FILLING IN THE GAPS

THE ROLE OF SELF-ADVOCACY GROUPS IN SUPPORTING THE HEALTH AND WELLBEING OF PEOPLE WITH LEARNING DISABILITIES THROUGHOUT THE PANDEMIC

CONTENTS

EXECUTIVE SUMMARY

This report describes research by The Open University on the role of self-advocacy groups in supporting the health and wellbeing of adults with learning disabilities during the coronavirus pandemic.

In July 2020 we spoke to staff and members of 11 self-advocacy groups, representing all regions of England, to find out what they had been doing to support members during lockdown.

The breadth and depth of their work during the pandemic was impressive. Self-advocacy groups responded very quickly, moving much of their work online while also providing essential offline support, and face-to-face practical help where required. Our research shows how and where self-advocacy was 'filling in the gaps' left by other services. The key findings are:

1. Self-advocacy groups worked hard (and fast) to support members to get online, helping to bridge the 'digital divide' that many people with learning disabilities experience. They did this by providing remote technical support; helping members to develop their digital literacy skills; and securing funding to purchase technological devices. Zoom was for all the most accessible video conferencing app.

2. Self-advocacy groups provided extensive offline support, for example organising phone rotas, and sending information and activities through the post.

3. Self-advocacy groups played a critical role in supporting mental health and wellbeing during the pandemic by enabling people to stay socially connected; organising online activities and social events; and providing regular check-ins. Some members reported that the only social contact they had during lockdown was with their self-advocacy group.

4. Self-advocacy groups supported people's physical health during the pandemic in a number of ways. All took responsibility for adapting government public health advice on coronavirus to accessible Easy Read format. Several advised on healthy eating and the importance of physical exercise. Some supported members to access and use health services, particularly where these had changed due to COVID-19.

5. Self-advocacy staff provided essential frontline services to people, delivering food packages and medication.

6. Self-advocacy staff and volunteers sometimes stepped in to support people in or close to crisis relating to mental or physical health, or safeguarding.

7. Self-advocacy groups signposted members to essential public services and third sector initiatives. They acted as intermediaries where members had difficulties accessing services.

8. Many groups mobilised a local volunteer network to extend their capacity to provide support.

9. Self-advocacy groups went 'above and beyond' during the pandemic, with staff often working seven days a week to provide support.

10. As self-advocacy groups became more confident in using online technologies during the pandemic, this strengthened connections between them across different regions of the country.

RECOMMENDATIONS

FOR SERVICE PROVIDERS

- Providers should support their service users to access technology to allow them to stay connected.

- Providers should make provision for people with learning disabilities who do not have access to technology and adapt to their preferred method of communication.

- Providers should recognise that Zoom is the video conferencing app that people with learning disabilities find most accessible.

FOR GOVERNMENT

- Government policy should support digital inclusion for people with learning disabilities (e.g. through funding of equipment and support) and make provision for those who do not have access to technology.

- Government policy should be informed by awareness of the difficulties faced by people with learning disabilities during the pandemic, in particular the need to provide accessible information on the coronavirus.

FOR COMMISSIONERS

- Commissioners should recognise the skills, networks and reach of self-advocacy groups, and their capacities to innovate and respond in times of crisis and act accordingly when allocating funds.

- Commissioners should use their role in contracting services to require that digital inclusion is provided for all residents and service users.

- Commissioners should take into account the level of work created by the pandemic for self-advocacy groups and the pressures on their resources in terms of equipment and manpower.

- Commissioners and service providers should take steps to remedy the gaps in services highlighted by this report to inform future services/ service provision. Particularly urgent concerns are difficulties accessing food and medication and physical/mental health care in times of crisis for those who do not have anyone to act as intermediaries.

FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

- Seek out and join a group – if you cannot find one locally, you might find one to connect to online.

GLOSSARY OF TERMS

LEARNING DISABILITY

For the purposes of this report we are using the term 'learning disabilities' to refer to some form of difficulty with experiencing and acquiring new information, which typically starts in childhood and impacts on ability understand new or complex information, to learn new skills and to cope independently (Department of Health, 2001).

