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Our contribution to the OHCHR study on the right to participate in public affairs

AUTISTIC PERSONS' RIGHT TO EQUAL PARTICIPATION

Autistic Minority International, an 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, aiming 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), and human rights treaty bodies.

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).

We greatly appreciate the opportunity to be able to provide our input to the study on "best practices, experiences and challenges and ways to overcome them with regard to the promotion, protection and implementation of the right to participate in public affairs in the context of the existing human rights law with a view to identifying possible elements of principles guiding this implementation" that the United Nations Human Rights Council (HRC) requested of the Office of the High Commissioner for Human Rights (OHCHR) and that will be presented to the HRC at its September 2015 session. We will limit ourselves to discussing and stressing just a few points of particular relevance to autistic persons (starting on page 2). Many of them will be applicable to other persons with disabilities also.

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: "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."

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"¹. 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.

With regard to the right to participate in public affairs, or more specifically autistic persons' right to full and equal participation in political and public affairs, which is guaranteed by article 29 of the Convention on the Rights of Persons with Disabilities (CRPD)², we must strive first and foremost to abolish and repeal any and all mental health and guardianship laws that deprive or serve to deprive autistic persons of legal capacity and equal recognition before the law, in line with article 12 of the CRPD: "States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. [...] States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. [...] States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."

¹ http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/67/82

² <http://www.un.org/disabilities/convention/conventionfull.shtml>

In its General Comment No. 1³, the Committee on the Rights of Persons with Disabilities elaborates that "Equality before the law is a basic general principle of human rights protection and is indispensable for the exercise of other human rights. [...] States parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others. Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision-making regimes such as guardianship, conservatorship and mental health laws [...]. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others. [...] The denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote [...]"

"[P]ersons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity. The Committee reaffirms that a person's status as a person with a disability [...] must never be grounds for denying legal capacity [...]. Legal capacity and mental capacity are distinct concepts. [...] Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity. [...] Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity. [...] Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities [...]."

"The right to equality before the law has long been recognized as a civil and political right, with roots in the International Covenant on Civil and Political Rights. Civil and political rights attach at the moment of ratification and States parties are required to take steps to immediately realize those rights. As such, the rights provided for in article 12 apply at the moment of ratification and are subject to immediate realization."

To date, the CRPD has been ratified and acceded to by 152 States parties and signed by 7 more countries. Most of the States parties to the CRPD are also States parties to the International Covenant on Civil and Political Rights (ICCPR). They themselves recognized that the ICCPR must be interpreted in light of – and enlightened by – the provisions of more recent human rights treaties when it comes to mental health and guardianship laws and the deprivation of persons with perceived disabilities such as autism of legal capacity and equality before the law, including with regard to their right to participate in public affairs.

Specifically with regard to political participation, the Committee on the Rights of Persons with Disabilities in its General Comment No. 1 further states that "Denial or restriction of legal capacity has been used to deny political participation, especially the right to vote, to certain persons with disabilities. In order to fully realize the equal recognition of legal capacity in all aspects of life, it is important to recognize the legal capacity of persons with disabilities in public and political life [...]. This means that a person's decision-making ability cannot be a justification for any exclusion of persons with disabilities from exercising their political rights, including the right to vote, the right to stand for election and the right to serve as a member of a jury. [...]"

³ <http://daccess-ods.un.org/access.nsf/Get?Open&DS=CRPD/C/GC/1&Lang=E>

"States parties have an obligation to protect and promote the right of persons with disabilities to access the support of their choice in voting by secret ballot, and to participate in all elections and referendums without discrimination. The Committee further recommends that States parties guarantee the right of persons with disabilities to stand for election, to hold office effectively and to perform all public functions at all levels of government, with reasonable accommodation and support, where desired, in the exercise of their legal capacity."

All this is grounded in article 29 of the CRPD, on participation in political and public life, which enshrines that "States Parties shall [...] [e]nsure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, [...] facilitating the use of assistive and new technologies where appropriate [...], [g]uaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice", and "[p]romote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, [...] including [...] [p]articipation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties" and "[f]orming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels."

