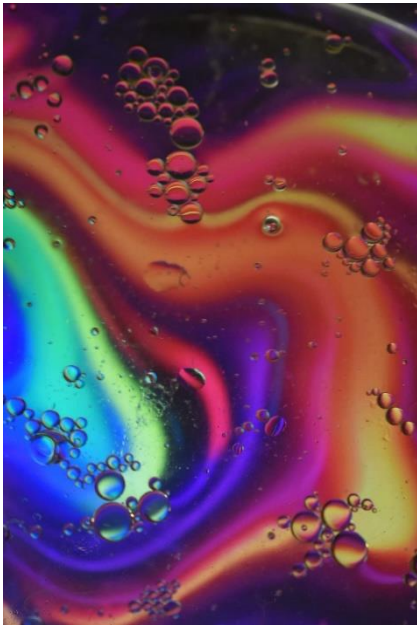


The Effect of the Coronavirus Pandemic on People with Learning Disabilities Across Wales

Phase Two - Amber



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A report into the experiences of people with learning disabilities across Wales and the activities of learning disability self-advocacy groups throughout the amber period of the Coronavirus Pandemic 2020.



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Since the beginning of the Coronavirus outbreak in the United Kingdom in March 2020 when vulnerable people were advised to self-isolate and shield; and the subsequent instructions regarding a widespread lockdown announced on 23 March affecting all people across the UK; All Wales People First has been monitoring the effect on people with learning disabilities across Wales.

Our first report published in May, highlighted the issues experienced by members and groups during lockdown and the red phase of the Welsh Government roadmap to lead us out of the coronavirus pandemic.

This report gives an overview of people's experiences predominantly during the amber phase of the plan.

Effects reported by self-advocacy groups

Requests for information on the impact have sent to all self-advocacy groups that are members of All Wales People First.

Responses from groups can be divided into three categories:

1. The effect of the situation on the organisation and its staff
2. How organisations are continuing to support their members
3. How members are feeling and coping with the lifting of lockdown

The common themes from the responses can be summarised as follows:

1. The effect of the situation on the organisation and its staff

During lockdown, all offices closed, face-to-face activities stopped and staff worked from home.

For those offices that have now begun reopening, staff are blending home and office working to reduce the number of staff present at any one time. Access is restricted to staff (and in some cases, volunteers) only. Social distancing is in operation with PPE, screening and hand washing facilities available as required. Cleaning regimes are more thorough and frequent and staff's health is being monitored regularly through temperature checking and risk assessments.

Some offices are in the process of being adapted to enable reopening in the near future.

Some groups have conducted risk assessments for their staff and deemed it too high a risk to reopen at all for the time being.

Several groups have reported that they are reviewing their office needs going forwards. Homeworking has become an established practice and it may be more cost effective to no longer have an office base – renting meeting space as and when required for activities and events. This will also benefit the local environment if less travelling is required for daily commutes.

2. How organisations are continuing to support their members

Groups are continuing to find new and innovative ways of supporting their members, building on the ways of working implemented early in lockdown. Some groups have secured funding to purchase devices such as tablets and mi-fi to enable members to access online activities.

In a few counties, group staff and volunteers have delivered wellbeing packages to their members and vulnerable people in their area. These packs have contained toiletries and treats with some items being donated by local businesses. They have been designed to lift spirits and reconnect with people who have been feeling isolated and lonely during lockdown.

In several areas there has been some face-to-face contact with members, largely through socially-distanced outdoor activities just as local walks. However in other areas there has been no face-to-face work as risk assessments for staff and members have deemed it to be too risky due to the size of the population in that area (predominantly urban). There would be too many other people around and therefore a greater chance of catching the virus.

All groups are continuing to support members through online activities such as chats, video calls, games and events and also posting activity packs and conducting telephone check-ins.

3. How members are feeling and coping with the lifting of lockdown

Groups have told us that their members became largely accepting of the lockdown situation within the first couple of months. It took a while for issues around access to groceries and medication to be resolved which caused much anxiety but in most cases, solutions were found.

Boredom and being “fed up” have been commonly reported feelings particularly around those who are digitally excluded. In some cases (predominantly supported living accommodation) those who have been able to access the internet have had their use restricted due to other people needing to use the connection or policies that don't allow the use of certain programmes (eg Zoom).

There is a very mixed response in all areas to the lifting of restrictions. For some people it couldn't come soon enough and they have been making the most of being able to go out and socialise. For others there is great anxiety about virus infections increasing again as more people are in contact with each other (particularly in shops where people would be strangers to each other) and they are avoiding going out especially at busy times of the day.

