



Learning Disability England

# Being Seen, Being Heard

LEARNING DISABILITY ENGLAND'S ANNUAL CONFERENCE 2026



**Jodie Williams**

**Lisa Hopkins**

**Trustee Co Chairs**

**Learning Disability England**

**Being Seen, Being Heard**

**LEARNING DISABILITY ENGLAND'S ANNUAL CONFERENCE 2026**



**Gary Bourlet**

**Rachael Hall**

**Learning Disability England**

**Being Seen, Being Heard**

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GOOD LIVES

In



Learning Disability England



10

years time



# How it all began...

For a long time, people with learning disabilities have not been seen or treated as equals

I tried to change this by setting up People First England

Supported by Housing & Support Alliance

People First England and Housing & Support Alliance wanted to do more – something new.



# How it all began...

Change wasn't happening fast enough because people weren't working together.

Gary and the Housing and Support Alliance brought like-minded people together to create a movement for change.

These self-advocates, families and organisations worked with Gary and the Housing and Support Alliance to build Learning Disability England.





# Learning Disability England is Founded

2016

- Learning Disability England will be Led by people with learning disabilities, families and allies
- It was launched at the House of Lords.
- Lifetime memberships handed out



## The Rep Body Recruit Trustees

2018

- The 1st Chief Executive is recruited
- A new board of trustees was set up to help make sure Learning Disability England is well managed and meets its purpose.



## Supported Self-Advocacy Together

2019

Learning Disability England started working with 5 self-advocacy or human rights organisations as 1 of 7 **social movements for better health** that **Nesta** supported for a year.



## The Covid-19 Pandemic Hit

2020

- Fortnightly online sessions helped members stay informed, connected, and resilient.
- LDE joined with researchers to do a study on how the coronavirus pandemic changed the lives of people with learning disabilities.
- Members successfully campaigned for people with learning disabilities to be higher priority for vaccination.
- Learning Disability England shifts much of its working online



## First Rep Body Elections and Conference

2017

- To help ensure the organisation could be member led, a representative body was set up to guide priorities and make decisions.
- The first annual conference was held in Birmingham.



## Forming a Partnership with JMS Trust

2018

Learning Disability England started a partnership with JMS Trust. The trust has since worked with 64 families to support them to set up their own supported living.



## The First Good Lives Meeting

2020

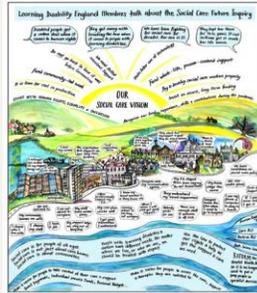
40 self advocates came together in Birmingham to speak about what it will take for everyone with learning disabilities to be able to live their good life.



# Members Contribute to the Social Care Future Inquiry

2021

Evidence from members was coproduced between self advocates, family members and paid supporters, giving it a unique perspective. The shared vision and actions were used to influence and contribute to the work of the Department of Health and Social Care, including development of the Health and Social Care White Paper.



# The 'We Deserve Better' Project Begins

2022

This project was carried out with the University of Central Lancashire, Manchester Metropolitan University and The Race Equality Foundation and looked at the barriers that trigger people with a learning disability from ethnic minority backgrounds to die at an average age of just 34. It made recommendations for policy, practice and research.



# Co-leading on No Research About Us Without Us

2022

Gary Bourlet becomes Colead on a project examining the barriers that stop research from including people with a learning disability.

- Produced tools and guidance to be used to help people carry out and take part in inclusive research.



# Campaigning to stop misuse of DNAR and the Development of LeDeR

2020

- Members identified misuse of DNAR notices, partnered with the British Institute of Human Rights and created a DNAR toolkit with Turning Point.
- Members views were gathered to ensure the new LeDeR policy prioritised sensitive and authentic communication with bereaved families



# The Good Lives Framework shared

2021

The Good Lives Framework, grounded in rights, lays out what people said they need to live well with ideas for change and examples of good practice.



