Geneva, 13 March 2015

Our comments on the Draft Principles and Guidelines on Remedies and Procedures of the United Nations Working Group on Arbitrary Detention

ARBITRARY DETENTION OF AUTISTIC PERSONS

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 its Task Force on Child Protection, and a partner in the WHO's Mental Health Gap Action Programme (mhGAP).

We participated actively in the Working Group's Global Consultation on the Right to Challenge the Lawfulness of Detention before Court, held in Geneva in September 2014, making oral statements on both the criminal detention of autistic persons[1] and the institutionalization of autistic children and adults[2].

We greatly appreciate the opportunity to be able to comment now on the text of the Working Group's "draft principles and guidelines on remedies and procedures on the right of anyone deprived of his or her liberty by arrest or detention to bring proceedings before a court without delay, in order that the court may decide without delay on the lawfulness of his or her detention and order his or her release if the detention is not lawful", developed at the request of the United Nations Human Rights Council (HRC) and to be presented to the HRC at its September 2015 session. We will however 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, too.

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 lifelong neurological difference that is both genetic and hereditary. There is no cure, and we do not believe that a cure will ever be found.

[1] http://www.ohchr.org/Documents/Issues/Detention/Consultation2014/AutisticMinorityInternational1.pdf
[2] http://www.ohchr.org/Documents/Issues/Detention/Consultation2014/AutisticMinorityInternational2.pdf

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"[3]. 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 arbitrary detention of autistic persons, we strongly support the general direction of the Draft Principles and Guidelines, expressed unequivocally in paragraph 112: "The involuntary committal or internment on the grounds of disability or perceived disability, particularly on the basis of psychosocial or intellectual disability or perceived psychosocial or intellectual disability, is prohibited." We are grateful to find an ally in the Working Group, who will recognize this basic principle of the Convention on the Rights of Persons with Disabilities (CRPD)[4].

[3] http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/67/82
[4] http://www.un.org/disabilities/convention/conventionfull.shtml

To date, the CRPD has been ratified and acceded to by 152 States parties and signed by 7 more countries. Unfortunately, many of these States parties have yet to amend or repeal mental health and guardianship laws that allow for the involuntary detention, and in particular the indefinite institutionalization, of autistic persons. This despite the fact that even the WHO's World Health Assembly, in its mental health action plan of 2013, found that "stand-alone mental hospitals" are associated "with poor health outcomes and human rights violations"[5]. Often, mental health and guardianship laws at the same time deprive us of legal capacity and equality before the law and thus the possibility to challenge involuntary mental health detention in court. We urge the Working Group (and, later on, the HRC) to withstand any pressure from unreformed states to adopt less stringent standards and hold States parties to the CRPD, instead, to their international commitments.

We furthermore believe that Principle 20, paragraph 59, should be developed more fully to remind states of their obligation to amend or repeal mental health and guardianship laws so as to guarantee legal capacity and equal access to justice for all persons with disabilities, and that paragraph 113 should be expanded to read "persons with disabilities are [...] entitled to guarantees in accordance with international human rights law, necessarily including the right to liberty and security of the person *and the right to equal recognition before the law*" (legal capacity).

In paragraph 112, you rightly distinguish between "disability and perceived disability", both of which are prohibited as grounds for involuntary detention. You even single out "psychosocial or intellectual disability or perceived psychosocial or intellectual disability". It is unclear to us why in subsequent paragraphs you eschew the term "perceived", and speak in paragraph 115 (a) and (b) of "mental" rather than "psychosocial" disability (unlike in 115 (h) and (i))? The same applies to Principle 20, when comparing paragraph 59 (perceived; psychosocial) to paragraph 60 (no mention of perceived; mental). "Psychosocial" is also used in paragraphs 9 and 54, "mental" in paragraph 77 (c).

Autism is often mistakenly *perceived* as a mental illness or an intellectual disability, particularly if an autistic child or adult does not speak. Fact is, though, most autistics, be they children or adults, are able to express themselves if barriers are removed and reasonable accommodation, such as assistive and augmentative communication devices and/or access to electronic communication online, is provided. Other autistic persons may get misdiagnosed as mentally ill by psychiatrists who are unfamiliar with the autism spectrum or ignorant of the differences in presentation between children and adults.

For this reason, we feel that paragraphs 60-63 and 113-115 do not sufficiently cover autism. Because the reality and *perception* of autism are so frequently misaligned, we ask that you retain the distinction between disability and *perceived* disability (particularly perceived psychosocial, mental, and intellectual disability) throughout the text (paragraphs 9, 11, 16, 54, 60-61, 63, 77 (f), 107, 113, 115, and footnotes as appropriate) and add the term "psychosocial" disability whenever you speak of "mental" disability (and vice versa). This applies as well to paragraph 115 (b) where you speak of "mental impairment". Such an impairment, too, may be merely *perceived*. (Paragraphs 77 (c), 115 (g) and (i) also use "impairment".) Autism, along with other conditions, is also

[5] http://www.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf?ua=1

commonly considered a "developmental" disability or impairment (see, for example, the 2012 UN General Assembly resolution). We therefore appeal to you to include the term "developmental" alongside the other disability and impairment categories.

