

*Challenging Behaviour – National Strategy Group*

# “Weathering the Storm”

Coproducing good support for life for children, young people and adults with learning disabilities whose behaviours challenge, against a backdrop of change and adversity

[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

E: [nationalstrategygroup@theCBF.org.uk](mailto:nationalstrategygroup@theCBF.org.uk)

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# Housekeeping

- We are recording the presentations, and these will be made available after the meeting
- Please make sure you're on mute during the presentations if you aren't speaking
- Use the chat if you have any questions or comments
- During breaks/lunch, please don't leave the meeting (you can turn off your camera and microphone)
- If you do leave the meeting, you can join again using the original link
- Email [becky.wetherly@thecbf.org.uk](mailto:becky.wetherly@thecbf.org.uk) if you are having any technical problems
- If you're posting about today's meeting, please tag us!



[@cbfdn.bsky.social](https://bsky.app/profile/cbfdn.bsky.social)



**The Challenging Behaviour Foundation**

# The backdrop for this meeting

- People with learning disabilities still face significant health inequalities
- Families have to navigate and battle complex systems
- Health, education, social care, housing and more are siloed, making joint working harder



# The backdrop for this meeting

- Reviews of adult and children's social care
- The Mental Health Bill – and what it means for community support
- Changes to the health landscape – NHS England, integrated care boards, and the Department of Health and Social Care



# Refocusing on rights – the Challenging Behaviour Charter

"Children, young people and adults will be supported to exercise their human rights (**which are the same as everyone else's**) to be **healthy, full and valued members of their community** with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability."

Early intervention

Person-centred planning

Rights to community, leisure, housing, work and education

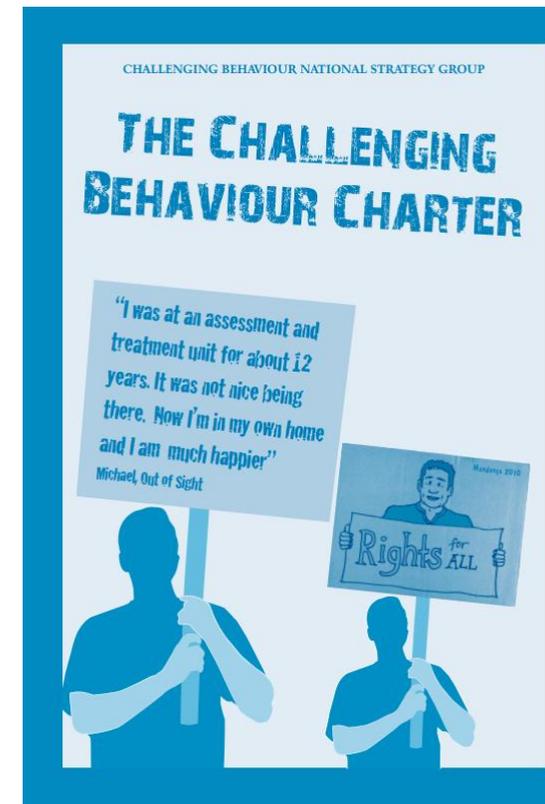
Health needs met

Reducing restrictive practices

Positive behaviour support

Family support

Evidence-based – knowing what works



# What today's meeting covers

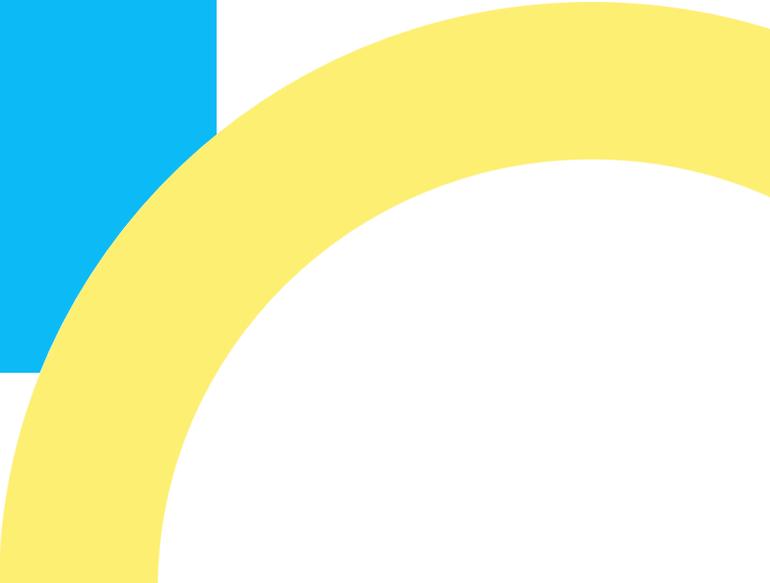
- Family carer perspective
- Mental Health Bill update
- Workshops (morning)
- Adult Social Care resource
- Why coproduction matters, and how to do it
- Workshops (afternoon)
- Feedback and reflection
- Closing presentation



