



Disabled people in Britain and the impact of the COVID-19 pandemic

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Background

There are 11 million disabled people in Britain; 45% of them are aged over 65. Many disabled people have co-morbidities. Some live in congregate living situations or depend on social care workers or personal assistants. All this means that disabled people may be at higher risk of Coronavirus (SARS-CoV-2), and of having worse outcomes from COVID-19.

What did we do?

We talked to 69 disabled people in England and Scotland in June-August 2020 (Table 1). We talked to men and women, and we also talked to care-givers of disabled children. We did talk to people from Black and Minority Ethnic communities, but they were under-represented.

Table 1. Respondents by impairment category

Impairment	Number
Autism/neurodiversity	8
Cognitive impairment	5
Intellectual impairment	19
Mental health condition	18
Physical impairment	33
Sensory impairment	15
Total (some participants had multiple conditions)	98

We also talked to 28 people in England and Scotland who worked for disability organisations, or worked in education or health or social services.

We did many interviews on Zoom, but also on the telephone and some by email. All interviews were transcribed. We analysed the interviews and discussed them together. All names were anonymised and no one we spoke to is identifiable in this or other publications. The project received independent ethical review.

What did we find?

COVID-19 has had a huge impact on people and organisations we talked to. Measures to respond to COVID-19 also had a huge impact. A CEO of a large disability organisation put this succinctly:

'I mean without being dramatic I think it's been catastrophic. I think it has taken existing inequalities that disabled people experience and it has magnified them and exaggerated them'. (SO12)

Every day life has been disrupted.

People described how their health care and support had changed significantly. Routine physiotherapy, speech and language therapy and occupational therapy were cancelled. Attempts to replicate these therapies either via video conference or phone were not perceived to be particularly successful. Many routine annual check-ups were cancelled, raising the risk of preventable medical problems being missed. Provision and servicing of assistive products and aids to daily living was severely affected.

All this may lead to lack of functioning and increased dependency, with potential negative impacts on caregivers. Caregivers expressed concerns about long-term negative impacts for disabled children, affecting their health, development and education.

People were fearful about the virus. They were anxious about going out. Many found it impossible to practise proper social distancing. Adam said: *‘it’s...like, missing out the shaking hands with people and giving them a hug and things like that. As a blind person I’m missing out on the whole lot because of social distancing.’ (S15)*

People who were deafened or hard of hearing talked about the problems facemasks caused and the abuse they received if they asked people to remove them to help understanding: transparent masks for lipreading have been in very short supply, leaving people excluded from the spoken world.

Disabled people appear to have been an afterthought in the response to COVID-19. For example, we heard how provision was often made for non-disabled children who were learning from home, but not, at first, for children with special educational needs and disabilities, and learning materials were often inaccessible or inappropriate.

Personal Protective Equipment (PPE) was provided for hospitals, but not for care homes, and then in care homes, but not for homecarers and personal assistants. Some disabled people’s organisations had to step in and source PPE for their members.

Social care has failed to respond effectively.

Our research participants described how the pandemic and protective measures to avert contagion had led to increased reliance on their family and other informal carers. First was the closure, or suspension of day centres, day services and large sections of the social care system, large numbers of social care contracts were cancelled, put on hold, or severely limited. Second, some of our participants were anxious about having too many people coming into their own homes and wanted to reduce contact. As a result, where it was possible, they preferred using family members who were already part of ‘their social bubble’.

If new needs arose it was often hard to get support and in some areas social care assessments were suspended for up to four months, leaving those with newly acquired impairments or where support needs increased, without the help they required.

Social services appear to have been largely absent in some authorities where we conducted interviews. People told us how for some funding for their normal support services had been stopped completely and they had been left without any other alternative. Others had been offered phone support, one person we spoke to for example described how his support had been reduced from 12 hours a week to one short phone call a week.

Many families are struggling, both financially and emotionally. And for many, it has caused deep stress, when juggling caregiving and working from home, and for parents of young children, schooling also thrown in the mix. A mother of a young man with profound learning disabilities described how the normal respite and short break support she received had been stopped completely and she had not been contacted by social care for over four months.

