Statement of Catalina Devandas Aguilar

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Date: 10 August, 2020

1. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This statement is true and correct to the best of my knowledge and belief.

2. The views I express in this statement are my own based on my education, training and experience. They are not intended to represent any views of the United Nations.

Professional background

3. I am currently the first United Nations (UN) Special Rapporteur on the rights of persons with disabilities (Special Rapporteur). I have held this position since 1 December 2014.

4. The mandate of the UN Special Rapporteur on the rights of persons with disabilities is a special procedure of the UN Human Rights Council. Special procedures are independent human rights experts with mandates to report and advise on human rights from a thematic or country-specific perspective. They comprise Special Rapporteurs, Independent Experts and members of Working...
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Groups, supported by the Office of the United Nations High Commissioner for Human Rights.

5. Pursuant to resolutions A/HRC/RES/26/20 and A/HRC/RES/35/6, I am mandated to:
   a. Develop a regular dialogue with States and other stakeholders for the identification, exchange and promotion of good practices related to the realization of the rights of persons with disabilities;
   b. Receive and exchange information and communications on violations of the rights of persons with disabilities;
   c. Consult with and involve persons with disabilities and their representative organizations in a participatory manner in the conduct of my work;
   d. Make concrete recommendations on how to better promote and protect the rights of persons with disabilities, including on how to promote development that is inclusive of and accessible to persons with disabilities;
   e. Provide technical assistance in support of national efforts for the effective realization of the rights of persons with disabilities;
   f. Raise awareness of the rights of persons with disabilities;
   g. Closely cooperate with other UN human rights mechanisms and UN entities to advance the rights of persons with disabilities in a coherent manner;
   h. Integrate a gender perspective throughout the work of the mandate;

6. In the discharge of these functions, I:
   a. Act on information submitted to me regarding alleged violations of the human rights of persons with disabilities by sending urgent appeals and communications to concerned States to clarify and/or bring this information to their attention;

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b. Conduct country visits upon the invitation of the Government, to examine the state of protection of the human rights of persons with disabilities in the given country. I submit a report of the visit to the Human Rights Council, presenting my findings, conclusions and recommendations. My country visit reports are the documents marked EXP.0027.0001.0814, EXP.0027.0001.0835, EXP.0027.0001.0855, EXP.0027.0001.0874, EXP.0027.0001.0894, EXP.0027.0001.0914, EXP.0027.0001.0934, EXP.0027.0001.0957, and EXP.0027.0001.0978.

c. Participate in conferences, seminars and panels on disability-related matters and issue press releases.¹

d. Report annually to the Human Rights Council and the General Assembly, in accessible formats, about the global state of protection of persons with disabilities, my main concerns and the good practices observed in relation to the rights of persons with disabilities. I formulate specific recommendations with a view to enhancing the protection of the human rights of persons with disabilities. My annual thematic reports are the documents marked EXP.0027.0001.1013, EXP.0027.0001.1028, EXP.0027.0001.1053, EXP.0027.0001.1077, EXP.0027.0001.1101, EXP.0027.0001.1123, EXP.0027.0001.1144, EXP.0027.0001.1164, EXP.0027.0001.1186, EXP.0027.0001.1205 and EXP.0027.0001.1228.

7. Prior to my role as Special Rapporteur, I worked extensively on disability rights and inclusive development over the past 20 years. I worked with the World Bank, the United Nations Department for Economic and Social Affairs, and international

donor organizations that supported the work of organizations of persons with disabilities to promote the implementation of the Convention on the Rights of Persons with Disabilities (CRPD). I was previously part of the disability rights movement at the national, regional and international levels and continue to work closely with organizations of persons with disabilities.

8. I followed the Master Program in Human Rights at the University Carlos III, Madrid, and the Master Program in Disability Studies at the University of Costa Rica. I also hold a Law degree from the University of Costa Rica.

