



Quality of Life Standards

Book 3: My health and safety



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.

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 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 3 of 3 of the Quality of Life Standards

Book 1: Living a full life, my home and employment and *Book 2: Communication, the way people work with me, being in control* can be found on [our website](#) alongside this publication.

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.23-25).

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.

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A photograph of a swimming pool with a white text box overlaid on the water. The pool has a metal ladder with two handrails. The pool deck is made of grey tiles, and the water is a vibrant blue. The text box contains the text "Section 7: My health".

Section 7: My health

W.T.

Being in hospital

- I should have access to a learning disability liaison nurse if I need one.
- Hospital staff should be trained in supporting people with learning disabilities and autistic people.
- I know how to get in touch with the learning disability nurse when I go to hospital.
- Staff must make reasonable adjustments for me. This means they must work with me and people who know me well to understand how they can make my hospital visit and treatment easier for me and then put these things in place for me. This might include having somewhere quiet to wait, avoiding busy parts of the hospital, having some tests done away from medical equipment, doctors taking stethoscopes off to talk to me, etc.
- Hospital staff must explain my condition and treatment to me in a way I can understand.
- Hospital staff must let me make decisions about my treatment unless I am not able to. They must not assume that because I have a learning disability or I am autistic that I cannot make decisions about my treatment even if what I want is not what they think is best.
- If I am not able to make decisions about my health and treatment then any decisions must be based on what is best for me and my health not on the fact that I have a learning disability or I am autistic.
- Do not resuscitate must not be written on my notes just because I have a learning disability or I am autistic.

Hospital passports

I should have a hospital passport.

This means:

- The passport should include details of any medical conditions I have and must be reviewed regularly to make sure it is always up to date.
- It should explain:
 - What my conditions might mean for my hospital stay or visit
 - How best to support me while I am in hospital
 - Things that are important for health care staff to know about my culture and explain
 - How best to communicate with me
 - Any allergies that I have
 - What I do or how I look when I am in pain
 - Who I want you to talk to about how I am doing in hospital
 - If I might want to see a chaplain or faith leader while I am in hospital

Discharge

I should not stay in hospital longer than I need to.

This means:

- Decisions about when I leave hospital should be based on my medical condition or the reason for my admission, not on the fact I have a learning disability.
- Hospital staff should work with me and people who support me to help me leave hospital when I am ready.
- Hospital staff must explain any changes to my medication to me in a way that I can understand.
- Hospital staff must make sure that any support I need when I leave hospital is ready for me.

A smiling man with glasses and a white lab coat is sitting at a desk with a laptop. The background is a bright, clean office setting with a green plant on the left. A semi-transparent blue box is overlaid on the image, containing text.

Primary care

- I have the right to choose my GP.
- I have the right to change my GP if I am not happy with them.
- I have the right to be included on the Learning Disability register if I want to be. This means I will be called for an annual health check.
- I will have information about my local health facilitation team.
- If I am over 14, I have the right to an annual health check. This should be done by my GP or nurse who works with the GP.
- I should have a Health Action Plan. It should include details of any health conditions I have and any support or treatment I need.
- Under the Mental Capacity Act 2005, health staff must let me make decisions about my treatment unless I am not able to. They must not assume that because I have a learning disability or I am autistic that I cannot make decisions about my treatment even if what I want is not what they think is best.
- If I am not able to make decisions about my health and treatment then any decisions must be in my best interests based on what is best for me and my health not on the fact that I have a learning disability or I am autistic.

Screening

I have the right to have all screening tests that are available to everyone else.

Staff must make reasonable adjustments for me.

This means:

- Staff must work with me and people who know me well to understand how they can make my screening test easier for me and then put these things in place for me.
- I have a right to have the test and the results explained to me in a way I can understand.

Health staff must let me make decisions about my treatment unless I am not able to.

This means:

- Staff must work with me and people who know me well to understand how they can make my screening test easier for me and then put these things in place for me.
- I have a right to have the test and the results explained to me in a way I can understand.
- They must not assume that because I have a learning disability or I am autistic that I cannot make decisions about screening tests even if what I want is not what they think is best.
- If I am not able to make decisions about my health and treatment then any decisions must be based on what is best for me and my health not on the fact that I have a learning disability or I am autistic.

Postural care passports

If I have the label of Profound and Multiple Learning Disability I should have a postural care passport.

