

The background is a dark green color with several stylized virus icons. There are two large green virus icons, one in the top-left and one in the bottom-right. There are also three smaller white virus icons, one in the top-right, one in the bottom-left, and one in the top-center. The text is centered in the middle of the page.

The COVID Pandemic And Its Inequalities for Adults with learning disability in Tameside

Who are we - People First Tameside



A user led organisation supporting adults with learning disabilities to have a voice in Tameside.

People First is a local charity set up in 1997



What we do...



We run many different groups where people can talk about anything they are worried about, to talk or to get information.

We work with services to let them know how we feel.

We raise awareness and educate the general public and professionals about issues people with learning difficulties face, including Hate Crime, School and Hospital Disability Awareness Training.

We offer training for people with learning disabilities in Lifeskills, Independent living, Health and Employment.

People First Tameside are members of other groups such as: The Learning Disabilities Partnership Board, the Greater Manchester Mayoral Disabled Peoples Panel and the Inequalities Reference Group in Tameside.



Why we have done this project – the purpose

People First, has been asked to support people with learning disabilities to speak up about how they felt during the COVID pandemic.

We would like you to hear our voices so that things can be made better in the future.

People First listened to people with learning disabilities including younger people, those harder to reach, communities of BAME, LGBTQ, Older adults and Men.

We would like to say 'Thank you' to all the people who got involved with this project.



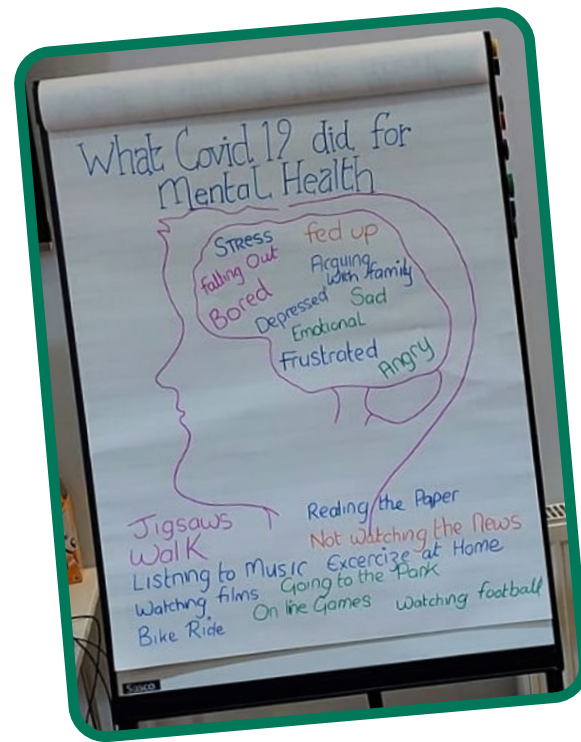
Lockdown Our Story, Our Lives...



- We put a survey together to ask people their experience of COVID-19
- A small project was made for each of the survey questions to gain more in-depth information.
- An Inequalities Group was established called Our Story, Our Lives...

The project was shared with the Inequalities Reference Group during the summer and late autumn of 2021.

The following pages tell us some of the findings from questions asked to people who took part in the project.



The pandemic made us feel lonely,
isolated, frustrated, angry and scared.



How did COVID-19 effect your mental health?

- Worn out and upset.
- Crying a lot.
- Was all over the show.
- Staring at the same four walls everyday.
- Brain all over the place.
- Stressed, Depressed, Scared.
- Grieving of lost ones.



Information received about COVID-19



- I did not get anything from my social worker
- TV announcements need to have a translator for different languages.
- No sign language for those who are deaf.
- Too many big words I did not understand.
- My mum had to explain it to me in a simple way.
- It was all new words like 'lockdown', 'COVID-19 or Coronavirus, are they the same thing', 'Variant - what does that mean', 'Stay-home' - can I not go out to the shops? I was so scared'.



