

Changing Our Lives

# Quality of Life

Standards & Toolkit

# Foreword

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People with learning disabilities have the right to lead their lives like anyone else. They must have the same opportunities and responsibilities, and be treated with the same dignity, respect and human rights. The Government is firmly committed to improving their lives by removing barriers to participation in society, and promoting greater inclusion and equality, and better life chances.

These Quality of Life standards have been written by over 650 young people and adults with learning disabilities, in partnership with their peers with a range of physical disabilities, sensory impairments and mental health needs.

The standards are intended to raise the aspirations of people with learning disabilities and their families from around the country, so they can both speak out and take action when people with learning disabilities are not being supported to live as equal citizens. Being an equal citizen in today's society is important to all of us.



The 3 fundamental principles underlying the standards are:

**Equal citizenship and integration**- the standards are based on a model of equal citizenship where people with learning disabilities are seen and respected as equal citizens in society, being integrated into the community as active participants.

**Personalisation** – the standards are not a set of service standards; they are based on the assumption that people decide what support they need to be independent, who will provide that support, and where and when that support will be provided so it is timely and meets their particular needs.

**Quality** – the standards are about quality as defined by people themselves. These standards set the benchmark for commissioners and providers alike, as well as giving people with learning disabilities a set of “ordinary aspirations” against which they can measure the quality of the support they are receiving.

These standards must aim to raise people's expectations, reflect aspirations about what a good quality of life really means. The standards apply to all people with disabilities, whatever their level of disability. They are standards about having a full and valued life. I strongly encourage all commissioners and providers to make sure that staff working in services apply them in everything they do.



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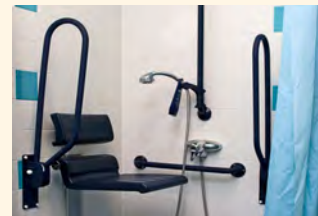
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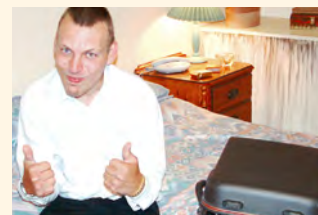
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# Introduction

The Quality of Life standards aim to raise people's expectations about what a good quality of life really means.

The standards have been written by over 650 children, young people and adults with learning disabilities and autism.

We have also written these standards in partnership with our peers with physical disabilities and mental health difficulties to make sure these standards work for everyone's life.

The standards are based on people with disabilities being seen and respected as equal citizens in society.



# These standards aim to raise people's expectations

## What being an equal citizen means to us:

We are valued as people first, as loving family members, as rebellious teenagers, as paid employees, as community leaders, as home owners and tenants, as neighbours, as friends and partners. We have a disability but this should not, and does not define us.

We are seen in society and have active lives in society. We do not live in service land and stay in segregated services where the only people we meet have disabilities.

We are living an 'ordinary' life, with its challenges and responsibilities. We are not kept away from any risk and we are not over protected. We take our own risks and make mistakes, we change our mind and get into trouble, just like other people.

We are in control of our own lives, making our own choices about where we live, who we live with, who we have relationships with, where we work, how we spend our own money and what we do to both learn and have fun. Being in control of these things improves our quality of life.

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 about equal citizenship. They are standards about having a full and valued life!



# These standards aim to raise people's expectations

## The standards apply to all people with disabilities

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

Sometimes people question the mental capacity of people with learning disabilities. They make the assumption that people can't make their own decisions or do things for themselves. This is wrong. Just because I might struggle to make decisions in one area of my life, does not mean I lack capacity in all areas of my life. Everyone in my life needs to start by assuming I have the ability to be in control of my life.

You need to have this in your mind as you read these standards. And also remember whatever my disability, I have a right to a good quality of life. For example, if I have a learning disability and have no formal way of communicating such as words or a sign or symbol system, sometimes I get frustrated if people don't understand what I want or how I feel and then I express myself through my behaviour, this does not mean I should have a poorer quality of life. It might mean it takes more time and more effort to support me to achieve a good quality of life, but I have a right to a good quality of life just like anyone else.

## Who are these standards for?

These standards aim to raise people's expectations about what a good quality of life really means. They are aimed at commissioners who buy services, providers of service and staff who work with people with disabilities and people with disabilities themselves.

## Quality of Health Principles

We have not talked about health in these standards because we have already written the Quality of Health Principles which are in NHS contracts in England. The Quality of Health Principles were written by people with physical disabilities, people with sensory impairments, people with learning disabilities, people with autism, as well as older people and people with mental health needs. They tell staff, commissioners and people with disabilities what makes a good patient experience.



## Section One

# Being in control of my own life

**I have a right to make my own choices and be 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 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 have a right to 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 just because I have a disability and over protecting me, will not enable me to learn and develop as a person.

I have the right to be treated with respect and as a person first.





I have a right to  
learn new things

### **I have a right to be 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, to make sure my wishes are acted upon.

### **I have a right to be 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 have a disability, so they end up with lower expectations of me and my life. I have high expectations; I am capable of great things.

