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Living with disability in a COVID-19 world

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Last September, at a time when COVID-19 had gripped the world, we published a literature review about the transition from adolescence to adulthood for young people living with cerebral palsy (Boyle et al., 2020). This showed there is little evidence of consideration of disability as a human rights issue, as understood by Shakespeare et al. (2018), nor is there any significant public involvement in research design in this area. This may reflect the research emphasis within the rehabilitation professions which has been criticised for not sufficiently including the voices of disabled people themselves (Shakespeare et al., 2018).

As health professionals with backgrounds in occupational therapy, physiotherapy and nursing we took a critical view with a consideration of disability as both a health and human rights issue which has influenced our thoughts regarding the new challenges we all face in a COVID-19 world. As such this editorial highlights three concerns. The first, is the risk that the needs of people living with disability may be neglected. Second, the need for evidence relating to this new phenomenon. And third, that such research is designed and carried out in a way whereby people living with disability have been included.

Between January to November 2020 approximately two-thirds of deaths as a result of coronavirus were disabled people and the risk of death was three times higher for those living with more severe levels of disability (Office for National Statistics [ONS], 2021). Further, according to the ONS (2021), people living with disability were disproportionately affected by coronavirus who are also particularly disadvantaged in many areas when compared with non-disabled people. For example, concern has been expressed about the UK's vaccine arrangements for high risk groups such as children with complex disabilities (Ryan, 2021), and the reduction in social care for disabled people (Wall, 2021). It appears also that disabled people are becoming less physically active with twice as many feeling the virus has greatly reduced their ability to partake in physical activity compared with non-disabled people leading to loneliness and social isolation (Activity Alliance, 2021).

Effective, equitable services in a COVID-19 world will be particularly challenging where there are competing demands for financial resources. Drummond and Lannin (2020) praise practitioners for adapting quickly to work in new ways in response to the crisis but also highlight the need to ensure interventions are based on evidence. According to The Health

Foundation (2020) the pressure on public resources is huge, yet the government remains committed to investing in long-term and wide-ranging reform of NHS and social care services. Therefore, research to support evidence-based practice in this new COVID-19 world is paramount and we welcome this journal's commitment to publish high quality research (Lambert, 2020). We now live too with a new phenomenon – long COVID – with health professionals arguing the need to listen to the lived experience (Gorna et al., 2021). In this regard we are heartened that this journal's research strategy will prioritise “Well conducted and reported qualitative research” (Lambert, 2020: 487).

We hope especially there will be an emphasis on research that includes public involvement as recommended by Atkin et al. (2020), including young people living with severe levels of disability. Harries et al. (2020: 4) encourage public involvement in research suggesting researchers ask themselves “How do you seek feedback from a broad range of people, rather than focussing on those most easy to engage?” This is a key point to ensure public involvement has depth and is not simply tokenistic. Although there is limited research about the use of public involvement in research design, the benefits seem to include development of user-friendly information and appropriate recruitment strategies (Brett et al., 2014). But more research is necessary and especially so in relation to Harries et al.'s (2020) point about reaching out to those who might be challenging to engage.

Watson (2021) reminds us of the need to use public money wisely highlighting the COVID-19 challenge and the need for new knowledge to inform rehabilitation and recovery that is clinically and cost effective. This, we believe, will be important for those living with high levels of disability as demand on services is likely to increase over the coming years, and there is much that is unknown about the virus and how this might affect young people living with severe levels of disability. Such challenges accelerate the need for rehabilitation services to be based on equality and partnership

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to ensure the needs of severely physically disabled youth are considered equally alongside other groups. As the world adapts to accommodate the virus such developments will inform the management of any necessary social shielding, access to vaccinations, and education, leisure and work opportunities. We hope this response to the COVID-19 challenge will be disability inclusive, this means valuing the lived experience and listening more to people living with disability.

Researchers committed to the involvement of service-users and the public should be encouraged as this will result in well-designed studies that resonate with those who use services. This will also help practitioners understand what makes a difference in terms of impact, inform how we can ensure person-centred work is central to what we do, and how we can work effectively with families and carers - all areas of research priority for occupational therapists (Royal College of Occupational Therapists, 2019). We look forward, therefore, to reading research in the *British Journal of Occupational Therapy* based upon principles of inclusivity enhancing justification of valuable research to our research community and more importantly to research participants, people like them and people close to them.

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