The Valuing People Alliance continues, One of the VCSE Health and Wellbeing Alliance

# Creation of the Cost of Living Hub and Housing Guide

2022

- To help members with increases in the cost of living Learning Disability England brings together helpful information and resources.
- Learning Disability England, Housing LIN and Ace Anglia Collaborated on the Planning Where You Live Housing Guide.



# Three National member Conferences

2023

Learning Disability England held three national conferences in London, York and online with 440 attendees 62 speakers focused on Good Lives. Annual conferences have continued to help make connection and change happen for members.



## Big Organisational Priorities in a Vision for Change

2023

Rep body and trustees work together on a big plan that includes 4 big priorities Learning Disability England will work on to move towards it's vision for the future.



## How We Survive and Thrive Project Begins

2024

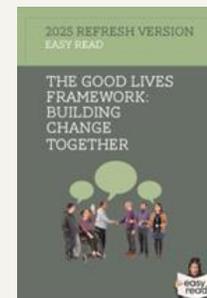
The How We Survive and Thrive Project begins, looking at how we can ensure people with learning disabilities are in the best place to survive and thrive if there is another pandemic.



## The Good Lives Framework is Refreshed

2025

The Good Lives Framework, grounded in rights, lays out what people said they need to live well with ideas for change and examples of good practice.



## Celebrating 10 years at the Being Seen, Being Heard Conference

2026

At the fastest-selling conference in Learning Disability England history, members celebrated how people with learning disabilities are being seen and heard in their communities - marking 10 years of coming together to work towards better lives for people with learning disabilities and their families.

## The Good Lives Manifesto is produced

2024

- 400 members were part of making the manifesto, bringing people and organisations together on what they think are the most important priorities for the next government to take action on to make Good Lives possible.



- Members keep sharing stories of Good Lives real-time impact

## New Trustees are Recruited

2024

Jordan Smith, Parmi Dheensa, Kristiina Cooper join as new trustees and Debbie O'Neil stands down.

