|  |  |  |
| --- | --- | --- |
| D:\usr\campos\TSB-Reference\Logos\ITU\sigleITU.gif | INTERNATIONAL TELECOMMUNICATION UNION**TELECOMMUNICATIONSTANDARDIZATION SECTOR**STUDY PERIOD 2017-2020 | JCA-AHF-367 |
|  |  | **JCA-AHF** |
|  |  | **Original: English** |
| **Question(s):** | N/A | Geneva, 11 June 2019 |
| **DOCUMENT** |
| **Source:** | Autistic Minority International |
| **Title:** | ICT Accessibility for Autistic Persons and Self-advocacy Online and Off |
| **Purpose:** | Information |
| **Contact:** | Erich KofmelAutistic Minority InternationalSwitzerland | Tel: n/aFax: n/aE-mail: e.kofmel@autisticminority.org |

|  |  |
| --- | --- |
| **Keywords:** | Autism; Self-advocacy; Accessibility; Internet; Augmentative and Alternative Communication; Peer support |
| **Abstract:** | Access to the Internet has given rise to a global autistic self-advocacy movement. Organizations and groups such as Autistic Minority International, run by and for actually autistic persons, and individual self-advocates rely on accessible ICTs to organize the autistic community across borders. Web accessibility is key for peer support and the sharing of non-medicalized first-hand information on autism among autistic persons and with the wider public. Augmentative and alternative communication allows autistic children and adults to make their own decisions and claim their rights as persons with disabilities individually and collectively even if they do not speak. Communication preferences and accessibility requirements of the diversity of autistic persons must be further studied and increasingly taken into account in the design of accessible ICTs. Obstacles and barriers to accessibility must be removed with regard to all disability constituencies, including autistic persons. |

Text of the invited oral presentation by Erich Kofmel, President of Autistic Minority International (www.autisticminority.org/about-us), at the JCA-AHF meeting on 11 June 2019, at ITU headquarters in Geneva, Switzerland:

Thank you, Madam Chair.

Autism is an often invisible condition, even to other autistic persons. We were only able to find each other with the advent of the Internet, and increased access to the Internet has led to the emergence of an autistic community in cyberspace, with a distinct shared identity and culture, and given rise to a global autistic self-advocacy movement. Even those of us who do not speak may be able to express themselves in writing online, as evidenced by Internet fora that unite autistic persons across the spectrum, however severe our condition may be perceived to be by others, and from children and adolescents to persons in their fifties, sixties, or seventies often diagnosed subsequent to a child or grandchild having been found to be on the autism spectrum.

Our organization, Autistic Minority International, is part of that wider community. We are a Geneva-based NGO and the first and only autism self-advocacy organization, run by and for actually autistic persons, active at the global political level. We aim to combat bias and prejudice and advance the interests of an estimated seventy million autistic people, one percent of the world's population, at and through the United Nations, World Health Organization, human rights treaty bodies, and other international organizations, including ITU. Since 2013, we have participated in more than one hundred UN system and related meetings and conferences and made countless written submissions to UN bodies, frequently on issues of digital accessibility and rights online. More recently, we have been especially concerned about autism-related activities of the ITU and WHO Focus Group on Artificial Intelligence for Health that are rooted firmly in the medical model of disability and the pathologization of autism.

Contrarily, as autistic self-advocates we view autism not as a disorder or disease to be prevented, cured, or eradicated, but as a lifelong neurological difference, both genetic and hereditary, that is equally valid. We seek to oppose the false narratives and negative stereotypes promoted by organizations of misguided parents of autistic children that may perceive us as burdens, governments and charities run by non-autistic persons that frame autism as a global epidemic, and so-called autism "experts" that recommend the subjection of autistic children to behaviour modification and "normalization" or would institutionalize us altogether. We, autistic people, are the true experts. Web accessibility is key for peer support and the sharing of non-medicalized first-hand information on autism among autistic persons and with the wider public. The Internet enables us to share our own experiences and perspective.

Too often, it is wrongly assumed that autistic persons cannot or should not be consulted about decisions that will affect us, many of them potential sources of human rights violations, such as our living arrangements or medical and psychological treatment. Instead, non-autistic parents, caregivers, social workers, authorities, and medical professionals make decisions on our behalf, but without our consent. Most autistic children and adults can make their own decisions if barriers are removed. Augmentative and alternative communication allows us to advocate for ourselves and claim our rights as persons with disabilities individually and collectively even if we do not speak. AAC must not be abused to effect behaviour modification, but respect children's autistic identity, and autistic children must not be deprived of AAC devices in order to force them to speak. Instead, they must be empowered to defend their human rights through the use of digital media.

That said, we would like to stress that the accessibility needs of autistic persons should not be generalized. Autism is a spectrum condition and our needs are different from individual to individual, depending on where on the autism spectrum we are. Some of us are so-called computer geeks or nerds, who may be web developers or video game testers themselves, while others have an intellectual disability or cognitive impairment. In the development of ICTs and design of accessibility features and products, as well as in the drafting, negotiation, implementation, and execution of accessibility legislation, policy, guidelines, and standards, it is important to consult and involve autistic adults themselves, including autistic researchers, programmers, and engineers and autistic-led groups and self-advocacy organizations, not just the non-autistic parents of autistic children or representative organizations of persons with disabilities that do not include actually autistic persons among their members.

For some of us, the first hurdle in accessing the Internet is to access the necessary hardware and software. The vast amount of information and specific details can be overwhelming. Sales staff should be trained in dealing with autistic persons, and be given sufficient time to explain to us at our own speed, or alternatively electronics stores that specialize in selling to persons with disabilities should be subsidized. A possibility is also to attach such specialized access providers and stores to existing support and service centres for persons with disabilities, for example those that already advise on assistive technology products. Commercial materials and packaging should be easily understandable. Particularly for those autistic persons who do not speak it is important that customer service hotlines of producers and providers should be accessible by text, not just by phone.