Those who have returned to work and volunteering are feeling happy to be back to some sort of normality and being able to talk to others. Some who have gone back to meeting larger groups of people on a social basis are feeling uncomfortable without PPE and social distancing and are keen to return home after self-assessing the risk to themselves and others that they might live with.

Members have been made aware of the need to rebook medical appointments and procedures that might have been cancelled due

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to lockdown. They are being supported to do this where necessary. We are aware of one example where a member is due to undergo a medical procedure and has been clearly told of the need to isolate for 14 days beforehand and also after the procedure whilst ongoing care is required (dressing changes, check-ups etc.)

Maintaining social distancing is posing some communication problems between members, particularly those with hearing and/or speech issues. Some members are also struggling to remember that they shouldn't hug people not in their "bubble", particularly when they are glad to see somebody they haven't seen for a while!

There are reports of issues in town centres where cafes, pubs and restaurants are placing tables on streets making it difficult to maintain distance between pedestrians and causing hazards for people with wheelchairs, mobility scooters, guide dogs and walking aids. This is causing great anxiety and leading some people to decide not to go out at all.

Shopping and eating out are popular socialisation opportunities for people with learning disabilities however it is a less enjoyable experience at present. People are reporting being rushed to leave venues so that more people can come in due to reduced capacities. There is little consistency in shops with some enforcing strict social distancing measures – limiting the number of customers, routing people through the store etc. – whereas others have done little except for screens around the tills and stickers on the floor.

Tourist numbers have also increased dramatically since lockdown has lifted. This is less of an issue in areas used to tourist numbers that

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already have large car parks, wide roads, toilets and other facilities. However some local beauty spots that usually have a trickle of visitors are seeing large influxes of people meaning roads are becoming blocked for emergency vehicles, there is increased traffic for local people to negotiate and a lot of rubbish is being dumped and left behind. Again, this is leading to anxiety and a reluctance for people to leave their homes.

The confusion remains around what constitutes rules and guidance and differences between the countries of the United Kingdom. National news has a focus on the situation in England so messages get missed or misinterpreted by members. Most groups are providing regular information relevant to the local area to try and mitigate this. All Wales People First produce regular video news updates shared on social media with the latest up to date information relevant to Wales. We have also produced a toolkit for members and groups to use with links to the latest information on a range of topics that might concern people coming out of lockdown. This is updated regularly to keep it relevant.

However there is also confusion within local authorities and service providers as to how rules and guidance from Welsh Government should be interpreted and this is causing human rights issues for people with learning disabilities. This is particularly prevalent in shared living accommodation and the creation of extended households. Due to the increased risk to individuals and those they live with of people spending more time with others outside of their household, many providers have put outright bans on people staying overnight with

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family and friends. This is being done without explanation of reasons and individual situations being assessed.

We are aware of one case where two people with learning disabilities sharing accommodation were forced to self-isolate for 14 days because one of them went on an overnight caravan holiday with their family. Both were confined to their bedrooms for the period with limited contact from staff. When the other individual tried to return to their volunteering opportunity after the period of isolation they were sent home and were told they had to undergo another period of isolation. This was down to a misinterpretation of rules in that area by service providers and the local authority.

In another case, a member could not go on a holiday with his family as his care provider was following advice given by Public Health Wales and information given on the gov.uk website 'Coronavirus (COVID-19): guidance for care staff supporting adults with learning disabilities and autistic adults. He was told the day before he was due to leave.

In a third example a member who has been living his mother during lockdown, has been told by his housing provider than he is welcome to return to his home but must self-isolate for 10 days after doing so. If he then goes away for a night, he will have to undergo another period of self-isolation.

Contact with and from social services for members has been very sporadic over the lockdown. Some members have had regular contact and 'check-ins', some have had the occasional call and some have had no contact at all. There doesn't seem to be a pattern of certain Local Authorities making contact – it's varied within regions.

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Despite these challenges, there are some positives and possible long-term change coming from this experience. In some areas, members are beginning to question their level of need for day centre services and are wanting to reduce their attendance. They feel more confident and comfortable in staying home and interacting with others through digital channels and accessing the local community.

Members have increased their skills in using technology particularly those who were reluctant to give it a go in the past. Some are participating in online training and are gaining confidence in leading and delivering it too.

Some groups are reporting better attendance at online events and activities than previous face-to-face opportunities so they are actually increasing membership and member engagement. Quizzes and online games are bringing members and staff closer together as they “battle” against each other to win! People with learning disabilities are gaining confidence and skills to lead these activities too.