The passport should contain:

- Details and photos of how I should be positioned through the day and night
- Details of any equipment I use and how to use it
- Details of how to transfer me when I need to be moved
- Describe how people know I am uncomfortable or in pain
- Details of the professionals and people who are involved in my postural care

It must be reviewed regularly by people who are involved in my postural care to make sure it is always up to date.



Complaints

I have the right to make a complaint.

This means:

- People should listen to my complaint. It should not be ignored.
- I should have support to make a complaint if I need it.
- There should be no barriers to making complaints.
- I should have information about how to make a complaint in easy read.
- I should know how to escalate my complaint if I am not happy with the response I get.
- If my complaint is not dealt with, I should have support to work out what other options I have. For example, I am able to contact a solicitors to be able to discuss my concerns towards my care or the Ombudsman.



My medication

I will have information about my medication in a way I understand.

This means:

- Staff who support me must have training in the medication that I take and know what the side effects are.
- I must not be taking medication that I don't need. I must not be given antipsychotics, or other medication for mental health that I do not need.
- If I am taking antipsychotic medication, I must be supported to reduce the medication as much as possible.
- If my medication does not suit me, I need to be supported to come off it or change medication.
- Organisations that support me should be signed up to the STOMP pledge (stop the over medication of people with learning disabilities).
- I should be offered alternatives to antipsychotic medication like talking therapy.



Mental health

- I have the right to access mental health services if I need them.
- Staff in mental health services must make reasonable adjustments for me. This means they must work with me and people who know me well to understand how they can make my assessment and any treatment easier for me and then put these things in place for me.
- I have the right to support from advocacy if I need it. If I am sectioned under the Mental Health Act I have the right to an Independent Mental Health Advocate (IMHA).
- I have the right to receive information in a way that is accessible to me.

A photograph showing a person's arm from the left side, holding a clenched fist. In the background, a person wearing a yellow shirt and blue jeans is cowering on a wooden floor, covering their face with their hands. The background is a plain, light-colored wall.

Section 8: Staying safe

Understanding abuse

There are many different types of abuse:

- **Physical abuse** is anything that causes me physical harm. This includes hitting, pushing, shaking, and giving too much medication or medication that I do not need.
- **Emotional abuse** is when someone says hurtful things to me, or when someone shouts and swears at me. It could be bullying and threats that make me feel afraid or humiliated.
- **Sexual abuse** is any sexual activity that I do not understand or do not want.
- **Financial abuse** is the illegal or improper use of my money. This includes anything I own, my pension and my bank account or savings.
- **Neglect** is when I don't have the help, support or treatment I need. This includes not giving me food, drink or medical care.
- **Domestic abuse** is when someone in my own household is abusive towards me (this could be, physical abuse, emotional abuse including trying to control me, sexual abuse, financial abuse or neglect). The abuser could be my partner, a family member or a carer.
- **Discriminatory abuse** means when someone treats me unfairly by being racist or sexist. Or I might experience abuse based on my age, my disability, my faith or my gender. I may be the victim of hate crime: A hate crime is any crime which the victim (or someone else) thinks happened because of who they are. The person who did the crime was hurtful, unfriendly and unfair to the victim because of the victim's ethnic or national origin, gender, disability, age, religion or belief, sexual orientation or gender.
- **Institutional abuse** means repeated poor care of vulnerable adults or groups of individuals through neglect or poor professional practice.
- **Professional abuse** is exploiting my vulnerability by taking advantage of my trust, and not acting in my best interest.
- **Forced Marriage** is being forced to get married by others, usually family. I may be tricked into going abroad, physically threatened and/or emotionally blackmailed to do so.
- **FGM (Female Genital Mutilation)** is a procedure where the female genitals are deliberately cut, injured or changed, but there is no medical reason for this to be done.
- **Online abuse** is any abuse that takes place on the internet. This can be through social media, gaming, emails, text messages and other online messaging, live streaming. Online abuse can be cyber bullying, grooming, sexual abuse, financial abuse.
- **Modern Slavery** is being forced to work for little or no pay through threats or violence and having no control over what work you do or where you do it.

In the event of abuse:

If I am abused, staff working with me or people close to me, like my family or friends, need to report this to the safeguarding team and maybe the police as well.

Safeguarding is about keeping people safe from abuse and neglect.

In each area of England, there are safeguarding teams that my staff should have the contact details of. If they think or I think I am being abused or experiencing neglect, they need to tell the local safeguarding team and if they think it is a crime, they also need to tell the police.