9. My curriculum vitae is the document marked EXP.0027.0001.1246.

The need for a human rights-based approach to disability-inclusive emergency planning and responses

10. Persons with disabilities represent around 15 per cent of the world's population. They are more likely to live in poverty compared to their peers without disabilities and, due to structural inequalities linked to attitudinal, environmental and institutional barriers, are less likely to access employment, health, education, social protection and other services. Persons with disabilities also experience multiple and intersecting forms of discrimination.

11. In conflict and emergency situations, persons with disabilities are often among the most adversely affected, sustaining disproportionately higher rates of morbidity and mortality. The COVID-19 pandemic is revealing and deepening pre-existing inequalities, and exposing the structural discrimination and exclusion experienced by persons with disabilities.

12. Disability-inclusive responses and policies are critical to enable persons with disabilities to participate in and benefit from emergency planning and response

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3 United Nations Department of Economic and Social Affairs, Disability and development report: Realizing the Sustainable Development Goals by, for and with persons with disabilities, 2018 (EXP.0027.0001.1530).

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processes. This entails considering disability-related issues in all public policies and programmes and, where appropriate, these policies and programmes must consider disability-specific measures. Persons with disabilities may have particular needs, which cannot be met by making general programmes inclusive, but which can be remedied by establishing disability-specific programmes. Disability-inclusive responses also enable the meaningful participation of persons with disabilities in all cycles of policy-making.

13. The CRPD represents the highest standard of protection for the rights of persons with disabilities and a major paradigm shift in the approach to disability. In line with the CRPD, policy development in relation to planning for and responding to emergencies should move away from the charitable and medical approaches, towards a human rights-based approach. A human rights-based approach considers persons with disabilities as rights holders, rather than mere receivers of protection, rehabilitation and/or welfare. Persons with disabilities must be placed at the centre of all policy responses, as agents and beneficiaries.

14. The CRPD, reinforced by the 2030 Agenda for Sustainable Development and other relevant international processes, calls for the inclusion of persons with disabilities in the sustainable development agenda. In this framework, Article 11 of the CRPD obliges States parties to take all necessary measures to guarantee the protection and safety of persons with disabilities in situations of risk, including humanitarian emergencies and natural disasters. This provision is key for ensuring that national and local coordination mechanisms, as well as preparedness and response plans to COVID-19, are inclusive and consider the rights of persons with disabilities.

15. A human rights-based approach to disability is required to build inclusive emergency planning and responses. Policy responses must adhere to and promote international human rights norms and standards, including those established in the CRPD. In that regard, States' responses to COVID-19 must be implemented within a policy framework that prohibits all forms of discrimination.
on the basis of disability, including the failure to provide reasonable accommodations as well as responding to multiple and intersecting forms of discrimination to ensure that the most marginalised among persons with disabilities are not left behind. In addition, States must ensure accessibility, accountability and close consultation and active involvement of persons with disabilities and their representative organizations, in accordance with Articles 4(3), 29(b) and 33(3) of the CRPD.

16. Historically, persons with disabilities have experienced structural inequalities linked to attitudinal, environmental, and institutional barriers. First, attitudes that lead to discrimination and/or misconceptions about persons with disabilities. Second, environmental barriers that prevent access to public spaces, education and health facilities, workplaces, and modes of transportation; and obstacles to accessible information and communication. Third, institutional barriers, including discriminatory legal and policy frameworks that perpetuate segregation and institutionalisation, which lead to violence, abuse and neglect; and the lack of support services. All these barriers are reproduced and heightened in the COVID-19 responses.

17. Persons with disabilities are also more likely to experience higher rates of violence, neglect, abuse and exploitation, and are among the most adversely affected in any crisis. Advancing the rights of persons with disabilities and ensuring their inclusion in COVID-19 responses is thus essential to ensure substantive equality for all, including persons with disabilities and their families.

Key themes and observations from the COVID-19 pandemic

18. The COVID-19 pandemic has revealed that the foundations of States’ implementation of the rights of persons with disabilities need to be strengthened urgently. The crisis of COVID-19 is deepening pre-existing inequalities and

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barriers experienced by persons with disabilities, exposing the extent of exclusion and highlighting that States must work on disability inclusion.

