



# Applying the CRPD to People With Intellectual and Developmental Disability With Behaviors of Concern During COVID-19

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## Abstract

People with intellectual and developmental disability (IDD) are a vulnerable population in all aspects of access and participation, abuse and neglect, and being subject to the use of restrictive practices. Accordingly, they are a group whose human rights can be impacted where equal access to supports, services, and accessible information is compromised. The current COVID-19 pandemic is a global humanitarian emergency that has had a devastating impact across the world, for all people. Growing concern has been raised about the impact of the COVID-19 virus on the health of people with disabilities and there has been subsequent development of strategies and protocols to promote equal access to information, health supports, and services. People with IDD have high levels of underlying comorbidity that increases their risk of contracting COVID-19 and measures to protect them from infection are critically important. However, those measures may trigger behaviors of concern and increase the risk of being subjected to restrictive practices. While some attention has been paid to the health impacts of COVID-19 on people with disabilities, there has been less paid to the impact on the human rights of people with IDD who present with behaviors of concern. The aim of this paper is to provide a hypothetical exploration of the impacts of pandemic prevention measures on people with IDD and behaviors of concern in the context of the Convention on the Rights of Persons with Disabilities (CRPD). In the absence of available guidance for working with people with IDD with behaviors of concern during COVID-19, we suggest behavior support response plans that aim to ensure that people with IDD with behaviors of concern are supported properly in a time of significant disruption for them, thereby safeguarding their human rights.

**Keywords:** COVID-19, human rights, intellectual and developmental disability, restrictive practice

## Introduction

The coronavirus disease (COVID-19) virus was first detected in Wuhan City, Hubei Province of China. It was identified as the causative virus by Chinese authorities in early January 2020 and in March, the World Health Organization (WHO, 2020b) declared the coronavirus disease (COVID-19) as a pandemic with more than 19 million cases of COVID-19 and over 1.2 million deaths world-wide (WHO, 2020a) at the time of writing this manuscript. The WHO immediately issued public advice on protective measures against COVID-19 and countries around the world instituted a range of protective and stringent measures through declaring legislative emergency powers and or public health orders that impact on the civil liberties of their citizens.

A range of necessary measures to minimize the spread of the COVID-19 virus have been introduced that include border closures, social distancing, limitations to public and private gatherings, limitations to nonessential movements and travel,

self-isolation and quarantine, good hand hygiene, and the use of personal protective equipment. While there are specific protective measures being rolled out in each country to address the spread of COVID-19 amongst its citizens, how these measures are translated to people with disabilities, including those with intellectual and developmental disability (IDD), and their carers has not always been apparent or specifically addressed. Prior to the COVID-19 pandemic, people with disabilities faced widespread barriers in accessing healthcare despite having higher levels of comorbidities and underlying health conditions (WHO, 2015), and are likely to be additionally and further disproportionately affected in the current pandemic due to serious disruptions to the services they rely on (WHO, 2020b).

## The Relevant CRPD Articles during COVID-19

The purpose of the Convention on the Rights of Persons with Disabilities (CRPD) "...is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity" (p. 4). The CRPD applies to all people with disabilities, mandating the social or ecological

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approaches that are the basis of the realization of their human rights (United Nations, 2006). Hence, the CRPD emphasizes the fundamental human rights of people with disabilities in all settings and in all situations. Of particular relevance in the COVID-19 pandemic is CRPD *Article 11: Situations of risk and humanitarian emergencies* which mandates member states take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including humanitarian emergencies and the occurrence of natural disasters. Many member states have used state legislative powers or disaster emergency powers during COVID-19 to protect their citizens. Further, the CRPD *Article 25: Health* mandates the provision of health services to people with disabilities without discrimination on the basis of disability and CRPD *Article 21: Freedom of expression and opinion, and access to information* highlights the critical importance of providing accessible information during COVID-19.