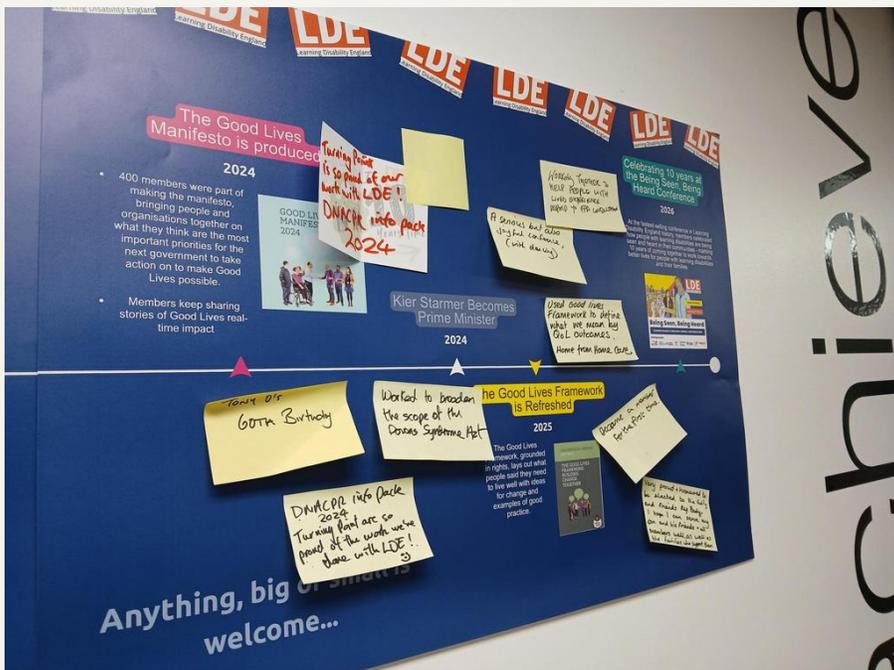
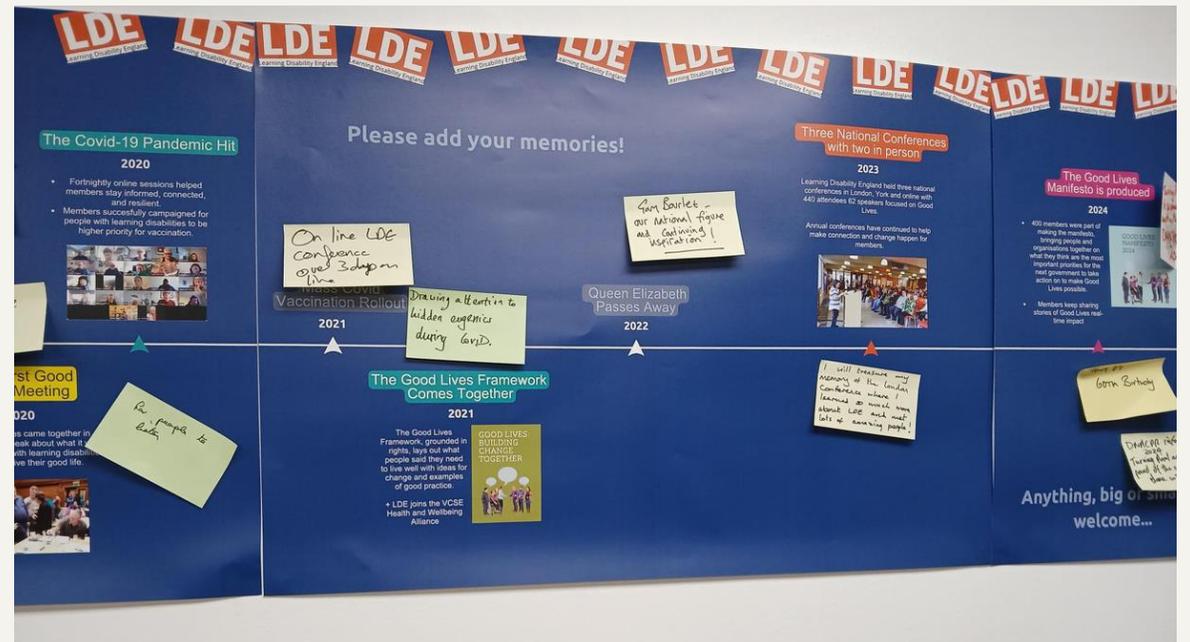


## Learning Disability England has 785 members

2026

Learning Disability England reaches 785 members - that's 785 organisations and individuals coming together to work towards good lives. This is a 45.9% increase from 2020.





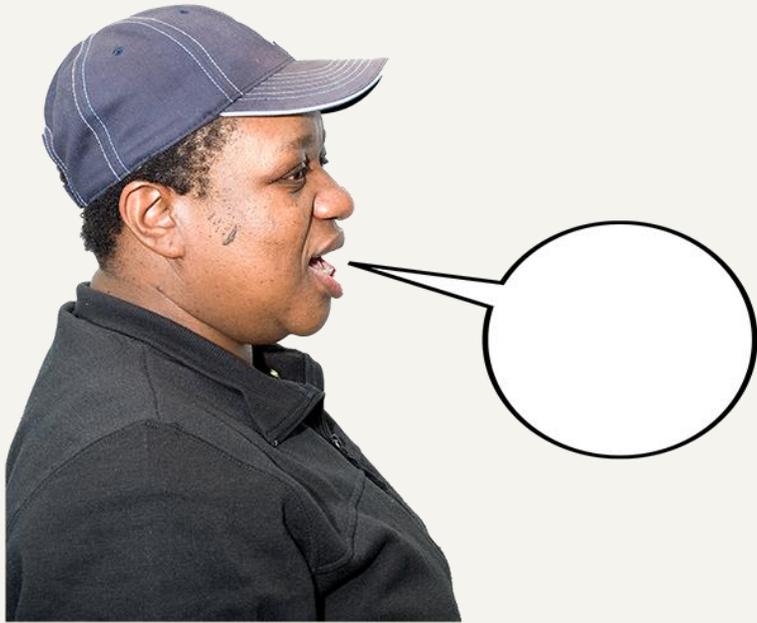
We asked people to start sharing their own memories of Learning Disability England in Birmingham...