### **I have a right to be independent in my life.**

#### **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 have a disability 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 have a right to learn new things.**

#### **This means:**

I am able to learn to do new things. Just because I have a disability 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 have a disability 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.



## Section Two

# My Voice

### Communication

#### This means:

- I will have a Communication Passport. This is a way of telling people how I communicate. It could be a book, a DVD or a CD-ROM. It should be updated regularly. It should travel with me into the community and places I go. I should always have a copy of my own Passport. It should not be filed away and forgotten.
- I will be involved in creating my Communication Passport.
- All information should be made easy for me to understand based on what it says in my Communication Passport.
- If I need them, I will have Speech and Language Therapy working with me.
- My staff 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 or other ways of communicating.
- People should talk to me, even if I use other ways of communication. I should not be left with no one talking to me or acknowledging me.
- I will have an interpreter work with me if I need one.

I have a right to have my communication respected and to be communicated with in a way I understand.



# 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 have a disability does not mean I need 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 plans I may have are:

## A Transitions Plan

This can have different names such as a “Getting Ready Plan”. This plan tells people what I will do in my life after school. This will include my education, paid work, travel, housing, my health, my friends, my personal budget and leisure activities.

## Education, Health and Social Care Plan

This is a new plan I have as a child that enables education, health and social care services to all work together so I have better outcomes in my life.

## Support Plan

This tells people what support I need in order to have positive outcomes in my life.

## Person Centred Plan

A Person Centred Plan tells people about my hopes and dreams. It has an action plan which says how I will achieve my dreams.

## End of life plan

This is a plan which tells people what I would like at the end of my life.

No matter what type of plan I have, these are my rights:

**I have the right to be 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 on a DVD or CD-ROM. It might also be in Braille.
- Make sure I have a copy of all of my plans. My plan belongs to me and I should know where it's kept.

**I have the right for my plans to talk about me in a positive way.**

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.

**I have the right to see any information about me.**

This means that 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 have the right to be reminded 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.

# My Meetings

**I may have lots of meetings such as a person centred planning meeting, an assessment meeting, a support planning meeting, a review meeting or a transitions meeting.**

- A **person centred planning meeting** looks at my hopes and dreams for the future. People in this meeting work with me to see how my dreams can become real.
- An **assessment meeting** is where I work with a professional to find out about me, my needs, what I want to do, what I am good at and what support I need.
- A **support planning meeting** is where I work with a support broker to look at how I can spend my personal budget or direct payment, so I can have a good life.
- A **review meeting** is where I meet with a professional to check that all the things in my assessment are being done. In this meeting, I can also tell people when things aren't happening and ask for things to be done. My life should get better because of this meeting. If it doesn't, things need to change.
- A **transition meeting** happens when I am about 14. In the meeting all areas of my life are planned for, including education, paid work, travel, housing, my health, my friends, my personal budget and leisure activities.

**I might have other meetings when I am growing up as well. But no matter what type of meetings I have, these are my rights.**

**I have the right to 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, such as on a minibus, at McDonalds 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.

**I have the right to 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.

**I have the right to be supported to chair my meetings.**

**This means:**

- 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.

**I have the right for my meeting to 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.

**I have the right to make the meeting 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.

**I have the right to have 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.



# Speaking Up for Myself and Advocacy

## **I have the right to support from advocacy.**

### **This means:**

- I have support to go to self-advocacy groups. A self-advocacy group is independent of services. It is a place where I can meet other people with disabilities. We can work together in the group to support each other so we have better lives, and other people with disabilities 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 have a right to have my views heard without my family being there.**

### **This means:**

- Although my family is really important, I need to be listened to first.

## **I have the right to make a complaint. This means:**

- 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.

## **I have the right to vote and understand why I am voting.**

### **This means:**

- I am supported to vote in local and general elections.
- I have easy to understand information about voting and support if needed to get to the polling station.

I have a right to have my views heard without my family being there





I have the right not to be abused, hurt or neglected.

## Section Three

# Staying Safe

There are lots of different types of abuse:

- **Physical abuse** is anything that causes me physical harm. This includes hitting, pushing, shaking, and giving too much medication.
- **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.
- **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.
- **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.



**I have the right to be supported to understand what abuse is.**

**This means:**

- I have clear easy to understand information about the different types of abuse.
- The people that support me in my life should understand what the different types of abuse are.
- I understand that abuse means I am being harmed by something that is being said or done to me.

**I have the right to be treated with dignity and respect and 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.

**I have the right to know who I report abuse to.**

**This means:**

- Information about who to report abuse to is available in lots of different accessible formats. People support me to understand this information.
- 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 have the right to understand what to expect when I report it.**

**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 have the right to be 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 have the right to be 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 have the right to be 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 what an independent advocate does as this has been explained to me.
- I know who to tell that I need an independent advocate.

### **I have the right to 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.
- Going to my local Neighbourhood Watch meeting.
- 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.

