





Autumn 2022- Spring 2024



Tim Heaven
Co-chair



Jan Marriott
Co-Chair







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About this report



This is a report about what the Learning Disability Partnership board has been doing since September 2022.



The Learning Disability Partnership Board brings together different people and groups who want to make things better for people with a Learning Disability in Gloucestershire.





We have two co-chairs:

Jan Marriott and Tim Heaven



Every Partnership Board meeting we invite people to speak about things that are happening in Gloucestershire.









We also have a time in small groups where people tell us what they think.



We have a time of 'You said, We did' – where we talk about what we have done.





How things have changed with our meetings



In 2022, The Learning Disability Partnership Board started meeting in person for one meeting and then online for another meeting.

We had our meetings on Zoom in November 2022 and March 2023.



We have tried meeting in different places.

We met at the Music Works.



We met at Shire Hall.



We met at the Museum.



We are now meeting at the Treasure Seekers new hub in Eastgate Street.









We are still meeting with the other partnership boards at the Collaborative Partnership Board.

This meets every 2 months.



We want to say a big thank you to everyone who has helped keep the LDPB going and making it such a positive group.







What the Learning Disability Partnership Board has been doing this last year



In August 2022, we did a short survey.

We asked people what is stopping you from having a good life?

In September 2022, we told the partnership board what people had said.

We asked people to choose what are the four things the Partnership Board should be looking to change.

They decided on these four things.



 Making sure people have information in a way they can understand



Improving the support for young people when they become adults.



3. Helping people with managing money and benefits.







4. Helping people to get jobs and volunteering jobs.



We planned our meetings around the four things people said we want to change.

November 2022 – The priorities



People talked about the priorities in groups.



They said:

It would be good to have a 'kite mark' (award) for good accessible information.









It would be good to have peer support and training for families delivered by people who have already been through the transition to adult services.



Jo Williamson and Amie Wilson talked about updating the Health and Social care frameworks.

These are a set of rules or standards that people who give care (providers) should follow.



People talked about the framework in small groups. What they said was sent to Jo Williamson.



Simon Shorrick showed the Respect video.

You can watch it here: https://www.youtube.com/watch?v=Yrq
1zQotkaY



Respect is a form that tells health care workers your choices in an emergency.

It is a purple form that is kept by the person.









Simon asked everyone to tell people about the form and the video so that more people get one.

January 2023 – Work and volunteering



Tim shared what people said before about what stops them getting a job.



Debbie talked about paid work, voluntary work and work experience.

She explained how they are different.



Sometimes employers think it is ok to treat people with learning disabilities differently at work.

It is important to make sure people do not get taken advantage of.









Debbie from Inclusion Gloucestershire and Kirsten from the Employment and Skills hub will put together a leaflet about the different kinds of work.



Stuart from the Department of Work and Pensions (DWP) is a Disability Employment Advisor (DEA).

He told us about how some benefits change if you work, and some don't.



He told us about Access to Work.



He told us Mencap and Seeability have good Easy Read information about benefits.

You can find some here: https://tinyurl.com/2sp52y9d



Kirsten told us about how the employment and skills hub helps people with work.

They can help to make a profile which has all the information about you and the support you need with work.









They can help you if things are not going well in work.

You can contact them on 01452 725776.

Or email them:

<u>employmentandskillshub@gloucesters</u> <u>hire.gov.uk</u>

Dominika told us about how people can volunteer or work for the Gloucester Health and Care Trust.



Contact Richard Hobbs if you want to find out more

Richard.hobbs@ghc.nhs.uk



There are lots of Experts by Experience in the Trust but they need more with a learning disability or Autism.

Experts by Experience are paid. They interview staff, design services and check they are doing well and train staff.

You can find out more by emailing: Partnershipandinclusion@ghc.nhs.uk

We talked in groups about the question:



'What can we do to help more people get work?'









If someone wants to employ a person with lived experience of a disability they can ask Forwards forwards@gloucestershire.gov.uk



Jan Burn said we can encourage people to get a job by telling them about the skills they can learn and the people they may meet.



Janet Hawkins said a lot of people are scared things will go wrong if they get a job.



