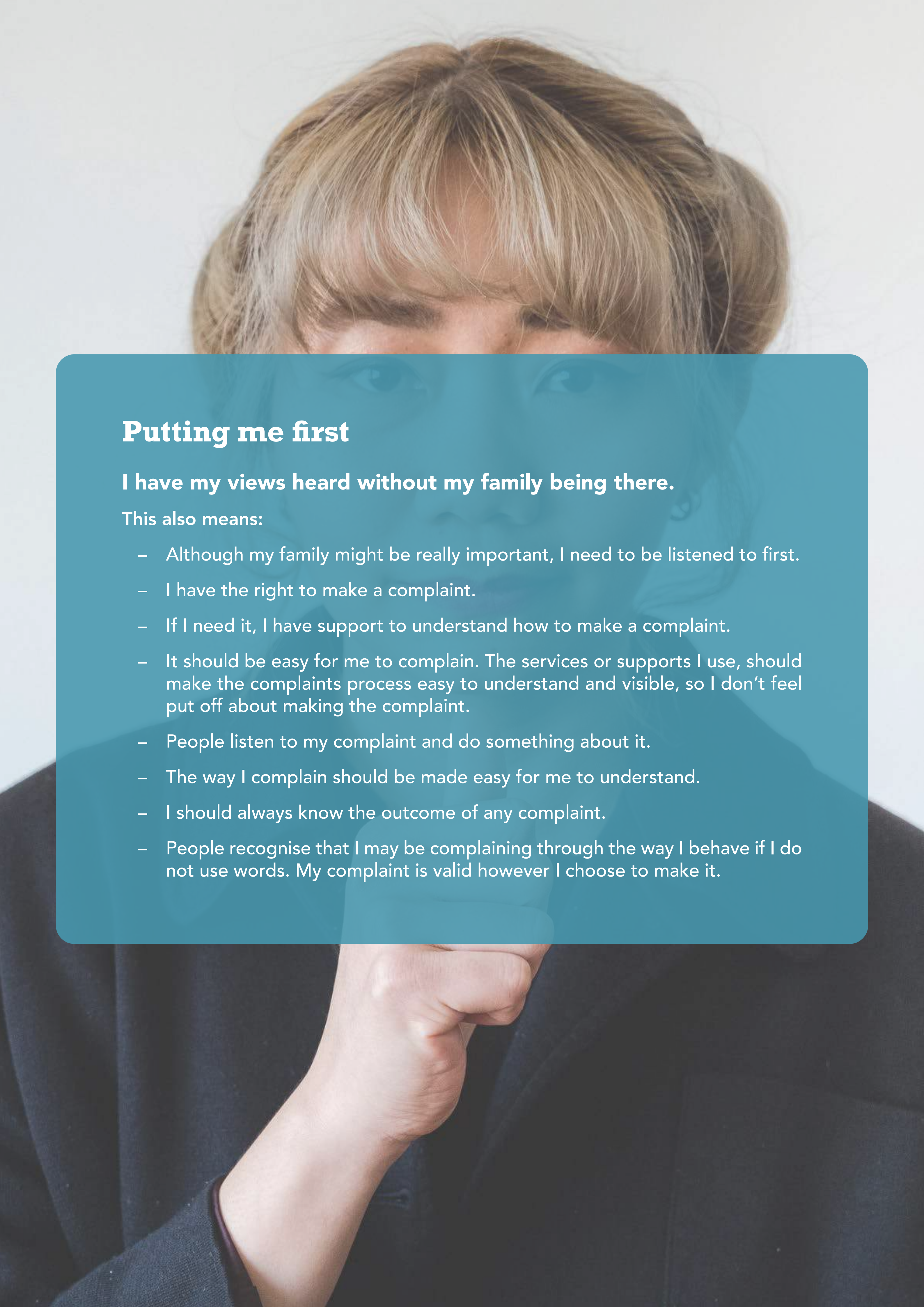
Rights based advocacy

- An advocate may work with you short or long term to make sure that your rights are being upheld

Issue based advocacy

- An advocate may work with you for a short time about a particular issue.

Whatever type of advocacy I have it should be culturally competent, taking time to understand my culture and spirituality.

