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AUTISTIC VOICES MUZZLED: DIVERSITY OR UNIFORMITY AFTER COVID-19?

Autistic persons' participation and leadership in public affairs are held back by persistent systemic barriers, stemming from the pre-COVID-19 period, but massively reinforced and exacerbated during the pandemic. Governments the world over have imposed protective measures on their populations without giving due consideration to how these will affect autistic people and others with disabilities. Some of these measures have resulted in new and additional barriers for us and silenced autistic self-advocates in public. The autistic community is one of the most marginalized among disability constituencies, and it has been left further behind because of this crisis, which is far from over. It should not be expected that autistic leaders will suddenly emerge and participate in COVID-19 response and recovery efforts when diverse answers and perspectives have been rejected in favour of uniformity throughout this period, and even before, and intellectual openness has given way to moralistic rigour and a dearth of public discourse in most countries and globally. Despite the promises of UN jargon and buzzwords, we are not "building back better". We are not even "building forward better", as has been proposed alternatively by civil society. The post-COVID-19 world is shaping up to be less inclusive and less accessible to most of us. Autistic people's full and equal participation in public affairs seems very far off.

The right of autistic persons to participate in public affairs depends first of all on the recognition that autism is not a disorder or disease to be prevented or cured, but a lifelong neurological variation that is both genetic and highly hereditary. Autism is just as valid as any other neurotype. Autistic self-advocates have been striving to popularize the concept of "neurodiversity" to counter the ongoing pathologization of autism and its framing as a global epidemic and huge financial burden by the World Health Organization (WHO) and many of its Member States. The prevailing and widespread bias and prejudice against the estimated seventy million people, or one percent of the world's population, who are on the autism spectrum hinder our full and equal participation in all areas of economic, social, cultural, and political life, and only autism acceptance will guarantee our inclusion and allow us to participate, and lead, without fear of repercussions.

Many of us still have to hide their autism because of mental health and guardianship laws that deprive autistic persons of legal capacity and thus exclude them not only from public decision-making, but even from decisions about their own lives. Despite ratifying the UN

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[1] Organized by by the 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 as a virtual meeting

Convention on the Rights of Persons with Disabilities (CRPD), many countries have yet to repeal such discriminatory laws and practices. Moreover, States often have specific autism laws that are equally based in a medicalized view of autism and must be abolished or amended. A first autism acceptance law was enacted by Malta in 2016 with the input of autistic persons themselves, including Autistic Minority International. The Maltese national Autism Advisory Council has been chaired by an autistic self-advocate ever since. We hope that this will serve as a model for other countries to follow.

Articles 12 and 29 of the CRPD, which to date has been ratified or acceded to by 182 States Parties, including the European Union, do not permit the exclusion of persons with disabilities from the right to participate in political and public life for any reasons or any considerations. No judicial assessment is required or indeed permissible. Instead, equal recognition before the law must be accompanied by the provision of any supports autistic persons and other persons with disabilities may require in exercising their legal capacity, such as assistance in voting by a person of our own choice. Even those of us who do not speak are as a rule able to express themselves through assistive and augmentative technologies, communication books, boards, or cards, or written electronic communication and make their opinions and wishes known. It is unacceptable that those who are institutionalized are customarily deprived of access to such aides, thus often rendering them silent and defenceless victims of forced treatment, sedation, or restraint, unable to communicate physical or sexual violence to anyone. During the height of the COVID-19 pandemic, they were at an even greater risk of abuse, segregation, isolation, abandonment, and neglect once visitors were prohibited. Many people sadly died in psychiatric institutions and care facilities. Instead of being subjected to coercive medical or therapeutic practices, all surviving autistic children and adults should be taught self-esteem, self-confidence, and how to advocate for ourselves as a matter of urgency.