# 'Groundhog Day': a family carer's perspective

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Cristina Di Santo, Family Carer

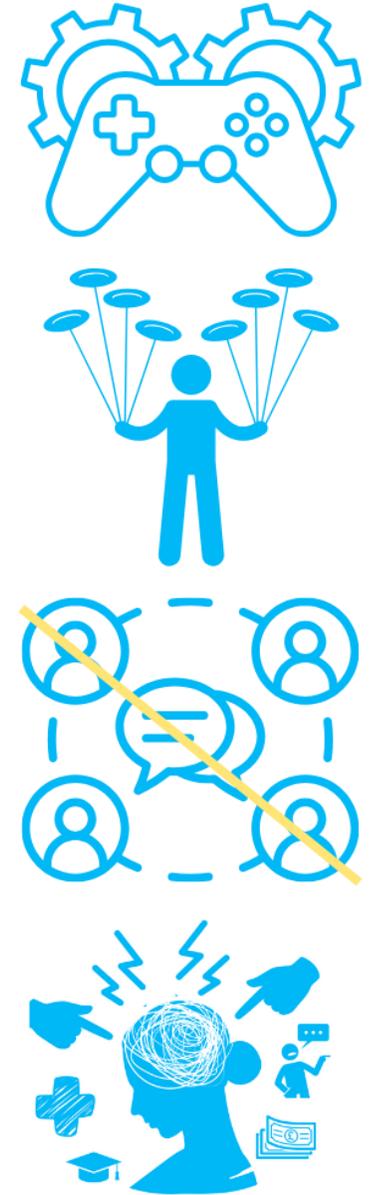
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# Our Story

- **Max, 13**
- Only child
- Complex needs including non-speaking autism, ADHD, epilepsy, a severe learning disability and can display behaviours that challenge
- Our journey has been **complicated and difficult but not unique**
- In September 2024, just before he turned 12, Max moved to a residential setting **almost 200 miles from the family home**

# Our Story

- Moving for better options
- The system is like a computer game\*  
\*except you don't know the rules or where you are
- 'Spinning plates'
- Not being heard by services
- Parent Blame and siloed systems
- Trauma responses
- The road to residential



# Viv's Story



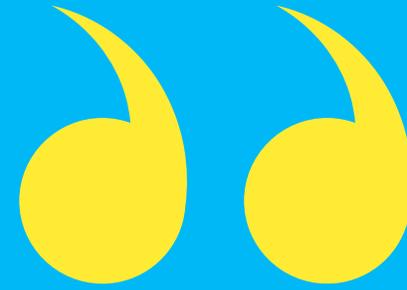
- Daniel moved to a residential setting over 200 miles from home, aged 9
- Fought to bring Daniel back to his local community so he could be closer to family
- Set up the CBF in 1997 to try to push for change for families

# Why the CBF is still needed today

- There remains work to be done and the CBF is more needed than ever.
- The political landscape remains unclear and service providers and service users are in limbo.
- System feels like it is stuck in Groundhog Day
- Families are still fighting to get help and support – increasing desperation felt from families getting in touch with the CBF Family Support team.

# What needs to change

- Services need to stop, think, LISTEN.
- Families and service providers are stronger by working together.
- Stop putting those with the most complex needs on the “too difficult” pile.
- Improve inclusivity and address inequality.
- Services should be delivered through a trauma lens.
- Stop working in siloes – a holistic approach to care and support would achieve more.