# What did people say?

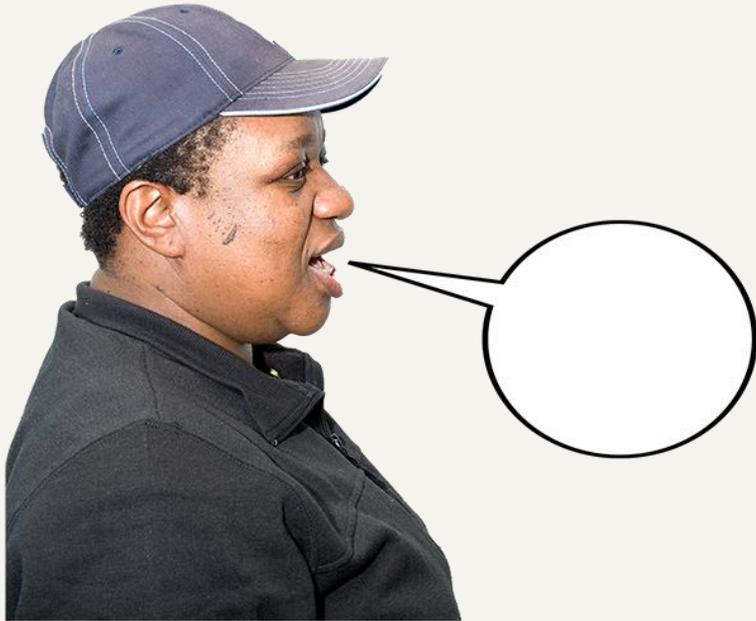
One person said 'I remember Gary Bourlet coming to speak at our managers conference - we were so excited for the future!' (2016)

Someone remembered attending one of the first conferences of Learning Disability England back in 2017 - they said 'it was hilarious and fun'

Someone said they remembered from 2021 'the online LDE conference over 3 days...'



# What did people say?



Turning point mentioned the DNACPR information pack they put together with Learning Disability England in 2024 - they said 'we're so proud of the work we've done with LDE!'

One member said in 2025 they remember 'using Good Lives to define what we mean by quality of life outcomes'.

# What can you remember?



Can you remember anything you and Learning Disability England did together since 2016?



You can use the mentimeter to add your own memories...

Here is a QR code to access the menti...





East Sussex County Council  
The Involvement Matters Team and  
Learning Disability Commissioning Team

**Do you see me?**

**There's more to me than a learning disability!**



Sonia Reed  
The Involvement  
Matters Team



Dominic Steel  
The Involvement  
Matters Team



Jeanette Gallivan-Young  
Learning Disability  
Commissioning Team



Emma Pierssene  
Learning Disability  
Commissioning Team



Hello, I'm Sonia





Hello, I'm Dominic



Hello, I'm Jeanette





Hello, I'm Emma

# So, who are The Involvement Matters Team?



# The Involvement Matters Team



**ALL** of IMT have been affected by Hate Crime



**ALL** of IMT have had people stare at them, laugh at them, shout names, or worse...  
Just because of who we are



IMT wanted to do something about it, so we started a campaign...



# The Involvement Matters Team



There's more to me than  
a learning disability!



# The Involvement Matters Team

## Key messages from our campaign



- IMT want people to change the way they think and feel about people with a learning disability



- IMT do not want to be defined by their learning disability



- IMT want people to remember that having a learning disability is a part of who they are, but it's not the only thing



- IMT want people to understand who we are, NOT who you think we are!