Autistic persons' right to participate in public affairs, guaranteed by the CRPD, and the fight against stigma and abuse must begin with our involvement in any and all public policy decisions with regard to autism. Autistic adults, and not just non-autistic parents of autistic children, must be consulted and included in all matters relating to autism policy at all levels of government. Actually autistic persons must be appointed to any and all public bodies concerned with the development, implementation, monitoring, and evaluation of mental health and autism policy. We call on States and the UN to engage and consult with autism self-advocacy organizations, run by and for autistic persons themselves, at the local, national, regional, and global levels as well as provide funding and technical support to such organizations, so as to enable them to represent our interests. If there are no formal autistic-led organizations in a country yet, it is better to involve informal groups and networks or individual autistic self-advocates rather than just parents and no actually autistic adults at all. It must always be left to the autistic persons themselves to decide what level of formality and organization is right and manageable for them.

It is of great concern to us that States and the UN are not sufficiently taking into account the diversity of needs of persons with disabilities, particularly those of us with often invisible disabilities. The needs of autistic persons are different from those of someone who is blind or uses a wheelchair. So-called representative organizations of persons with disabilities too often exclude actually autistic people, usually in favour of working with non-autistic parents of autistic children instead. Many such parents and their organizations have goals that contradict our own. They will support early intervention and forced behaviour modification, which we reject, and their awareness and fundraising campaigns may in fact increase stigma and prejudice against us. Still, they are being listened to, and we are not. They need no accommodations and share the goal of normalization that permeates cross-disability umbrella bodies that we are not a part of. Such umbrella bodies do not speak for us, and neither are parents' organizations that do not meaningfully include actually autistic adults in their leadership, autism-related charities run by non-autistic people – however powerful and well-funded they may be –, self-proclaimed medical experts and professionals, or country coalitions of disabled persons' organizations preparing alternative reports for the UN Committee on the Rights of Persons with Disabilities without seeking autistic input even from individual self-advocates. We ourselves must be allowed and invited to participate in public affairs, at all levels up to the UN, and public consultations and other events must be made accessible to those of us who do not speak, are unable to participate in physical meetings, or have sensory processing issues. One way of doing so would be through fully interactive remote participation, not just a one-directional webcast, and importantly, written interventions must be facilitated and given the same time and weight during meetings as oral input.

In order to equip autistic persons to participate in public affairs, and become leaders, it is essential that we be given access to inclusive quality education, so as to permit autistic children to acquire the skills necessary for a life of self-advocacy and autonomous or supported decision-making in the personal realm and beyond. By educating autistic individuals, we will educate the autistic community. This, in turn, will lead to the creation of more and stronger organizations run by autistic persons themselves representing our community in the public arena. Unfortunately, during the COVID-19 pandemic, many more autistic children did not receive any education at all due to school closures. While we welcome opportunities for autistic children to learn remotely, avoiding the pressures of being bullied in mainstream classes or segregation into special education systems, the pandemic demonstrated that schools everywhere are ill-prepared for providing such alternative forms of education, particularly to the most vulnerable students.

Crucially, our right to participate in public affairs also includes the right to employment in the public sector, on an equal basis with others. All public sector jobs, up to the most senior ranks of management and leadership, must be available to autistic candidates with the requisite qualifications and skills, regardless of their autism. The public sector needs to set an example both for inclusiveness and accessibility. Unfortunately, it appears that Russia, for instance, does the opposite by excluding a whole range of persons with psychosocial disabilities from joining the civil service. This includes people living with schizophrenia, and presumably also autistic persons, who in Eastern Europe are often reclassified as schizophrenic upon reaching adulthood because there are no services and support provided for autistic adults. Clearly, such regulations and practices are discriminatory under the CRPD and must be abolished immediately.

