

JUSTICE FOR LB TOOLKIT



Advocacy Focus has developed this toolkit for professionals who work with people, it is designed to support both the professional and the person they are working with.

LB is Connor Sparrowhawk. LB was a fit and healthy young man, who loved buses, London, Eddie Stobart and speaking his mind. He lived in Oxford and was in the sixth form of a local special school. LB was diagnosed with autism, learning disabilities and epilepsy.

LB's mood changed as he approached adulthood and on the 19th March 2013 he was admitted to hospital, the STATT (Short Term Assessment and Treatment Team) inpatient unit run by Southern Health NHS Foundation Trust.

LB drowned in the bath on 4th July 2013. An entirely preventable death. Hopefully the toolkit and the other great work across the UK will help prevent unnecessary deaths like Connors.

This toolkit has been co-produced with people who need support across Lancashire.

WHAT'S IMPORTANT TO ME?

My family
London buses
Eddie Stobart
Chunky Stan (my dog)
Reading horrible histories
Septic tanks
The Mighty Boosh
YouTube videos of lorries loading and unloading cross-channel ferries



#JusticeforLB

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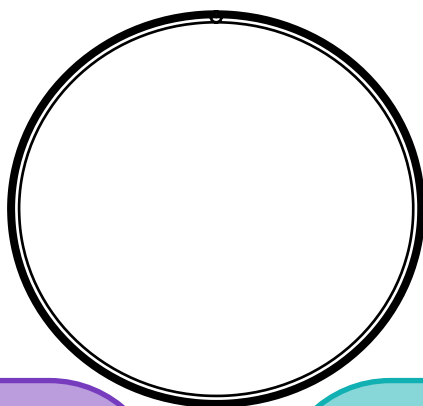
WHAT YOU NEED TO KNOW ABOUT ME?

Diagnosis of autism
Learning disability
Epilepsy
Mood changes
Anxiety

WHAT PEOPLE LIKE ABOUT ME?

I speak my mind
Quirky
Eccentric
Very lovable character
Sense of humour

WHAT'S IMPORTANT TO ME?



**WHAT YOU NEED TO KNOW
ABOUT ME?**

**WHAT PEOPLE LIKE ABOUT
ME?**

COMMUNICATION

HOW WE FEEL

WE'RE NOT LISTENED TO. WE'RE NOT GIVEN TIME TO TALK. WE'RE ADULTS NOT CHILDREN. WE'RE LABELLED AS BEING 'UNABLE TO COMMUNICATE NORMALLY'. WE'RE TALKED DOWN TO, OR PATRONISED. PROFESSIONALS GO AROUND IN CIRCLES. PEOPLE DON'T ALWAYS CONSIDER WHAT CAUSES US ANXIETY. NOBODY REALLY ASKS US WHY? WE'RE NOT GIVEN THE TIME TO THINK OR TO RESPOND. IT'S LIKE TALKING TO A BRICK WALL. NO EYE CONTACT/OR TOO MUCH EYE CONTACT. PROFESSIONALS NEED TO DO MORE LISTENING AND LESS WRITING. FORMS ARE REALLY RIGID. QUESTIONS ARE TOO VAGUE. NO RAPPORT. NOT WAITING FOR ME TO FINISH. YOU DON'T TAKE ME SERIOUSLY. JUMPING FROM TOPIC TO TOPIC. TOO MUCH INFORMATION AT ONCE. PHONE CONVERSATIONS CAN BE REALLY CONFUSING. YOU USE NOTES AS THE ONLY SOURCE OF INFORMATION. YOU DON'T KNOW ME. TOO SERIOUS. TOO MANY PEOPLE IN THE ROOM. THE WRONG PERSON IS THERE. BEING TOO PROFESSIONAL AND COLD.

-Quotes taken from people within Lancashire

WHAT WE WANT YOU TO DO

Get to know me:

Build rapport with me in my way.
Ask me how my day is going.
Ask me how I feel but be specific.
Check who I really trust.
Tell me who you are, about your job.
Find out who I am.
Refer to me, not to my notes and listen to me, don't just write.
Give me credit.
Use humour.

