



Learning Disabilities: Showing Resilience Through the Covid-19 Pandemic

People First Groups: South East Wales



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Executive Summary

There is a plethora of evidence that tells us of the profound impact that the covid-19 pandemic has had on the lives of people with a learning disability and their families and carers.

The covid-19 pandemic radically altered the daily lives of people with a learning disability, with many not able to attend day centre or work, with some people needing to work remotely with little or no support. Personal Protective Equipment exacerbated existing communication barriers, and intensified feelings of uncertainty and confusion. People with a learning disability reported difficulty in recognising symptoms of covid-19, and understanding the fast-changing Government guidelines about testing, isolation and social distancing. In addition, people with a learning disability have difficulties in accessing healthcare in ordinary times, and adapting to online consultations with healthcare professionals has been particularly challenging.

There has been an enormous strain on families and carers during the covid-19 pandemic, with intense demands of continual caring; and often work commitments being managed alongside full-time caring responsibilities. In some cases, adult relatives with a learning disability who normally lived in residential services moved back to live within the family home (with no additional support).

The Hear Our Voice in Lockdown project and the wider Showing Resilience in the Covid-19 pandemic work provided a platform for people with learning disabilities; parents and unpaid carers; organisations supporting people with learning disabilities; health and social care service providers; academics and decision makers to come together to ensure that in the midst of the chaos that the covid-19 pandemic produced, voices and experiences could be heard and influence immediate and longer term decisions to help design the 'new normal' of life with covid-19 and beyond.

Self-advocacy groups have been identified as fundamental throughout the pandemic, with People First groups purchasing a range of technological devices for people with a learning disability across their localities. Self-advocacy quickly moved online, keeping people connected and building a robust support network.

It is clear to see the negative impact of covid-19 on the lives of people with a learning disability, with words such as fear, confusion, scared and stressed being common words used. However, it is important to acknowledge the new found levels of resilience that has been demonstrated by people with a learning disability whilst navigating the covid-19 pandemic.

Despite the obvious challenges, people with a learning disability, appeared to embrace this new norm. Many people with a learning disability found a new freedom, and deeper connections, with some acting as befrienders to others, or carers to their older relatives. Peer support became a priority and people with a learning disability came together to find innovative, and new ways to stay connected, and advocate for themselves and others.

Expectedly, when asked about hopes for the future, discussion focussed on an overall desire for social connection. However, these was also a perception that lockdown had allowed a time of reflection, and time to prioritise things that were good, and make changes, where needed, to improve services and life experiences in the future.

It is hoped that the experiences and voices of those who participated in the Showing Resilience in the Covid-19 pandemic work captured within this report will not only help build understanding of the experiences of people with learning disabilities throughout the covid-19 pandemic, but the desire and opportunities for them to live a more meaningful life in a world after covid-19.

Dr. Stacey Rees (TRAC Coordinator / Lecturer)
University of South Wales

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“I felt like I was in prison, I did, because I was just locked in my room. I couldn't do anything, and my anxiety was going through the roof, and I had really bad problems in my brain, I was just overthinking things all the time, I was. I just couldn't cope. I lost my routine and I really need my routine because I'm on the autistic spectrum and I've got to have my set routine.

It really helped me when Teams started and I did activities. Things like bingo, that's my favourite, the quiz, and I ran my own history group and that's helped me to meet new people I've never met before, and that was really good. Making new friendships has helped me a lot, and have given me support” – Gemma, Pontyclun

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Introduction

According to the Office for National Statistics (2019) Estimates of the Population for the UK, England and Wales, Scotland and Northern Ireland, there are just over 1.1 million adults with a learning disability in the UK, of which approximately 54000 can be found in Wales.

Life for those with a learning disability has never been easy, and whilst they faced many inequalities prior to covid-19, these have been exacerbated by the pandemic. The Coronavirus Act, 2020 challenged the human rights of many in a bid to keep us all safe. Overnight our lives were turned upside down as war was waged on an invisible enemy that had caught us off guard and was winning the battle. Restrictions on our movements and behaviours were quickly imposed as a campaign of fear ripple through our streets, and the message of Stay Home, Stay Safe, Save the NHS rang as an anthem to try and bring unity and a sense of 'we're all in this together'.

However, that tag line 'we're all in this together' couldn't have been further from the truth for many, including those who have a learning disability, or a range of other complex needs. Equally, life was very different for the health and social care staff who were propping up the frontline unsure of what the next hour was about to bring them and exhausted from the impact of both the physical and emotional ammunition the covid-19 virus was firing at them. Health and Social Care services as we knew them closed, re-purposed and changed under the Coronavirus Act, 2020, threatening legal rights to access elements of the support people with a learning disability, as well as others, needed to help them overcome a number of personal, health and societal barriers, and to live their

best life possible. The covid-19 pandemic dramatically altered the daily routines of people with a learning disability. Many could no longer attend day centre, or were moved to reduced days and hours as capacity of services was decreased to adhere to covid-19 safety and infection prevention regulations.

Others had volunteer placements postponed, those with paid jobs had to find ways to try and work remotely with little support, and the way in which at home carers and support workers were able to interact with individuals was largely limited and became very clinical. Personal Protective Equipment made people feel like they were in some sort of movie, like E.T, and intensified fear, confusion and misunderstanding.

Equally, this time became increasingly difficult for a number of parents and unpaid carers who had to suddenly take on full-time caring roles, following the lack of access their loved one had to health and social care services. Some parents and unpaid carers still had to work full-time and had to learn to balance the needs of their loved one, with their work responsibilities. Additionally, parents and carers had to desperately try and keep up with changing restrictions and regulations to ensure their loved one didn't fall through the net and that they were doing everything they could to decrease the risk of the household contracting covid-19.

People with a learning disability were deemed to be at greater risk of experiencing the worst side effects of contracting the virus, with those who did contract it being five times more likely to be admitted to hospital and eight times more likely to die. In addition, “worrying attitudes and prejudices about the value of the lives of people with learning disabilities surfaced [through the] use of DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) orders” being placed on their files (BMJ 2021; 374:n1701 Covid 19: People with learning disabilities are highly vulnerable). As a result, people with a learning disability were placed on the vulnerable persons list and advised to shield, which restricted their movements even further.

For those who access and rely on adult health and social care services, this time of uncertainty, fear and confusion created a set of circumstances that had the potential to adversely affect both their physical and mental wellbeing, as routines were dropped and the realities of loneliness and isolation were intensified.

However, instead of just accepting their fate, some people with a learning disability embraced this time of change and restrictions, and as a result, found a unique opportunity to flourish, identify new strengths and skills and develop a deeper connection to their surrounding world than they had ever been able to do before. In some situations, and with the right support, people with a learning disability triumphed. Their adaptability, innovation and new found freedom, opened minds that began to ask ‘what if’, unlocking the gate to a path of future endless possibilities.

As this eruption of resilience developed, services that supported people with a learning disability, especially those in the

third sector and a step removed from the frontline battle, also found themselves in a unique position of opportunity. There was an obvious need to bridge the void that had been left by the closure and repurposing of health and social care services, as well as the harnessing of endless possibilities this stop-gap reflection period provided. Mobilisation of limited resources and sharing learning became essential tools in providing people with hope and purpose, inspiring them to find new coping mechanisms and challenging them to drop the mundane day-to-day routine and forge their own exciting paths for the future.

As a way to empower and value the voice and experiences of people with a learning disability, and capture the impacts and changes that evolved throughout the covid-19 pandemic, People First groups across South East Wales came together with the Cwm Taf Morgannwg Our Voice Matters project, and the University of South Wales TRAC (Teaching, Research Advisory Committee) team to develop a project where people with a learning disability could share their stories and experiences in a way in which trends and patterns could be identified and learning could be obtained: Hear Our Voice in Lockdown.

The Hear Our Voice in Lockdown series aimed to provide a platform for people with learning disabilities; parents and unpaid carers; organisations supporting people with learning disabilities; health and social care service providers; academics and decision makers to come together to ensure that in the midst of the chaos that the covid-19 pandemic produced, voices and experiences could be heard and have influence in shaping immediate and longer term decisions to help design the ‘new normal’ of life with covid-19 and beyond.

To highlight the learning of the Hear Our Voice in Lockdown project. An annual conference has and will be held, with opportunities to share, discuss and debate how life has been impacted by covid-19 for those with a learning disability across South East Wales and beyond; as well as any learning or insights that have been gained. Themes identified from these annual conferences have then led to further specific events on topics such as daytime opportunities, supported and independent living and friendships and peer support, where discussions have helped develop action plans, future service reviews and reform and innovative solutions to

overcome issues and barriers. Contained within the pages of this report, summaries of, and findings from each of the annual conferences will be presented, alongside some of the support mechanisms and innovative actions that have been undertaken by each People First group, to ensure their members can be appropriately engaged and have their voices heard in lockdown. The report will conclude with an overview of the hopes and recommendations people with a learning disability, and those supporting them have identified to build on the resilience they have developed through lockdown to help give them a more meaningful life in the future.





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“We knew lockdown was going to be hard for our members, so right at the beginning of lockdown we spoke to them [our members] and they helped us design activity packs to keep them busy.

They asked for things like colourings, word searches and competitions, and we also included informative activities such as the hospital passport in case they needed to go into hospital, the Keep Safe Cymru Card, and advice on eating healthy and home safety.

A lot of our members don't have access to the internet, phone, laptop or email addresses, so the activity packs were a good way to engage them and help us stay connected” – Danielle, Training and Development Worker, People First Bridgend

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The Importance of Self Advocacy



Self-advocacy, or having a voice of your own, is a really useful and important skill for people to have so that they can identify issues or needs that they may be experiencing and express themselves fully about the things that they like and the things that they would like to see changed. Self-advocacy understands that people are experts of their own lives and therefore they are the best people to explain what they are experiencing, and help develop desired action steps or potential solutions; and stand firm until things change for the better.

At the heart of self-advocacy is respect. It is about enabling people to respect themselves enough to want, and fight for, the best life possible, as well as enabling others to be able to listen, appreciate and take appropriate action on the stories and experiences that people share.

People First is a self-advocacy movement for people with a learning disability which started in Oregon, USA in 1974. The movement began when a person with a

learning disability said they didn't like being called 'retarded' or 'handicapped' and instead wanted to be treated with respect and equality. The individual wanted people with learning disabilities to be seen and treated as 'people first'. As the movement has grown and developed momentum, People First groups have started in areas all over the world, including all across Wales. The People First groups involved in this project covered the South East Wales region and aim to:

- **Collect people's views**
- **Find out what is going on in their area that people with a learning disability can get involved in/access**
- **Find out what is important to people and campaign to improve their lives**
- **Send and support representatives to local, regional and national decision making bodies to help ensure that the voice of people with a learning disability is included and listened to**

Project Partners



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“As we entered the fourth week of lockdown and infection rates and death rates rapidly rose, letters were being sent to some of our members to shield and we knew that this pandemic was going to be around for longer than we had envisaged. We talked to some of our members who we had already issues with some of the iPads we already had and asked them what did we need to do?

They asked us to look for funding to buy more iPads to get as many members connected with us as possible, as members wanted to stay connected and offer each other as much support as they could and enable them to connect with family and friends to relieve isolation, loneliness and anxiety. Members also needed to be kept up to date with the latest developments in a way that they could understand as it was becoming so confusing. Since receiving the iPads, members have told us that the iPads have been a lifeline for them. They have learnt new skills such as FaceTime and Zoom and are enjoying connecting with family and friends” – Dawn, Operations Manager, RCT/Cwm Taf/ Blaenau Gwent People First

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Finding Ways to Connect: Self Advocacy Goes Online

As the covid-19 pandemic escalated and lockdown measures came into force, it quickly became apparent that there was a section of society that were at increased risk of the negative impacts of loneliness and isolation due to their digital disconnectivity.

This section of society included people with a learning disability who had little or no skills, money or equipment to join the transition into digital service delivery, and meant that they had limited access to connecting with the outside world during lockdown. As a result, many people with a learning disability lost the opportunity to have voice, choice and control over their lives during the pandemic, and as some services to support them were either stopped, postponed or transitioned onto digital platforms, People First groups across South East Wales recognised that they had a role to play in bridging the expanding digital poverty gap that was developing for their members.

