MIDTERM REPORT

How are the needs of people with disabilities addressed in national policies related to COVID-19 public health measures? An analysis based on the UN Convention on the Rights of Persons with Disabilities

Funders: Quebec Population Health Research Network (RRSPQ) and Quebec Rehabilitation Research Network (REPAR)

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Report Summary

Persons with disabilities experience heightened risk of harms in the context of the COVID-19 pandemic. The uncertainty of the trajectory of the pandemic coupled with shifts in the pandemic response creates a context where stringent and ongoing analysis of risk and risk response is warranted. Public health measures, such as quarantine, shelter-at-home and lockdown, will have different impacts on persons with disabilities. Policy responses that are aligned with the provisions of the UNCRPD will mitigate potential harms and serve to promote equity. In this research study we are analyzing country-level policies related to COVID-19 in 14 countries. This study assesses the alignment of these policies with indicators from the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The 14 countries included for analysis are: Canada, India, Australia, France, South Africa, Jamaica, Fiji, Philippines, Zimbabwe, Rwanda, Haiti, Malawi, Ireland, Guinea. These countries are signatories of the UNCRPD and have English or French as one of their official languages. Our selection was also guided by the goal of diversity based on geography (different continents) and income levels (based on World Bank categories). We collected online, publicly available COVID-19 policy documents from these 14 countries. We began the search in July 2020 (back searching to January 2020) and continued with monthly document collections. We analyzed these documents using the CRoss Industry Standard Process for Data Mining (CRISP-DM) and followed an inductive and deductive computational text mining using WordStat8. The team developed a categorization model based on the UNCRPD general articles and indicators proposed by the UN Office of the High Commissioner for Human Rights (OHCHR) to assess alignment of policies with the UNCRPD. We also developed a categorization model specific to COVID-19 and used a combination of both dictionaries to conduct our analysis.

In this report we describe findings from our analysis of COVID policies from Jan-Dec 2020. There was considerable variability in the number of policies created across countries both in absolute terms and relative to country size. Of the 14 countries, countries with the most policies were India, Jamaica, South Africa and Canada. Fewer policies were identified

from countries in the low-income category. Across all countries, the UNCRPD articles that were most frequently identified were Articles 11 (humanitarian emergencies), 19 (living independently) and 24 (education). Comparing between countries, we also identified trends. For example, article 19 was much more likely to be identified in policies from high income countries. More detailed analysis was also conducted within articles. For example, within Article 11, the subcategory 'prevention and response' is the most commonly referenced. We also found changes over time, with emergency responses and accommodations in the first months of the pandemic evolving to higher frequency discussion of vaccine-related topics in December 2020 within high-income country policies. To illustrate the alignment with the UNCRPD among country-level priorities, we present detailed descriptions of the articles most focused on in four countries (one from each income level group). We used the UNCRPD categorization model to conduct a content analysis of policies and issues that respond to the UNCRPD requirements specific to the context of the pandemic, and also to highlight gaps in the inclusion and consideration of the needs of persons with disabilities in all policies and responses. This report provides an initial high-level overview of the policy domains addressed by governments allowing us to comment on the general alignment between these policy domains and the requirements of the UNCRPD.

We have identified the following key findings from this initial analysis. First, the alignment of countries' responses with the UNCRPD indicates a gradual shift from emergency responses in the beginning of the pandemic (Article 11), to issues related to service provision and programs that accommodate a more "chronic" reality and impacts of restrictions in the daily life of citizens such as education and community living. Second, some countries had special considerations made for individuals with disabilities who face multiple layers of marginalization such as children, women, indigenous persons, and gender diverse. Third, we did not note particular differences between responses of countries based on income categories and regions. Fourth, although some policies recognized the vulnerability of persons with disabilities and flagged the need to concentrate efforts to consider this population, few documents outline concrete actions to address these issues beyond recognition of potential vulnerability or awareness raising.

Introduction

Persons with disabilities (PWD) experience heightened risks in the context of the COVID-19 pandemic. The amplified risk for this group occurs in terms of the potential for increased risk of morbidity and mortality from the virus, the challenges in accessing information and protective measures efficiently during and emergency, and the economic and social vulnerability of this group which may be exacerbated during emergencies and neglected in government responses. International agencies have highlighted these elevated risks and the extent to which they have multiple, converging sources (UN, 2020, WH0, 2020).

In the context of the pandemic, persons with disabilities may have limited access to public health information, experience difficulties to comply with social distancing orders due to support needs or because of institutional housing, or encounter challenges pertaining to personal protective measures such as handwashing due to inaccessible sinks or hand pumps (EFHOH, 2020). Evidence is demonstrating that persons with intellectual and developmental disabilities are more likely to be infected with COVID-19 and more likely to die from it than others (Turk et al, 2020; Landes et al, 2020), and people with physical disabilities are experiencing decreased access to health care, including essential rehabilitation services, in addition to exacerbated mental health challenges, and community participation restrictions (Lebrasseur et al, 2020).

In the context of COVID-19, policy decisions and frameworks have also been identified as potential sources of harm. Concerns have been raised and lawsuits launched, for example, about disability discrimination and ableism in frameworks for triage and resource allocation (Savin and Guidry-Grimes, 2020). Advocates in the United States pushed Congress to consider the unique needs and limitations of PWD when crafting its triage protocols, pointing out ways that early drafts would leave many persons with disabilities without adequate ongoing services (Solomon, et al, 2020). Impacts have also been felt at the level of programs. For example, access to assistive devices was impeded when, at the beginning of the outbreak, the government of Ontario, a province in Canada, categorized assistive device retailers as a non-essential service and let these retailers faced restrictions in their operations (Monsebratten, 2020). Moreover, vulnerable groups

such as children have struggled to access essential health and education services during the pandemic, and parents have not been able to access respite and support services to guarantee continuity of care (Gonzalez et al., 2021; WHO, 2020)

Many of the considerations to protect and uphold the rights of persons with disabilities during a crisis are embedded in the provisions of the UNCRPD. Incorporating considerations for persons with disabilities and addressing the identified risks is a requirement for signatory countries. Article 11 of the UNCRPD states that "States Parties shall take... all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters." The uncertainty of the trajectory of the pandemic coupled with shifts in the pandemic response creates a context where stringent and ongoing analysis of risk and risk response is warranted. Public health measures, such as quarantine, shelter-at-home and lockdown, will have different impacts on persons with disabilities. Policy responses that are aligned with the provisions of the UNCRPD will mitigate potential harms and serve to promote equity.

An important lesson of the COVID-19 pandemic has also been the importance of structuring, monitoring, and integrating experiences across countries (The Lancet, 2020). Cross-country comparison of COVID-control policies, for instance, have allowed for a better understanding of effectiveness of different policies in reducing the spread of the virus (Wibbens et al, 2020). Collecting and analyzing national level policies can support such learning. This project, funded by the RRSPQ and REPAR, aims to inform and support the development of policy responses that are inclusive of persons with disabilities, according to the UNCRPD, to help mitigate potential harms and promote equity as the COVID-19 pandemic evolves, and to inform future emergency responses.

