

A rapid assessment of COVID-19 implications for disabled people in Cornwall (UK)

Executive Summary

This document is a summary of findings from a rapid assessment of COVID-19 implications amongst disabled people in Cornwall. A team from the user-led charitable company, [disAbility Cornwall & Isles of Scilly](#), contacted 83 disabled people in the county between 17 to 24th April 2020 to collect the data. The questions addressed related to: COVID-related self-isolation practices, access to Personal Protective Equipment (PPE), employment of personal care assistants, life-changes due to COVID-19, and key hopes and concerns for the next couple of weeks and over the longer-term.

Most respondents (72%) were self-isolating because of COVID-19, felt socially isolated (61%), were not receiving support from a charity, the NHS or their community (74%), and 35% had experienced problems in securing PPE where required. Overall, this rapid assessment demonstrates a number of pertinent and highly significant livelihood, social care and support needs that are not currently being met. Disabled people without access to family care, financial support or technological assistance are at particular risk, alongside families dealing with multiple health conditions and livelihood challenges.

This crisis could have been an opportunity for meaningful engagement with the disability community, to understand how people learn to cope with long-term day-to-day uncertainty and unpredictability in this current crisis and the particular challenges they face. However, the current governmental response has, instead, devalued and pushed disabled people further to the margins and at greater risk.

Notable opportunities for alleviating many of the concerns raised include:

- Ensuring a more comprehensive governmental approach to identify and notify (in writing) disabled people and carers who have been overlooked in terms of their shielding needs;

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- Communication of these needs to food providers and pharmacists to ensure disabled people have timely and regular access to essential deliveries;
- Introducing flexibility within Direct Payments spendings to ensure that care and livelihood needs of disabled people can be met in this crisis time;
- Provision of necessary PPE and COVID-19 testing kits for all personal assistants and formal/informal carers in a timely fashion;
- Ensuring that, without any negative financial repercussions, key workers with health conditions or new household care responsibilities are supported by employers to self-isolate;
- Mainstreaming more inclusive forms of information provision and communication that do not presume universal access to Information Technology (IT);
- Provision of online/phone health and social care counselling and services for disabled people in self-isolation with specific needs and their family members with new care responsibilities;
- Collaboration with the disability community in the production and sharing of any lockdown easing plans to meet the needs and concerns of disabled people;
- Ensuring that the detrimental changes to social care provision, introduced by the Coronavirus Bill, are reversed as soon as possible, to prevent the breaching of human rights and wellbeing needs of disabled people.

In summary, at least some of the concerns that are identified and discussed in this report could be alleviated through introducing a more comprehensive identification and notification approach for shielding needs, allowing for more flexibility in the use of Direct Payments during this crisis time, ensuring timely provision of PPE and financial support for carers and assistants, mainstreaming more inclusive forms of communication, providing better access to online/telephone counselling and health services, and collaborating with the disability community in planning processes concerning the easing of lockdown.

Introduction

This document is a summary of findings from a rapid assessment of COVID-19 implications amongst disabled people in Cornwall. A team from the user-led charitable company, disAbility Cornwall & Isles of Scilly (<https://www.disabilitycornwall.org.uk>), contacted 83 disabled people in Cornwall between 17th and 24th April 2020. Using telephone interviews and an online survey, the participants were asked about COVID-related self-isolation practices, access to Personal Protective Equipment (PPE), employment of personal care assistants, life-changes due to COVID-19, and key hopes and concerns for the next couple of weeks and over the longer-term. The main findings of the assessment are presented below.

Survey participant profile information

The survey participants included¹ disabled people over the age of 18 years (60% were under 50 years old), 94% noting disability or a long-term health condition, 62% female, and people self-identifying with multiple 'protected characteristics'. Most of the participants (72%) were self-isolating because of COVID-19, felt socially isolated (61%), and were not receiving support from a charity, the NHS or their community (74%). Moreover, 35% of the respondents had experienced problems in getting the required PPE.

Personal care assistant employment

In responding to a question regarding access to information about employer responsibilities in case of employing a personal care assistant, a little more than half the respondents (54%) had the required information. However, key concerns were raised regarding:

- Ambiguity about their responsibilities as an employer of personal care assistants; concerns for the wellbeing of their carers if they were unable to pay them; conflicting information from insurance companies regarding the applicability of the furlough scheme to personal care assistants.
- Loss of reliable personal care assistants through shielding or fear of losing personal assistants should they or the assistants become infected. This was linked to further concerns, including: the health risks and practical difficulties of moving to a care home; confusion about the possibility of recruiting a family member as a care assistant when unable to access usual carer support, or when concerned about agency carers entering the home without access to appropriate PPE; difficulties in getting budget holders to pay for family members as carers; loss of household income when family members have to cease paid work to replace the loss of external care support.
- Concerns about lack of access to PPE for carers, or to COVID-19 testing (for vulnerable people and their carers).