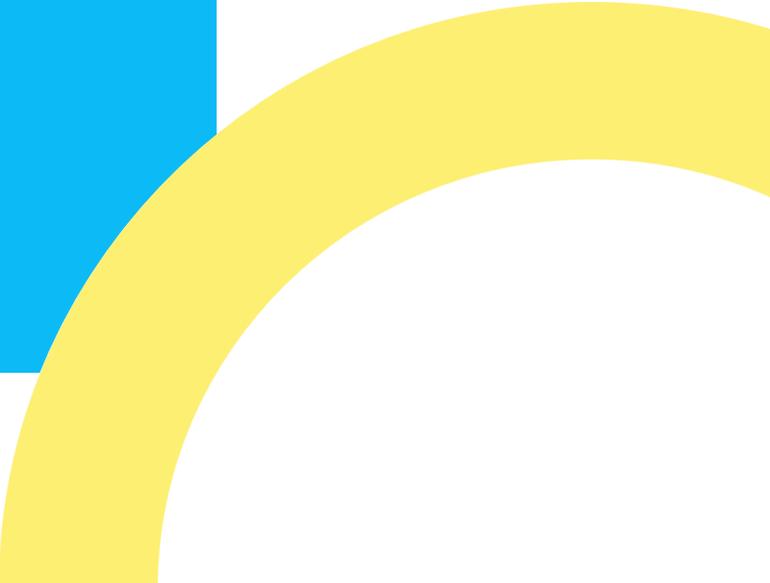
**“I have lost trust and hope in the  
system”**



# Mental Health Bill Update

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Megan McIvor, Policy Lead – Neurodiversity,  
Disability and Learning Disability, Department of  
Health and Social Care



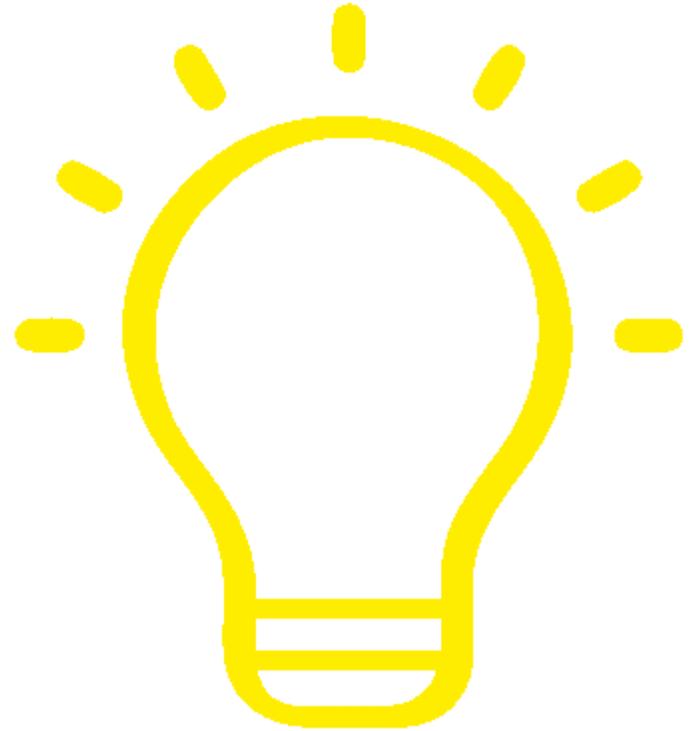
# Workshops

- There are 5 workshops – starting with presentations, followed by discussions
- Workshops will be repeated in the afternoon so you can attend 2 out of the 5 topics
- If you didn't express a preference for any particular workshop, we will allocate you to one
- The aim of these workshops is to **identify existing issues** and **develop solutions that address barriers to good support**



# Workshops

- **One piece of information or support available right now** that supports people with learning disabilities and their families
- **One big systemic issue** where we could work together to co-produce change
- **One practical solution** which you or others in the meeting could implement tomorrow to make a difference