We implore the United Nations to set a powerful example for States on the transformative changes that are desperately needed to ensure the participation and leadership of autistic persons in building a disability-inclusive, accessible, and sustainable post-COVID-19 world by revolutionizing how it conducts its own business, starting with sessions of the Conference of States Parties to the CRPD (COSP) and World Autism Awareness Day (WAAD) observances, both events held annually at UN headquarters in New York or now virtually during the pandemic. The reason why autistic persons are almost entirely absent from COSP is because organizations of self-advocates cannot get accredited as a consequence of overly restrictive and formalistic requirements such as having a constitution, by-laws, financial statements, annual reports, a governing body, and documented confirmation of activities. As autistic persons we struggle with organizing ourselves, due to our actual or perceived impairments as much as disabling barriers put up by others, which means that most autistic-led groups, organizations, networks, movements, or campaigns are very informal and entirely self-funded, often based and operated on social media, lacking formal structures, hierarchies, or documentation. Frequently, autistic-led groups are transnational, with people organizing around a shared language rather than national borders, and these groups are not registered with the authorities anywhere. Autistic Minority International, based in Geneva, Switzerland, is the first and only autism self-advocacy organization, run by and for autistic persons themselves, active at the global political level. We have participated in and contributed to multiple sessions of the Committee on the Rights of Persons with Disabilities and over a hundred other UN system and related meetings and conferences since 2013, yet even we do not qualify to get accredited and participate in COSP in our own name. How can we possibly provide leadership if we are locked out? For identical reasons, we also cannot obtain consultative status with the UN Economic and Social Council (ECOSOC), limiting our possibilities even further. Autistic persons' exclusion from COSP and our invisibility on that global stage mirrors and reinforces the invisibility of autistic people and lack of autism acceptance at the national level in most countries, including those that have ratified the CRPD. The fact that the UN does not seem to notice that entire disability constituencies are missing from its pre-eminent disability-related event of the year and has not addressed this inequity after fourteen sessions is very distressing. The cross-disability paradigm prevalent at the UN hides and perpetuates the systemic exclusion of entire constituencies of disabled persons. The UN needs to respect autistic realities and preferences and persons with disabilities in their diversity and accept the organizational forms that are experienced and preferred by actually autistic people, not assume some non-autistic one-size-fits-all organizations that autistic people are expected to conform to if they want to be included and consulted. For anything to change at all, the UN must change first.

It is equally incomprehensible to us that, after fourteen years, the annual event at the UN to observe WAAD – justly to be renamed World Autism Acceptance Day –, is still dominated by non-autistic participants and speakers. Rather than the UN deciding on a theme each year in a manner that can only be described as intransparent, we suggest that a committee of autistic adults, including autistic parents of autistic children, from all around the world be formed and allowed to set the theme and priorities of WAAD and suggest potential speakers to be invited. Too often, the theme seems chosen to tie in with general disability-related thematic work happening in some part of the UN system, without much regard as to whether it is of particular relevance to autistic people at that time. Autism is then added in the title or description, but the theme could just as easily apply to any and all other disability constituencies indiscriminately. Especially in April 2021, rather than discussing inclusion in the workplace in a post-pandemic world, presumably because the Committee on the Rights of Persons with Disabilities is drafting a General Comment on the right to work and employment, we believe there would have been much more pressing concerns the autistic community would have liked the world to become aware of and discuss whilst the COVID-19 pandemic was still raging on and many of us were (and are) suffering in silence and isolation. It should go without saying that the UN must stop inviting any speakers promoting a medicalized view of autism or compliance-based "therapies" such as Applied Behaviour Analysis (ABA), which autistic self-advocates consider akin to torture, disrespectful of children's autistic identity, and conditioning them to acquiesce even to sexual abuse. Instead, more autistic self-advocates from countries other than the USA should be invited to speak, even when the event is not held virtually and this might incur travel expenses, as the situation in the USA may not be representative of the situation autistic people find themselves in almost anywhere else in the world. WAAD should reflect that diversity of autistic experiences. There are emerging autistic self-advocates in other parts of the world whose pioneering work would greatly benefit from the visibility and exposure speaking at the UN could bring them at home. In turn, they might then serve as role models for other autistic persons who may feel encouraged to step forward and start speaking up. Autistic Minority International would welcome the opportunity to advise on this. Autistic people must be empowered to lead on WAAD!

