

Learning Disability Partnership Board

**What happened at our meeting on
Tuesday 25th July 2023**



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Who was there?

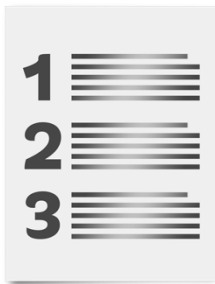
Tim Heaven - LDPB Co-Chair	Deborah Livingstone – Independent Supporter and LeDer Reviewer
Jan Marriott - LDPB Co-Chair	Hayden Price – Expert by Experience Inclusion Gloucestershire
Emily Luckham – Health and Wellbeing Projects Manager at Inclusion Gloucestershire	Simon Shorrick - Strategic Health Facilitator for Learning Disabilities at GCC
Tammie Flook – Expert by Experience inclusion Gloucestershire	Vicky Curtis – Action for Children Kingfishers
Debbie Worrall – LDPB, Your Voice and Research Co-ordinator at Inclusion Gloucestershire	Tina Yates - Action for Children Kingfishers
Tamsin Morgan – Gloucestershire Parent Carer Forum	Dan Horton - Action for Children Kingfishers
Paul Yeatman - Independent Supporter and LeDer Reviewer	Ryan Harte - Action for Children Kingfishers
Nick Baker - Expert by Experience Inclusion Gloucestershire	Moses Dube – Modern Matron Learning Disabilities
Lara Gillman – Senior Commissioning Manager GCC	Andy Davis – Lighthouse Manager Kingfisher Treasure Seekers
Clare Howell – Training Manager Inclusion Gloucestershire	Gill Parkinson – Training Manager Kingfisher Treasure Seekers
Jan Burn – Director Kingfisher Treasure Seekers	Judith Williams – Parent/GHC Employee
Holly Beaman - Head of Integrated Commissioning for Learning and Physical Disabilities at GCC	Hayden Price – Expert by Experience Inclusion Gloucestershire
Louise Waller - Building Circles	Bren McInerney – Community Volunteer
Bryony Steel – Commissioning Officer GCC	Taylor Dovgan – Event and Wellbeing Manager Prosperity Care and Wellbeing
Steve Roberts – Interpretation Lead Cotswold Canals Connected	Beth Townsend – Volunteer social and activity coordinator Building Circles
Ben Langworthy – Senior Project Officer Active Gloucestershire	Hannah Abel – Trainer Building Circles
Emily Trigg – Positive Behaviour Support Team GCC	Caroline Smith – Engagement and Inclusion NHS Gloucestershire

GCC means Gloucestershire County Council
GHC means Gloucestershire Health and Care Trust

What we talked about:



Tim shared the ground rules for the meeting.



He also shared the 4 priorities for the partnership board. They are:



1. Making sure Making sure people have information that is easy to understand.



2. Better support for young people when they become adults.



3. Helping people to look after their money and benefits.



4. Helping people to get jobs and volunteering

You said, we did:



At the last meeting we talked about getting ready for adulthood. We asked if people wanted to talk about it some more.



Tamsin said we need to talk about transport and Dynamic Keyworkers.



Jan from Treasure Seekers said they are talking with families as they are starting discos for teenagers in September.



Emily said we have not heard from staff in education or talked about people being excluded from school and specialist schools.



It was agreed that the next meeting in September will be about money and benefits.



The meeting in November will be about getting ready for adulthood.



Holly said there will be an event with the Autism partnership board about what is happening when people go into or leave hospital (Transforming Care).

The Accessible Information Standard



Tim told us that the Accessible Information Standard is about making sure disabled people have information they understand.



It is the law that the NHS and social services have to do this.



There are 5 rules that they have to follow



They have to find out about your information and communication needs.



Put these needs on your record.



Share your communication needs.



Make sure the right people know about the support you need with communication.



Make sure you get that support.



It is important for people to know their rights under the Accessible Information Standard.



Caroline said that she is working on making the Accessible Information Standard happen but NHS staff don't always get it right.



Simon said he tried to get GPs to follow the standard but they still don't know about it.



Jan Thomas said that phone calls are difficult where you have to press a number depending on what your call is about.



Hayden said that it is hard to wait on the phone and it is hard to know what number to press.

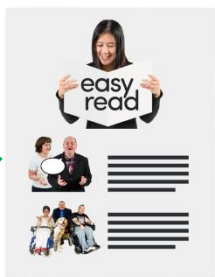


Jan Burn said when people are anxious they might sound aggressive and people taking phone calls need training on how to deal with this.

