

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

This report has been written by Lorna Rouse, Liz Tilley, Jan Walmsley, and Shaun Picken, with contributions from Jane Seale and Louise Wallace.

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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.