**Persons with disabilities are disproportionately affected by COVID-19**

**Health effects**

19. Persons with disabilities are among those most impacted by COVID-19, experiencing greater risk of contracting, developing more severe symptoms, and dying from the virus.

20. Persons with disabilities may be at greater risk of contracting COVID-19 because of:

   a. barriers to implementing basic hygiene measures, such as hand-washing. For example, hand basins, sinks or water pumps may be physically inaccessible, or a person may have physical difficulty rubbing their hands together thoroughly;

   b. difficulty adhering to social distancing guidelines due to additional support needs, or because of institutionalization;

   c. the need to touch things to obtain information from the environment. For example, braille on public buildings, or for physical support;

   d. barriers to accessing public health information, which is often inaccessible.

21. Moreover, persons with disabilities may be at greater risk of developing severe disease if they become infected with COVID-19 due to underlying health conditions; and barriers to accessing health care. Further, people with disabilities may also be disproportionately impacted because of serious disruptions to the support services they may rely on.

**Barriers to accessing education, healthcare and other essential services**

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*World Health Organization, *Disability considerations during the COVID-19 outbreak*, 26 March 2020, p 2 (EXP.0027.0001.0999); see also Inter-Agency Standing Committee, COVID-19 response: Applying the IASC guidelines on the inclusion of persons with disabilities in humanitarian action, June 2020, p 2 (EXP.0027.0001.1251).*

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22. Persons with disabilities are particularly disadvantaged by the socio-economic consequences of the COVID-19 pandemic and government responses. For example, students with disabilities are the least likely to benefit from distance learning solutions such as online learning, particularly those with intellectual disabilities. They face several challenges, including inaccessible distance learning approaches, a lack of support, barriers in accessing the internet, and inaccessible software and learning materials. Therefore, there is an increased risk of students with disabilities being excluded from education.\(^7\) Likewise, persons with disabilities are more likely to lose their job, experience greater difficulties returning to work, and have reduced access to social insurance.\(^8\)

23. Persons with disabilities have also experienced significant disruptions to services, support systems, and informal networks during the COVID-19 pandemic, such as personal assistance, sign language and tactile interpretation, and psychosocial support.\(^9\)

24. Further, persons with disabilities experience poorer access to health care and poorer health outcomes than the general population.\(^10\) This is due to structural factors, such as stigma and stereotypes, discriminatory legislation and policies, barriers to accessing primary and secondary care, limited availability of disability-specific services and programmes, poverty and social exclusion. These poor health outcomes increase their risk of getting COVID-19 and dying from the virus. The poor health outcomes are not the direct result of their impairments, but of the barriers in access to health and implementing healthy lifestyles. The COVID-19 pandemic has heightened these barriers.

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\(^7\) United Nations Secretary-General, Policy brief: The impact of COVID-19 on children, 15 April 2020, p 7, 8 (EXP.0027.0001.0796); UNICEF, COVID-19 response: Considerations for children and adults with disabilities, 8 April 2020, p 1 (EXP.0027.0001.0809).

\(^8\) International Labour Organisation Brief, COVID-19 and the world of work: Ensuring the inclusion of persons with disabilities at all stages of the response, 4 June 2020, p 4 (EXP.0027.0001.1374).

\(^9\) International Disability Alliance, ‘Voices of people with disabilities during the COVID-19 outbreak’ (EXP.0027.0001.2005).

\(^10\) United Nations Secretary-General, Rights of persons with disabilities, 73\(^{rd}\) sess, item 74(b), UN Doc A/73/161, 16 July 2018, [72] (EXP.0027.0001.1386).
25. Persons with disabilities have experienced barriers to accessing healthcare during the COVID-19 pandemic such as accessing medicines, rehabilitation, and assistive devices due to the increased pressure on healthcare systems.\textsuperscript{11} Furthermore, persons with disabilities experience a greater risk of discrimination in accessing healthcare and life-saving procedures due to ableism, including triage protocols based on discriminatory criteria (for example, ventilators or intensive care units).\textsuperscript{12}

