

Welcome to



Building Alliances: Working together

Thursday 24th January 2019 | The Friends Meeting House, Manchester

Mount St, Manchester M2 5NS | #BuildingAlliances | www.bit.ly/BuildingAlliances19



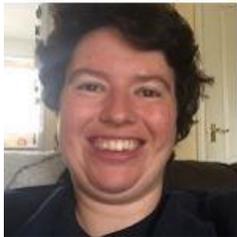
Opening Session



Jenny Carter
LDE Lifetime Member



Lynn Jackson
LDE Representative Body Member



Vicky Buckingham
LDE Representative Body Member

Loud Voices – Learning and influencing together

We are a group of self advocates, families and support workers and managers who came together on a 6 month programme to learn how to influence politics and the media. We learned about finding what we care most about and ways to get our message out there. We did social media, media and politics training and have started using what we learned to get out there and make changes. Most importantly we learned about all our different skills and talents and how when we work together, we are so much stronger.

In our presentation we will showcase the work we have been doing, our campaigns and the successes we've had so far, and we will talk about what it means for us to work together.

Presenters:

Vicky Buckingham, Lynn Jackson, Gary Bourlet, Mark Brookes, Alicia Wood, Jordan Smith, Kate Chate, Claire Garrod, Liz Wilson, Mark Brookes, George Sinclair

Building alliances and the media

Kate Ansell



Kate is a disabled filmmaker. She has over 15 years experience making TV programmes.

For Channel 4 News, she produced and directed No Go Britain, a series of special reports highlighting barriers for disabled people in the UK, and featuring members of Learning Disability England. For the BBC, she has overseen several Panorama investigations, including some about how welfare reform affects disabled people. She's also worked for BBC-3 and Channel 4 on series like One Born Every Minute and Don't Turn Around.

She joined the BBC again in 2018. Now she's part of their Daytime commissioning team. The team make decisions about what programmes to put on television, and help production teams make them.

Tea & Coffee break

12.15

Workshops begin at

12.40



making it real

how to do personalised care and support

Building Alliances: Working together



 **think local**
act personal

Making it real – the journey so far

- What good personalised care and support looks from a citizen's perspective
- First produced 2012, now revised
- Address the gap between personalisation 'talk' and lived experience
- Produced through lots of co-production
- Six themes with *I* and *We* statements
- Whole lives, community focus, across sectors



I statements

What good personalised care and support looks like if it is working well

- *I am valued for the contribution I make to my community*

We statements

What organisations and their people need to do to make sure actual experience lives up to the I Statements

- *We have a 'can do' approach which focusses on what matters to people*



making it real
how to do personalised care and support

Six themes of Making it Real



LIVING THE LIFE I WANT, KEEPING SAFE & WELL

Wellbeing and independence



HAVING THE INFORMATION I NEED WHEN I NEED IT

Information and advice

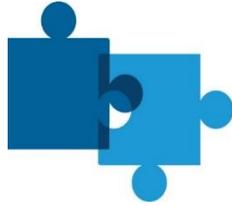


KEEPING FAMILY, FRIENDS AND CONNECTIONS

Active and supportive communities



Six themes of Making it Real



MY SUPPORT, MY OWN WAY

Flexible and integrated care and support



STAYING IN CONTROL

When things need to change



THE PEOPLE WHO SUPPORT ME

Workforce



making it real
how to do personalised care and support

What's in it for people?

- A basis for **conversations** with local services that focuses on making things better

What's in it for organisations?

It can help to:

- **look at current practice** against the statements, identify areas for change and develop plans for action



The art of personalisation

- Building a library of inspiration:
 - Manor Community re-designing their care and support plans around the 'I' Statements
 - Wirral Evolutions engaging with people, families and staff to discuss how well their experience rates against the 'I' Statements and agree the most important things to work on together to improve
 - Hobbs Field residential home involving people who live there in recruiting staff



Group Discussion

- The / statement tables:
 - Look at your / statements and discuss:
 - What can services do to make this a reality for people?
 - Agree one point to feed back

Group Discussion

- The *We* statement tables:
 - Look at your *We* statements and discuss:
 - What needs to happen to put them into practice?
 - Agree one point to feedback

How can you get involved?