The pandemic has illuminated the fragility of social bonds for disabled people, particularly people with intellectual disabilities. Once funding and staffing are withdrawn, a person with autism or intellectual disability or a mental health condition might be isolated, spending most of the day alone or inside, and with no meaningful activity. There is increased anxiety and loss of confidence. For people with existing mental health issues the pandemic has made things worse and there has been limited access to specialised services. For many we spoke to, with limited social options, boredom was one of the key features of the lockdown period:

'There's nothing I can do to make my day shorter. At the moment I'm trying to sleep to get rid of some of the day.' (Megan, S10)

These issues would have been much worse but for the role played by the third sector. At the start of the pandemic many organisations completely changed the way they

work, filling in the gaps left by social care and helping people's mental health and wellbeing. The third sector not only acted to bring people together, they also provided direct services: PPE, food, digital devices.

Zoom and other digital technologies have become very important.

The pandemic has been a moment when online communications have been more important than at perhaps any time in their history. Many areas of life – health, education, employment, retail, entertainment – have been largely and sometimes exclusively accessed via the internet. This has benefitted many disabled people, because it has removed access barriers, as long as they have internet access (disabled people face a digital divide which more than twice as bad as that faced by non-disabled people). The best disability organisations understood the threat of a digital divide, and moved fast to prevent it.

Entirely new online networks, such as “The Staying Inn” have been established for people with learning disabilities and organisations have used social media to bring disabled people together.

Online access can do many things. But it cannot replace human touch and connection, which is central to the work of primary care doctors and health workers, rehabilitation therapists, and social care workers. Children crave to be in school with their peers. Adults want to go to work, or to day centres, to see their friends. This highlights the value of being together in real life, and of human touch.

Participants felt there had been failures of communication and leadership

Clear communication in a health emergency is indispensable (Goggin and Ellis, 2020). But there has been frustration over the actions of the UK government. Communication was badly handled. Many people were also unsure about how to protect themselves.

The science about COVID-19 has been evolving, which cannot be blamed on anyone, but the messaging as to which people needed to shield and which did not have to continued to be unclear. Voluntary organisations and schools have received conflicting information, often at the very last minute. Nevertheless, our evidence is that many disabled people's organisations and other community groups have played a key role in getting the right information across.

Government daily briefings highlight the general public health significance of COVID-19, but were not sufficient to help people with learning difficulties in particular to understand what they should do differently. Nor has there been routine sign language interpretation of UK government briefings, which sends a very negative message. The Scottish Government has done better.

Conclusions

Our data suggest that many disabled people and their families have felt abandoned and forgotten during the pandemic. For disabled people it has exposed magnified existing structural failings and inequalities. In many cases their needs were not protected and the response of the state has compromised their human rights.

Suggestions for improvement

Policies need to be put in place to try and ameliorate and rectify the harm caused to disabled people by the pandemic. Lessons need to be learned from the difficulties and solutions identified in the pandemic.

Short term

The needs of disabled people have to be fully considered in COVID responses. Assessments need to consider the implications of decisions on different impairment groups and those with combined impairments. Decisions should be communicated in accessible formats.

Local authorities should make it clear that social care packages will be fully reinstated and resources will be invested to address the backlog in social care assessments. Social care is central to enabling disabled people to live independently in society.

The reestablishment of social supports and services, including day centres and other activities, is urgently needed. COVID-19-safe alternatives need to be developed and health and social care funders and providers must work with disabled people and their organisations to develop new ways of delivering support.

Measures need to be taken to ensure that disabled children receive support to 'catch up' on the educational provision that they were excluded from during the pandemic.

Health and rehabilitation services need to urgently address the physical health needs of disabled people.

The third sector need to be supported, to ensure it can continue to provide help to disabled people and their families. Three ways to achieve this are: to work with the sector as equal partners rather than contractors; to reduce unnecessary reporting and administration; and to provide fair and longer-term funding.

Medium to long term

The social care system has been broken for some time; its vulnerability has been exposed by the pandemic. An overhaul of the system is required that places the individual and their care at the centre. In order to achieve good quality social care provision, secure funding is required.

Policymakers and social care providers must work collaboratively with disabled people and their organisations to address their needs during the rest of this pandemic and after and in anticipation of comparable future crises.

Post-pandemic social change is required to enable disabled people not only to regain what has been lost through the pandemic, but also to gain full citizenship rights in the United Kingdom.

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