Following a number of successful funding applications, People First groups were able to purchase and distribute a range of technology devices to people with a learning disability across their individual localities. Staff also worked remotely with connected members to develop training packs and set up I.T. support software to ensure the technology devices distributed could be used as effective resources to reduce loneliness and isolation and promote self and peer advocacy by connecting members to various platforms, meetings, events and workshops where they could have a valued voice and be listened to. Staff also worked hard to identify and implement a number of

safeguards to ensure members were safe online, and this has included expanding the training materials for members to cover issues such as scammers, online mate/hate crime, and personal online safety.

Through the use of these devices, staff and members learnt how to have multiple caller FaceTime, Zoom, Teams and Messenger calls to hold weekly local meetings, but also connect with others outside their immediate geographical area; regionally, nationally and in some cases globally. As the pandemic continued, people with a learning disability learnt how to lead workshops, training sessions and run conferences online, helping them develop a range a transferable employability skills for the future.

This digital connectivity also meant that covid related information could be disseminated quicker in a variety of Easy Read formats. Members and their families reported how helpful this information was, and this work led to further conversations with Public Health Wales about the importance of Easy Read information, and has led to the creation of a regional Health Champions team as a partnership between Cwm Taf People First, People First Bridgend, Cwm Taf Morgannwg University Health Board, Swansea Bay University Health Board and the regional Research, Improvement, Innovation Coordination Hub.

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“It’s brilliant having an Ipad. I am discovering new things with it all the time like listening to music and how to record music, using FaceTime to speak with others.

Before I got the Ipad I was lonely and isolated and feeling depressed, now I get to chat with my People First friends” – Carl, Pontypridd

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2020 Conference

On 18th June 2020, project partners came together to hold their first Showing Resilience event. The event was branded and run as a Q&A session with people with learning disabilities from across South East Wales to provide insight into what life was like for them during the first lockdown period, and what things they felt needed to change within their communities and the services they access, to help improve their future livelihoods.

Learning Disabilities Showing resilience through the COVID-19 pandemic: Things we need you to know!

1. What was life like for us before lockdown

The event was designed to showcase not only people's individual and collective experiences, but also the creative and innovative ways people with learning disabilities had been utilising to navigate lockdown one, and the covid-19 pandemic in its earliest days.

The event attracted 61 registrations of interested parties from across the UK, with 41 out of those 61 attending the event. While most of the attendees were localised to South East Wales, others joined from areas of West Yorkshire, Manchester and Lancaster.

2. What has life been like for us during lockdown

Breakout rooms were used throughout the session to ensure that a diverse range of quality conversations could take place and that attendees could interact with a number of different members from across the South East Wales region.

"Having breakout sessions meant we were able to hear from a wide range of individuals about their experiences. Being able to ask questions directly was also really valuable" – Session Attendee

3. What needs to change for the future

"I think my voice was heard because they all listened to me and everyone was asking questions, and everyone was nodding" – Session Panellist

When things were normal: what life was like for us before lockdown

Before lockdown, People First group members reported that in general life was good. They recognised that they did face a number of different barriers when life was 'normal' and some stated that they did experience some levels of loneliness and isolation because of their learning disability before lockdown.

Many indicated that lockdown restrictions had shown them just how much freedom they used to have and how they often took for granted all of the things that they could do, like spending time with family and friends, and that they didn't realise how important these things were until it was taken away from them.

"before lockdown we were going to meetings often and talking about things that mattered to us and that made us feel good. Life was just more enjoyable then" – Sammy, Blaenau Gwent People First

"life before lockdown was better than what it is now, I used to really enjoy going to work and spending time with friends" –Rebecca, Cwm Taf People First

"I enjoyed life before lockdown. I was always busy in my volunteer role and spent weekends with my family. I used to enjoy shopping and going to Weatherspoon's for food and drink" – Ffion, Caerphilly People First

"my life was so busy before lockdown. I used to go to day centre and did work placement with People First on a Friday. My favourite activity was going out for a meal and I love clothes shopping" – Julie, People First Bridgend

"Before lockdown I attended a dance class"
– Sarah, Monmouthshire People First

"Before lockdown I enjoyed going to see my boyfriend and going out with different groups. I used to go to concerts and liked meeting famous people" – Nicole, Caerphilly People First

"Life before lockdown was busy/hectic. I used to go to lots of meetings with People First, TRAC, Bevan Advocates and the Learning Disability Ministerial Advisory Group. These made me feel valued and good that I had purpose" – Lynne, Cwm Taf People First

"I used to volunteer at the Lakeside two days a week and I really enjoyed the social side of going there, chatting to people, serving people, cleaning tables – I got to meet new people all the time" – Terri-Ann, Cwm Taf People First

"before lockdown I used to do loads of things like, going to the gym and fitness classes; going on shopping trips to different towns and cities; and doing work and volunteering. I worked in the charity shop and the garden nurseries, and I was a volunteer dog walker. I liked being busy and doing different things" – Adam, People First Bridgend



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“I was playing darts with my local team before lockdown happened, and being part of this team was something I really enjoyed.

Now the pubs are shut so I can't go and play darts, and I miss playing in my team” Sammy, Nantyglo

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Eruption of Fear:

All the Things that Changed

As covid-19 spread and lockdown measures came into force, life change for us all. People with a learning disability reported that covid-19 and lockdown had negatively impacted their mental wellbeing and their lives in general.

People First members used words such as fear, anxiety, bored, stress, alone, scared and depressed when describing what life was like for them in lockdown. They also used the word confusion frequently and many stated that they struggled to understand what 'the germ' was and still had no idea what was going on! When reflecting back on 'all the things that changed' because of coronavirus, People First members highlighted the following as reasons why they felt this way:

- **Shops closed**
- **No buses**
- **Didn't feel like anyone cared about us**
- **Increasing death rates**
- **No (or limited) day centre services**
- **Too much confusing information**
- **Masks, gloves and aprons**
- **Locked in my room**
- **Alone**
- **Couldn't see my friends and family**
- **Couldn't see my doctor**
- **Didn't know where to go for help**
- **No more routine**
- **Shielding letters from the government**
- **Scared to use the computer/didn't know how**

"we haven't really had any support during this time, and we don't know who to ask about getting support... we feel like we have been forgotten about or that we have to go out and do our shopping ourselves when we should be shielding" – Mike and Sue (Mike's mother/carer), People First Bridgend

"life is shit now! I feel depressed and anxious all the time. The pubs and bingo are shut and I have nothing to do now" – Rebecca, Cwm Taf People First

"the deaths because of covid-19 have scared me, and now I check the death rates everyday" – Sammy, Blaenau Gwent People First

"my mum was worried about what was happening with the service and safety measures in day centre" – Gavin, People First Bridgend

"at first, I found lockdown relaxing, but then all the stories were misleading and confusing, and I didn't know where I could go to find out the truth, and this has caused me stress. I also started struggling by only communicating via video calls" – Rhiannon, Newport People First

"watching the news made me depressed, seeing all the death rates" – Leanne, People First Bridgend

"I don't like being indoors all the time, I feel depressed. I would usually keep busy but my routine has gone out of the window. I would really like to go out and about and I really want to have more exercise" – Chloe, Blaenau Gwent People First

"I am bored of lockdown as I usually go out and about and at the moment I don't go out at all, and this is really difficult for me. I find lockdown difficult as no one has the answers" – Bradley, Cwm Taf People First

"having autism has made lockdown difficult. I have had trouble setting a new routine as I have found change hard" – Ffion, Caerphilly People First

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“I feel so sad for my sister, she has deteriorated drastically [in lockdown] and I fear she will never recover from this. She is stuck in a virtual prison and I feel sad for her. We have been totally abandoned. If we all die, I don't think anyone would even notice. My sister has suffered terribly and now this has happened she doesn't want to go back to day centre. She could walk before but now she can't and she is losing her ability in other ways. We struggled so much without carers, but since they started to come back in [my sister] brightened up a bit immediately. They are brilliant and she has missed them so much” – Binky, Carer and Member of The Grapevine



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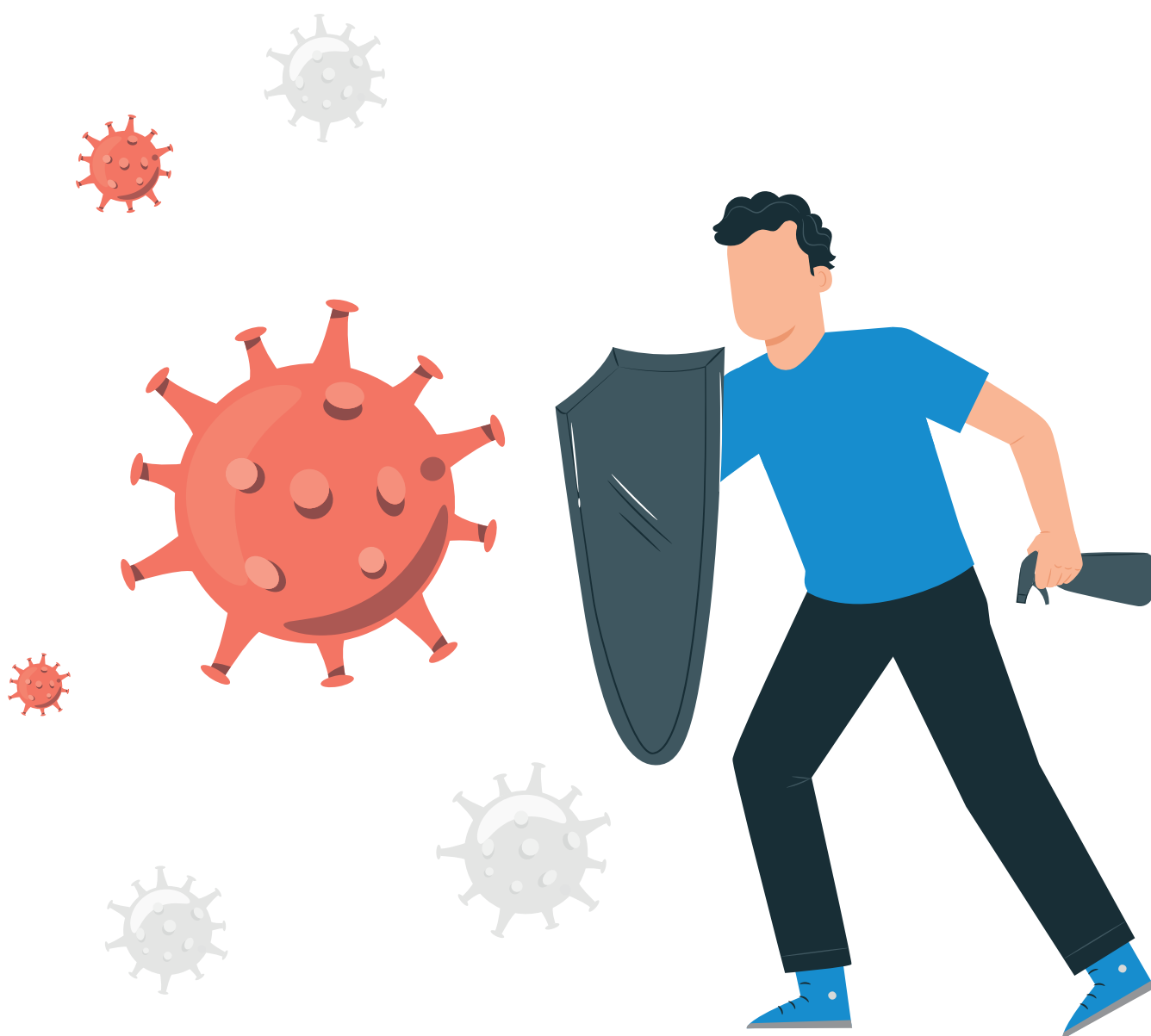
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“I am fed up of doing nothing, but I don't want to catch the germs because I am scared. I moved back to my mam's house but it's not easy and I want to go back to my own home, but I also want to be safe. I am just worried about the germs, that's why I am here at home. It is safer. I am going to stay at my mothers until these germs are over because I am afraid.” – Darren, Treherbert



Surviving lockdown

Despite the fear that covid-19 and lockdown generated for People First members, and the increased negative impacts of loneliness and isolation, it was clear from the breakout room discussions held at this event, that people with learning disabilities have built a new found level of resilience whilst trying to navigate the confusion and rules.