Another decisive factor contributing to the lack of meaningful participation of autistic persons at the UN, as well as at local and national levels of decision-making, are non-inclusive and inaccessible language and practices. Consultations held by the UN and governments tend to be jargon-laden, buzzwordy, stuffed with acronyms and insider references, and highly prescriptive in nature, particularly with regard to format and content, for instance calling for submissions that follow paragraph numbers and provide specific amendments to the wording of a draft document. This may make it easier for the authors to collate inputs they receive and be achievable for professional disability advocates with advanced academic degrees, but it excludes autistic people, almost all of whom are unpaid volunteers, often without access to even basic education, and most other grassroots activists, people with intellectual disabilities, children with disabilities, and so on. It also makes it impossible for autistic self-advocates to provide a deep narrative account of autistic life that might allow readers to comprehend how and why our situation is different from that of other disability constituencies. In an oral statement we made to the Committee on the Rights of Persons with Disabilities in 2018, regarding their draft General Comment on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, we urged that the practices of that Committee in particular should set a better example for the kind of consultations we want States Parties to the CRPD to hold with disabled persons and their representative organizations. But of course, this applies to all UN entities dealing with disability inclusion and participation. While we greatly appreciate the invitation to this Expert Group Meeting, participants are expected to produce a number of deliverables (3-5 page analytical paper, 5-8 minute presentation – later changed to 5-6 minutes, elsewhere it says 10 minutes –, one paragraph biography) at short notice and send and copy them to varying UN and external e-mail addresses, even before the actual virtual meeting stretching over four consecutive mornings with its numerous technological complications begins. It is doubtful anyone with a cognitive impairment would be able to comply with all the instructions, sometimes contradictory, received in numerous disjointed e-mail messages and documents. It may be very hard even for non-autistic people. It simply feels overwhelming. That said, organizers of this EGM have been very accommodating once issues were pointed out to them. Still, the problem is systemic. In another instance, an autistic woman from Australia we nominated to a current advisory group of UN Women on the development of a disability marker for its work and spending as part of a COVID-19 response initiative just informed us that "the document from UN Women was more than I expected and to be honest, it is really hard to process. I very much am struggling with it". This whilst due to the pandemic she has been stuck "in lockdown for 5 weeks and has been extended for another 4. Having everyone home is somewhat destabilising so I am very much 'mum' and keeping everyone else on track". Work at the UN continues at pace, just as inaccessible as ever, whilst autistic volunteers are dealing with new and additional challenges and stresses hindering our full and equal participation and leadership.

Moreover, it is discriminatory and non-inclusive language and practice when the UN continues to speak in its documents and events solely of persons with psychosocial and/or intellectual disabilities, and somehow this is meant to cover autistic people as well. But most of us do not, or not fully, identify with either of these constituencies. We do not consider autism to be a psychiatric condition, although it may be wrongly perceived by others as such, and most autistic persons do not have an intellectual impairment. Such phrasing is therefore stigmatizing and obstructs our efforts to achieve autism acceptance. We have frequently recommended that the wording in UN documents, on websites, and elsewhere, be amended so as to list autistic persons in our own right, namely: persons with psychosocial or intellectual disabilities and autistic persons. This has happened on occasion in documents of the Committee on the Rights of Persons with Disabilities and the former UN Special Rapporteur on the rights of persons with disabilities, but much too infrequently and inconsistently to catch on across the entire UN system and beyond. This terminology must change, just as today we speak of persons with psychosocial rather than mental disabilities, in spite of the exact wording of the CRPD. Autistic self-advocates were not present when the CRPD was drafted, and this exclusionary phrasing has consequences as it affects the visibility of autistic persons in real life. For example, the 2018 annual meeting of the Global Alliance of National Human Rights Institutions (GANHRI) focussed, partly in joint session with the Committee on the Rights of Persons with Disabilities, on monitoring the rights of persons with disabilities and ensuring their participation. A representative of the Zimbabwe Human Rights Commission was surprised to learn from our three oral statements, owed to the non-participation of other disabled persons' organizations, that the CRPD equally applies to autistic people and expressed his appreciation for learning about this in an effusive intervention to the entire room. He promised that going forward autistic persons would be included in CRPD monitoring and other disability-related activities in his country. Constituencies of persons with disabilities that are not visible at COSP and in UN language are likely to be forgotten or neglected in national disability action and empowerment plans, not invited to local and national consultations, and so on. It cannot be that UN jargon creates realities on the ground that autistic people are supposed to submit to. We do not consent to our erasure!