More information received about COVID-19

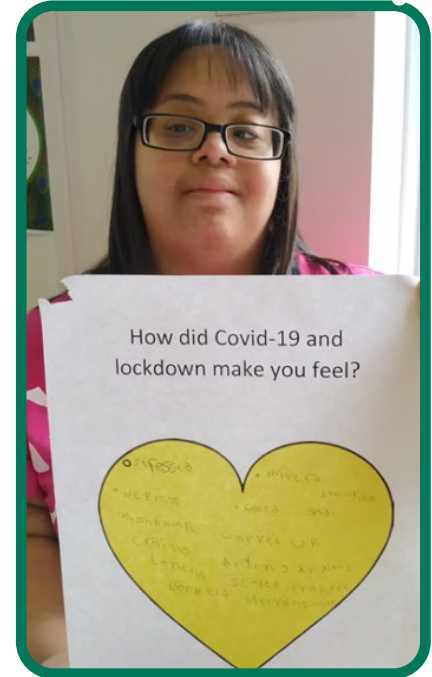
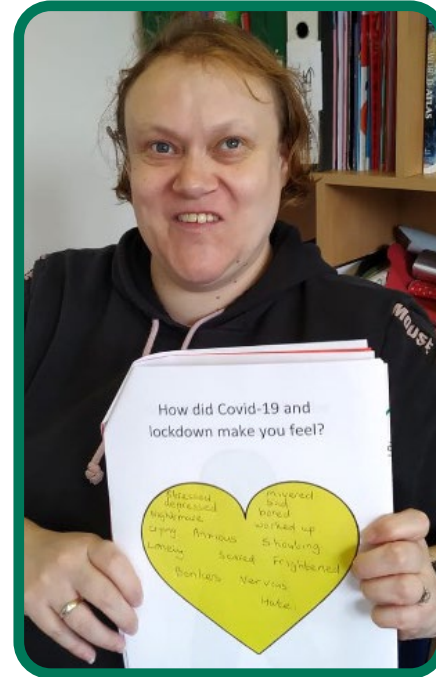
- I don't like watching the news, it scares me, how do you know what to do if you don't watch the news?'
- Pathways sent some good videos to People First who shared them
- Tameside did not send me anything through the post
- Staff helped me to understand
- Constant hand washing/ Sanitizing gel.
- Made hands dry and cracked.



How did COVID-19 and lockdown make you feel?



- Nervous
- Depressed
- Mithered
- Anxious
- Bonkers
- Sad
- Lonely
- Worked Up



COVID-19 Vaccine

- I have autism no one helped me to feel safe
- No problems, felt tired afterwards, slight pain at sight of injection.
- Felt brave as was a bit nervous.
- Felt ill the day after the first jab.
- Just felt tired.
- GP not recognizing LD as priority.
- Mum was not allowed into vaccination hall, had to go in by myself.
- The hall was too big I felt scared and didn't want to go back for my second Jab.
- Everything happened too fast
- There were too many people in the hall, I don't like injections.
- The staff were friendly
- I was poorly for a week afterwards, it felt like I was infected



Hannah's Story



Hannah (24 years old) lives with her family.


Hannah has a learning disability after a heart transplant when she was 6.

Hannah has an extremely low immune system; she needs to be careful with what she eats, and she cannot be in direct sunlight.

Hannah's heart condition has affected her mental health and she often suffers from acute anxiety. This stops her doing the things she loves.

Hannah's mood can quickly turn from hysterical laughter to crying and panic attack.

Pre-covid Hannah enjoyed being with her friends in a large group. She was learning independent living skills, and learning to cook 'cheesy pasta!'.



Hannah's Story (continued)



Hannah stopped everything during the pandemic she was terrified of having a heart-attack.

Staff and friends called her with videocalls, Hannah would tell us she was sad and missed her friends.