Autistic persons' right to full and equal participation in political and public affairs must begin with our involvement in any and all public policy decisions with regard to autism. Too often it is wrongly assumed that autistics cannot or should not be consulted about decisions that will affect us, many of them potential sources of human rights violations. Instead, non-autistics, among them parents, health professionals, so-called autism experts, politicians, and civil servants, make decisions on our behalf, but without our consent. Most autistics can make their own decisions and contribute to collective decision-making if barriers are removed. Even those of us who do not speak may, for example, be able to express themselves in writing online, as evidenced by Internet fora that unite autistics across the spectrum, from least to most severe.

Autistic self-advocates must be consulted and included in all matters relating to autism policy at all levels of government. Autistic self-advocates must be appointed to any and all public bodies concerned with the development and/or implementation of autism policy. For this purpose, we call on States parties to the CRPD, and all other states, to engage and consult with autism self-advocacy groups at the global, national, regional, and local level as well as provide funding to such organizations so as to enable them to represent the interests of autistic persons, as demanded by article 4 of the CRPD: "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."

A best practice example in this regard is Ari Ne'eman, President and co-founder of the Autistic Self Advocacy Network in the United States, who in 2009 was nominated by

President Barack Obama to the National Council on Disability, a federal agency charged with advising Congress and the President on disability policy issues. He was confirmed by Senate in July 2010 and currently chairs the Council's Entitlements Committee. From 2010 to 2012, he served as a public member to the Interagency Autism Coordinating Committee, a federal advisory committee that coordinates all efforts within the Department of Health and Human Services concerning autism. Appointed by the then Governor, Ari Ne'eman also served as Vice Chair of the New Jersey Adults with Autism Task Force, where he represented autistic adults in reviewing the state's autism services. He had previously served on the New Jersey Special Education Review Commission.

Unfortunately, in most countries autistic self-advocates are not given the opportunity to participate equally in public policy that affects them. The public discourse on autism is dominated by negative stereotypes, often perpetuated by the very organizations that would presume to be speaking for us. It is of paramount importance that decision-makers at all levels start working with autistic self-advocacy organizations and initiatives, rather than continuing to rely on autism-related organizations run by often misguided parents of autistic children, with no or little autistic involvement. The wishes and interests of parents or guardians who may perceive autistic children as burdens must never be confused and equated with the best interests of the child or those of autistic adults.

Autistic individuals or representatives of autism self-advocacy organizations must also be included in any and all psychiatric committees of visitation and autism self-advocacy organizations be granted access to autistics that are institutionalized, so that their situation may be investigated, autistics can be educated about their rights, and organizations may act on behalf of those deprived of their liberty.

In order to enable autistic persons to represent themselves and participate in public affairs, it is of course imperative that we be given access to inclusive quality education. The CRPD recognizes in its preamble "the importance of accessibility to [...] education [...] in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms" and devotes article 24 entirely to education: "States Parties recognize the right of persons with disabilities to education [...] without discrimination and on the basis of equal opportunity. States parties shall ensure an inclusive education system at all levels and life long learning directed to [...] [t]he full development of human potential and sense of dignity and self-worth, and [...] [e]nabling persons with disabilities to participate effectively in a free society. [...]"

"In realizing this right, States Parties shall ensure that [...] children with disabilities [...] can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live; [...] [r]easonable accommodation of the individual's requirements is provided; [...] [e]ffective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion. [...] States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others."

In March 2014, the HRC unanimously adopted resolution 25/20 on "The Right to Education of Persons with Disabilities"⁴, "[r]ecognizing that progress has been made, yet deeply concerned that many persons with disabilities in all regions continue to face significant obstacles in exercising their right to education without discrimination and on the basis of equal opportunity, [and d]eeply concerned at the violence, stigmatization and discrimination [...] which leads to their exclusion and hinders and often prevents their access to education". The HRC "[u]rges States to consult closely with and actively involve persons with disabilities and their representative organizations in designing, implementing, evaluating, and monitoring policies and programmes relating to educational matters".

Specifically with regard to autistics, the UN General Assembly in its 2012 resolution shows itself "[d]eeply concerned that children with autism spectrum disorders, developmental disorders and associated disabilities in all regions of the world experience challenges in accessing [...] education, training and intervention programmes [...], [r]ealizing that the challenge [...] is particularly acute in the developing world, resulting in increased difficulties for [...] education [...] systems trying to meet their needs". UN member states recognize "that [...] an innovative, integrated approach would benefit from a focus, inter alia, on [...] [e]nhancing inclusive educational programmes suited to infants, children and adults with autism", while "[e]mphasizing the unique needs of each person with autism across a spectrum of different characteristics and experiences".