A number of concerns have been raised about the response to the COVID-19 pandemic for people with disabilities, highlighting fears that (1) they have been ignored in government and community responses, (2) they may not be gaining equal access to healthcare, (3) necessary personal protective equipment is not available for carers, (4) congregate settings have a high risk of contamination, and (5) there is a lack of accessible information about the pandemic and measures to prevent infection (see Centre of Research Excellence in Disability and Health, 2020; Disabled People's Organisation Australia, 2020; Office of the High Commission on Human Rights, 2020a; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020).

These concerns indicate that the human rights of people with disabilities in relation to health, risk and emergency situations and access to information may be further eroded during the pandemic. In response there has been, albeit late (Kavanagh, 2020), the development of targeted management and operational guidelines and protocols dealing with responses to COVID-19 for people with disabilities (Australian Government, Department of Health, 2020; International Disability Alliance, 2020; Office of the High Commission on Human Rights, 2020b; Spanish Committee of Representatives of Persons with Disabilities, 2020; WHO, 2020b). Primarily, these recommendations and guidelines are targeted responses to the impact of the COVID-19 pandemic on the health of people with disabilities, acknowledging the greater risk of people with disabilities contracting the virus while experiencing disproportionate disadvantages in accessing healthcare and information compared to the general population.

As with people with disabilities generally, people with IDD are also significantly disadvantaged in relation to gaining access to necessary healthcare despite being a population with higher health needs. Emerging research has demonstrated that people with IDD have higher prevalence of the specific pre-existing health conditions associated with poorer COVID-19 outcomes and a mortality rate at a younger age (Turk, Landes, Formica, & Goss, 2020). Further, concerns have been raised about further disadvantage through the use of screening tools to prioritize access to healthcare for people who have contracted the COVID-19 virus. For instance, in the UK, the use of a screening tool that had been developed for older frail populations

potentially led to people with IDD being rated as a lower priority for access to healthcare where they were identified as being dependent upon others in activities of daily living, an underlying aspect of IDD (Alexander et al., 2020).

What has received less attention than the issues of health vulnerability is the risk of the impact of COVID-19 restrictions on the rights and well-being of people with IDD who present with behaviors of concern such as verbal or physical aggression, withdrawal, self-harm, property damage, and criminal offending (Allen, 2009; Chan, French, & Webber, 2011; Dunlap, Sailor, Horner, & Sugai, 2010; Lowe et al., 2007). Behaviors of concern are influenced by environmental factors such as the physical environment, inadequate staff communications, disrupted social interaction opportunities, limitations to personal freedom, restricted living environments, disruptions to routines, the absence of staff not trusted or known to the person with IDD, staff turnover, and not having contact with their family members (Olivier-Pijpers, Cramm, & Nieboer, 2020). These environmental factors are exacerbated under necessary pandemic restrictions designed to prevent infection.

### People With IDD and Behaviors of Concern

While it has been established that the health of people with IDD is highly vulnerable in the COVID-19 pandemic, the very restrictions and disruptions to daily life that are necessary to prevent infection can also have an effect on behavior (Alexander et al., 2020; Courtenay, 2020). Enforced social distancing as well as disruptions to routines and supports can lead to the occurrence of behaviors of concern or the escalation of existing behaviors. Further, increasing isolation to protect people with IDD from infection not only further marginalizes and isolates a group of people already highly marginalized and isolated, it can also decrease oversight and scrutiny, increasing the risk of human rights abuses.

While research is not yet available on the effects of pandemic restrictions on behaviors of concern for people with IDD, there is anecdotal evidence that pandemic restrictions can affect people with IDD in many ways that cause distress, result in behavioral changes and impact on quality of life (Courtenay, 2020). Stringent restrictions on daily living will be particularly distressing for people with IDD where they do not understand these changes and where there has been no assistance or accessible information provided to assist them in understanding. In the COVID-19 pandemic, people with IDD are likely to be affected by:

- Sudden disruptions to routines, ability to engage in daily activities (including work, leisure and education), and disruptions to the supports and services they are provided, including availability staff changes and shortages.
- Further social isolation due to restrictions on visits or visiting family, friends, and other people in their support network.
- Increased boredom associated with underactivity and frustrations due to the restrictions imposed.
- Increased time spent within the home potentially increasing co-tenant interpersonal friction, especially where it is a forced co-tenancy arrangement.