"it's great to have the iPad. I get to see everyone. I love it so much. I have learnt how to use Zoom and FaceTime to speak and see all my friends. Life would be a disaster if I didn't have the iPad" –
Chloe, Blaenau Gwent People First

"my way of getting out of my depression has been cooking to get me out of wanting to kill myself" – Rebecca, Cwm Taf People First

"during lockdown I have stayed connected via zoom. I brought a puppy who I am going to call 'Princess', she is a chihuahua. I have also become an ambassador for Gig Buddies during lockdown"
– Nicole, Caerphilly People First

"iPads have been brilliant and has helped me stay in touch with everyone over the pandemic. I have also been gardening a lot during lockdown. I wasn't into gardening before, but I been watching videos on my iPad about allotments and it has inspired me" – Sammy, Blaenau Gwent People First

"The hardest bit is staying in. I am used to going out and about every day, so it is difficult to stay in all the time. I am getting very bored. To keep myself busy I am helping my dad at his allotment and I like listening to music. I hope that my support worker can come this week and take me for a walk. I also like the zoom meetings I do with People First because they keep me connected with others and I think it is important that meetings still happen. The quiz night we do on a Thursday has been good, loads of people take part and it is fun" – Bradley, Cwm Taf People First

"I suffer with anxiety and depression but have found support from friends and family makes a massive difference. Outside support has also been a help; talking and connecting via zoom and Facebook. To stay connected and help my mental health, I have been spending more time online and using technology and I have noticed a massive increase in the amount of scam emails and cold callers that are circulating" – Ffion, Caerphilly People First

"everything is on the computer now. I do lots of activities on Teams like zumba, quiz, bingo and we do our People First Advisory Group Meetings on there" – Raymond, People First Bridgend

Get on your bike, but not on the bus!

Issues with transport for people with learning disabilities is not a new problem related to covid-19 and lockdown, however government guidance concerning public transport has intensified this issue and the barriers it causes.

With heightened levels of fear across our society, and limitations on the number of people allowed within a public transport vehicle, the few interactions People First had experienced with transportation during lockdown was largely negative, rooted in a lack of understanding, empathy and patience.

Reduced services have seen some people with learning disabilities left at a bus stop for over 2 hours as they waited for their usual bus, which on eventual arrival, they were refused entry due to capacity restrictions.

Another member reported how they had been shouted at by a bus driver when they were trying to get to a hospital appointment and this had left them upset and anxious.

The confusion people with learning disabilities expressed in relation to lockdown rules, alongside changing information not in an Easy Read format, had left them frustrated as they couldn't identify why they were being treated in this manner.

"a bus driver shook his head and drive straight past me when I was waiting at a bus stop. When I complained they said he didn't see me, but I saw him looking at me and shaking his head saying no. There was loads of space on the bus, it wasn't even packed, and it was late at night" – Sammy, Blaenau Gwent People First

"I had a really bad experience with a bus driver and my husband. The bus driver didn't have patience and was very rude to us. No one had masks on, on the bus" – Rebecca, Cwm Taf People First

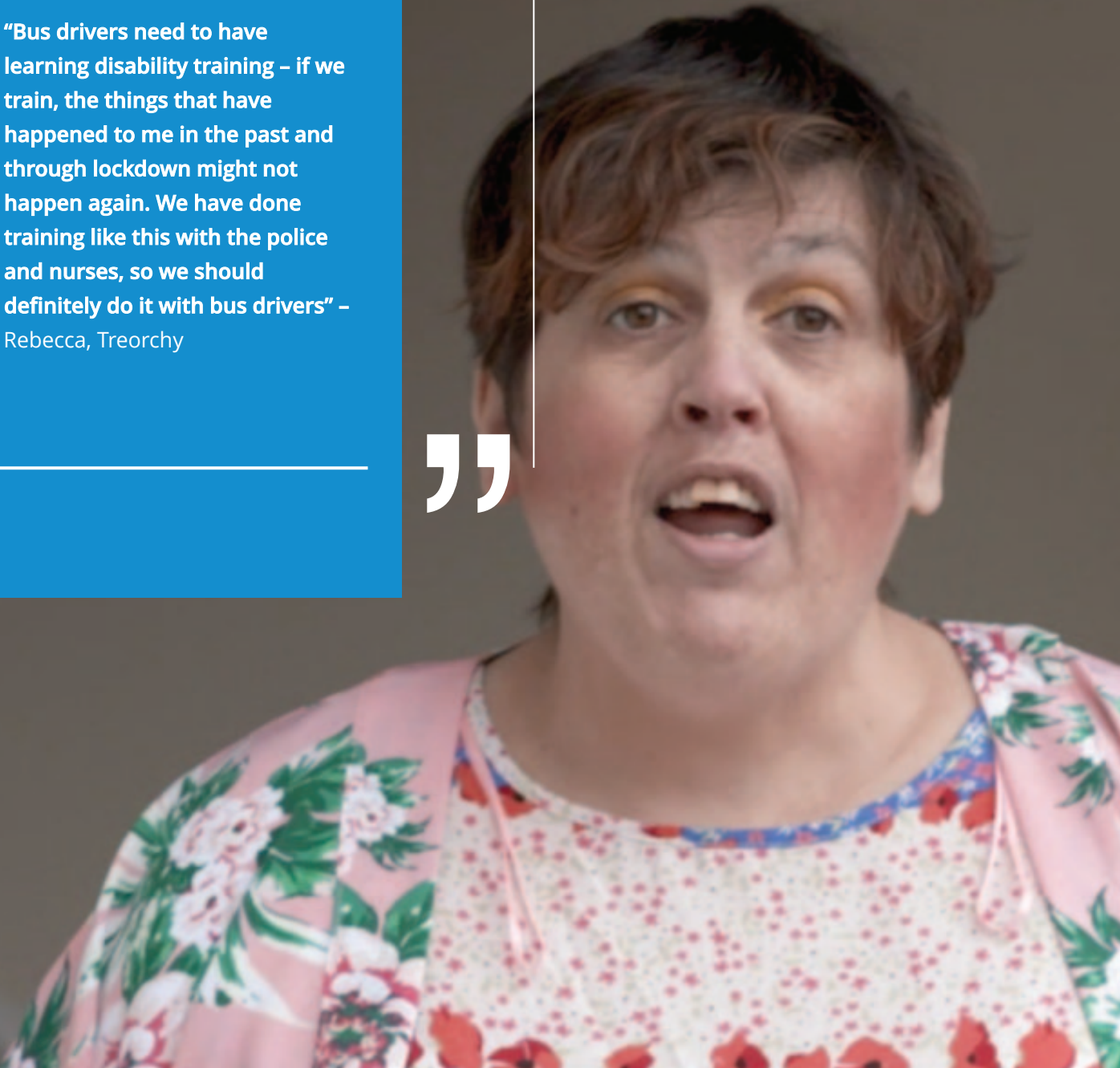
"just before the pandemic, my son started a travel training programme and now that has been put on hold and will set him back a lot" – Sheila, parent

"my son has a disability, and when he went out he got lost and when to a pub to ask for directions. They shoed him out and didn't help him. There were no busses, and he suffers from anxiety and panic attacks. The police came and took him home as he was disorientated, after some girls in a car outside the pub helped him and phoned the police to assist him" – parent

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“Bus drivers need to have learning disability training – if we train, the things that have happened to me in the past and through lockdown might not happen again. We have done training like this with the police and nurses, so we should definitely do it with bus drivers” – Rebecca, Treorchy

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Hooray! Lockdown is ending...Or is it???

Whilst People First members expressed a desire for things to get back to normal, there was an acknowledgement that this post lockdown normal would be very different to what life was like before lockdown.

They talked about social distancing measures and Personal Protective Equipment, and whilst some identified these things as the key to their freedom, for others they invoked a new sense of fear and anxiety. There was also a sense of worry regarding other people, and whether or not they would follow the rules. Some members had received shielding letters and feared they would be required to stay in isolation for much longer periods than everybody else, as no clear end date had been provided. They spoke about how difficult it would be when you know other people, including your friends and family, would be able to go out and do things again, and you couldn't.

"we need to get back to normal. I can't wait till lockdown is over and for everything to be normal" – Sammy, Blaenau Gwent People First

"open the shops so that we have somewhere to go" – Rebecca, Cwm Taf People First

"I have a job in a care home and I want things to get back to normal, but I am worried about covid-19" – Nicole, Caerphilly People First

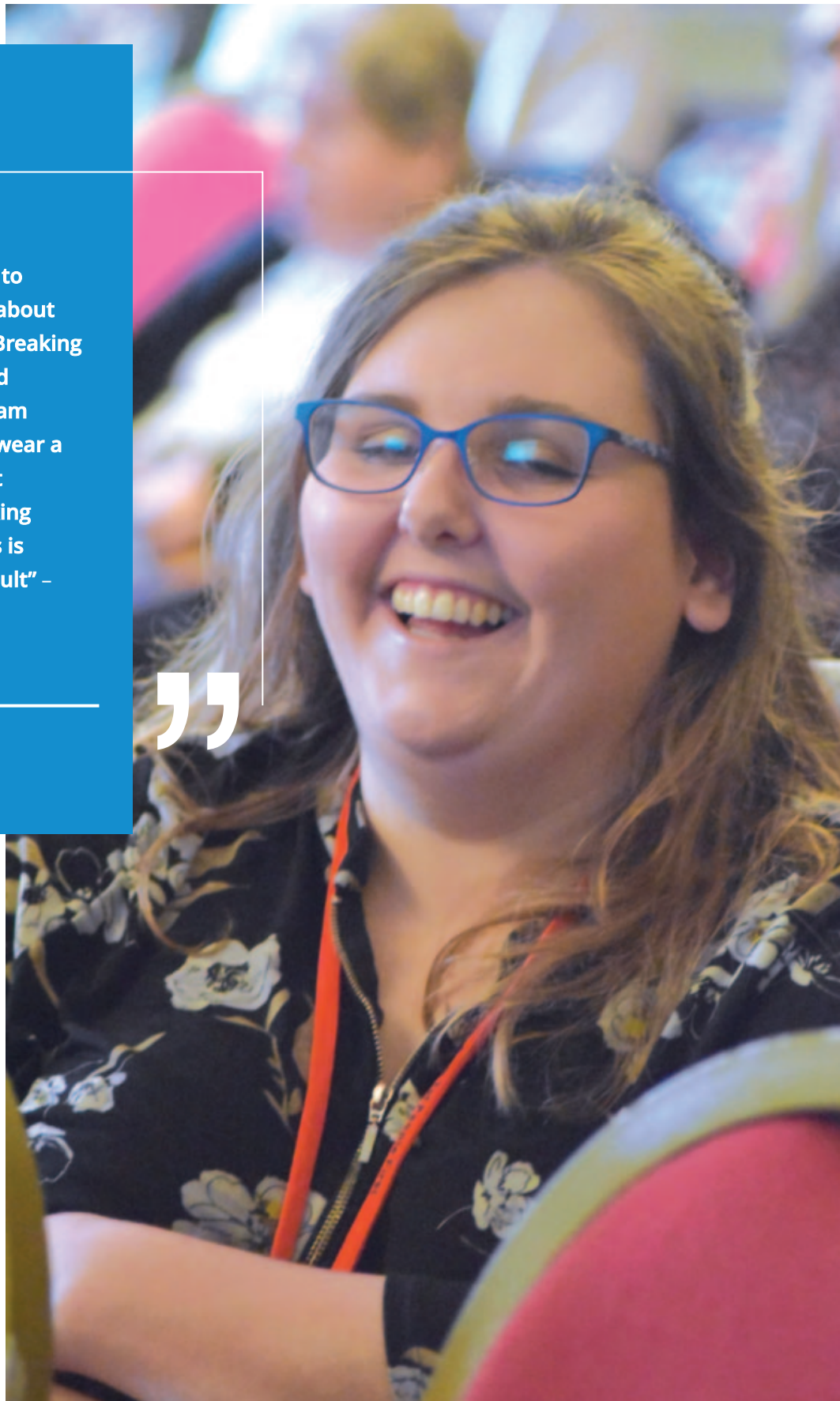
"I would rather wear a mask and go out to keep myself mobile than being stuck in the house" – Sarah, Monmouthshire People First

"I see the future as returning to normality but with 2 meters distancing, but I feel scared of the second wave, I think I am going to find normality hard. Masks freak me out; seeing people in masks makes me anxious" – Rhiannon, Newport People First

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“I want things to go back to normal but I get anxious about people not wearing PPE. Breaking social distancing rules and coughing and sneezing. I am nervous about having to wear a face mask and people not listening to me and breaking rules. I have OCD and this is making things more difficult” – Ffion, Caerphilly

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The possibility of what if – life imagined after lockdown

Breakout room discussion within the event concluded by exploring what needs to change as we move forward both in lockdown and as lockdown comes to an end. These discussions had a more strategic focus and talked about how people with learning disabilities could continue to have voice, choice and control within their lives.

