Submission of the Disability Rights Fund & International Disability Alliance INB7, November 2023

The Disability Rights Fund and the International Disability Alliance express serious concerns about the continued dilution of human rights in the latest draft of the pandemic agreement.[1] The text overlooks critical lessons from the pandemic, providing only token references to human rights, that leaves adherence to standards at the discretion of States. We are all too aware of the consequences this had for certain groups, including persons with disabilities and older persons, such as neglect in social care, glaring health disparities, discrimination during medical triage, loss of support systems, increased risk of violence, poverty, isolation, and death.[2]

We advocate for a text that is truly responsive to the lessons from the countless of lives lost and the widespread inequalities exposed, to ensure that we do not repeat the mistakes of the past. This instrument should be anchored in and aligned with international human rights standards, including the Convention on the Rights of Persons with Disabilities, ratified by 188 States Parties including the European Union.

In particular, we urge States and other stakeholders to take action on the following ten points in accordance with their obligations under international human rights law:

1) Restore previous provisions related to **respect for human rights, non-discrimination and respect for diversity, gender equality, and the right to health, specifically the stand-alone provision on human rights,** to ensure that PPR is embedded in human rights and rights-based approaches. (Articles 3, 16)

2) **Expand prohibitions of discrimination to include explicitly the grounds of disability, gender and age** and expand references to equitable representation on those grounds (Preamble paragraph 2,[3] Articles 1(i), 9(3)(b), 19(2)(d)).

3) Amend the **definition of persons in vulnerable situations** to explicitly identify groups[4] and/or draw attention to amplified risks for persons in settings like care homes, residential facilities, prisons, other places of detention and humanitarian environments. (Article 3(1)), current text)

4) Incorporate throughout the text the obligation to **ensure participation in decision-making, through close consultation and active involvement, of persons especially those must affected in vulnerable situations as it relates to PPPR**.[5] (Article 7 and throughout)

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[1] During the COVID-19 pandemic DRF & IDA participated in the COVID-19 Disability Rights Monitor, an initiative to gather information and testimonies on the experiences of persons with disabilities and on how States responded concerning this population. A report was published based on the testimonies of over 2000 respondents across 134 countries that drew the worrying conclusion that states overwhelmingly failed to take sufficient measures to protect the rights of persons with disabilities in their responses to the pandemic. Our submission is based on those findings.

[2] WHO Global report on health equity for persons with disabilities (2022) pp 6, 17, 35; The Missing Billion Initiative report (2022), p 6.

[3] This is limited to the provision of the WHO Constitution drafted in 1946: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."

[4] Groups most at risk including persons with disabilities, older people, persons living in different forms of detention, persons living in emergency and humanitarian situations, among others.

[5] This will enable informed policymaking and developing responses based on the lived experiences of those at most risk, particularly as it relates to addressing social, environmental and economic determinants of health and tackling the socioeconomic impacts of pandemics. (e.g., see CRPD article 4(3) and other human rights treaty provisions on participation in decision-making).

5) **Provide comprehensive guidance on how States can address the social, environmental and economic determinants of health and the socioeconomic impacts of pandemics** to strengthen resilience against their spread and impact, by addressing key factors of vulnerability,[6] and conserving livelihoods, protection from violence, access to health including SRHR, education, housing, food, WASH, social protection including social services and supports. (Article 17 & throughout)

6) **Restore previous provisions on ensuring accessible public health education, information and communications to ensure real time information** in accessible and alternative languages and formats including sign languages, Braille, captioning, audio description, plain language, easy to read, large print, screen-reader accessible, and child friendly information and communications.[7] (Article 18)

7) **Conduct human rights training of health workers to ensure rights-based approaches and eliminate discrimination, stereotypes and biases in the delivery of healthcare services, especially at times of resource scarcity** where individuals may be more at risk of being denied treatment on account of ableist and ageist assumptions that their lives are less worthy of saving.[8] (Article 7)

8) Adopt **compulsory criteria for procurement to ensure accessible or universally designed pandemic-related products**, such as PPE, as an element of quality countermeasures. (Article 13(3))

9) Ensure that **research and development of PPPR is inclusive of at-risk communities and populations most impacted by pandemics through their participation** in the design of research goals to ensure that their diverse needs are met in the development of universally designed countermeasures and other innovations to address pandemics.[9] (Articles 9(2)(c), 9(3)(b), (c))

10) **Call for the collection and availability of data disaggregated by age, gender, disability,** including for public health surveillance, research and development, to better monitor the impact of measures of those populations most at risk, in line with confidentiality, privacy and data protection standards. (Articles 3, 4, 9)

We remain at your disposal for any further information or clarifications, please reach out to vlee@disabilityrightsfund.org and jclyne@ida-secretariat.org.

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[6] e.g. phasing out congregate settings and strengthening community based services and supports, also linked with the current agenda to transform care economies focusing on the rights of both care receivers and care providers. Persons with disabilities and older persons are overrepresented in congregate settings. Publicly available national data up to 26 January 2021, covering 22 countries, showed that an average of 41% of deaths linked to COVID-19 were among residents in care homes. Moreover, people with disabilities are overrepresented in the prison population, particularly persons with intellectual and psychosocial disabilities.

[7] The insufficiency or absence of pandemic-related information and communications in accessible formats left many people with disabilities and others behind and more exposed to risks. See Articles 9, 21 of the CRPD and General Comment no 2 of the CRPD Committee on accessibility; UNSG Policy Brief on a disability-inclusive response to COVID-19 pp.9; Aarhus Convention (UNECE Convention on Access to Information, Public Participation in Decision-making and Access to Justice in Environmental Matters).

[8] In the face of the pandemic and fear that health systems could be overwhelmed, several countries had adopted frameworks for prioritisation and systems of pre-emptive triage denying people with disabilities equal access to hospital treatment.

[9] Inequality perpetuated in PPPR stems from unequal attention to and participation in the design of research. In order to ensure the right to enjoy the benefits of scientific progress and its applications to all people, and to address the impacts of pandemics on all populations, underrepresented groups should be included and participate in the design of research questions, protocols and methodology to reflect and capture their lived experiences. See Committee on Economic, Social and Cultural Rights, "Statement on the Coronavirus Disease (COVID-19) Pandemic and Economic, Social, and Cultural Rights", 17 April 2020, E/C.12/2020/1, General Comment 25 (2020) on science and economic, social and cultural rights, 30 April 2020, E/C.12/GC/25.