



MAKING EVERY CONTACT COUNT (MECC)

Review of MECC Resources for the Workforce
Supporting People with Learning Disabilities and
Autistic People

Recommendations Report
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‘Making Every Contact Count (MECC) for the workforce supporting people with learning disabilities and autistic people.’

Executive Summary

Through conversations both locally and nationally, it has been questioned how appropriate the materials and approaches used in the MECC e-learning, and the face-to-face training, are for supporting staff who work with people living with a learning disability and/or autistic people.

As a result, in June 2021 a small working group of colleagues from Health Education England, Lancashire and South Cumbria NHS Foundation Trust and Lancashire Recovery College was formed to investigate this.

The vision is to improve the health and wellbeing of people with a learning disability and/or autistic people, and to reduce health inequalities between the general population and people with a learning disability and/or autistic people.

This report sets out recommendations for how MECC resources should be tailored to enable health care staff to have effective MECC conversations with people living with a learning disability and/or autistic people.

Fundamental to this process is co-production alongside people with lived experience of learning disabilities and autism.

Making Every Contact Count (MECC)

MECC enables the opportunistic delivery of consistent and concise information about healthy behaviours by using the millions of day-to-day interactions that happen as part of providing our services. MECC enables individuals to engage in conversations about their health across organisations and populations. MECC maximises the opportunity within routine health and care interactions for a brief or very brief discussion on health or wellbeing factors to take place.

Context

In 2020 staff within Lancashire and South Cumbria Foundation Trust undertook the updated MECC training offered by the Integrated Care Systems (ICS). It was suggested that the training programme did not provide materials to support staff who work with people living with a learning disability and/or autistic people.

MECC is important to everyone’s physical health because it addresses the key health-harming behaviours of smoking, alcohol misuse, unhealthy diets, and physical inactivity. In the UK, it is estimated that over a third (36%) of all deaths and 29% of disability adjusted life years (DALYs) are attributable to these behaviours¹.

People who have learning disabilities experience more ill health and premature mortality than the general population and it has been estimated that almost a quarter (24%) of deaths that occurred in adults with learning disabilities in 2020 were



preventable. The most frequently recorded causes of these preventable deaths were ischaemic heart disease (22%), aspiration pneumonia (12%) and strokes (8%). These deaths are in part related to the health harming behaviours covered in a MECC conversation. Autistic people also experience increased morbidity and reduced life expectancy (20-36 years) compared with the general population². Again, these poor health outcomes are likely to be linked in part to disparities in exposure to behavioural risk factors. For example, autistic people are more likely to have a poor diet, obesity and limited physical activity compared with their non-autistic peers³. They are also more likely to experience a range of barriers to accessing health care and support, both relating to the nature of autism itself, and to inadequate provision of reasonable adjustments⁴. It's therefore important that staff are equipped with the skills and knowledge to have these conversations.

The Learning Disabilities Mortality Review (LeDeR) programme was established in May 2015 in the response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities. The findings demonstrated that on average someone with a learning disability lives 20 years less than someone without learning disabilities. It is the first national programme of its kind in the world, being led by the University of Bristol^{2, 3}.

Research has shown that on average, people with a learning disability and/or autistic people die earlier than the general public, and do not receive the same quality of care as people without a learning disability or who are not autistic. The issues and causes of death identified within the national LeDeR annual report (published May 2020), alongside the findings from locally completed reviews, reflect the many challenges that people with a learning disability face².

We know that people with a learning disability are four times more likely to die of something which could have been prevented than the general population⁵. Data from NHS Digital⁶ provides the following key facts:

- On average, females with learning disabilities have around a 27-year shorter life expectancy than the general population, and males had around a 23-year shorter life expectancy than the general population.
- People with learning disabilities are more likely to have epilepsy, 22% of those with a learning disability have epilepsy compared to 1% in the general population.
- They are more likely to suffer with hypothyroidism, diabetes, heart failure, chronic kidney disease or stroke.
- They are less likely to receive cancer screening.
- Are more likely to be obese between the ages of 18-35 and more likely to be underweight once they are over 64.
- They are more likely than the general population to suffer from constipation.
- They are more likely to have a diagnosis of dysphagia and Aspiration Pneumonia is the leading cause of death for this population.

The NHS Long Term Plan aims to ensure the whole NHS has an awareness of the needs of people with a learning disability and autistic people, working together to improve the way it cares, supports, listens to, works with and improves the health and wellbeing of them and their families. MECC provides an opportunity to do this.