Having access to clear information that helps people with learning disabilities fully understand the current situation with regards to covid-19 was seen by everyone as essential to ensuring they could be empowered to make good and safe decisions about their lives.

A large proportion of these conversations centred around the lack of Easy Read information, with some event attendees not knowing what Easy Read was or how to go about finding Easy Read versions of public information to share with people. One of the biggest concerns in relation to this was that the letters that were sent to people with learning disabilities from the Government about covid-19 and shielding were not in Easy Read and therefore People First members often had to get help from someone such as a family member, support worker, or neighbour to help them understand what they were being told. Again, some expressed how this had caused anxiety as they could see it was an important letter but they didn't know what it was about until someone could help them read it.

Additionally, a lot of People First members expressed that much of the confusion they had experienced through the pandemic and lockdown periods had been caused by the mixed/differing messages that were being communicated by the UK Government and the Welsh Government. They indicated that moving forward they would like to see such messages being streamlined and communicated clearly, outlining distinct instructions in an understandable manner. It was also

acknowledged that this wasn't just an issue for people with learning disabilities but for many members of the general public, and therefore finding better communication solutions would be beneficial to all.

Another emerging theme that came out of this last round of discussions, was the need to raise awareness of learning disabilities within the community. Whether through direct training for service providers and frontline staff, or finding ways to positively challenging the systematic stereotypes that are largely associated with learning disabilities. People First members were very clear in their desire to remove the societal barriers that stop people with learning disabilities living meaningful and purposeful lives.

Finally, the importance of social activities and community interaction was highlighted, with People First members asking for these things to continue as we move forward both in and out of lockdown. They discussed the things that would need to change or be put in place to allow them to meet up in person and not just on FaceTime and Zoom. Some of the things they explored included: having more opportunities to socialise and create friendships, which is something they have struggled to do in the past; being allowed and supported to go on holiday; re-engaging in sports activities; and being supported to be in a relationship and start a family of their own if they want to.

“some people don’t treat people with learning disabilities with any respect. Moving forward we need to create more understanding and raise awareness about learning disabilities in our community, so that people can access places like pubs and be treated like everybody else” – parent

“we need to be empowered to make our own decisions about our health” – Lynne, Cwm Taf People First

“we need to find ways for people with a learning disability like me to get a job. I really want a paid job so that I can go shopping” – Adam, People First Bridgend

“We need information about what we can and can’t do and for people to include us when making these decisions” – Darren, Cwm Taf People First



“

“we need more opportunities for social activities – Ffion from Caerphilly People First has been doing a quiz night every Thursday on zoom, and everyone enjoys the chance to be social even though we are locked in. It is important that these kinds of things still happen after lockdown so that we can spend time with our friends.

We also need to stop the confusion. We need Welsh Government and UK Government to work together better to stop the confusion about what the rules are where we live, and we need more Easy Read information to stop us from being confused” –
Lynne, Porth

”



2021 Conference

On Thursday 24th June, 2021, project partners came together to hold their second Showing Resilience event: 12 months on. As with the previous event, the session was designed as a Q&A session with people with learning disabilities from across South East Wales to provide insight into what life had been like for them through the continuing cycle of lockdown periods and changing restrictions as globally we still faced the covid-19 pandemic 1 year later.

**Learning Disabilities
Showing resilience
through the COVID-19
pandemic:
12 months on!**

**What life in
lockdown
was like for
me**

**The things I learnt
about myself and
others during
lockdown and the
covid-19 pandemic**

**What I would like
to see happen now
that lockdown is
easing**

This event was designed to allow opportunity for reflection on individual and collective experiences over the past 12 months to help drive the hopes and vision people with learning disabilities have for a post covid-19 world.

The event was attended by 43 individuals, and generated a lot of conversation about the learning and insight that had been gained as People First groups developed covid response plans to help increase connection

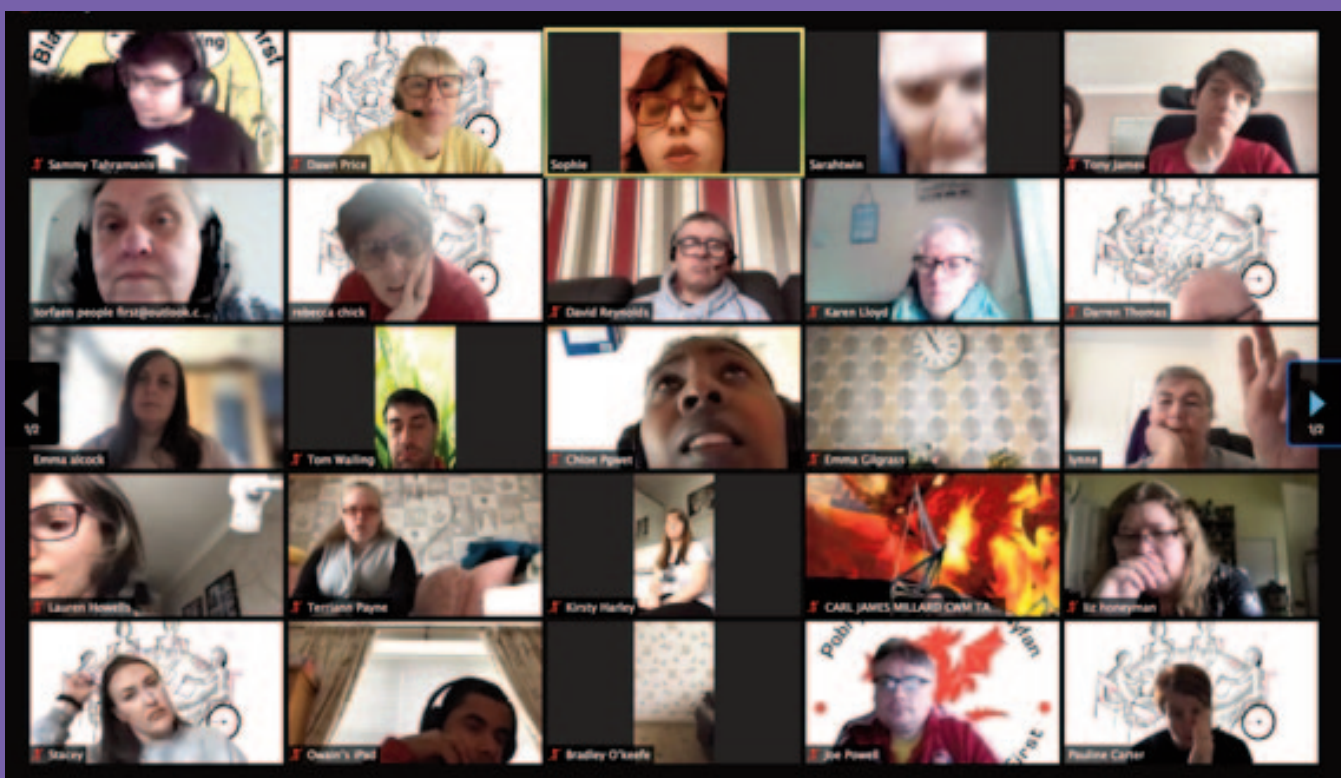
and support their members to re-engage in their communities following intense periods of lockdown and the continuing confusion about rules, vaccinations and life in general.

Breakout rooms were once again used throughout the session to ensure that a diverse range of quality conversations could take place and that attendees could interact with a number of different members from across the South East Wales region.

Blaenau Gwent People First



- 24 iPads gifted to people with learning disabilities across Blaenau Gwent
- Weekly virtual meetings run to identify and respond to members needs and provide a platform for them to discuss the things that are important to them – What Matters To Me project
- Telephone and doorstep welfare checks
- Online discussions with Blaenau Gwent County Borough Council regarding daytime opportunities offers for people with learning disabilities
- Self-care packs for the community
- Walking wellbeing groups



“

“Through the pandemic the iPads were really good and really helped me as I was able to ring my friends and to have conversations with them.

It was also good to have People First meetings online in the beginning, but now as the pandemic has gone on, it is getting harder to connect with people on the iPads and I think it is time we start to get people together again, as it can be easier to get things like questionnaires done when we can have a conversation together about it” -
Chloe, Brynmawr

”



People First Bridgend

People First Bridgend
Pobl Yn Gyntaf Pen-Y-Bont



putting people first
rhoi pobl yn gyntaf

- Bi-weekly virtual advisory group meetings with 7-10 members
- Member activity packs
- Member online training sessions
- Online training delivery to professionals
- Online quiz and activity sessions
- Chatty Thursdays wellbeing checks
- STORM National Pilot participation
- Bridgend County Borough Council Supported Living Consultation
- My Day My Way project and online conversations with Bridgend County Borough Council about daytime opportunities service review
- Engagement activities for the Regional Partnership Board and Public Service Board statutory assessments
- Virtual Medical Staff Training
- Bridgend County Borough Council Budget Consultation

Chatty Thursdays
10am - 2pm

Danielle from People First Bridgend is available for a chat!

Give Danielle a call, text, video message, facebook post, messenger message or video call.

Have a chat about anything you like, TV, Food, Film, Games— whatever you like!

07377 920416

People First Bridgend
Internet Safety Training
Suitable for people with additional learning needs.

Thursday 24th January 2019 – Session 1
Thursday 21st February 2019 – Session 2
12.30-2.30pm

- Learn how to be safe online.
- Check your social media settings.
- Learn what to do if you have problems online.

Training room at Apollo Business Village,
Heol Parsondy,
Aberkentig,
Bridgend,
CF32 9RF

Contact Danielle Wagstaff to book a place.
01656 668 314
07977920416
danielle@peoplefirstbridgend.co.uk

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“Everything is on the computer. Every Tuesday and Friday’s I was doing my own home gateways on Teams. We’d do like darts, bingo, coffee morning, quiz, choir, loads of different activities on it. We were also doing People First Advisory Group Meetings on zoom, and it was good but I was missing seeing people. I was missing all my friends and going out. It’s good now that things are changing and I can now do more things face-to-face with People First Bridgend” – Raymond, Bridgend

”



Caerphilly People First



- Weekly virtual social nights
- Weekly Tik-Tok group weekly
- Health/Covid-19 related information dissemination and Q&A sessions
- Restrictions and Welsh Government covid-19 related updates
- Lockdown mental health and wellbeing activity sheets and ideas
- Wales wide covid-19 interviews about people with learning disabilities experiences
- Co-production work with Welsh Ambulance Service
- Reconnect Focus Groups
- Virtual Medical Staff Training
- Technology training packs for members to connect virtually

Live Q+A about the vaccine with Hannah and Ffion



When: Wednesday 10th March 2021



Where: Zoom



Time: 1PM




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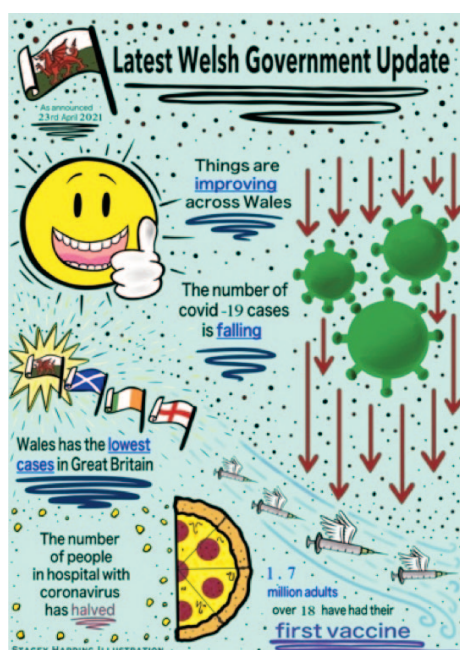
“Our members were so desperate for normal to return that we were doing our best to find funding so that we could ensure our offices meet the guidelines for social distancing etc. We are looking to purchase all the correct PPE and fit screen in the office so that it will be safe for us all. We know that some of our members are anxious about the coronavirus and so we have been including them in conversations about how we can get the office and our normal activities up and running as quickly as possible, in a way that they feel happy with” – Christy, Project Coordinator, Caerphilly People First

”

