

Geneva, 4 May 2015

Written contribution to the Half-Day General Discussion on the "Right to Just and Favourable Conditions of Work" of the Committee on Economic, Social and Cultural Rights (CESCR)

## **EMPLOYMENT OF AUTISTIC PERSONS AND ADVERSE CONDITIONS OF WORK**

Autistic Minority International greatly appreciates the opportunity to be able to provide our input to the Half-Day General Discussion on the Committee's Draft General Comment on the "Right to Just and Favourable Conditions of Work" with regard to article 7 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). While (in line with the 5-page maximum stipulated by the Committee) we will have to limit ourselves to discussing and stressing just a few points of particular relevance to autistic persons, many of them will be applicable to other persons with disabilities, too.

Our NGO, headquartered in Geneva, is the first and only autism self-advocacy organization – run by and for autistic persons – active at the global political level. We aim to combat bias and prejudice and advance the interests of an estimated seventy million autistics, one percent of the world's population, at and through the United Nations, World Health Organization (WHO), human rights treaty bodies, and other international organizations. Autistic Minority International is an associate member of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO), a member of the NGO Forum for Health, a Geneva-based consortium of organizations committed to promoting human rights and quality care in global health, a member of UNICEF's Global Partnership on Children with Disabilities (GPcwd), and a partner in the WHO's Mental Health Gap Action Programme (mhGAP).

By way of introduction, let us stress that autistic self-advocacy is about more than disability rights. Autism is a distinct culture and identity. The only one we know. Regardless of where in the world we live, autistics are more like each other than like the people surrounding us. Autism is a neurological difference that is both genetic and hereditary. There is no cure, and we do not believe that a cure will ever be found. The autistic minority includes those diagnosed with Asperger's syndrome and various other conditions on the autism spectrum as well as those children and adults who remain undiagnosed.

In 2007, the United Nations General Assembly declared 2 April World Autism Awareness Day. On that day in 2013, UN Secretary-General Ban Ki-moon wrote<sup>1</sup>: "This international attention is essential to address stigma, lack of awareness and inadequate support structures. [...] Now is the time to work for a more inclusive society, highlight the talents of affected people and ensure opportunities for them to realize their potential."

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<sup>1</sup> <http://www.un.org/en/events/autismday/2013/sgmessage.shtml>

In 2012, the United Nations General Assembly unanimously adopted resolution 67/82 "Addressing the Socioeconomic Needs of Individuals, Families and Societies Affected By Autism Spectrum Disorders, Developmental Disorders and Associated Disabilities"<sup>2</sup>. In this resolution, the UN member states recognize "that the full enjoyment by persons with autism spectrum disorders [...] of their human rights and their full participation will result in significant advances in the social and economic development of societies and communities" and stress "the important contribution that non-governmental organizations and other civil society actors can make in promoting human rights for [...] all individuals with autism spectrum disorders [...] and their integration in societies". The GA voices its concern "that persons with autism spectrum disorders [...] continue to face barriers in their participation as equal members of society" and calls this "discrimination" and "a violation of the inherent dignity and worth of the human person".

As individuals and as a group, autistics continue to be denied the "four key pillars of minority rights", as identified by the UN's Special Rapporteur on Minority Issues, Rita Izsák: "protection of existence and prevention of violence against minorities; promotion and protection of minority identity; equality and non-discrimination; and the right to effective participation in all areas of public, economic and social life".

Our very existence is in danger as long as autism, without regard to severity, continues to be viewed as something to be eradicated. Violence against us takes the form of behaviour modification, institutionalization, and abusive medical and therapeutic practices, such as electric shocks. Instead, we should be taught self-esteem, self-confidence, and how to advocate for ourselves. The autistic minority also includes those of us who hide their condition for fear of discrimination. This is no longer tenable at a time when millions of children diagnosed with autism come of age and many more get diagnosed as adults. Autism awareness must lead to acceptance, recognition, and respect for autistics. Only autism acceptance will ensure our full and equal participation in all areas of public, economic, and social life.

On occasion of World Autism Awareness Day 2015, the UN Special Rapporteur on the Right to Health, Dainius Pūras, and the UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, released a joint statement<sup>3</sup> calling "for an end to discrimination against autistic persons [...]. As part of human diversity, autistic persons should be embraced, celebrated and respected. However, discrimination against autistic children and adults is more the rule rather than the exception. In many countries, autistic persons lack access to services which would support, on an equal basis with others, their right to health, education, employment, and living in the community. When available, services are too often far from human rights friendly or evidence-based. [...]"