A project group was formed to:

Lead a review of MECC resources used in Lancashire & South Cumbria to ensure they are fit for purpose to enable all staff to have effective MECC conversations with people living with learning disabilities and/or autistic people.

We had a multi-organisational working group see **Appendix 1** for membership.

Resources reviewed

Whilst this work was taking place the [Making Every Contact Count Toolkit](#) was released. This includes many resources, but they are not specific to the workforce supporting those people living with learning disabilities and autistic people.

All resources are available on [e-learning for health](#).

Review process

Focus groups reviewing each of the three MECC modules took place on 20th, 25th July and 1st August 2022. The groups included:

- Project Coordinator, Recovery College
- Trainee Advanced Clinical Practitioner (Nurse) Learning Disabilities) Lancashire & South Cumbria NHS FT
- Speech and Language Therapist; Learning disability Services, Lancashire & South Cumbria NHS FT
- Peer Support Worker Facilitator, Lancashire & South Cumbria NHS
- Consultant Nurse/Associate Director of Nursing (Autism Service)) Lancashire & South Cumbria NHS FT
- Programme Support Manager – Lancashire and South Cumbria Integrated Care System (ICS), HEE NW

In addition to this, feedback was collected via an online form. This allowed colleagues working in L&SC to undertake the training and review it in their own time. Respondents came from the following backgrounds:

- Trainee Nursing Associate
- Consultant Psychiatrist
- Community Learning disability Nurse
- Assistant Psychologist
- Community Learning disability Support Worker
- Nursing Assistant Practitioner
- Occupational Therapist



Group feedback

The resources

The feedback regarding the resources was well received and easily accessible:

- The online training was easy to access, presented well and user friendly.
- “Usually, I do not like online training as much as in person, but I felt this topic worked well online, especially as it allowed you to spend as long as you would like looking at resources”
- Good examples, including multiple ways of showing this (e.g. video and images and written)
- Informative and simple to understand
- Subtitles available on the videos, which made them more accessible.

Key themes from focus groups

Each participant was asked to feedback on content, on how suitable the content was for them working with patients or people with learning disabilities and/or autistic people. Highlights are below and full responses are in **Appendix 2**.

1. No data in the e-learning resource was specific to those people living with learning disabilities and autistic people when it is different to the general public. E.g. it advises of the top 5 causes of death but there is no mention of top causes of death in people with learning disabilities and/or autistic people, which differs to those listed.
2. There is no messaging to carers of those with learning disability and/or autistic people about changing health behaviours as conversations may be with support staff/carers/families as well as the service users themselves.
3. There are additional health risks for those living with learning disabilities and autistic people compared with the general public.
4. The Person-Centred Approaches examples could be more learning disability specific, open conversations may not always be the best tactic as support and suggestions may be more advantageous. Signposting gives the person the responsibility for contacting other organisations for additional, expert support to help them. This is not always possible for those living with learning disabilities and autistic people. They may need additional support and guidance contacting services.
5. Resources need adaptations as to how this would be used with individuals with learning disabilities and autism. By definition, if the individual has a learning disability, then their communication skills will be affected and therefore, they may need alternative forms of MECC contact.
6. Starting with open questions and then having options ready should the individual require a closed question or forced alternative. In some ways, it may feel more directive, but would be more meaningful for the individual.
7. For learning disability, it needs more content regarding communication and person centred to enable service users to understand the meaning of it.
8. Each question has resources available on a link for each one, these resources are often not suitable for those living with learning disabilities and/or autistic people.



RECOMMENDATIONS

Recommendation 1: ***National resources to be updated with an additional section: 'MECC for the workforce supporting those living with learning disabilities and /or autistic people.'***

This would integrate guidance on the skills and learning required to deliver MECC conversations with someone with a learning disability and/or autistic people into the existing learning package.

It is essential for this to be co-designed with people with lived experience.

Recommendation 2: ***Curation of signposting resources that are accessible to people with learning disabilities and/or autistic people, and families and carers.***

Regions and Integrated Care Systems to develop signposting resources hosted on an easily accessible open access platform.

See **Appendix 3** for examples of resources / organisations that could support workforces working with those living with learning disabilities and/or autistic people.

Recommendation 3: ***Development of resources to support MECC conversations for people with learning disabilities and/or autistic people (where they are not currently available).***

Not all MECC resources reviewed were accessible to people with learning disabilities and/or autistic people.

