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Written submission to the 115th session of the Human Rights Committee

REVIEW OF AUSTRIA: "EUGENIC INDICATION" ABORTIONS

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. 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, and a member of UNICEF's Global Partnership on Children with Disabilities (GPcwd).

In June 2015, Autistic Minority International and the German Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (ESH) made a joint contribution to the Half Day of General Discussion commencing the Committee's process of developing its General Comment No. 36 on the "Right to Life" with regard to article 6 of the International Covenant on Civil and Political Rights (ICCPR)¹. Our joint contribution focused on disability-selective abortion and prenatal genetic screening and other tests that would allow the abortion of fetuses "at risk" of autism – as is already the case today with fetuses found to be "at risk" of trisomy 21 (Down syndrome).

In Austria, disability-selective late-term abortions are permitted right up to the birth of the baby, without any restrictions. The official term used for such abortions in Austria is "eugenic indication"^{2 3}.

In 2013, the Committee on the Rights of Persons with Disabilities found in its Concluding Observations on Austria: "While the Committee recognizes women's right to reproductive autonomy, [...] [t]he Committee is concerned at the apparent link between this provision and the fact that, according to statistics from the Organisation for Economic Co-operation and Development, birth rates of children with Down syndrome in Austria fell by 60 per cent between 1995 and 2006. [...] The Committee recommends that the State party abolish any distinction, allowed by law, in the period within which a pregnancy can be terminated based solely on disability."⁴

¹ <http://www.ohchr.org/Documents/HRBodies/CCPR/Discussion/2015/AutisticMinorityInternational.doc>

² <https://web.archive.org/web/20080424010822/http://oe1.orf.at/69347.html>

³ <http://www.behindertearbeit.at/38341/keine-gesetzesanderung-bei-eugenischer-indikation/>

⁴ <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnzSGolKOaUX8SsM2PfxU7s9lOchc%2bi0vJdc3TEt6JuQH6d6LwuOqunaiCbf0Z0e%2b%2fWMB4CH5VprCrZY%2bNACxgG%2b3FQ4iHroX8O6TU68Yogo>

We believe that any laws allowing for and easing the abortion of fetuses based solely on disability must be deemed discriminatory and invite the Committee to align its jurisprudence with that of the Committee on the Rights of Persons with Disabilities and the Convention on the Rights of Persons with Disabilities (CRPD), ahead of the adoption of its General Comment No. 36.

We consider "eugenic indication" legislation, such as in Austria, and ongoing research to find a prenatal genetic test for autism, which often is publicly funded, nothing short of preparations to a eugenic genocide against disabled persons and a grave violation of the autistic community's right to survival and autistic individuals' right to life.

How imminent this danger is, and the sore absence of a human rights perspective regarding the legality of late-term abortions of fetuses diagnosed with a (possible) disability, became fully evident when UN member states agreed, by consensus, the final text of the post-2015 development agenda (now called "Transforming Our World: The 2030 Agenda for Sustainable Development"). During the last two weeks of negotiations in July 2015, and without any public consultation, they decided to include language that seeks the prevention of autism and other so-called developmental disorders: "We are committed to the prevention and treatment of non-communicable diseases, including behavioral, developmental, and neurological disorders, which constitute a major challenge to sustainable development."⁵

According to all UN member states, the world's sustainable development depends on the elimination of persons with disabilities. It is the very definition of eugenics.

Please recall that autistic persons do not view autism as a disorder or disease at all, but as a lifelong neurological difference that is equally valid.

While those who introduced this language into the post-2015 agenda obviously were targeting autism, the addition of behavioural and neurological disorders (classifications which may include autism in some parts of the world) and the link to non-communicable diseases (NCDs) opens up the possibility that this language will be used to seek and justify "prevention" of a wide range of other disabilities or conditions, particularly (but not limited to) those that exist from (or before) birth, such as spina bifida, (congenital) hydrocephalus, cerebral palsy, Down syndrome, and possibly even certain psychosocial disabilities (mental health is clustered together with NCDs at the WHO), such as schizophrenia of childhood (a diagnosis that in some countries is applied to autistic children, as well).