- **Think** about how you might use it
- **Take time** to have proper conversations with everyone who needs to be involved
- **Agree** how you will use Making it Real to **get better** at personalisation
- **Register with TLAP**, making sure your plan has been agreed through **co-production**
- You should look to **push on** and not just capture what you already do
- **Do the 'do'** and share your learning within one year
- **If you need help ask us.** Our National Co-production Advisory Group can provide advice
- **Look** at what others are doing on TLAP website



Making it Real website

A framework to support good personalised care and support for providers, commissioners and people who access services.



RECRUITING NEW STAFF

Using Making it Real, Hobbs Field care home involved people they support in choosing staff.



WHY IT MATTERS

Anna Severwright describes the difference Making it Real will make to her.



LATEST NEWS/BLOGS

Kate Sibthorp & daughter Maddy, and James Sanderson, give their perspectives on the new Making it Real.

ABOUT MAKING IT REAL →

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Find out more

www.thinklocalactpersonal/makingitreal

makingitreal@tlap.org.uk



The NHS Long Term plan – Connections and alliances

Katie Matthews



Katie is a Learning Disability and Autism Network Manager at NHS England.

She is a part of a team of four Network Managers, two with a learning disability, autism, or both and two without. They use the co-working model where people with different strengths and abilities collaborate to get the best from each other.

Katie's team acts as a bridge between NHS England and a forum of people with a learning disability, autism, or both, family carers, advocates and supporting organisations.

Ray James CBE



Ray is the National Director, Learning Disability, NHS England

Ray brings a wealth of experience and knowledge from a career in local government to his new role leading NHS England's work to transform care for people with a learning disability and their families/carers.

He has served as Executive Director of Health, Housing and Adult Social Care at Enfield Council for over a decade and is a Past President of the Association of Directors of Adult Social Services (ADASS). Ray was awarded a CBE for services to Adult Social Care in the 2018 New Year's Honours List.

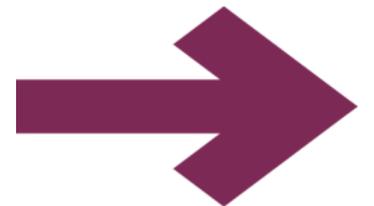
Building alliances: Working together on our shared goals

Ray James, National Director for Learning Disability

Katie Matthews, Learning Disability and Autism Network Manager

NHS England Learning Disability Programme team

January 2019



What's happening?



Last year, the NHS turned 70 years old!

The Prime Minister is going to give the NHS extra money for the next 5 years, so it stays fit for the future

Planning for the next 10 years of the NHS



The NHS has made a plan about what needs to happen in the next 10 years and how the money should be spent

Learning disability and autism are priorities in that plan.

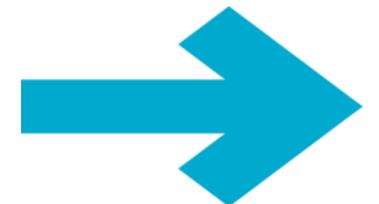


The NHS long term plan

Learning Disability England helped us to have conversations about the future.



- Almost 2000 answers to online questions
- More than 20 written replies
- 7 LD England regional events
- 2 NHS England national events
- We LD nurses Twitter chat
- Webexes, meetings for clinicians, and self-advocacy groups held meetings



What's in the plan overall



- The plan is about making a difference throughout people's lives, starting with a stronger focus on children and young people with the most complex of needs.
- Our ambitions are that across the whole NHS and wider society, we do more **to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.**



Providing the best start in life



- Improving waiting times for children and young people's autism diagnosis.
- Keyworker for the most vulnerable children and young people and their families.
- Work with the Department for Education and local authorities to improve their support for children and young people.
- Children with a learning disability have their needs met by eyesight, hearing and dental services



Reducing health inequalities



- Expanding the use of STOMP STAMP reviews



- Do more to keep people well with proactive care in the community; so that more people can live in or near to their own homes and families.



