

**Written evidence submitted by Dr Andrew Power (University of Southampton)  
and Laura Kerr (People First Dorset) (CVD0030)**

## 1. Introduction

1.1 We are writing this response representing a group of academics at the University of Southampton and staff at a self-advocacy organisation, People First Dorset (PFD), which empowers people with learning disabilities with lived experience of the COVID-19 virus restrictions. Our collaborative work is undertaken via an ongoing relationship through the *Southampton Platform for Inclusive Research and Ideas Together (SPIRIT)*. This comprises a network of academics and disability organisations across the south coast of England. PFD, a member of SPIRIT, facilitates over 450 people across Dorset living primarily in the community, through supporting friendship and peer networks and advocacy, and building confidence and social skills. The members of the platform have recently completed a two-year ESRC funded research project<sup>i</sup> exploring the experiences of personalisation and have since been engaged in a follow-up research impact project (covering the COVID19 time-period). More details of the two members contributing to this submission is provided in Section 4.

1.2 We are submitting evidence for this call to highlight the role that the self-advocacy sector is playing during the COVID-19 pandemic and ensure that the perspectives of those with lived experience of learning disability are represented to Parliament. Our submission focuses on the **mental health of disabled people (with learning disabilities), including the effects of isolation.**

## 2. Key Recommendation

2.1 The Government's recognition of the need to address social care presents an opportunity to engage with the challenges that have arisen in the wake of COVID-19. However, it is important that appropriate support is given to the voluntary sector self-advocacy organisations, to capitalise on their important work during the disruption that COVID-19 presents. The self-advocacy sector can help people create and sustain networks of peer-support with other people with learning disabilities in the community, and stay informed of COVID-19 related developments.

2.2 **Key Recommendation:** In response to the COVID-19 pandemic and its impacts on disabled people, the government should ensure self-advocacy opportunities reach people with learning disabilities in the most vulnerable and isolated situations. This would require significant government investment to enable local authorities to incentivise self-advocacy groups in their area and to enable Learning Disability England to facilitate a national network of self-advocacy organisations.

## 3. Mental health of people with learning disabilities

**ITEM: *The mental health of disabled people, including the effects of isolation, access to mental health services and the implications for disabled people of temporary changes to the Mental Health Act.***

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<sup>i</sup> Economic and Social Research Council: Reclaiming social care: Adults with learning disabilities seizing opportunities in the shift from day services to community lives (ES/P011764/1; Feb. 2018-Feb 2020): <http://selfbuildingourlives.org/>

- 3.1 People with learning disabilities are a group particularly vulnerable to isolation and poorer mental health.<sup>1</sup> **Prior to COVID-19**, our research identified how isolation can be experienced and combated within this group. With the advent of personalisation, our research found that due to the individualised nature of personal funding, some people with learning disabilities who are living alone are lacking the support or opportunities to remain connected with others in their community.
- 3.2 In response to this gap, self-advocacy organisations have played a key role to create and sustain networks of friends, peers and neighbours with learning disabilities. We found that peer-support, facilitated through friendship clubs and self-advocacy groups, has the potential to combat isolation by building people’s networks, community engagement skills, and capacity for change.<sup>2</sup> PFD is an example of an organisation which provides both a self-advocacy ‘Speaking Up’ group and a Friendship Club, that typified some of the initiatives we found in our research.
- 3.3 **Since COVID-19**, PFD has continued to facilitate its self-advocacy and friendship group. They call members regularly who do not have access to digital resources i.e. smart phones, laptops or who do not wish to use Zoom. There are group zoom calls, coffee mornings – with bigger groups of people – and now a fortnightly newsletter aimed at giving people up to date information on COVID-19 in an accessible format. The newsletter also has friendship pages, speaking up pages, activities, mindfulness, cooking recipes – and a page at the back to send us back feedback in a freepost form. This is being done in conjunction with the local authority, Clinical Commissioning Group and hospital – and currently being posted to over 700 people.
- 3.4 Through these networks, PFD has continued to play a vital role in keeping its members connected, providing a social anchor point in people’s lives and maintaining positive mental health. A lot of this work has focused on digital exclusion, by addressing people’s variable levels of access and confidence with online digital technologies. They have found that this has enabled people to talk about how their routines have been significantly interrupted, helped their understanding of rules about social distancing and infection control, and addressed their heightened anxieties during the crisis.
- 3.5 In addition, PFD and many other disabled people led organisations and related initiatives (e.g. **Books Beyond Words: a [series of Covid-19 books](#)**) have created easy-read Covid-19 guidance dealing with some of the more uncomfortable discussions that we may all need to have in respect of coronavirus. During this time, Learning Disability England has been providing a key central role liaising with self-advocacy organisations around the country and facilitating the dissemination of COVID-19 resources ([LDE Coronavirus Information and Work Hub](#)). This builds on previous work self-advocacy organisations have been engaged in, facilitating discussions about connecting and keeping safe online, as our research found. This work that self-advocacy organisations is especially important as people with learning disabilities, particularly those not known to services or in receipt of support, have been reportedly left anxious by inaccessible COVID-19 guidance.
- 3.6 The recent experience of PFD, and the sector more widely, demonstrates the key role that self-advocacy organisations can play. The crisis provides an opportunity to recognise and support this sector. In our research, we found that it is precarious, typically reliant on charitable funding and small fixed-term grants. Consequently, it varies regionally due largely to this limited funding context.

## 4. Contributors from SPIRIT research and advisory group

4.1 Within SPIRIT, the following two members have contributed to this submission:

- a. **Dr Andrew Power** is Associate Professor in Human Geography at University of Southampton and has been researching experiences of people with learning disabilities for the past 15 years. He is co- founder of SPIRIT and has worked closely with the learning disability self-advocacy sector in research and engagement.

Web: <http://www.southampton.ac.uk/geography/about/staff/ap2r10.page>

- b. **Ms. Laura Kerr** is Manager at People First Dorset. She has over 20 years creating better opportunities and empowering people with learning disabilities to lead a full life within their community. She set up the Friendship Club for People First Dorset in 2008. Over 2,000 people with learning disabilities have attended its user-led events, creating numerous positive outcomes.

Web: <https://www.peoplefirstdorset.org.uk/>

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## References

<sup>1</sup> Power, A., Bartlett, R., & Hall, E. (2016). Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity. *Journal of Intellectual Disabilities*, 20(2), 183–193.

<https://eprints.soton.ac.uk/386134/>;

<sup>2</sup> Link to final report: Self-Building Our Lives. DOI: <https://doi.org/SOTON/D1352>;

Also see: Tilley E, Strnadová I, Danker J, Walmsley J, and Loblinzk J (2020) The impact of self-advocacy organizations on the subjective well-being of people with intellectual disabilities: A systematic review of the literature, *Journal of Applied Research in Intellectual Disabilities*, Early View,

<https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12752>