SELF-ADVOCACY ORGANISATION

Self-advocacy means knowing your rights and responsibilities, speaking-up for your rights, and being able to make choices and decisions that affect your life. In the context of this report, we will use the term 'self-advocacy organisation' to refer to any group or organisation that supports people with learning disabilities to develop the capacity and confidence to self-advocate.

SUPPORT WORKER / STAFF MEMBER

In the context of this report we have used the terms 'support worker' and 'staff member' to refer to someone who is not a self-advocate but is employed by a self-advocacy organisation to support the organisation's activities. This includes: supporting members to self-advocate and supporting project management and the day to day running of the organisation.

TECHNOLOGY

We are using a broad definition of technology in this report in order to capture all possible kinds of support that might be provided to people with learning disabilities during the COVID-19 pandemic. For example, technologies that support communication with others, access to information or services or engagement in leisure, educational and therapeutic activities. Typical examples of technology include: mobile and Smart phones; tablets, personal computers and laptops; communication apps such as Zoom, Skype and WhatsApp; the Internet and apps available online such as YouTube; social media apps such as Facebook and Twitter; games consoles; MP3 players and other devices that play stored music.

ACKNOWLEDGEMENTS

1   INTRODUCTION

This report is about the ways self-advocacy groups have supported members during the pandemic.

People with learning disabilities are especially vulnerable to the challenges associated with the COVID-19 pandemic and its management *(Courtenay & Perera, 2020; Gulati, Fistein, Dunne, Kelly, & Murphy, 2020; Lodge, 2020).*

Things they have to deal with include:

- Loss of contact with family and friends
- Reduced contact with health and social care staff
- Reductions in care packages
- Shopping and obtaining medication
- Closure of day services
- Sudden changes to routines and activities
- Loss of roles as workers or volunteers
- Understanding and adapting to measures such as self-isolation, social distancing and mask wearing
- The emotional impact of COVID-19 related media information

(Courtenay & Perera, 2020; Langdon, 2020).

Since the start of the COVID-19 pandemic, self-advocacy groups have adapted to work with members at a distance, both online such as Zoom and Facebook and using more traditional media such as phones and post. The Open University decided to fund research to document precisely how they were operating.

The first-hand experiences from self-advocacy group members described in this report begin to give an idea of the role these groups have played to fill in the gaps in support experienced by people with learning disabilities during the national lockdown prompted by the COVID-19 pandemic.

This report aims to describe the role of self-advocacy groups in supporting the health and wellbeing of adults with learning disabilities during the pandemic.

2   METHODS

2.1   RECRUITMENT AND PARTICIPANTS

We selected 11 self-advocacy groups, representing all regions of England. We knew either from personal contact or from their online presence that these groups continued to be active during the national lockdown of March to June 2020.

The 11 groups were invited to take part by email. All agreed.

During July 2020 the researcher did 17 interviews. A total of 38 participants (22 self-advocates, 14 support workers and two family members) took part.

Self-advocates included trustees and committee members.

People in supporting roles included self-advocacy co-ordinators, advocates, an office coordinator, project workers and two family members.

2.2   INTERVIEWS

Semi-structured interviews were guided by an interview schedule focused on exploring how self-advocacy groups were supporting members' health and wellbeing during the coronavirus pandemic, including their access to and use of technology. A separate strand of the study focused specifically on access to technology (see Seale, 2020).

All interviews took place in July 2020. Due to COVID-19, all interviews were conducted remotely (four by phone and 13 online). People were asked which medium they would prefer.

Two self-advocates asked to see a copy of the interview questions beforehand to help them prepare. Some people used assistive technology and messaging/ chat facilities in online platforms to communicate during the interview.

Three self-advocates and one staff member chose to be interviewed individually. All others chose to be interviewed in a group consisting of self-advocates and/ or staff/family members. Interviews were audio recorded and transcribed.

Data were analysed for themes on the role of self-advocacy groups in supporting members during the pandemic.

2.3   ETHICS

Ethical approval to conduct the study was granted by the Open University's Human Research Ethics Committee (HREC/3604/Seale). An accessible easy read information sheet and consent form was provided, and all participants gave informed consent before being interviewed. People with learning disabilities could choose to have someone they know with them during the interview such as a family member.