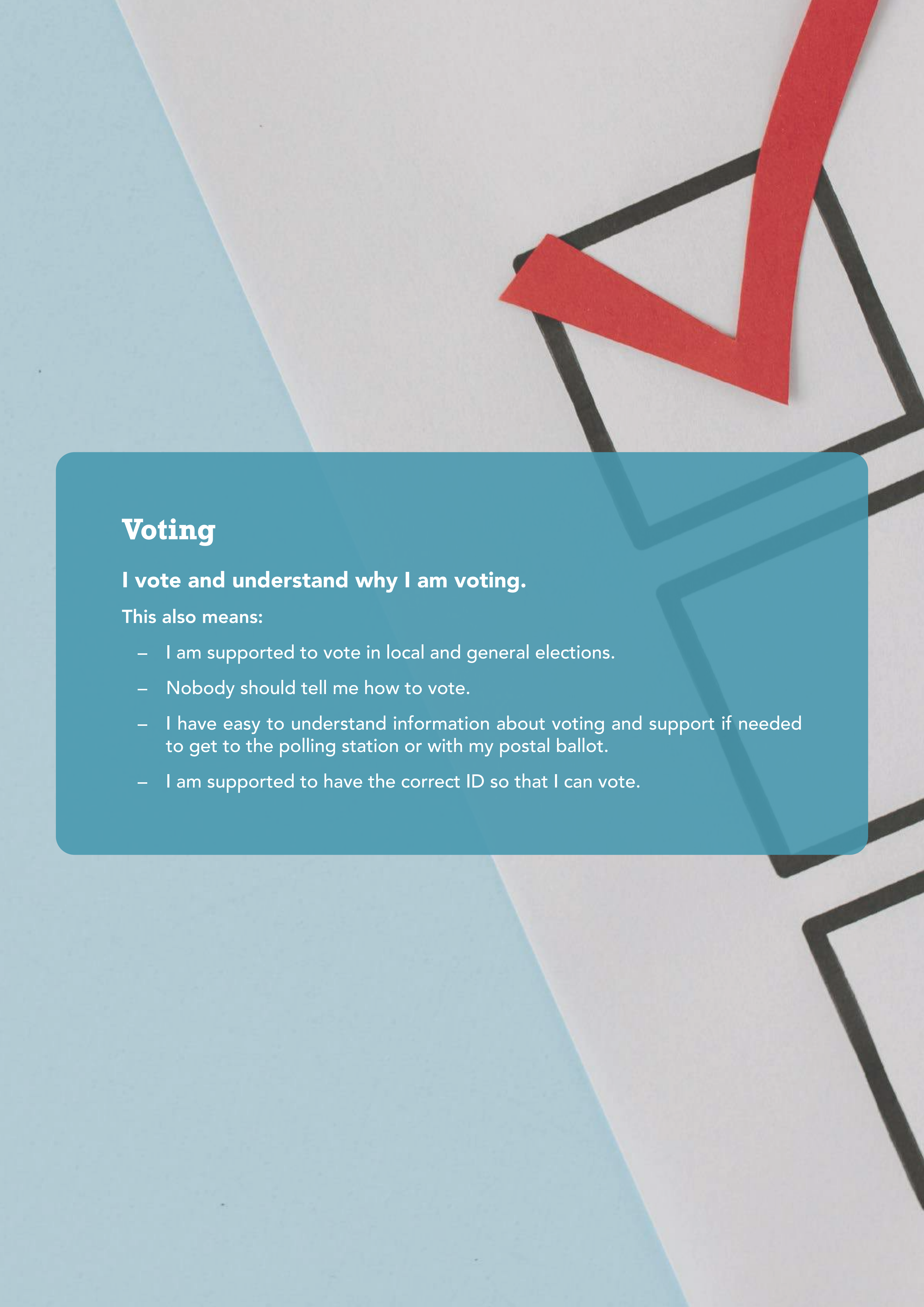


Putting me first

I have my views heard without my family being there.

This also means:

- Although my family might be really important, I need to be listened to first.
- I have the right to make a complaint.
- If I need it, I have support to understand how to make a complaint.
- It should be easy for me to complain. The services or supports I use, should make the complaints process easy to understand and visible, so I don't feel put off about making the complaint.
- People listen to my complaint and do something about it.
- The way I complain should be made easy for me to understand.
- I should always know the outcome of any complaint.
- People recognise that I may be complaining through the way I behave if I do not use words. My complaint is valid however I choose to make it.