Cwm Taf People First



Cwm Taf People First



- 60 iPads disseminated across Rhondda Cynon Taf and 10 iPads disseminated across Merthyr Tydfil
- Illustrated and Easy Read covid-19 information and updates for members
- Weekly virtual meetings run to identify and respond to members needs and provide a platform for them to discuss the things that are important to them – What Matters To Me project focus groups
- Telephone and doorstep welfare checks
- Online discussions with both Rhondda Cynon Taf and Merthyr Tydfil County Borough Council's regarding daytime opportunities offers for people with learning disabilities
- Launch of a dedicated My Day My Way project to help co-produce future daytime opportunity services and offers
- Self-care packs for the community
- Stepping Out into Nature project for reconnection and wellbeing
- Virtual Medical Staff Training
- Health Champions project with Cwm Taf Morgannwg University Health Board
- Self-care and activity packs
- Accessible Communication Research for the Cwm Taf Morgannwg Regional Partnership Board
- Film making and Song writing
- Created paid job opportunities for 5 people with learning disabilities and 15 volunteering opportunities

“

“we were able to get some funding from the covid-19 relief fund to create some self-care packs as we knew lockdown was having a negative impact on some of our members mental health, and so we wanted to do something positive. A team of our members got together on FaceTime and decided what should go in the self-care packs and who they should give them to. The idea was to show that people with learning disabilities can help others rather than just receive support during a time like this, challenging the stereotype that they are vulnerable and always in need of help rather than being able to offer it” –

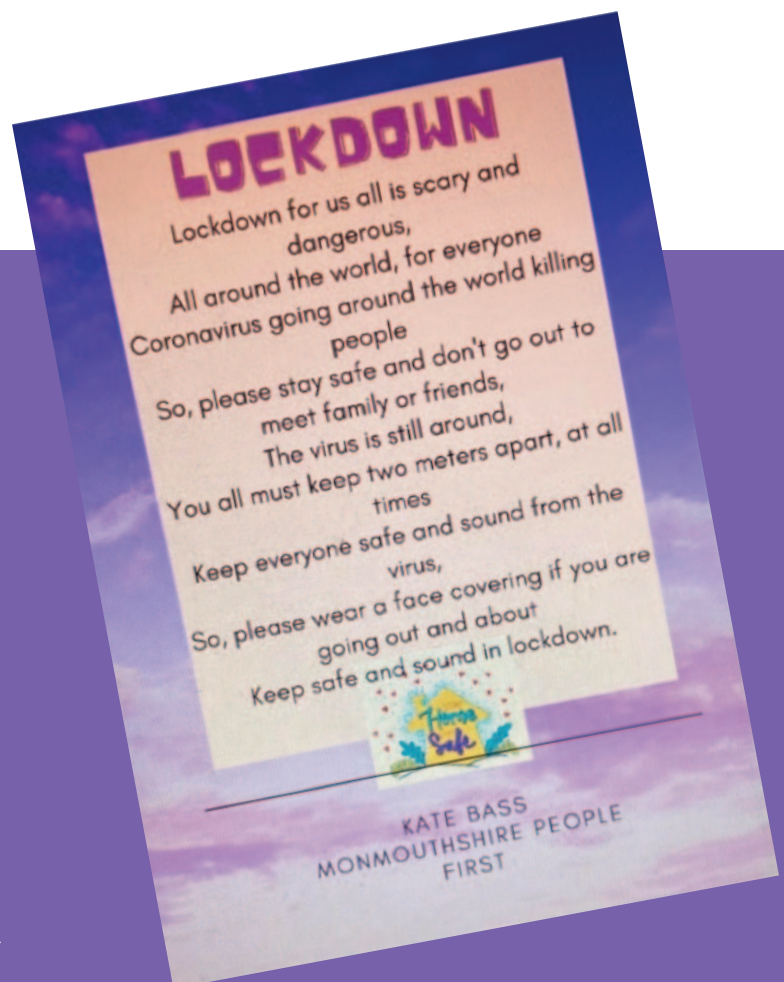
Emma, Project Coordinator, Cwm Taf People First

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Monmouthshire People First

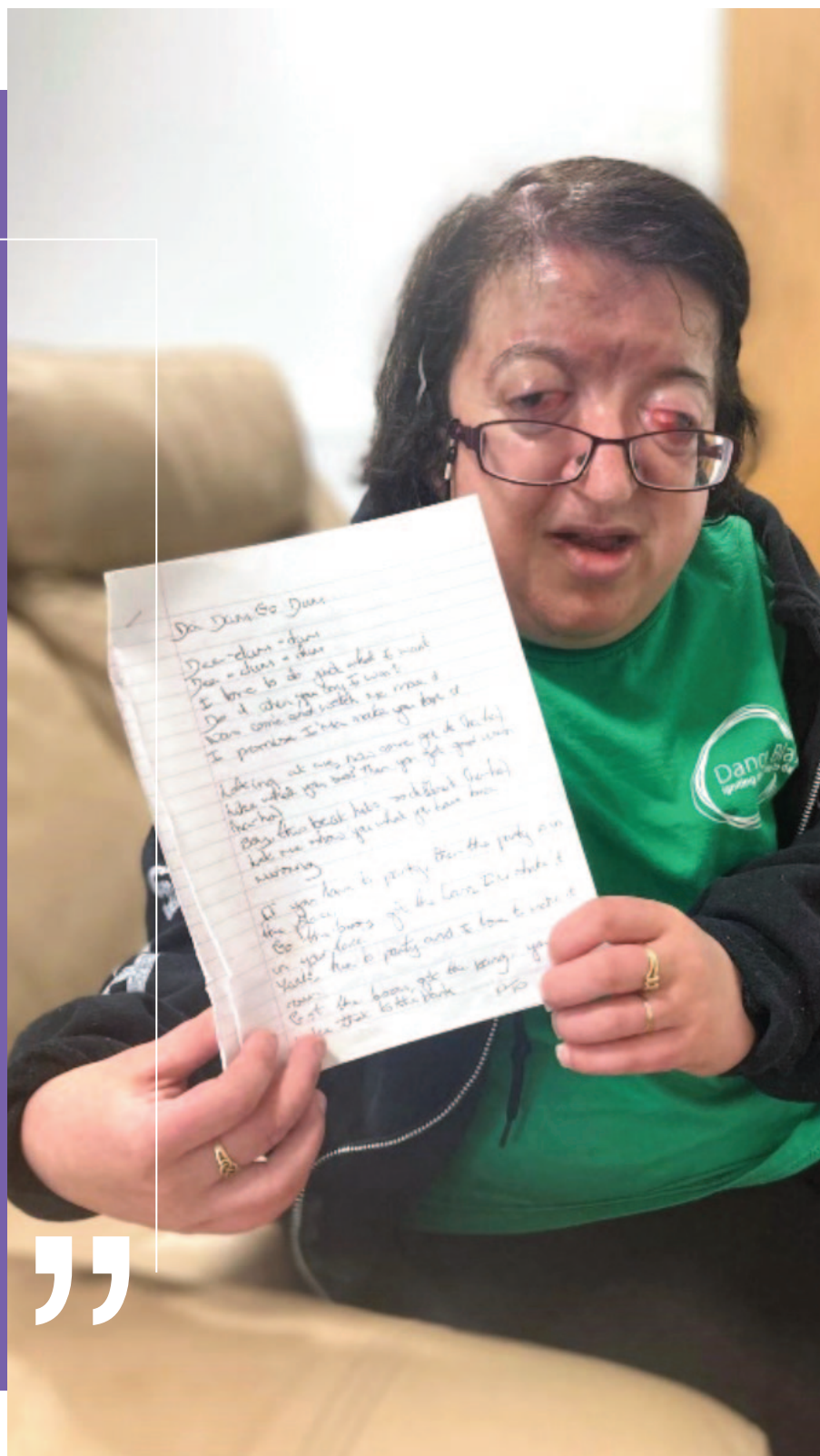


- 22 iPads disseminated across Monmouthshire to people with learning disabilities
- Created a paid job opportunity for a person with learning disabilities
- Creation of Easy Read training guides for connecting online
- Zoom wellbeing check-in's with members
- Letter writing and picture drawing for local nursing staff and patients
- Poem and journaling workshops
- Befriending project to reduce loneliness and isolation
- Online social activities
- Doorstep welfare visits
- Postal deliveries and activity packs



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“I became a befriender to those who are feeling lonely and isolated in lockdown. It was a wonderful opportunity to share hobbies and make friends. Being able to make calls and speak to people gave me a real sense of value and self-worth. I felt inspired to be helping someone else and I have also received a befriender during lockdown and its been lovely to be on both sides of that. I also wrote letters to patients in hospital and this kept me busy and made me feel good that I could cheer someone up and make sure they didn't feel alone at this time. Sometimes I would talk about the pandemic and other times I would talk about other things” – Sarah, Monmouth



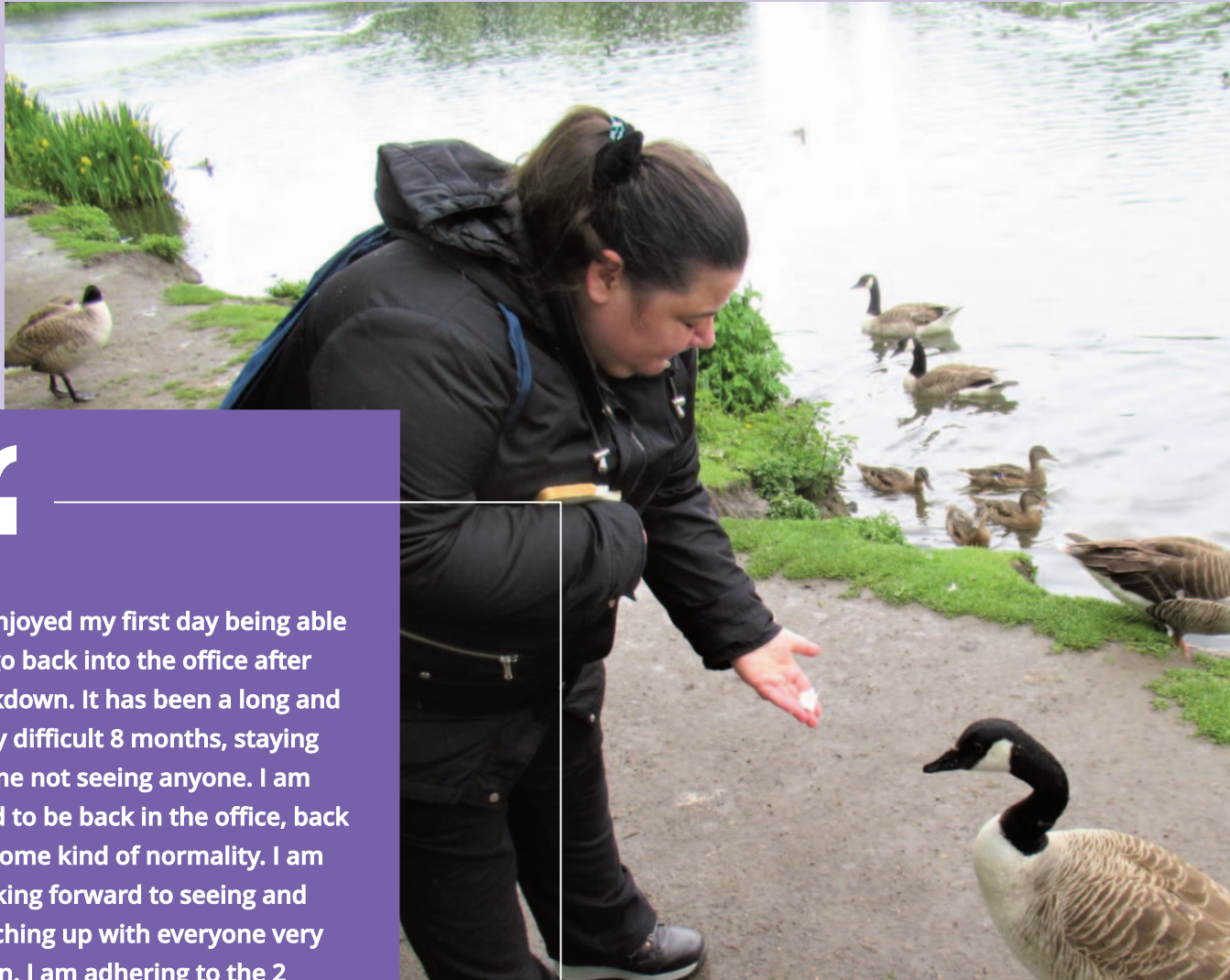
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Newport People First