Preoperative echocardiographic diagnosis of anterior mitral valve leaflet fenestration associated with infective endocarditis

OBJECTIVE: Although reported infrequently, fenestration of the mitral valve leaflet is a rare but important cause of mitral regurgitation. It is often associated with infective endocarditis. We report a case of anterior mitral valve leaflet fenestration associated with infective endocarditis. The diagnosis was made preoperatively by echocardiography. The patient underwent successful surgical repair. This case highlights the importance of a high index of suspicion for this condition in patients with infective endocarditis and mitral regurgitation.

KEYWORDS: Anterior mitral valve leaflet fenestration; infective endocarditis; echocardiography; mitral regurgitation.



Clare said that people want to get it right and her team have been asked to make lots of leaflets accessible.

Makaton

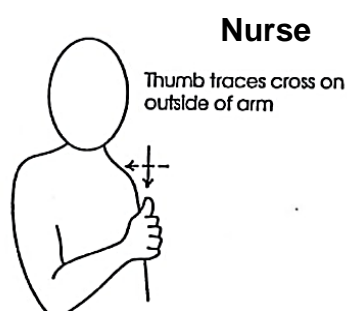
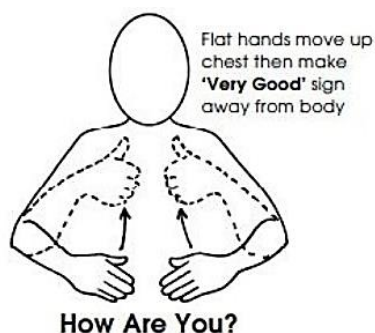
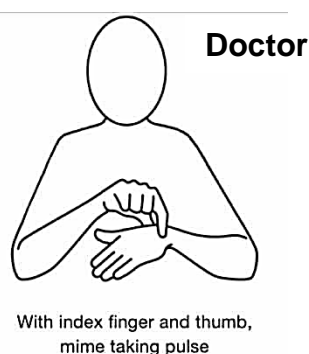


Gill from Kingfisher Treasure Seekers taught us some Makaton signs.

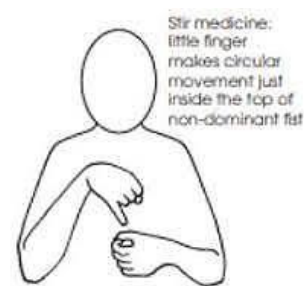


She told us that Makaton is not a language like British sign language that deaf people use. Makaton signs go along with spoken words.

Here are some of the signs she showed us:



To Hurt/ Pain



Medicine

What is Easy Read?



The image shows a vertical form titled "Please fill in this easy read form". At the top left is a small icon of a person holding a sign that says "easy read". The form has three sections: "Your name" with a small person icon, "Address" with a small house icon, and "Phone" with a small mobile phone icon.

Tammie and Clare told us that Easy Read is a way of giving clear information with simple words and pictures.



To make good Easy Read you need to make sure Experts by Experience are involved.



If you don't have Easy Read information it can mean you miss important things like not going to the doctor because you don't understand the online appointment system.



Tim said using the 24 hour and 12 hour clock can be confusing.



Clare said it helps the picture to be clearer if it has a white background and it is important to have space in between words and pictures.



Simon said that Photosymbols have good pictures that you pay to use.

The Accessible Information Standard in Gloucestershire



Caroline said that the standard is being improved and a new one will be coming out.



She is looking at why people aren't following the standard.



Some people are worried about getting it wrong.



There is no computer system to share how people like to be communicated with, it has to be written down.



There will be training on the standard from September this year.



They have made a video about the challenges people have with communication.



Holly said that it is important that Caroline also works with social care as they are being inspected soon.

Group chat:
What information do you get that is hard to understand?
How do you like people to tell you things?

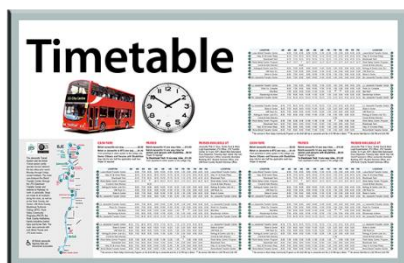
Things people said were hard to understand:



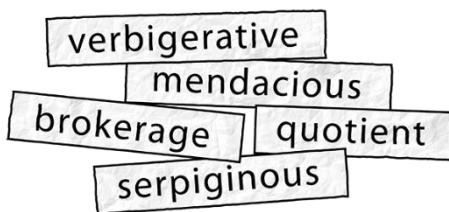
All bills, particularly when they are only online to save paper.



