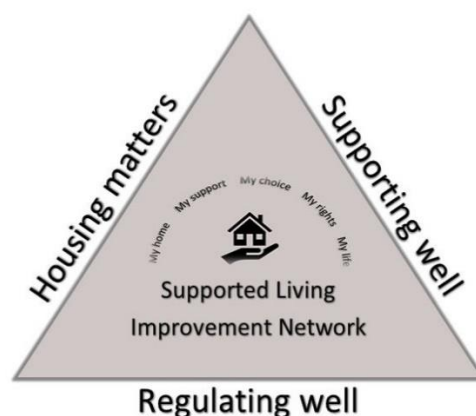


Report summary, Links and recommendations: September 2024

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



Words that may be hard to understand



Communicate and **communication** means how we share information with other people.

For example, **talking** and **writing** are ways to share information or **communicate** with other people.



Label

A **label** is a name that we use to describe some groups of people.

For example

- A wheelchair user
- Adult with Challenging Behaviour
- An Epileptic.






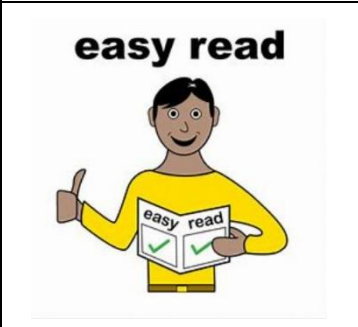
Stigmatize

To **stigmatize** means to treat someone or something unfairly by disapproving of them.

For example

Labels should not define a person; they take away from the person and focuses on the disability.

Easy Read Contents

 <p>Stop Hello Eat Words Person Day Open</p>	<p>Section Description</p> <p>Words that may be hard to understand</p> <p>Words in bold may be hard to understand. You can check what all the words in bold mean on page 2.</p> <p>You might like to have someone to support you when read it.</p>
 <p>Key Findings</p>	<p>Additional Sections Available</p> <p>Key Findings and Introduction</p> <p>People need information that they can access and understand. Clear succinct information needed for autistic and other medical conditions.</p> <p>People with a learning disability require more, and different, forms of support to ensure they stay in good health.</p>
 <p>Structure of this report and methodology</p>	<p>Structure of this report and methodology</p> <p>This report explores respectful and inclusive language and communication in health and social care for people with a learning disability and Autism.</p>
 <p>easy read</p> <p>easy read</p>	<p>Easy Read Good Communication</p> <p>Easy Read Summary of this report</p>

Executive summary

Background

This document summarises the findings and recommendations of the Respectful and inclusive language and communication in Health a sub-group of the Supported Living Network. 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. 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 communication within health and social care 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. Lack of understanding through poor communication, results in a lack of services:

The survey confirmed the need to talk to the person first to ensure inclusion, family carers or support staff will help them, out if they have them. That people need time to take in the information, that they can access and understand, in a suitable format for them i.e. Easy read or non-verbal communication Body Language and Tone. Clear succinct information meeting the Accessible Information Standards, avoiding professional language, jargon and abbreviations that exclude understanding of the general public. Sensory overloaded can make focusing difficult, leading to frustration and the need to be removed from the situation.

The Survey told us that training should be considered as a factor in improving Communication. **To be most effective training should be offered not only to professionals but also to family members.**

This key learning was developed by making suitable recommendations (See the recommendation section), linking to examples of good practise.

All staff Health and Social Care can improve the support they offer to people with a Learning Disability and those with Autism, by following the recommendations and good examples offered in this report.

Prevention is better than cure, and it enables people to live longer, healthier lives. The 2022 Learning Disabilities Mortality Review (LeDeR) found the median age at death was 63 for adults with a learning disability. This is significantly less than the median age of death in the general population (19 years for men and 23 years for women) LeDeR found that 42% of deaths of people with a learning disability were avoidable (LeDeR, 2023).

A number of barriers are stopping people with a learning disability from getting good quality healthcare, these barriers include making the correct diagnosis, failure to recognise that a person with a learning disability is unwell, staff having little understanding about learning disability, anxiety or a lack of confidence for people with a learning disability, not enough involvement allowed from carers and inadequate aftercare or follow-up care. Communication is fundamental for improvements in all of these areas.