Workshop	Facilitators
<p><b>Upholding rights: how can reforms to social care improve the lives of children and young people with learning disabilities whose behaviour challenges and their families?</b></p>	<p><b>Connor Johnston</b> (Senior Lawyer, Law Commission Review of Disabled Children's Social Care)  <b>Elly Chapple</b> (Family Carer)</p>
<p><b>Getting the transition to adulthood right</b></p>	<p><b>Heather Harper</b> (Young Person Participation Coordinator, KIDS)/<b>Charles Mollet</b> (KIDS)  <b>Gemma Harpum</b> (CBF Family Support Lead)</p>
<p><b>Making neighbourhood health work for people with learning disabilities whose behaviours challenges</b></p>	<p><b>Dr Amy Dissanayake</b> (National Specialty Advisor, NHSE; Deputy Chief Medical Officer, NHS Sussex)  <b>Viv Cooper</b> (Founder, The Challenging Behaviour Foundation; Family Carer)/<b>Debbie Austin</b> (Family Carer)</p>
<p><b>Using public money better: what reforms are needed to realise independent living in the community for people with learning disabilities whose behaviour challenges?</b></p>	<p><b>Bella Travis</b> (Policy Manager, Mencap)  <b>Emma Austin-Garrod</b> (Families Lead, Mencap; Family Carer)  <b>Jacqui Shurlock</b> (CEO, The Challenging Behaviour Foundation)</p>
<p><b>Supporting adults with learning disabilities and their family carers as they grow older: what is needed and how can it be achieved?</b></p>	<p><b>Jenny Steeples</b> (Family Carer)  <b>Marie Lovell</b> (National Practice Innovation Lead, Skills for Care)</p>

**Support to navigate the  
social care system – a  
resource for family carers of  
adults with learning  
disabilities whose  
behaviour challenges**

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Gemma Harpum, Family Support Lead, CBF





The Challenging  
Behaviour Foundation

making a difference to the lives of people with severe learning disabilities



# ADULT SOCIAL CARE

A new information resource from the CBF

GEMMA HARPUM  
FAMILY SUPPORT LEAD

[www.challengingbehaviourfoundation.org.uk](http://www.challengingbehaviourfoundation.org.uk)

[info@thecbf.org.uk](mailto:info@thecbf.org.uk)

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## WHAT DO FAMILIES LIKE ABOUT THE CBF'S SUPPORT?



CBF

“CBF are very professional, understanding, supportive and informative. I feel they understand and will support you for as long as needed. **The useful information sheets and website has up to date information for parents and families.** The support CBF have offered my family has been invaluable, I feel confident and not alone. I am so grateful for the support given by the CBF team.”

EMAIL FROM A FAMILY CARER FOLLOWING FAMILY SUPPORT'S INVOLVEMENT





## WHY IS THIS RESOURCE NEEDED?



Approximately 52% of families who receive support from the CBF Family Support Team need help with navigating Adult Social Care or NHS Continuing Health Care.

Nearly 2000 people have looked at the area of the CBF website relating to adult social care this year

When we begin supporting a family on average they rate their empowerment (having all the information they need improve things for their relative) as 5.6 out of 10.

**We want everyone supporting their loved one to have ALL the information they need.....**



<https://www.challengingbehaviour.org.uk/information-and-guidance/housing-education-leisure/resource-adult-social-care/>

