

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

Phase One



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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 initial lockdown period of the Coronavirus Pandemic 2020.



13 May 2020 (All Wales People First)



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

Since the beginning of the Coronavirus outbreak in the United Kingdom in March 2020 when vulnerable people were advised to self-isolate; and the subsequent instructions regarding social distancing 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.

This report gives an overview of people's experiences during the initial lockdown period to early May 2020.

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Covid-19

Covid- 19 is a new disease

Oh, everyone around the world is Quarantine

Really is making things frightening

Ok would you now just let us carry on living

Now we must stay at home

And stepping into the unknown

/

Very annoying that

I've been wishing

Really hoping it will be over soon

Using our time to draw rainbows

So thankyou NHS & all other frontline staff you're our heroes

Effects reported by self-advocacy groups

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

Responses from groups can be divided into four categories:

1. The effect of the situation on the organisation and its staff
2. The effect of the situation on the people they support
3. Strategies and activities that have been implemented to mitigate the effects of 1 & 2
4. Shielding issues

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

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

In line with many companies and organisations across the UK, all groups have closed their offices and staff are working from home. They remain contactable via telephone and email and are making use of software such as Microsoft Teams to communicate with each other.

Commissioned income from Local Authorities appears to be still available, though targets and delivery plans might not be fully met during this time. Income from other sources such as grants and trusts is not so readily available as many have suspended applications or are diverting their attention to supporting causes linked directly to the coronavirus crisis. This might have a knock-on effect for job security going forwards.

It is also unclear whether support workers will qualify for the £500 bonus announced for Welsh care workers. We expect this to be clarified in due course.

2. The effect of the situation on the people they support

People with learning disabilities are struggling to various degrees with the situation. Most are reporting feelings of loneliness and isolation and the cancellation of group meetings and events are leading to boredom and frustration. This is increasing as time is going on.

Those with mental health issues are struggling to remember the reasoning behind the sudden changes and a small minority are exhibiting some extreme behaviour including suicidal thoughts and assaults on support staff. There is a concern that people are not sharing their feelings and talking about their issues as readily over the phone as they would do in person. Some areas are reporting an increase in advocacy referrals for issues related to the criminal justice system with frustration-related violence being seen more often as the situation continues. Where required, support workers are calling in other organisations and agencies to help those most vulnerable and in need of urgent support.

People with learning disabilities living independently are feeling more abandoned than those in supported accommodation or those who live with their parents or carers. Some people are benefitting from community support schemes to access groceries and collect medication as delivery slots bookable online from the large supermarkets are in short supply and difficult to access. There can be a lack of trust in online shopping for larger items such as furniture with people wanting to go in search of shops that may be open to look at available items.

13 May 2020 (All Wales People First)

Shopping for essential supplies is posing some issues. Where delivery slots are acquired, out of stock items are not being substituted, forcing people to visit local shops in person anyway. The price of fresh goods (fruit and vegetables etc.) also appears to be increasing in some local shops making budgeting difficult.

People used to paying monthly bills with cash are also struggling as shops are favouring card payments. Some have had phones cut off due to running out of credit and being unable to buy top-up vouchers. In some cases the telephone is their only means of communication.

Statutory letters offering help, advice and instructions from local services, the Prime Minister etc. are slow to arrive and when they do, there is no support available to help with reading and understanding of the content.

The lack of an end date or defined timescale is causing confusion as are the multiple news updates from a variety of sources, most of which are difficult to understand. There is a need for more accessible information from a select group of trusted sources. As time is going on this is being compounded by different, often conflicting information coming from the governments of each country. As national media tends to be England-focused, most of what is reported are the rules and restrictions there rather than in Wales. This is sending mixed messages about what can and can't be done during this time.

Many routine medical appointments have been cancelled and services such as physiotherapy have also been stopped. It is too early to tell what effect this will have and it will be important to ensure that

13 May 2020 (All Wales People First)

postponed appointments are rearranged and not abandoned completely.