Public Health England (PHE) estimates there are about 1.3 million people with a learning disability in England, including over 950,000 adults aged 18 years or over.

Having identified issues within communication, the Respectful and inclusive language and communication sub-group was established.

At the end of 2021, CQC set up a Supported Living Improvement Coalition, to look at how they can improve their regulation of supported living services, confirming best practice in supported living services and influencing future design and build programmes in line with Right Support, Right Care, Right Culture and the Reach standards which introduce the fundamental principles of Support for Living.

Having identified issues within communication, the Respectful and inclusive language and communication sub-group was established. as it was recognised as an opportunity to identify and spread areas of good practice in communication. To ensure 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 is crucial for their inclusion and empowerment. Remember, effective communication is a two-way process that requires effort and understanding from both parties.

In order to achieve our goals, the group decided that they needed to set up a survey to find out what respectful language looks like for each person who may draw from social care. The Survey was launched in a Care Quality Commission blog by Stefan Kallee in "Continuing the work of the Supported Living Improvement Coalition". The Survey was open for three months and the results from this survey were used to put together the information, highlighting good practice ensure that key learning can be shared, using videos or in accessible formats such as easy read.

Working with Mencap Voices Council they encouraged the need to develop easy read guidance to support the Microsoft Form. They also suggested in order to increase the opportunities for people to complete the survey, that the guidance be printable with a return address to enable this.

The sub-group brought together many different views, building on individual experiences, sharing personal and professional learning from the group within our own organisations and communities to broaden the discussion. The group met through virtual meetings using Microsoft teams, for the chat platform, allowing people from across the country to be involved. Many thanks to Natasha of United Response for facilitating this service for the group.

The Supported Living Network was establishing at the end of 2023 and run independently of CQC's Supported Living Improvement Coalition. The Network continued in three parts Supporting People Well, Housing Matters and Regulating Well. The meetings being run by or have involvement from people who use services and their representatives, supported and attended by health and social care partners when necessary. The Supported Living Network will continue to spread learning of what really helps people in

supported living and make sure people's human rights and choices are protected, people are treated as equals, fairly and with respect.

Anyone responsible for staff training would benefit from taking on board the principles explained in this report in order to put people at the centre of their support service.

Recommendations for effective communication with people with a learning disability and autism

In this chapter we set out our recommendations, which are based on the responses the group also gathered existing recommendations for respectful and inclusive language and communication and developed additional recommendations to cover the gaps identified.

The responses to the survey were used to identify by research available literature and publication of relevant examples of good practice.

Communicating respectfully with individuals who have learning disabilities is crucial for their inclusion and empowerment. Remember, effective communication is a two-way process that requires effort and understanding from both parties. By following these recommendations, you can create a more inclusive and supportive environment for individuals with learning disabilities.

Here are our recommendations to ensure effective and respectful communication:

1. **Use Accessible Language:** Say important points clearly and concisely, opt for simple, clear language and avoid jargon or complex words that might be difficult to understand. You do not need to use baby talk, but be mindful of checking the person's understanding. Regularly check to ensure that both of you are understanding each other correctly.^{1 2}
2. **Be Patient:** Take the time to listen and do not rush the conversation. Allow the person to express themselves at their own pace. Encourage one-to-one communication. Let the person with the learning disability guide the conversation. They know best how they communicate and understand. Have a sense check - Would I use that Language in my kitchen with my Family, or at the café or pub with my Mates? ³
3. **Talk to the person first to ensure inclusion:** if they can't answer a question carers or support staff will help them out.
4. **Employ Different Communication Tools:** Be prepared to use visual aids, gestures, drawings or other tools to facilitate understanding, use multiple modes of

¹ Your guide to Communicating with people with a learning disability

<https://www.elft.nhs.uk/sites/default/files/2022-03/Your%20Guide%20to%20Communicating%20with%20People%20with%20a%20Learning%20Disability.pdf>