One of the rare autistic participants in COSP, a young woman from Canada, registered trough a non-autistic accredited organization in 2018, and currently also participating for us in the UN Women advisory group mentioned before, recounted her experiences preparing for her attendance and with UN headquarters' dismal lack of accessibility for autistic people in an impressive oral statement: "Both gathering the funds to cover travel expenses and leaving the country are acts which risk my access to food and housing. I not only had to resort to begging and borrowing but literally selling my body – plus withstand being attacked for publicly admitting this and told that my decision to reclaim my autonomy after being sexually abused multiple times shouldn't be shared even though it exemplifies both autistic vulnerability and our resourceful resiliency. After managing the many pitfalls of travel, which are exacerbated for autistics, I was spoken down to with angry contempt by five different people across two UN offices for accidentally being in the wrong place and politely asking questions. I was sneered at when I was struggling not to cry. That is not accessibility. Even if more autistic people were invited to participate, most could not. Pushing past emotional and physical limitations to achieve attendance at events catches up with those of us who do it, requiring months of careful effort to repair the damage from just a few days of participation. Environments and consultations which force us to adhere to neurotypical expectations mean we must endure agony for the sake of preventing pain".

Myself, I addressed related issues in 2019 in an oral statement during the Regional Consultation on the Plan of Action for Integrating Volunteerism into the 2030 Agenda in the UNECE Region, organized by UN Volunteers (UNV) as part of the UN Economic Commission for Europe's Regional Forum on Sustainable Development: "We believe that in the developed countries of the UNECE region it is very often assumed that volunteering is a luxury, a product of affluence. We are dismayed that the section in the Synthesis Report titled 'Empowering the most marginalized' does not actually talk about empowerment, or about the many ways in which volunteers from the most marginalized groups, those left furthest behind, are being punished for volunteering. Persons with disabilities are among the least empowered, and autistic people the most marginalized even among them. Private and state funding for autism advocacy goes to organizations of parents of autistic children rather than to us, actually autistic adults. So we are forced to volunteer in order to represent and defend our interests, what we call self-advocacy. Due to our communication difficulties, we are at a great disadvantage in doing so. But we cannot stay silent [...,] we can only become visible and make our voices and lived experience heard through volunteering. Since 2013, Autistic Minority International has represented the interests of autistic persons at and through the United Nations, World Health Organization, and human rights treaty bodies. We have been doing this as an entirely self-funded volunteer organization, with no external funding whatsoever. Very often we are the only persons in a United Nations conference room who are not getting paid for being there. Even worse, we have to pay ourselves for travel and accommodation in New York or Geneva. Autistic people often put their lives at great risk in order to be recognized as rights holders and listened to. [...] To us, volunteering is not a luxury, a way to 'give back', but it means hardship we endure to improve the situation of our peers. Next time you walk along the streets of Geneva, look out for autistic delegates to UN conferences sleeping in their cars because they cannot afford the prices of hotels, or even hostels, in this city. That's the reality of volunteering for autistic people, at the global and regional, but also at the national and local level. States across the UNECE region force us to volunteer our time for self-advocacy, and then punish us for doing so. Not just depriving autistic-led organizations of funding, but then depriving autistic volunteers of their means of survival. Way too often, autistic persons lose their disability benefits because our unpaid participation in conferences or events or in online campaigns or other self-advocacy activities is seen as evidence that we could earn a living in the first labour market instead. Personally, I was denied disability benefits, support, and services for just that reason, even though after a day or two at the UN it takes me a week, and sometimes a month, to recover enough energy to leave my room again. Just because I can do something one day does not mean I can do it every day. Autistic people, and other persons with disabilities, must not be pushed into extreme poverty for volunteering. Autistic Minority International strongly supports the introduction of Universal Basic Income schemes that would truly empower autistic persons and give them the freedom and security to devote their time and often very limited energy and restricted ability to interact with people to volunteering for our rights, for our full and equal inclusion, and against continuing and pervasive inequalities in the UNECE region".