- Not having the ability to use and/or the technical resources for virtual social connections with family and friends,
- Increased risk of carer stress due to activity, support, and service disruption (including unavailability of respite and the cancellation of daily activities outside the family home), potentially leading to diminished ability to engage in proactive and positive responses to behaviors of concern.

Responses to behaviors of concern that stem from pandemic restrictions can result in abuse and other maltreatment as well as other impacts upon well-being and human rights. Many people with IDD who present with behaviors of concern are subjected to restrictive practices, such as physical, chemical or mechanical restraint, containment, and seclusion (Wardale, Davis, Vassos, & Nankervis, 2016; Webber, McVilly, & Chan, 2011). Such practices that restrict a person's liberty or freedom of movement can contravene the CRPD, especially where the use is unregulated (Chandler, White, & Willmott, 2018). Behaviors of concern that arise in the context of pandemic restrictions can further increase the use of restrictive practices, including unregulated use.

While there is no published evidence that people with IDD and behaviors of concern have been subject to higher levels of restrictive practices during the COVID-19 pandemic, it has been reported psychiatrists in the UK are seeing increases in request for psychotropic medication to assist families and carers to manage challenging behaviors (Courtenay, 2020).

It is important to reiterate that responses to behaviors of concern that are restrictive or have become aversive or punitive are inconsistent with human rights (French, Chan, & Carracher, 2010; Owen & Griffiths, 2009). Hence, it is all the more critical during the period of COVID-19 that there is deeper consideration of the application of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) on people with IDD and behaviors of concern who may be at higher risk of being subject to restrictive practices.

### Human Rights, People With IDD, and Behaviors of Concern

As previously outlined, *Article 21 of the CRPD Freedom of expression and opinion, and access to information* highlights the critical importance of providing accessible information to people with disabilities. The need for targeted COVID-19 information for people with disabilities has been recognized as well as the need for this information to be available in multiple formats (WHO, 2020b).

For people with IDD, there is the need for easy read and other augmentative and alternative communication (AAC) formats, to provide them with information about the COVID-19 virus and the required precautions to protect them. As the pandemic has progressed, there has been growing availability of resources explaining COVID-19, the necessary pandemic restrictions, and ways to avoid infection for people with IDD. These accessible resources use multiple formats including easy read resources, illustrated guides, podcast, photosymbols, and videos.

However, people with IDD also need accessible information about how the measures to minimize infection will affect

them, particularly any required restrictions and disruptions to their daily lives. This information needs to be readily available, easily accessible and understandable, and available in multiple formats. Importantly, the format of this information should be tailored to the individual's communication and comprehension support requirements for it to be effective (Chinn & Homeyard, 2017) and also readily available to those who support them.

Also necessary is information about the ways that people with IDD will be supported to be actively involved in decision-making and planning for necessary changes in their daily lives. Accessible information and involvement in decision-making enables a person to participate in decisions and plans about changes to their day-to-day life, the form of these changes, and acceptable alternatives for the duration of the pandemic measures. By engaging the person and their support network in active communication and engagement helps to mitigate sudden, unexplained changes in a person's life or restrictions that are not understood and can be triggers for behaviors of concern.

*Article 16 Freedom from exploitation, violence and abuse.* The relationship among challenging behavior and abuse, neglect, and inappropriate treatment is well established. People with IDD with behaviors of concern are more at risk of being abused and neglected (Lowe, Allen, Brophy, & Moore, 2005), with behaviors of concern also identified as a predictor of abuse and inappropriate treatment (Emerson & Einfeld, 2011). Violence and abuse can occur in the context of attempts to manage or control behaviors, or to protect the person themselves or others from harm resulting from behaviors of concern. In other cases, violence and abuse may be a retaliatory response from those in contact with the person with IDD, including caregivers and co-residents and neglect can arise where there is an avoidance of interactions with the person (Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2014).