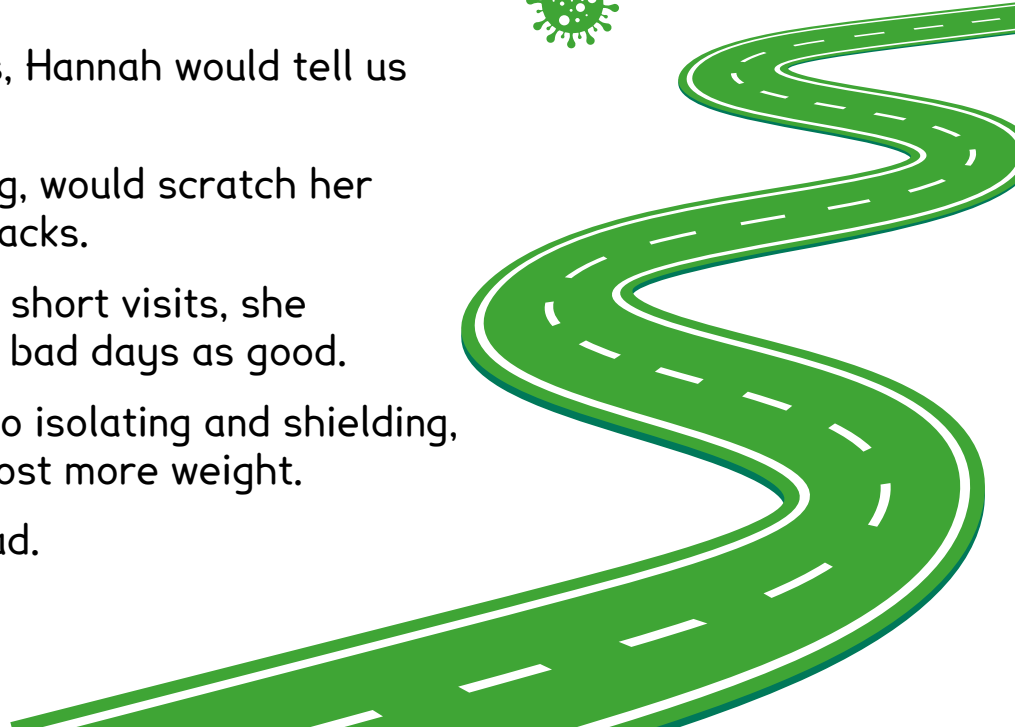
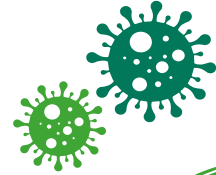
At times Hannah would stop eating, sleeping, would scratch her face, pick scabs and have regular panic attacks.

Hannah tried to go back to her old life with short visits, she struggled with her nerves and had as many bad days as good.

Another Lockdown, and Hannah went back to isolating and shielding, her mental health was shattered, and she lost more weight.

Covid knocked what little confidence she had.

It will be a long road to recovery.



Stories of...



Food

I cannot cook very well, so rely on my mum who works and is in her 70's to help, I eat at the places I go to, or buy a sandwich from the shop and have takeaway foods or toast. Imagine when all your lifelines have been taken from you and you have just cereal in the house!

I was scared no one around me to help. Food packages eventually came with potatoes and packet soup, stuff I don't know how to cook and that didn't make any sense to me!

You had to order online on an app!
I just have no idea how to do this!



Stories of...



Health

I have a lot of worries about my health and so ring the GP often and sometimes go to A&E to ask for support and reassurance. I was too scared to go to the GP and hospital so I suffered, with my physical and mental health. It was scary. I just didn't know. My heart was beating fast and I was worried I would have a heart attack.



Transport

My Family live a bus ride away, I couldn't see them during COVID, I felt very cut off I was scared to use transport for a long time afterwards. I can't wear a mask with my asthma it makes me dizzy and cannot breathe, people say horrible things if I don't wear the mask. They make you feel like a rule breaker. They don't understand and give you dirty looks. It made me feel bad.



Stories of...



Housing

- Lonely and Vulnerable
- Noisy and Scared
- Trapped in
- People knock in my door. I am frightened.
- People pretending to be my friends, coming in my flat and taking stuff
- They tell me I have a house so I'm not priority
- Boris made me stay in a place I was already scared and hated. It made me feel ill.



We Need...



- Better housing and choice
- Access to information
- To belong within our community
- To be supported to have friends, and relationships
- A right to work and to be respected within the workplace
- To be included in making decisions about our health and our lives



Nationally – Shocking numbers

- A public health review told us that **6.3 times more people with learning disabilities died** than those who do not have learning disabilities.
- Among people with learning disabilities, **far more young people died with coronavirus than in the general population**; the death rate among people with learning disabilities aged 18–34 was a shocking **30 times higher**.
- **A third of people with learning disabilities who died were living in residential care.**



The background features several stylized virus icons. In the top-left corner, there is a large green virus with dark green spots and protrusions. In the top-right corner, there is a white virus with dark green spots and protrusions. In the bottom-left corner, there is a white virus with dark green spots and protrusions. In the bottom-right corner, there is a large green virus with dark green spots and protrusions. The background is a dark green color with lighter green wavy shapes.