¹ It is understood that some surveys were completed by carers or family members writing on behalf of the disabled person.

- Broader anxieties regarding the potential inability of care homes and the social care system to cope with the scale and impact of COVID-19 as a result of a perceived long-term lack of government investment.

“We have no PPE to use if needed, and hand sanitizer. Should automatically be put on government’s extremely vulnerable list due to rare neurological condition. PPE should be available just in case we need it. Priority for delivery for shopping should be for carers too, as in home carers. We have no ID cards, no uniforms and can’t take care for with us to shop and have to queue like everyone else”.

Participants who did not have access to the required information (20%) also raised the following concerns:

- The failure to make relevant information available to d/Deaf people throughout the COVID-19 crisis.
- The tendency for Direct Payment providers to assume ubiquitous IT access when providing key information.
- Dissatisfaction with the ambiguous support provided by some organisations, including the NHS, local government and insurance companies.
- Lack of access to advice, support or care from agencies (with the exception of disAbility Cornwall & Isles of Scilly), leaving a sense of being deeply isolated, forgotten, vulnerable and a “burden”.
- Lack of information around what to do, especially in the event of personal or carer infection/illness.

- Thoughts of self-harming due to isolation from family; anxiety and basic livelihood needs not being met.

“Personally I have not been supported by charities in my local community despite the fact of living alone. There are many like me that's fallen through the cracks. We are really socially isolated due to our complex health conditions, but even more so now”.

Life changes due to COVID-19

A number of key issues were raised in response to a question about life changes due to COVID-19, particularly around personal and familial impacts, community support, and what could have happened differently to ease the situation, as summarised here.

- *Disabling responses to COVID-19:* Respondents felt that disability has been forgotten in comparison to the needs of the NHS, key workers and older people. They felt substantially devalued in being asked to sign DNR (do not resuscitate) paperwork. Those with complex disabilities and invisible conditions, in particular, felt overlooked. Some respondents raised the issue of increased disability stigma with the misperception that disability enhances the likelihood of being a virus carrier.

Many expressed concerns about cancelled medical and physiotherapy appointments, and the worsening of other conditions as a result of the crisis (mobility issues, cognitive conditions, mental health, and hygiene). One participant lacked access to a functioning shower/bath or washing machine despite raising the issue as an emergency repair need several times with their housing provider. Those with continued care support expressed major concerns about the lack of PPE and explained that some care needs could no longer be met due to the increased time required for new sanitising procedures and precautionary practices. Some called for more information on how to self-isolate to minimise the detrimental impacts of doing so on

specific health conditions (e.g. finding appropriate facilities and possibilities for physical exercise to retain joint and muscle strength).

- *Family care:* Many respondents indicated increased reliance on family support to meet care needs due to the challenges in recruiting and retaining personal care assistants during the current crisis. Some expressed concerns about the resulting health of family carers particularly when they also had pre-existing health conditions that were worsening as a result and had no external respite from care provision. In some cases, this was creating new household tensions (particularly when family members could no longer engage in paid employment as a result of increased informal care responsibilities), and difficulties in finding a balance between family-life and work.

Individuals who did *not* live with family members reported a strong sense of isolation, depression and anxiety, as a result of being cut off from family and/or from previously valued local activities and supportive organisations. Some raised concerns about the health of family members in key worker roles, particularly those who were still expected to work with underlying health conditions (e.g. asthma).

“Anxiety has sky rocketed, having impact on relationships and work as key worker. Community support is amazing but not needed to call on it as have partner. Anxious as have 5 year old on home schooling. Partner also key worker so balancing work, childcare, shopping and just general life is a nightmare”.

- *Access to food and basic livelihood needs:* One of the most frequent issues raised concerned the lack of access to healthy, affordable food; this included being overlooked within the Government (shielding) list of vulnerable individuals, and therefore lacking priority access to online supermarket deliveries. Even when listed, some noted challenges in accessing online food shopping, particularly without the support of personal assistants. Those reliant on deliveries from local shops or other

online sources noted the difficulties of higher food prices. One person lacked a freezer and therefore needed regular deliveries.

Many self-employed disabled people explained their struggle to meet basic livelihood needs, including food and basic heating/electricity costs. One respondent was working hard to access and deliver food to other vulnerable people in their community, despite their own health needs and concerns.