We are pursuing this aim through a comprehensive international analysis of a purposeful selection of 14 countries' national policies in response to the COVID-19 outbreak in relation to the provisions of the UNCRPD. The following section provides an overview of the UNCRPD, which is the framework of commitments that we are using to assess the nature of the policy responses put forward by the countries included for analysis. Following this section, we provide an overview of our methods and results.

Overview of the Field of International Disability Rights Law and Policy

The UNCRPD is an international treaty that clarifies and codifies the rights of persons with disabilities. It defines disability as resulting from the interaction between "long-term physical, mental, intellectual or sensory impairments" and the many institutional, physical, and social barriers that "hinder their full and effective participation in society on an equal basis with others" (UN General Assembly, 2007, p. 8-9). As of January 2021, the UNCRPD has 182 parties (UN Treaty Collection, 2021). Pursuant to article 4, states parties are obliged to protect and implement the rights included in the UNCRPD by adopting, abolishing or amending domestic laws, policies and regulations; considering disability rights and consulting persons with disabilities in the development of policies and programs; adopting measures to eliminate discrimination against persons with disabilities; and taking steps to promote accessibility and universal design (UN General Assembly, 2007, p. 5-6). State parties are also obligated to set up national focal points as well as independent mechanisms to promote, protect and monitor the implementation of the UNCRPD (UN General Assembly, 2007, p. 20). Finally, state parties must cooperate with other states and international organizations to support the realization of disability rights internationally (UN General Assembly, 2007, p. 19).

The rights protected under the UNCRPD include civil and political rights such as the right to life (art. 10), legal capacity (art. 12), access to justice (art. 13), personal liberty and security (art. 14), freedom from torture (art. 15), freedom from exploitation, violence, and abuse (art 16), physical and mental integrity (art. 17), liberty of movement (art. 18), freedom of expression and opinion, and access to information (art. 21), privacy (art. 22), and participation in political and public life (art. 29). It also encompasses social, economic, and cultural rights that are critical to the well-being of disabled persons, including rights to respect for home and the family (art. 23), education (art. 24), health (art. 25), work and employment (art. 27), an adequate standard of living (art. 28), and participation in cultural life, recreation, leisure, and sport (art. 30). Finally, the UNCRPD contains provisions that address particular challenges faced by persons with disabilities, including accessibility (art. 9), independent living and inclusion in the community (art. 19), personal mobility (art. 20), and habilitation and rehabilitation (art. 26).

As a whole, the UNCRPD provides a "human rights model of disability" that can be used to design, implement, and evaluate policies and practices in a manner that respects, protects, and fulfils the rights of disabled people (Theresia, 2016). To enhance the role of the UNCRPD

as a planning and monitoring tool, the Office of the United Nations High Commissioner for Human Rights, in consultation with disabled people's organizations, UN agencies, civil society, and experts, has developed a set of indicators, known as Bridging the Gap. The Bridging the Gap indicators set out objective criteria for each of the articles in the UNCRPD that can be used to measure, through quantitative or qualitative data, the efforts of states to comply with different attributes of a human rights provision (EU & OHCHR, 2018). These indicators are further divided into three categories: structures, such as the adoption of laws and policies, that indicate a commitment to implementing a given right; processes that measure the extent to which states seek to implement their commitments through the creation of specific institutions, policies, and programmes and the allocation of resources; and outcomes that capture the impacts of the measures adopted to fulfil different human rights (OHCHR, 2012).

The UNCRPD also outlines the obligations that governments owe to persons with disabilities in a range of contexts, including in public emergencies, such as a pandemic. A thematic study on the rights of persons with disabilities under Article 11 developed by the OHCHR explains what a human rights approach to disability entails in the context of emergencies (UN Human Rights Council, 2015). To fulfill their obligations under the UNCRPD, states are most notably expected to: (1) adopt or reform their emergency response and recovery policies and practices that respect, protect, and fulfil the human rights of disabled people; (2) ensure that information related to emergencies is made available in formats accessible to persons with different types of impairments at all stages of an emergency; (3) foster the active and meaningful participation of persons with disabilities, including of women, men, boys and girls with disabilities of all ages, at all levels; (4) allocate resources to ensure that their efforts are inclusive of and accessible to persons with disabilities and build capacity among officials, personnel, and stakeholders intervening in emergency situations regarding the rights of persons with disabilities.[1] Most recently, several international organizations, bodies, and experts have emphasized the continuing application of the UNCRPD in the context of the COVID-19 pandemic and the importance of ensuring that states comply with their obligations in the development and implementation of their pandemic control and recovery efforts (OHCHR, 2012; UN Committee on the Rights of Persons with Disabilities, 2020).

[1] Ibid. at paras. 54-60. The importance of disability inclusion in the context of emergency response and recovery efforts is further emphasized in the Sendai Framework for Disaster Risk Reduction, a nonbinding international instrument adopted by states at the World Conference on Disaster Risk Reduction held in March 2015 and later endorsed by the UN General Assembly in June 2015. G.A. Res. 69/283, annex II, Sendai Framework for Disaster Risk Reduction 2015 – 2030 (June 23, 2015).

Aim

This project aims to analyze the policy response to COVID19 specific to persons with disabilities, by analyzing national level policies using the provisions of the UNCRPD as the reference point.

Methods

Country Selection

Our first selection criterion was countries who have ratified the UNCRPD. We also chose countries across four income categories (low, low-middle, upper-middle, and high) and five geographic regions in order to account for variation in context. We selected countries that had French or English as an official language, considering the language capability of the research team and the analysis program we used. Based on these criteria, the final list of countries includes: Canada, India, Australia, France, South Africa, Jamaica, Fiji, Philippines, Zimbabwe, Rwanda, Haiti, Malawi, Ireland, Guinea.

Policy Search and Selection

We then collected policy documents from these countries related to COVID-19. We defined policy as a directive (e.g., a plan, guidelines, statements) published by a national government. Inclusion criteria were: national-level documents accessible online and published by national authorities (i.e. government) in English or French (both language documents were obtained when available), specific to COVID-19 including general pandemic preparedness legislation and exclusion criteria were: social medial postings, previously published policies related to other infectious disease outbreaks or pandemics not specific to COVID-19, sub-national level guidance or policies. In countries where these documents proved difficult to identify, we supplemented our data collection by accessing the COVID-19 Law Lab (https://covidlawlab.org/), and other COVID-related databases such as AfricanLii (https://africanlii.org/africanlii-covid-19) and Asian Preparedness Partnership (https://app.adpc.net/publications/by-country/2#view-date).

We also accessed Official Government Gazettes (not part of the government website, but official state source for decrees, policy docs, etc.) for the Philippines, Zimbabwe, Rwanda, and France (for a complete list of data sources please refer to Appendix X). [2]

Country profiles were created with available information on political structure, GDP and other indicators to help situate our analysis in the broader country context. We also completed the country profiles with fiscal policies from the IMF and OECD.