All letters are difficult but especially those with too much information



Bus timetables and maps



Anything with medical words.



Online GP appointments.



Important information like insurance, pension, tax, benefits.



Education, Health and Care Plan

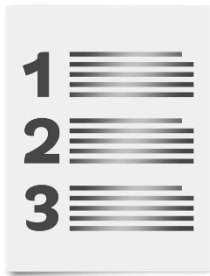
How people said they like to be told things:



By someone they trust.



By phone call with a follow up text message or letter with important information.



A letter with short bullet points which is clear and to the point.



Having appointment reminders the day before.

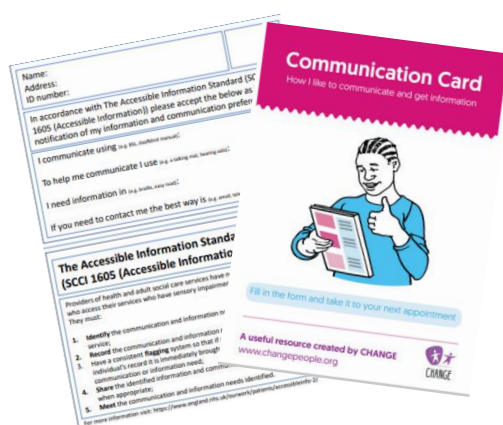


The same way every time. Not a letter, then a text, then an email.

Communication Cards

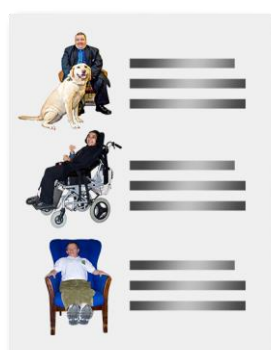


Communication cards let the NHS and social services know how you want to be communicated with.




We looked at a letter about communication by Mencap, the NHS communication card and one by Change.


Simon said the Health Passport has this information on.





Caroline says that a card which is short and straight to the point is best.


Hello,

 I have a learning disability and would like to join the Learning Disability (QOF) Register.

 I would like some extra help to access the surgery.

 These are the ways I would like to be supported: (Please tick which ones apply to you)

 I would like to get easy read information and letters
Yes ☐ No ☐

 I would like extra time for my appointment
Yes ☐ No ☐

Bryony said she liked Mencap's letter because it is clear but it could be shorter.



We need to ask more people with learning disabilities what works best for them.



Simon said that social prescribers could help filling the communication cards out.

Anything else to talk about?



Simon showed the video from the Big Health Day.



The next Big Health Day is on 14th June 2024.

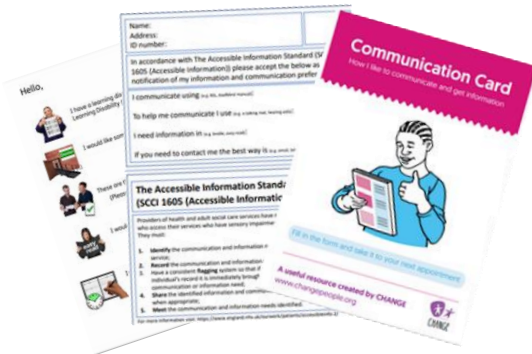


The Easy Health Website has lots of Easy Read information about health issues.



The Your Voice team have written a letter to the MP responsible for transport, Mark Harper. Everyone agreed that the partnership board should sign the letter too.

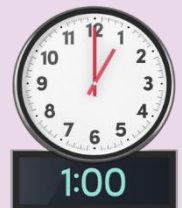
Actions:



Ask people with learning disabilities what sort of communication card they would like.

Next meeting:

The next meeting is on
Tuesday 26th September
from 11am – 1pm.

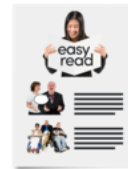


We will let you know
where the meeting
will be soon.



Presentations

What is the Accessible Information Standard? (AIS)



The Accessible Information Standard is about making sure that disabled people are given information in a way they can understand.



It is the law for the National Health Service and Adult Social Care services to follow this.



The standard is to make sure disabled people have information they can read or understand.