Paragraph 115 (d) should explicitly mention support through the provision of assistive and augmentative communication devices and access to electronic communication online, including whilst in detention and during court proceedings. Only this will ensure that autistic persons who do not speak are able to exercise their legal capacity, without any undue influence. This is supported by the Office of the High Commissioner for Human Rights (OHCHR) in its "Thematic study on the right of persons with disabilities to live independently and be included in the community"[6], presented to the HRC in March 2015, which states that "some persons with autism have found that support provided online may be more effective, in certain cases, than support received in person". The de-institutionalization of autistic persons calls for unimpeded access to online peer support.

We miss any guarantee, either in Principle 20 or Guideline 20, regarding the right to legal representation specifically for persons with disabilities (or perceived disabilities). The lack of any such guarantee might be misinterpreted as meaning that persons with disabilities do not require legal representation if only they are given sufficient other support. This would of course be an erroneous conclusion and should be avoided at all cost.

That said, as autistic self-advocates providing peer support to autistic persons who are involuntarily detained, we are extremely appreciative of paragraph 115 (j), whereby "Persons with disabilities shall be provided with legal or other appropriate support, including [...] peer support mechanisms so detainees can be educated about their rights, and organizations may act on behalf of those detained against their will". We have no doubt that this recognition will greatly help our cause and advance respect for the rights of autistic persons everywhere.

We admire paragraph 115 (l): "[R]elief should consist of measures such as requiring mental health facilities to unlock their doors[!] and inform people of their right to leave[!], and establishing a public authority to provide for access to housing, means of subsistence and other forms of economic and social support in order to facilitate de-institutionalization and re-entry into the community[!]. Such assistance programs should not be centred on the provision of mental health services or treatment, but free or affordable mental health services and treatment, including alternatives that are free from medical-model diagnosis and interventions[!], as well as both access to medications and assistance in withdrawing from medications, should be made available for those who desire them". May many states share the Working Group's vision and follow this roadmap!

Strike or amend paragraph 115 (m): Up to this point, Principle 20 and Guideline 20 have successfully established and demonstrated, in line with the CRPD, that there is never a "necessity" (or justification) to deprive a person of their liberty, against their will, on the basis of disability or perceived disability (which is however what, according to footnote 147, seems to be referred to here). Such detention is always arbitrary, never a necessity, and thus there is no need for periodic re-evaluation. Correspondingly, paragraph 62 should also be amended to clarify that it does not concern involuntary mental health

[6] http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Documents/A_HRC_28_37_ENG.doc

detention (the jurisprudence listed in footnote 81 pre-dates the CRPD and does not reflect current international law and human rights standards).

We would welcome a specific paragraph on the situation of children with disabilities, corresponding to article 3 of the CRPD, which demands "Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities", and article 7, whereby "States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right".

We feel that Principles 18 and 20 and Guidelines 18 and 20 do not currently pay sufficient attention to children with disabilities or perceived disabilities, such as autistic children, that are detained involuntarily. Children with disabilities have essentially the same rights as adults with disabilities, but their access to justice may be obstructed by parents, guardians, or caregivers who consent to their often indefinite detention, not because it is in the best interest of the child, but because they perceive such a child as a burden. The "evolving capacities of children with disabilities" and their "right to express their views freely on all matters affecting them", and thus to provide or withhold consent to their ongoing detention, are habitually disregarded in such cases and no support that would allow them to challenge their detention in a court of law is provided to those children.

Paragraph 106 does not speak to the plight of children with disabilities when it accepts that "deprivation of liberty is a measure of last resort". If any kind of "involuntary committal or internment on the grounds of disability or perceived disability, particularly on the basis of psychosocial or intellectual disability or perceived psychosocial or intellectual disability, is prohibited" (paragraph 112), then this must be true for children as much as for adults. The CRPD does not permit involuntary disability-based detention as a "last resort" for anyone, regardless of age. The wishes and interests of misguided parents and guardians must not be confused and equated with the best interests of the child. It is never in the best interest of the child to be deprived of liberty.

Finally, persons with disabilities or perceived disabilities have inexplicably been omitted from Principle 5 on non-discrimination, which we urge you to rectify (paragraph 22). Disability-related adjustments must be made to account for autistic persons' particular vulnerability whilst being held in a place of detention (we recommend to insert this in paragraph 115 (f)), and it must be ensured that autistic persons, and other persons with disabilities, appearing before court have not been sedated or otherwise drugged against their will (an important addition to paragraph 115 (i)). Training should also be provided to judges, tribunal and legal officers on how to apply the CRPD (paragraph 119).

Thank you for your consideration.

Erich Kofmel, President
Autistic Minority International