Resources should be developed in response to the LeDeR - Action from learning reports such as CVD risk reduction.

It is essential they are co-designed with people with lived experience.



APPENDICES

APPENDIX 1

1.1 Membership of the project steering group:

- Alison Farrar, Public Health Workforce Lead, HEE NW (co-chair)
- Annamaria Pomfret, Administration Support, LSCFT
- Fiona Ball, Workforce Planning Lead and NW Learning Disabilities & Autism Lead, HEE NW
- Jane Beenstock, Consultant in Public Health, LSCFT (co-chair)
- Kieran Uttley, Trainee Advanced Clinical Practitioner (Learning Disabilities), LSCFT
- Michelle Murphy-Tyrer, Programme Support Manager, HEE NW
- Nick Lowden, Public Health Project Manager, HEE NW
- Samantha Porter, Trainee Advanced Clinical Practitioner (OT), LSCFT
- Sarah Jackson, Autism Clinical Pathway Lead and Trainee Approved Clinician, LSCFT
- Shaun Everitt, Project Coordinator, Lancashire Recovery College
- Suzie Smith, Senior Operations Manager for Recovery & Resilience, LSCFT

APPENDIX 2

Feedback from focus groups:

What is MECC and why is it important?	
ELfH resources	<ul style="list-style-type: none"> • For learning disability and/or autistic people the top causes of death are very different to general population – neurological conditions such as epilepsy and suicide for autistic people due to mental health and learning disability is aspiration pneumonia due to poor oral health, choking and respiratory conditions • On MECC training it advises of the top 5 causes of death but there is no mention of top causes of death in learning disability and/or autistic people. • Leading causes of death for people with a learning disability and autistic people are very different – LeDER - https://leder.nhs.uk/ • Links at the end of session 1 to include links for learning disability and autism resources • No statistics re learning disability i.e., re health needs • Need a resources link to health widget health, NHS - https://www.nhs.uk/widgets/conditions/setup.php?uid= • Need something about the messaging to carers of those with a learning disability and/or autistic people about changing health. • Nothing on the training mentions PW learning disability or autistic people and may need extra time with MECC conversations.



	<ul style="list-style-type: none"> • Under the knowledge section following the questions, there is a tab called 'links. Can we add a tab here for resources specific to learning disability and/or autism? • Having the right resources embedded for PW learning disability and autistic people hyperlinked to link to suitable resources. • Conversations may be with support staff/carers/families rather than with the service users themselves. • What support can be provided to families around activity, health eating, drink awareness, drug awareness etc for someone who has caring responsibilities.
Links from the ELfH Resources	<p><u>One You 'How are You' Quiz</u> The reviews thought it was a great way to initiate conversations, but the delivery may not be suitable for those living with Learning Disabilities and Autistic People. These include:</p> <ul style="list-style-type: none"> • Use smiley faces instead of words of 'feelings'. • At the end of the quiz, it provides you with a score out of ten which is not good for someone with learning disability or/and autistic people and can have a completely different meaning. • Each question has resources available on a link for each one, these resources are often not suitable for those living with learning disabilities and autistic people. <p>Interestingly <u>Drink Aware has a specific page for LGBTQ</u>, the group are unaware of anything to link this for the cohort they work with.</p> <p><u>MECC Link</u></p> <ul style="list-style-type: none"> • On MECC Link website there is a link to provide information for 'Veteran Support.' Can we have one for learning disability and autistic people? • Add a learning disability tab to the MECC link list. • Add autism tab to the MECC link list
Other	<ul style="list-style-type: none"> • Is there smoking cessation advice, drink and drugs awareness for someone with learning disability and/or autistic people. • Do we already have all accessibility to available resources, and it is about making them more available and easily readable and accessible to someone with learning disability and/or autistic people. • Cuckooing (drug dealers who take over the home of a vulnerable person in order to use it as a base for county lines drug trafficking) or hate crimes both have a high rate in people with learning disability. • Is there smoking cessation advice, drink and drugs awareness for someone with learning disability and/or autistic people. • Explore printable resources. • Starting with open questions and then having options ready should the individual require a closed question or forced alternative. In some ways, it may feel more directive, but would be more meaningful for the individual.