### **I have the right to 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 have been abused I have the right to get information about counselling services.**

#### **This means:**

- I will be 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 they do and how they can help me.





## Section Four Personal Care

I have the right to receive my personal care in a way that is respectful



Sometimes I may need personal care. This is when someone supports me to go to the toilet, keep myself clean or change myself. I have these rights for my personal care.

I have the right to receive my personal care in a way that is respectful and in a way in which I choose.

**This means people who work with me should:**

- Support me to be as independent as I am able, in all of my personal care. Enable me to have access to equipment if this is going to make me more independent in my personal care, for example a shower seat.
- Work with me to find out how I want to receive my personal care. This should be recorded in a way I can understand.
- Support me to have my personal care in private.
- Understand my personal space and let me know what they will be supporting me with before it happens. For example, staff should tell me they are supporting me to go to the toilet and not just take me there.
- People should know my preferences. For example if I like a shave every other day, or every day, or if I like my nails painted. These things should be in my Support Plan or my Life Book, which may record my life history if I am older person.
- Support me to have a bath or a shower when I choose and not when it's convenient for workers or a service.
- Arrange for the staff who support me with personal care to be the same gender as me.



## Section Five

# Having a Full Life

### Being part of the local community

**I have a right to be a valued member of the community.**

**This means:**

- I will get to know my local community and go to activities in my local community, for example clubs, theatre or leisure activities.
- I will be supported to develop hobbies, if I want to and learn about things that interest me.
- I will go where everyone else goes, and not always use 'services' that work with people with disabilities.
- I will 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.
- I will find out about religious and cultural groups and activities in my area and be supported to do things with people from my own cultural background, if that is what I want.
- I will practice my religion.
- I will be supported to have good relationships with my neighbours.
- I will be supported to develop in local leadership roles, for example, town crier, Expert by Experience advisor to Council Scrutiny Committee.

I have a right to be a valued member of the community.



## Travel

**I have the right to travel on public transport just like any other person.**

**This means:**

- I will be offered travel training so I can travel independently with confidence.
- If I have my own car through mobility allowance I will 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 have a right to go on holiday**

**This means:**

- I will go on holidays that I choose. I will choose whether I want to go alone or with friends, my family or my partner.
- I will be supported to visit different places on holiday so I can find out what sort of holiday I like best.

## My family

**I have a right to have my family 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.
- Keep my family up to date with things about me.

## My friends and relationships

**I have the right to have support to see my friends and make new friends.**

**This means:**

- I will keep in contact with friends, seeing them at my home, their home and other places in the community.
- I will see my friends in private. I won't have staff listening in on my friendship.
- I will go places and meet new friends.
- I will have friends stay over in my home if I wish.



**I have the right to 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 is provided for me in a way I can understand.
- I have support to get married, have a civil partnership or live with my partner.
- I have a right to 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 have a disability, I will not be able to parent my child.

**I have a right to express my sexuality and gender.**

**This means:**

- I will go to gay bars and venues, if this is what I choose.
- Cross-dress, if this is what I want to do.
- Speak to professionals or self-help groups, if I need support with my sexuality or gender.



## My Money

**I have the right to look after my own money, with support if I need it.**

### **This means:**

- I have support, if I need it to look after my own money. If I understand how to look after my own money, I will keep it with me. 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.
- I will have independent financial advice.
- I will be supported to get advice from Welfare Rights, if I don't work.
- If 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.



## My Education

**I have a right to reach my full potential by learning new skills and knowledge.**

### **This means:**

- Being supported to reach my potential as independently as possible, so that I can have an active life.
- Being supported to prepare for being an adult and having adult responsibilities.





**I have a right to an education that prepares me for paid employment**

**This means :**

- Having careers advice and information from a specialist employment support service from the age of 14.
- Having a school curriculum that prepares me for the world of work, not a lifetime in services.
- Having 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 a right to understand what I will gain from any education I take part in**

**This means:**

- Getting skills and qualifications which I can use to get myself a job and a career. This means I am not left in the same dead-end college course year after year, making no progress.



**I have a right to an education that prepares me for paid employment**



## Section Six

# My Home

I have a right to live  
in a home that I have  
chosen

**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 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 support housing**

Extra support 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 socialize 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's my home. People might be paid to support me in my home, but it's my home.



## Where I live

**I have a right to live in a home that I have chosen**

### **This means:**

- 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 am told which housing options will give me more independence.
- I am supported how to find one of these places to live.
- All of this information is given to me in an easy to understand way.
- 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.
- 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.



## Who I live with

**I have the right to 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 will mean I am at risk of being labelled "challenging" if I don't get on with them.
- 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.



## Tenancy agreement

**If I live in supported living, I have a right to a tenancy agreement.**

### **This means :**

- I will be supported to understand my responsibilities under this tenancy agreement. This tenancy agreement will be in easy read. It will also 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. 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.
- 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.