These are the 4 things which we would like professionals and people to do more of...

This is the easy read report there are often long words and language which make it hard for us to understand, so we have written this in our words for everyone to understand. There is a much longer and more difficult report at the bottom of the page and to follow if you need more information.

1. I would like people to **Listen to me**. Advocacy groups will support everyone to speak up and get our voices heard.



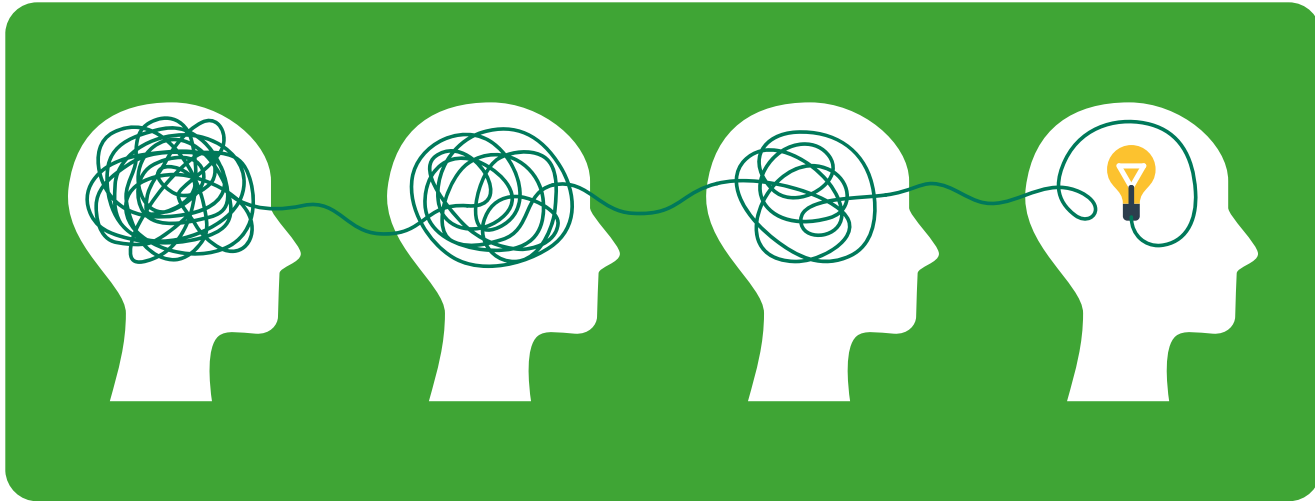
1. To strengthen the voices of those with learning disabilities in the borough of Tameside through investing in self-advocacy and creating opportunities for people's voices to be heard, enabling people with learning disabilities to take control of their lives.

2. Talk to me and find out what I would like, don't tell me what you think is best for me. I want a say in where I live and who I live with, getting a job, who my friends are, my health and who supports me. It is my life, support me to keep learning and live well. **I want to have choices.**



2. Ensure organisations and services engage with people with learning disabilities at every stage co-designing instead of presenting people with a “done deal”. This includes the design of housing, health plans and support services.

3. Give us clear and easy messages so that we understand what is happening, this did not always happen during COVID. Ask us and check that we understand. We feel isolated, **do not leave us behind.**



3. Build back the confidence of people with learning disabilities to re-enter an improved life after the pandemic. Ensure improved communication, information is accessible, reasonable adjustments are made and support services are available within Health, Social Care, Education, GP's, Policing, Social Workers, Voluntary Sector and other settings. Leave no-one behind.

4. Services need to LISTEN, they should all do this everywhere they might need training so that they understand better. I can help them to **make things better for everyone.**



4. To develop good practice guidance which adheres statutory services to inclusion to every stage of service planning and development, good practice to ensure measurable outcomes to address inequalities in service design and delivery.

Thank You!

Thank you to everyone who took part in the survey, to people with learning disabilities at People First Tameside for being great leaders on the project and to parents and carers who supported people to tell their stories.

We hope people can help us to make a change in Tameside and beyond, to support us all to have the best life we can live.

We hope you enjoyed hearing some of our stories, we have tried to keep it short. The longer report follows.