3   WHAT WE FOUND OUT

3.1   THE IMPACT OF THE PANDEMIC

First, for context it is worth briefly noting some of the ways people reported that the pandemic had impacted on members.

- Emotional impact – people described feeling too anxious to leave their home, bored, sad, lonely, anxious, depressed, 'teary' and scared.
- A worsening of mental health problems such as anxiety, depression and suicidal feelings.
- Isolation.
- Struggle to access food or medication.
- A reduction or withdrawal of support services for some people who live alone.
- Although some people praised support staff, others described a lack of understanding from staff about the impact of the pandemic on their emotional wellbeing.
- Worsening physical health due to lack of exercise or poor diet.
- Safeguarding issues, such as increase in local antisocial ehaviour, hate crimes and loan shark activity.
- Some people temporarily moved in with family during lockdown. This led to loss of independence and, for some, a less accessible living environment.
- Some people were shielding for long periods due to their own health conditions or the conditions of those they live with in supported living/communal environments.

3.2   THE THEMES

The themes illustrate the role of self-advocacy groups in supporting people by filling in the gaps heightened or created by the pandemic.

Throughout the interviews, self-advocates and staff members argued that self-advocacy groups have picked up support needs neglected by other organisations. One support worker said:

"What we were doing, is picking up things that people are saying that aren't being picked up by the providers and the council."

We start with the topic of remote working because this was a prerequisite for groups to be able to stay active. Further detail on the role of technology can be seen in the separate report (Seale, 2020).

3.3   REMOTE WORKING

All 11 groups reported a rapid shift to working remotely with members, either online or through other methods.

3.3.1 SUPPORTING PEOPLE ONLINE

Most groups embraced technology to support members during lockdown. It enabled groups to stay connected and run activities to support health and wellbeing. It enabled self-advocates to continue working on pre-COVID-19 projects that required collaboration with other organisations such as the NHS or local authorities, via Zoom and Microsoft Teams. Adapting to online working required considerable planning, effort and innovative thinking. Although some members were familiar with some smart phones, social media and apps, most groups had little or no previous experience organising online meetings and had to learn and train others in new software/ platforms. Getting started involved some trial and error with most groups finding Zoom particularly accessible. Lockdown also led to greater activity on group social media accounts like Facebook, requiring input from staff.

3.3.1.2   GETTING ONLINE

Most (10 out of 11) self-advocacy groups put considerable effort into enabling members to access technology. This included sourcing funding for or donations of equipment such as laptops, smartphones and ipads; setting up technology and providing training in how to use email, social media and platforms like Zoom; negotiating with family or paid carers on technology/internet access; support to use technology from home; advice for technical issues.
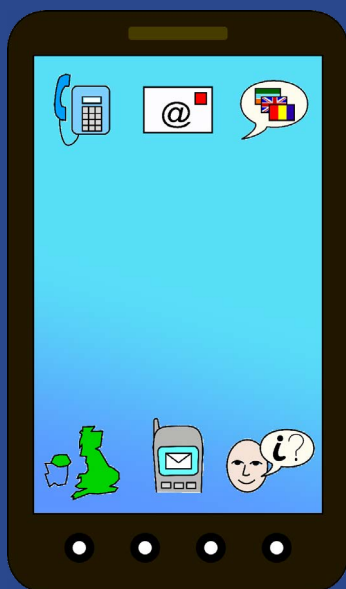
"So all the devices got delivered to, well to my address anyway, and I delivered them to staff members who then set them up. Then the staff team that had cars would deliver them. And then there was a few people that were really struggling, and there's I think four or five examples where a staff member has sat in the garden or on a doorstep chatting with somebody inside the house."

SUPPORT WORKER

Some felt self-advocacy groups were filling gaps which *should* be the role of social care support staff and felt strongly that people with learning disabilities should be supported to access technology. One self-advocate said 'the support workers should be helping them to do what they want to do.'