² Communicating with people with a learning disability

<https://www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability>

³ Gloriously Ordinary Lives <https://www.gloriouslyordinarylives.co.uk/the-five-tests>

communication. Be aware of the many non-verbal information of Medical need that support communication, such as Hospital passports, Health Action Plans and Communication plans

5. **Be aware Body Language and Tone:** Remember that communication is not just about words. Non-verbal cues like body language and tone of voice play a significant role. People with learning difficulties may exhibit reluctance to admit being unwell for several reasons, look for changes in behaviour or Body Language.
6. **Make Adjustments:** Be flexible and willing to make reasonable adjustments to your communication style to meet the needs of the individual.⁴
7. **Show Respect:** Treat individuals with learning disabilities with the same respect and dignity you would expect for yourself. This includes respecting their right to make decisions about their lives.
8. **Protect people from sensory overload:** create a 'sensorily safe' environment, try and identify which stimuli causes difficulty and either reduce or eliminate them, try to work with, and not against it, adjusting the way you interact.⁵
9. **Ensure written information is available in a format that people can understand:** All organisations that provide NHS care and / or publicly-funded adult social care should provide information that meets the Accessible Information Standard, which is a legal requirement.
10. **Allow people to prepare in advance of their meeting or appointment:** Ensuring people have the right information in advance of the assessment, fully involve the person, their family and any appropriate paid support, approach people for feedback.
11. **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'
12. **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

Health and social care service need to get better at joining up services and information across the sector, protecting the information as it is used, to provide opportunities for better service delivery through digital, mobile, flexible tools to enable our staff to maximise their efficiency, support of staff to do their work more easily and collaboratively in multidisciplinary multi-organisation teams.

⁴ **Royal College of Speech and Language Therapists - Five good communication standards**
<https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf>

⁵ **Top 5 autism tips for managing sensory differences** <https://www.autism.org.uk/advice-and-guidance/professional-practice/sensory-differences>

Communication tips

Here are some recommendations for **communication tips** for effectively interacting with autistic individuals, whether it's your child, pupil, colleague, or friend:

1. **Getting and Keeping Their Attention:**

- Always use their name at the beginning of communication to signal that you are addressing them.
- Ensure they are paying attention before asking questions or giving instructions.
- Use their hobbies, interests, or the activity they are currently engaged in to engage them.

2. **Processing Information:**

- Say less and speak slowly.
- Use specific key words, repeating and stressing them.
- Pause between words and phrases to allow time for processing.
- Avoid using too many questions.
- Use less non-verbal communication (e.g., eye contact, facial expressions, gestures).
- Consider visual supports (such as symbols, timetables, and Social Stories) if appropriate.
- Be mindful of the environment (noise, crowded spaces) as sensory differences can affect processing⁶.

3. **Avoiding Open-Ended Questions:**

- Keep questions short and structured.
- Offer options or choices.
- Be specific rather than asking broad questions (e.g., "Did you enjoy your lunch?" instead of "How was your day?").

4. **Ways to Ask for Help:**

- Provide visual help cards if appropriate.
- Be clear and straightforward in your communication.

5. **Being Clear and Literal:**

- Avoid irony, sarcasm, figurative language, and rhetorical questions.
- Explain what you mean clearly.
- Autistic individuals may take statements literally, so clarity is essential.

6. **Addressing Distressed Behaviour:**

- Use a behaviour diary to understand the purpose behind behaviour.
- Offer alternative ways to express "no" or "stop."
- Adjust reactions to inappropriate behaviour (avoid shouting or excessive attention).

Remember that each autistic person is unique, so adapt these strategies based on individual needs and preferences. Patience, empathy, and understanding go a long way in effective communication with autistic individuals.⁷

⁶ <https://www.autism.org.uk/advice-and-guidance/topics/communication/tips>

⁷ <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/45/2022/10/More-than-words-supporting-effective-communication-with-autistic-people-in-health-care-settings-3.pdf>

Conclusions

This report has brought to attention the communication issues that if not understood significantly add to the well documented stark health inequalities that people with a learning disability and Autism face and as identified by LeDeR the immense challenges involved in addressing them. The 2022 LeDeR report highlighted the high numbers of premature and avoidable deaths of people with a learning disability. In this report we have focused on communication barriers and highlighted some of the good practice that already is proven to work in more enlightened areas. That make services as accessible for people with a learning disability and autism as for everybody else. We considered the survey results which backed-up the concerns raised in reports by CQC⁸ and that offered through the Oliver McGowan Mandatory training for the Health and Social Care workforce to better support people with a Learning Disability and Autism.