- Doorstep welfare checks
- iPad dissemination to members
- creation and doorstep delivery of mindfulness packs
- weekly zoom meetings, activities and quizzes
- outdoor wellbeing activities
- iPad training sessions
- BBC News interviews
- Maildrop to members





“

“I enjoyed my first day being able to go back into the office after lockdown. It has been a long and very difficult 8 months, staying home not seeing anyone. I am glad to be back in the office, back to some kind of normality. I am looking forward to seeing and catching up with everyone very soon. I am adhering to the 2 meter social distancing policy when visiting the office.” -
Rhiannon, Newport

”

Our Voice Matters



- CTMLockdownVoices Campaign to give citizens a platform to share their experience of lockdown and the covid-19 pandemic to help influence covid related regional and local decisions and shape future recovery models
- Hear Our Voice in Lockdown online conversation series bringing together people with learning disabilities across South East Wales, parents and carers, professionals and decision makers to discuss service areas including daytime opportunities, supported and independent living, friendships and relationships, and health
- Creation of the co-produced Kindness in Lockdown poem and video
- Accessible Communication Research for the Cwm Taf Morgannwg Regional Partnership Board with Cwm Taf People First and People First Bridgend
- Leading on the My Day My Way project to help co-produce future daytime opportunity services and offers with Cwm Taf People First and People First Bridgend



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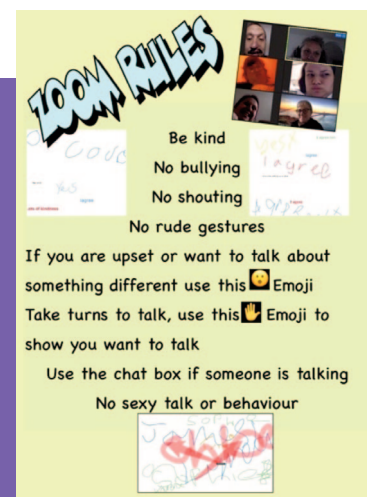
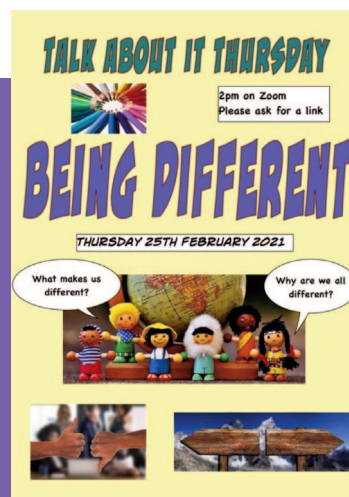
“it has been really important to create opportunities for people to step away from the chaos of the pandemic and to talk and listen to others to build a detailed picture of the impact covid-19 and lockdown has had on people with learning disabilities, their parents and carers and the support services that work with them, giving people a chance to understand what others are facing. By doing this we have been able to open up conversations and inspire hope for a better life once this pandemic is over, not simply returning to normal but making a better normal that will ensure people with learning disabilities can live a life that is meaningful and full of purpose, which will enable them to fulfil their full potentials; and that parents and carers are given the support they need, and value they deserve.” – Jenny, Our Voice Matters

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Torfaen People First



- Coffee and Chat, Tea and Talk sessions
- Using FaceBook Messenger, Teams and Zoom to stay connected with members and hold meetings
- Creating weekly newsletters to let everyone know what is going on
- Talking to other People First groups about our Safe Places project to help them start their own Safe Places projects in their area as we come out of lockdown and people start to go out in the community again
- Relationships project looking at the importance of people with learning disabilities being able to have a relationship if they choose
- Weekly members quiz
- Online training to help members stay connected and be able to take part in consultations and conversations happening with services
- Weekly 'Talk about it' sessions to give people a chance to talk about their experiences on different topics
- Working on 'A Good Day' project with Torfaen County Borough Council to look at what a good day is for people with learning disabilities



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“Living in a world where there is coronavirus is very hard and not fun because we have to stay in and we can't see our friends and family or anything so it is very hard, but on the up side the staff have been ringing us and have been trying to help us, but it is very hard to be happy when you can't go out anywhere. We want Torfaen to work on getting us back to the office as soon as possible because we are missing all of our friends” – Sophie, Cwmbran

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TRAC: Teaching and Research Advisory Committee



- Monthly virtual TRAC meetings to consult with the Advisory Committee and update them on teaching progress and new pieces of research
- Developing new virtual teaching methods so that TRAC can still teach and interact with student nurses virtually
- Supporting and attending annual student conferences
- Assisting in the recruitment and interviewing process for new student learning disabilities nurses
- Holding research meetings virtually to discuss findings and results
- Ensuring representation and participation of a wide range of people with learning disabilities in the Covid-19 Impact Study
- Allocating student nurses as befrienders to make welfare checks to people with learning disabilities through lockdown



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“TRAC is made up of members from People First groups across South East Wales, who were involved in teaching our student learning disability nurses, as well as some of our other nurses in other fields. TRAC would normally teach our students live, face-to-face, but all of a sudden because of covid that had to change as we weren't allowed to have that many people in one room anymore, and so we had to learn how to develop recorded lectures to make sure students were still hearing from TRAC members and being taught by people with learning disabilities. All of our research had to move online as well. Despite the difficulties we've managed to pull off this switch to online virtual learning because we have a fantastic TRAC team. They have stepped up to the mark, overcome all the challenges that were presented and supported our students, and supported us as researchers, and we couldn't have done it without them!”

– Steve Walden,
Lecturer, University of South Wales

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Experiences of Covid-19 Vaccination

At the time of the second Showing Resilience event most People First members, as well as other attendees had received their first dose of the covid-19 vaccine. Some had also received their second dose.

Many recalled that getting the vaccine was a scary experience but that it was a necessary one as it was the key to unlocking their future freedom and for us as a society to be able to move forward out of lockdown's and into the 'new normal' that was continuously referenced. Some members of Caerphilly People First in attendance at the event shared their experiences of receiving the vaccine, and Torfaen People First shared some of the Easy read information they had created to help other members understand the vaccine process and to reduce anxiety for others who were yet to get fully vaccinated.



"I received my first COVID vaccine. I was a little anxious at first as I am afraid of needles. The nurse was patient and kind and explained what was going to happen. This made me feel much calmer. It was over like a flash and I only experience slight arm pain after the jab. I had a rest and took some paracetamol" – Hannah, Caerphilly



"I wasn't clear where or when my vaccine would be. No-one explained things to me. I didn't know what was going on and everyone was wearing masks, and gloves and aprons. I couldn't understand what they were saying and I felt very scared. After my first vaccine I did get sick. The second time was a bit better as I didn't have so much anxiety and I didn't get sick"

- Nicole, Caerphilly



"I had my first covid jab on the Tuesday afternoon. I was frightened. On the Wednesday morning I couldn't get out of bed and my arm was stiffer. I had, not like a headache, but my head was feeling funny. I had my second jab a couple of weeks ago and again I had a headache in the afternoon but was feeling better by the night"

- Natalie, Caerphilly

Covid Vaccine



Most of us got a phone call, saying where to go and the day and time



Some of us went to the leisure centre



GP Surgery

Some of us went to our doctor's



We all had the vaccine and got cards or letters saying what vaccine we had





It was just a scratch, the nurses were kind, I was a bit achy afterwards

It was just a little scratch, it didn't hurt. I was really pleased with myself

My anxiety was very bad but it didn't hurt, just a little prick. I hugged my bear tight. After I had a headache and was shaken but I think that was my anxiety

I am really happy I had it done now I will be able to be with my friends and family soon

It was ok, I am strong

Vaccine Day Checklist



10:30

Time



Place



Face mask



Things to do



You can take what you need to feel safe and calm, one of us took a small teddy in their bag and cuddled it while they had the injection



Skills I have learnt in lockdown

Lockdown was hard for a lot of us, but it also provided an opportunity for us to learn a whole range of new skills. At the 2021 Showing Resilience conference, people with learning disabilities reflected on all of the things they have learnt, and skills they have developed and how they were now using these to better their lives.

"I learnt how to work from home by using programs like FaceTime, Zoom, Teams and Blackboard. At first, I used to get really frustrated, but as lockdown continued, I learnt how to focus myself and adapt to a new routine. This has helped me to not be afraid to try new things and when things are hard, like learning to use Teams, to keep practicing until I can do it" – Lynne, Cwm Taf People First

"I have learnt that I am clever and that learning new things makes me happy" – Hannah, Caerphilly People First

"Learning to use Zoom, FaceTime and Teams was hard during lockdown, but it was good that I did it because it meant that I could join meetings, see my friends and have a chance to have my voice heard. I enjoyed having the iPad and it was really important to me so that I could still work form home. I also used it to learn new exercises in the house and we did song writing on it" – Tom, Cwm Taf People First

“Lockdown has taught me that I can be patient when things go wrong and because of my autism that is a big deal. I don’t like when plans change and routine is important to me, so this has been a good skill to learn as it can help me in lots of situations in the future” – Ffion, Caerphilly People First

“Lockdown has shown me how important my friends are to, because I missed them so much when I couldn’t see them” – Nicole, Caerphilly People First

“I learnt how to use my iPad and join Zoom and FaceTime to take part in meetings and talk to my friends. I also learnt that it was important to keep a distance and that meeting outdoors is safer than indoors” – Sam, Cwm Taf People First

“Covid and lockdown has taught me how strong I am” – Natalie, Caerphilly People First

“I started doing online courses and liked learning lots of different new things. The other things I learnt to do in lockdown was cooking and I made some really nice cakes” – Sammy, Blaenau Gwent People First

Our Hopes for the Future

To conclude the 2021 Showing Resilience event, attendees were asked to discuss what they would like to see happen in the next 12 months. The following suggestions were made:



- No more masks
- Travel restrictions lifted
- No more Zoom
- See my family more often
- No Covid Passport
- See my doctor face-to-face
- To be able to go to congregation
- To be able to go back to work in the office full time
- To go on holiday
- To go back to having face-to-face meetings
- To be able to go places without worrying about the rules and restrictions
- To be able to give training to medical students and student nurses face-to-face
- To get a paid job so I can go shopping
- To go back to fitness classes
- To have a birthday party
- To go back to college because getting qualifications is important to me
- To get me hair and nails done so I can feel glamorous again
- To go to the library
- To go to the pub for lunch
- I wouldn't mind going back to day centre
- To play darts again with my team
- To be more independent and do my own shopping, cooking and managing my own diary
- To start volunteering in a charity shop
- To make new friends in my area as I have moved
- To do new things with Personal Assistant and get out to new places
- To meet some of the new friends I have made on the iPad and to travel to new places to see them

Unsurprisingly, the majority of hopes suggestion reflected people with learning disabilities overall desire for social connection. However, there was also a notion that lockdown had made them reflect on their lives and prioritise the things that are good for them, and to consider making changes to help them live a more meaningful life in the future. Whilst there was some desire to return to things like day centre, many were open and intrigued by different things that they might be able to do, like undertaking volunteering and looking for paid work. The idea of independence was also a hot topic, with lockdown showing people that they are more resilient and able than they think, inspiring them to assess new possibilities and be open to trying new things. For those that want to return to college, there was talk of changing the subjects they are learning, moving away from generic independent living skills courses and instead wanting to do things like catering, hair and beauty and music/media.



2022 Conference

On Thursday 1st December 2022, the project partners came together to run a final Showing resilience event to reflect on all that had been learnt through the pandemic and to think about “what’s next” for TRAC. This was held in person at the request of project partners who wanted the theme of ‘reconnection’ to be central to the event. Taking on the style of a conference, the event provided a platform for a number of keynote speakers to share their thoughts, findings and personal experiences of the covid-19 pandemic, and how people with learning disabilities had developed and shown resilience throughout.

In addition to the keynote speakers, attendees were able to participate in a range of breakout workshops. The information gathered through these workshops has been analysed to form this final section of the report.

**Learning Disabilities
Showing resilience
through the COVID-19
pandemic
– FINAL CONFERENCE**

Living with covid

how do we carry on living a meaningful life with covid as a normal part of society

Taking responsibility

for my own health and what do I need from a good healthcare service

Grief and bereavement

reflecting on those who have died as a result of the pandemic and supporting those who miss them

Hopes and dreams for the future

In total 63 people attended this final conference and fed into the information presented in this section of the report.