INCLUDED	EXCLUDED
• DIRECTIVES, PLANS, GUIDELINES, STATEMENTS • AUTHORED BY NATIONAL GOVERNMENTS • ACCESSIBLE ONLINE • ABOUT OR REFERENCING COVID-19 • PANDEMIC PREPAREDNESS LEGISLATION • OFFICIAL GOVERNMENT GAZETTES	• SOCIAL MEDIA POSTS • LEGISLATION AND POLICIES PUBLISHED BEFORE 2020 SPECIFIC TO PREVIOUS OUTBREAKS (E.G. EBOLA, SARS 1, ETC.) • SUB-NATIONAL LEVEL POLICIES (E.G. PROVINCIAL LEGISLATION) • GOVERNMENT GAZETTES (SEE NOTE)

Data Extraction

Each document was categorized according to the following characteristics: Country, region, income category, language, and source. We included a source variable for the documents in order to specify whether the document was collected from a government website or from another database. These variables allow the team to explore the dataset in the context of specific characteristics and to make comparisons. We also obtained COVID-19-related information from the 14 included countries through the Oxford database (Ritchie et al, 2021a).

We used a computational text mining approach to analyze the COVID-19 policy documents. Using the CRISP-DM (Cross-Industry Standard Process for Data Mining) approach to text mining, we analyzed data from the policy documents obtained cumulatively from January 2020 of the 14 countries. [3] We analyzed the documents inductively (keyword frequency

[2] In cases where the number of policies collected through web searches was very low, Government Gazettes were accessed and added to the corpus in order to increase the validity of results generated using text mining methods.

[3] Policies were collected each month beginning in July 2020 and added to the corpus. Policies originally published between January and June 2020 were included if they were still accessible on government websites in July 2020, even if they had been archived. Documents published between January 2020 to June 2020 which were subsequently removed prior to July 2020 were not collected.

analysis, phrase frequency analysis, named entity extraction and topic modeling) and deductively (creation of key variables including: income category, region, and language) to compare across inductively generated items, and categorization model of articles and indicators within the UNCRPD. Categorization models captured articles in the UNCRPD to assess the alignment between countries' policy responses during COVID-19 and the convention principles.

The categorization model is based on the Bridging the Gap indicators for the UNCRPD (created by the UN OHCHR) and covers all 50 articles of the convention. The model was created in both French and English. As we proceed with our project, we are validating these models (i.e. testing the accuracy of these models with the data that is being collected to make sure the analytical framework returns meaningful information in the text mining procedure). The validation was carried out to determine how closely the model corresponded with the UNCRPD indicators.

We also analyzed the key words obtained from each article within some of the documents to obtain a better overview of how these key words (related to the UNCRPD articles) are described in the text of the policy documents. We present our initial analysis in this report.

Preliminary Results

Overview of Country Profiles

As noted, our analysis focused on 14 countries representing four income categories and five geographic regions. The confirmed cases between January-December 2020 varied across the fourteen countries as shown in Figure 1. Of the fourteen countries included in our analysis, the COVID cases per million as of December 31, 2020 ranged from a high of 41,022 in France to a low of 54 in Fiji. Apart from South Africa, an upper-middle income country that had the third highest COVID cases of our 14 countries, Canada, Ireland, and France experienced the highest rates of COVID. The latter three countries represented three of the four high-income countries included in our analysis; the fourth being Australia, which was much lower with roughly 1000 cases per million. The countries in the low-income category (Guinea, Haiti, Malawi, Rwanda) reported between 300-1000 cases per million. Importantly, the variation in case rates may be attributed to several different factors including testing capacity, the impact of stringency measures, geography, and volume of travel within and in and out of the country. The focus here is to present the numbers as reported, keeping in mind the need for further analysis to attribute the conditions that shape these numbers. The policy response to the COVID outbreak across countries varied in both the timing and comprehensiveness (i.e., stringency).

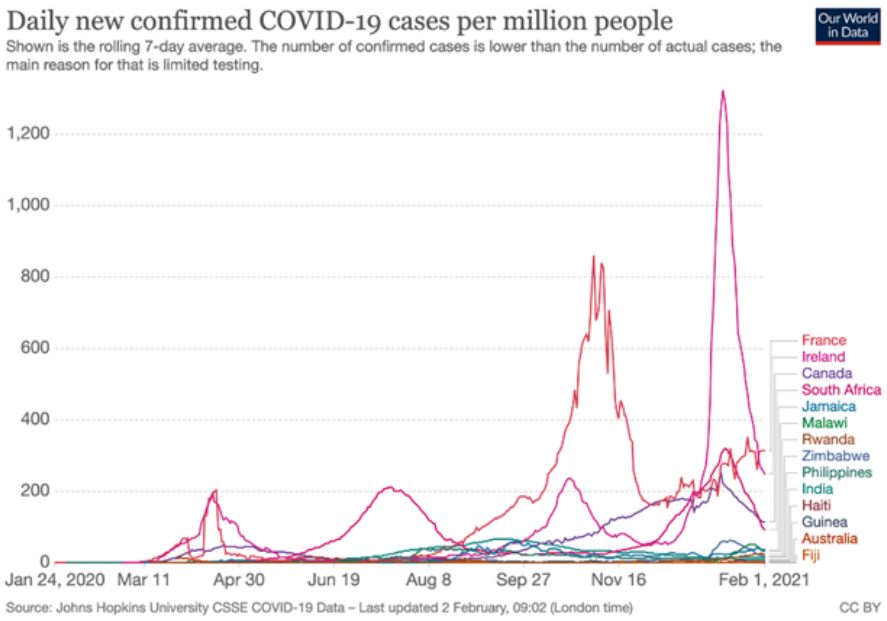

Figure 1. Confirmed cases over time for the 14 sample countries (Ritchie et al, 2021b).

The Oxford University 'Our World in Data' developed a Stringency Index to evaluate and monitor government response to the COVID pandemic where a maximum score of 100 represents the strictest response. The index is made up of nine indicators: school closures, workplace closures, cancellation of public events, restrictions on public gatherings, closures of public transport, stay-at-home requirements, public information campaigns, restrictions on international movements, and international travel controls. It is important to note that the stringency score assigned to a country reflects the strictest set of policy responses within the country. The score may not reflect policies at the national level, but rather a subnational region with the strictest set of policies, and they have no specific directive related to persons with disabilities. When applied to our sample, we find that at the end of our period of analysis (December 2020), the Stringency scores ranged from a low of 40.74 (Guinea) to a high of 84.26 (Ireland). The pattern of stringency over time aligns with our finding that the bulk of policies were established between January and July 2020 (refer to Figure 2), with a substantial upsurge in policies across countries in March 2020. Most countries experienced a gradual but sustained rise in daily cases from March to October 2020. Exceptions include Australia where a rapid spike (wave 1) in cases in March was followed by a dramatic decrease in incidence followed by another rapid spike (wave 2) in August followed by another dramatic decline in cases. It is important to note that no specific analysis was done to the direct association between stringency measures and the cases incidence, and to reinforce that these measures or outcomes are not disaggregated by population characteristics such as disabilities.