## My home inside and out Private space

**I have a right to choose what my home is like inside and out.**

**This means:**

- I will choose how my home is decorated.
- I will choose my furniture and all other things for my home like a cooker for my kitchen and my TV.
- I will choose what I have in my garden. For example, if I want a lawn and flowers.

## My personal things

**I have a right to 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.

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

**I have a right to private space to either be on my own or entertain guests.**

**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.
- 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 and or any staff should always ask me if it's ok for them to go in my 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 the right to be supported 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. 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.**

- I will have support, if I need it, to shop for my own food.
- I will choose what I eat and drink and when I want to eat and drink.
- I will have support to prepare my own food.
- I will choose what time I get up and go to bed.
- I will choose what I wear and have support to shop for my own clothes.
- I will choose what happens in my home, including who comes to my home and who does not come.

For more information on rights around choices and being independent see section one and five.

**I have a right to 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.**

### **Some examples of telecare:**

- An alarm which hangs around my neck. I 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.

### **This means:**

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

## Accessible home

**I have a right to 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 will have adaptations if I need things to make it more accessible. For example, if I need a ramp, handrail, loop system or a fire alarm system with flashing lights.





## Section Seven

# Employment

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

**I have the right to be supported to have paid employment. Just because I have a disability does not mean I can't work. With the right support I can find paid employment.**

**I expect to receive support to help me get a job in a person centred way.**

**This means:**

- 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, such as employers and other staff who support me.
- Providing information and advice to me that I can understand.
- 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 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.





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

**This means:**

- 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.
- Making sure that I'm not put in a dangerous or risky situation that might cause me harm.
- Not putting up with harassment 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.



**I expect to receive support when I start my job.**

**This means:**

- Making sure that I choose the job I want and make my own decisions.
- Having a plan, led by myself, 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 want to make sure I'm good at the work I do, and have the skills to do it.**

**This means:**

- To support me understand what I have to do, and explain 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.



## Section Eight

# Buying My Own Support

**A Personal Budget is money you can use to organise and buy your own care and support.**

**A direct payment is money given to people to pay for their support.**

**Direct payments give people more choice about the care and support they want.**

**I should have control over my own support and the services I access by having a personal budget.**

**This means:**

- I will be told how much money I have to spend on my support.
- Social services may keep my money for me and I will tell them how I want it to be spent, or I can have the money as a Direct Payment and use it to either employ my own personal assistant or buy a service.

**I have a right to always be offered a personal budget as the first option of managing my support.**

**This means:**

- I should be told about a personal budget at every review meeting.
- I have a right to have support to complete a self-assessment. This could be from my Care Manager or support brokerage.
- My family and those close to me could also be involved if this is what I want.

**I have a right to have support to decide how I spend my personal budget.**

**This means:**

- This will be from the support broker.
- My support broker will be able to tell me what services and support are out there for me and help me decide how I want to spend my budget.
- My support broker should tell me about the universal services that are available not just services for people with disabilities.

**I have the right to a good quality service or support with the money I spend from my personal budget.**

**This means:**

- The support brokerage team will know about the quality of different services and supports. They will be able to give me this information.

**I have a right to use my personal budget to facilitate friendships and relationships.**

**This means:**

- I can use my personal budget to access my local community so that I can meet new people, make friends and find a relationship if this is what I want.



## My Personal Budget

**I have a right to be told about personal budgets in a way I understand.**

**This means:**

- This could be in easy words and using pictures or someone explaining personal budgets several times. I may not want a personal budget straight away but it should still be offered and explained to me.

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

**This means:**

- My review will be with my Care Manager.
- 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.
- From the age of 16 I will be supported to manage my personal budget myself.
- My Care Manager will talk to me about how I can manage my personal budget myself and what this will involve.



## Direct Payment

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

**This means:**

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



**I have a right to always be offered a personal budget as the first option of managing my support.**





## Section Nine

# Short Breaks

I have the right to ask for a direct payment or a personal budget for a short break.

A short break is when I spend time away from my family carers.

This could be staying away from home, either overnight or for a few nights.

It could also be doing things away from home like going to a youth group, a trip to the cinema with support or some other leisure activity.

It might also be having a paid person come into my home to support me when my family is out or when my family needs a break. This is called domiciliary care.

It might also be living in a family for a short period of time. This is called shared care.

Whatever short break I have, these are my rights.

**I have a right to be supported to travel independently to the short break if I choose to.**

**This means:**

- I will have support to travel on public transport so I can be more independent.
- I will be supported to get a bus, tram or train pass.

**I have a right to choose my own short break.**

**This means:**

- The short break needs to be right for me and not just right for my family.
- I can choose when I have my short break and the times should suit me.

**I have a right to a short break plan.**

**This means:**

- My short breaks will be set out for the year in a plan.
- The plan will be produced in a way I can understand.
- The plan will be produced in partnership with me and my family.

**I have the right to ask for a direct payment or a personal budget for a short break.**

**This means:**

- I can choose what I spend the money on for the short break.