## Adult Social Care (England)

Support options, housing, personalisation  
and living a good life





## WHAT'S INSIDE?



1. Introduction



2. Understanding your relative's rights



3. Assessing needs and care planning



4. Choices

5. Plans

6. Funding

7. Reviews, re-assessment and revisions

8. Frequent challenges

9. Safeguards

10. Who can help?

11. Appendix 1: questions to ask  
support providers

12. Appendix 2: checklist of plans

# **Lunch**

we will be starting again (promptly!) at

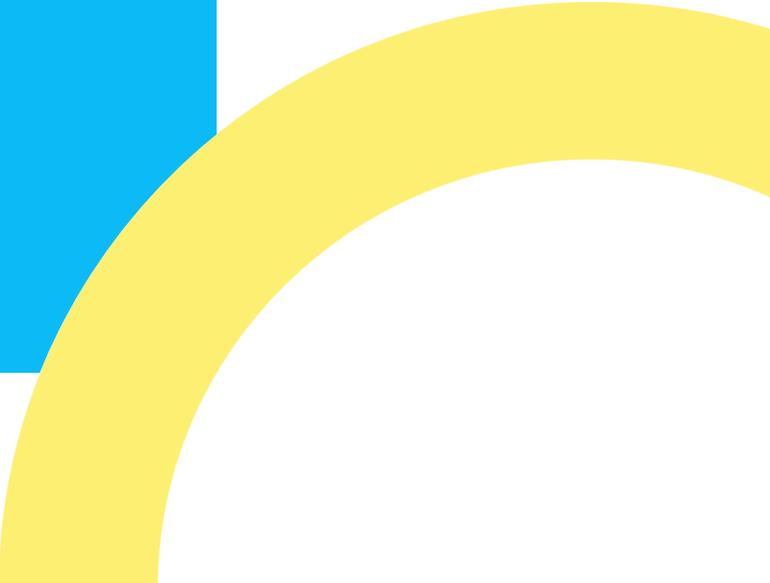
**12.20pm**



# Why families must be equal partners at the table

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Dame Philippa Russell DBE



# Unsung heroes, war weary veterans – or equal partners co-producing a better future?

[Dame Philippa Russell, Vice-President Carers UK - philipparussell118@gmail.com]



# **THE AMBITION – WHAT WE WANT – A bigger, bolder and braver view of social care!**

- ‘We ALL want to live in the place we call home with the people and things we love, in communities where we look out for one another, doing things that matter to us.’ *[Social Care Future]***
- But a ‘reality check’ shows both big ambitions and increased pressures across all sectors – how can WE ourselves shape a very different future when everything is changing?**

# **‘Collaborative care’ – ‘we are the experts by experience’ working with the NHS and social care but we’re team players too. Use us or lose us!’**

- **Caring often means managing complexity!** Pandemic underlined the importance of mutual respect, recognition and coproduction
- **‘It was crisis management, not care and support’.**
- **Carers increasingly care coordinators** [for multiple services in and out of social care and the NHS – *we need information and recognition as partners in care to care well*]



# Looking to the future – More inter-generational care and increase in *younger* people caring or needing care and support.

- Planning for digital futures – NHS major commitment to ‘the NHS in your pocket’ but we still need people; What should a modern workforce look like?
- Reconnection and ordinary lives: we still have a digital divide, but a wealth of opportunities from AI to robots supporting more independent living at home.



# **‘Building back better’ – ‘ASK US! *We’re the experts, if you listen.*’ Putting carers themselves at the heart of health and social care reform and asking what THEY want.**

- **Peer support** – Sharing the journey, shaping reform!
- **Managing change**
- **Co-production and creativity**
- **‘Having the big conversations** to influence, co-design and co-produce a better future. Solidarity matters!’



# ***'Care is often about transitions – What's his future, what happens when I'm not here?'***

- **'Demographic change** – the first generation of disabled people who are likely to outlive their parents!
- **'The big anxiety** – *we need a revolution in housing with support. For many people housing is part of a triangle of care.'*
- **The right to a family life and an end to isolation and seclusion.**



## **Social Care Reform? – We already have the legal framework to support carers. Can we ensure that it works?**

- Care Act 2014 gives carers a legal right to a carers assessment (which should embrace health and social care as appropriate).
- Carers have ‘parity of esteem’ with the person they support, or do they?
- Carers should be asked IF they are willing and able to carry out the care specified in their relative’s care plan.
- Looking after the ‘care market’ – many carers need to share their care with care workers, Personal Assistants and care homes – we need to recognise our shared ‘community of care’.

# Coproduction and Collaborative Care – Equal Partners and Activists or Powerless Spectators?

‘The NHS and Social Care are changing – we now have a SHARED responsibility for health and wellbeing. We now need patients and family carers as ‘activists’, as valued and expert partners round the table. True coproduction is challenging, but we cannot transform lives without it.’

