



Self Advocacy, Independent Living and Digital Inclusion

Digital Exclusion: another type of virus!

Introduction

People First is a national user led self-advocacy organisation working with people with learning difficulties and their self-advocacy groups. Our mission is to promote the voice of people with learning difficulties as equal and valued citizens. We give information, advice, support, and training to break down the barriers we face.

Many people with learning difficulties were struggling before Covid-19, with reduced services and support, cuts to benefits, inaccessible assessments and even less support and opportunity to get online than the rest of the population. Covid-19 has seen the digital divide between those who have access to information and communications technology and those who do not, increase giving rise to inequalities in access to opportunities, knowledge, services and goods. This has had a negative impact on mental health, anxiety levels, emotional wellbeing and living independently in the community.

Being able to connect with people, services and information helps people with learning difficulties

maintain their independence, social connections, access to financial information and other services. During lockdown, limited support, or in some cases the withdrawal of support, resulted in people finding themselves more isolated.

In 2017, 56% of adult internet non-users were disabled. Though the percentage of disabled adults not using the internet has been declining, in 2018, it was 23.3% compared with only 6.0% of those without a disability (ONS, 2019). This is a barrier that we need to break down; just like we did with the barriers we faced around employment and social inclusion over the last 30 years.

People First recognises there are additional safeguarding challenges arising as a result of the Covid-19 outbreak for people with learning difficulties. It has been a time when frequent contact needs to be maintained. We are aware of the increased risks people with learning difficulties are exposed to when there is less face-to-face contact and a reduction of support and monitoring due to the lockdown. Some of the risks include scamming of people who live alone, increased isolation, higher incidents of domestic abuse and neglect.

We are also concerned about people with learning difficulties not understanding health guidance and being refused treatment due to their disability.



What we did

During the first few weeks of lockdown we communicated with our staff and members, using our Supporting Each Other Equals Power (SEOEP) service to find out how best to communicate with them on a regular basis.

We completed questionnaires to find out exactly how people were coping and what they needed.

We supported individuals to connect and get online to join meetings, activities and attend appointments. This included training for people with learning difficulties to be able to facilitate online meetings. This mutual (peer) support helped people who would have otherwise been socially isolated. This has been important learning that we now want to adapt and develop for our member organisations

In the second week of April we set up a Covid-19 Support and Action Group for self-advocates around the country. We wanted to provide a safe online space for people to share concerns, information and ideas. It was also an opportunity to discuss the coronavirus guidance, which many people found confusing. You can listen to People First Director Andrew Lee talk about the group [here](#).

We provided practical support for people to get online and use Apps such as Zoom, WhatsApp and Microsoft Teams. Some of our members helped others who didn't

have Smart phones by phoning them live while on a Zoom meeting so they could take part.

People with learning difficulties have been facilitating the meetings with administrative support. Group members choose the topics they want to discuss each week and think about any action they want to follow up on.

Members of the group have shared their thoughts about the benefits of being able to connect digitally during lockdown.

'I've been meeting up with people I wouldn't be able to meet with regularly under normal circumstances.'

'Important to hear from others around the country and the different things they're doing. I really enjoyed meeting and listening to other folks.'

'It helps with the mental health side of things – helps me feel better.'

'Really good to share our views about things.'

'It's really helped me during Lockdown, shows me I'm not alone.'

'Getting information such as for patient advocates and local support.'

'It'll be good to keep these meetings going as well as start meeting up with others in person – use a mix of technology and face-to-face.'

The level of peer support in the group increased over the weeks. People started to share their fears and concerns about issues such as 'Do Not Resuscitate' and Shielding. People also spoke about other world events such as Black Lives Matter. This resulted in collective action that produced the following:

- [**Our Statement in Support of the Statement Covid-19 and the rights of Disabled People**](#)
- [**Our statement in support of Black Lives Matter**](#)
- [**Our Accessible Information Campaign Letter**](#)
- [**Our Position Statement on Assessment and Treatment Units \(ATUs\)**](#)

Members also produced videos on the importance of accessible information. Watch [Olcay Lee](#) and [Ray Johnson](#).

Members of the group would like to continue to meet digitally beyond lockdown. They would like self advocacy organisations to be better connected so they can join forces on important issues.

