The Impact of COVID-19: Article 11 (Situations of risk and humanitarian emergencies)

Introduction

Chronic Illness Inclusion (CII) understands the COVID-19 pandemic as a clear instance of a situation of risk and humanitarian emergency, thus falling under the remit of Article 11. This section draws on evidence gathered in April 2020 through a survey conducted by CII about the impact of the COVID-19 pandemic on people with energy limiting conditions (ELCs), in response to a call for evidence by the Women and Equalities Parliamentary Committee. 776 people responded, of whom 85% were women.[[1]](#footnote-1)

We have highlighted where the evidence also has implications for other Articles of the UNCRPD.

Evidence summary

Our survey results showed a population at increased risk from COVID-19 due to underlying chronic conditions but excluded from the government’s policy response. These people’s needs were being ignored and their health and wellbeing was deteriorating. 82% of respondents reported that the pandemic had had a negative impact on their overall wellbeing. The overwhelming majority of our respondents were disabled women, who were already at greater risk of marginalisation and exclusion (**Article 6: Women with disabilities**).

28% of our survey respondents did not know if their chronic condition placed them at higher risk according to government guidance. This showed the need for clearer guidance, both for people living with chronic conditions and the shops and services expected to respond to their needs (**Article 21: Freedom of expression and opinion, and access to information**).

“When I asked if I could check with the GP if I was in the vulnerable group I was told to look online.” **– Woman in Yorkshire and the Humber, living with fibromyalgia.**

86% of respondents reported that the pandemic had had a negative impact on their ability to access food and essential supplies. Many of these people were largely housebound and reliant on supermarket deliveries. They were denied access because of overwhelming demand and unclear guidance. The policy deprived disabled people access to the essentials for survival (**Article 9: Accessibility, Article 28: Adequate standard of living and social protection**).

“I seem to be in a category where I'm not vulnerable enough to get help with essentials like food shopping, but too vulnerable to catch Covid and survive.” –  **Woman in Wales, living with fibromyalgia and stenosis of the spine.**

“I'm on the 'vulnerable' list but not the 'extremely vulnerable' list - I am concerned about the possible effects of coronavirus on me but there is no support available with things like shopping. As a younger person with no visible disability I fear I wouldn't be allowed to use shopping hours dedicated to vulnerable people.” – **Woman in London, living with ME.**

“We have lost both our incomes, and we were already using foodbanks before the lockdown. We can't access them now, and nobody has been in touch from the various services that were in contact with us. I am very concerned about accessing food as I cannot stand for long at all and queuing would be out of the question at supermarkets.” – **Woman in Scotland, living with fibromyalgia.**

“I am housebound and one of the forgotten ones. I feel very isolated, frightened, anxious, lonely, hungry, very tired, hopeless. I am hungry due to the fact I need home delivery groceries and it's a three-week wait. I am nearly down to my last scrap of food from my freezer and I don't know what I am going to do. I sleep a lot lately, very tired probably because of my high dose of medications and very little food.” – **Woman in Northern Ireland, living with arthritis, complex regional pain syndrome (CRPS), dystonia, fibromyalgia, degenerative disc disease (DDD), heart condition.**

“When I told the supermarkets how I rely on delivery to get basics, they responded with a script about the government’s ridiculously limited list of vulnerable groups each time. I was completely brushed aside.” – **Woman in East Midlands, living with ME, polycystic ovary syndrome (PCOS), IBS.**

Of the respondents under the regular care of a GP or specialist for chronic conditions, 66% reported disruption to care during the pandemic. This has long-term implications for people’s health and will place increased pressure on the NHS and social care once the current crisis has passed (**Article 25: Health**).

“The lack of access to medical help for anything other than coronavirus is very scary. Plus, if I get the virus will they decide I’m not worth saving because of my conditions?” **– Woman in North West England, living with Graves’ disease, thyroid eye disease, anxiety disorder, depression**

“There has been a major impact on the ability of people with severe chronic illnesses to access support and healthcare. I am extremely concerned about the backlog this is going to cause down the line, as there are already significant waiting times for specialists. The NHS has been underfunded for so long that I am terrified I won’t have any access to this specialist care when the pandemic subsides. Our conditions are not going away and I think the lack of care during this time will cause irreversible damage to many of us and make our conditions even worse. I think policy makers have to understand that many people with chronic and rare diseases already feel like we are forgotten, but there are millions of us and this could cause a tsunami of healthcare problems after the pandemic earthquake.” – **Woman in East Midlands, living with asthma, fibrous dysplasia, hypermobility syndrome.**

