

Geneva, 2 September 2014

Oral statement at the Global Consultation on the Right to Challenge the Lawfulness of Detention before Court of the Working Group on Arbitrary Detention

PANEL 5: INSTITUTIONALIZATION OF AUTISTIC CHILDREN AND ADULTS

Thank you, Mister Chair.

Autistic self-advocates view autism not as something to be prevented or cured, but as a neurological difference that is equally valid. We understand autism awareness as only the first step on the way toward autism acceptance, recognition, and respect for autistic persons. Only autism acceptance will ensure our full and equal participation in all areas of public, economic, and social life, as called for by a 2012 resolution of the UN General Assembly, and only autism acceptance will meet the requirements of the Convention on the Rights of Persons with Disabilities (CRPD).

It is a common misperception that autism only affects children. Fact is, many autistics grow up without a diagnosis. Autistic persons form a particularly vulnerable group when it comes to involuntary mental health detention. They frequently get misdiagnosed by psychiatrists who are unfamiliar with the autism spectrum or ignorant of the differences in presentation between children and adults.

In May 2014, the 194 WHO member states adopted an autism resolution committing themselves "to shift systematically the focus of care away from long-stay health facilities towards community-based, non-residential services", echoing both the CRPD and the WHO's mental health action plan of 2013, which notes the association of "stand-alone mental hospitals [...] with poor health outcomes and human rights violations". So says the WHO.

There can, in particular, be no justification for the prolonged and often indefinite institutionalization of children and adolescents simply because they are autistic or otherwise disabled. The wishes and interests of parents or guardians who may perceive such children as burdens 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.

In order to guarantee the right to challenge involuntary mental health detention before court, peer support mechanisms, such as those provided by autistic self-advocacy groups, must be granted access to autistic persons who are institutionalized, so that their situation may be investigated, autistics can be educated about their rights, and organizations may act on behalf of those detained against their will.

While it seems customary to deprive institutionalized persons with disabilities, including autistics, of access to information and communication, this is particularly devastating to

those of us who do not speak and rely on the Internet as their sole means of communication. Being cut off from online communication also means being cut off from the autistic community and any available peer support.

Finally, it must be ensured that autistics appearing before court have not been sedated or otherwise drugged against their will.

Thank you.

Erich Kofmel, President
Autistic Minority International

Background information

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". 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".

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.

Autistic Minority International welcomes contact from and is open to collaboration with UN member states, the UN system, the wider NGO community, autism charities run by non-autistics, researchers particularly in the social sciences and international law, the private sector, and individuals.