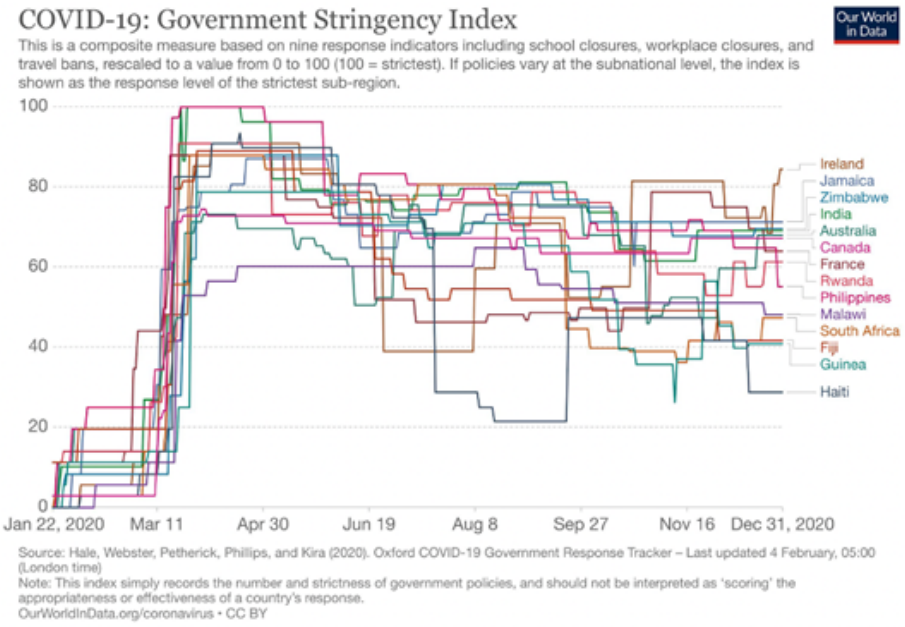

Figure 2. Government stringency scores over time for the 14 sample countries.

Overview of Country Policies

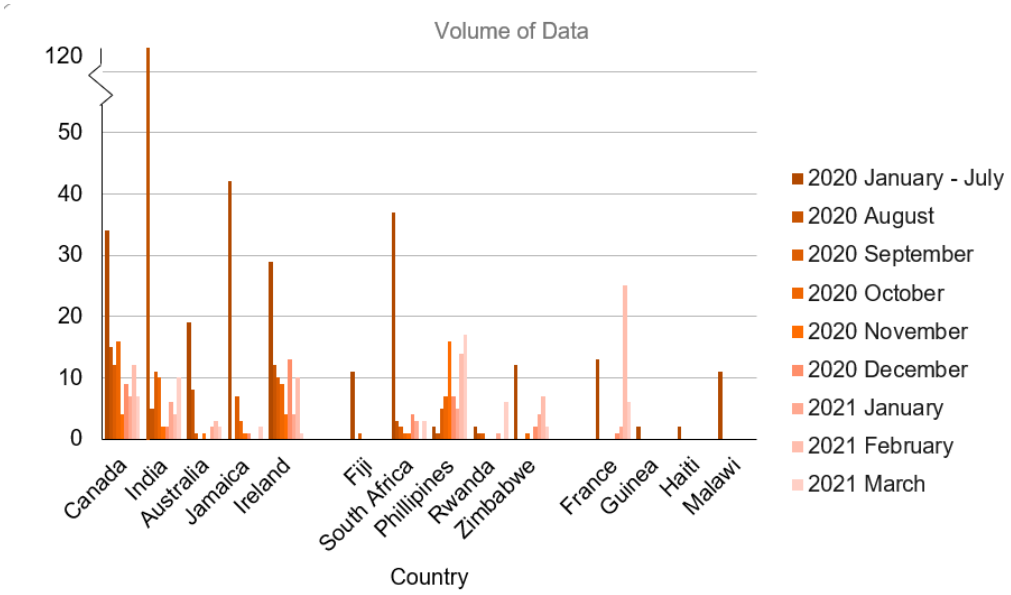

Figure 3. Policy documents retrieved per country over time.

As can be expected, we found the bulk of COVID-related policies were established by national governments at the beginning of the outbreak between January and July 2020. The largest absolute (i.e., not adjusted for population) number of policies were established by India (n=120), followed by Jamaica (n=42), South Africa (n=37), and Canada (n=34) (See Figure 3 for volume by country over time). The distribution of total number of policies between January and July 2020 was similar across high (n=95), upper-middle (n=90), and lower-middle (n=134) income categories. We found fewer policies in the low-income category (n=17) relative to the other income categories. It should be noted that the countries we included in our analysis within this category experienced later upsurges of cases, as presented in the previous section. While the overall number of policies developed in response to the COVID pandemic provides some generic indication of government action, the nature and quality of the policies require analysis to determine the extent to which these policies cover the range of needs within the population.

The following sections present results from our analysis of the categorization model, which assesses alignment with the articles of the UNCRPD.

Most Frequent UNCRPD Articles Cited

In order to assess the degree to which UNCRPD compliance is reflected in government response to COVID, we used the multi-level categorization dictionary that we developed based on the Convention on the Rights of Persons with Disabilities (CRPD) Indicators (see details above in methods). [4]

We used this dictionary to analyze the full dataset of policies that we had collected between January 2020 and January 2021. Figure 4 shows the most highly referenced articles. Article 11 (Humanitarian Emergencies) indicators were the most frequently addressed by the collected policies. This finding reflects the broader context of the review: the global public health crisis of COVID-19. Other articles that are more frequently addressed include Articles 19 (living independently), 24 (education), 12 (equal recognition before the law), 23 (family) and 30 (cultural life). Interestingly, despite the nature of this emergency as an infectious diseases crisis, the analysis found few instances of Article 25 (health), with only 7 documents referencing health indicators related to the CRPD, equivalent to just over one percent of the total documents collected.