Build trust with me:

Don't go and chat with the other professionals. about me as you leave, I might be watching you.
Don't seek answers from other people in the room, when I'm there.
My family/carers views are theirs, not mine.
Be on time and do as promised.

Focus on me:

Don't just use the form, find different ways to get what the information from me.
Make sure you know what body language to use, I might actually like eye contact.

Don't go round in circles, be direct with me.

Don't talk down to me, or look to others for the answers.

Don't pressure me for an answer.

Put yourself in my shoes, think how it might make you feel.

I'm me, I'm not my condition.

Wait until I finish talking.

Don't jump from thing to thing, one at a time. Give me time to think and speak.

Helping me understand:

Break it down, keep it relevant.

Don't go to other people for the answer, let me do it.

Do I really need a communication passport, is it really mine or what other people think?

Take the time to give me the information in a way I can understand.

Phone conversations can be really hard, do the important stuff face to face.

Don't overwhelm me with:

Professionals
Other people
Information
Questions

Focus
Issues

Communicating:

Use my preferred method of communication.

The one I use now!

Take your time to prepare things using my preferred method.

Make sure everything I need to know is accessible to me.

Give me time to process.

Give me time to think.

Give me time to answer.

Don't fill awkward silences, see above.

Make sure I feel comfortable.

Do it one at a time – face to face.

Use the things I know.

Use the aids that I have – don't give up on the 1st try.

Don't speak down to me.

Take your time.

PERSON CENTRED APPROACHES

MAKING IT ABOUT ME

HOW WE FEEL

UNIMPORTANT. LABELLED. A PROBLEM NOT A PERSON. A MEDICAL CONDITION NOT A PERSON. IGNORED. WE'RE NOT THE SUM OF MY CONDITIONS. OUR VIEWS AREN'T AS IMPORTANT. MY ANGER OR FRUSTRATION ISN'T ME. NOTES MATTER MORE THAN WE DO. OUR HOBBIES AND INTERESTS AREN'T AS IMPORTANT AS EVERYTHING ELSE. YOU'RE NOT INTERESTED IN ME. WE WANT CHOICES. WE WANT ACCESS TO OUR MONEY. LOTS OF DIFFERENT STAFF STRESS ME OUT. IT TAKES TOO LONG TO GET GOOD CARE. CHANGES TAKE TOO LONG. WE HATE BEING LABELLED. ANXIETY ISN'T THAT IMPORTANT TO YOU. WE ARE PEOPLE, NOT PROBLEMS. WHO ELSE DO WE SPEAK TO WHEN YOU AREN'T THERE? WE'RE JUST PART OF YOUR JOB. WE'RE YOUR FUNDING PROBLEM.

-Quotes taken from people within Lancashire

WHAT WE WANT YOU TO DO

Make sure I'm important:

When it's my life, other people's convenience shouldn't be a factor.

I am a person, not a condition, not a group.

Keep in regular contact with me.

Keep your promises – if you can't let me know and why.

Arrangements with me are important – Be on time.

Do what we agreed.

Let me know if you can't do something.

Make it about me.

Look at me for answers – not everyone else.

Call me not my carers.

Ask me about who I want there with me.

Make my view the important one – find out what I mean.

Make it about me

Don't focus on my condition.

I need to be an important factor.

I don't want to be labelled, I am a person who has a condition, not a condition person.

Spend time to get to know me – with me.

Don't rely on other people to know me.

I need to be involved in everything I can.

I am more than the problems and barriers before me.

My behaviour

It's a reaction to how I feel, not who I am.

Shouldn't be the whole focus of my life.

Isn't something that should determine my life.

Support, not penalty.

Sex and Sexuality

Do not dismiss my beliefs.

Do not label me.

My sexuality can be fluid or not, just like everyone else.

Sex is just as important to me as anyone else.

My sexual identity is important.

We feel love like anyone else does.

We understand that there might need to be protection for me – help me to understand why though.