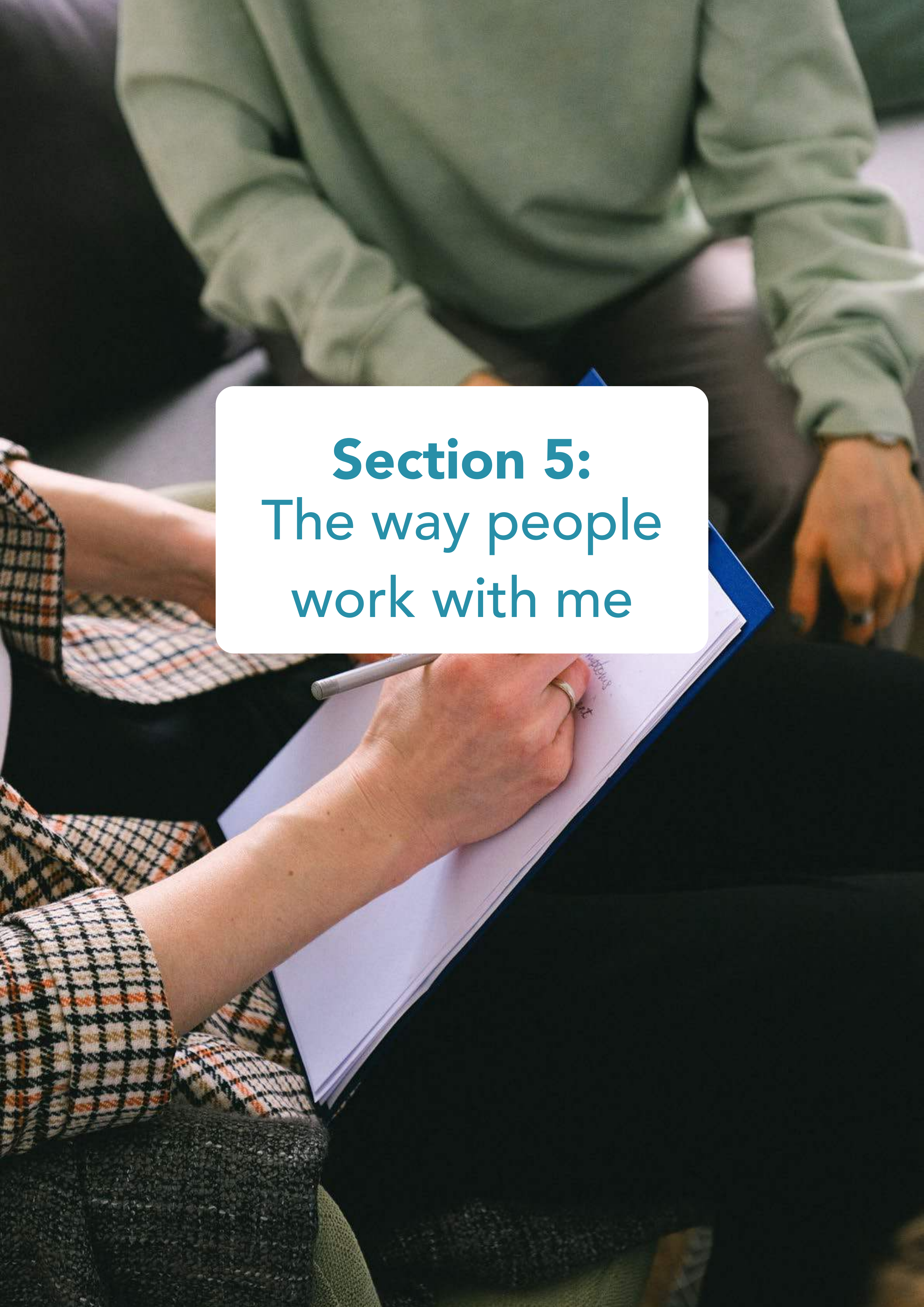
Voting

I vote and understand why I am voting.

This also means:

- I am supported to vote in local and general elections.
- Nobody should tell me how to vote.
- I have easy to understand information about voting and support if needed to get to the polling station or with my postal ballot.
- I am supported to have the correct ID so that I can vote.

Section 5:
The way people work with me



Professionals who work with me

Professionals should work with me as an equal.