“I have been unable to get shopping in as I’m unable to get a delivery and can’t go out for it. I have no access to my support networks. I can’t have an appointment with my therapist. I’m struggling a lot more than usual”.

Concerns for coming weeks/longer-term future

When asked about concerns for the coming weeks and over the longer term (into summer and autumn 2020), and any kinds of support that might improve their situation in the future, responses echoed many of the concerns raised above:

- *Information:* In the near future, respondents called for changes to ensure d/Deaf people start receiving emails or phone texts instead of phone calls to secure key information; to gain more information from Cornwall Council about what is happening locally; to receive clear information on the strategy about coming out of lockdown and what it means for disabled people (including ensuring disabled people are not overlooked in this process). Over the longer term, respondents emphasised the need for separate advice to be shared with disabled people on COVID-19 and how they will be prioritised in terms of care and treatment. In particular, they felt that groups with special needs (e.g. d/Deaf people, people with autism, people with complex disabilities, and older people) should be explicitly considered and communicated with, in inclusive modes, as lockdown is eased.

- *Social care provision:* With substantive worries about social care provision, respondents felt that care workers and disabled people need to be tested regularly for the virus in the very near future. They also called for greater access to PPE; more support from health professionals and GP surgeries; more empathy and flexibility from budget holders for disabled people; clear guidance around the flexible use of direct payments; access to emotional support for mental health issues; advice about how to cope if social care packages are discontinued. With regards to longer-term concerns, respondents hoped for continued opportunities to recruit personal care assistants; reassurance that care services for disabled people will be protected; and that mental health needs will be considered carefully if self-isolation for disabled people is extended until a vaccine is developed.

“My main concern is that life for those with disabilities will be more difficult. Whilst self-isolation is nothing new when much of society is still inaccessible and ignorant of the needs of disabled people, in many ways disabled people feel more marginalised, vulnerable and discriminated against than at any time during the last 30 years. A comprehensive review of how health and social care is provided to disabled people needs to be undertaken at some point to take into account how an individual can survive in order to even stand a chance of being able to thrive”.

- *Shielding recognition:* For the near and longer-term future, regarding current shielding concerns, respondents hoped that the “hit and miss” approach of the government in terms of sending ‘shielding’ letters could be replaced with something more systematic and inclusive of disabled people with diverse needs and circumstances.
- *Family and community interaction:* Respondents expressed a strong need, in the near and longer-term future, to re-join families and friends to reduce feelings of isolation and improve mental health.

- *Livelihood needs:* In terms of the significant livelihood challenges that respondents are facing, calls were made (in both the near and longer-term future) for more structured provision of food and medication supplies for disabled people; to receive online help in terms of food shopping; and to return to work and work placement activities.

"I'm worried that I'm not going to be able to get any shopping at all. I'm worried I'm going to end up hurting myself or someone else. I need support with most aspects of my life usually, so now I feel I need more emotional support and help with shopping"

"I'd hope to be able to return to full time placement, recruit a new personal assistant. I'm concerned that I'll need extra support to be able to manage shops and busier spaces again".

Recommendations

Considering the concerns and issues raised by those involved in this rapid assessment, the following recommendations are suggested to improve the situation:

- Ensuring a more comprehensive Government approach to identifying and notifying (in writing) disabled people and carers with overlooked shielding needs;
- Communicating these needs to supermarket and other food providers, along with pharmacies, to ensure timely and regular access to food and medicine deliveries;
- Introducing flexibility in the spending of Direct Payments to ensure care and livelihood needs can be met in these unprecedented times;
- Providing necessary PPE and COVID-19 testing for all key workers (including personal care assistants and formal/informal care workers);

- Ensuring key workers with existing health conditions or new household care responsibilities are supported by employers to self-isolate without detrimental financial repercussions;
- Mainstreaming more inclusive forms of information provision and communication that do not presume universal access to Information Technology (IT);
- Providing access to online/phone counselling and health support for self-isolating individuals with specific health needs and family members with increased care responsibilities;
- Collaborating with the disability community to produce and share a clear plan for how the needs and priorities of disabled people will be respected and met as lockdown restrictions are eased;
- Ensuring the changes introduced by the Coronavirus Bill to social care needs assessment and provision processes are reversed as soon as possible and do not continue to infringe upon the human rights and wellbeing needs of disabled people.
- Considering the many interdependencies between health and social care systems, and the many uncertainties and emergent outcomes of the COVID-19 pandemic, adopting a complex system approach to policy that joins up many laudable interventions and responses across these sectors could be a valuable way forward.