People said that employers have to pay for some of Access to Work costs.

This can be a lot of money for small employers. The partnership board will write to MPs about this.







March 2023 - Work and Getting ready for being an adult



Jessie Hoskin talked about the work Barnwood Trust is doing to help employers have more disabled staff.

It is called 'Empowered Employers' https://empoweredemployers.co.uk/



Inclusion Gloucestershire told us about their research.

They asked disabled people what worried them the most.



People were most worried about money and how everything costs a lot more.



Vicky Townsend told us about what happens to help a young person to be ready to become an adult.



Young people can start to plan for being an adult when they are 14.









They can plan for work, training, where they will live, being healthy and friendships.



Gloucestershire has a plan to help people with this called a 'Preparing for adulthood' strategy.



People said that parents say there are too many professionals involved.



Vicky said that they are trying to make education and health care plans better and happen quicker by having more staff working on them.



People said young people might not feel very confident about saying what they want when they are becoming an adult.









Vicky said that a leaflet is being made which tells families about the support young people can have with becoming an adult.



Building Circles said that they are working with colleges supporting students who are over 16.

May 23 - Getting ready to be an adult



Steven Kelly and Jo Walker told us about what the transitions team does.



It works with people aged 17 and older who have special educational needs or a disability.



They look at the support that a young person might need as they become an adult.



Some people said there should more support for moving to adult health services as well.









Commissioners are trying to get money to pay for someone to work with young people with complex needs.



A parent said they are often told to get in touch with different services who then say they can't work with them.



People said that transition support should happen earlier than 17 so that it is less stressful for parents and young people.



Tamsin Morgan from the Parent Carer Forum told us about parents and carers experiences of transitions.



One person's son was taken off the parent's NHS app when he was 16 and they could not order his medication anymore. He could not order his medication until he was 18.



Parents did not know that transition support can start when the young person is 14.









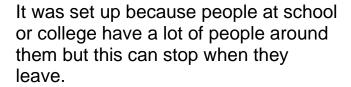
The best way to share information about transitions is with the new Preparing for Adulthood booklet.



The parent and carer forum helps people with transitions by having information events, coffee mornings and making sure parents know about important things.



We heard about The Building Connections project by Philip Douch.





The project is to help people who have left school or college to have more people around them.



Anna told us about the Welcome Groups she has run for 16 to 25 year olds.



Some young people are now becoming leaders and helping other people with what they need in their life.





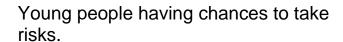




We asked people: What one thing would make a difference for young people getting ready to be an adult?

They said:

Parents having relationships and support from other parents





Better health support that is as good as social care support

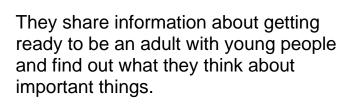


Having good quality information that tells you what is coming next.



Having a worker who supports people through the transition time.

Martha and Robyn told us about the Future Me project.











Robyn and the other Youth Representatives have put together a survey and made films about Education, Health and Care Plans.

July 2023 - Having information that you can understand



Tim told us about Accessible Information Standard.



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



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



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









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



People said that phone calls are difficult where you have to press a number to tell people what your call is about.



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



Claire Howell from Inclusion Gloucestershire said people want to get it right.

Her team have been asked to make lots of leaflets in Easy Read.



Gill Parkinson from Kingfisher Treasure Seekers taught us some Makaton signs.



Tammie and Claire told us about what Easy Read is.









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



Claire 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.



We asked people to talk about:

What information do you get that is hard to understand?

People said:



Bills



Letters with too much information

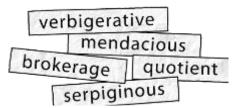








Bus timetables and maps



Anything with medical words.



Important information like insurance, pension, tax, benefits



Education, Health and Care Plans



We talked about using a communication card to let the NHS and social services know how you want to be communicated with.



We looked at some different choices.

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







September 2023 - Managing our money



Judy Krasker from DOSH talked about who can get PIP and what to do if you are turned down.



The PIP form is not Easy Read so it is important to be careful and get help with it.



When you have filled in the PIP form it can take a long time to hear back.