This means:

- Professionals should always treat me with respect.
- Professionals should see me as a person first. They should have training in how disabled people are equal citizens with equal rights.
- They should make reasonable adjustments in the way they work with me if this is what I need. Reasonable adjustments are changes that services need to make to ensure I am not disadvantaged.
- Professionals should always speak to me directly, not to my family or paid support. If I need help to understand something I can choose to have support with this.
- Professionals should give me information in a way that I can understand.
- The professionals who work with me are there to support me to be actively involved in decisions about my life. They are not there to make decisions on my behalf.
- If it is found that I am lacking the capacity to make a big decision about my life, there should be a best interests meeting to establish what is best for me. Advocacy should be involved in this process. My family should also be involved, if this is what I want.

My support staff

I choose who works with me.

This means:

- I am involved in creating job descriptions and interviews for people who are paid to work with me. This means I can choose people I know I will get on with and who will do things that I want to do.
- I can change the people who work with me if they do not do a good job.
- I am involved in reviewing my staff if I want to.
- I know how to change these people by making a complaint or asking for a new person.

I have people that work with me treat me with respect and support me to lead the sort of life I choose to lead.

This means:

- The people who work with me see me as a person first, and see my disability second. They have training in how disabled people are equal citizens with equal rights, as well as training in how to support disabled people to be independent and in control of our own lives.
- The people who work with me work flexibly, so they are there when I need them. They should arrive on time. They should not be early or late.
- The people who work with me work where I need them to work. This could be in my home or could be out and about.
- The people who work with me communicate with me in a way I understand and want them to. They have training in how I communicate.
- The people who work with me take an active interest in learning about my heritage and culture. My culture is an important part of who I am and it is important that my support recognises this.

- The people who work with me give me as much notice as possible if they can't support me and someone else needs to support me instead.
- The people who work with me support me, if I want, to make an Easy Read agreement with me, which says how they will support me and how I will treat them. This should also include information about how I can change my staff if I am not happy.
- The people who work with me are there to support me to be actively involved in decisions about my life. They are not there to make decisions on my behalf. If it is found that I am lacking the capacity to make a big decision about my life, there should be a best interests meeting to establish what is best for me. Decisions must always be about what is best for me, not what is best for my staff.
- Advocacy should be involved in this process. My family should also be involved, if this is what I want.
- The people who work with me understand I can challenge things I don't agree with, without being judged and labelled as difficult.
- The people who work with me should treat my home and possessions with respect.
- The people who work with me have the right values, skills and knowledge to support me well.
- As well as mandatory training and training in things that they need to know to support me well (such as specific communication systems or specific health conditions), my support staff have training in:
  - How disabled people are equal citizens with equal rights
  - How to support disabled people to be independent and in control of our own lives
  - How to support me to have an ordinary life

Meetings, planning and my life

Lots of times in my life, I will make decisions and do things and I will not plan for them at all. Just because I am disabled does not mean I need a meeting and a plan for everything. It does not mean I have to go to a meeting to make every change or decision in my life. It does not mean I always need people around me to help me to decide what I want to do with my life. I am in control of my life and therefore I can make decisions without always planning. However, sometimes I will have a plan or go to a meeting that is about my life.

Some of the meetings I may have are:

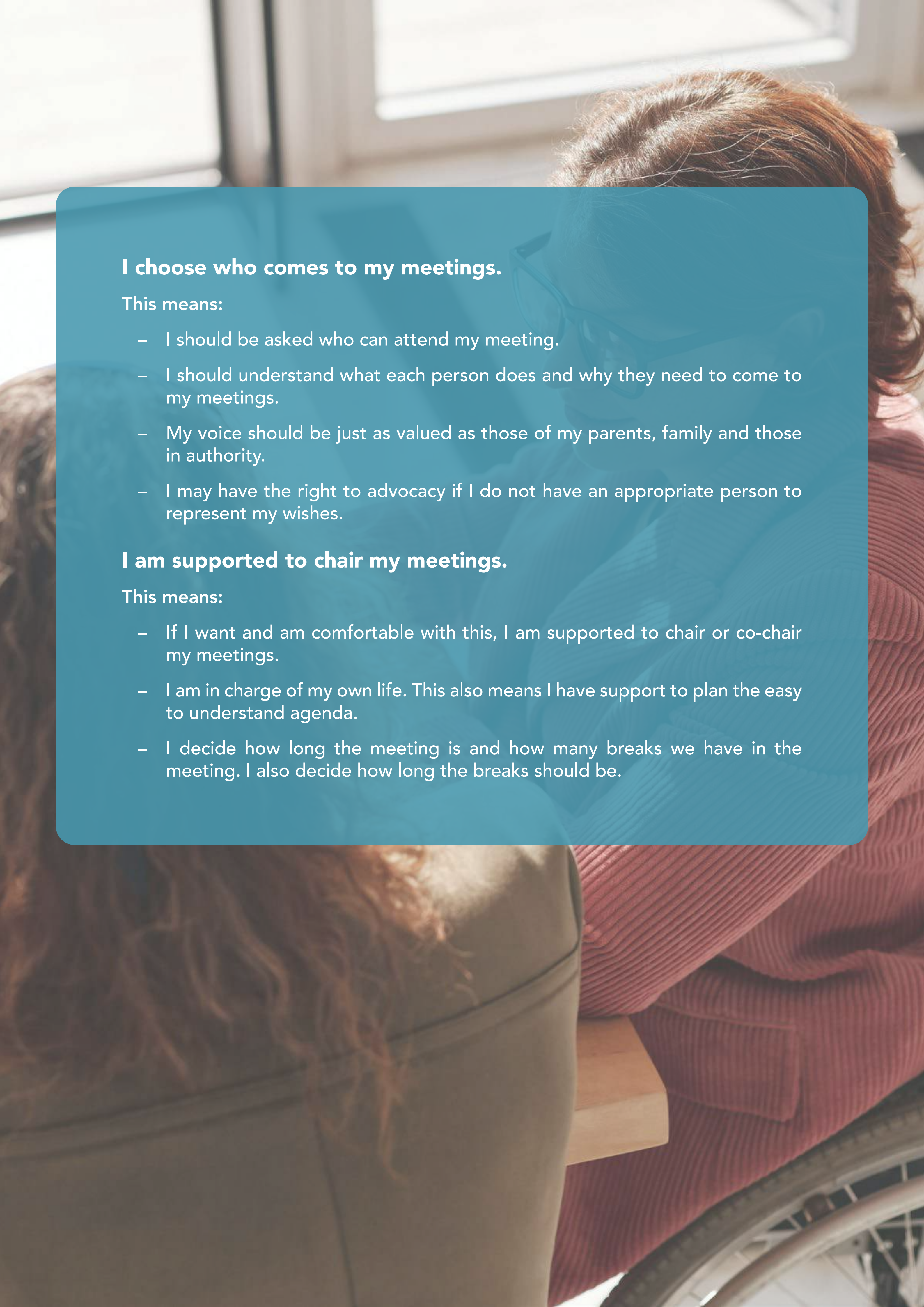
- A person centred planning meeting
- An assessment meeting
- A support planning meeting
- A review meeting
- A transitions meeting

I might have other meetings when I am growing up as well.

I choose where and when my meetings will be.

This means:

- My meetings could be in the evening or at weekends.
- My meetings might take place in different places where I feel comfortable such as on a minibus, at McDonald’s, at a hall attached to my local mosque, church or temple or a sensory environment.
- Sometimes my meetings may need to talk about things that are confidential, so I may need to have my meeting somewhere private.
- If possible my meetings should be arranged so that they are on the same day or at the same time. My meetings should not take place at a time that is difficult for me and members of my community for example during Friday prayers (or any other commitments).



I choose who comes to my meetings.

This means:

- I should be asked who can attend my meeting.
- I should understand what each person does and why they need to come to my meetings.
- My voice should be just as valued as those of my parents, family and those in authority.
- I may have the right to advocacy if I do not have an appropriate person to represent my wishes.

I am supported to chair my meetings.

This means:

- If I want and am comfortable with this, I am supported to chair or co-chair my meetings.
- I am in charge of my own life. This also means I have support to plan the easy to understand agenda.
- I decide how long the meeting is and how many breaks we have in the meeting. I also decide how long the breaks should be.

My meeting will be easy for me to understand.

This means:

- People in my meeting should make sure they use types of communication I can understand in the meeting.
- If people ask me questions, they need to make sure I understand what I've been asked. They also need to make sure I understand the answers.