This is so Health and Social Care workers can communicate well with them.



This would include:

- Doctors



- Dentists



- Hospitals



- Pharmacies



- Social Workers

The rules of the standard are that the NHS and Social Care must:



- Find out about your communication and information needs



- Make sure these needs are on your record



- Make sure the right people know your support



- Share your communication needs



- Make sure you get the support you need



- It is important that everyone knows their rights



- People are still learning about the standard so they might need reminding



- There are communication cards that you can use to share your communication needs

We will show you later

Downloadable easy read guide on
the Mencap website



Welcome to this Easy Read Presentation with **Inclusion Gloucestershire**



'The most basic of
human needs is to
understand and
be understood'

Ralph Nichols

Disabling Barriers

Factors in a person's environment that,
through their absence or presence, limit
functioning and create disability.

(WHO - World Health Organisation definition)

Easy Read means:

- ✓ Giving information clearly
- ✓ Writing in simple language
- ✓ Adding pictures to show meaning
- ✓ Using clear fonts



Who is Easy Read for?

People with learning disabilities

People for whom English is an additional language

Everyone



It's the law...

Public sector organisation websites must be accessible.

Public sector websites must include an accessibility statement.

Public sector mobile apps must be accessible.

'Perceivable,
operable,
understandable
and robust'



But we make things so complicated...

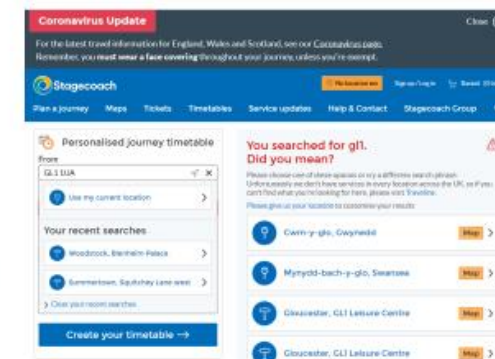


Tammie's frustration with the bus timetable and ticket prices!



Single & return tickets	
Single	£4.50
Return	£7.20

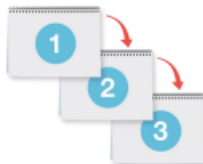
Day tickets	
Daytime	£7.50
Weekend	£7.00
10-15 September	£10.00



The Easy Read Process

Step One (Planning):

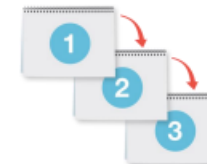
- Think carefully about who will read the document
- Write down the important messages
- Think about interesting content that adds meaning (characters or case studies)
- Find pictures that help show the meaning



The Easy Read Process

Step Two (Creating):

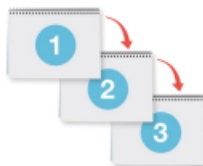
- Use Arial 14 font
- Set line spacing at 1.3 or 1.5
- Set a left-hand margin of 5 for pictures
- Use words that say something to as many people as possible
- Explain jargon



The Easy Read Process

Step Three (Reviewing):

- Are sentences short?
- Is the language simple?
- Can I take out any unnecessary words?
- Is it clear, concise and complete?
- Check it out with Experts by Experience



**BIG
Words**

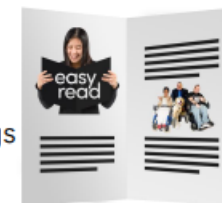
Some Top Tips

Do:

- Give the document a meaningful title
- Keep sentences and paragraphs short
- Keep the layout simple
- Use bullet points, numbered steps, subheadings

Don't:

- Use colour or shape only to show meaning (e.g. 'click the green button.')
- Use footnotes (give explanations in the document).
- Use images containing text.



Easy Read The Power of Pictures



**What
would
you do?**



**What's the
message?**



**What feeling
does this show?**



What emotions do you see?

Photosymbols



Work with the NHS
Work Placement
NHS England and NHS Improvement

We want lots of different people to work in our organisation.
This is very important to us.
It helps us look at things in lots of different ways.
It helps us understand what people want.
It means we get better at what we do.

You can work for us if you are a student at a college or university, or if you were a student. You can work for us for:

One month in August 2022

One day each week for one year. This will be from September 2022 to August 2023. This is paid work.

Five days each week for one year. This will be from September 2022 to August 2023. This is paid work.

You can work in the office and at home.
You will work as part of a team.

We will give you lots of help.

