

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



Prepared by Philippa Davies

Photograph by Stacey Traylor -
submitted to our Through Your
Eyes "Life in Lockdown"
Competition for members

A report into the continued experiences of people with learning disabilities across Wales and the activities of learning disability self-advocacy groups throughout the Coronavirus Pandemic 2020/21.





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 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.

Our second report published in August signalled some acceptance of the situation and glimmers of hope that a 'new normal' would soon be reached with groups re-starting face-to-face activities and restrictions beginning to lift to allow social activities to take place in person.

It was hoped that this report would feature experiences from a "green phase" of the pandemic, when things were operating as they were pre-pandemic with perhaps some changes for the better.

However, the reality is far different. We are now in a third lockdown, with the past five months being a rollercoaster of changing rules and restrictions. The number of cases of coronavirus are at an all-time high as new strains are transmitted more easily between people.

Effects reported directly on and by people with learning disabilities.

Our members and members of People First groups have become accepting on the whole that there is no known end date to the pandemic, and we have to keep following rules and guidelines. However the feelings of anxiety, frustration and confusion highlighted in the first report have resurfaced again due to the frequently changing nature of these rules. We have continued to produce regular bilingual coronavirus updates on our Self-Advocacy TV Youtube Channel to provide members with the latest information and guidance in a consistent, easily recognisable format.

There is hope amongst members that the vaccines now being administered will allow a return to normal however that seems a long way off at present.

The rollout of a vaccination programme has been well received. Initially there was some hesitancy as little information about the vaccines, their testing and safety was available in an Easyread format. It would be difficult to make an informed decision without that. However as more information has been produced by various organisations, the vast majority of members are keen to receive the vaccine as soon as possible including those who consider themselves to have a phobia of needles.

A poll promoted on social media and hosted by Survey Monkey in December 2020 gave a 94% "Yes" response to the question "Would you take the Covid vaccine if it was offered to you?" Many members

have also stated publicly on their Facebook profiles that they will take the vaccine once offered.

Some members have shared their thoughts and hopes for the vaccine via videos which have been shared on our Facebook page and through our Youtube channel.

Membership of All Wales People first has not increased significantly over the pandemic but engagement with existing members has increased greatly. There are several possible reasons we can identify for this:

1. Members can access our events more easily online rather than face-to-face.
2. Because they are accessing our events, we are more visible to them and they are more likely to approach and interact with us.
3. Members are talking more with each other and identifying issues they would like to address and change in their lives.
4. Members have had more time to evaluate the support they receive and their personal circumstances and are feeling empowered to seek change and improvement.

The increase in digital accessibility and confidence has led to new friendships forming between members who otherwise may not have met due to geographical constraints. Members are getting together for virtual gigs, parties, quizzes and other social events with promises to meet up in person when the pandemic is over.

26 August 2020 (All Wales People First)

Members have had time to evaluate their living situations and are exploring other options such as independent living or cohabiting with partners.

One member has acquired a dog to give her a reason to keep active and company as she lives alone.