My meeting will be made personal to me.

This means:

- Sitting people where I want them to sit, standing up when I want to stand up or bringing personal things with me that I like.

Positive things happen as a result of my meeting.

This means:

- My meeting should not be all about talking. I expect people to do what they say they are going to do.
- My meeting will bring about positive changes in my life. If this doesn't happen, I have the right to complain.
- My meetings might help to create a plan or the meeting might review a plan that I already have like:
  - Transitions Plan
  - Education Health and Care Plan
  - Support Plan
  - Person Centred Plan
  - End of Life Plan
  - Discharge Plan

I may not have any plans but if I do, I should only have the plans that I need. No matter what type of plan I have, these things should happen:

I am involved in all of my plans.

This means:

- I should have support from the people I work with to:
  - Take part in making plans and checking my plans regularly.
  - Understand my plan. This will mean sitting down with me and taking the time to explain in a way I understand.
  - Make sure my plan is made in a way I understand. This could be in easy words, pictures, symbols or it could be digital, on a tablet or computer. It might also be in Braille.
  - Make sure I have a copy of all of my plans. My plans belongs to me and I should know where they are kept.

My plans talk about me in a positive way as a human being first.

This means:

- My plan is about me as a person and all the great things about me. It's not just about my disability or the illnesses I may have.
- My plans needs to reflect my culture and be informed by my heritage.

I see any information about me.

This means:

- As long as it is safe for me to see the information about myself, I should be supported to do so. There may be times when seeing the information would not be right for me.

I know that any information about me is to be kept confidential.

This means:

- My files and personal information are stored in a confidential way and no information about me is shared without my agreement.

Section 6:
Being in control

Being in control of my own life

I make my own choices and I am in control of my own life.

This means:

- I choose where I live, who I live with, what sort of job I have, what I do for fun or to socialise, how and what I choose to learn, how and if I worship, how I spend my money, who my partner is and what I do with them. I make lots of other choices as well about my life. All of my choices are mine to make.
- Having these choices means I am in control of my life. I can set my own path in life and this feels good.

I take risks and make mistakes.

This means:

- People can let me know the possible consequences of my choices and if there might be any risks, but I still have a right to make up my own mind about what I do in my life. Making mistakes and taking risks is one of the ways we all learn in life. Wrapping me up in cotton wool and overprotecting me just because I am disabled, will not enable me to learn and develop as a person.

I am listened to and have my wishes acted upon.

This means:

- People really hear what I have to say and are interested in what I have to say.
- People respect what I say and understand that what I am saying is important to me.
- When people have heard what I say, they work with me if I want or need them to in order to make sure my wishes are acted upon.

I am treated with respect as a person first.

This means:

- People will not always define me in relation to my disability. When this happens my disability is what people see first and is often all people see. This affects the way people talk to me, the way they behave around me and the way they work with me or support me. They often believe my options are limited because I am disabled, so they end up with lower expectations of me and my life. I have high expectations; I am capable of great things.

I am supported to be as independent in my life as I am able.

This means:

- Like everyone in society I do some things for myself and sometimes I want or need other people to do things for me.
- Just because I am disabled does not mean I want or need to have everything done for me. However, being independent does not mean I do everything for myself. It means I do as much as I am able to for myself. I will have some support with the things I find difficult. And the things I cannot do myself, someone else will do for me but in a way that I want them done.

I learn new things.

This means:

- I am able to learn to do new things. Just because I am disabled does not mean I cannot learn. I may need extra support to learn new things and it may take me longer sometimes, but I can still learn. My learning should be encouraged and supported.
- I have many gifts and talents and these should be developed. Just because I am disabled does not mean I have no abilities. I have gifts and talents and things I am good at, just like other members of the community, and these should be celebrated.

Paying for my support through a personal budget

Under the Care Act 2014 I have a right to a personal budget if I need support from social care.

A personal budget is the money from social care needed to pay for my care and support. Knowing my personal budget can help me to plan better and meet my needs in a way that works for me.

There are a few different ways of receiving a personal budget. One of them is called a direct payment. This means that I receive the money to pay for my care and have more choice and control. People say that they want their personal budgets in different ways depending on what would work best for them.