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3.3.1.3   LEARNING NEW SKILLS

Learning new skills and building confidence with technology has been a positive and potentially lasting benefit of lockdown. Some groups described being 'pushed' into greater use of technology. Both staff and self-advocates were surprised at the skills and confidence members had developed. One support worker told us:

'I've been amazed at some of the service users who have taken it on as well ... We just didn't think it was possible'.

Technology reduced barriers to involvement. Some people felt more confident to contribute to online meetings. Barriers relating to travel were removed. Self-advocates found functions such as mute in Zoom useful to take control when chairing meetings. One self-advocate told us:

"Well it means that I can get talking to people and then record what they say. It makes, it's not that it makes you feel important but it's oh I'm doing something that I need to do. I'm actually doing it, so it's given us some control, not over, not overbearing control, but just some sort of control of what's happening."

SELF-ADVOCATE

| Examples of online support |
| --- |
| Regular meetings, campaigns and projects online |
| Group chats and activities |
| 1-1 chats or advocacy |
| Easy read guides and videos e.g. to using Zoom. |
| Sourcing IT equipment (through funding or donated/refurbished equipment, training in unused equipment) |
| Training to use technology |
| Support to buy, set up and use new technology e.g. tablets, laptops, WiFi. |
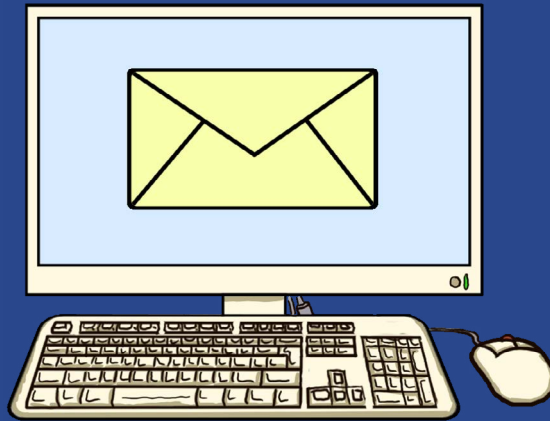
3.3.1.4   A DIGITAL DIVIDE

Although there were many success stories of people with learning disabilities accessing technology, there remains a notable digital divide. Some were unable to connect despite the efforts of self-advocacy groups.

Barriers to getting connected online
Wi-Fi costs
Resistance from family / paid social care supporters
Limited time with support staff
Safeguarding concerns
Family or paid social care supporters who lack technical knowledge
No or restricted access to the internet or IT equipment
The person is fearful of technology.

Many made the point that, although they appreciate the benefits of technology, they 'miss the human contact' of face to face meetings and getting out and about. Staff members highlighted that it is more difficult to pick up signs that people are struggling when working remotely. This topic is covered in more detail in our separate report on the role of technology (Seale, 2020).

3.3.2   SUPPORT USING OFFLINE METHODS

All groups emphasised the importance of offline methods of support. This was particularly important at the start of lockdown whilst making arrangements/testing out online meetings and remained vital for those who cannot or prefer not to go online.

3.3.2.1   PHONE ROTAS

Supporting people via phone has been a major activity for all, requiring great effort and organisation. Regular phone calls allowed groups to check on welfare, support mental health and reduce isolation and loneliness. Calls were often made by staff and volunteers without learning disability, but groups also set up phone buddy systems where self-advocates called each other for mutual support.
Staff highlighted that different people have different needs regarding regularity of calls and preference for talk or text/recorded messages. One self-advocate in a phone buddy scheme said, 'It's just nice to have a chat to somebody, especially if you're feeling lonely and on your own.'

3.3.2.2   NEWSLETTERS

Five groups produced a newsletter to reach out to members who were not online. They included:

- Advice and ideas on ways to improve health and wellbeing
- Members' messages
- Activities like puzzles, colouring in, competitions,
- People's experiences of lockdown
- Accessible information such as government guidelines
- Exemption cards for masks that people could show on public transport.

Groups also came up with ways of helping people contribute to newsletters:

"And then at the end we've got a question, a feedback form, so it's usually a question, is there anything you want to ask or tell us. So we want to keep finding out how people are doing. And that last page, so people write on one side, they fold it up, get a bit of sellotape and stick it down, and then stick it in the post. It's free post."