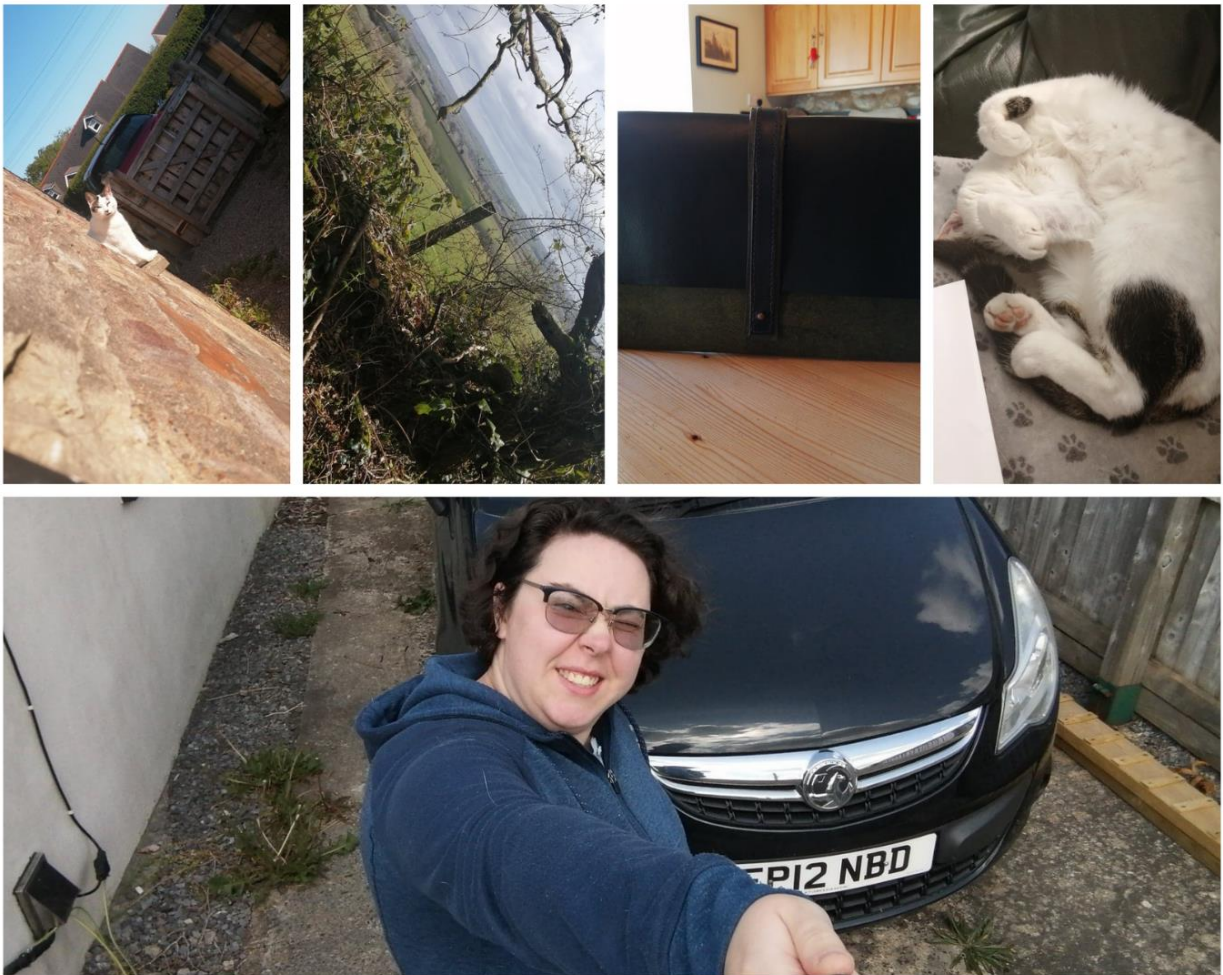
A competition run by our Through Your Eyes project asked members to show us – through photography and video - their highlights and experiences of 'Life in Lockdown'. We received many excellent entries showing positivity and accomplishment despite the abnormal times:

26 August 2020 (All Wales People First)

Through Our Eyes photography competition



'Life in lockdown'