"More investment is needed in services and research into removing societal barriers and misconceptions about autism. Autistic persons should be recognized as the main experts on autism and on their own needs, and funding should be allocated to peer-support projects run by and for autistic persons. It is about providing individuals and families with the necessary skills and support to have choice and control over their lives. It is also

<sup>2</sup> [http://www.un.org/en/ga/search/view\\_doc.asp?symbol=A/RES/67/82](http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/67/82)

<sup>3</sup> <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787&LangID=E> (English),  
<http://www.ohchr.org/FR/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787&LangID=S> (Spanish),  
<http://www.ohchr.org/FR/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787&LangID=F> (French),  
<http://www.ohchr.org/FR/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787&LangID=C> (Chinese)

about equal opportunities, access to inclusive education and mainstream employment to achieve equality and rights enjoyment by autistic persons. It is about promoting their independence and respecting their dignity. Autistic persons should be respected, accepted and valued in our societies, and this can only be achieved by respecting, protecting and fulfilling their basic rights and freedoms."

The United Nations dedicated World Autism Awareness Day 2015 to the theme of employment of autistic persons<sup>4</sup>: "It is estimated that more than 80% of adults with autism are unemployed. Research suggests that employers are missing out on abilities that people on the autism spectrum have in greater abundance than 'neurotypical' workers do – such as, heightened abilities in pattern recognition and logical reasoning, as well as a greater attention to detail. The hurdles that need to be overcome to unleash this potential include: a shortage of vocational training, inadequate support with job placement, and pervasive discrimination."

Ban Ki-moon added<sup>5</sup>: "Now is the time for even greater access and work opportunities for persons with autism. This year, I am pleased to launch an employment 'Call to Action', inviting businesses to make concrete commitments to employ people on the autism spectrum. We encourage public offices, corporations, and small businesses to have a closer look at the way they perceive people with autism, to take the time to learn about the condition and to create life-changing opportunities. People with autism have enormous potential. Most have remarkable visual, artistic or academic skills. Thanks to the use of assistive technologies, non-verbal persons with autism can communicate and share their hidden capabilities.

"Recognizing the talents of persons on the autism spectrum, rather than focusing on their weaknesses, is essential to creating a society that is truly inclusive. [...] That is why it is so important for employers to [...] enable work environments where they can excel. This important mission can only be achieved with appropriate vocational training and adequate support alongside a recruitment process that can allow people to successfully integrate into workforces around the world. [...] [L]et us join forces to create the best possible conditions for those with autism, so that they can make their own contribution to a future that is fair and sustainable for all."

The UN recommends<sup>6</sup> "that employers make concrete quantifiable pledges to increase the proportion of their workforce that is comprised of individuals on the autism spectrum [...] [t]o demonstrate leadership in addressing the unacceptably high unemployment rate of adults on the autism spectrum, [...] improve the quality of their products and services by tapping the specialized talents of employees on the spectrum, [...] achieve a better understanding of their customer base by having a workforce that better reflects the general population [and] offer an attractive work environment to employees – a workplace where people with autism thrive is generally a great place for all employees to work."

While many autistic persons go unnoticed in the workforce, or at most may be thought of as weird or odd, distant or aloof, arrogant or egotistical, this comes at a heavy price. We

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<sup>4</sup> <http://www.un.org/en/events/autismday/index.shtml>

<sup>5</sup> <http://www.un.org/en/events/autismday/2015/sgmessage.shtml>

<sup>6</sup> <http://www.un.org/en/events/autismday/2015/action.shtml>

may mimic others' behaviour in order to hide our condition and pretend to be "normal", but it never feels natural. Many of us experience a middle age burnout when the decades-long effort of keeping up a façade becomes just too much. Fear of discrimination in the workplace is the primary reason why autistics choose not to be open about their autism.

Other barriers and obstacles at work include an over-reliance on teamwork, overstimulating work environments, and possible repercussions due to most autistics' aversion to small talk and difficulties multitasking, which collectively mean that in fact an ever increasing number of autistics are forced out of a job and into disability. Far from being able to realize our potential, society seems to have stopped valuing the unique contributions made by persons on the autism spectrum throughout human history.