SELF-ADVOCATE

Other forms of offline support have included socially distanced visits, practical support such as facilitating phone calls with GPs and arranging medication deliveries and, for some, preparations to safely return to offices as lockdown began to ease.

Offline methods of support
Writing letters
Regular phone calls
Joining group Zoom meetings by phone
Hard copy meeting minutes
Newsletters by post
Information/activity by post
Socially distanced visits

3.4 SUPPORT OF MEMBERS' HEALTH AND WELLBEING

All groups prioritised health and wellbeing. This included supporting people to stay connected, have routine, a sense of purpose and to have fun. Activities centred on mental health, physical health and sometimes supporting people in crisis due to mental health, physical health or safeguarding issues.

3.4.1 SUPPORTING MENTAL HEALTH

3.4.1.2 STAYING CONNECTED

The groups tried to support mental health and reduce isolation and loneliness by keeping people connected. This was done through phone rotas/buddies, online activities, social media groups and newsletters. Opportunities were provided for one-to-one chats as well as group meetings and communal activities. One self-advocate reported:

> "I've got a telephone buddy I ring up regularly, and I ring up other people as well, because I just like to talk to the members. I live on my own, and I get lonely as well, it's just nice to have a friendly voice to talk to and see what they've been up to."
>
> **SELF-ADVOCATE**

Additionally, all groups supported mental health by providing a space where everyone can talk about the emotional impact of the pandemic. Both self-advocates and paid staff reported that sharing experiences and knowing that others were going through the same thing was helpful. Some staff members said that it was important not to trivialise what is happening and for everyone to know 'that it's OK to not be OK'.

3.4.1.3   KEEPING BUSY AND HAVING FUN

Groups provided opportunities to stay occupied and mentally active, giving people a sense of purpose, structure and routine.

Some groups were able to keep people in work through the continuation of pre-COVID activities and campaigns adapted to remote ways of working. For example, moving regular group and committee meetings online and converting in-person training of healthcare professionals into Zoom sessions. New campaigns, projects and events have also been developed in response to the coronavirus. One self-advocate said that they were 'always busy' doing self-advocacy work 'which I really do enjoy, I love it'.

Staff, volunteers and family members also benefited from the sense of structure, purpose and connectedness that working with self-advocacy groups brought, saying 'I value and I've enjoyed' it and that connecting with members had lifted their mood. Some staff credited their work with helping them through lockdown because of the connectedness and 'just the whole community feel of it'.

Self-advocates and staff described the need to strike a balance between activities that revolved around work and the coronavirus and the need to take a break and have fun. Self-advocates and staff came up with many ideas for fun social and creative activities that could be held remotely – an online nightclub, coffee mornings, quizzes and competitions, online art gallery and poetry sessions.

Groups also ran online activities aimed at promoting wellbeing, like sessions on relaxation and advice on good sleep and stress management.

Examples of activities to promote connection and wellbeing
Quizzes and competitions (within the group and with other self-advocacy groups)
Bingo
Weekly art challenges/creating an online art gallery
Online discos
Online coffee mornings
Beauty treatments
Film nights (online)
Hard copy activities posted out to members e.g. Colouring in, spot the difference, word searches
Writing and sharing poetry

3.4.2   SUPPORTING PHYSICAL HEALTH

Self-advocacy groups supported physical health in two main ways: by promoting good physical health online and by providing support relating to healthcare services.

3.4.2.1   PROMOTING PHYSICAL HEALTH

Promoting good physical health included cooking videos/activities; walking groups; clarifying government rules on leaving home for exercise; sharing or holding online exercise sessions. Some groups tried to raise awareness of health issues including online sessions on spotting cancer symptoms, health checks and raising awareness that GP/health services were still available during the pandemic.

