

Check against delivery

25th session of the UN Committee on the Rights of Persons with Disabilities,
14 September 2021, opening meeting continuation (1 pm)

Thank you, Madam Chair.

Another autistic self-advocate and I, in affiliation with Autistic Minority International, were invited as experts to the UN Expert Group Meeting on the participation and leadership of persons with disabilities in building a disability-inclusive, accessible and sustainable post-COVID-19 world¹, organized last month by UN DESA, UN Women, and the Inter-Agency Support Group on the CRPD². Our expert recommendations with regard to autistic persons³ call for the removal of pre-existing systemic barriers such as discriminatory mental health, autism, and guardianship laws, often depriving us of legal capacity, full inclusion of actually autistic adults rather than just non-autistic parents of autistic children in public consultations, policy-making, implementation, and monitoring, provision of funding to organizations and groups led by and for autistic self-advocates themselves, making public sector jobs available to autistic candidates on an equal basis with others, and ensuring accessibility of UN and government consultations to the diversity of persons with disabilities, including self-advocates.

To overcome the medicalized view of autism, the name of World Autism Awareness Day must be changed to World Autism Acceptance Day, through a General Assembly resolution, and autistic persons must be empowered to lead on WAAD, rather than the UN setting the theme and priorities each year. The official observance at UN headquarters must invite emerging autistic self-advocacy leaders from all regions of the world to speak, representing the diversity of autistic experiences. Also, we implore the UN and States Parties to change the overly restrictive and formalistic COSP⁴ accreditation requirements so that self-funded volunteer organizations of autistic self-advocates and other informal grassroots groups of persons with disabilities can get accredited, in particular if they have actively contributed to the work of this Committee.

Additionally, the UN must institute and communicate an exemption from wearing a face mask on UN premises for persons with disabilities holding a medical or psychiatric dispensation. Persons with disabilities unable to wear a mask, including many autistic self-advocates, will otherwise be excluded from participating in physical UN events during COVID-19 recovery, including in-person sessions of human rights treaty bodies. States must guarantee that persons in need of a dispensation are able to obtain it and won't be harassed for using it. Virtual events held by the UN and civil society should allow for full interactivity and meaningful participation of attendees who are not invited speakers. Text chat must never be turned off, and a remote moderator should read out written chat

¹ <https://www.un.org/development/desa/disabilities/egm-disability-inclusive-postcovid19.html>

² United Nations Department of Economic and Social Affairs (UN DESA)/Division for Inclusive Social Development (DISD)/Programme on Disability and UN Women/Disability Inclusion and Intersectionality Global Portfolio (DIIP), in collaboration with the UN Inter-Agency Support Group on the Convention on the Rights of Persons with Disabilities (IASG-CRPD), held 3-6 August 2021 as a virtual meeting

³ https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2021/08/KOFMEL_PAPER_revised.pdf

⁴ Conference of States Parties to the UN Convention on the Rights of Persons with Disabilities (CRPD)

contributions aloud and verbatim during virtual events and hybrid events with remote participants.

Finally, instead of referring to "persons with psychosocial or intellectual disabilities" in UN documents and on websites, the UN must recognize autistic persons as a separate constituency, i.e. "persons with psychosocial or intellectual disabilities and autistic persons".

Thank you⁵.

Erich Kofmel, President
Autistic Minority International

⁵ FULL RECOMMENDATIONS:

- UNITED NATIONS: 1) Change the name of World Autism Awareness Day to World Autism Acceptance Day (WAAD) through a General Assembly resolution
- 2) Empower autistic persons to lead on WAAD, and form a committee of autistic adults, including autistic parents of autistic children, from all around the world to set the annual theme and priorities of WAAD and suggest potential speakers to be invited to the official observance at UN headquarters, with a focus on inviting emerging autistic self-advocacy leaders from all regions of the world to speak, representing the diversity of autistic experiences
- 3) Cooperate with States Parties to change COSP accreditation requirements so that self-funded volunteer organizations of autistic self-advocates and other informal grassroots groups of persons with disabilities can get accredited and participate in their own name, in particular if they have contributed to the work of the Committee on the Rights of Persons with Disabilities (for example, by making written submissions for country reviews or thematic consultations, speaking at civil society briefings or Days of General Discussion, and/or organizing side events, etc.)
- 4) Instead of referring to "persons with psychosocial or intellectual disabilities" in UN documents and on websites, recognize autistic persons as a separate constituency, i.e. "persons with psychosocial or intellectual disabilities and autistic persons"
- 5) Institute and communicate an exemption from wearing a face mask on UN premises, including in indoor common areas and conference rooms, for persons with disabilities holding a medical or psychiatric dispensation, even if the document is not in English
- UNITED NATIONS AND CIVIL SOCIETY: 6) Refrain from holding one-directional virtual events and change the format to allow for full interactivity and meaningful participation of attendees who are not invited speakers, avoid turning off features of video conferencing platforms that enable the full and equal participation of particular constituencies of persons with disabilities, namely text chat, and ensure that a remote moderator reads out written chat contributions aloud and verbatim during virtual events and hybrid events with remote participants
- UNITED NATIONS AND NATIONAL AND LOCAL GOVERNMENTS: 7) Simplify the language used in consultations and documents aimed at persons with disabilities by avoiding or explaining jargon, buzzwords, acronyms, and insider references, and formulate requests for input as openly and accessible to the diversity of persons with disabilities, including self-advocates with low levels of education, intellectual disabilities, or cognitive impairment, and children with disabilities, as possible
- NATIONAL AND LOCAL GOVERNMENTS: 8) Repeal or amend discriminatory mental health and guardianship laws, as well as specific autism laws, that are based in a medicalized view of autism, psychosocial and intellectual disabilities and deprive autistic persons of legal capacity and thus exclude them not only from public decision-making, but even from decisions about their own lives, and provide any supports autistic persons and other persons with disabilities may require in exercising their legal capacity
- 9) Consult and include autistic adults, and not just non-autistic parents of autistic children, in all matters relating to autism and disability policy at all levels of government, and appoint actually autistic persons to any and all public bodies concerned with the development, implementation, monitoring, and evaluation of mental health and autism policy
- 10) Engage and consult with autism self-advocacy organizations, run by and for autistic persons themselves, or alternatively informal groups and networks of individual autistic self-advocates, and provide funding and technical support to such organizations and groups, so as to enable them to represent the interests of autistic children and adults
- 11) Make all public sector jobs, up to the most senior ranks of management and leadership, available to autistic candidates with the requisite qualifications and skills on an equal basis with others, regardless of their autism
- 12) Guarantee that all areas of political, social, cultural, and economic life, including but not limited to public transport, grocery stores, vaccination sites, workplaces, and in-person public consultations, remain fully accessible, without discrimination or intimidation, to persons with disabilities who cannot wear a face mask, if mandated, by instituting and widely communicating an exemption from wearing a mask for persons with disabilities holding a medical or psychiatric dispensation, and ensure that persons entitled to such a dispensation are in fact able to obtain it and won't be harassed for using it