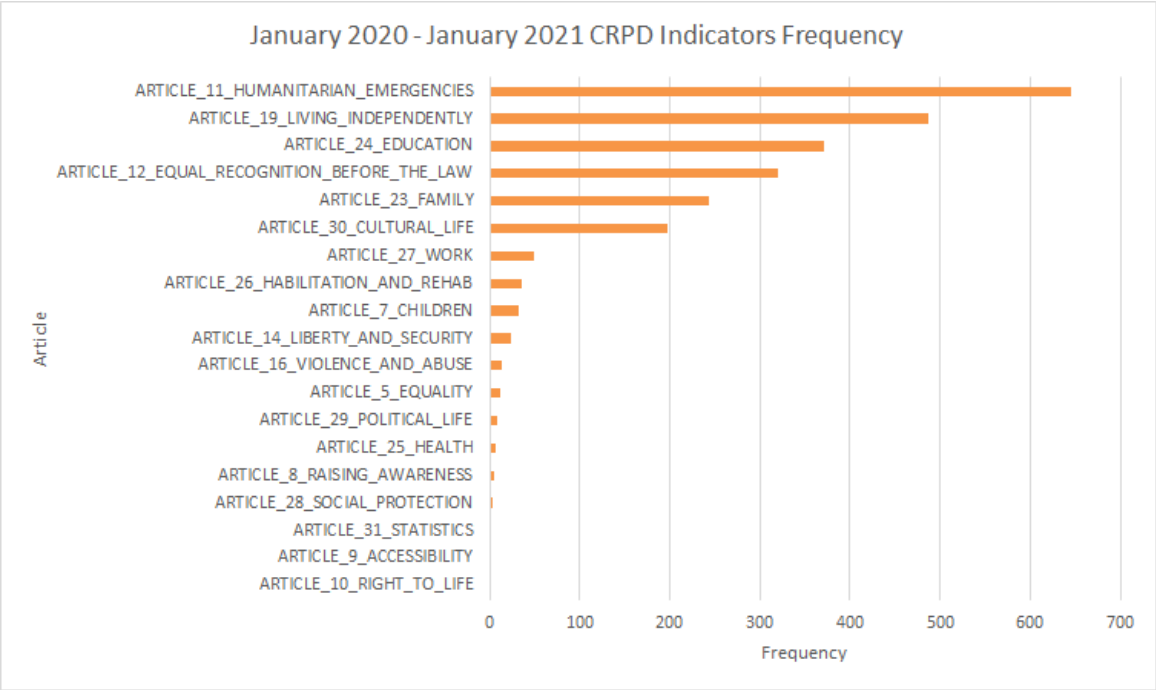

Figure 4. Frequency of the 20 UNCRPD articles' indicators captured in the policy documents from January 2020 until January 2021

[4] A total of 30 indicators linked to the first 33 articles of the CRPD were developed by the European Union in partnership with the OHCHR

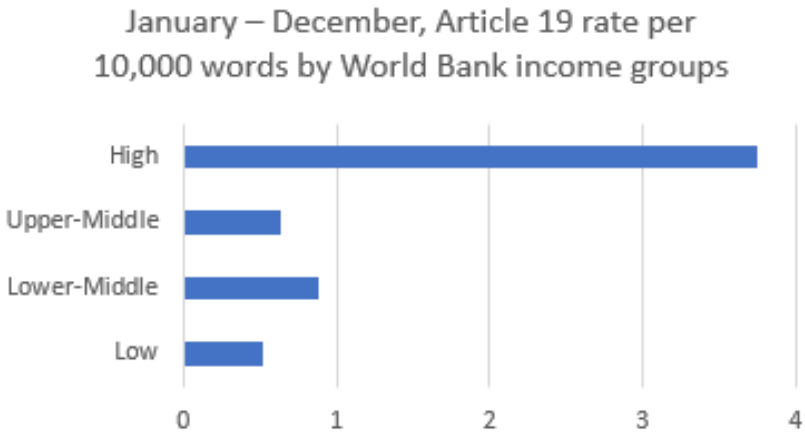

Figure 5. Rate per 10,000 words at which Article 19 is referenced in the data for each of the four World Bank income groups

Comparing the frequency of indicators associated with particular articles provides information about the policy-making priorities within and across countries during the pandemic. More specifically, we can examine the frequency with which the indicators linked to a particular UNCRPD article arise in policy documents by looking at a rate per 10,000 words (to adjust for the wide range in number and length of policy documents between countries). Using this metric, comparisons can be made across countries, or between groups of countries based on geographic region or income category. As an example, Figure 5 shows the rate with which Article 19 (Living Independently) occurs in the dataset, broken down by World Bank income categories of high income economies, upper-middle income economies, lower-middle income economies, and low income economies. The figure displays a considerably greater emphasis on independent living in the community within policy documents from High Income Countries when compared to all other income categories. By contrast, Figure 6 records the rate with which Article 5 (Equality and Non-discrimination) occurs in the dataset, dissected by World Bank income groups as well. This figure illustrates a higher focus by low-income countries on this article compared to other income groups, followed by high income countries, and none in the policies retrieved from low-middle and high-middle income countries.

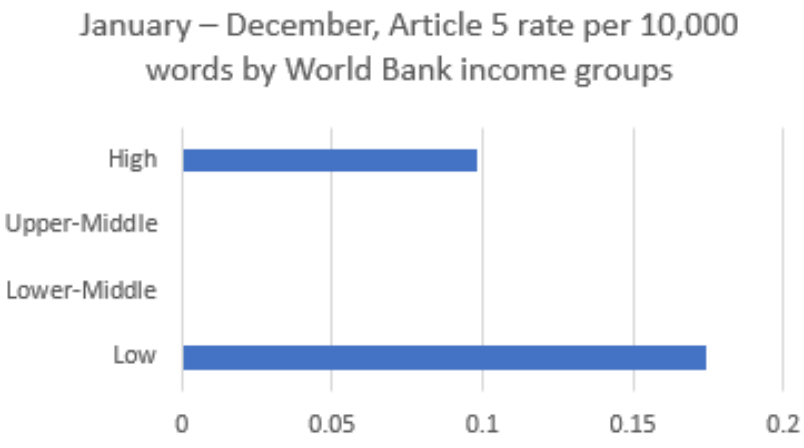

Figure 6. Rate per 10,000 words at which Article 5 is referenced in the data for each of the four World Bank income groups

As mentioned above, the categorization dictionary can be applied at different levels to examine specific sections of an article or multiple articles. Figure X shows a breakdown of Article 11 into its subsections and subcategories. The results show that the emphasis of references to indicators listed in Article 11 focus on the subcategory Prevention and Response within the subsection Structure. Other results all fall under general subsection indicators, as opposed to referencing specific subcategories within Structure, Process, or Outcomes, however there are far fewer of these results compared to Prevention and Response. We can also gain insight into the timeline of the prevalence of Prevention and Response by looking at the rate per 10,000 words of the subcategory for each month between July 2020 and January 2021 that the documents were release. Figure X shows a trend of these indicators being referenced increasingly often until October and then a decline.