3.4.2.2   SUPPORT WITH USING HEALTH SERVICES

Support relating to using healthcare services included facilitating and supporting members to make and attend appointments, particularly where these processes had changed due to COVID (moved to online/phone). Self-advocacy groups also helped to familiarise people with COVID related changes to healthcare environments. Some groups hosted online meetings or made videos with healthcare professionals such as GPs and learning disability nurses to explain how things are different when visiting GP surgeries or hospitals and to give advice and answer questions. Some self-advocates shared videos and blogs about their own experiences of using healthcare services during the pandemic. One staff member described how these activities had 'broken down … barriers that people sometimes have with going to the doctor or nurse.' Groups also helped people prepare for possible hospital stays including working remotely on hospital passports or a 'COVID grab sheet' with 'key information if somebody ends up in hospital'.

3.4.2.3   FOOD AND MEDICATION

Self-advocacy groups have also supported members to access the basics for maintaining physical health such as food and medication. Self-advocates and staff members explained that getting shopping and medication was difficult for some members during lockdown due to loss of support and difficulty using online systems. Eight groups described supporting access to food or medication by arranging deliveries from shops/pharmacies; making referrals to local charities, supporting members to navigate online systems; providing information (e.g. on priority shopping, online shopping, use of lanyard systems) or making deliveries in person through staff, volunteers or self-advocates (see section 3.5). One self-advocate who was shielding explained that their group's office co-ordinator 'phoned up and I told her what I wanted ... she used to leave it on the doorstep'. Additionally, five groups arranged events or shared information on cooking skills (including healthy eating and budgeting). One group described working with local supermarkets to raise awareness of the difficulties people with learning disabilities faced when trying to shop during the pandemic.

Activities to support physical health
Interviews or online information sessions with healthcare professionals
Making NHS advice accessible
Liaising with GPs over reasonable adjustments to surgery and online appointments
Making films to raise awareness of cancer symptoms
Liaising with or signposting members to healthcare services
Alerting NHS England to the adverse impact of the coronavirus on people with learning disabilities
Facilitating contact with GPs and medication delivery
Encouraging or supporting people to go for a walk
Online sessions or videos to increase physical activity e.g. yoga, stretching, Zumba
Preparing for healthcare appointments and visits e.g. hospital passports
Online cooking sessions
Support to set up online shopping/shopping deliveries e.g. film about Morrisons boxes
Delivering shopping and medication in person

3.4.3   SUPPORT IN TIMES OF CRISIS

Self-advocacy groups sometimes stepped in to support people in or close to crisis relating to mental health, physical health or safeguarding issues. Reasons for this type of support included urgent need for physical or mental health care, the stress of (remote) PIP reviews and experience of increased local antisocial behaviour or hate crimes during lockdown.

Support in times of crisis often involved groups flagging concerns to get appropriate support including 'referrals to psychology and psychiatry' and raising concerns with learning disability nurses. Seven groups described providing advocacy between members and their service providers for ongoing difficulties with their support or cuts and changes in the climate of COVID. They also helped people undergoing PIP or social care assessments to complete forms or take part in remote meetings (see also Providing practical support) Section 3.6.

3.5   PRACTICAL SUPPORT

Some people with learning disabilities experienced greater need for practical support during the pandemic due to the need to self-isolate and/or a reduction or loss of their usual support networks or a withdrawal or reduction of support services during lockdown. One staff member explained people 'were losing the day services, the home support, their social lives, you know, everything was just crumbling.' Because groups had worked hard to maintain support and connection it often meant they were the first port of call for members in need of practical support. It also meant that staff and volunteers were in a good position to 'pick up on little things' and to 'see that actually some people are struggling' during their phone or online contact.

3.5.1   SIGNPOSTING AND REFERRALS

The most commonly described type of practical support was sharing information about or actively referring people onto other services or sources of support such as food banks and local organisations/schemes that could arrange ordering and delivery of shopping and medication during lockdown. This is a clear example of self-advocacy groups going 'above and beyond' during the pandemic.

"So for example we've had one person who was really struggling and on their own ... Ended up in hospital because they drank too much, and rang our team at three o'clock in the morning to say I need some help, I don't know who to call. And so the team responded, and have been supporting that person since. And there's been another incident where they rang somebody, and had to go to their home, and go into the home, and we don't offer care like that at all. But they were in a bad state, because they'd drunk too much, and again had to support them, help them back up, and contact the safeguarding, contact services to make sure that person was getting the support that they needed."