## Leisure Short Breaks

**If my short break is a leisure activity, I have a right for this to be a meaningful activity that encourages my independence.**

### **This means:**

- I go to leisure activities that everyone else goes to in my local community. I have a right to go where everyone else goes, and not always use services for people with disabilities.
- I try new activities even if I choose not to carry on with them. I try new things even if there is some risk involved, as long as people try to keep me safe.
- I do activities that reflect my cultural needs.

**I have a right to accessible leisure activities.**

### **This means:**

- Staff at the activity should be able to communicate with me. They should ask me how I communicate and look in my Communication Passport.
- The staff should be trained in different ways to communicate.
- The activities should be accessible to my physical needs, and any needs I may have if I have a sensory impairment.

## Domiciliary care

**Domiciliary care is when a paid person comes to support me in my home. This gives my family carers a short break. If I pay for this with a personal budget or a direct payment, I have the rights set out in section 8 of these Standards (Buying My Own Support).**

**If my short break is support in my home, these are my rights:**

**I have a right to choose who comes in to support me.**

### **This means:**

- If the staff member comes from a care agency, they must arrange for me to meet this person before they come in to support me.
- The care agency must send the same person every time, if this is what I want.
- I can choose to change the person if they are not good.
- I can choose a man or a woman.
- The person should support me at times that suit me and my family.
- The person must understand my communication, my needs and the things I like and don't like.

**I have the right to choose what type of things the person supports me with.**

### **This means:**

- They should get to know me and what I like and what I don't like.
- They should do things I like and not things that make their life easier. For example, if I want to play football or go to the pub, it is their job to support me with this, otherwise they are not suitable for the job.





**I have the right to  
choose how I spend  
my time**

## Staying away from home on a short break

My short break might mean I stay away from home in another family, or in a residential setting. Or I might go on holiday for my short break. I have these rights:

### **I have a right to stay in a place that I have chosen.**

#### **This means:**

- I will have support to choose what sort of place I go to.

### **I have the right to private space so that I can be on my own if I want to.**

#### **This means:**

- I will be asked when I want private space and this will be made available for me.
- People will knock the door before they come into my room.
- If I am busy I can ask people to come back later.
- I will use the phone in private.

### **I have the right to stay in a place that is easy to get around.**

#### **This means:**

- The place I stay has things in it that make it easy for me to move around. For example, I might need a ramp to get in and out and I might need handrails, or if I am deaf I might need a loop system.

### **I have a right to keep and enjoy my own things.**

#### **This means:**

- I can lock my own room to keep my things safe.
- I can decide who comes into my room.

### **I have the right to decide when I get up and when I go to bed.**

#### **This means:**

- I will be able to choose the time I get up and time I go to bed.
- If I am a young person, I may need to go to bed earlier in the week if I have school or college. At the weekend or during holidays I can choose what time I get up and go to sleep.

### **I have a right to choose what I wear each day.**

#### **This means:**

- People support me to choose the clothes I wear each day.

### **I have the right to choose what I eat.**

#### **This means:**

- I will have a choice of what I eat on my short break. People will explain to me what the choices are in a way that I understand.
- If there is a menu, this will be easy for me to understand with pictures or symbols. Or it might be made easy to understand in another way.



**I have the right to choose how I spend my time. This includes what I do in the day, evening and weekend.**

**This means:**

- I am supported to make informed choices about how to spend my time.
- The activities I am supported to do enable me to be as independent as possible.
- I am supported to access activities used by anyone in the community, not just activities that disabled people do.
- I am supported to do things with my friends or partner.
- I am supported to be in control of my own money, if I go out shopping or to a place where I can spend money.

**I have the right to have people treat me with respect.**

**This means:**

- People treat me as an individual and value the positive things about me.
- People do not dwell on negative things or see my disability first.
- People will include me in decisions.

**I have the right to be supported to be as independent as possible when staying on my short break.**

**This means:**

- I will do as much for myself as I am able, with support.





## Section Ten

# The Way People Work With Me

This section of the standards is about people who work with me. These could be staff I employ through a direct payment, or staff that work with me through a supporting service. They could also be people that support me in other ways such as social workers, or support brokers.

### **I have a right to choose who works with me**

#### **This means:**

- I am involved in interviews for people who are paid to work with me, such as supporting staff.
- I can change the people I work with if they do not do a good job. I know how to change these people by making a complaint or asking for a new person.

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



**I have the right to 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 people with disabilities are equal citizens. As well as training in how to support people with disabilities 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.
- 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 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.
- 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 ability to make some decisions 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.
- The people who work with me speak to me directly and not my paid support or my family.
- The people who work with me understand I can challenge things I don't agree with, without being judged and labelled as difficult.





# Quality of Life Toolkit

## Quality Checking across England

**This toolkit gives an overview of some of the ways the Quality of Life standards can be used to both check the quality of support and services and to challenge culture and develop new practice.**

It is impossible to put a step by step guide for how to check services and supports into one toolkit, as there are now many different organisations around the country working with people with disabilities to lead quality checking programmes. These quality checking schemes have developed in local areas led by independent self-advocacy or rights based organisations like Changing Our Lives or Skills for People, whilst others have developed in provider organisations like Choice Support.