# The Involvement Matters Team

## There's more to me than a learning disability!





# The Involvement Matters Team

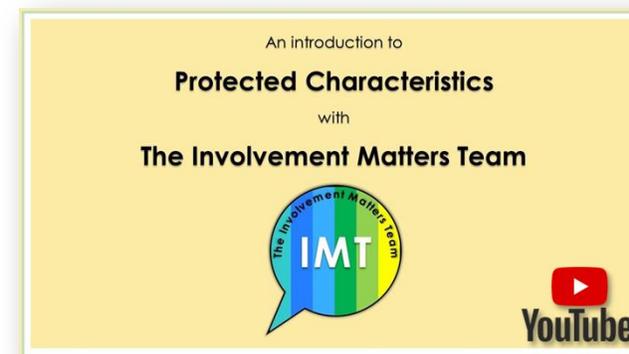
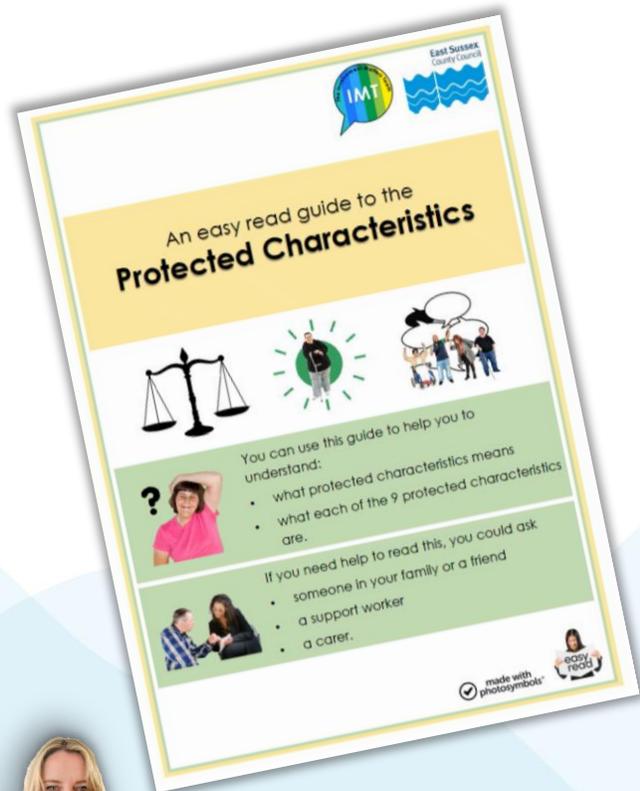
## There's **STILL** more to me than a learning disability!





# Easy read resources

## Equality and the Protected Characteristics



# The Involvement Matters Team

## Discriminatory abuse



# Representation Matters



# Involvement Matters Team

## Co-production in Commissioning

### a. Interviews



### b. Tendering



### c. Training



### d. Accessible information





# The Involvement Matters Team

## IMT want you to remember...

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Knowing I have a learning disability tells  
you **NOTHING** about **ME** as a person!

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# The Involvement Matters Team



I am an individual like you, no different,  
no more, no less.

We are part of society; we always have  
been and we always will be.



Dominic – IMT Member

# Easy read, contact details and video links



**Easy read:** [Learning disability - easy read | East Sussex County Council](#)

**Email:** [ldpb@eastsussex.gov.uk](mailto:ldpb@eastsussex.gov.uk)

## Video links

Discriminatory Abuse



 [Short film](#)

 [Full length film](#)



 [The Friendship Group](#)



 [Sarah Gordy, MBE, receives her Doctorate](#)



 [There More To Me Than A Learning Disability](#)

 [There's STILL More To Me Than A Learning Disability](#)

9 in 10: A film about hate crime



 [Part 1](#)

 [Part 2](#)



**We are having a short  
break**

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**Tabitha Jay**

**Department of Health and  
Social Care**

**Learning Disability England**

**Being Seen, Being Heard**

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Department  
of Health &  
Social Care

# Policy including people with a learning disability and autistic people

Tabitha Jay, Director of Mental Health and Disabilities, Women's Health and Maternity,  
Department of Health and Social Care (DHSC)

For Learning Disability England online Conference 11/03/2026

# Introduction



My name is Tabitha Jay and I am a director at the Department of Health and Social Care.