I am supported to understand what abuse is.

This means:

- I have clear easy to understand information about the different types of abuse.
- I have access to safety training so that I know how to stay safe online.
- The people that support me in my life should understand what the different types of abuse are, recognise these if they happen and know what to do next.
- I understand that abuse means I am being harmed by something that is being said or done to me.

I live my life free from abuse, hurt or neglect. I am treated with dignity and respect and I am not to be harmed.

This means:

- I understand that I should not be abused, hurt or neglected.
- I understand that this will be on purpose or by accident.
- I am given information about human rights in a way that I understand. I understand this means I should be treated with dignity, equality and respect.

Reporting abuse

I know who I report abuse to.

This means:

- Information about where to report abuse is available in lots of different accessible formats. I have support to understand this information if I need it.
- I understand that when I report abuse, this information can remain confidential if I want this to. This means that it stays private. If I am going to be made more vulnerable and I will be at risk from further abuse, my information can not always stay confidential.
- I have a right to have my voice heard. What happens to me is 'all about me' and I am in control of it.
- I understand that I should be supported to be involved in what is happening, why it is happening and what might happen next.
- I know who to talk to if I am worried about anything I see online.

I understand what to expect when I report abuse.

This means:

- I understand that my voice must be heard.
- I understand that my wishes will be followed.
- I understand that I will be kept up to date from start to finish.
- If the outcome is different to what I expect, I have the right to know why.
- I understand that this needs to be explained to me in a way that I can understand.
- I understand that I have the right to an appropriate adult or an intermediary if I need one. This is someone who can help me to understand the questions I am being asked.

I am given the chance to talk about my experience.

This means:

- Information is available in a way that I understand about my experience.
- After my safeguarding situation has been investigated, people may ask me for my views about the experience. They might ask me to complete a "customer survey". This will ask me questions about the experience of being supported through safeguarding. This survey needs to be accessible for me. I might want this to remain confidential.

I am supported by somebody I trust.

This means:

- I can change the people who are supporting me, if I don't trust them.
- I am told how I can do this and how I can make a complaint.

I am supported to get my voice heard.

This means:

- I have been given information that I can be supported through the safeguarding process.
- I have been given information about who could possibly support me throughout the process. This might be someone I know and trust or an advocate.
- It is my choice whether or not to report something. I should not feel forced into reporting something. Also people should not try to scare me into not reporting something if I want to. I should be supported to do what I choose.
- I understand that there may be situations where someone else has to report something that has happened to me if they feel I am at risk.

I understand how I can stay safe.

This means:

- I will have access to lots of different ways to find out about staying safe including:
 - Easy to understand information about staying safe.
 - Being involved in my local Neighbourhood Watch meetings.
 - Speaking to the police or another agency about safety in the home.
 - Knowing important numbers to ring if I feel unsafe.
 - Finding out about fire safety.
 - Being involved in a self-advocacy group, or self-help group.
 - Knowing about the Safe Places scheme in my area.
 - Having access to telecare to help keep me safe. This is equipment like an alarm which I wear and I can press if I feel unsafe. Or it might be a sensor that goes off if I fall over.
 - Having an emergency card that has my details on and who to contact in an emergency.

I can complain if I am not happy.

This means:

- I understand I have a right to complain and how to do this.
- I know how to access an accessible complaints form and can get independent support or advocacy to make the complaint.
- My voice will be heard and I will be kept up to date with the process. I will be supported to be involved in what is happening, why it is happening and what might happen next.
- If I am not happy with the outcome of my complaint I have support to take this further.

If I have been abused I can access information about counselling services and sources of support including helplines.

This means:

- I am told about counselling or support services that will support me with my particular needs.
- I have had information about different counselling or support services that are in a way that I can understand.
- I have been supported to understand what support services do and how they can help me.

Restraint and restrictive practices

Restraint is when health or social care staff restrict the movement, freedom and actions of people they support. Restraint can only be used when everything else has been tried and there is no other way to keep the person or other people safe. Restraint must never be used as a punishment or just to cause a person pain or make them unhappy.

Restraint includes:

- **Physical restraint** - when staff stop the person moving part of their body. For example, holding them so they cannot hurt other people.
- **Chemical restraint** - when medicine is given to calm someone down or sedate them.
- **Mechanical restraint** - when staff use something else to stop the person using part of their body. For example, a helmet, belt or splint on their arm.
- **Seclusion** - when staff keep someone away from other people, this could be in a locked room. It is usually so they cannot hurt them.