These organisations all work slightly differently. However, all of the 'quality checking' models have these things in common:

- The quality checking process is led by a paid person or team of people with disabilities. All organisations recognise these paid individuals for their life experiences as "Experts by Experience" but also train these individuals to gather evidence against set standards.
- The focus of all quality checking centres around improvements in quality of life so more time is spent with individuals, family carers and people close to them, and less time is spent looking at paperwork, plans and talking to professionals.
- Common tools used are informally spending time with the individual to chart their life, observation, checking people's plans with permission and checking accessible information and environment.
- All of the work is based on the belief that people with disabilities are equal citizens.

Some of these organisations have come together to form the Association of Quality Checkers. This Association will sign post commissioners, providers and anyone who is interested to local quality checking organisations.

# Changing Our Lives Quality of Life Programme

## 1. What is a Quality of Life audit?

A Quality of Life audit is a person centred way of measuring how services and community supports enable people with disabilities to lead an 'ordinary life'.

We define an 'ordinary life' as:

- being part of the community
- being employed
- having access to education which enables you to develop as an individual
- living in your own home
- being in a relationship
- having friends and family around you.

If people with disabilities are supported to lead an 'ordinary life', they are recognised as equal citizens, not defined or limited by their disability. It is important to remember that this applies to ALL people with disabilities; no one is too disabled, too complex or too challenging to lead an 'ordinary life'.

As the audit measures how services and community supports enable people with disabilities to lead an 'ordinary life', Quality of Life audits can be used in any provision. Here are some areas where they have been used in the past:

- Supported living
- Residential and nursing care
- Short breaks including residential respite, support in the home and a range of community provision
- After school clubs, youth clubs and nurseries
- Leisure provision
- Youth and community groups and organisations
- Direct payment and personal budget provision
- Social work teams both in adult and children's services
- Or used as a person centred way of measuring the effectiveness of a whole service, for example, local authority learning disability services.

**Over the last 3 years our Quality of Life audit team worked with 1241 people covering 165 services.**

## 2. Audit measures

As each audit focuses on an 'ordinary life', each audit is measured against the Quality of Life Standards.

## 3. Individual outcomes and longer term cultural change

As the audits are person focused and not service focused, they not only aim to bring about life changes for the individual, but also push beyond service improvements, to service redesign and longer term cultural change. For this reason the actions identified from the audit need to be owned by those people in Local Authorities or Clinical Commissioning Groups who can make a decision about commissioning and finance and in provider organisations by the CEO and board of trustees or directors. As the Quality of Life programme sits within an organisation that is independent both of statutory bodies and provider agencies, this better enables us to advocate for change.

### Example

An audit covering 60 people with learning disabilities using a range of local supported living provision could bring about:

- improvements to the individual's lives that were part of the audit
- a new vision and commissioning strategy for supported living
- a reinvigoration of the market
- an awareness amongst the wider population of people with disabilities of the range of housing options available to them.

### Example

Working with Anytown provider, an audit covers 50 people in 8 residential homes. The audit could bring about:

- improvements to the individual's lives that were part of the audit
- as the audit showed people did not have the same opportunities living in a residential home, as they would have in their own tenancies, the provider working with local commissioners and a housing association decided to offer people packages of support in their own tenancies over time. This change was reflected in the provider's business plan and was welcomed by commissioners.



## 4. Quality Team

The audits are led by both young people and adults with disabilities who are seen as Experts by Experience, in conjunction with a Quality Partner.

The role of auditor is a professional role; the auditor is not there to give their personal perspective as a person with a disability, although we acknowledge the life experiences the person may have gives them an important and unique perspective. The auditor is there to measure quality of life against the Quality of Life standards by gathering a robust body of evidence from a range of sources.

The Quality partner is an experienced individual who has an understanding of both the policy and practice context of the area being audited, as well as an approach and value base which means they do not take over and work as an equal with the auditor with disabilities.

## 5. Methodology

A range of tools are used in each audit and these are adapted dependent on the focus of the audit. They include:

- spending time with individuals and 'walking through' their life, getting to know them and asking them a series of questions about their experiences; if appropriate with permission telling their story
- meeting with the person's family to explore their experiences and views
- unannounced visits of services and supports, where possible
- interviewing staff teams, managers, Directors, CEO
- observation of practice with a focus on communication and interaction between professionals/staff and people they work with
- checking people's plans e.g. person centred plans, communication passports and other documents for best practice
- checking strategic documents such as commissioning strategies, business plans for providers

To find out more about the Quality of Life programme you can contact us on  
[ask@changingourlives.org](mailto:ask@changingourlives.org)

# Some of the ways the Quality of Life standards and audit approach are being used by commissioners



## Changing Our Lives partnership work with Sandwell MBC

Since 2008 the Quality of Life standards have been embedded in adult learning disability provider contracts in Sandwell. In the last 3 years (April 2011- March 2014) paid auditors with learning disabilities from Changing Our Lives Quality of Life audit team have worked with over 500 people on audits covering over 50 services including nursing homes, residential care, supported living, day services, short breaks and NHS campuses.