**Institutionalization**

26. The pandemic has also shown that urgent efforts are required to end institutionalization. Institutionalized settings may differ in size, name and set-up, but they have the following defining characteristics, as identified by the CRPD Committee:

a. obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from;

b. isolation and segregation from independent life within the community;

c. lack of control over day-to-day decisions;

d. lack of choice over whom to live with;

e. rigidity of routine irrespective of personal will and preferences;

f. identical activities in the same place for a group of persons under a certain authority;

g. a paternalistic approach in service provision;

h. supervision of living arrangements; and


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i. usually also a disproportion in the number of persons with disabilities living in the same environment. 13

27. Persons with disabilities are systematically placed into institutions and psychiatric facilities, or detained at home and other community settings, based on the existence or presumption of having an impairment. They are also overrepresented in traditional places of deprivation of liberty, such as prisons, immigration detention centres, juvenile detention facilities and children’s residential institutions. In all these settings, they are exposed to additional human rights violations, such as forced treatment and restrictive practices. 14

28. Social care institutions, nursing homes, psychiatric facilities, and group homes, where persons with disabilities, including older persons with disabilities, are often institutionalized, have become hotspots of the pandemic. 15

29. Persons with disabilities living in institutions are more likely to contract the virus and have higher rates of mortality. 16 Persons with disabilities in institutional settings, as well as detention facilities and penitentiaries, experience significant barriers to implementing basic hygiene measures and physical distancing, and have limited access to COVID-19-related information, testing and healthcare. Further, the emergency measures implemented by governments to control the spread of COVID-19 have accelerated the pre-existing human rights violations in institutions, such as neglect, restraint, coercive measures, isolation and violence.

13 Committee on the Rights of Persons with Disabilities, General comment No. 5 (2017) on living independently and being included in the community, UN Doc CRPD/C/GC/5, [16(c)]
15 Adelina Comas-Herrera, Joseba Zalakain, Charles Litwin, Amy T Hsu, Elizabeth Lemmon, David Henderson & Jose-Luis Fernandez, Mortality associated with COVID-19 outbreaks in care homes: Early international evidence, (2020), LTC Responses to COVID-19: International Long-Term Care Policy (EXP.0027.0001.1441), see also Joint Statement: 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, 1 April 2020 (EXP.0027.0001.1249);
30. I am also concerned about the isolation of persons with disabilities in institutions, where visits are restricted. Limiting their contact with loved ones leaves persons with disabilities unprotected from any form of abuse, neglect, and violence.

31. Further, children, girls and women with disabilities are disproportionately at risk of gender-based violence, exploitation, and abuse due to confinement measures. For instance, violence by caregivers is the most common form of violence experienced by children. They are also often witnesses to domestic violence against women. Such acts of violence are more likely to occur while families are confined at home and experiencing intense stress and anxiety.

32. Measuring how persons with disabilities are affected by COVID-19 is critical to better understanding and preparing for any future emergencies or disasters. Doing so will provide data to inform how policies and responses ensure that the needs of persons with disabilities and pre-existing inequalities are taken into consideration to build inclusive emergency planning and responses.

**States’ responses to the COVID-19 pandemic**

33. In most cases, States’ responses to COVID-19 have been neither accessible nor inclusive of persons with disabilities. For example, the lack of mainstreaming of disability and targeted actions; barriers to accessing to public information and essential services; the disruption of support systems; and the lack of active involvement of persons with disabilities in the development of government responses, have contributed to their exclusion in responses to the pandemic. It has been brought to my attention that some of these factors could have occurred in Australia, in particular the disruption of support systems.

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34. However, I can underline some promising practices. France, Peru, and Spain introduced exceptions to confinement rules that enabled short outings for persons with autism.\textsuperscript{21} In New Zealand, the website of the Ministry of Health provides accessible information, including sign language and easy to read.\textsuperscript{22} In Canada, the COVID-19 Disability Advisory Group was established with the participation of persons with disabilities, to advise government responses to the pandemic.\textsuperscript{23} The United Kingdom of Great Britain and Northern Ireland established systems to guide parents while at home to better support the educational process of children with disabilities.\textsuperscript{24} Papua New Guinea is working with United Nations Women and partners to integrate COVID-19 aspects to improve counselling and gender-based violence case management services that will target women with disabilities.\textsuperscript{25}

35. I also commend the Australian government for establishing the Advisory Committee for the COVID-19 Response for People with Disability.