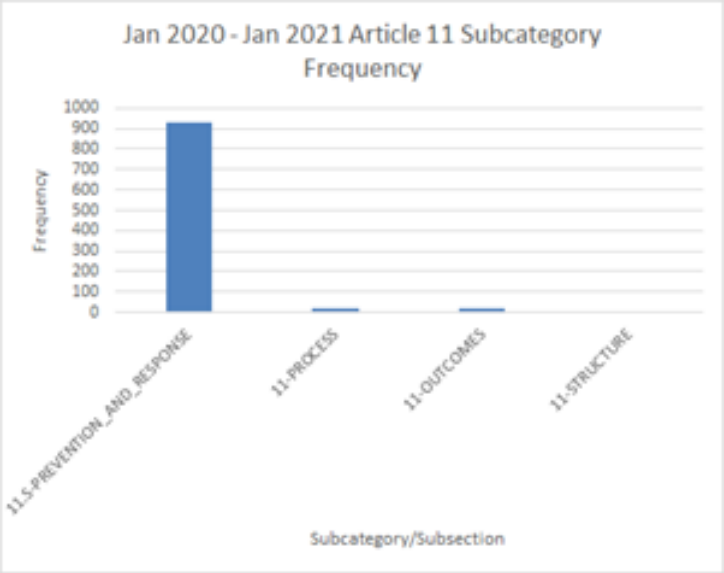

Figure 7. Total number of times each subcategory of Article 11 is referenced in the data set

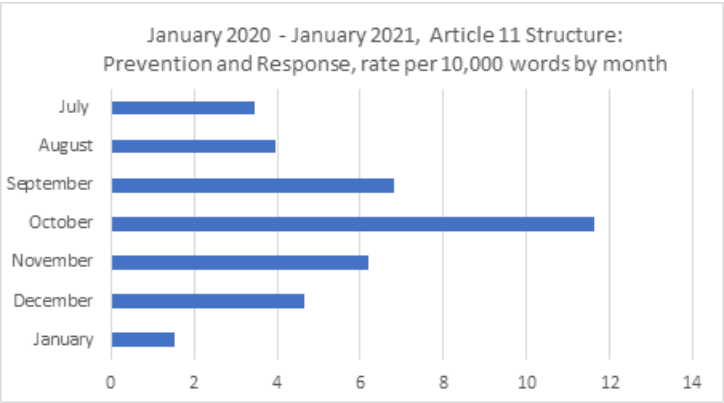

Figure 8. Rate per 10,000 words at which Structural indicators of Article 11, subsection Prevention and Response are referenced in each month that the data was collected.

Co-occurrence Modelling: Identifying Which Terms Occur Close Together

Another inductive method that we applied is cluster analysis, or co-occurrence modelling. This method identifies pairs or groups of words that frequently overlap with each other in a particular document. Co-occurrence modelling also identifies the proximity of clusters (that is, how close these groups of words are to each other). To illustrate the sorts of results that can be generated, a section of the cooccurrence dendrogram is reproduced in Figure 9, detailing just a few of the clusters identified. As we move forward, we will use these clusters to identify new topics of interest within the data. These clusters can point to content in the policy documents that can be further analyzed qualitatively.

For example, the graph below shows some obvious co-occurrences, such as "activities including social distancing gatherings", but also indicates that disability occurred commonly in conjunction with mental support, suggesting a policy domain of interest that is not specifically included in the UNCRPD framework. In turn, this combination could be analyzed more closely in order to better understand the connection between these concepts.

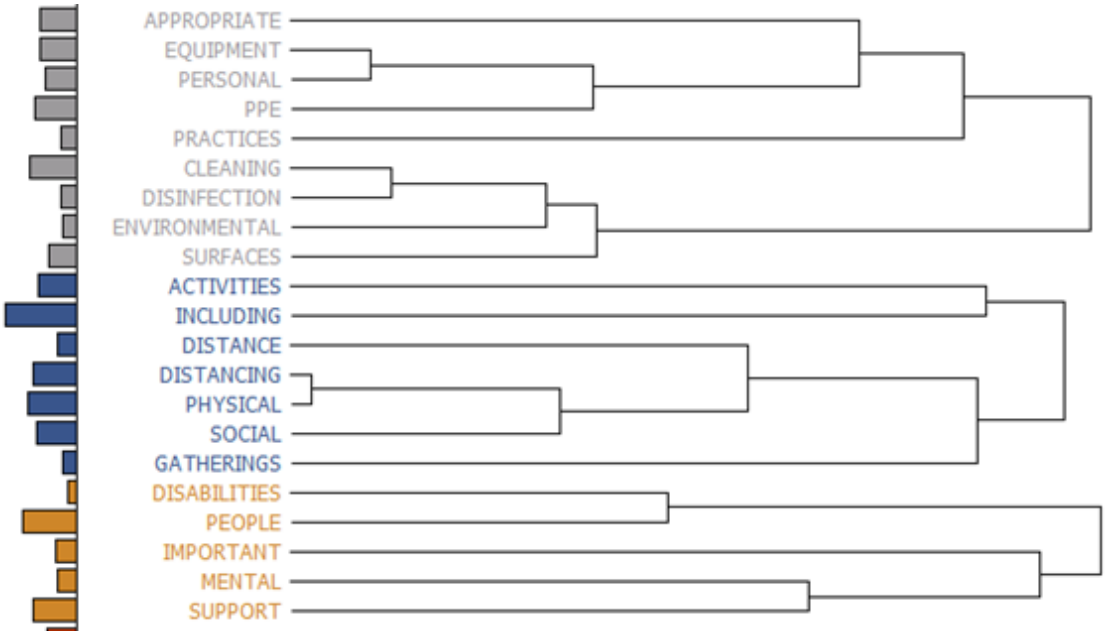

Figure 9. Cluster analysis of co-occurring words.

General Frequency of Reference to UNCRPD Content

The alignment of countries' responses with the UNCRPD indicates a gradual shift from emergency responses in the beginning of the pandemic (Article 11), to issues related to service provision and programs that accommodate a more "chronic" reality and impacts of restrictions in the daily life of citizens such as education and community living.

The emergency orientation of policies in the beginning of the pandemic is exemplified by the following excerpts from India and Jamaica. In India's main COVID-19 public health guidance document, published in July 2020, considerations for persons with disabilities are made in relation to emergency hospitalizations and transportation measures associated with by ambulance transport to health care settings, emphasizing that the presence of a disability guarantees consulting with the caregiver for decision-making and for obtaining information that would be confidential in a non-emergency situation:

"If the patient is a minor (aged 16 or less) or the patient in incapacitated, for example, in medical conditions like dementia or physical disability etc, the caregiver is deemed to be authorized to consult on behalf of the patient" (NIMHANS, 2020)

The same consideration is made in Jamaica's initial policy responses to the pandemic and lockdown restrictions, guaranteeing that persons with disabilities are exempted from the strict measures being adopted at the time:

"*A person who under sub-paragraph 3 is permitted to leave an abode or place of residence, or to leave or enter a specified area [due to health condition or disability]"* (Government of Jamaica, 2020)

The frequency of references to aspects related to the UNCRPD also reflects the different waves and stages of the pandemic where periods of more stringent public health measures required policy responses that were more restrictive of citizens' abilities to do activities such as visit family (Article 23) and circulate in the community (Articles 30, 19).

To illustrate differences in policy priorities across countries, we will present a comparison of cumulative frequencies of UNCRPD articles mentioned in one country from each of the four income categories. Articles related to community living and education, situations of risk

and humanitarian emergencies, and respect of the family were among the top cited articles across these 4 countries.