The Quality of Life audit team has also audited the impact of the Community Learning Disability Team on the lives of the people they support and a young people's audit team called the Quality Crew has taken the audit model into children and young people's services. In the last few years the Quality of Life audits have also started to measure the impact of a range of universal services.



## Key factors that have helped this work succeed

- Sign up from senior leaders in Sandwell. This has ensured the findings from audits not only improve the lives of individuals, but that they also help shape the social care landscape across the borough. The Quality of Life standards are embedded in Adult Services commissioning priorities and selection processes. In practice this means that aspirations expressed by people with learning disabilities in the Quality of Life standards are helping to shape the market and drive up quality locally amongst providers.
- Many people have been part of the Quality of Life audit process over several years, so the audit team has got to know individuals and established relationships with them over time. This has enabled the Quality of Life team to have a depth of understanding of people's lives and so they are better able to champion the rights of these individuals when they may be experiencing poor quality services or support.
- Regular meetings between Changing Our Lives and contract and commissioning leads where audit themes and local intelligence gathered by the audit team is shared. This local intelligence is used to shape the market, and both celebrate good practice and challenge poor practice.
- Relationships with providers are developed by the Quality of Life audit team so best practice is shared and used as a catalyst for cultural change.
- Best practice documents are shared, e.g. Communication Passports, person centred care plans.
- The Quality of Life standards are used to train staff and learning from training is measured via staff supervision and appraisal systems.



# Quality of Life Standards in Dudley MBC

Stuart Lackenby,  
Head of Commissioning, Efficiency and Making It Real



In Dudley we have embraced the Quality of Life standards as a mechanism to enable us to ensure that through the delivery of social care support we positively improve the quality of people's lives and challenge provision that reduces people's independence or restricts people's rights. As such the Quality of Life approach is central to our Making It Real work across Dudley. This approach has involved building the Quality of Life standards into our:

- Assessments
- Support plans
- Contracts
- Dudley quality standards
- Quality checking processes
- Workforce development.

This work was completed in partnership with Changing Our Lives and means that the Quality of Life standards run as a golden thread to every thing we do.

Having redesigned our assessment and plans, our next step will be to retrain our workforce to deliver the Quality of Life approach. This will be done in partnership with Changing Our Lives and will bring about a significant cultural shift, changing the way we work. It will not be acceptable for people's lives to be summed up in time and tasks that relate to personal care.

The Quality of Life standards are being included in all of our contracts with external providers and as such each organisation will from a commissioning perspective be expected to demonstrate the positive outcomes they are delivering in people's lives against the standards. Our residential and nursing contracts will include the Quality of Life standards by July 2014. Our expectation is that the introduction of the standards will bring about a reduction in safeguarding alerts and complaints and bring about an improvement in people's overall quality of life.

The standards are also an integral part of our soon to be launched Dudley Quality standard scoring providers as either a bronze, silver or gold and making this information publicly available. When in place this will provide local people with information about providers to enable them to make informed choices around the support they require.

We are working with Changing Our Lives to develop a Quality of Life audit team made up of paid auditors with disabilities. This team will take a person centred approach to checking the quality of services, ensuring that local people with disabilities are leading active and ordinary lives in our community.

# Driving Up Quality Code

An excellent example of a provider lead quality scheme is the Driving up Quality Code which has been developed by members of the Driving Up Quality Alliance. A steering group of representatives from provider organisations chaired by the Housing and Support Alliance has led on the work with support from: the Care Quality Commission, the Department of Health, the Association of Directors of Adults Social Services, the Challenging Behaviour Foundation and NHS England.

The Driving up Quality Code sets out 5 key areas that indicate the practices of a good organisation:

1. Support is focused on the person
2. The person is supported to have an ordinary and meaningful life
3. Care and Support focuses on people being happy and having a good quality of life
4. A good culture is important to the organisation
5. Managers and board members lead and run the organisation well



The Driving up Quality Code is voluntary and providers who sign up will be making a public commitment to the principles of the code. Providers from the various sectors including housing, support, residential care and healthcare providers will be asked to self-assess against the code annually, and there will be a mechanism for anyone to challenge a provider.

Health and Social Care Commissioners will be encouraged to sign up to the code to say that they will use it in their commissioning processes and work with providers who have adopted the code. The alliance will make public the commissioners that do and don't sign up to the code. Information about who has signed up to the Code and how organisations are working towards meeting the Code is publicly available on [www.drivingupquality.org.uk](http://www.drivingupquality.org.uk)

# Community Integrated Care

## Changing Culture with the Quality of Life Standards



Community Integrated Care is one of Britain's biggest health and social care charities. Founded 25 years ago, we support almost 5000 people with learning disabilities, mental health concerns, autism and age-related needs, including dementia. Our charity has recently launched a five year strategy, with the aim of becoming the UK's Leading Health and Social Care Charity over the coming half decade. One of the ways that are looking to achieve this bold ambition is by signing up, and wholeheartedly committing to, the Quality of Life Standards.