In the COVID-19 pandemic, restrictions where behaviors of concern (or behaviors of protest; Ramcharan, Nankervis, Strong, & Robertson, 2009) can unexpectedly arise in a crisis situation or as a reaction to imposed "shutdowns" and reduced activities and interactions, planned, and proactive responses based on a functional behavioral assessment are unlikely to be in place. In these circumstances, there is a high chance that abuse, neglect, or inappropriate practices can occur.

In other situations, a person with IDD may have in place a positive behavior support plan with identified strategies to proactively and positively respond to the previously assessed functions of the behaviors. However, with COVID-19 restrictions, the planned strategies may not be able to be implemented as intended. For example, a known trigger for behaviors of concern may be decreased by ensuring the person is engaged in activities and interactions of their choice, outside their home. During movement restrictions or self-isolation, such strategies in a person's behavior support plan may not be able to be implemented. This can lead to increases in behaviors of concern and difficulties in implementing proactive strategies. Without the ability to implement planned strategies to prevent or de-escalate behaviors of concern, caregivers may respond to behaviors inappropriately, resulting in exploitation (such as the use of coercion in an attempt to control behaviors), abuse, violence, and inappropriate treatment.

In the scenarios highlighted here, Article 16 can be breached through the misapplication and/or unauthorized use of restrictive practices (such as seclusion, containment, physical restraint, chemical restraint, or mechanical restraints). Additionally, giving effect to a public health order of quarantine or self-isolation may mean that people with IDD may be inadvertently subject to restrictive practices, such as increased use of psychotropic medications of a sedative quality or physical restraints being applied to keep the person in self-isolation or quarantine.

Of further concern is that quarantine, “lockdown,” or social distancing/self-isolation measures can lead to the exclusion of visitors to supported accommodation and other settings, resulting in the reduction of formal and informal oversight mechanisms. Oversight mechanisms both intentionally and incidentally detect incidents of unauthorized use of restrictive practices, other inappropriate or unlawful practices, abuse, neglect, and breaches of human rights. In the absence of such oversight, the risk of violence, abuse, neglect, and exploitation is increased (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020). Thus, the COVID-19 pandemic measures may lead to further isolation of people with IDD, increase the frequency and intensity of behaviors of concern, and, with less scrutiny and oversight, risking people with IDD to exploitation, violence, and abuse.

The CRPD recognizes the human right to the *Protection of the integrity of the person* (Article 17). In the context of behaviors of concern Article 17 is particularly directed towards protection from restrictive practices and compulsory treatment and it provides a powerful mandate for a positive behavior support model that promotes a rights-based approach to service delivery and alternatives to restriction and compulsion methods as methods of controlling and modifying behavior (Chan et al., 2011). Positive behavior support is an evidence-based multicomponent approach that recognizes the human rights of the people with IDD. Positive behavior support addresses quality of life first and foremost, then the functions of a person’s behaviors of concern and support for the person’s development of functionally equivalent skills.

### **The Need for a Systemic and Tailored Response to Behavior Support Needs During Pandemic**

Just as tailored COVID-19 strategies and protocols have been developed to address the health needs of people with disabilities, there is the need to develop similar tailored and systemic responses that address behavior support needs to prevent abuse, neglect, cruel, and inhumane treatment and to protect the integrity of people with IDD with behaviors of concern. As such, in addition to health response plans there is the need for proactive behavior support response plans in the times of pandemic, including the current COVID-19 pandemic.

The development of pandemic proactive behavior support response plans should be system-wide as well as aiming to minimize disruption in the day-to-day lives of people with IDD. Response plans for behavior supports should also aim to minimize behaviors of concern that arise from distress and disruption, avoiding the use of restrictive practices. Behavior support response plans would include the following.