"Prevention" of autism is framed as a matter of financial burden to families and the state, as in an August 2015 press release on research conducted in the US, which estimates "Autism Cost [...] to Reach Nearly \$500 Billion, Potentially \$1 Trillion, by 2025" in the US alone⁶. Of course, that study was sponsored by Autism Speaks, a notorious US charity that claims to speak for autistic persons worldwide (also at the UN), but does not have any autistic persons in its leadership⁷. According to their mission statement, they seek to

⁵ <https://sustainabledevelopment.un.org/content/documents/7891TRANSFORMING%20OUR%20WORLD.pdf>

⁶ <http://www.autismdailynewscast.com/autism-cost-estimated-to-reach-nearly-500-billion-potentially-1-trillion-by-2025/29932/pressrelease/>

⁷ <http://jerobison.blogspot.ch/2013/11/i-resign-my-roles-at-autism-speaks.html>

fund "research into the causes, prevention, [...] and a cure for autism"^{8 9}, and their co-founder is on record as saying that their ultimate aim is to "eradicate autism for the sake of future generations"¹⁰.

Autism Speaks enjoys the support of the wife of UN Secretary-General Ban Ki-moon as well as a large number of first ladies the world over¹¹. Since 2012, the charity has donated at least one million US dollars for autism research and programming to the WHO^{12 13}, which led to an infamous WHO autism consultation in September 2013, co-hosted with Autism Speaks, to which not a single autistic person was invited. The Director of the WHO's mental health department is a member of Autism Speaks' Global Action Committee (established in January 2015)¹⁴. We just made a submission to the Committee on the Rights of Persons with Disabilities highlighting Qatar's collaboration with Autism Speaks in terms of autism "awareness-raising" at and through the UN (article 8 of the CRPD¹⁵), which leads to results such as this language in the post-2015 agenda.

A counterpoint from a human rights perspective was set in April 2015, when 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 statement¹⁶ 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. [...] Autistic persons are particularly exposed to professional approaches and medical practices which are unacceptable from a human rights point of view. Such practices – justified many times as treatment or protection measures – violate their basic rights, undermine their dignity, and go against scientific evidence.

"Autistic children and adults face the proliferation of medicalized approaches [...]. This may be particularly harmful and lead to the deterioration of their condition. All too often, such practices amount to ill-treatment or torture. The autism spectrum should be understood from a broader perspective, including in research. We call for caution about enthusiastic attempts to find the causes of autism and ways to 'cure' autism through sophisticated but not necessarily ethical research. Autism as a condition is a critical challenge for modern health systems, in which we need to ensure that the practice and science of medicine is never again used to cause the suffering of people."

Prevention of autism is only to be achieved by prevention of birth. Large sums of money from both public and private sources are expended on research trying to find a prenatal

⁸ <https://www.autismspeaks.org/about-us>

⁹ <http://www.eu-aims.eu/the-group/consortium/autism-speaks/>

¹⁰ http://web.archive.org/web/20110407083057/http://www.parade.com/articles/editions/2008/edition_01-27-2008/Autism_Changes_Everything

¹¹ <https://www.autismspeaks.org/news/news-item/remarks-mrs-ban-soon-taek-spouse-un-secretary-general-ban-ki-moon>

¹² <https://science.grants.autismspeaks.org/search/grants/world-health-organization-collaboration>

¹³ <https://science.grants.autismspeaks.org/search/grants/collaboration-between-who-department-mental-health-and-substance-abuse-and-autism-speaks>

¹⁴ <https://www.autismspeaks.org/about-us/press-releases/autism-speaks-launches-global-action-committee>

¹⁵ http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/QAT/INT_CRPD_CSS_QAT_21324_E.doc

¹⁶ <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)

genetic test that would allow the abortion of foetuses "at risk" of autism or, less likely, the manipulation of such foetuses in the womb to prevent autism from developing¹⁷. Neither is acceptable to the autistic community, and neither respects the right to life – that is, the continued right to be born – of autistic individuals.