In the analysis of documents from January 2020 to July 2020, in these four example countries, in the first months of the pandemic we can see specific mention of persons with disabilities in the initial public health measures. In the second period of analysis (August to December 2020), issues related to access to services become more prominent. Education services (Article 24) were adjusted in many settings and shifted to online platforms. Considerations specific for persons with disabilities that may not have been present in the initial emergency response documents, became more prevalent in the guidance for the general population or in public health recommendations. For example, in India and Malawi we see recognition of different experiences and conditions associated with vulnerability that persons with disabilities may face in relation to mental health, living conditions and socio-economic considerations:

"PwD are just as vulnerable to anxiety, apprehensions, sadness and grief, irritability, sleep disturbances and withdrawal as their non-disabled peers. These are common reaction, but they may be qualitatively or quantitatively different, depending on the type of disability and age of the PwD. Persons with intellectual and developmental disabilities, especially, may require assistance in understanding the current crisis and consequent disruptions to their routine lives. They will also require in adhering to recommended hygiene measures." (NIMHANS, 2020).

"*The plan targets populations and families affected by the outbreak of COVID-19 both health-wise and economically, especially those marginalized and vulnerable, including children, women, elderly, people with disabilities, children in institutions, people with HIV/AIDS and chronically ill, and those in hard to reach locations or with poor access to service"* (Government of Malawi, 2020).

Some countries had special considerations made for individuals with disabilities who face multiple layers of marginalization such as children, women, indigenous persons, and gender diverse. It is assumed that populations of persons with disabilities who are at the interface of multiple disadvantages can experience a greater impact from the pandemic and therefore unique needs should be carefully considered in the public health efforts and measures. For example, the following statement from a policy document in Canada illustrates the recognition of the intersection of gender and disability: *"Plans should be inclusive of and*

accessible to women and gender diverse women, men, and all gender diverse persons with disabilities" (Government of Canada, 2020b). There was also recognition in Canada's policy of the need to attend to the unique circumstances of different communities. For example, the following quote illustrates the recognition of the common and unique needs of indigenous communities: *"[...] First Nations, Inuit and Métis communities may not be exposed to public health awareness campaigns to the same degree as urban communities with unlimited access to internet and public information campaigns [...] considerations to culture, health literacy, disabilities, and language can present barriers to adoption of public health advice"* (Government of Canada, 2020a)

Although some policies recognized the vulnerability of persons with disabilities and flagged the need to concentrate efforts to consider this population, few documents outline concrete actions to address these issues beyond recognition of potential vulnerability or awareness raising. The few concrete actions clearly described are mostly considerations for accessibility. For example, the following statement from a policy document in Canada states, "*Access to handwashing facilities can be increased, ensuring accessibility for individuals with disabilities or other accommodation needs"* (Government of Canada, 2020). Another from South Africa notes, *"Persons with disabilities must receive information about infection mitigating tips, public restriction plans, and the services offered, in a diversity of accessible formats with use of accessible technologies [...]*" (Government of South Africa, 2020). While the following statement from Malawi urges the provision of materials to ensure safety and access, *"[...] provide material for quarantine facilities to make sure that protocols and facilities are child-friendly and address rights and needs of vulnerable populations, including children and people with disabilities"* (Government of Malawi, 2020).

India's policies were particularly aligned with the UNCRPD both in aspirational guidance and in concrete action plans. The country has advocated for accessibility of communication materials for persons with different needs since the first pandemic communication and guidelines. They have also considered reviewing the disaster protocols to make sure they included the needs of persons with disabilities, including consideration for other medical conditions that may expose this group to a higher risk - as exemplified in the main COVID19 general guidance documents from India: *"all plans and programmes should be inclusive, with specific attention to the needs of and challenges faced by PwD E.g. Public communication and education materials, should be accessible to PwD with different challenges, quarantine facilities should be cognizant about challenges faced by PwD, helplines should be accessible to persons with different disabilities[...]"* (NIMHANS, 2020). There was also recognition of the

unique health vulnerabilities of persons with disabilities: *"one area in which requires more focus is the scrutinization for disaster protocols which may be discriminatory to persons with disability. PwDs have a higher chance of experiencing severe respiratory illness and suffering from additional co-morbidities[…]"* (NIMHANS, 2020).

Compliance with UNCRPD general principles and Article 31 (Statistics and Data collection) was noted in Malawi's documents: *"Advocate for surveillance systems to include systematic collection of age/sex categories as well as vulnerabilities, including disability friendly data"* (Government of Malawi, 2020). Data collection is suggested by the UNCRPD as a key mechanism to assess and implement policies that address the "barriers faced by persons with disabilities in exercising their rights" (UN General Assembly, 2007, p. 19). Collecting disaggregated data (by disability type, age group and region) that can inform the specific issued being faced by individuals with disabilities during the pandemic is fundamental to develop policies that are targeted, effective, and compliant with a human rights normative framework, and that in the immediate country's response and in future policy development.

We found examples of social supports in India's policies. The adaptation of monetary, service, and other material supports was noted as an important aspect of the emergency response both for the health and social well-being of persons living with disabilities:

"Continued access and uptake of welfare provisions and or emergency supports are needed. Government agencies can aid the situation by pro-actively preserving and delivering benefits access in such a situation, such as advance payments of pensions and ensuring quick access to services. Continued service delivery may have beneficial impacts on reduction of post disaster morbidity" (NIMHANS, 2020).

"A PwD may derive a lot of satisfaction in going to rehabilitation facility, chat with friends and work in vocational sections. Many get a sense of community at rehabilitation facility and feel that ' I'm not alone' [in reference to consider rehabilitation services as essential services] (NIMHANS, 2020).

This section has pointed to the range of policy responses taken to address the needs of persons with disabilities. The UNCRPD provides an important reference point to assess the adequacy of these responses and was indeed created to unify the types of policy commitments that signatory countries to do respect the rights of persons in regular policy development, but also in emergency responses such as that imposed by the COVID-19

pandemic.

In the current preliminary analysis we did not note particular differences between responses of countries, in relation to persons with disabilities, across different income categories and regions. In this partial analysis of 4 countries it is clear that some countries like India have purposefully created particular guidance for this population. India is also the country with far higher volume of documents produced, among all the 14 countries, but it is still clear that there is attention to persons with disabilities, whereas other countries may not have as much, even when accounting for total document volume and country size.

In the concluding section below we extrapolate on possible interpretations of some of these findings and point to the further analysis that we will conduct in this dataset, as well as some initial considerations for policy responses in alignment with the CRPD.

Conclusion and Key Points

The findings presented in this report indicate the quantity and scope of policies established by governments to address the needs of persons with disabilities during the COVID pandemic. We see that all 14 countries have established such provisions to greater or lesser extents. Our findings suggest that certain articles of the UNCRPD, such as Article 19 on Independent Living, occurred with greater frequency in high-income countries than low-income countries. This finding and others that point to variation in articles addressed by country level policy requires further investigation to determine the context. The emphasis on independence as a positive aspiration and the often-negative connotation of 'dependency' has cultural origins and may hold different value in different settings (Fine & Glendinning, 2005). This type of question, that interrogates the assumptions underlying policy prescriptions, can further inform our understanding of government responses. What our analysis can point to is the frequency with which the policy documents referenced content from the UNCRPD articles based on our categorization model. What requires further investigation is the nature of the policy guidance and the conditions that led to the establishment of this policy content. Our analysis of key words in context in the four example countries provides important indications of the type of considerations being made by governments. For example, we find that across the four countries, governments provided written recognition of the intersectional considerations for persons living with disabilities, such as income and gender, and the unique considerations required based on the type and extent of impairment.