- Continue and 'accelerate' LeDeR



Reducing health inequalities



- Staff will receive information and training on supporting people with a learning disability, autism or both



- Staff know how to provide reasonable adjustments



- People to have digital flag on patient records, to best meet their need

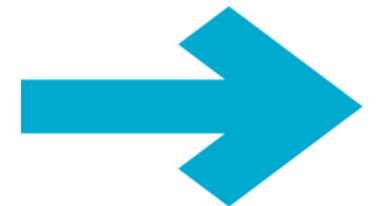


Continuing Transforming Care



- Use of CTRs and CETRs
- Work with the CQC to implement recommendations on restricting the use of seclusion, long-term segregation and restraint.

‘Least restrictive practices’ – supporting people in the ways that protect their rights.



Continuing Transforming Care



- Commitment to people living in homes not hospitals – continuing Building the Right Support. Further reducing how many children, young people and adults are treated in specialist hospitals.
- 7-day specialist multidisciplinary service and crisis care to support people in their communities.



More needs to change!



Improving things for people with a learning disability, autism or both needs a change of culture and attitude.

There needs to be better understanding of learning disability and autism – and this should be in all staff's training



More needs to change!



Services must work well with people and their families and with each other.

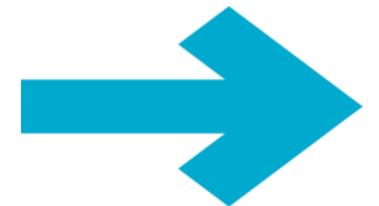
Support must be person-centred – designed around each person as an individual.

Learning disability improvement standards will be introduced for all services funded by the NHS.

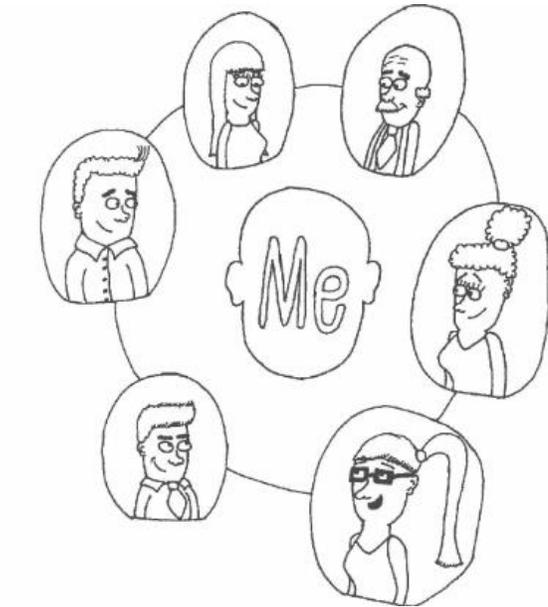




This work must be done with people and their families and carers.



Transforming Care - achievements



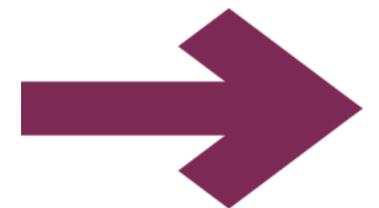
19% reduction in inpatient beds

Thousands of CTRs taken place – majority leading to decision to no admit

Ask Listen Do

STOMP (and soon STAMP)

Annual Health Checks



Transforming Care – achievements and challenges

Our rights, our lives



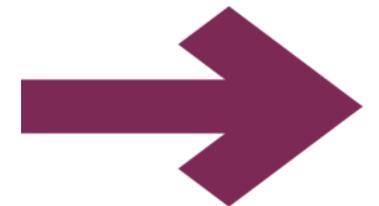
Some areas are doing better than others

Capital grants for housing

More funds for Transforming Care Partnerships

CQC work on registration of providers of services

**Still much more needs to change:
Community services, support for
children and young people**

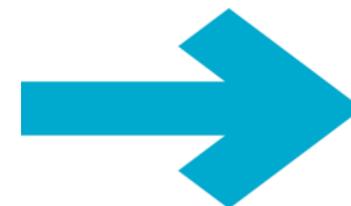


Employment of people with a learning disability



NHS England and NHS Employers launched a pledge to employ more people with a learning disability - NHS organisations encouraged to sign up .