MY CHOICES, MY LIFE

HOW WE FEEL

THE LAST PERSON ASKED ABOUT A DECISION. NOT LISTENED TO. NOT TRUSTED. YOU JUST DO IT ANYWAY. PEOPLE TAKE OVER. TOO MANY QUESTIONS. PEOPLE JUST TURN UP. NOT ENOUGH TIME IS GIVEN TO UNDERSTAND US. THEY JUST ASSUME THEY KNOW AND DON'T ASK. PRIVATE IS PRIVATE. OUR RELATIONSHIPS AREN'T IMPORTANT. WE'RE GIVEN TOO MANY OPINIONS – NO DECISION MADE. ASSUMPTION OF LACK OF CAPACITY. NOT LISTENED TO. NOT GIVEN TIME TO WORK IT OUT. NO TIME TO TALK THINGS THROUGH. REFUSAL TO HELP BECAUSE YOU DON'T LIKE MY DECISION. CONDITIONAL OFFERS AREN'T FREE CHOICES. NO REAL CHOICES. NO VALUE TO ME AS A PERSON.

-Quotes taken from people within Lancashire

WHAT WE WANT YOU TO DO

Family and Relationships

Find out who I most value or trust.
Value my relationships.
Trust who I say I value.
My relationships are important.
My parents might know me better than anyone.
My best friend might know me more than anyone.
My partner might know me better than anyone.
We understand that there might need to be protection for me – help me to understand why though.
Make sure I understand, I want to understand.
Make sure everything is about me.
We feel love like anyone else does.

Choices/Decisions

Just because I make a decision you don't like, don't withdraw my support.
Make sure no one takes over.
Too many questions at once are too hard to answer, give me time.
Make sure its confidential
My private information should stay that way
People see things differently
If we are able to make my own decisions, let me make

bad ones without threatening to remove support
Never assume
Make sure we don't have capacity
Give us a chance to learn what we need to know
With us, not for us
Listen to us
Trust we can do things
Give us time, to talk, to decide and to learn

Lifestyles/Activities

Our lives don't end after 9pm at night and on the weekends.
Ask are we doing enough.
Don't just offer activities you know, think about me.
No conditional offers.
It's what is good for us that's important, not what you know.
Don't just pay lip service to my needs.
Don't leave us with nothing because it's difficult.
We need support that fits, not just available.
We sometimes want to try new things.
We need you to think outside of the box a bit, I'm more than just everyone else
Are we really getting the opportunity to learn, grow

and develop.

A home not just a place we live in

We need our own space
We need to live somewhere where we could get along with other people
Our home needs to be a home and not just a place to be
Think would you consider living here yourself
Have I got the right support for the life I live
Do we really get to make my own choices
We want to live somewhere I call my own, even if it is just a room
We need to be near the people and things we love
Temporary accommodation needs to be temporary accommodation
Make sure I am offered all the choices available
Give me time to think about it
The people who support me need to know about me
My life needs to be the priority in my own home and environment.

COMMUNICATION:

A brief snapshot of the Communication Profile and the Toolkit

The Communication Profile is something that has been made for people to fill out themselves and for their support staff to explain the important things about them.

The communication profile is more accessible than trying to disseminate the information within a care plan.

MEET...

How I COMMUNICATE

Tell people how you communicate, do you use aids, pictures, tools, signs or your behaviour?

You CAN HELP ME...

Let people know what they need to do or use to help you communicate.