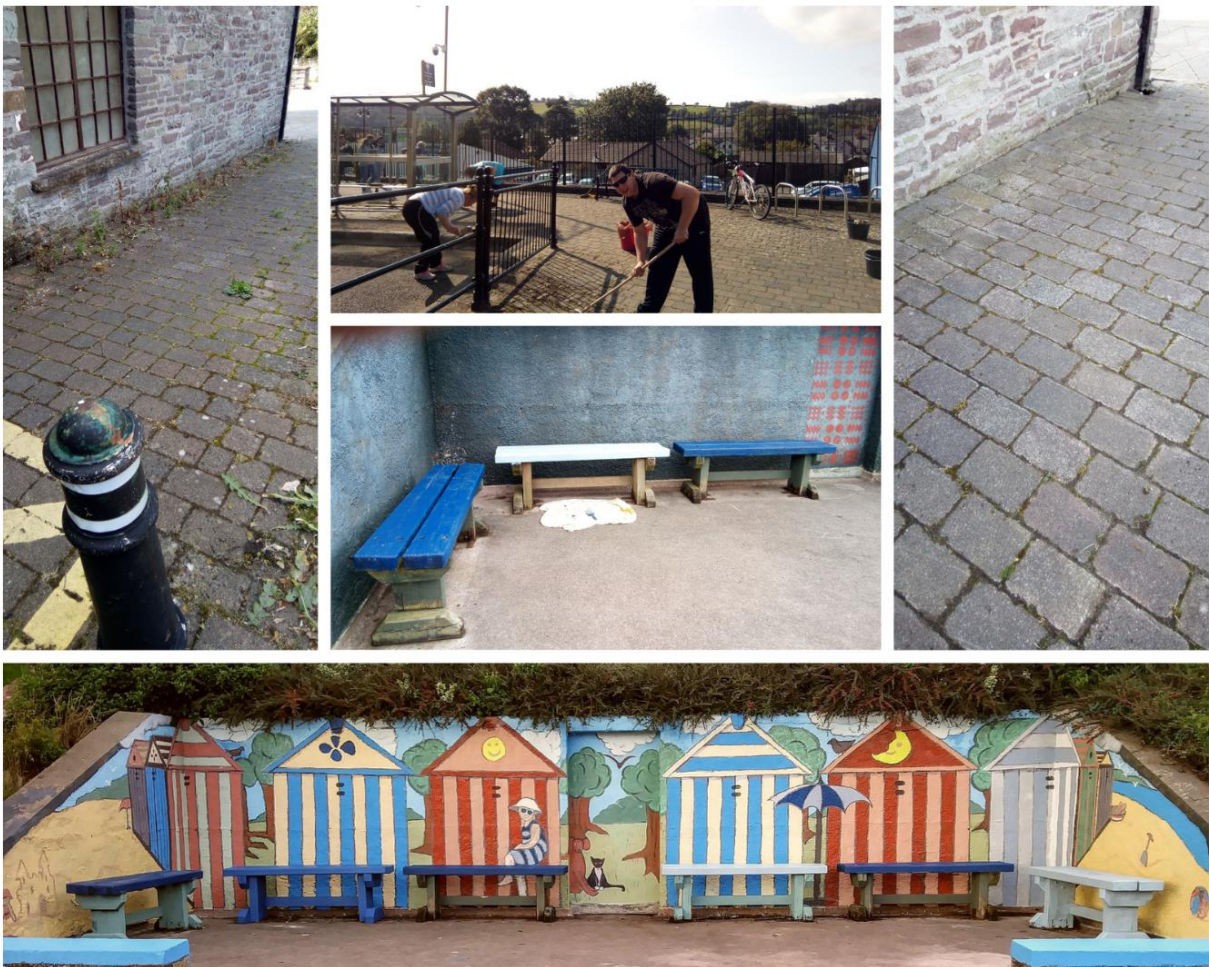
Anna Howell

26 August 2020 (All Wales People First)

Through Our Eyes photography competition



'Life in lockdown'



David Whittle

26 August 2020 (All Wales People First)

Through Our Eyes
photography competition
'Life in lockdown'



Stacey Traylor

The effect of the situation on People First/Self-advocacy organisations and their staff

The majority of offices remain closed with staff working from home. Those that are open operate on a rota basis to limit the number of staff and volunteers present at any given time. Face-to-face contact with members is much reduced and, in some cases, limited to crisis or emergency situations.