SUPPORT WORKER

"...there has been support available with nearly everything, it's just a question of knowing where to find it. ... I disseminate that information about different sorts of support that people can get and also link people in with services or refer them in as well. "

SUPPORT WORKER

Groups acted as intermediaries where members were experiencing difficulties using or accessing services:

- Helping people to navigate healthcare appointment making systems
- Dialling in to online or phone meetings with healthcare appointments or PIP assessments
- Contacting services to flag concerns relating to support, health and safeguarding issues due to reduced support services
- Alerting learning disability nurses to healthcare concerns

AN EXAMPLE OF PRACTICAL SUPPORT THROUGH REFERRAL

...they had support every day to help them cook food, and then come lockdown they left, and the person didn't know how to use their microwave because the support staff did it. So they had no hot dinner, and they said well I'll go and buy and sausage roll, I'll class that as my hot dinner for the day. So we then managed to talk to them, and speak to a meals on wheels service who then started to deliver the food. So that worked a lot better for them, they had a proper time and they had a proper meal as well."

SUPPORT WORKER

3.5.2 FACE TO FACE SUPPORT

Five groups described providing practical support themselves –
going shopping for people or picking up and delivering their medication.

"They've (some members) had four different people ring them a day, and then a visit and their meals cooked, and all their shopping done and all their washing … It's not where we've gone out and sourced other agencies to do it, it's literally been done by us. "

SUPPORT WORKER

Examples of practical support
Medication deliveries
Arranging meals on wheels
Dropping off shopping and medication
Driving people to hospital
Organising hearing aid replacements
Providing mask exemption cards or letters
Flagging healthcare or safeguarding concerns to healthcare or social services/service providers
Signposting or referring people to local resources like foodbanks
Support with managing finances.

3.6 ACCESSIBLE INFORMATION AND RESOURCES

Self-advocates and staff highlighted the difficulties caused by the lack of accessible information and resources from Government and the confusing nature of information given during daily briefings. This motivated groups to produce and share accessible information and resources on social media and through newsletters. Staff described clarifying information during online meetings and over the phone. Some self-advocates were clear that providing accessible information about the pandemic was the Government's legal responsibility but that self-advocacy groups had been left to pick up this task.

Groups also cleared up misinformation because 'sometimes people hear stuff off the internet that's not true.' When members of one group reported they had heard that they shouldn't have the vaccine 'because it will be bad for black people', the group contributed to a Race Equality Foundation document which clarified that 'there is no evidence at the moment to suggest that the vaccine is harmful to people from black communities.' (Race Equality Foundation, 2020)

Staff explained that providing information has been challenging because the rules changed regularly and are often unclear 'you're trying to tell them what the guidelines are, you're not sure yourself because they're unclear'.

Accessible information provided by self-advocacy groups:
Daily government briefings
Reminders that Coronavirus is still circulating as lockdown eases
Clarifying the relationship between the coronavirus and race
Guidance on wearing masks and using public transport (including exemption cards)
Clarification of exemptions from some restrictions.

Ensuring clear understanding helped to allay fears, enabled people to follow guidance and to safely increase activities such as using the bus and shopping.

"So I've had to spend ages looking for the accessible copy, easy read copy, and I'm like thank god for that, because I can truly understand it. Because from the official one you're like, I was like what does this truly mean? ... This is the thing, it's like in a pandemic you shouldn't have to ask for something to be made accessible."

SELF-ADVOCATE

3.8   CARE FOR MEMBERS

Self-advocates and staff highlighted that self-advocacy groups care for their members. Groups went to great lengths to reach out, to reduce isolation, support wellbeing. This is demonstrated in the time, thought and effort put into supporting people as described in each of the sections above. Members emphasised how important this was at a difficult time.

"So I'm in contact with my group all the time and I think that's the same with a lot of people as well. I think that's really important, because I get insecure a lot, I feel insecure, I feel lost in myself. But my group is always there, been there to pick me up, even through lockdown. So they've offered me one to one help with things and phone calls and stuff and advice and information. So yeah, they've been really good. They've been a lot, well it's been, I think they've overworked themselves to help other people should I say."