I have responsibility for mental health, neurodiversity, disability, learning disability and women's health.

# The 10 Year Health Plan



We want to make sure everyone gets the healthcare they need, which the government set out in a 10 Year Health Plan. We will do this in three ways:



1. We will give you more healthcare in your neighbourhood and at home.



2. We will use more technology to make it easier for you to see a doctor and get healthcare, which means more things like using apps, computers and the internet.



3. We will help you stay as healthy as possible, like making it easier for you to choose health food and do more exercise.

# Neighbourhood Health



There will be more health services in local neighbourhoods where people need it.



We will make it easier to get help with your health. We will give people appointments on the same day when they need it.

We will make sure people do not wait a long time for an operation or to get help from staff in accident and emergency.



The Neighbourhood Health Service will bring people together from lots of organisations, including doctors, to create new neighbourhood teams.



# The Mental Health Act (2025)

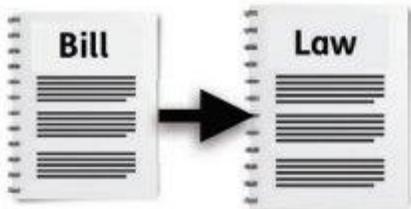


We have heard that the Mental Health Act (1983) is not always working for people.

- For example, autistic people with a learning disability are often detained in hospital when they could be better supported in the community.



The new Mental Health Act (2025) will make changes so that the original Act (1983) works better for people.



The new Mental Health Act (2025) was given royal approval on 18 December 2025. This means that it will become the law in the future.



# The Mental Health Act (2025) - learning disability and autism



If someone with a learning disability or autism does **not** have a mental health condition, the law will say that mental health law cannot be used to keep people in hospital for more than 28 days.



A care, education and treatment review is a meeting to check how an autistic person or a person with a learning disability is being cared for. These reviews will help people to leave hospital as soon as they are ready.



A Dynamic Support Register is a list of people who need support to stay out of hospital. It should make sure people are getting the right support so they don't need to go to hospital.



# What will happen next?



Work is starting this year to update the Mental Health Act Code of Practice. The Code of Practice is a guide to help health and care staff follow the Mental Health Act.



We will also write new guidance to help staff deliver Care (Education) and Treatment Reviews, Dynamic Support Registers and organising community support.

We will be asking different groups of people their views on this guidance so that it works well for everyone.



Other changes need the right staff and community support before they can be turned on.

# Thank you

Tabitha Jay, Director of Mental Health and Disabilities, Women's Health and Maternity, Department of Health and Social Care (DHSC)



Anup Upadhyaya

My Life My Choice

Learning Disability England

**Being Seen, Being Heard**

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Co-partnership in  
our area.  
Our Oxfordshire  
Councillor Deal.



My Life My Choice  
Campaign Champions





Who are we?

# About us

## My Life My Choice



We make sure learning disabled people have good lives.



We make sure learning disabled people are taken seriously



We make sure learning disabled people are empowered.

# About Me



Anup Upadhyaya  
Campaign Champion



# MLMC Champions 'County Councillor Deal'

# Councillor Deal - why we did it



- Make sure new Councillors knew what mattered to learning disabled people
- To agree on: what worked well; what could be better; how we could help one another.
- To sign them up to empower and support our aims, members and work.

# Councillor Deal - what we did part 1



- A sub group of Champions worked on 3 areas that mattered most to our members.



- Social Care
- Education and employment.
- Planning (Good Place To Live!)