What we see in the policy responses indicates most often intention or consideration, but not necessarily action taken. In this sense, the lack of mention of persons with disabilities (as reflected by a low or inexistent frequency of citations) or specific actionable points beyond guidance may be a reflection of the types of documents obtained: a country-level response, rather than more regional, municipal or program level guidance. Government policy at the national level often provides overarching frameworks for action, leaving the establishment and implementation of actionable programs to sub-national governments. This is certainly the case for federated states like India and Canada, where jurisdiction for health and social care is situated with provincial or state governments. While the structural considerations are

important, it is also important to note that these initial findings may indicate the existence of gaps in policy responses, failing to transform intention into concrete responses. Some of the most "tangible" measures adopted by different countries to the population in general was emergency financial supports during the pandemic. This consideration of the cumulative and extraordinary financial support needs that persons with disabilities may have were only mentioned once in the documents analyzed to date. This may reveal a neglect of the particular needs of persons with disabilities, and the "second thought" nature that persons with disabilities and other historically marginalized groups occupy in policy making. More attention must be given to those within the disability community who face multiple vulnerabilities such as, but not limited to children, indigenous peoples, and gender diverse. These groups are at risk for being neglected through the entire crises, from access to information, to deprivation of essential services and in the considerations for recovery measures such as job security and financial supports.

Our findings were not able to determine if governments actively consulted with or facilitated participation of disability persons organizations or individuals with disabilities in informing policy responses or considerations. Although we know this is the case in Canada, for example, of creating a Disability Council to advise government, this was not particularly reflected in this initial analysis of the four most cited articles in a sample of four different countries. While this may be a limitation of our methodology, it does reflect the absence of explicit mention of consultation processes in policy documentation. The explicit inclusion of this type of content is important for transparency.

References

European Federation of Hard of Hearing People (EFHOH). (2020). EFHOH Newsletter | December 2020. Retrieved from efhoh.org/wp-content/uploads/2020/12/EFHOH-December-Newsletter-2020.pdf

European Union (EU), UN Office of High Commissioner for Human Rights (OHCHR). (2018). CRPD Indicators. Bridging the GAP. https://bridgingthegap-project.eu/crpd-indicators/

Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. Ageing & society, 601-621.

Government of Canada. (2020a). Community-based measures to mitigate the spread of coronavirus disease (COVID-19). https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/health-professionals/public-health-measures-mitigate-covid-19.html

Government of Canada. (2020b). Infection prevention and control for COVID-19: Interim guidance for acute healthcare settings. https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/health-professionals/infection-prevention-control-covid-19-second-interim-guidance.html

Government of Jamaica: Ministry of Justice. (2020) Disaster Risk Management Order No 6. https://moj.gov.jm/sites/default/files/The-Disaster-risk-Manag.-no.-6-Order.pdf

Government of Malawi. (2020) National Coronavirus Disease (COVID-19) Preparedness and Response Plan: March – June 2020. https://reliefweb.int/report/malawi/national-covid-19-preparedness-and-response-plan-march-june-2020

Government of South Africa. (2020). Disability – Coronavirus COVID-19. https://www.gov.za/covid-19/individuals-and-households/disability-coronavirus-covid-19

Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. Disability and Health Journal, 13(4), 100969.

Lebrasseur, A., Fortin-Bédard, N., Lettre, J., Bussières, E. L., Best, K., Boucher, N., ... & Routhier, F. (2020). Impact of COVID-19 on people with physical disabilities: A rapid review. Disability and health journal, 101014.

National Institute of Mental Health and Neuroscience (NIMHANS). (2020) Mental Health in the times of COVID-19 Pandemic: Guidance for General Medical and Specialized Mental Health Care Settings. https://www.mohfw.gov.in/pdf/COVID19Final2020ForOnline9July2020.pdf

Ritchie, H., Ortiz-Ospina, E., Beltekian, D., Mathieu, E., Hasell, J., Macdonald, B., Giattino, C., Appel C., Roser, M. (2021b). Coronavirus (COVID-19) Deaths – Statistics and Research. Our World In Data. https://ourworldindata.org/covid-deaths

Ritchie, H., Ortiz-Ospina, E., Beltekian, D., Mathieu, E., Hasell, J., Macdonald, B., Giattino, C., Appel C., Roser, M. (2021a). Coronavirus (COVID-19) Cases – Statistics and Research. Our World In Data. https://ourworldindata.org/covid-cases

The Lancet. (2020). COVID-19: learning from experience. The Lancet. 395(10229):1011. https://doi.org/10.1016/S0140- 6736(20)30686-3

Theresia, D. (2016). Disability in a human rights context. Laws, 5(3). https://doi.org/10.3390/laws5030035

Turk, M. A., Landes, S. D., Formica, M. K., & Goss, K. D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. Disability and Health Journal, 13(3), 100942.

United Nations (UN). (2020). Policy Brief: A Disability-Inclusive Response to COVID-19. United Nations, retrieved from https://www.un.org/sites/un2.un.org/files/sg_policy_brief_on_persons_with_disabilities_final.pdf

UN General Assembly. (2007, January 24). Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, A/RES/61/106. Retrieved from https://www.refworld.org/docid/45f973632.html

UN Committee on the Rights of Persons with Disabilities. (2020). “Joint Statement: Persons with Disabilities and COVID-19 by the Chair of the United Nations Committee on the Rights of Persons with Disabilities, on behalf of the Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility.” UN Office of the High Commissioner for Human Rights. https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25765&LangID=E

UN Human Rights Council. (2015, November 30). Thematic study on the rights of persons with disabilities under article 11 of the Convention on the Rights of Persons with Disabilities, on situations of risk and humanitarian emergencies, A/HRC/31/30. Retrieved from https://www.refworld.org/docid/56c42c744.html

UN Office of the High Commissioner for Human Rights (OHCHR). (2012). “Human Rights Indicators: a Guide to Measurement and Implementation.” UN Office of the High Commissioner for Human Rights. https://www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf

UN Office of the High Commissioner for Human Rights (OHCHR). (2020, April 29). “COVID-19 and the Rights of Persons With Disabilities: Guidance.” UN Office of the High Commissioner for Human Rights. https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf

UN Treaty Collection. (2021, April 19). Convention on the Rights of Persons with Disabilities. UNTC. https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en

Wibbens PD, Koo WW-Y, McGahan AM. (2020). Which COVID policies are most effective? A Bayesian analysis of COVID-19 by jurisdiction. PLoS ONE, 15(12): e0244177. https://doi.org/10.1371/journal.pone.0244177

World Health Organization (WHO). (2020). Disability Considerations During the Covid-19 Outbreak. World Health Organization, retrieved from https://apps.who.int/iris/bitstream/handle/10665/332015/WHO-2019-nCov-Disability-2020.1-eng.pdf?sequence=1&isAllowed=y