**Access to psychosocial supports and services.** For the provision of emotional and other supports to the person with IDD when dealing with loss, anxiety, and confusion. This is likely to include telehealth services.

**Communication.** Ensuring that there is accessible information in formats and methods tailored to the person with IDD to enable them to understand the risk of COVID-19 infection and the reason for changes in their life, and how long these may last (e.g., see Beyond Words, 2020). Also having clear and easily accessible information available to the person’s support network to assist them in supporting the person with IDD to understand restrictions and the effects on their day to day life.

**Involvement in decision-making.** Ensuring direct and meaningful involvement of the person with IDD in the decisions about how pandemic measures will be implemented in their day-to-day life, including any alternatives to the usual arrangements/activities that are being disrupted as well as what could be done differently that would not affect their quality of life. This includes actively engaging with family and others who know the person well to inform the best ways to make the accommodations required for pandemic measures.

**Monitoring change.** Monitoring any behavioral changes or signs of distress in light of the implementation of pandemic prevention protocols and rules and the immediate provision of supports and actions to address the communicative function of behaviors of concern.

**Positive behavior supports.** Ensuring that existing positive behavior support plans are revised to accommodate any necessary changes in the person’s circumstances due to pandemic protection measures, based on an updated functional assessment of behavior. This includes updated strategies that address physical and social environmental changes as well as the functions of any behaviors of concern.

Timely and immediate access to behavior support specialists who are able to offer advice and support on positive behavior support plan changes, and/or immediate strategies in crisis situations as well as consideration given to establishment of a rapid response team of specialist behavior support practitioners. Access to specialist behavior supports should be accessible for all people with IDD and their family and other carers, not just for those who are existing users of behavior support services and supports.

Ensuring that careful monitoring and support is in place to ensure the revised positive behavior support plan is consistently implemented as planned.

**Support for family and carers.** There is recognition that family and carers are partners in behavior supports and require immediate and easy access to training, information and resources in positive behavior supports, developed, and delivered by behavior support specialists. This development of skills and knowledge in positive behavior supports should be universal, across service providers, and families. Further, there is emergency accommodation available for families whose family

member with IDD is engaging in behaviors of concern that are a risk of physical harm to others in the household.

### Restrictive practices as the least restrictive alternative.

Where reactive strategies to behaviors of concern are required to keep the person and others safe, it is ensured that these are the least restrictive and are innovative alternatives and are only implemented as a last resort response to behaviors of concern. Pandemic behavior support response plans should include provision for the continuation, expansion, or introduction of safeguarding mechanisms to protect the human rights of people with IDD during pandemics. This includes the monitoring and reporting requirements in relation to any use of restrictive practices is in place as well as mechanisms to detect the use of restrictive practices that are unauthorized or misapplied.

**Risk assessment.** Ensuring that risk assessments encompass both health and behavioral risks and there is the proactive development of risk management strategies, in conjunction with the person, their family, and other carers.

### Conclusion

Justifiable concern has been raised in relation to the responses to COVID-19 for people with disabilities. As a result, tailored COVID-19 strategies and protocols for people with disabilities are being developed for the health sector. However, these strategies and protocols do not address the human rights of people with IDD and behaviors of concern. The concerns for human rights for people with disabilities in the current pandemic are not just those related to health, risk, and humanitarian emergencies.

The global pandemic of COVID-19 presents significant challenges to people with IDD who present with behaviors of concern, their families, and service providers. A responsive and considered approach as suggested in this paper is essential in facilitating the safety and well-being of people with IDD so that they can cope with, and adjust to, the jurisdictional lawful requirements during COVID-19. It is also important to protect and uphold the rights of people with IDD during this unprecedented time and to ensure that adherence to lawful requirements do not overreach into an erosion of the rights of the person with IDD.

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