Restraint is not always wrong. In a very small number of situations, it can be the right thing to do. In Law, there are strict rules about using restraint and all staff should follow the rules. If they break these rules it is abuse and it should be reported.

I should not be prevented from doing the things I want to do or made to do things I do not want to do unless there is a real possibility of harm to me, my staff or the public if no action is taken.

If I am at risk of being restrained in a health or care service:

- People who support me should get to know me and talk to me about what helps me feel safe.
- People who support me should work with me to find other ways of keeping me safe before they use a restrictive practice.
- I should have an individualised detailed support plan. This should be up to date, written with me/by me and show all the ways of supporting me before a restrictive practice is used. Plans that I might have include a Wellness and Recovery Action (WRAP) plan or a Positive Behaviour Support (PBS) plan. The plan should identify proactive strategies that support me to have a good life and to strengthen my communication and life skills, as well as reactive strategies for what to do (or what I want you to do) when I become distressed.
- My plan should include how to prevent incidents arising, how to de-escalate or calm things down, and how to respond safely if incidents do still occur.
- My plan should include my wishes about particular approaches including medications, what staff can do to help me calm down or, if I need to be restrained, how to make this less distressing.

If I am restrained I should be supported afterwards.

- I should receive support from people who are supportive, compassionate and understanding, at a time and in a place that suits me.
- I should always have the opportunity to debrief. This means talking to someone I trust who can support, reassure and listen to me to ensure my physical and emotional wellbeing. It also means talking about what happened to learn more about how it can be avoided in the future.
- My plans should be updated to reflect any new learning.
- If I believe that I have been restrained unlawfully I have a right to report it (see above).

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 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.

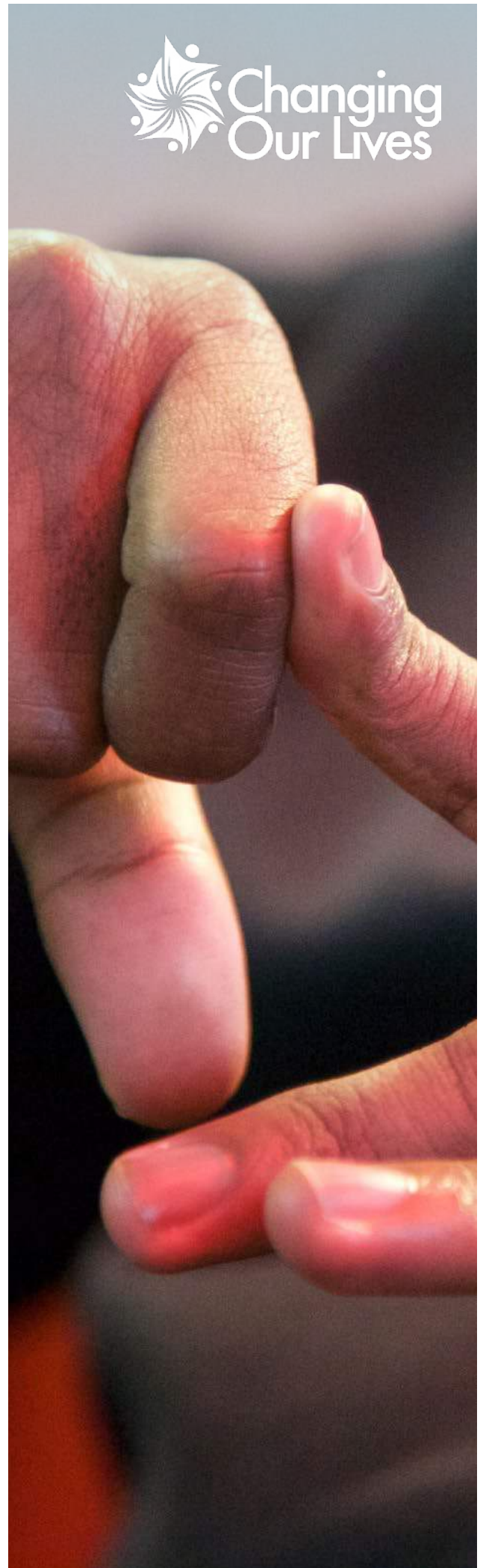
Making an ordinary life *possible.*

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