“Diabetes nurse appointment cancelled, diabetes annual review cancelled including eye screening, endoscopy for Crohn’s cancelled, asthma annual review cancelled. I used to have monthly GP review - cancelled, but I can contact by phone for emergency.” – **Woman in East England, living with diabetes, Crohn’s disease, asthma, endometriosis, post-traumatic stress disorder (PTSD).**

“Hospital appointments for pain injections, neurologist, infusions have all been cancelled.” – **Woman in London living with spinal cord injury, chronic pain, neurogenic bladder and bowel, osteoporosis.**

“Appointments I have fought for and waited almost a year for have been cancelled.”
**– Woman in South West England, living with myalgic encephalomyelitis (ME), postural orthostatic tachycardia syndrome (POTS), irritable bowel syndrome (IBS),
ulcerative proctitis.**

“The doctors are unable to grasp ‘don’t phone me, I can’t hear’. It’s all so much harder.”
**– Woman in South West England, living with ME, rheumatoid arthritis (RA), hearing impairment.**

“I have mental health therapy twice a week; this has been cancelled and nothing has been put in place. All specialist appointments that I've been waiting 9 months for have been cancelled or even discharged.” – **Woman in South East England, living with ME, fibromyalgia, POTS, anxiety, depression, costochondritis, asthma, IBS, interstitial cystitis, non-alcoholic fatty liver disease (NAFLD).**

“I have sought medical support for infections but been unable to make contact with my medical surgery as my only way I can communicate is via email (I am too weak and disabled to use the telephone) and the surgery now only replies to telephone calls. I have no support and no one to telephone for me.”
**– Woman in South West England, living with severe sweating disorder, severe ME, multiple chemical sensitivity (MCS), spinal nerve disorder, complex PTSD.**

“I had a text saying not to contact them unless it's an emergency.” – **Woman in Scotland, living with ME.**

56% of respondents reported that their health had declined since the pandemic began, with a significant number reporting the detrimental impact of increased stress and anxiety (**Article 25: Health**).

Many respondents reported experiences of discrimination in shops, the NHS, the media and public conversation. People reported feeling unseen, unheard and unvalued (**Article 5: Equality and non-discrimination**).

“I was very upset to see that because I need a carer, the NHS considers me too frail for ventilation and my life not worth saving. Hard to live with this hideous, soul-crushing disease knowing the NHS doesn’t consider me worth saving. Not sure I’ll ever trust the NHS again.” – **Woman in London, living with ME.**

“I feel the whole 'management' of the pandemic by central & local governments has been discriminatory as we have been completely overlooked.” – **Woman in East Midlands, living with fibromyalgia, Sjogren’s syndrome, osteoarthritis, spondylitis, sleep apnea, depression, disassociation disorder, PTSD.**

“It has been incredibly difficult to prove you are disabled because people apply old-fashioned criteria of what is a disability to police access to things like supermarkets.” – **Woman in East Midlands, living with asthma, fibrous dysplasia, hypermobility syndrome.**

“I stopped in the park for a rest and was shouted at for stopping. It made me anxious to go out again.” – **Woman in East Midlands, living with ADHD, dyspraxia, PTSD, IBS, chronic pain.**

“I feel a bit like the experiences of disabled and chronically ill people have been at once co-opted and erased. We are experts in isolation yet we've been ignored/told we are expendable.” – **Woman in Scotland, living with fibromyalgia, c-PTSD, PCOS, Hashimoto's disease.**

“Politicians not talking to, but talking about, disabled people (when they remember us) has been quite painful to experience. The 'oh, it only kills people with a pre-existing condition,' as though that doesn't include anyone they think is listening. It's never 'your life is valuable and we're doing all we can to support you' - it's often in the third person.” – **Woman in East England, living with a thyroid condition.**

“The marginalisation of people whose disabilities makes them literally the most vulnerable to a novel virus is richly ironic. I have particularly experienced this in work/educational settings: for instance where concern is expressed 'for those whose loved ones and family may be more vulnerable', rather than those who may be more vulnerable themselves.” – **Woman in London, living with Behçet’s disease.**

1. Ruddock, A. and Gkiouleka, A. (2020) “*I feel forgotten.”: A Submission by the Chronic Illness Inclusion Project to the Women and Equalities Committee inquiry into the impact of coronavirus (covid-19) on people with protected characteristics*.Centre for Welfare Reform. Available from: <https://citizen-network.org/library/i-feel-forgotten.html> [↑](#footnote-ref-1)