If they turn you down but you still think you need PIP, you can tell them why.

Citizen's Advice can help you to do this



Client Affairs told us about their work.

They are a small team who work for Gloucestershire County Council.









They act as a person's deputy which means they look after their money if they can't do it.



The Enablement Team told us about what they do.

They are part of Gloucestershire County Council too.



They have 6 drop ins in libraries across Gloucestershire.



They work with people to improve their wellbeing and to be more independent.

They can help people with cooking, shopping, problem solving, keeping safe and more.



They can help people money by going through bills and setting up direct debits.

They help people open bank accounts and do budgeting.



To get help from them people should go to the adult help desk and ask to be referred to them.









The Enablement team may be able to work with carers. Carers can go to the drop in to find out.



It was agreed that it would be good to share some flyers about the Enablement team.

November 2023 – Getting ready for being an adult and care home contract.



Jan Burn from Kingfisher Treasure Seekers told us about the barriers that young people are facing and how Treasure Seekers helps families.



Some young people don't feel able to go to school.



Treasure Seekers run a 'safe space' on a Saturday afternoon where children and their family can come along.



One young person really didn't want to go to school and their mum kept getting referred from one organisation to another.









Inclusion Gloucestershire told us about their project finding out about support people have had to be healthy.



Chris Gratton told us about the contract (set of rules) the council uses for care homes. He said it needs to be updated.

The new contract will be for all residential and nursing homes, but it will have a part about supporting people with learning disabilities.



The new contract will include how care homes will give people good quality care.



Chris wanted to know what people think needs to be in the contract.



Jan Burn said that lots of people can't come to Kingfisher Treasure Seekers events because there is a lack of transport or drivers in care homes.









We asked: What still needs to change for young people and who can help?

People told us lots of things. Some of them were:

Training for parents that is not too expensive including

- Positive behaviour support
- Positive neurodiversity courses which also thinks about the family



Training for teachers, school staff and on understanding special needs.



Help when children are younger with diagnosis and meeting the right people to help.



More transport to go to activities.







January 2024 - The Health Action Group Update



Simon Shorrick and Cody Gingell gave us an update from the Health Action Group.



The Health Action Group has been busy.

They have checked and changed some things like the pre health check questionnaire



The health passport



The health action plan



They have told people what they think about some things like the 'Respect' form where you put what you want to happen if you get ill.



The 'What matters to me' orange folder









The group has helped people who were worried about having an operation.



It is a place people can talk about difficult health problems like being in pain or grief.



Simon runs the Big Health Day.



The group has a newsletter.







What are we proud of this year?





We are proud that we have had a clear plan this year.

We listened to people in the survey and we planned our meetings to talk about the things that matter to people.



After our meetings we have decided what the board is going to do about barriers we heard about.

At the next meeting, we have been having a 'You said, We did', and we check what changes have happened.

We have agreed to do lots of things over 2022 and 2023.



We made a leaflet with the Employment and Skills Hub so people with a Learning Disability know who can help them to find a job.

It also tells them about the different types of work and volunteering.



We are proud of the communication cards that we have made and are printing.









We are happy that we wrote a letter to the MP about how we need ticket offices at train stations.

They decided we can keep having ticket offices.



We are pleased that our MP wants to talk to us about how to make the benefits system easier for people to understand.

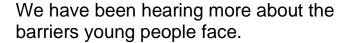
We look forward to working on this with him.



This year it was good for the Co-Chairs to talk to the Providers Forum with the Co-chair from the Carers Partnership Board.



We are pleased that the Partnership Board has had the Parent Carer Forum, Parent Carers and Children and Families Commissioning coming to our meetings.





We are proud that we now have a Facebook page and can share lots of the things that are going on with our board members.









We have started an extra online meeting for people who can't come to our face-to-face meetings.

This has been good.



We have been going to the Building Better Transport group to keep talking about problems people have with transport.

We will keep working to make this better.



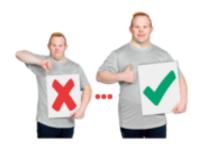
We are happy that people have kept coming and working together to make the partnership board great.