My name is Ffion, I am 25 years old, I live with my mam and stepdad and my cat Oscar J who helps me with my autism and I have a nephew called Lucas who I love very much. I am the Chair and Executive assistant at Caerphilly People First. Yes, that's correct in May 2022 I was given a paid opportunity at Caerphilly People First and now I have paid employment and a contract. This is something I thought I would never have when we were in Lockdown. I really struggled with my Autism and mental health during Lockdown. My nephew was born in the December 2020 and from January 2021, I couldn't see him only over the fence and at a distance. I had no routine and was constantly waiting for Mark Drakeford to do his COVID updates every Friday even though I knew this would make my anxiety and depression worse but I just wanted it to end. I did lose nearly 2 stone during COVID and this is something I also struggle with. I feel like I've had a weight taken off my shoulders where my mental health, Autism and weight is considered as I have recently gone to the doctors and asked for help. This was a massive thing to do especially when you have Autism and worry about what everyone thinks of you.

I want to share a few highlights of my journey from the past year highlighting my resilience through the pandemic. I love how we are getting back to normal and that we don't need to wear masks. I feel like my freedom is back and I can finally go out to meetings face to face not on a zoom screen and I can finally plan a Christmas party for our members. I have a quote I kept saying to myself during lockdown "When times are tough be grateful that you are alive and you can get up and smile everyday it may be stormy now but it never rains forever".

I feel proud that I have had all my COVID jabs. I don't like needles and I had my 4th Jab last Thursday and braved myself and had my Flu Jab last Wednesday. That was my first time ever having the flu jab. I hate needles but I just keep saying to myself that my health and mental health are important and if it means I can go out and have freedom then everything is fine. I didn't feel anything on my 4th or my flu jab either and didn't have no symptoms only an achy arm. I would like to get this message across to everyone - please have your COVID and Flu jabs if you haven't already. If you're scared or don't like needles then before you go sit down with someone you trust or someone who supports you and talk about coping techniques that you can take or do when you're at your appointment. " – Ffion, Caerphilly People First

Living with covid-19 now and in the future – Workshop Findings:

During the first workshop session of the conference, groups were asked to consider how people with learning disabilities can continue to live meaningful lives even though covid-19 is still in our communities. From group reflections three main themes emerged: the impact of the covid-19 pandemic and lockdown on people with learning disabilities; how to live a meaningful life moving forward; and covid-19 prevention measures and keeping people safe. Highlights from these group reflections have been captured under each of the three themes over the next part of this report, interwoven with projects and stories of people with learning disabilities and professionals working on the front line:

Theme 1: The impact of the covid-19 pandemic and lockdown on people with learning disabilities

The change in routine because of covid- 19 made people think outside the box

Some people were more focused in meetings when working from home

Innovate Trusts' Insight App has been a fantastic tool which helped people to cope through lockdown and keep living their lives

Covid-19 lockdown gave people with learning disabilities a voice

Separation from family was a massive adjustment and people had very little support to cope

Covid-19 made people with learning disabilities reliant and de-skilled some people who were quite independent before – eg. Travel training and confidence

Covid-19 made communities stronger

Day Centres – some people didn't like going there so are happy that they no longer have to go there and can do their own thing

Online groups have helped people to be able to stay social and connected and has helped to eliminate isolation

Some people do more exercise since covid

People need access to technology and iPads to stay connected

Overwhelmingly the reflections offered by the groups were positive, represented by the green covid bubble statements above, which acknowledges how time and reflection space has allowed for an attitude shift in relation to individuals thoughts and feelings about the covid-19 lockdown periods. During the first of the online Showing Resilience Conferences in June 2020, people's attitudes to lockdown were largely negative, with many stating how it had generated an adverse effect on their mental health. However, two years on people have now come out the other side and can see the actual and/or potential benefit it has had on shaping their lives now. This then allowed people to turn their focus onto the future and what support they felt they needed to be able to live a meaningful life with covid-19 still present in our communities.

Theme 2: How to live a meaningful life moving forward

Carry on going out and about, getting involved and volunteering

Having more freedom but still taking precautions

Use the skills we learnt in lockdown like with technology

Preparing for 'just in case'

Adapting and learning from past experiences and the knowledge we now have

Employers and more flexible to our needs and hybrid working allows more people to have balance in work

Give people company and support to go out and see friends and family

Annual health checks are needed

Encourage people to live their lives

Community newsletter to tell people 'What's on offer' in their local community

Need better access to services and groups for combatting mental health and loneliness

People with learning disabilities want more to do. There is not enough access to the things they want to do

Some people still prefer online and are scared, so hybrid working and activities are essential



A Right to Life

A Right to Life was a creative project developed by Cwm Taf People First in 2021. It was established at a learning disability hackathon event that aimed to explore identified themes from individual and collective experiences during the covid-19 pandemic. One of these themes was the exasperation of health inequalities for people with learning disabilities, and perceived human rights breaches in relation to the blanket introduction of Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) orders during the first wave of the pandemic. This issue came to light when a member of Cwm Taf People First received a letter from their GP surgery advising them that a DNACPR order had been placed on their file. This meant that if they were hospitalised due to covid-19 during the pandemic and required life saving interventions such as mechanical ventilation they may not receive it. This left people with learning disabilities feeling less valued than other population groups in society (Bloomer, A, 25.01.2021, Learning Disabilities Today article: Do not resuscitate orders and learning disability: where are we now?)

The 'A Right to Life' project aimed to provide a platform for people with learning disabilities to speak out against such inequalities, advocate for their human rights, and share their personal experiences, thoughts and feelings in relation to their own health and the healthcare services they access/receive. Supported by specialist music therapist Erin Williams-Jones, founder of Musaïc Minds, the group made up of people with learning disabilities, parents and carers, and professionals decided to create a protest song to help get their message across to reduce the risk of future inequalities and encourage work to begin to develop positive changes towards current inequalities being faced. The project shared their findings and the completed song and music video at the Showing Resilience Conference as a plea for professionals to co-produce with them in the future to design solutions and inspire hope.



"We wrote it as a protest song to say this isn't right, this isn't fair, it's not right to put Do Not Resuscitate thing on anyone's file regardless if they have disabilities or not. We were saying about why that is wrong and that it should be changed, and we thought doesn't everyone have a right to life and that's what inspired the song A Right to Life... we could have chosen any genre of song but we chose a protest song because we wanted it to have a proper message behind it"

Lloyd, Chairperson of the RCTCBC Partnership Board, Cwm Taf People First

V1:Suffering in silence
Treated like a child
Do not resuscitate on all my files


Please can you see me?
Please can you hear me?
I need you to mend me
Take the time don't jump the gun

Pre-chorus: The past is history
It's time to move on
You won't push us aside
This is 2021

Chorus: A Right to Life
My time isn't borrowed.
Just let me breathe,
I have a right to tomorrow

V2: We need to change the system
We've lost the human touch
More training to doctors and nurses
We must reasonably adjust.

Learning Disability nurses are needed,
We need cluster advocates.
Put a nurse in each practice
We have a voice: LISTEN TO US!



I HAVE
RIGHT TO
TOMORROW

Theme 3: Covid-19 prevention measures and keeping people safe



This section of conversation was mainly split into two categories: bright ideas for improvement in the future (yellow speech bubbles) and practical measures that everyone can take to help stop the spread of covid-19 and other viruses, and to keep themselves and -other safe (blue speech bubbles). From this part of the discussion, it was clear that making vaccinations as accessible as possible was highly important to the majority of conference attendees. Many people shared their own vaccination stories from both the perspective of receiving a vaccination and also from working in a vaccination centre.

Vaccination Stories



"My name is Hannah and I volunteer at Caerphilly People First. Having all my vaccines has been a very scary experience. I was anxious every time as I am afraid of needles, but this hasn't stopped me going for all my jabs because I know how important it is to keep us all safe. My journey this year has been a more positive one and I love being back at work and going out for food with friends. Although I am afraid of needles my experience having my jabs was made easier because I had them done by lovely nurses and my mum was there to support me. I will continue to have my COVID vaccines for my protection and to keep others safe."



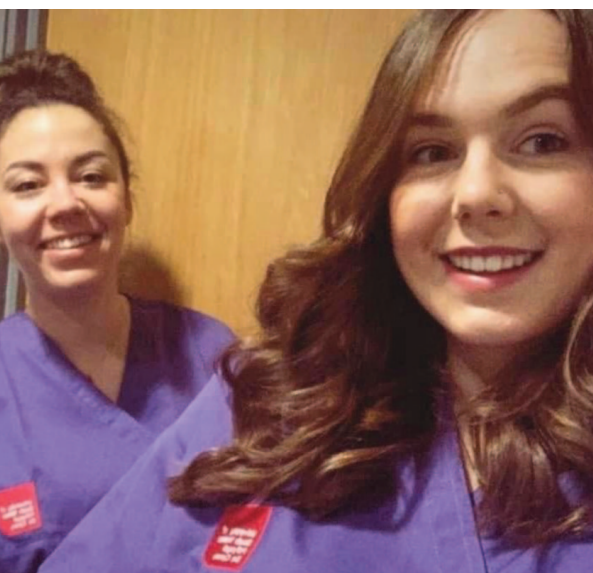
"My name is Nat and I am volunteer at Caerphilly People First. This time last year some of you might of met me at the conference online where I talked about having my COVID jabs. I was frightened and felt not very well after, and I was the same on my second jab and had to go to bed with a headache. I did feel better in the evening and my arm didn't ache as much. Since last year I have had the other vaccinations and I did suffer with headaches after both, but I am glad I had the vaccine because I can now see all my family and go to the office to work. I live in a bungalow with 2 other people and I found this really difficult during the start of the pandemic because we were all stuck in together. Now I love having my freedom back and not having to wear a mask everywhere. I can see Darcey my niece and I help my sister look after her. I hope for the future we don't need COVID jabs but I'm happy to have mine if it means seeing my family and friends."



During the conference we heard from two student learning disability nurses who had worked in vaccination centres in South East Wales, to learn about their experiences of the pressures faced by staff and the reasonable adjustments on offer to better support people with learning disabilities through the vaccination process. A reasonable adjustment is a change to remove disadvantage for someone with a disability. The Equality Act, 2010 outlines a duty to make reasonable adjustments, meaning that the needs of an individual should be at the centre of their care, and that staff in vaccination centres should be actively looking to put reasonable adjustments in place to make the process of having a vaccination easier and more effective for people.

Examples of reasonable adjustments that should be considered include:

- Using back or quieter entrances for people with learning disabilities and other complex needs so that the experience is less overwhelming for patients and their carers
- Quiet waiting rooms for patients to reduce the chance of individuals becoming over stimulated and increasing anxiety
- Learning disability experienced nurses who will have the right knowledge on how to support someone with a learning disability
- Longer appointments and more time to talk to patients to ensure understanding of what is happening and to allow for adequate processing time and space to ask questions
- Easy Read information leaflets for people with learning disabilities and their carers
- Community vaccinations that go to individuals who struggle to attend vaccination centres
- Supporting carers to streamline the process, including offering joint appointments so that they can be vaccinated at the same time as the person they are caring for to remove the need for them to attend separately
- Vaccinations in the car that offer families a smoother and quicker process, especially for those with mobility issues and complex need



“working at the vaccination centre was fast paced but enjoyable work. It was great to be part of such a massive workforce during such an important time in the world. However, there could have been better measures in place for people with learning disabilities.

Although there were definite efforts made for reasonable adjustments, in some cases more could have been done – quiet times; longer appointments specifically booked rather than requested on the day; more learning disability trained staff present if required. Overall, it was a positive experience but I would have felt more comfortable with more effort being made to accommodate people with learning disabilities better”

Jade, University of South Wales Student Learning Disability Nurse

My Health – Workshop Findings:

As attendees entered the second workshop session of the conference, groups were asked to consider what people with learning disabilities can expect from a good healthcare service, as well as reflecting on the things that they can do to keep themselves healthy. Highlighted below in red speech bubbles were reflections on negative experiences group members had encountered prior to and through the covid-19 pandemic, with green speech bubbles representing the good things they had experienced as well as their aspirations for healthcare service improvements.