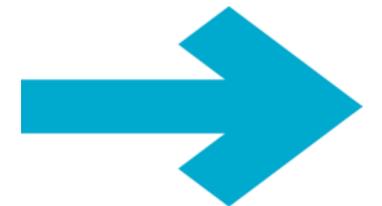
There are people with a learning disability working for NHS England as well as family carers – this benefits patients and the public.



Our shared goals – overall



- Equal access
- Good experience
- Best possible outcomes
- All means all

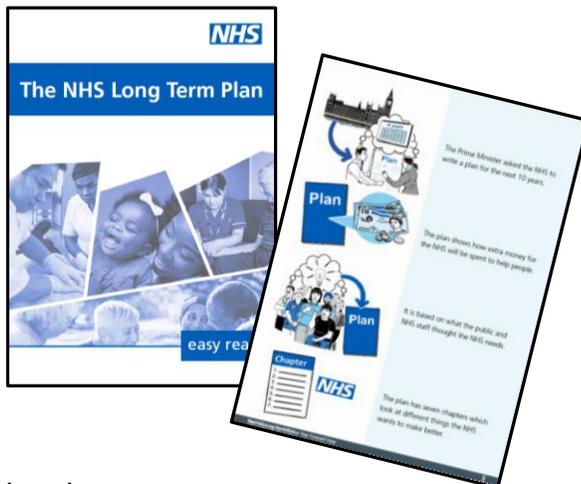


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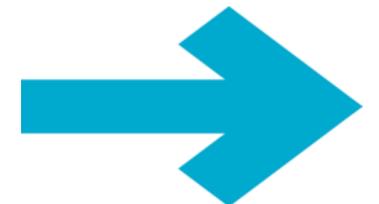
The NHS Long Term Plan is available at www.longtermplan.nhs.uk



Search online for 'the NHS long term plan for learning disability and autism video'



There is an easy read version of the plan ...hopefully you have all got a copy from our stall here today!



Workshops

3.00pm

Tea & Coffee break

4.00pm



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how to do personalised care and support

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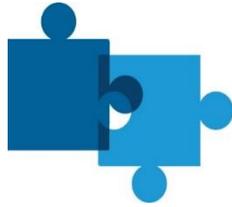


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makingitreal@tlap.org.uk





Learning Disability England

What we are working on now and next

Our big aims

**LDE**

Learning Disability England exists to make life better for and with people with Learning Disabilities and their families.

We want to make sure

- What is important to people with Learning Disabilities is heard and understood
- There is a change in behavior in service design and delivery that builds on rights
- Through our members we show coproduction and real collaborative working making a difference
- We live our values and model the change we want

How we are working



1. Membership – stronger links and more members
2. Influence and campaigning – speaking up and sharing others important work
3. Solving problems together & sharing what works
4. Share information and build networks so we learn together

Helping to Make Self-Advocacy Stronger



- Helping to find and share evidence on what difference self advocacy makes
- Connecting self advocates and sharing information on what self advocacy groups there are

Housing Choices- Making Sure People Know About Different Options



- Find out what is happening on housing choices – do people have less choice?
- Work together on what matters to people – is people with learning disabilities experience different?

Influencing Funding Decisions and Understanding How it Affects Peoples Lives



- Share the difference funding choices are making.
- For example Sleep ins, Mental Capacity Amendment Act
- Speak on what matters to people to challenge decisions made only based on money

Being Part of the Future Social Care



- Telling the decision makers what is important for people with learning disabilities
- Bring together a shared voice on a Green paper
- Working alongside the NHS on the 10-Year Plan and showing how social care matters in that

Partnership with JMS Trust

The logo for JMS Trust features the text "JMS Trust" in a large, white, sans-serif font on a bright pink rectangular background. Below this, the text "Supported Living Funding" is written in a smaller, white, sans-serif font on a dark blue rectangular background.

