

In the time of the pandemic: safeguarding people with developmental disabilities against coronavirus

For the past three months, the world is trying to deal with the coronavirus infection and its impact on populations and societies. Whilst no one is exempt from contracting Covid-19, the disease particularly attacks the elderly and those with underlying conditions. These groups have the highest mortality rates as shown by existing data (Weiss and Murdoch, 2020).

Amongst the most vulnerable groups are people with developmental disabilities with or without mental ill health and/or behaviours that challenge. They are also those most likely to die from preventable causes, have lower health literacy and ability to seek help and access health services (Glover et al, 2017). . They have additional comorbidities including obesity, diabetes, respiratory disease, long term psychotropic use which all increase their susceptibility to more severe forms of covid-19. Further, people with developmental disabilities and their families are likely to face social adversity as well as health inequalities. People with developmental disabilities are isolated, out of work and may have little access to freely available information which they may not fully understand and therefore, being unable to enact public health advice.

Given the lack of specific treatment for covid-19, people with developmental disabilities must be assisted to access appropriate support in the event of illness. Anecdotal accounts from medical and other health and social care professionals working with people with developmental disabilities internationally, suggest that an overwhelmed care system may need to make some very difficult choices at a time of shortage of resources such as use of ventilators. Clinical care based on assumptions about frailty or disability must be resisted and patient advocacy for those vulnerable patients must be at the forefront of all professionals involved in their care.

Further, the impact of the coronavirus pandemic on people with developmental disabilities, stems not only from a general susceptibility due to underlying health conditions but also due to the emotional burden of the pandemic on the person with disability and their carers, paid and family.

The pandemic has created a host of health and social challenges which are likely to compound the disadvantages experienced by people with developmental disabilities daily. Issues such as social isolation in the form of social distancing may cause more distress if prolonged and its purpose is not fully understood; living with family at close proximity may cause particular difficulties where there may be ongoing problems between family members or when respite support is no longer available; staff absence and/or lockdown of existing facilities due to covid-19 related illness in others is likely to also elevate the risk for potential relapse of mental illness or the display of behaviours that challenge.

Any guidance by public health agencies and governmental entities will need to target many levels at once, individual and professional, health and social care, local and national care systems, legislation. Health and social care staff need to be able to recognise the symptoms of the disease, triage and advocate for the person with developmental disorder's welfare and rights;, inpatient and housing facilities who may be at high risk for outbreaks must have contingency plans to detect and contain them and to also support their staff to maintain their own health and be given all necessary personal protections to provide direct care. Health and social care providers who work with families must be able to identify and support families who are most at risk and provide flexible approaches to prevent harm. A recent rapid review of the psychological effects of quarantine (Brooks et al, 2020) The authors indicate that, based on evidence from past pandemics, quarantine may cause significant

distress often expressed with symptoms related to trauma, anger and confusion and maybe long standing. There is no reason to believe that people with developmental disorders will not experience these emotional difficulties which may be misconstrued as behaviours that challenge. Other symptoms of mental distress were reported as being boredom, frustration, fears and anxiety about loved ones or about being infected. It is therefore paramount that people with developmental disabilities across the lifespan receive reassurance, clear communication and carers should try to facilitate a degree of contact with the outside world within the limits set by official guidance.

The clinical and academic community in the field of developmental disorders has been quick to react to the implications of this group being sidelined due to the unprecedented nature of the challenges presented by the pandemic. Many organisations and individuals have put together advice that can be used by clinical staff treating covid-19 patients in emergency and critical care, as well as in outpatient and inpatient medical and psychiatric facilities. There has also been a spate of easy read resources tailored to people with developmental disabilities. All of those resources can be used alongside a country's government advice to ensure that people with developmental disabilities and their paid and family carers are given suitable information and are empowered to enact health policies and adapt to what we must all do as citizens to combat the pandemic.

Finally, we need disaggregation of all the data collected during the pandemic by disability group for both those who have beaten covid-19 as well as those who succumbed to the disease. The data will promote transparency on the one hand and on the other, will lead to the development and implementation of appropriate interventions to catastrophic public health events which are more likely to disadvantage vulnerable populations.