SELF-ADVOCATE

"... we've really come together and supported each other and we've been honest with each other ... we've cried happy tears, sad tears, but we've really bonded and become stronger and if I didn't have this I don't think I'd be in a good place. And I really feel sorry for a lot of people out there that are in jobs that don't have the support group that we automatically have and I think I wonder how they're coping."

SUPPORT WORKER

Working together to get through the experience of lockdown strengthened existing relationships. One group described it as feeling 'like a second family'. Some staff, self-advocates and family members said that they did not know how they would have got through lockdown without their group. It had given something to focus on and a space for mutual support.

3.9 THE ROLE OF NON-LEARNING DISABLED STAFF

The care that groups had for their members can be seen in the efforts of staff to keeping things going. Staff and members commented on how people had gone above and beyond their usual roles, including being available at different times of day and at weekends 'like being on constant call'. Large scale operations were rapidly planned, put into practice and refined under difficult circumstances. Setting up and implementing phone rotas was described as 'time consuming' and 'draining'.

3.10 ESTABLISH – OR BUILD UPON – CONNECTIONS WITH OTHER GROUPS ACROSS THE COUNTRY

Some groups established new or built upon existing connections with other groups for fun activities such as quiz challenges and for sharing useful information and experiences. Groups connected online, holding Zoom meetings and talking on social media. One group described speaking to self-advocates in Mexico and Kenya. This was made easier through increased use of technology during the pandemic. Learning Disability England provided a platform for connecting different groups and enabling information sharing, especially about what people have learnt during the pandemic. These connections were cited by many as a positive outcome of the pandemic and 'opened up possibilities' for the future.

4 CONCLUSION

The pandemic was an isolating experience for people with learning disabilities, leading to a reduction in social networks and support and left some people in extremely vulnerable situations. Self-advocacy groups played a crucial role in supporting members by filling gaps in support that were heightened or created by the pandemic.

Filling these gaps has required considerable effort and flexibility, rapidly responding to the needs of members. Most of the groups in the research supported people using online methods including attempting to overcome barriers to digital inclusion for people with learning disabilities. They were creative in developing ways to support people using offline methods, acknowledging that some members do not have access to technology. This opened the way to support people by combatting isolation, providing things to do, accessible information and practical support.

Groups showed care for each other creating a 'community' or 'family' feeling that helped people to get through lockdown. Most said they will take forward some of what they have learnt – increased use of technology and connecting with other self-advocacy groups.

The research begs the question as to what was happening to people who are not members of a self-advocacy group or similar. Given the amount these groups were doing to support members, it is a question with some urgency.

5 RECOMMENDATIONS

FOR SERVICE PROVIDERS

- Providers should support their service users to access technology to allow them to stay connected.

- Providers should make provision for people with learning disabilities who do not have access to technology and adapt to their preferred method of communication.

- Providers should recognise that Zoom is the video conferencing app that people with learning disabilities find most accessible.

FOR GOVERNMENT

- Government policy should support digital inclusion for people with learning disabilities (e.g. through funding of equipment and support) and make provision for those who do not have access to technology.

- Government policy should be informed by awareness of the difficulties faced by people with learning disabilities during the pandemic, in particular the need to provide accessible information on the coronavirus.

FOR COMMISSIONERS

- Commissioners should recognise the skills, networks and reach of self-advocacy groups, and their capacities to innovate and respond in times of crisis and act accordingly when allocating funds.

- Commissioners should use their role in contracting services to require that digital inclusion is provided for all residents and service users.

- Commissioners should take into account the level of work created by the pandemic for self-advocacy groups and the pressures on their resources in terms of equipment and manpower.

- Commissioners and service providers should take steps to remedy the gaps in services highlighted by this report to inform future services/ service provision. Particularly urgent concerns are difficulties accessing food and medication and physical/mental health care in times of crisis for those who do not have anyone to act as intermediaries.

FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

- Seek out and join a group – if you cannot find one locally, you might find one to connect to online.

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