JMS Trust

Supported Living Funding

- The aim of JMS Trust is to help people with learning disabilities and their families to set up their own supported living house.
- Partnership allowed the role of Family Engagement Worker to be developed

Spokespeople

WE WANT YOU!

**LDE**

TO BE A SPOKESPERSON!

WE ARE STRONGER, LOUDER, TOGETHER!

- To help make change happen we want to support a wide network of people be spokespeople — self-advocates, families and friends, and staff from organisational members.
- This would involve sharing your experience and knowledge on issues important to you.

What matters to you about our work



What is most important for Learning Disability England to do first?

Is there anything you want to share or tell people about?

Are we working together in the best way?

Launch Transgender Support Guide



Michael Fullerton

Michael is Clinical Director with CMG. Michael is a Learning Disability Nurse and works for a provider organisation supporting adults with learning disabilities and/or autism. Michael was aware that CMG are supporting people who are thinking about transitioning from the gender they were assigned at birth, or they are a trans man or woman. He felt it important that CMG are able to support and advice people who are trans or thinking about this. As there is not much easy read information available about this, he felt that it was important to develop a guide



Shaun Webster

Shaun is a person with learning disability working for CHANGE as an International Project Worker and Volunteer Coordinator. Shaun began at CHANGE in 2003 and has worked on numerous projects, including the Rights of Children - Europe Project, where he worked on the closure of institutions for children across a number of European countries. For his work on the NHS Accessible Information Standard he was awarded an MBE. He has delivered training within the UK, across Eastern Europe, in Africa, and the Middle East on Inclusion, good communication and making information accessible. Shaun is a role model for young people with learning disabilities, using his skills and expertise to put the messages about Human Rights and Inclusion on an international platform. Shaun co-led the easy read projects with CMG on Keeping Safe Online, Transgender Support, and Pornography.