We want you to feel safe and to speak up.
We will listen to what you say.

Work with the NHS
Work Placement
NHS England and NHS Improvement

You will do office work.
You will work with a computer.
You will help with meetings and reports.

We will help you learn new things.
We will help you build confidence.

We want you to:
Work hard and do your best.
Respect other people.

If you want to work with us, fill in the application form. We can help you with this. Call Denise on 07919 573 262 to tell us you want help.

If you have a CV, you can send it to us too.

Send this to us by the 30th of January 2022.
Email it to: england.school@nhs.net

We will interview people in March 2022.

Thank you for your time 😊

What are your questions?



Thank you for listening 😊



Accessible Information Standard in Gloucestershire



Caroline Smith
July 2023



@NHSGlos
www.nhsglos.nhs.uk

Part of the One Gloucestershire Integrated Care System (ICS)

What are we doing in Gloucestershire?

Working together



What are we doing in Gloucestershire?



Understand what health and care staff know about the Accessible Information Standard



What stops staff from doing the right thing?

What are we doing in Gloucestershire?



Developing training and information so that staff know what to do.

Starts in September 2023



Sharing people's experiences with health and care staff.

What happens next?



Evaluate the training – 2024



Make sure people know they can ask for support

Keep checking!



Check that people have the support they need



Provide further training for staff

Questions or comments?



Mencap's Communication Letter

Hello,



I have a learning disability and would like to join the Learning Disability (QOF) Register.



I would like some extra help to access the surgery.



These are the ways I would like to be supported:
(Please tick which ones apply to you)



I would like to get easy read information and letters

Yes ☐ No ☐



I would like extra time for my appointment

Yes ☐ No ☐



I would like you to remind me about my appointment with a phone call / text

Yes ☐ No ☐



I would like to see a doctor who knows me well

Yes ☐ No ☐



I would like the doctor to use simple words and speak slowly

Yes ☐ No ☐



I might need support to make decisions about my health

Yes ☐ No ☐



I would like my appointment to be at a time that suits my needs

Yes ☐ No ☐

1

2



I would like to be seen quickly because I find waiting hard

Yes ☐ No ☐



I would like you to use pictures or objects to help me understand

Yes ☐ No ☐



I have my own communication aids which you can use with me.

Yes ☐ No ☐

Please write any other support needs here

The best way to contact me is (please tick how you would like to be contacted):



Text message ☐



Phone Call ☐



Easy read letter ☐ Other (Please write) ☐

3



I am happy to share extra information on my Summary Care Record. Please help me to do this.

Yes ☐ No ☐



Name:



Address:



Email:



Phone number:



Signed:



Date:

4

NHS's Communication Card

Name:
Address:
ID number:

In accordance with The Accessible Information Standard (SCCI 1605 (Accessible Information)) please accept the below as formal notification of my information and communication preferences.

I communicate using (e.g. BSL, deafblind manual):

To help me communicate I use (e.g. a talking mat, hearing aids):

I need information in (e.g. braille, easy read):

If you need to contact me the best way is (e.g. email, telephone):

The Accessible Information Standard (SCCI 1605 (Accessible Information))

Providers of health and adult social care services have new duties to support those who access their services who have sensory impairments and/or learning disabilities. They must:

1. **Identify** the communication and information needs of those who use their service;
2. **Record** the communication and information needs they have identified;
3. Have a consistent **flagging** system so that if a member of staff opens the individual's record it is immediately brought to their attention if the person has a communication or information need;
4. **Share** the identified information and communication needs of the individual when appropriate;
5. **Meet** the communication and information needs identified.

For more information visit: <https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/>

Change's Communication Card

What professionals have to do



1. Ask

Find out if a person has any communication or information needs and if so what they are.



2. Record

Record those needs in a clear way. This can be done on a computer or on paper.



3. Highlight

Make sure that a person's needs stand out in their records.



4. Share

Include information about a person's communication needs when sharing other information about them.



5. Act

Make sure people get information which they can use and understand.

Communication Card

How I like to communicate and get information



Fill in the form and take it to your next appointment

A useful resource created by CHANGE
www.changepeople.org



About me



My name is:



My date of birth is:

Date

Month

Year

My address is:



How I communicate



I communicate using:

E.g. BSL, deafblind interpreter



To help me communicate I use:

E.g. hearing aid, talking mat



I need information in:

E.g. braille, easy read



The best way to contact me is:

E.g. mobile, email