On 7th July the Covid-19 Support and Action Group spoke about digital exclusion. Points from the discussion included:

- *It's been important to be able to communicate online during lockdown for our mental health.*
- *It would be good to encourage other people to get online that haven't been able to so far.*
- *We learnt a lot about keeping safe online after getting 'zoom bombed' during the first weeks of lockdown.*

- *It's not just having the right devices and tech to use to get online but having access to the internet.*
- *We've had to be creative, connecting people on their phone while on zoom meetings.*
- *We've put a lot of effort supporting people to get online and although it was hard work and some people still haven't got tablets and mobiles, it has really made a positive difference.*
- *Some people have been more involved and connected than they were before lockdown as a result of getting online*
- *I wouldn't have coped if I hadn't been able to connect with people online.*
- *It should be everyone's right to be online and access the internet one way or another.*
- *It's an essential service these days with so much moving to online such as, shopping, banking, welfare benefits, recruitment, advice services.*
- *There will always be some people who can't or don't want to be online and prefer face-to-face or phone meetings. We must ensure that support is in place.*
- *Before Covid-19 it was almost impossible to get support to get online or do tech things.*
- *Worried that we won't have any events in the future. We don't want everything online.*
- *How do we pressure and protest online? It's important to do this in person together at times.*
- *We need to think about how digital platforms are used to exclude our voices – we don't get heard or listened to online.*

- *A lot of digital things are hard to get on to and get a grip of. Logging in and logging out, remembering passwords and making sure us and our information is safe and secure.*
- *There are too many inaccessible and confusing websites.*
- *We need accessible guidance and direct support to get online.*
- *Being online is now the 'new normal' so we need to work on the barriers we face to get online.*
- *It has meant we can meet more people we don't usually get to meet from other areas around the country and from other countries. It can widen our world.*
- *We have to be aware of costs and deals so we don't run up big bills. Some people don't get a lot of money left after their support and living costs.*
- *Many people living in residential homes, supported living and in hospitals have not been able to get online. In some cases people have been stopped by staff and told they're not allowed.*
- *We shouldn't have to kick up a fuss to get set up online.*
- *We need to keep an eye on the 'limits and controls' put on people in places like ATUs where there are 'blanket rules' like you can't have any visitors or you can't communicate virtually.*
- *We need to speak up for ourselves online the same way we've been supported in groups.*
- *Some people have been using mobile phones for texting and WhatsApp and social media.*
- *It's been a struggle to get online in supported living but once sorted it's been really good.*

- *It's been really important to be online since I lost my day services. I've been missing seeing people.*
- *Advocacy services need to help with digital inclusion. They should be supporting people to set themselves up online. Help with the tech, managing passwords and using different devices.*
- *Since the office has been closed I've been working from home and found it really hard at first but I've got used to it. Tried different ways of communicating and having small group meetings have worked well.*
- *Some campaigns organised online about learning disabilities and learning difficulties have excluded us. We're on catch up and only just getting used to communicating online and agreeing collective action. We need good and regular support to help us organise ourselves.*
- *There can be a lot of fighting and bullying on social media so we need to know how to protect ourselves. Keeping safe is really important.*
- *A lot of the information about Covid-19 had been online, even if it's in easy read we can't always access it. Also, not all support workers will help you with documents.*
- *Applications for Covid-10 testing and other important information is all online now.*
- *We've had a lot of activities and social meetings online, not just meetings.*
- *Not everyone is willing or able to get online.*

Learning

1. Setting up online meetings requires careful planning. Initially meetings did not have adequate security and we were 'Zoom bombed' by people being abusive and sharing inappropriate images. This was quickly rectified and safeguards were put in place.
2. The support that people with learning difficulties get on a day to day basis is focused on a traditional model of care rather than a modern model of support. This meant that some people were told by their carers or supporters that they couldn't have help to get online or use technology as it wasn't in their job description.
3. Our members spoke about how support was more flexible when based on a Personal Assistant (PA) model where support is tailored to what you need and want rather than what a service thinks you should have.
4. People with learning difficulties living in supported living, residential care or who were in Assessment and Treatment Units (ATUs) had their communication channels restricted and had even less support to get online. We were told about 'blanket rules' being applied, such as people not being allowed to use communal phones because of coronavirus.
5. People with learning difficulties were at risk of being scammed either by online or cold callers offering to get shopping for a charge.

6. Statutory services were slower to respond to the needs of people with learning difficulties (particularly people living in the community with little or no support) than local voluntary sector and self advocacy organisations.
7. People with learning difficulties have not been well connected to local mutual aid networks in their community.

Recommendations

1. Commissioners and providers to fund digital support for social inclusion activities and include in job descriptions, expanding on traditional care tasks.
2. Government and local authority to have the expertise in place to produce accessible public health guidance for all at the point of publication.
3. A national funded programme of digital inclusion and digital skills development to give people living at home or in services the right skills, equipment and broadband.
4. Resource self-advocacy groups to provide the support necessary to ensure people are digitally connected and rely less on institutions and services, and are not isolated. For example Digital Ambassadors and Champions programme (Iriss, 2020).

5. Ensure there are alternative routes for people to access support and services and stay connected to their communities.
6. Establish Corporate Social Responsibility (CSR) relations with tech companies to increase access to internet and devices.
7. Accessibility standards for websites to be better promoted and enforced under the Equality Act and Human Rights Act.

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