How to have a MECC conversation:	
ELfH resources	<ul style="list-style-type: none"> • For learning disability, we would need to do a bigger piece around communication and person centred to enable service users to understand the meaning of it. • Smile for LD would be good but not for autistic people and they would need to be separated out long eye contact isn't good for autistic people. • Need to think about signposting with either an easy read or a mind map. • People with learning disability and/or autistic people wouldn't necessarily understand what damage is done or caused or what the consequences are and might not be able to relate it to themselves that they are making the wrong choices. • Need to enforce stop smoking with pictures for example a picture of a heart with a cigarette so they relate to them. • Some would benefit from closed questions. Try closed questions to see if you can get the information, you need but if not then change to open questions. • Need to consider the carers role within this session. Some aren't going to be able to have a one-to-one conversation like in the video, and this will become challenging for both. • How can this be re-enforced because verbally may not be good enough for them to understand. • Training package doesn't consider 'nuances' of learning disability and/or autistic people e.g., regimented diet, forensic history, community access etc. • Should link to mental capacity act. • Person centred approaches – could be more learning disability specific – Need specific learning disability communication pointers.
Links from the ELfH Resources	<ul style="list-style-type: none"> • Healthy eating booklets for LD don't necessarily explain what they mean, and they would be hard to understand. If you asked, what do you mean by feel, smoking is not specific to them and are not going to understand some of the meanings.
Other	<ul style="list-style-type: none"> • Suggested doing a trial with some of the care homes and see if they've used MECC and what they provided. • Need to offer easy read materials. • Look to supplement pack rather than taking everything away that takes away the meaning of MECC – information, leaflet or supplementary pack. • Open questions around health issues may cause difficulties for people with communication needs e.g., difficulty generating ideas, understanding language used, better with yes or no questions. • Open discovery questions – 'what' / 'how' questions can be difficult for those who struggle with generating ideas or answers.



Signposting	
<p>ELfH Resources</p>	<ul style="list-style-type: none"> • ‘Signposting gives the person the responsibility for contacting other organisations for additional, expert support to help them.’ – This is not always possible for those living with learning disability and/or autistic people. They may need support contacting services. <p>National Resources</p> <p><u>NHS Choices</u> – Apps are good and could be used to support clients. Like other resources, no easy read and many not suitable for those living with learning disability and/or autistic people.</p> <p><u>MECC Link</u> (Discussed in session 1)</p> <ul style="list-style-type: none"> • On MECC Link website there is a link to provide information for ‘Veteran Support.’ Can we have one for learning disability and/or autistic people? • Add a learning disability tab to the MECC link list. • Add autism tab to the MECC link list • The training talks about resources needing to be: Accurate, Current, Contact Details, Relevant, Accessible. The reviewers agreed but are unsure if there are resources that are accessible. A good example is <u>MENCAP Dealing with Bereavement Resources</u>

ONLINE RESPONSES TO FEEDBACK ON RESOURCES:

1.1 Positives:

- Engaging and informative
- It was easy to navigate /use friendly
- Not too much information
- Interesting ways to approach subjects and how to talk about the subjects in conversation
- It was helpful to be given frameworks to use and resources.
- Good examples, including multiple ways of showing this (e.g. video and images and written)
- Easy to understand
- Informative and simple to understand
- Usually, I do not like online training as much as in person, but I felt this topic worked well online, especially as it allowed you to spend as long as you would like looking at resources.

1.2 Question: Do you think the training is relevant to those working with people living with learning disabilities and autistic people?

- More information about barriers people may present when trying to discuss health.



- It needs to be more specific for this group of people and I think this may be best achieved via a specific additional module
- Needs adaptations as to how this would be used with individuals with learning disabilities and autism. By definition, if the individual has learning disability, then their communication skills will be affected and therefore, they may need alternative forms of MECC contact.
- Yes. It is hard sometimes to approach those who have a learning disability and/or autistic people if you are unaware how best to support someone. With more training provided it helps those who are supporting someone with a learning disability and/or autistic people to carry on providing the healthcare they need.
- Need to be adapted to the level the patient is functioning at
- I think that MECC is important for all people, including those with learning disabilities and/or autism. However, I feel it would be helpful to have more specific information regarding supporting those with learning disabilities and/or autism as it may require more skills to communicate with them.

1.3 Question: What could make it more suitable for those working with people living with learning disabilities and autistic people?

