

Our Vision Our Future



Thank you for inviting us to speak today.

We are a user led charity run by and for adults with learning disabilities. We are a self-advocacy group based in Chesterfield and have been running for 31 years.



Today we are doing a presentation looking at ways in which inaccessible information can cause more barriers for people, like us, with learning disabilities. This can make us feel even more excluded, lonely, frustrated and forgotten about.

It can also lead to more serious issues where important information is not understood and people do not have the right support to help them understand and make decisions. This can be especially important when related to health and wellbeing.



When people cannot get information that is easy for them to understand and use, it can affect how well they live, the help they get from others, their ability to live on their own, and their involvement in their community.

We are working together to make changes for a more inclusive and accessible world and healthier and happier lives.

Making Information Accessible





Accessible Information and the Law

By law, disabled people have the right to be treated equally and to have information made accessible to them. This is stated in The Equality Act, 2010 and The Disability Discrimination Act (DDA).

A new Accessible Information Standard was also introduced on 24th June 2015 by the Standardisation Committee for Care Information (SCCI).

The Accessible Information Standard tells organisations how they should ensure that disabled patients, service users and, where appropriate, carers and parents, receive information in formats that they can understand, and that they receive appropriate support to help them to communicate.

All organisations that provide NHS or Adult Social Care must follow the Accessible Information Standard by law. The standard came into effect on 31st July 2016.

Accessible information means thinking about the needs of people who find reading and writing hard.

Easy Words and Pictures has writing in short simple sentences without any hard words or jargon.

Easy Words and pictures also uses clear, easy to understand pictures that support these words.

This type of information is very accessible to people with learning disabilities, but also to people who find reading and writing hard, or do not have English as a first language.

Making information easier to understand

Words and language

Think about the hard words and change them into easy-to-understand words. Abbreviations, jargon, or hard words should not be used.

Examples of jargon words

- Acumen means 'ability or skill'.
- Oedema means 'swollen ankle'.
- Tachycardia means 'fast heartbeat'.
- Innovated means 'bring in new ideas'.
- Collaboration means 'working together'.
- Dissemination means 'spreading information'.

Examples of abbreviations

Words should not be shortened September not 'Sept' Wednesday not 'Wed' Road not 'Rd'



Examples of hard words

- Contemplate use 'Thinking'
- Annual Leave use 'Holiday'
- Participation use 'Taking part'
- Arid use 'Dry'
- 'Isn't' better to use 'is not'
- 'Don't' better to use 'do not'

Use full names

Derbyshire Voluntary Action not 'DVA' The Disability Discrimination Act not 'DDA'. Learning Disabilities not 'LD'

Link: Doctor Can't Communicate https://www.youtube.com/shorts/o3t4TuXt5Rk



Tips on Creating Easy Read

| | | Information should be broken up into clear chunks. |
|-------------------|--------------|--|
| | | Each chunk focusing on one main piece of information. |
| | | Each sentence should be on a new line. |
| | | Check the information is in the right order and makes sense. |
| | | It should not be cluttered. |
| ✓Lowercase | × UPPERCASE | Use small letters not CAPITALS |
| ✓ and | × & | Use 'and' not the symbol '&' |
| <mark>√</mark> 21 | × twenty-one | Numbers should be written in figures - '21' not 'twenty-one' |

| 11 12 1 9 3 8 4 7 6 5 | Most of our members prefer the time in a 12 hour clock |
|--------------------------------|---|
| 07:30 | Some people prefer the 24 hour clock |
| ✓ Arial 16 × Arial 16 | Arial16 text is good and clear, use bigger if needed. |
| Arial Narrow | We also use Arial Narrow, as agreed with members, as Arial is bigger and creates too many lines, this can be confusing. |
| | Print on one side, it is hard to follow information when printed on both sides. |

| Headings 18 or larger in bold | Headings 18 or larger in bold |
|---|---|
| Spl- 🗙 it | Words should not be split over two lines with a dash or hyphen. |
| | The pictures should be clear, check that they have not lost their shape when changing their size or moving them. |
| easy read tread | Put pictures on the left and writing on the right. |









Our Vision Our Future

Example of easy read - Our meeting rules

Meetings

Our rules

Mobile phones should be turned off or on silent



Arrive on time



Support each other to take part. Be kind and patient.



Listen to what others have to say



1 person speaks at a time Do not butt in







Avoid using jargon and explain acronyms like DCC - Derbyshire County Council.

Use easy words like 'working together'.

Make sure everyone understands.

Personal things that are said in this meeting are private and must not be talked about outside this meeting

Asking questions is good There are no silly questions

Getting the Right Support



Please fill in this easy read form

No matter how accessible the information is, some people will need extra time and support to help them to understand it.

Not everyone will understand an easy read letter, the pictures will help to give an idea of what the letter is about but support to understand it and what to do may also be needed.

It is not unusual for people with learning disabilities to receive important letters but have no one to help them with them. Because of this, important information can get missed.

During Covid and lockdown our members became more able and confident at using their phones for keeping in touch with Our Vision Our Future members, their friends and workers.