[Kings Fund, 2025]

‘Creating genuine partnerships requires professionals and services [across hospitals and communities] to work differently, as well as a new and systematic approach to engaging patients, carers and the community itself in all decisions about their health and wellbeing. We need to learn from lived experience – and see it as a valued resource.’

[NHS 10 Year Plan, 2025]

# A final reflection..... 'people matter most!'

Maya Angelou

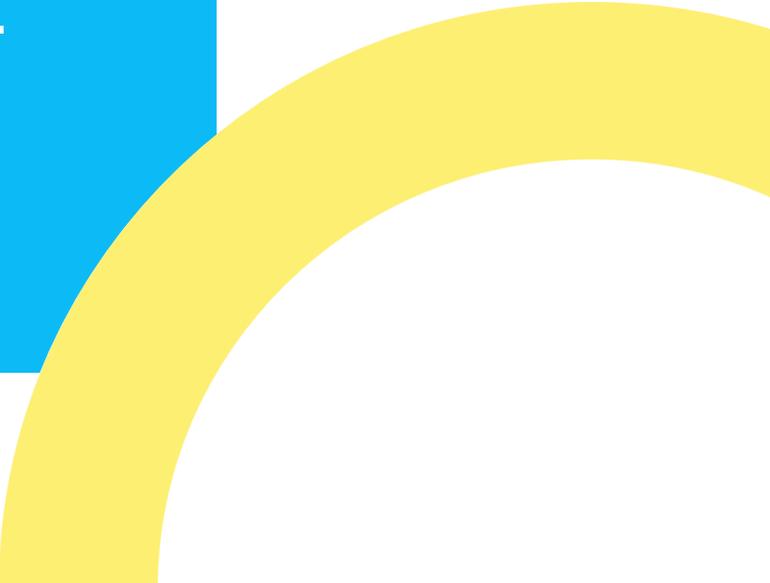
I've learned that  
people will forget what you said,  
people will forget what you did,  
but people will never forget  
how you made them feel.

[InspirationBoost.com](http://InspirationBoost.com)

# Nothing about us without us: the importance of self-advocacy

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Campaign 4 Change and SeeAbility



# Ensuring everyone has a voice: what can be done to involve people with severe or profound and multiple learning disabilities

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Taylor Anderson, Project Manager, CBF

Oliver Smithson, Senior Strategic  
Improvement Coach, IMPACT

Direct engagement with people with severe or profound and multiple learning disabilities

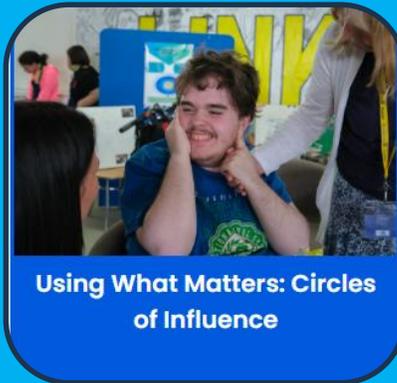


# What Matters to Me

*Influencing policy with the experiences, preferences and views of young people with severe or profound and multiple learning disabilities*



Finding out What Matters:  
Principles of Meaningful  
Engagement



Using What Matters: Circles  
of Influence



Influencing What Matters:  
Transition to Adulthood



# Methodology



## Gathering experiences, preferences and views

Using a mixed-method approach to understand what matters to and for young people with severe or profound and multiple learning disabilities

1

### GATHERING BACKGROUND INFORMATION

Develop a robust understanding of individual needs, likes and dislikes before directly engaging

2

### OBSERVATIONS

Observing communication and participation in activities with familiar communication partners to understand and record observable indicators

3

### DIRECT ENGAGEMENT ACTIVITIES

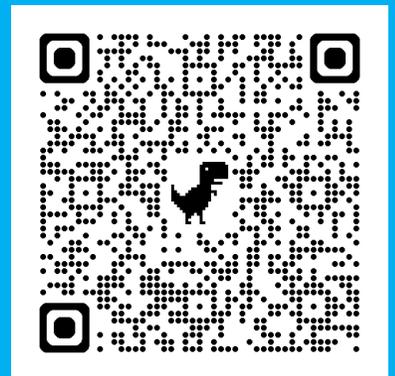
Using the background information, tailor and carry out activities, following the principles of engagement to ensure it is positive and meaningful