Ensuring a disability-inclusive response and recovery to COVID-19

36. The COVID-19 pandemic offers an unprecedented opportunity to rethink our laws and policies to be more inclusive of persons with disabilities. To this end, the pandemic and its socio-economic consequences require strong international cooperation between and among States, in partnership with international and regional organizations, civil society and organizations of persons with disabilities,


to provide a disability-inclusive COVID-19 response and recovery. As the international community starts moving towards a process of Building Back Better, it is necessary to reflect on how we ensure disability-inclusive investments and policies which translate into universally designed systems, inclusive societies and communities that guarantee substantive equality for all, including persons with disabilities.

37. The CRPD must be the guiding framework for building an inclusive COVID-19 response and recovery. To this end, some key considerations from a human rights-based approach need to be taken into account.

Recommendations

38. First, ensure disability is mainstreamed into all COVID-19 response and recovery efforts, coupled with targeted actions which address specific requirements for persons with disabilities that cannot be met by making general responses disability-inclusive. Mainstreaming means that all general policies and programmes must be designed to be as inclusive as possible, in order to not create or perpetuate existing barriers, and must incorporate a disability perspective into policymaking. Further, disability-specific measures are important when particular needs of persons with disabilities cannot be met by mainstreaming disability into COVID-19 responses. This combination of mainstream and targeted measures is essential to ensure the systematic inclusion of persons with disabilities.

39. Second, ensuring accessibility of facilities, information, communication, services, and programmes is also fundamental to an inclusive COVID-19 response and recovery. If public information, buildings, transport, communications, technologies, goods and services are not accessible, persons with disabilities cannot take necessary decisions, live independently and quarantine safely, or

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access health and public services on an equal basis with others. Accordingly, all public advice campaigns, information, and communication must be available in accessible means, modes and formats.

40. Third, ensure meaningful consultation with and active participation of persons with disabilities and their representative organizations at all stages of COVID-19 response and recovery, from planning and design to implementation and monitoring. Participation is a core human rights principle and a basic condition of democratic societies. The participation of persons with disabilities and their representative organizations in public decision-making related to COVID-19 will ensure States are more responsive to the actual situation of persons with disabilities, and add to efficiency and innovation in government responses.

41. Fourth, establish accountability mechanisms to monitor and ensure disability inclusion in the COVID-19 response and recovery. Inclusive investments must be guaranteed to support disability-inclusive outcomes. Governments, donors, United Nations agencies and other actors need to establish mechanisms to monitor investments to ensure they are reaching persons with disabilities. If persons with disabilities are excluded, the recovery process risks exacerbating pre-existing inequalities. In that regard it is important that the reallocation of funds to support COVID-19-related activities does not affect nor undermine disability inclusion efforts.

42. Finally, improving monitoring and measurement of the impact of responses on persons with disabilities. Disaggregated data collection is crucial for this. Measuring the impact of responses is critical to generating valuable information for evidence-based decision making necessary to develop policies consistent with the rights of persons with disabilities and measure progress towards disability inclusion.

43. Every crisis can also become an opportunity, let us pave the way for a disability-inclusive response and recovery to COVID-19 that will better serve everyone now and into the future.

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Royal Commission

44. I would encourage the Royal Commission to make concrete recommendations to the Australian government on how to implement an inclusive response and recovery to COVID-19 that promotes and protects the rights of all persons with disabilities, in particular, recommendations on how to improve laws, policies, structures and practices to ensure their right to live free from violence, abuse, neglect, and exploitation. This will require confronting the root causes of violence, abuse, neglect and exploitation within structures and systems, which includes a charitable and medical approach to people with disabilities that leads to continued segregation, isolation and institutionalization of persons with disabilities.

Signed: [Signature]

Date: 10/8/2020

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Date: 12/8/2020