We also made good use of WhatsApp video calls and Zoom meetings. Communicating like this has been very useful and we have continued to have some meetings like this when it is not possible to meet in person.

Most of our members still prefer to have meetings in person.



Maria Britland

I am visually impaired

I was born in Italy and speak Italian

I learned to speak English

I read Braille and read by touch



It helps when people introduce themselves and tell me what they do

Speak clearly Don't use jargon or big words

Doctors and Hospital letters – I have to ask my dad or my carers to read them to me I am an independent woman Some of the information is personal I am not happy about this, It makes me feel angry and disappointed.

I asked the hospital to stop sending texts with links for appointments - they have now stopped doing this and call me. I am happy with phone calls I can speak up for myself and ask questions if I need to

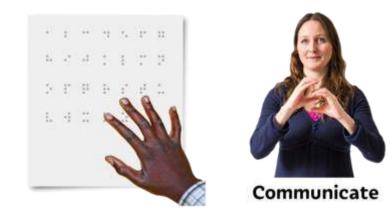


It would be good to get my letters in braille I have been asking about this since March 2022. I have spoken to the Patient Advice and Liaison Service (PALS), Learning Disabilities Lead Nurse at the hospital and Healthwatch Derbyshire

I still do not get letters in Braille.

Good things that can make communication better

- Use words with pictures.
- Use signing like Makaton or British Sign Language (BSL)
- Use Braille touch reading.
- To help me to understand, I may need you to tell me more than once.
- I may need help to remember.
- Explain things in a way that I understand.
- Make sure I am listening and can hear you.
- Some people have hearing aids but do not have them switched on.
- Avoid background noise.
- We may need support, but it is important that family or carers do not get carried away and speak for us.
- It would be good to have the same doctor, they keep changing.
- Care workers keep changing, this is hard for me when they do not understand me.
- I feel more comfortable with a lady doctor as I can talk to her without getting embarrassed.
- Having enough staff for appointments so you are not rushed.
- Being on the Learning Disability Register should give me more time, I don't like to be rushed it makes me anxious.
- I get stressed when I am hurried, to get more confident to talk I need plenty of time.
- If it is a phone appointment, I always write down what I want to say, it throws me off if I get interrupted.
- I prefer face to face appointments, I had 6 appointments over the phone during lockdown.
- I need time and encouragement to speak up for myself.
- I need to feel the person I am speaking to is listening and interested in what I am saying and that I have their full attention.



- Make sure everyone in the meeting is included, encouraged, and supported to speak not just nodding their head and saying yes when they really have no clue about what I am saying.
- At my doctors there is a bleep for the next patient. I have asked them to use my name and call me in, this has not been done.
- Having support with someone who understands what I am saying.
- Help me to feel relaxed, I may be nervous.
- Speak to me at my level, sit down if needed.
- Use good eye contact and clear speech.
- I can understand what you say to me as long as you make it meaningful to me and use words I understand.
- I will not always say when I do not understand unless you check with me.
- I do not like it when people raise their voices at me.
- I need support to read and understand official paperwork and to complete forms, I like to be fully involved in what is written about me.
- I need time to adapt to changes.
- Take time to listen to me and give me a chance to tell you what I want.
- Check that you have understood me.
- Discuss things with me and help me to make decisions.
- With bigger decisions I will need help to understand the options fully and to think things through.
- Use good friendly body language
- Not everyone with a learning disability needs pictures to help them to understand information but easy words without jargon helps, along with support to remember it and reply when needed.



How poor communication makes me feel

- Lonely
- Upset
- Switch off
- Bored
- Stressed
- Tense
- Fed up
- Takes away confidence
- I do not feel my happy self
- You do not get to know me
- Frightened
- Uncomfortable
- Worried
- Being worried makes you want to go to the toilet; it makes you feel sick
- Not included
- Forgotten about
- Lose my confidence
- Cross
- Angry
- Confused
- Distracted not able to concentrate
- Nervous
- If you are not listened to at the Doctors, it makes you feel worse.
- Doctors' appointments by phone taking a picture of what is wrong is hard. I can not do it - it stresses me out



How good communication makes me feel

- Confident
- Calm
- Happy
- Relaxed
- Chilled out
- More able to speak up
- More able to take part
- My needs are met
- I feel included
- Enjoy talking
- The same as everyone else
- Important
- Lively
- Interested
- Engaged nice to have a conversation with someone
- Connected
- Opportunity to make friends
- Makes it easier to listen
- Helps me to remember
- I feel I am being listened too



Thank you for listening



We welcome any feedback, questions or comments about the presentation



Useful Websites

Change People: https://www.changepeople.org/

Learning Disability Service: https://www.learningdisabilityservice-leeds.nhs.uk/easy-on-the-i/

Mencap: https://www.mencap.org.uk/

NHS: https://www.england.nhs.uk/wp-content/uploads/2018/06/make-it-easy-easy-read.pdf

Ability Net: https://abilitynet.org.uk/factsheets/what-easy-read#simple-table-of-contents-1

Photo Symbols: https://www.photosymbols.com/account

Chat GPT: <u>https://openai.com/chatgpt</u> Cut and paste documents - ask to make language simpler.