4

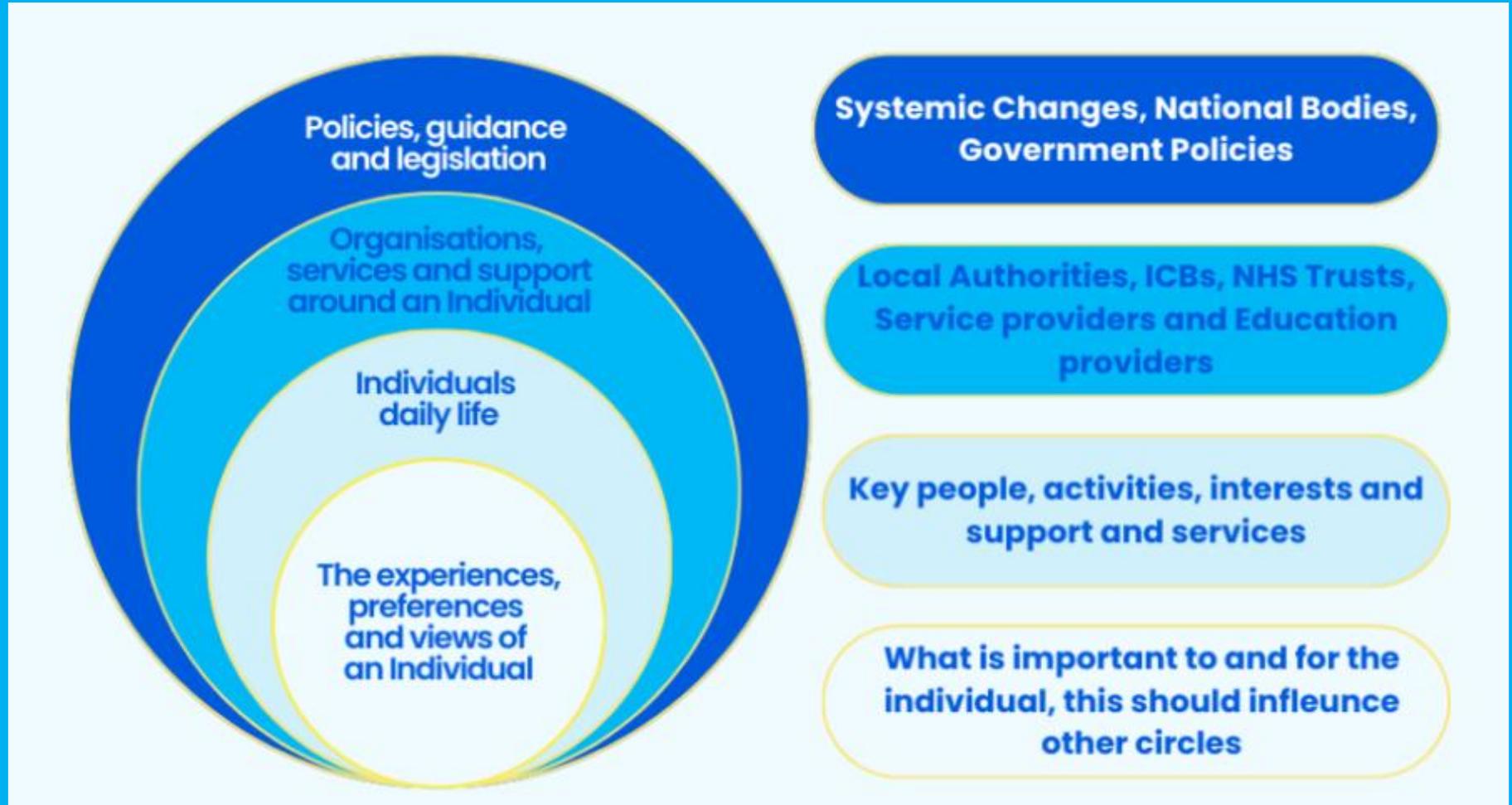
### INTERVIEWS, FOCUS GROUPS AND SURVEYS

With family carers and support circles before, during and after the engagement period

**What Matters to Me Methodology:  
Using a Mixed Method Approach**



# Importance



# Designing day services around people's ambitions



- IMPACT supported Persona Care and Support in Bury from Sep 2024 to Aug 2025.
- Our aim was to improve a day service provided from 8 community centres for over 150 people.
- We recognised the need to involve people with people with complex communication needs (profound and multiple learning disabilities).