The Quality of Life standards are key to us, because in many ways they reflect our own organisational values:

- We Respect
- We Enable
- We Aspire
- We Deliver
- We Include

Community Integrated Care has focussed on delivering three key projects:

- Personalisation
- Driving up quality and standards
- Voice of the people we support.

### Big Change Event

In April 2014, Community Integrated Care held an event in York, where our senior management team came together to review progress in the first year of our five year strategy. At this event, our Quality Improvement Managers, Shelagh Murphy and Gary Dixon, were delighted to introduce the Quality of Life Standards and our plans to use them in our organisation.

Inspired by a presentation from Changing Our Lives, our Regional Directors and Regional Managers made public pledges about how they would achieve the Quality of Life Standards in the services they oversee. These pledges reflected a commitment to make tangible changes in practice and policy across the organisation. Here are some examples:

- We will ensure that we do not have 'offices' in people's own homes and that people have access to all areas of their homes at all times.
- We will update our current Dignity & Values Training, to incorporate themes from the QOL standards and really challenge our practices.
- We will ensure that meetings about the people we support include that individual, take place in a place that they choose and that their attendance is non-negotiable, unless they choose to opt out. We will strongly advocate this practice with all external stakeholders.
- We will look at individual supported time for each person in senior care residential - as a pilot initially.
- We will ensure that rotas are built around the people we support and their aspirations, not what is convenient for staff.

Subsequently, it has been agreed by Community Integrated Care's Executive Team that these pledges will be turned into key performance indicators for our charity.



## **Development of a Peer Review team**

Community Integrated Care is working with Changing Our Lives to recruit, train and support a Peer Review team. Their first audit will focus on the 'My Voice' section of the Quality of Life Standards. In May 2014, we held two open days with the people we support, one in Durham for the North East region and another in Leicester for the Central region, to explain these important roles.

We will be following this day up with another event with the Changing Our Lives team to support our new Peer Reviewers to prepare for their important role. Three individuals from each region we work in will go to training and shadow a Quality of Life Audit with experienced auditors from Changing Our Lives before carrying out their own Quality of Life audits.

In preparation for the first audit which will focus on the My Voice section of the Quality of Life standards, we have designed a self-assessment based upon the Quality of Life Standards which has been sent to over 230 of our learning disability services to gather information from the people we support, and their support staff. This information will then be analysed by our Quality Team, who will make recommendations that will be shared with our staff and the people we support.

## **Embedding Quality of Life standards into planning documents.**

Community Integrated Care is currently undertaking a significant service modernisation programme. As part of this process we are starting with the basics - one of the main themes of our personalisation project is to develop the best support planning tool for our organisation. We've now got a fully developed plan for how we are going to do this, which involves aligning the Quality of Life Standards as Outcome Headers within support plans. This gives us a readymade quality monitoring tool to identify whether or not the people we support are really enjoying a great quality of life.

## **Evaluation of cultural change**

Community Integrated Care and Changing Our Lives are currently in discussions with a university academic about evaluating the impact that the Quality of Life approach will have on our organisation.



The Association of  
**Quality  
Checkers**

national forum  
of people with  
learning disabilities



Brimfield Consultants





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Everyone has a right to a good life. The Quality of Life Standards set the benchmark for what a good quality of life looks like. The greatest strength of the framework is that it has been created by people who use services, to inform and educate the people who commission and deliver those services and support. This is a great opportunity for us to listen, learn & connect - to ensure that people with a learning disability and autism are treated with respect and as a person first.

**Andrea Pope-Smith, Joint Learning Disability Lead ADASS** ”

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What most of us want more than anything else is to live the life we want in our community of choice, with a home, a job, friends, a sense of belonging and support to achieve the things that are important to us. We want to be seen and respected as equal citizens in society, and this is really important not just for individuals, but for the community we live in – which can be richer when everyone is included. Implementing the Quality of Life Standards can help people achieve these 'ordinary aspirations' which are really important for us all. They are an excellent tool. Please use them.

**Sue Turner, Learning Disability Lead, NDTi** ”

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The only way forward! People themselves setting the standards for services and supports so they can truly be equal citizens.

**Dr Simon Duffy, Centre for Welfare Reform** ”

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Mencap is pleased to endorse these Quality of Life Standards, which people with a disability have co-produced. Through this process, people with a disability have been able to identify what they really want from their lives and have their voices heard. These standards clearly define what every person involved in supporting people with a learning disability should aspire to in order to achieve equal citizenship for all.

**Jan Tregelles, CEO Royal Mencap Society** ”



Changing Our Lives

# Quality of Life

## Standards & Toolkit

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