We applaud the few business enterprises that provide jobs particularly aimed at autistics, namely in the field of information technology. Unfortunately, most autistics who are open about their condition do not have superior IT skills, and jobs for us are scarce. It is our hope that the Committee's General Comment may help improve understanding between autistics and non-autistics and sensitize all sectors of the economy for autistics' – and other persons with disabilities' – plight and potential alike.

With regard to specific provisions of the Draft General Comment, we welcome references to persons with disabilities, such as the guidance to States parties to the ICESCR, in paragraph 6, that "[t]he right to just and favourable conditions of work is a right of everyone, without distinction of any kind", including "workers with disabilities" and, in paragraph 12, that the principle of equal remuneration for work of equal value applies not only to women as compared to men, but also to persons with disabilities as compared to non-disabled workers. It might be useful to include here a reference also to those workers experiencing multiple forms of discrimination, such as women with disabilities when compared to non-disabled men and women and men with disabilities alike.

Paragraph 11 stresses that "Prisoners who accept work should receive a fair wage". Should this not also apply to those prisoners who are forced to work? Please include here, too, the right to a fair wage for those persons who are deprived of liberty and institutionalized against their will because of a (perceived) disability, such as autism, psychosocial, developmental, or intellectual disabilities, and who accept work or are forced to work during their (often indefinite) detention in such an institution. We also miss any reference to sheltered workshops that employ persons with disabilities, but equally do not pay them a fair wage. Labour inspectorates (paragraph 54) should have access to all prisons, institutions, and sheltered workshops.

In line with UN recommendations, we urge the Committee to call in paragraph 16 for the provision of a "wide range of vocational and other training measures" not just for women, but also for persons with disabilities, in particular autistics, who should also benefit from support with job placement and an inclusive recruitment process.

It is justified that "the minimum wage should apply systematically, protecting as much as possible the fullest range of workers, including workers in vulnerable situations such as workers with disabilities" (paragraph 26), as only fair and equal wages and remuneration and employment opportunities will allow autistics and other persons with disabilities to

live independently in the community and found a family and thus enjoy the rights guaranteed in articles 19, 23, and 28 of the Convention on the Rights of Persons with Disabilities (CRPD), which to date has been ratified or acceded to by 154 States parties.

We are concerned that the right of persons with disabilities, including autistics, to reasonable accommodation in the workplace is mentioned in paragraph 29 (and again in section iii of an unnumbered paragraph following paragraph 48) only with regard to health and safety. The observation that "denial of reasonable accommodation amounts to discrimination" is just as applicable with regard to accessibility and availability of any kind of work to persons with disabilities. Individualized reasonable accommodations are fundamental to employability and just and favourable conditions of work for any person with a disability.

We support the intentions of paragraph 33 to base promotions on merit, but doubt that seniority is an effective indicator of merit. On the contrary, a reliance on seniority discriminates against younger workers as well as women and persons with disabilities who, for a variety of reasons, including child rearing or systemic exclusion from the labour market, may have spent years off paid work or unemployed, without this diminishing their skills, qualification, competence, or merit. As autistic persons we appreciate greatly the Committee's suggestion that "social links" should be "irrelevant" for promotions.

Flexible working arrangements, as outlined in paragraph 48, in particular work at home and work by means of electronic communication, may be an especially advisable way to increase the employment rate of persons with disabilities, such as autistics, as long as such arrangements meet their individual needs and do not lead to isolation from work colleagues and superiors, a lack of information sharing, and discriminatory treatment in terms of work assignments, further training, and chances for promotion. The paragraph should be expanded to reflect such opportunities and concerns more clearly.

All public sector jobs must be available and accessible to persons with disabilities, including autistics, with the requisite qualifications and skills, on an equal basis with others. States parties *must* "ensure the adaptation of the work place or of working equipment for persons with disabilities in the public sector" and *legislate* for the private sector to do so. Incentives are not enough (paragraph 63). The public sector needs to set an example with regard to inclusiveness, accessibility, and reasonable accommodations. This may mean the introduction of "quotas or other temporary special measures to enable [...] members of discriminated groups to reach high level posts", including persons with disabilities. Similar quotas should be mandated for the private sector (paragraph 60).

Autistic self-advocacy organizations, as "organizations [...] representing persons with disabilities", look forward to assisting States parties to the ICESCR "in formulating, implementing, reviewing and monitoring laws, policies and regulations related to the right" to just and favourable conditions of work at the national, regional, and local levels (paragraph 55).

Thank you for your consideration.

Erich Kofmel, President  
Autistic Minority International