In 2020 and 2021, the UN has been carrying on as if the world can't stop. But the world has stopped for many of us. Autistic Minority International has reduced its participation in UN activities greatly over the past year as many of the short-form virtual events now put on seem further and further detached from autistic persons' life realities and far removed from the urgency of our daily struggles. The pandemic isn't over just because the UN has been talking about post-COVID-19 recovery almost since it started. Speculations about a post-COVID-19 world seem wishful thinking at best and premature, still. What we have learned quickly, however, are some valuable lessons about the inaccessibility and non-inclusivity of virtual UN conferences, in particular during the 2020 High-level Political Forum on Sustainable Development (HLPF). For example, 11,000 people from around the world apparently registered to participate in UNV's follow-up global technical meeting on reimagining volunteering for the 2030 Agenda, held over four days during the HLPF. But this is not meaningful participation. Like in so many other virtual events now, no one got to speak who was not a carefully selected invited speaker. The UN organizers set the agenda, and agreed on the outcomes, and there was no way any attendee could raise objections or highlight overlooked issues by making an oral statement from the floor, as had been possible before in actual conference rooms, with actual participants, participating actively rather than passively. There, you never knew what the next person was going to say. Now, it's all bland uniformity and suppression of dissent. The UN has become an echo chamber, having further shrunk civil society space and eliminated any challenging public discourse. Speaking up may not have made a difference then either, but at least we had a chance to be heard by someone, like the NHRI representative from Zimbabwe. That chance has disappeared for the foreseeable future, maybe forever. Participants now are just an audience, and treated as such, and UN staff mostly seem to approach virtual events, such as the ubiquitous webinars (often posing as side events to conferences), as if they were producing TV programming, or infomercials, for UN Web TV or YouTube. A staff member of the UN Secretary-General's Envoy on Youth, whose office organized a 2-hour virtual consultation with youth with disabilities in November 2020, made this inadvertently quite clear when writing in an e-mail: "I will share the run of show shortly". These time constraints and mindset come at the expense of accessibility even in disability-related events and meetings and when one of the themes purportedly is inclusion and the right to participate. We pointed out to them that potential autistic participants may not be able to speak at command, when prompted to do so, and many of us experience selective mutism, or they might require other accommodations, after learning that young persons with disabilities on the planning committee felt that the UN had been dismissive of their requests, including for scheduled breaks during the meeting. We welcome the opportunity to participate in this UN Expert Group Meeting precisely because it doesn't appear to follow the current trend at the UN, provides sufficient time for discussions and interactivity, and allows us to voice these concerns and misgivings freely. This in marked difference even to many virtual civil society events that have become equally one-directional, with way too many invited speakers to allow for any meaningful interaction with other attendees. As a member of the Joint Coordination Activity on Accessibility and Human Factors (JCA-AHF) of the International Telecommunication Union (ITU), the UN specialized agency for information and communication technologies, we were particularly discouraged by how disempowering and inaccessible the HLPF felt because of new technological barriers to the full and equal participation of autistic persons. This was extraordinarily noticeable thanks to the sheer mass of events happening in parallel over ten days. There were multiple video conferencing platforms employed across the conference, and each event and session organizer configured the platform they were utilizing differently, enabling and disabling technological features in a stunningly random fashion, so that it was never possible to get used to anything. Autistic people tend to like routine and dislike change, and this was constant change. We continue to advocate for interactive remote participation in physical conferences and meetings to make the UN more accessible to autistic persons, but the total lack of predictability makes fully virtual events, especially at the scale of COSP or the HLPF, a cognitive nightmare. Even during an HLPF side event of the Stakeholder Group of Persons with Disabilities the text chat, essential for the participation of autistic people who do not speak, was turned off, and then they ran out of time to answer at least one or two questions from the Q&A box. Other organizers, both UN and civil society, found a myriad of ways to set up and handle Q&A boxes, almost all confounding and cognitively inaccessible – forcing people to discuss technical problems and exchange links and e-mail addresses in Q&A instead of chat, new questions appearing in no logical order, or 250 questions clogging the box –, some had text chat enabled, but completely disregarded what was happening there, elsewhere the chat was in English only even though the meeting had interpretation in all official UN languages. Moderators kept instructing attendees to use functions that weren't there for non-speakers – like renaming themselves, when attendees couldn't even see a list of participants and therefore couldn't click on themselves, or changing views, e.g., from sign language to gallery view, when this wasn't enabled for those who weren't invited speakers. Some organizers and moderators clearly didn't know what video conferencing platforms look like on the side of attendees because they only ever participate as speakers, with full functionality. Instead of organizers being able to switch off features that would make virtual events more accessible to particular disability constituencies, participants should be put in control and have the power to personalize what the meeting looks like and how it functions for them. Ultimately, through ten days of the HLPF we did not get to ask a single question on the record, as part of the proceedings at least of some side event, VNR Lab, or SDG learning, training, and practice capacity-building workshop, never mind making a statement, anywhere. Interactivity was largely limited to polls. "Participation" like that seems futile and a misnomer. These technological liberties and constant unexpected changes have made autistic persons' lives miserable when trying to participate earnestly in virtual UN system and related events and meetings now. None of this bodes well for the future.