Personal budgets started in adult social care but some parts of the health service now offer a personal health budget. Sometimes people have funding from both health and social care. This is called an integrated personal budget.

I know about personal budgets. I have a right to be told what my personal budget is and to be supported to choose how to manage it.

This means:

- I should be told about a personal budget in a way that I understand. This could be in easy words and using pictures or someone explaining personal budgets several times.
- I may not want to manage my personal budget myself straight away but this option should still be offered and explained to me. Any questions I have should be answered.
- My family and those close to me could also be involved if this is what I want.
- If I am finding it difficult to understand and I don't have anyone else who can support me, I have the right to have a Care Act advocate.

I must be supported to choose the best way to manage my personal budget for me. I should have control over my own support and opportunities by having a personal budget.

This means:

- I must be involved in all decisions. Professionals must listen to me however I communicate.
- I can have a say in who manages the money (for example, me, my family, a service provider or a social worker).
- Even if the money is managed by someone else, I know how much money is available and I can tell them how I want it to be spent.

I have an assessment if I think I need support.

This means:

- Professionals will work with me to assess my needs. If I want more control over the assessment process I have a right to have a supported self-assessment.
- The assessment should include positive things about me, not just what I need help with.
- I should be able to say what I would like to happen and how I want to be supported. An advocate can help me with this if I need it.
- Professionals should listen to me and understand my ambitions. The plan should be what works best for me as an individual.
- I may have to pay some money towards my personal budget. This amount will be assessed and explained to me.

I have support to decide how I spend my personal budget.

This means:

- I know how much is available to spend.
- I have help, if I need it, to think about the different ways I can use the money to arrange my support. This could include "services", but could also include other things that aren't "services" that meet my needs such as a personal assistant to accompany me on holiday rather than going to a short break service.
- I have access to peer advice and support from disabled people in my area who can share their experiences and what worked for them.
- I have access to information I can understand about how good different options are.

I can have control over my personal budget.

This means:

- From the age of 16 I will be supported to manage my personal budget myself if this is what I want.
- Professionals will talk to me about how I can manage my personal budget myself and what this will involve.
- I can change my mind and make different decisions as I get more used to having a personal budget.

I can use my personal budget to enjoy friendships, relationships and family life. If I need support with this, then I can choose to use my personal budget for this purpose to help me meet my needs and achieve my outcomes.

This means:

- I can use my personal budget to design support that works for me. For example I could choose not to go to a day centre but to use my personal budget to go to places I want to visit so that I can meet new people, make friends and find a relationship if this is what I want.

I have regular reviews to make sure my personal budget is working for me.

This means:

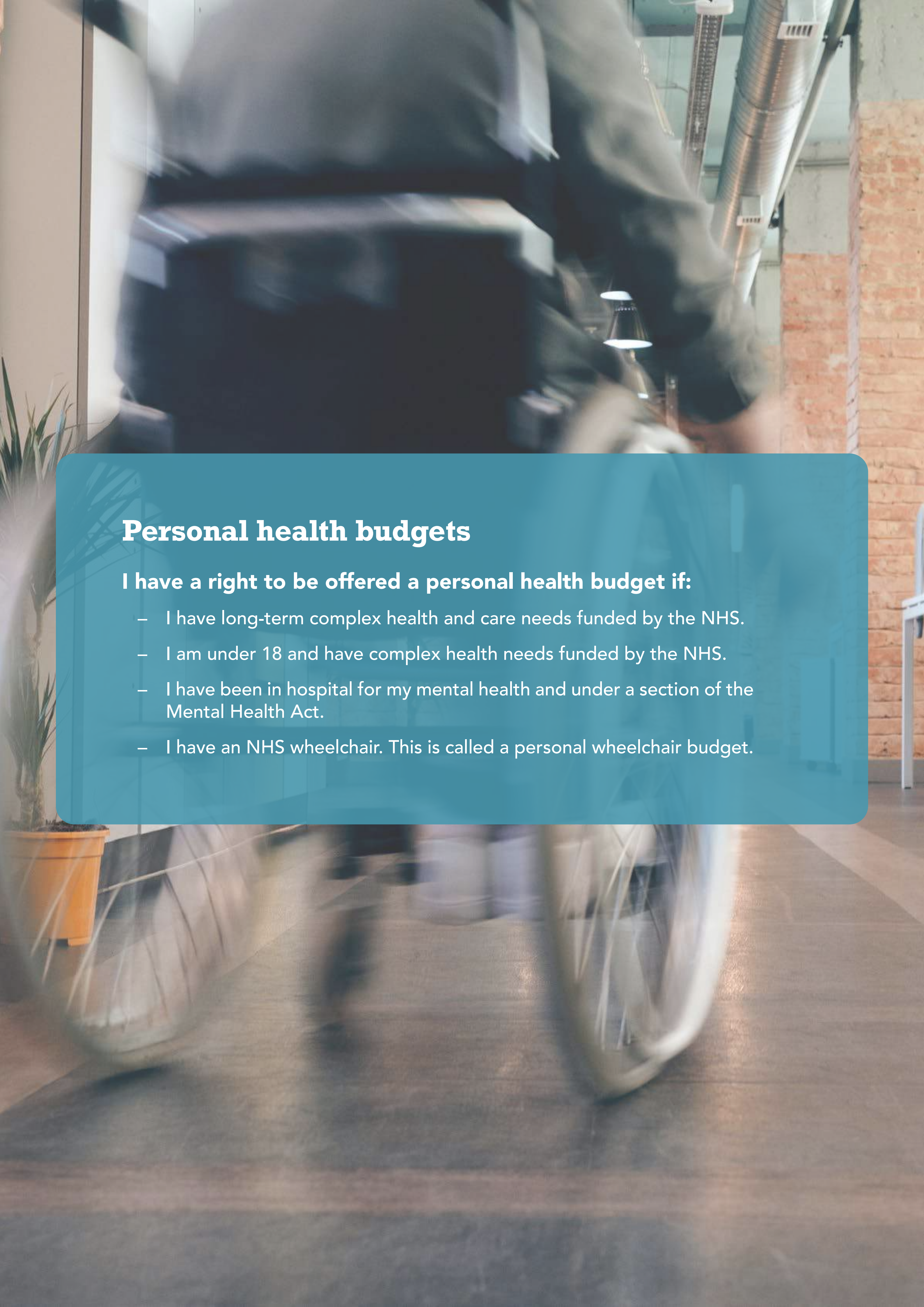
- My review will usually be with my social worker or Care Manager. I can choose to invite other people to the review
- I should also be able to contact my Care Manager if I feel my personal budget is not working for me and request a review.
- If I am not happy or disagree with a decision I have the right to appeal this at any time. I may be able to get support from an advocate to do this.

I may have a Direct Payment.

- If I decide to have a Direct Payment, I have a right to receive on-going support and information. This might be from a Direct Payment Support Service.

This means:

- This will include support to recruit my staff, write contracts of employment, payroll, complete the financial paperwork and deal with some staffing issues.



Personal health budgets

I have a right to be offered a personal health budget if:

- I have long-term complex health and care needs funded by the NHS.
- I am under 18 and have complex health needs funded by the NHS.
- I have been in hospital for my mental health and under a section of the Mental Health Act.
- I have an NHS wheelchair. This is called a personal wheelchair budget.

A personal health budget is an amount of NHS money to pay for health and wellbeing needs. A personal health budget can make it easier to get the right care and support and live my life the way I want to. Personal health budgets should help me to get better support and services if I do not always get the best out of the NHS. They should not make things worse.

In general, personal health budgets work in a similar way to personal budgets. There are a few different ways of receiving a personal health budget. I have the option to manage the money as a direct payment, a notional budget, a third-party budget or a mix of these approaches. I should be supported to choose the option that suits me best.

This means:

- I should have as much control over decisions as I want.
- I should know how much is in my personal heath budget.
- I should be supported to decide how to spend my personal health budget.
- I should be central in developing my personalised care and support plan and agree who is involved.
- I should be supported to agree the health and wellbeing outcomes (and learning outcomes if I am a child or young people with education, health and care plans) I want to achieve.
- I should have enough money in my personal health budget to meet the health and wellbeing needs and outcomes agreed in my personalised care and support plan.
- I should be able to use the money to meet my outcomes in ways and at times that make sense to me. This should be in my personalised care and support plan.
- If I change my mind and want to make different decisions as I get more used to having a personal health budget I should be supported to do so. I can request a review of my needs and my care plan at any time.
- I have a right to regular reviews to make sure my personal budget is working for me.

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*.

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