Requests for hospital passports and information about what it's like to be in hospital have increased as people realise the effects the virus might have if they were to catch it.

People are also becoming aware of the risk of mortality from coronavirus. This is causing anxiety for people's own lives and also how they will cope with the grief from losing somebody they know. This is heightened in the Maesteg area where a doctor's surgery sent out a letter suggesting that vulnerable people should consider signing a DNR to protect health and emergency staff. Though this letter wasn't sent because of a person's learning disability but due to other medical conditions, the surgery failed to consider the implications of a person with a learning disability receiving and understanding such a letter or that the normal levels of support that these people receive to deal with post and their daily living affairs has also reduced at this time. An apology has since been issued.

In one area where a popular person in the learning disability community has passed away from the virus, people have been shocked and it has influenced them to stay at home.

There are some small positives being reported. Some people with learning disabilities are gaining new skills and confidence in using social media, communication tools and other apps. Local communities are also rallying around to help their vulnerable people and it is hoped this will lead to more positive and proactive relationships in the future. Those living with others are also forming

13 May 2020 (All Wales People First)

stronger bonds and working more closely with each other. In some shared accommodation, residents are supporting each other by cooking meals for everybody and/or sharing tasks between them. However, some are reporting conflict and tension from too much time in each other's company. In one area there has been an increase in placement breakdowns, compounded by a reduction in respite provision.

3. Strategies and activities that have been implemented to mitigate the effects of 1 & 2

All People First groups are continuing to deliver some form of support to their members. This is being done in a variety of ways:

- Regular telephone calls to members with staff developing rotas to split the membership between them.
- Group video chats
- One to one video chats
- Group text chats
- Online video demonstrations of tasks and activities
- Regular updates, activity suggestions and competitions on social media
- Working with other organisations to deliver online activities to people with Learning Disabilities and other vulnerable people
- Postal activity packs
- Provision of information about the virus itself and the lockdown situation in easy read formats
- Some grocery and prescription collection and delivery support

The most common apps, websites and programmes being used are:

- Facebook (pages and specific groups)
- WhatsApp
- Zoom
- Facetime

In some areas it has been possible to lend equipment to members to help them to get online to access support with training being given where possible to assist with its use. Groups are also sourcing funding

13 May 2020 (All Wales People First)

to purchase and set up new equipment (mainly tablet computers) to provide to their members but funding is localised and not available to all.

However in one area it has not been possible to assist members to access Zoom due to the Local Authority restricting its use. This is due to media reports of data breaches rendering the facility a security risk in their policy. Support workers are unable to access Zoom on behalf of their service users.

Regular information is being given around the virus itself and the Government advice for social distancing, staying at home and regular handwashing.

Group staff are using Microsoft Teams as well as the apps above to remain in contact with each other and to formulate work plans.

Members are valuing the new type of support they are receiving from their local group staff. Local groups are also helping each other's members when they live in boundary areas and sharing ideas and good working practices between themselves.

4. Shielding Issues

Groups were asked if there were any issues with people being shielded that didn't need to be and conversely were there some members that should be shielding that were ignoring the guidelines.

This doesn't appear to be a widespread issue. There are isolated instances of people ignoring shielding guidelines and going out when they shouldn't. There are also some individuals not understanding that they need to shield because of a vulnerable person living in their home but they are complying nevertheless.

There is some confusion around the letter that has been sent to those who need to shield. It is very long, contains too many words and isn't personalised to the recipient. The generalised letter lists all underlying health conditions, all local Authority contact details, has too many variables and key messages are lost in the reams of text. It's not clear who within a partnership the letter applies to.

There are also a few reports of people choosing to shield though they don't qualify based on the criteria applied by Welsh Government. They are extremely concerned about how Covid-19 could affect them and are staying indoors completely or making very limited use of their outside space for some fresh air.

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 outbreak on them and the way they live their lives. This has been done through social media, video and telephone calls and e-mails.