Some doctors don't understand my health needs

I don't always get to see the same GP

Being passed onto someone else and you keep going around in circles

No mental health help - waiting lists are over 3 months long and by that time for some people it is too late

111 is not a suitable service for people with learning disabilities

The health service is in crisis since the pandemic

NHS Direct is not accessible

A & E waiting times are still too long

Privacy

People having to pay for private medical treatment due to long waiting lists

Proactive care

Having lots of choices and options about my healthcare

More health promotion - knowing what services are out there and how we can access them

Making reasonable adjustments

Support for quick discharge

Integrated services that put people at the centre

More Learning Disability Champions/ more dedicated learning disability nurses in cluster areas

Receiving a text message reminder for an appointment

Picture communication tools

ID - lanyard or uniform on support staff to make sure that are who they say they are

Advocating for the patient

Accessible information: audio, braille, easy read, sign language, videos

Staff being supported by other staff and being heard



“

“Covid reminded us how important annual health checks are for people with learning disabilities and so we want to make sure that everyone is able to have one and GPs understand why they are so important to us, so we made a training pack and a film to talk about them”

– Sam, Cwm Taf People First



Attendees also recognised that they had a role to play in keeping themselves healthy, taking responsibility for their own healthcare and helping to reduce the burden on an already over stretched national health service. They explored the things that they could do to keep themselves healthy and how to access the right health service at the right time as captured in the yellow speech bubbles below:





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“following covid restrictions being eased our members were able to meet outdoors and we were able to get some funding for a Stepping Out project which enabled us to run certain activities outdoors. It was at this point that our members said that they really wanted to be involved in Stepping Out into Nature but that they had experienced some issues around that, such as: not knowing where to go; not knowing how to get there; being worried about how accessible places are; not being able to meet up with friends close to home; and that information is not accessible when at venues...to overcome this we are doing an audit of 10 local parks and will produce a report for each of them so that if anyone wanted to access those facilities they would know exactly what there; what to expect; whether you can get there on public transport; are there good toilets; is it suitable for people in a wheelchair etc. so that people with learning disabilities can engage in local outdoor spaces easily and safely now and in the future”

– Lee, Stepping Out into Nature Project Coordinator, Cwm Taf People First

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Hopes and Dreams for the Future

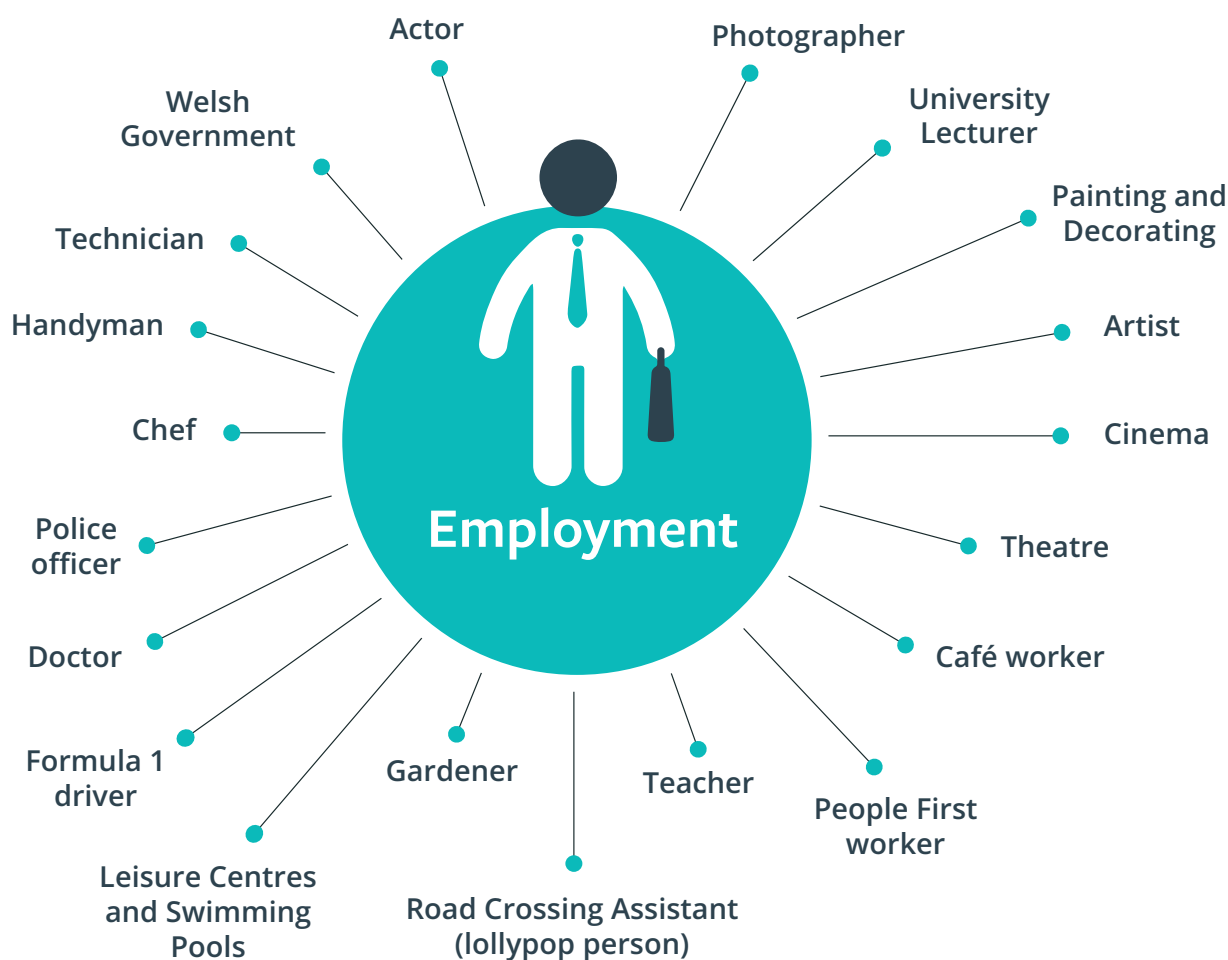
– Workshop Findings:

As attendees entered the final workshop session of the conference, groups were asked to consider what people with learning disabilities would like to see happen in a post-covid-19 world. Reflections centred around personal ambitions, but also a world of equality where having a learning disability meant that you didn't face stigma, discrimination and rejection and where everyone could choose what makes them happy.





A lot of the conversation in this workshop session centred around employment and the types of jobs that people themselves would like to try, or jobs where they would like to see a greater representation of people with learning disabilities in the future.



Project Summary and Conclusions

Before diving in to the lessons learnt and established conclusions from this project, it is useful to remind ourselves of what resilience is. During the final conference, Edward Oloidi, a research assistant from the University of South Wales reconfirmed the definition of resilience as ‘the ability to adapt and bounce back when things don’t go as planned’ (American Psychology Association, 2018). He also introduced the concept of the 6 domains of resilience to assist understanding of the projects context and provide a distinct narrative upon which we could evaluate the experiences of people with learning disabilities engaged through the project.



Drawing on the findings of this project, as well as the ongoing UK Research and Innovation study looking at the impact of Coronavirus and People with Learning Disabilities across the UK that Edward had been working on, the following conclusions were made to show how people with learning disabilities had demonstrated their resilience throughout the covid-19 pandemic:

Vision – People with learning disabilities played their part in keeping themselves and others safe. Whilst lockdown conditions were not ideal, many people with learning disabilities embraced the opportunity to learn new skills and become digitally connected. For some, lockdown created opportunities for employment and activity participation that had previously been blocked by barriers such as transport or rigid day centre service provision, and has allowed people with learning disabilities to think and act differently as we move into a world of living with covid-19.

In addition, people with learning disabilities have demonstrated a keen understanding of covid-19 prevention measures and adherence to the rules imposed to keep themselves and others safe. Throughout the project, people with learning disabilities have consistently discussed the importance and need for social distancing, wearing of the Personal Protective Equipment, and taking up of the covid-19 and flu vaccinations to ensure that we can all return to a level of 'normality' or more accurately a world where we can regain our freedom.

Composure – Many People with learning disabilities were able to demonstrate their adaptability in the face of large-scale change brought on by the covid-19 pandemic. Through support and determination to become more digitally savvy, people with learning disabilities have navigated the transition from face-to-face to virtual interactions well.

In a bid to keep themselves and others safe, they have learnt how to do shopping online to get the things that they need; to work from home using platforms such as FaceTime, Zoom and Teams to have meetings and complete set tasks by employers; and to lead and participate in virtual social activities. Doing things online has helped many to not only try new things, but to meet new people from outside of their current locality. It has enabled friendships and relationships to blossom and for people's ambitions to be stretched so that they can realise a meaningful life now and in the future.

Reasoning – Many people with learning disabilities were able to show creativity and problem-solving skills through the covid-19 pandemic. Given the opportunity, people with learning disabilities were able to guide and advise service providers to come up with new ideas and way of working that allowed progress of existing work and projects, but also aided the creation of new work and projects. People with learning disabilities have been crucial to the co-design of the 'new normal' and helping generate new ways to engage in service improvement especially in relation to healthcare, day service provision and supported living.

Health – Many people with learning disabilities have been able to transition to an online health support environment through the covid-19 pandemic. Whilst they had reported difficulties in accessing healthcare as a result of covid-19, most have now adjusted to telephone and online appointments with GP's and community nurses. People with learning disabilities have also used the challenges faced when accessing healthcare services through the pandemic to advocate for better services in the future that consider the needs of individuals more effectively.

Through continued work around the All Wales Health Profile and the acknowledgement of the importance of annual health checks, people with learning disabilities have been able to fully embrace opportunities to co-design and co-deliver training and resources to promote and improve the realisation of their rights and entitlements to live happy and healthy lives.

Tenacity – Some people with learning disabilities have been able to come out of the covid-19 pandemic and associated lockdown periods stronger, more connected, and with newly developed skills and opportunities. They have persevered, observed the rules and used this time to reflect and dream, allowing them to understand what matters to them and how they can advocate for those things better in the future.

People with learning disabilities have also started to appreciate their personal power and the value of their voice and experiences in enacting change and holding services and people to account, resulting in greater opportunities and the right capacity, skills and understanding for meaningful participation and co-production to drive service improvement and transformation.

Collaboration – Many people with learning disabilities have shown willingness to collaborate through the covid-19 pandemic by working together with their peers and with service providers and professionals to identify ways that individuals can access support and information, and engage in activities that kept them occupied during lockdown periods. Through the pandemic we saw collaboration with Public Health Wales develop to create Easy Read information about covid-19 and associated covid-19 rules. Illustrations were co-designed with people with learning disabilities to help better their understanding of what was going on and what role they needed to undertake in keeping themselves and others safe, and appropriate dissemination channels were identified to make sure this information reached people with learning disabilities in a timely and accessible manner.

People with learning disabilities also learnt how to lead and develop their own virtual activities linked to personal interest areas, in collaboration with service providers and utilising the Innovate Trust Insight App as well as other supported living providers platforms. Such activities included everything from cookery classes to quizzes and choir rehearsals to an online nightclub. Individuals worked with others to ensure that sessions were not only designed well and relevant, but were well advertised and encouraged people from all walks of life to get involved.

This collaboration has also played a crucial factor in bringing people with learning disabilities back together safely following lockdown periods, and has seen the likes of reconnection walks and activities co-produced to help individuals harness the freedom and friendships developed during the covid-19 pandemic and channel them into a meaningful future.

Whilst we know that the experiences of people with learning disabilities have been varied through the covid-19 pandemic, and that in some case individuals have felt trapped, alone and isolated, unable to access the care and support that they need, it is also clear that some people with learning disabilities have relished the opportunity that was presented to them during this time and have demonstrated a clear level of resilience to overcome and conquer. For those with higher complex needs the struggle continues, and it hasn't been as smooth a journey for them. However, as can be seen in this report, some people with learning disabilities have highlighted that they have been able to take ownership of their lives better because they have had to, as support they previously accessed disappeared, and this has left them more independent and with better prospects for the future. Therefore, when assessing the needs and vulnerabilities of people with learning disabilities in crisis situations, such as the covid-19 pandemic, it is vital that individuals are considered as individuals and that their individual circumstances, situations, needs and desires are taken into account to help identify what they can do, with a solutions focused lens, rather than what stands in their way so that they can strive to play their part in ensuring society recovers effectively.

“People with Learning Disabilities have shown resilience throughout the pandemic by their willingness to not only keep themselves safe but to protect others, follow the rules, advocate to get vaccinated and do what is right...my experience conducting the UK-wide Coronavirus and people with learning disabilities study that tracked people’s experiences, circumstances, and support throughout the pandemic has shown that People with Learning Disabilities can adapt and bounce back when things don’t go as planned. As researchers, and as a society, it’s vital that we recognise and appreciate the ability to adapt and bounce back from challenges amongst people with learning disabilities”

– Edward Oloidi, Research Assistant, University of South Wales





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