We do not know what will come after the pandemic, but more pressingly, we don't know what will come tomorrow, next week, or the following month. Constantly changing protective measures imposed by governments on their enfeebled populations, bypassing any public debate or accountability, have ruptured our lives as much as COVID-19 and caused many autistic self-advocates to cease public activities, sometimes even silencing them altogether, out of frustration, out of anger, out of feeling left behind. For some of us, including myself, this feeling hinges on the issue of face masks. The Swiss Federal Office of Public Health recognizes that "[t]here are many circumstances in which certain people cannot wear a face mask for health or disability reasons [...]. Here are some of the principle exceptions: [...] people with autism who, for example, cannot wear a mask because they panic [...]. A medical certificate issued by a doctor or psychotherapist is required as proof of dispensation on medical grounds [...]. The certificate must be shown to transport or sales staff on request. [...] The purpose of this exception is to prevent people who are exempt from wearing a face mask for health or disability reasons from being denied access to publicly accessible establishments or services, and to prevent them from being unduly discriminated against. [...] For some people with disabilities wearing a mask is a severe hindrance to their daily life. [...] We ask everyone to show solidarity and understanding"[2]. This leaflet would have been a lot more helpful had it not been published only half a year after masks became mandatory in Switzerland and if it had been accompanied by any kind of public awareness campaign. The government and public transport operators never communicated these exemptions, and the media never reported on them, except to insinuate that some people had obtained a dispensation fraudulently. Organizations of parents of autistic children and umbrella bodies of disabled persons' organizations proved too dependent on state funding to fight for us, their tame media releases being easily ignored. Public protesters were (and still are) discredited as "covidiots", any and all, indiscriminately. My own dispensation was issued by a psychiatrist, but many persons with disabilities, including autistic people, were not able to find anyone willing to issue a dispensation due to severe and incessant public pressure and long waiting lists. Autistic persons thus have been prevented from going to a store to buy groceries, being told to have them delivered instead, which many of us can't afford. Masking policies may also restrict autistic people from getting vaccinated. Even with the dispensation, I did not leave my room for eight months, except in the middle of the night, once or twice a month. The first time I went outside again during the day was to get vaccinated at a doctor's office. Then again a month later for the second shot, and two weeks after that, once I was fully immunized. By then it was mid-July. Only that last time, after the requirement to wear masks even in the open air and other measures had been lifted, did I not have to constantly defend myself to total strangers who felt entitled to stare at me and interrogate and admonish me for not wearing a mask. What autistic person would want to endure this? Who of us has the strength to handle it, withstand the anxiety, and the fortitude to go outside anyway? What gives these people the right to judge us? Literally, the government. The alarmist propaganda unleashed by the media. The muzzle put on anyone daring to ask questions. The suppression of public discourse in the interest of fearmongering. Not just in Switzerland, but everywhere. This post-COVID-19 world is a scary place for autistic people. It is shaping up to be less inclusive and less accessible to most of us. A young autistic man was arrested by police in Switzerland and subjected to involuntary psychiatric evaluation, simply for being caught without a mask on public transport and not able to verbally explain himself. A visually impaired female Swiss politician with other hidden disabilities was physically assaulted by train crew and forced to disembark. Autistic children are denied an education because schools refuse to recognize their dispensations. Hospitals have become effectively inaccessible. These are not isolated incidents, but new forms of systemic discrimination and intimidation. Face masks will prevent my return to the UN for in-person or hybrid meetings and conferences any time soon. As the United Nations Office at Geneva (UNOG) writes: "Masks are required in all indoor common areas on the premises, including conference rooms"[3]. Similar rules apply in New York. The UN does not communicate any exemptions from the