Written electronic communication must be recognized as Universal Design. The systematic discrimination of autistic persons, particularly those who do not speak, by public authorities, the legal system, and private enterprises, most importantly health and care providers, who refuse to communicate by e-mail rather than by telephone or in person or do not respond to electronic communication in a timely and comprehensive manner has gone on long enough. In order to remove barriers for autistic persons, the written word must be given equal weight as the spoken, and electronic communication, such as e-mails or text chat, cannot be treated as inferior to communication face-to-face or on the phone. Many autistic persons consider physical meetings and activities of any kind not barrier-free and thus inaccessible to them. Physical presence and speech must not be a requirement for impact.

We support online schooling as a means to remove barriers to inclusive education in mainstream classes, for example by permitting autistic children to follow and participate in the lessons remotely from home via the Internet and only attend school physically when they are ready to do so. Employing mobile technology, this might also be an effective way to provide access to schooling to autistic children and adolescents in developing countries.

We condemn the deprivation of access to information and communication of autistic children and adults who are institutionalized, often without their consent and against their best interests, particularly those who do not speak and rely on the Internet as their sole means of communication and for whom being cut off from the Internet also means being cut off from the autistic community and any available peer support. The de-institutionalization of autistic persons calls for unimpeded access to advice and assistance from experienced autistic self-advocates and autistic-led organizations online.

Talk of accessibility for "persons with disabilities" often hides the fact that only particular disability groups are benefiting from such measures. For example, lowering countertops is not accessibility for all persons with disabilities, but for wheelchair users and little people. It does not make the physical environment any more accessible to autistic persons who are neither. Speaking of persons with disabilities as if there were no differences between us conceals the continuing exclusion of autistic people and marginalizes us further. That autistic people are left behind may be even less apparent in the context of ICTs where discrimination happens in the seclusion of autistic persons' homes, and we tend to just find individual workarounds or self-censor so as not to give offence to anyone.

Online accessibility measures for other disability constituencies, however justified and well-intentioned, have the potential to make ICTs less accessible for autistic persons. For instance, a requirement by the admins of a Facebook group to include descriptions for all images, GIFs, and emojis and only post videos with captions and/or a transcript led to none of the autistic people in the group posting any of these. As one group member explained, making this mandatory severely reduces the accessibility of the group to autistic persons who frequently struggle with inertia and a lack of energy. There may also be autistic people unable to communicate in words, but who could communicate in images. While these things would always be preferable to have, making it an absolute rule will exclude information as well as people from the group.

In another instance, during the annual meeting of the Internet Governance Forum at UNESCO in Paris last year, IGF's Dynamic Coalition on Accessibility held a session. Two autistic persons were in the room, and I participated remotely. The moderator gave those in attendance physically ample time to express their views, including the verbal autistic persons, and he also asked for comments from remote participants. However, due to audio problems no remote participant could speak. Some of us, including myself, wrote comments about our experiences with remote participation in the text chat, but no one in the room read the chat and no one read out remote participants' written contributions. Being ignored is a common experience for autistic persons who do not speak, this time shared by all who could not speak due to technical difficulties. It should not be the case that the disregard of written communication in favour of the spoken word is a common occurrence in many cross-disability meetings.

Most autistic persons experience sensory information differently, being either hypersensitive or hyposensitive to sensory inputs such as noise, lighting, smells, textures of fabrics or food, large crowds, heat, and so on. All of these can lead to stress, anxiety, physical pain, sensory overload, and meltdown. While the Internet may reduce the need for us to expose ourselves to hostile physical environments, accessible ICTs for autistic persons must equally avoid potential triggers, from strobing lights in TV ads to unnecessarily busy websites. Unlike the accessibility needs of persons with so-called sensory disabilities, including the blind and the deaf, the visually impaired and the hard of hearing, autistic persons' sensory distress goes unrecognized and is not being addressed by accessibility guidelines and standards.

Accessibility for autistic persons across the spectrum could be improved by simple design choices such as consistency, clarity of structure, and predictability, muted colours, use of literal language and avoidance of metaphors, easy-read, pictogram, and voice-delivery options that are understandable to a wide range of persons with different modes of cognitive perception.

Let me conclude. The fact that as of 2019 44% of the world's population have no access to the Internet means that autistic persons in many parts of the world, but mainly in developing countries, cannot get the information online they would need to know to seek a diagnosis or to self-diagnose. There is a literal digital divide in the autistic community between western countries and much of the rest of the world, widened by language barriers that make it hard to pass on and spread unbiased information. Many of us were not diagnosed as children and remain unidentified because Asperger Syndrome was not added to the diagnostic manuals until the mid-1990s. Myself, I was only diagnosed at age 38. But getting an adult autism diagnosis is hard even in developed countries, where autistic people may resort to self-diagnosis when they are precluded from seeking formal assessment for financial reasons or due to a lack of professionals qualified to diagnose autism in adulthood.

Organizations and groups such as Autistic Minority International, run by and for actually autistic persons, and individual self-advocates rely on expanding Internet access and accessible ICTs to meet these challenges and organize the autistic community across borders. The importance of unrestricted access to online communication for autistic children and adults alike cannot be emphasized strongly enough. Communication preferences and accessibility requirements of the diversity of autistic persons must be further studied and increasingly taken into account in the design of accessible and inclusive ICTs. Very few autistic individuals or self-advocacy organizations have ever been consulted on how to improve accessibility for us. Obstacles and barriers to accessibility must be removed with regard to all disability constituencies, including autistic persons.

Thank you.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_