Our key findings confirmed that 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. Opportunities through 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.

This can be through the use of accessible language in meeting the Accessible Information Standards, making people reliant on support staff, if they have them. People need information that they can access and understand. Clear succinct information needed for autistic and other medical conditions. People need time to take in the information and 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, make adjustments. Staff need to be aware of body language and tone to 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. Staff need to be aware of body language and tone to ensure safe and effective wellbeing conversations and speaking up on health. There is a need to mirror information to demonstrate understanding, using the same terminology as the person to create trust.

Sensory overload occurs when you're faced with more sensory input than your brain can process. When a person is bombarded with multiple types of sensory input that they can't regulate. People who suffer should expect to be offered a 'sensorily safe' environment, try

⁸ https://www.cqc.org.uk/sites/default/files/20191125_9001508_briefguide-good_communication_standards_v2.pdf

and identify which stimuli causes difficult and either reduce or eliminate them, try to work with, and not against it, adjusting the way you interact

The information 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. 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. Ideally early identification should allow carers, service users and health professionals to work together in achieving good support. Lack of understanding should not mean a lack of services. Training should be considered as a factor in improving communication and to be most effective training should be offered not only to professionals but also to family members. 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

On the basis of the key findings through what we had been told in the survey, the group would like to promote the recommendations we have developed, linking to the examples of good practise, that already is proven to work in more enlightened areas. Making services as accessible for people with a learning disability and autism as for everybody else.

	Additional Sections Available
	Discussion In this report we have focused on communication barriers and highlighted some of the good practice that already is proven to work in more enlightened areas.
	Effective communication Pledge We would like to see all Trust/organisation commit to our 'Effective communication Pledge', creating a safe and supportive environment . Ensuring everyone including those with a learning disability and autistic people are afforded good communication so that their views are listened to, and their options are fully explained in a format suitable to them.
	Appendix A Questions developed for the survey
	Appendix B Continuing the work of the Supported Living Improvement Coalition
	Appendix C Response to the Questions from the survey
	Appendix D Links to Good Examples of Communication
	Appendix E Good Examples of Communication Information in Full
	Appendix F Learn more through online video sharing platform

Acknowledgements

To the **Care Quality Commission (CQC)** for initial establishing the **Supported Living Improvement Coalition**, and the **Respectful and inclusive language and communication sub-group along with continued support**.

To the **Supported Living Improvement Network** that independently continuing the work of the Coalition looking at:

- **Supporting people well**
- **Housing matters**
- **Respectful and inclusive language**

All members of the **Respectful and inclusive language and communication sub-group** for their contribution throughout this process and in particular for their support and feedback throughout the process of writing this report.

Particularly:

Natasha Weavers of United Response for establishing the Microsoft Form application for the survey and provided support to the group through access to the Microsoft Teams collaboration through meetings, chat, and file sharing.

The **Mencap Voices Council** for their support and encouragement in developing the easy read guidance to support the Microsoft Form.

Dr Katy Brickley of King's College London for putting together an easy read version of the survey guidance and questionnaire.

Stefan Kallee of the Care Quality Commission (CQC) for circulation of the survey and supporting information through his Blog.

All members of the **Respectful and inclusive language and communication sub-group** for circulation of the survey and supporting information. Continued attendance and contributions that have been invaluable throughout this process, especially their support and feedback in the process..

Jo Howell of the Northam Care Trust for developing an Easy Read and pledge documents as well as providing a postal return address for the survey questionnaire and condensing the recommendations to have more impact. Producing an Easy Read Summary of this report and the Effective communication Pledge.

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