Staff are reporting feeling exhausted and burnt out. They are finding it difficult to maintain the same momentum built up in the first lockdown that members have come to expect. Whereas more members are now able to access online activities and use devices, there is still an ongoing support need in this area as new apps are developed, or existing ones need updating.

Of course, there are still people who do not want to connect digitally. These need regular support over the telephone or in some cases, socially distanced face-to-face meetings.

The local restrictions, followed by a national firebreak lockdown, the easing of that and then the subsequent UK-wide lockdown since Christmas has resulted in changed information having to be shared with members time and time again to ensure they are aware of the current situation. This is very time and resource-heavy work.

Staff are finding the nature of the support that members require to be very intense. Many don't feel able to switch off at the end of a working day in case a member needs them so are taking calls into the evening and occasionally during the night. With most homeworking, members now contact staff directly on mobile phones rather than through a central number only manned during office hours.

Some organisations are also reporting that their staff are being asked to take on duties that would otherwise be done by a social worker. This is happening particularly where people need face-to-face help which requires local authority staff to make a case to be allowed to visit. There is less red tape for People First Group to undertake these visits so they are being asked to attend instead.

And staff are also concerned that they are missing people in their communities. With a less visible presence and other referral organisations working remotely, people with learning disabilities are not aware of the group and the services it provides.

Some organisations are fearful for their future as local authorities have not yet confirmed budgets for the next financial year. There are other sources of funding available for small projects or capital items but very little core funding to continue delivering current services if they are decommissioned.

In some areas this fear is being compounded by there being no other organisations delivering similar services and also a worry that day centres may not reopen leaving members even more isolated and unsupported.

Some groups are looking at fundraising ideas for the immediate and long-term future. Members are keen to restart sponsored events such as walks or fun runs but understand that these must be done in isolation at present. They require support to set up online giving pages and to arrange and promote what they are doing.

How organisations are continuing to support their members

Organisations are continuing to deliver activities to keep members engaged and supported. The vast majority of these are online. Many groups that are commissioned to deliver self-advocacy services only are also incorporating social activities to help member's wellbeing and reduce isolation. These take the form of quizzes, games, music events and general chat.

There are a few positives coming of this work.

- Members are increasingly confident in organising and running activities themselves.
- Geographical barriers are removed so new friendships are being formed and old ones rekindled between people across large counties and also further afield.
- With members being more confident online it is hoped that in the future, meetings and activities can be a blend of face-to-face and online which will increase participation and engagement.

For people who cannot participate in these online events, group staff are sending out activity packs, making regular telephone calls and occasional visits where necessary.

It is important to note the reasons why some people are not engaging with online activities. For some they have no interest in doing so and their choice is respected. For others there is a lack of available devices and groups are working hard to rectify this. But there are a further two reasons that are particularly concerning:

1. A lack of broadband access (particularly super-fast) and/or a lack of mobile coverage preventing people from being able to access the internet regardless of device availability. This is particularly prevalent in

rural areas who witness large towns and cities having faster and stronger signal through regular upgrades whilst they are left with very poor availability and little prospects of the situation improving for a long time to come.

2. Some staff in some supported living accommodation who are not digitally confident themselves are unable and/or unwilling to support residents to get online. This has also been witnessed amongst parents who care for a son or daughter with a learning disability and have no desire to become digitally included themselves.

Summary

There is no doubt that the ongoing pandemic and its associated ever-changing restrictions on everyday life is proving very difficult for people with learning disabilities and those that support them. No sooner do people adapt to new rules than they change, and people must live and behave differently again.

But people with learning disabilities are proving resilient, particularly when supported by staff within the groups. There is a new confidence to speak out and initiate change to improve futures. They are developing skills that can be used long after the pandemic is over.

But support staff are close to burnout as demands on their time and resources have increased dramatically. This is something we are monitoring closely and providing help where we can in the form of information sharing and identifying nationwide-issues that we can help to address through influencing and campaigning.