## How you helped us?

- Learning from *What Matters to Me*
- Staff workshops and training
- Long-term co-production commitment

## What's next for IMPACT?

- Revisiting Persona in 2026
- New resources and campaigning
- Opportunities for collaboration...

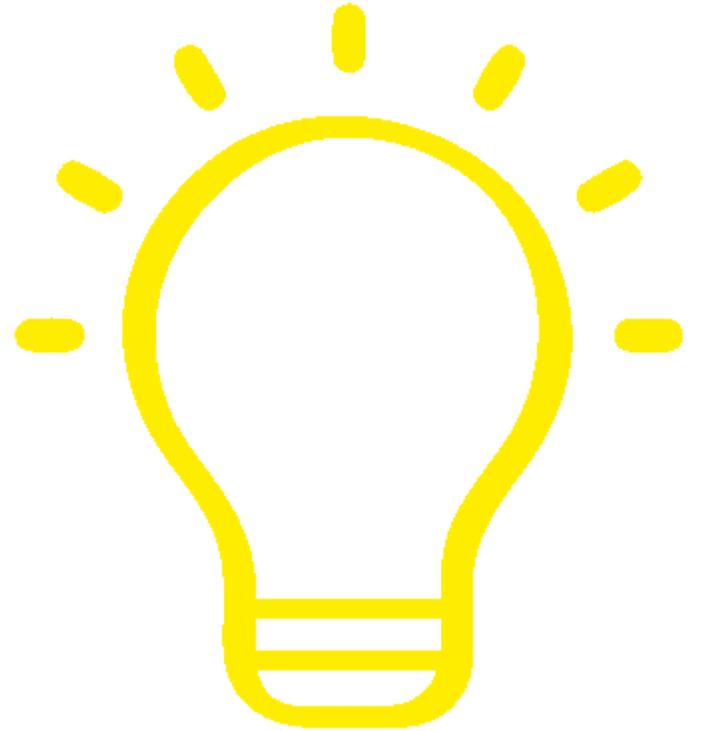
# Workshops

- Please note that you will be going into a different workshop to the one you were in this morning
- If you didn't previously say which workshops you would prefer to attend, we will allocate you to one
- After these workshops we will come back together as a group and share/reflect on what has been said in both the morning and afternoon workshops – we will be using Mentimeter for this



# Workshops

- **One piece of information or support available right now** that supports people with learning disabilities and their families
- **One big systemic issue** where we could work together to co-produce change
- **One practical solution** which you or others in the meeting could implement tomorrow to make a difference



# Feedback and reflection

- Workshop feedback
- Mentimeter – a chance for you to reflect and share what you've discussed!
- Go to Menti.com (it may be helpful to use a second device) and enter code 7995 4339



# Feedback and reflection

- What we've covered today

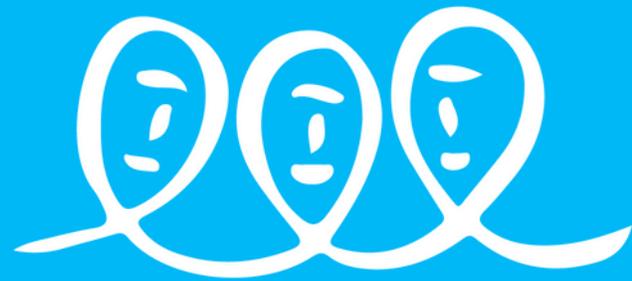


# Reflections on the past and looking to the future: putting our learning into action that improves lives

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Viv Cooper OBE, Founder, The Challenging Behaviour Foundation; Family Carer





# The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

[nationalstrategygroup@thecbf.org.uk](mailto:nationalstrategygroup@thecbf.org.uk)

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