Plans for next year - March 2024 - September 2025



We want to keep listening to what is important for people in our community and make sure we are talking about those things.

We want to make sure that we do something about what we hear.



We want to make sure things keep getting better for people who have a Learning Disability, their family, carers and those organisations who support them in Gloucestershire.











If anyone would like to join our in person or online meetings, they can email:

- partnershipboards@inclusio n-glos.org
- janmarriott@outlook.com
- <u>TimH@inclusion-glos.org</u>







Other Information

Here are some extra things that people might want to read.

- 1. Our Ground Rules
- 2. Our Survey
- 3. Our Survey Results







Ground Rules

Ground Rules



Everything must be in Easy Read.



People must use words everyone can understand.



People should not use acronyms.



Acronym means the first letters of a word for example 'FYI' which means for your information.



Do not use words that only people who do your job will know.



People should not use big words.

People should not talk too fast.







?	People can shout out if they do not understand what people are saying.
	It is important to have breaks.
	Everyone must make sure people with a learning disability can speak up and give their opinions.





The Survey

Gloucestershire Learning Disability Partnership Board Survey 2022

Hello! We are looking for your help. Our partnership board aims to make lives better for people who have a Learning Disability who live in Gloucestershire. We want to make sure that our partnership board works to improve the right things. Please can you help us by answering the question below. Your answer can be anonymous if you would like. If you want to tell us who you are, you can fill out your name at the bottom but you don't have to.

- 1. What is stopping people who have a Learning Disability in Gloucestershire from having a good life?
- 2. Please can you tell us a bit about who you are:
 - I have a Learning Disability
 - I am a family carer for someone who has a Learning Disability
 - I am a paid carer for someone who has a Learning Disability
 - I am a professional involved in services for people who have a Learning Disability
 - Other
- 3. Which part of Gloucestershire do you live or work? *







Survey Results







We have been asking people this question:

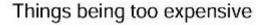
What is stopping people with a Learning Disability from having a good life?



We did an online survey and Tim went into the Gloucester hub and listened to people.



People at the hub told us some of the things that are stopping them from having a good life are:



Not having control of their own money

Not having enough money











Their health problems, like back ache and Covid symptoms

Their disability

Getting ill

Their mental health – hearing voices



Transport

They cannot use their bus pass until 9.30

It is hard to go to new places on their own.

They need someone to go on the bus with them.



Bereavement – not having family who are alive



They would like to live in a bigger home









Being shy

Places being too busy



Loud noises



The online survey got feedback from:
2 people with a Learning Disability
17 family carers
1 paid carer
11 professionals

People were from different places including Forest of Dean, Gloucester, Cheltenham, Stroud, Tewkesbury and Dursley.



People said there is more than one thing stopping people from having a good life.

25% of people said that cuts in funding have stopped people from having a good life.

They said they have to fight for funding.











Some people are not getting social care assessments or direct payments.

Social groups and day activities have been cut.

There are not enough safe and quieter places for people to go

Most of the accessible places are in Gloucester – not in other parts of the county.



25% of people said there needs to be more accessible transport

Better transport in the Forest of Dean

About a fifth of people said there are not enough accessible buildings.

More accessible timetables.



About 20% of people said people don't have the right support.









17% said there is not enough mental health support.

They said there are no community settings for people with a Learning Disability when they have a mental health crisis.



Some people said there is not enough staff, and not enough of the same staff.

They said carers are not paid enough and are not always trained well.



It is hard to get help from health services.

There are long waiting lists.



There needs to be better communication between the different professionals.









Cost of living



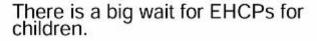
Not enough job opportunities



Housing is not good enough



We heard from some parent carers. They said they are not getting enough support.





There are not enough spaces in the right school for children.

There is not good support when people move from child to adult services









It is hard to get respite and funding for activities.

There are not the right holiday clubs for secondary school children.

There aren't enough mainstream inclusive after school activities.



People's attitudes

People with a Learning Disability being left out

People thinking someone with a Learning Disability cannot do as much as they can.



Places are not taking cash payments.



People with a Learning Disability often don't have a debit card and can't book things online.