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[2] https://www.bag.admin.ch/dam/bag/en/dokumente/mt/k-und-i/aktuelle-ausbrueche-pandemien/2019-nCoV/merkblatt-maskendispens.pdf.download.pdf/Factsheet_dispensation_for_wearing_a_mask_for_certain_people_with_disabilities.pdf

[3] https://www.ungeneva.org/en/covid-19

mask mandate, and even if it did, my dispensation is not in English and might not be recognized by UN security. As masks are unlikely to be abolished fully for a long time, regardless of whether someone is vaccinated, persons with disabilities unable to wear them, including many autistic self-advocates, will most likely be excluded from participating in physical UN events during a possible post-COVID-19 recovery phase and our voices remain silenced. That is a choice the UN has to make. It is a highly political choice. It is creating new barriers to the full and equal participation of persons with disabilities. The same is true at the local and national levels. As autistic self-advocates, our leadership at this moment demands that we raise the issue, however unpopular it may turn out to be. The UN must act on masks – and mask-related human rights violations against persons with disabilities. I am using this platform and my status as an expert invited by the United Nations to break the silence and testify. That is true participation.

The COVID-19 response at national and global levels highlighted and hid simultaneously the many ways in which autistic persons are still left behind and excluded, it exacerbated pre-existing systemic barriers to our participation and leadership in public affairs and created new and additional ones on top of it. Some autistic children and adults were quite literally left behind in institutions. Personal assistants that allowed a few of us to live independently and hold a job stopped showing up. For others again, isolation and loneliness were nothing new, but now they stayed inside alone for months. The stresses of dealing with ever-changing protective measures in addition to those of daily life exhausted many, including autistic women taking care of their families, and left them with no energy to engage in self-advocacy in the public realm. Others tried to be heard publicly, but their voices were silenced or ignored because what they said or wrote was controversial. UN jargon and buzzwords, such as "building back better", or "building forward better", and "leaving no one behind" were exposed by the pandemic as the empty promises they have always been. They fall short of the revolution we so desperately need to level pervasive inequalities. After COVID-19, will autistic voices continue to be muzzled, by face masks, stigma and prejudice, pathologization, destitution, uniformity of thinking, persistent barriers, the agenda of parents' organizations, exclusion from cross-disability bodies, barring from COSP, marginalization on WAAD? Or will diversity set us free? Are the UN and governments finally ready to accept, respect, value, and empower autistic persons on our own terms? If so, we are ready to lead.

Erich Kofmel, President
Autistic Minority International

PRACTICAL 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

Geneva, 6 August 2021