Much of what they have said mirrors the information we have received from the groups:

“More anxious”

“Fed up”

Frustrated and confused that I can't see friends and family”

“Missing people and can't wait to get back to normal”

“Stress when queuing for shopping”

“Usually proactive and now can't attend events”

However there have been positives:

“Enjoying doing the Gig Buddies zoom club called Kazoom where they play instruments and do karaoke on a Friday night”

Some members have provided further insight into the effect of the outbreak on their daily lives and relationships. The following pages contain extracts from their stories:

"The supermarkets have given set days for people who are vulnerable to do their shopping...our money goes into our bank account on a different day. It is very awkward and embarrassing when we are told we have to speak with a manager about our needs to shop together.

We find understanding the rules about lockdown quite difficult at times. They change a lot and that is a worry.

Paying the bills in the usual way is not possible. We usually pay over the counter. It is really hard trying to pay over the phone as the lines are so busy.

We are finding that communication is really hard for a lot of things right now. We feel quite vulnerable.

We are trying to support each other and stay connected with friends and family, but our mental wellbeing is a worry."

Anne & Neil

"We are a bit confused about the situation, and what the isolation rules mean for us.

Accessing food has been a bit of a problem for us. We don't have a debit card. We pay for our shopping by cash. All of the small local supermarkets close to us have stopped taking cash.

We are not used to being at home together all of the time. The lockdown changes have put our relationship under pressure a bit more than usual, but we do our best to support each other emotionally.

To keep positive, we have been keeping in touch with friends and family through Facebook, Messenger and by phone. We've also tried some new cooking recipes, reading and we've been for a walk."

David & Claire

“They use big words on the news, which I don’t understand. There’s so much news on the internet and on social media, I don’t always know what’s new, what’s current, and what is fake news.

I’m doing some work from home for my local People First group. It helps me to feel positive but it’s such a big change to my usual routine.

I’ve set up a few video call group chats, which have been fun. It helped me to be feel good having a part in helping other people with learning disabilities to stay connected.”

Ffion

“We don't live together, so we've not been able to see each other since lockdown, which is hard.

Our routines have been disrupted but were managing and mostly staying positive.

We've been keeping busy with our local self-advocacy network.

It's good that during this difficult time people with learning disabilities are trying new things to stay connected and are learning new skills.

Some members are not allowed access to the internet as the internet is available to staff only. Social media is playing such a big part in in people's lives right now, so having the choice about having access to the internet is so crucial.”

Michelle & James

“I’m feeling quite lonely and isolated most of the time right now. I live on my own independently. I usually have to be careful to look after my mental health as I have anxiety. Lockdown has given me a lot of time to reflect on how to be kind to myself.

My boyfriend lives in a residential care home, and we were not able to choose to lockdown together in my house. I feel frustrated and upset about this because people who don’t have a learning disability can make their own choices about moving in with a partner they don’t live with for the lockdown period.

I had problems with my breathing last week. My asthma and anxiety made me feel like I couldn’t breathe properly all day. I got a taxi to A&E. It was very frightening being there on my own. When I found out I was in the same area as some suspected Covid 19 patients I felt really scared.

It was so difficult understanding what people were saying with the masks on and I think a health passport would have been a big help to me.”

Lucy

Summary

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

People's freedom has been curtailed, support has reduced and relationships are being tested.

There is a strong need for accurate and clear information from trusted and reliable sources to aid understanding and compliance.

Self-advocacy group staff are continuing to support their members with new and innovative ways of working. This is helping to reduce isolation and loneliness but, in most cases, relies on digital inclusion and the ability to access mobile phones and tablets before apps and programmes can be explored.

But it is important not to forget the small positives that have been seen – increased community cohesion, discovering new hobbies and interests and learning new skills that will be of use in the future.

All Wales People First will continue to monitor the situation as we move into a period of easing restrictions and slowly returning to “normality”. A phase two report will follow with our findings from any process though no timescale can be given at this time.