Effects reported directly by people with learning disabilities

As well as speaking to groups and hearing from group staff, we have also spoken directly to our members with learning disabilities about the direct effect of the pandemic on them and the way they live their lives.

Whereas anxiety, confusion and a desire for things to return to normal quickly came through strongly in the first report, now there is a sense of acceptance, hope and a “new normal”.

Their feelings have been recorded in a diary format, the full versions of which can be read on the All Wales People First Website. Some extracts from those diaries can be found on the following pages:

“It will be weird going back to work – I’ve enjoyed lockdown because I’ve used Zoom and other technology to meet up with people and make new friends. I feel a little apprehensive about starting a new routine again and becoming part of the ‘new normal’. I have to put trainers on – it’s the first time I’ve worn shoes since lockdown!

The tourists are flocking back to west Wales! My family and I had planned to meet up in Saundersfoot but it’s going to be too busy so we need to think of somewhere else.

I saw my boyfriend in Carmarthen on Monday for the first time in 14 weeks. We had a wander around the shops. I went to Carmarthen by train – that was ok and the journey was quiet. You have to wear a mask and some seats are blocked off to enable social distancing. I’m getting used to wearing a mask now. The only time I find wearing one difficult is when I’m in a confined space with lots of people around me – then I find my breathing more difficult. But in a more open space with a mask on, my breathing is fine.”

Sophie

"I've lost 31 lbs on my diet; I haven't seen my boyfriend yet, he doesn't live in the same village as me. We chat on facetime every day though.

I've really enjoyed the Gig Buddies Kazoom parties I've attended and I've joined Electric Umbrella group too.

I've been out and about quite a lot recently. I've been shopping (and I wore a mask which felt ok). I also went to the Mountain View Ranch with my support worker and to Barry Island to go on the rides and have an ice cream. I'm going to Barry Island again at the weekend.

It's such a shame that we have to hold AWPf's conference virtually this year; we always have such fun when we get together. Last time we went up by train for it and we met someone from the TV programme 'The Undateables' – they were really nice."

Nicole

"I'm really excited to have been picked to take part in a research panel called Over the Mountain. I just heard today that I'd been chosen. I applied a while ago and it's given me a real boost. You get paid too!

I'm feeling great at the moment – much happier. I think it's because I've had a lot of positive feedback from people lately and I've been really busy.

We went to Tenby last weekend to open up the caravan. Tenby itself was too busy so we didn't go into the town.

I'm helping to organise a virtual event with the Welsh Ambulance Service for People First members, and it was our Caerphilly People First management meeting earlier this week – we've been looking at ways to re-open safely. We haven't set a date yet because we're waiting for our grant funding towards our cleaning equipment. People are worrying about a second wave of coronavirus so we need to be careful."

Ffion

“So excited! I’m off to Porthcawl with my Fiancé this weekend. We’re going to sit in a beer garden. Not done that in so long.

Bit of a quiet day today but the rest of the week is busy with work meetings. I’ve got three on Thursday.

I need to find time to pack for Porthcawl though because we’re going this Friday and back on Monday. Ben booked it last week as a last minute special treat. He’s treating me to a nice weekend away after the rough few months.”

Sam

“I’ve not been feeling good at all over the last few weeks. I started to feel a bit better last week when I could see my fiancé at social distance. It’s been so long since we saw each other.

Between not being able to see Kurt and my Grandfather being very unwell, it all felt too much, and I felt really anxious.

My Grandfather had Coronavirus and was very unwell, but thank goodness he’s pulled through and, on the mend now.

I can see quite a few queues outside shops as I’m walking through town. I won’t be going shopping though. People get too close even though we’re supposed to be social distancing.

When we walked to the beach over the weekend, it was good to see that everyone was keeping their distance so nothing like Bournemouth and Ogmores.”

Stacey

Summary

There is no doubt that the pandemic and subsequent lockdown has been difficult at best for most people. When these people also have a learning disability, it has become an extremely anxious, stressful and confusing time.

The confusion around different and fast-changing rules and guidance is evident and is compounded by different interpretations amongst service providers.

However as time has gone on, there has been an acceptance of the situation and people have developed skills and coping strategies to deal with an emerging “new normal”.

And people with learning disabilities are proving resilient and adaptable particularly when supported by staff within the groups. There is a desire to use this experience as an opportunity to make changes to working practices and services so that eventually the “new normal” could be better than what was there before.

All Wales People First will continue to monitor the situation. A further report will follow when Wales moves into another phase of coming out of lockdown. We hope this will be the green phase though are aware it could be a reversion to red should infection rates increase again.