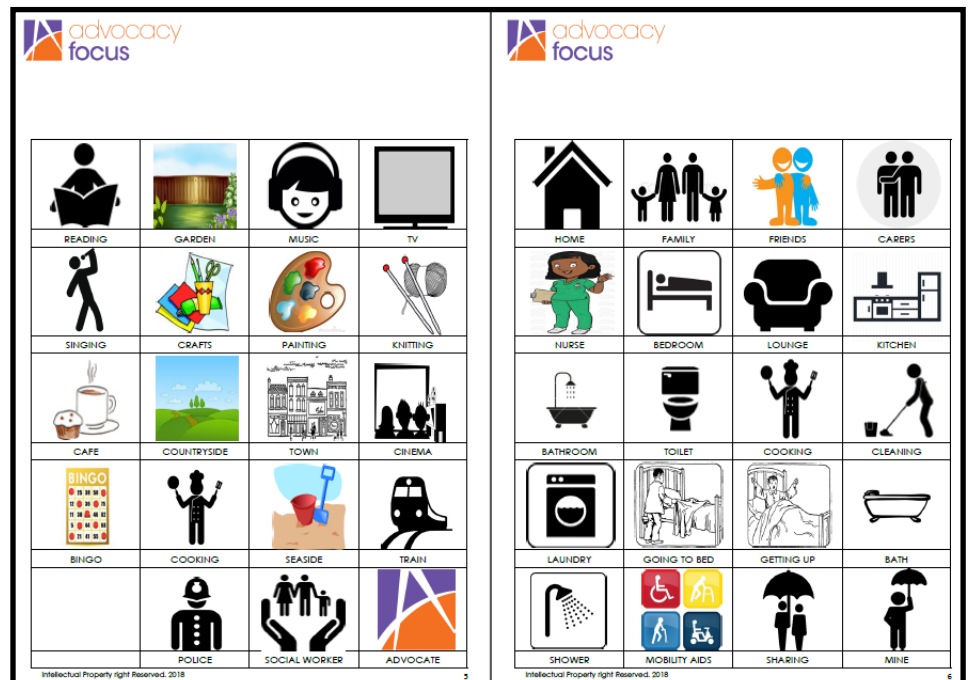
MY NAME IS...

THIS BOOK WILL HELP YOU TO GET TO KNOW ME AND HOW I COMMUNICATE.

The Easy Read will be available to download from our website: AdvocacyFocus.org.uk

This is a general tool that can be used to help people, understand concepts within the assessment process, there are two toolkits one with symbols and one with photographs to meet a wider audience.

This is the symbols version:



This is the photographic version:



FACE ASSESSMENT EASY READ: A brief snapshot of the Easy Read

We have made an easy read assessment which you can download from our website. Below are example pages from the easy read assessment.

advocacy focus		STAYING SAFE OUTSIDE	
ME	YES	NO	
Who helps me?			
How long and how often?			
What's important?			

advocacy focus		THINGS I LIKE TO DO THINGS TO THINK ABOUT:	
<ul style="list-style-type: none"> Staying in 			
<ul style="list-style-type: none"> Going out 			
<ul style="list-style-type: none"> The places I like to go 			

The full Easy Read will be available to download from our website:
AdvocacyFocus.org.uk

Who can help me with my assessment?

Family/Carer



Friend



Advocate



Whilst doing your assessment it is important for you think about these 5 things:

- Can you do it yourself?



- If you need help, who helps you?



- How long does it take?



- How often do you need help?



- How do you like to be helped?

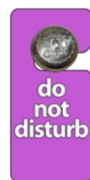


WELLBEING AND GETTING OUT AND ABOUT EASY READ

We have made an easy read about Wellbeing and Accessing the community.

When a social worker assesses you, the law says that they have to make sure your wellbeing is met. Wellbeing is the parts of your life that make you happy and healthy, these are:

- Dignity



- Physical and Mental health – Emotional Wellbeing



- Being safe and staying well



- Making your choices



- Work, College and Training



- Social and Money



- Family/Personal Relationships



- Where you live



- Being part of society



Getting out and about can include:

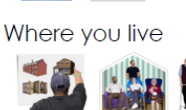
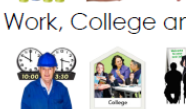
- Going Shopping
- Seeing Friends
- Getting a bus/train
- Exercise
- Getting your hair cut



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I MOVED CLOSER TO MY COLLEGE.

- Being safe and well
- Making Choices
- Work, College and Training
- Where you live



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The full Easy Read will be available to download from our website: AdvocacyFocus.org.uk

WHERE I WANT TO LIVE EASY READ: A brief snapshot of the Easy Read

We have made an easy read explaining the different types of place you can live, what things you might need to know and what things you might need to buy.