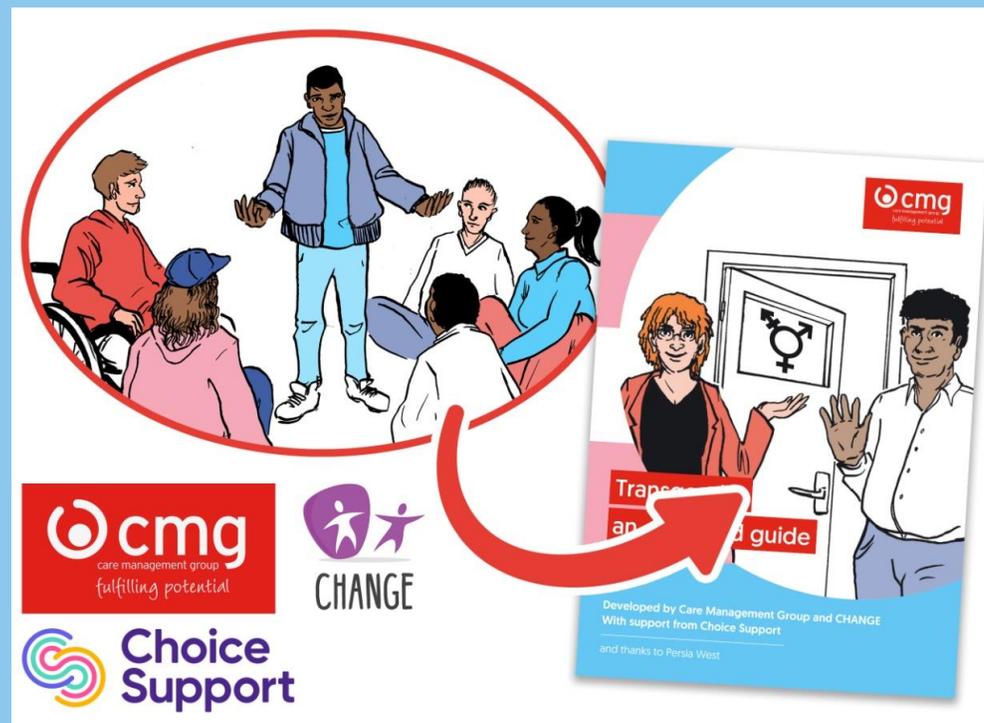


Jez Coram

Jez is Research and Development Manager at CHANGE and has worked with the organisation for eight years. He started at CHANGE in the Accessible Information Design Team as a Multi Media Designer, developing the CHANGE website, video projects such as the Bradford Sexual Health and Relationships Animations, and the Independence Pack, a pack to help people with learning disabilities move from ATUs back into the community. The pack won British Medical Association easy read patient information of the year in 2016. Jez co-led the CMG Accessible Information projects with Shaun.

Transgender Easy Read Guide

Learning Disability England Conference, 24th January 2019



How did the trans guide come about?



Keeping Safe Online

- Keeping Safe online guide in 2017
- Discussion on issues affecting people with learning disabilities with CMG
- Lack of accessible information on these topics e.g. Transgender support

How did we develop the Guide?



Process

1. Research
2. Writing
3. Design
4. Illustration
5. Review
6. Publishing

Sex and Gender



Your sex describes the physical body parts you were born with.



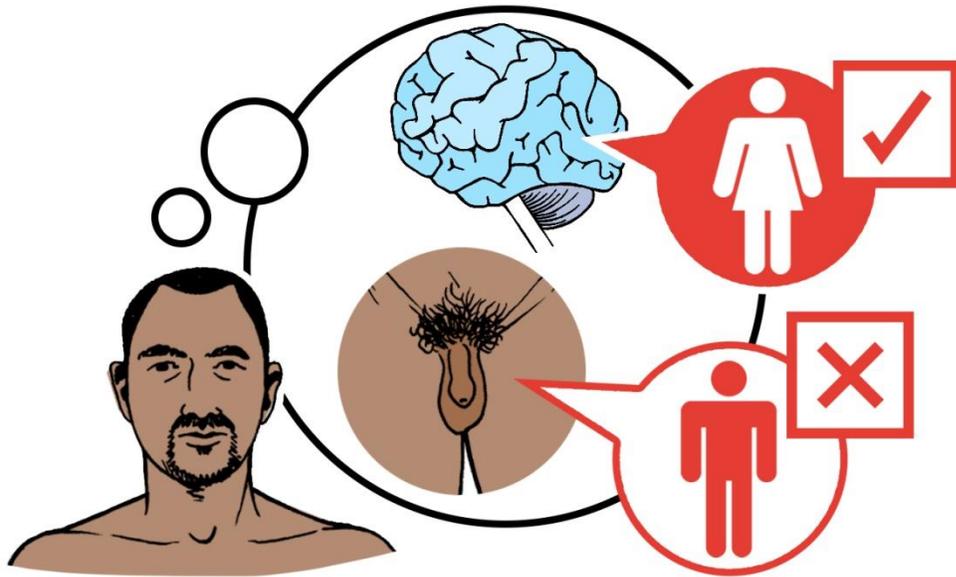
SEX



GENDER

Gender is different to sex and is how male or female you feel you are.

Transgender



Being transgender is when you know there is a difference between your physical sex and your inner sense of how male or female you are.

Challenges and Positives?

Shaun and Jez



'Alongside the guide to online pornography, this project has been one of the most challenging easy read documents to produce. This was due to the difficulty in translating the complexity and nuance of the language and terms and representing in illustration the sensitive nature of the issues faced by the trans community.'



'Over coming these challenges has been very rewarding for the team at CHANGE and a great learning experience. We are very proud of the document and the potential support it will provide.'

How do you get a copy of the Guide?



www.changepeople.org



www.cmg.co.uk



www.choicesupport.org.uk

