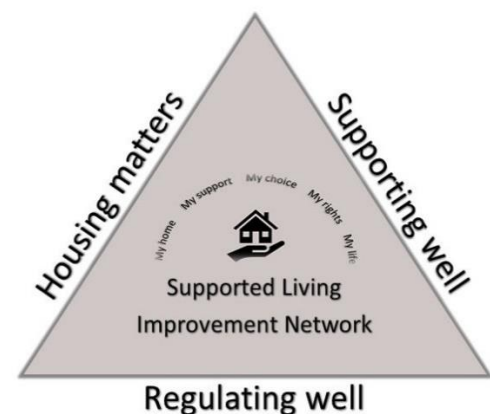


Key findings and Introduction: September 2024

Respectful and inclusive language and communication in Health and Social Care



Respectful and inclusive language and communication in Health and Social Care a sub-group of the Supported Living Network



Key findings

People with a learning disability require more, and different, forms of support to ensure they stay in good health. But there are profound disparities in access to health services for this group compared with the rest of the population.

Through what we had been told in the survey, the key learning was developed into recommendations, condensed to have more impact. Examples of good practise demonstrate that all disparities are avoidable.

Key findings were:

Missed Opportunities: Preventive forms of support that could help avoid health problems are often missed due to disjointed care and communication not well-suited to this population.

Efforts to improve healthcare access for people with learning disabilities are crucial. This report looks at how respectful and inclusive language and communication in Health and Social Care can positively improve support.

Use Accessible Language:

Professional letters often do not meet the Accessible Information Standards, making people reliant on support staff, if they have them.

Be Patient: The survey confirmed that people need time to take in the information and often especially financial information from Councils often very difficult to understand, along with the 'Professional' language used by some medical staff. Clearly Staff could be more inclusive, if they did not use the professional language, jargon and abbreviations that exclude understanding of the general public, too much information is written in a complex 'professional' way that few people really understand or read. The survey reinforced how important continuity of care is, looking at how a person's ongoing relationships with their clinical team, and the relationships between different team members looking after them, affects their care. That patient advocacy plays a crucial role in care support by ensuring that individuals receive the best care and services possible.

Talk to the person first to ensure inclusion:

If they can't answer a question carers or support staff will help them out. Need to promote the essential support of family or support staff. Families and care staff develop the skills they need to support an individual; professionals do not always have similar skills, relying on support of family or support staff when attend meetings or medical appointments. Interpreters and advocates are not often made available.

Yet professionals do not have confidence in that support and accuse families and care staff of speaking on behalf of person even though sign language has been used to find out the person's needs.

The Triangle of Care promotes an alliance between carers, service users and health professionals, aimed at promoting safety, recovery and to sustain wellbeing by including and supporting carers. For this it is important that carers

and the essential role they play are identified at first contact, or as soon as possible thereafter. Staff are 'carer aware' and trained in carer engagement strategies, with post(s) responsible for carers in place. Policy and practice protocols re: confidentiality and sharing information are in place. A range of carer support services is available and a carer introduction to the service is available, with a relevant range of information across the care pathway.

Lack of understanding, means lack of services:

The survey told us that Staff do not understand challenging behaviours can result by poor communication Staff expect person to write things down to help them, No social communication, No guidance in their care as no communication.

Employ Different Communication Tools:

People need information that they can access and understand. Clear succinct information needed for autistic and other medical conditions. i.e. in a suitable format for them i.e. Easy read. There is also a need for non-verbal communication of medical need containing, information about Hospital cards / Passports, communication passports and Single Page Plans etc.

Be aware Body Language and Tone:

Ensure safe and effective wellbeing conversations and speaking up on health. People struggle or avoid speaking about their health, to avoid medical investigations and unless extremely unwell, not even inform staff. People do not always understand the consequences of acknowledging that they are unwell.

Make Adjustments:

Reworded or phrased things differently suggest you hadn't listened to them carefully. Support without judgement is essential.

Show Respect:

Professionals need to understand that health needs are not the person's fault. The Survey told us that training should be considered as a factor in improving Communication. The employer needs to ensure their staff have the appropriate training for their roles. It was felt the Oliver McGowan Mandatory Training on Learning Disability and Autism, which is delivered in 2 Tiers, would greatly help improve understanding of the barriers within Health and Social Care. Employers have options regarding how they can ensure their staff complete part 2 of Oliver's Training, delivering a standardised training package, either in-house with their own trainers, through a partner organisation, or via an external training provider.

To be most effective training should be offered not only to professionals but also to family members.

Protect people from sensory overload:

Sensory overloaded can make focusing difficult, leading to frustration and the need to be removed from the situation.

Ensure written information is available in a format that people can understand:

Online services are often difficult to understand, option for paper copy of forms preferred.

Allow people to prepare in advance of their meeting or appointment:

Time to process, leaflets and repeating parts of the information needed for autistic and other medical conditions.

Communicate people's rights in a way they understand:

Ensure that all seriously ill patients, their carers and care support staff are able to request a second opinion if their condition worsens, this is 'Martha's Rule'

Information needs to be mirrored to demonstrate understanding, using the same terminology. Information should be available through clearer communications across professional and patient relationships. There is a need to mirror information to demonstrate understanding, using the same terminology as the person to create trust.

Always be person centred:

See the person not the label, while labels may open doors, they also close minds. Often we see, and even apply, a label before we've even met the person. And in doing so we attach all our associations and assumptions, and have our standard set of service solutions

Introduction

Prevention is better than cure, and it enables people to live longer, healthier lives.

Health and people with a learning disability¹

Health inequalities that people with a learning disability can experience are partly caused by poor quality healthcare. As well as this, there are a number of health conditions that people with a learning disability are more likely to experience, including epilepsy and dementia.

Health inequalities

On average, women with a learning disability die **23 years younger** than women in the general population.

On average, men with a learning disability die **20 years younger** than men in the general population (LeDeR, 2023; ONS, 2022).

Poor quality healthcare causes avoidable deaths

LeDeR found that 42% of deaths of people with a learning disability were avoidable (LeDeR, 2023).

Note: Mencap uses the term 'avoidable death' for deaths that could have been avoided by the provision of good quality healthcare.

Access to healthcare

There are 1.5 million people with a learning disability in the UK.

A number of barriers are stopping people with a learning disability from getting good quality healthcare

These barriers include:

- a lack of *accessible* transport links
- patients not being identified as having a learning disability
- staff having little understanding about learning disability
- failure to recognise that a person with a learning disability is unwell
- failure to make a correct diagnosis
- anxiety or a lack of confidence for people with a learning disability
- lack of joint working from different care providers
- not enough involvement allowed from carers
- inadequate aftercare or follow-up care.

(Heslop et al. 2013; Tuffrey-Wijnes et al. 2013; Allerton and Emerson 2012).

¹ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics#:~:text=There%20are%201.4%20million%20people%20in,the%20UK%20with%20a%20learning%20disability.>

The Supported Living Improvement Coalition having identified issues caused by communication, the Respectful and inclusive language and communication sub-group was established. The sub-group was recognised as an opportunity to identify and spread areas of good practice in communication. With the aim of ensuring that throughout work with people that their individual communication needs are central, rather than generalising how communication should be completed. To recognise how we speak about the language and communication used in people's lives and ensuring that the person lead's discussions about their lives.

Communicating respectfully with individuals who have learning disabilities and Autism is crucial for their inclusion and empowerment. Remember, effective communication is a two-way process that requires effort and understanding from both parties.