- Need to highlight increased physical health and mental health comorbidities in this group in the introduction
- Need reference to diagnostic overshadowing in simplistic terms and poor screening and uptake of tests offered leads to poorer health
- Some ASD specific issues highlighted e.g. difficulty changing routines and habits
- Awareness of different communication methods. Images, easy read, sign language
- Awareness of food as a reward
- Open questions can be difficult for our service users to understand, sometimes need to be focussed questions.
- Need to signpost to learning disability specific resources
- Does there need to be different information/resources/signposting for carers, families and service users?
- Videos of using MECC with people with learning disabilities and using forms of communication other than verbal
- Examples of easy read material
- Providing information in small chunks and over a period of time
- Communication guidance, would need to be a lot more person centred
- I believe support from learning disabilities teams in the community or hospital liaison and ask for advice or support, not just when it comes to referrals but for example if a learning disabilities patient needs to access the GP, provide support to receptionists or GPs themselves. Face to face training would also be good. Training on how those with autism have triggers and that this could lead to escalation and could lead to not attending future appointments.
- It would be helpful to have more resources specific for working with those learning disabilities and/or autism.
- Having people with learning disabilities and autism in the training



- Communication guidance would need to be a lot more person centred, also on working with the support network around the individual as appropriate.
- How to apply MECC for someone who may not be able to answer or respond appropriately to open questions or be able to think of solutions."

APPENDIX 3

1.1 Examples of resources / organisations that could support workforces working with those living with learning disabilities and autistic people. Desktop research raw data:

- Childrens Community learning disability and Behaviour Support Services – only for South Cumbria <https://www.lscft.nhs.uk/our-services/service-finder-z/childrens-community-learning-disability-and-behaviour-support>
- Autism unlocked - <https://www.healthierlsc.co.uk/mentalhealth/learning-disabilities/autism-unlocked-online-autism-support>
<https://lsc.autismunlocked.co.uk/family-resources/> this provides a sign up for monthly updates
- Lancashire and Cumbria autism support hub:
<https://www.lancashire.gov.uk/children-education-families/special-educational-needs-and-disabilities/health-and-wellbeing/learning-disabilities-and-autism/lancashire-and-cumbria-autism-support-hub/>
- Cumbria County Council -
<https://localoffer.cumbria.gov.uk/kb5/cumbria/fsd/advice.page?id=AzeCbnCo0l0>
- Lancashire and South Cumbria NHS have secured a small amount of money to pilot a new intensive support service to help autistic children and their families who are in crisis - <https://www.bwd-localoffer.org.uk/kb5/blackburn/directory/site.page;jsessionid=B8C70C031EBE9B2F61BF53A3FC866894?id=8MScpNmD3Hk>
- The Autism Service - <https://www.theautismservice.co.uk/>
- North West learning disability and Autism Operational Delivery Network - <https://www.nwodn.co.uk/>
- Lancashire Autism Families in Partnership-
<https://www.facebook.com/LancsAutismFamilies/>
- ELHT & Me - East Lancashire Hospitals NHS Trust Learning disability Liaison Nurse Service Network - <https://elht.nhs.uk/services/learning-difficulties>
- Healthy Young Minds Autistic Spectrum Condition (ASC) -
<https://www.healthyyoungminds.lsc.co.uk/information/professionals/autism-spectrum-condition-asc>
- Cumbria County Council: Autism Champions -
<https://www.local.gov.uk/case-studies/cumbria-county-council-autism-champions>
- South Cumbria Childrens Learning disability & Behaviour Support Service
<http://www.stgeorges.cumbria.sch.uk/Childrens%20LD%20July%20Newsletter.pdf>
- Lancashire Autism Service Ltd - <https://www.lancashireautism.org/about/>
- Quit Squad - <https://www.quitsquad.nhs.uk/>



- Learning disability and autism - <https://www.lscft.nhs.uk/services/learning-disability-and-autism>
- Autism Outreach Team - <https://www.lscft.nhs.uk/services/service-finder-z/autism-outreach-team>
- Children's Community Learning disability and Behaviour Support Service - <https://www.lscft.nhs.uk/our-services/service-finder-z/childrens-community-learning-disability-and-behaviour-support>
- Health Facilitation Team - <https://www.lscft.nhs.uk/services/service-finder-z/health-facilitation-team>
- Key Working Team - <https://www.lscft.nhs.uk/services/service-finder-z/key-working-team>
- Parents Action for Children – Additional Needs and Disabilities - <https://parents.actionforchildren.org.uk/additional-needs-disabilities/>

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