There are lots of different places you can live and the next two pages show what kind of places you can live in. They are split into two types: living with other people and living on your own.

What it might be like to:

SHELTERED HOUSING

Short secure tenancy no deposit.

Cheaper.

Less choice of places to live.

Your own place, landlord has set rules.

You pay rent bills and council tax on your own.

You will have to buy all your own furniture, carpets for inside the flat.

Carers can come and support.

Warden or an emergency call system in place.

Lounge with activities.

For older people

The full Easy Read will be available to download from our website: AdvocacyFocus.org.uk

PLACES WITH OTHER PEOPLE

- Living with family/friends



- Shared Lives



- Supported Living



- Care Home



- Nursing Home

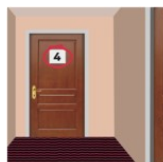


PLACES ON MY OWN

- Private Flat/House



- Social landlord Flat/House



- Sheltered Housing



- Extra Care Housing



WHAT IS A MENTAL CAPACITY


ASSESSMENT EASY READ:

A brief snapshot of the Easy Read


The Mental Capacity Assessment Easy Read gives people information around why an assessment is happening and how a decision is made.

5 RULES OF CAPACITY

1) PEOPLE NEED TO PROVE YOU CAN'T MAKE CERTAIN DECISIONS FOR YOURSELF.




2) PEOPLE YOU KNOW SHOULD GIVE YOU ALL THE HELP YOU NEED TO MAKE YOUR CHOICE - for example, pictures, symbols, videos, signing, time to think.




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3) OTHER PEOPLE MAY NOT LIKE YOUR CHOICE – This doesn't mean it's wrong.



4) THE DECISION BEING MADE SHOULD BE THE BEST ONE FOR YOU AND NOT ANYONE ELSE.



5) THE DECISION SHOULD GIVE YOU AS MUCH FREEDOM AS POSSIBLE.



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The full Easy Read will be available to download from our website: AdvocacyFocus.org.uk

This Easy Read is unlike the others as this is more of a information Easy Read rather than having a section for the person to fill out.

REDUCING RESTRICTIONS EASY READ:

A brief snapshot of the Easy Read

The Reducing Restrictions Easy Read informs people about the type of restrictions that might be in their lives. It also enables people to identify those restrictions, what they are not happy about and what they would like to change.



The full Easy Read will be available to download from our website: AdvocacyFocus.org.uk

Like all the Easy Reads available they can be used to enable people in lots of different ways such as informing them, giving them real-world examples and give that person the opportunity to think about these areas within their own lives.

USEFUL INFORMATION

There are some fantastic resources that have been created by other organisations around the following and links to the websites can be found on the [Justice for LB](#) section on our website.

- Human Rights Act (*a brief summary can be found below*)
- Equality Act
- Your Rights when you are living in the community
- MCA DOLS Easy Read
- MCA Easy Read
- Court of Protection Easy Read

There are 16 human rights. We have highlighted the most common Human Rights Articles as highlighted from our work within Health and Social Care.

Article 1: You have the right to life

Article 2: You have the right not to be treated badly or punished in a cruel way

Article 3: You have the right to freedom

Article 8: People should respect your private and family life

Some of your human rights can be limited, but this would need to be for a specific reason and CANNOT ever be taken away.

The Easy Reads available are not just for people with a Learning Disability; the goal was to make them for All. They would work well for people with Acquired Brain Injury and Dementia as they break down complex information in an easy to understand way.

Whilst the Easy Reads may not replace support or get people over the Substantial Difficulty Barrier they will go towards enabling and empowering people to be part of the process.



For more information and PDF downloads of the easy reads please visit our website:

www.advocacyfocus.org.uk/JusticeforLB

Co-PRODUCTION WORK

Resolve Group, Blackburn



Face to Face Group, Preston



Preston LD Forum



**Peer Advocates, Volunteers and
Independent Advocates**