Yet under no circumstances must the education of autistic children, adolescents, and adults aim at turning them into something they are not and cannot be, namely non-autistic. The general principles underlying the CRPD (article 3) include "[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity" and "[r]espect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities".

The right to participate in public affairs should not be viewed in isolation. Only once the right to legal capacity and equal recognition before the law and the right to education are fully realized will autistic persons be able to stand for public office and participate fully and equally in public affairs beyond matters concerning autism, mental health, and disability. Autistic women's participation in public affairs is restricted even further by intersecting forms of discrimination due to autism/disability and gender. The CRPD highlights in article 6 that "women and girls with disabilities are subject to multiple discrimination", only to be countered by "the full development, advancement and empowerment of women". All these rights, and more, need to be linked and jointly enforced for the right to participate in public affairs to be effective.

In order for autistic persons "to hold office effectively and to perform all public functions at all levels of government", it will be crucial to overcome the common misperception that autism only affects children. Fact is, many autistics grow up without a diagnosis. And whilst there is still a severe lack of professionals qualified to diagnose autism in adults, more and more autistic adults do get assessed and, finally, diagnosed, often subsequent to a child or grandchild having been found to be on the autism spectrum. Other adults may get diagnosed because of a so-called autistic middle-age burnout, an event that occurs when we can't go on hiding our autistic symptoms any longer, when keeping up

⁴ http://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/RES/25/20

the façade of normalcy starts to take too much energy, and the coping strategies we developed growing up ultimately fail.

Ours is an often invisible disability and therefore no adjustments or accommodations are made for us. We spend our lives running on against barriers that non-autistics can't even perceive. Many autistics describe autism as akin to a wall of glass between themselves and other people. By the very nature of autism we are at a disadvantage when it comes to being politically active. Challenges and severity vary widely between individuals, but generally include difficulties in social communication, such as understanding, and using, facial expressions, body language, tone of voice, and non-literal language, unusual speech and eye contact, apparent lack of empathy, dislike of small talk, sensory overload, faceblindness, and anxiety. The lack of recognition and understanding of autism in adults means that the provision of services and support for autistic adults remains scarce, and many of us may therefore not be able to exercise our rights, including the right to participate in public affairs, in a meaningful manner.

While it is impossible to say how many undiagnosed or undisclosed autistic persons may have held or currently hold public office, the former Member of Parliament, Leader of the National Party of Australia, Minister for Trade, and Deputy Prime Minister of Australia, Tim Fischer, subsequent to the autism diagnosis of one of his sons publicly speculated that he, too, might be on the autism spectrum⁵. His wife seemed to confirm this many years later⁶. Tim Fischer lately served as Chairman of Tourism Australia and Australia's Ambassador to the Holy See. Other autistic politicians may be prevented from disclosing their condition by the stigma and prejudice attached to mental health concerns and the fear of losing future elections.

Lastly, autistic persons' right to full and equal participation in political and public affairs also includes the right to employment in the public sector, on an equal basis with others. According to article 27 of the CRPD, "States Parties recognize the right of persons with disabilities to work, [...] to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work [...] by taking appropriate steps [...] to, inter alia [...], [e]mploy persons with disabilities in the public sector".

All public sector jobs must be available to autistic candidates with the requisite qualifications and skills, regardless of their autism. All public sector workplaces must be made fully accessible to autistic persons, and reasonable accommodations must be provided. While many autistics 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. Accessibility barriers 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 an ever increasing number of autistics are forced out of a job. Fear of discrimination in the workplace is the primary reason why autistics choose not to be open about their autism. The public sector needs to set an example both with regard to inclusiveness and accessibility.

⁵ <http://www.abc.net.au/am/stories/s72724.htm>

⁶ <http://www.cam.org.au/News-and-Events/News-and-Events/Melbourne-News/Article/15737/Judy-Brewer-Fischer#.VL7OeC74Xm4>

The public sector also has the duty to provide jobs and training, including apprenticeships, particularly aimed at autistics. It is our hope that increased awareness of autism may help improve understanding between autistics and non-autistics and sensitize all sectors of the economy for autistics' plight and potential alike.

Thank you for your consideration.

Erich Kofmel, President
Autistic Minority International