# Councillor Deal - what we did part 2



- A sub group of Champions worked on 3 areas that mattered most to our members.



- They thought of one thing in each of those areas that:

Worked well; could be better; what the Council could do; how we could help them.

# Councillor Deal - what we did part 3



When the document was ready, we sent a letter to the Leader of the County Council.

Her name is Councillor Leffman and she agreed to meet with us to talk about the deal.

When we met, Councillor Leffman said she liked the deal and she would encourage her cabinet to vote for it.



# Councillor Deal - what we did part 4



I went along to two cabinet meetings to present the deal.



I even went to the December one dressed as an elf (not recommended!)

They asked some tricky questions, but overall everyone agreed to support the deal.

# Councillor Deal - what we did part 5



Then in January I did my final presentation to the whole County Council.

I felt it went really good.

The Council voted for the deal, which made me so happy.



What will the deal  
mean we can do?



# 1 Social care



I am one of the Champions leading on our new 'Save Our Support' social care campaign.



The new Councillor deal means it is now Council policy to share good stories about people's support.



This will help make sure people's voices are heard and job gaps are filled.





## 2 Education and employment



I have already been part of Council run meetings to talk about adult training and employment.

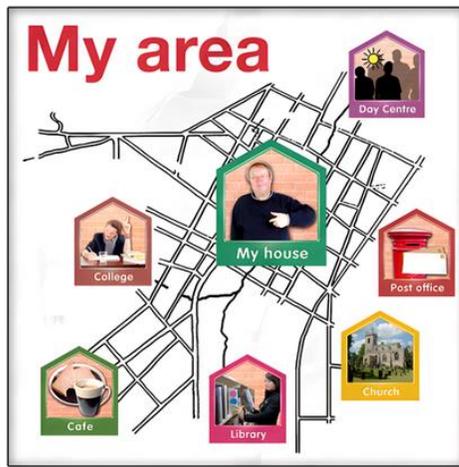


The Council Deal means it is now policy to make sure there are good employment schemes for everyone.



And also to share positive stories of good jobs and volunteering people have.





## 3 Good Places To Live



I am already part of a Council sub group looking at good places to live for our new learning disability strategy.



Our deal tells the Council that they must think about not just buildings, but things like shops and bus stops,



They also must share learning disabled people's stories about the good places they live.





Thank you for listening.



If you have any questions, ideas or want to help with our campaigns please contact James on the details below.



01865 204 214



[james@mylifemychoice.org.uk](mailto:james@mylifemychoice.org.uk)



Kate Lawson

Sense

Learning Disability England

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# Influencing policy alongside disabled people with complex needs

**Kate Lawson**

March 2026



**sense**

# Our strategy

**Vision** (what  
we want to  
change in the  
future)

**A world without limits for disabled people with complex needs.**

**Purpose**  
(why we're  
here)

**We're here to break down barriers alongside disabled people with complex needs.**



# Influencing change – what is it?

It means working alongside disabled people with complex needs for:

## **Power change**

Increase the voice and influence of disabled people with complex needs in decisions.

## **Policy change**

Shift the laws, rules and funding that shape lives.

## **Practice change**

Close the gap between what the system promises and what people get.

## **Culture change**

Transform public attitudes and the narrative around disability.



# Elevating lived experience



# Influencing social care example



# How to be seen and heard

**James Coney,**  
**News projects editor, Sunday Times**  
**and..... dad of Charlie**





**Why bother?**

## Child trust funds and the battle for Mikey Turner's money

Thousands of families were locked out of savings, until Andrew Turner  
started writing letters



**Pick your  
battle.....and  
keep fighting**



**Human tales win**

**Pick your battle**

**Be clear about your**

**objective**

**Be bold**

**Don't give in**

Please take a moment to let us know how you found today here:



[www.surveymonkey.com/r/CX5FGHY](http://www.surveymonkey.com/r/CX5FGHY)



Thank you

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