In Austria, the term "eugenic indication" (*eugenische Indikation*) is used to describe abortions of foetuses after they have been diagnosed with a (possible) disability. Paragraph 97 (1) (2) of the Austrian penal code (*Strafgesetzbuch*)¹⁸ states that such abortions are not punishable, at any stage of the pregnancy, if "there is a serious risk that the child will be mentally or physically heavily damaged" (*eine ernste Gefahr besteht, daß das Kind geistig oder körperlich schwer geschädigt sein werde*).

In 2002, Gerard Quinn, Director of the Centre for Disability Law & Policy at the National University of Ireland, Galway, and Theresia Degener, current member of the Committee on the Rights of Persons with Disabilities, wrote: "The relative invisibility of people with disabilities can have a dramatic impact on their enjoyment of civil rights. The right to life has been violated through abortion on the basis of disability."¹⁹

In 2011, the Committee on the Rights of Persons with Disabilities in its Concluding Observations on Spain took note of an act that "decriminalizes voluntary termination of pregnancy, allows pregnancy to be terminated up to 14 weeks and includes two specific cases in which the time limits for abortion are extended if the foetus has a disability: until 22 weeks of gestation, provided there is 'a risk of serious anomalies in the foetus', and beyond week 22 when, inter alia, 'an extremely serious and incurable illness is detected in the foetus'. [...] The Committee recommends that the State party abolish the distinction made [...] in the period allowed under law within which a pregnancy can be terminated based solely on disability."²⁰

As this demonstrates, there is no clash between women's sexual and reproductive rights, least of all the hard-won sexual and reproductive rights of women with disabilities, and the right to life of persons with disabilities from conception, that is, the individual right to be born and the right of disabled minorities, such as autistics, not to be extinct from the earth, as long as embryos and foetuses diagnosed with or "at risk" of a disability enjoy the same legal protections as others.

In Austria, no abortion will be punished if it is performed during the first three months of a pregnancy (paragraphs 96 and 97 (1) (1) of the penal code). This time frame should apply regardless of whether a foetus may be born with a disability or not.

There should be no extended impunity for late-term abortions based solely on disability.

¹⁷ While in such a scenario birth would still take place, we believe it would not be the same person that is being born. Such research raises huge ethical questions about who or what is a human being, and the inviolability and integrity of human life, that we, as a society, have not even started to debate. Also, the consequences of such manipulations of the human genome are not well understood. The long-term threat they may pose to the individual and future generations down the line is immeasurable.

¹⁸ <http://www.jusline.at/index.php?cpid=ba688068a8c8a95352ed951ddb88783e&lawid=11&paid=97&mvpa=106>

¹⁹ <http://mek.oszk.hu/09400/09466/09466.pdf> (page 26)

²⁰ <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhslxq2MuIdp%2fqMKQ6S>

Disability-selective late-term abortions are discriminatory and amount to eugenics – which at least in Austria is openly acknowledged.

Worldwide, routine prenatal testing for trisomy 21 has led to a sharp decrease of children born with this disability – about 90% of pregnancies with a diagnosis of Down syndrome are terminated²¹ (despite 99 percent of persons living with Down's reporting that they lead a happy life²²) –, and the same is true for fetuses prenatally diagnosed with spina bifida, sickle cell anaemia, cystic fibrosis, muscular dystrophy, fragile X syndrome, and so on. Many children and adults with fragile X syndrome and some children and adults with Down syndrome also meet the criteria for a diagnosis of autism.

In addition, preimplantation genetic screening and diagnosis during in vitro fertilization (IVF) – permitted in Austria since January 2015²³ – may show an embryo's genetic predisposition for a disability or impairment and lead to the destruction of the embryo solely because of this.

The development and spread of new reproductive technologies has meant that all over the world persons likely to belong to a disabled minority have increasingly been denied the right to life, that is, the right to be born.

At the same time, we know today that disability is a social construct. The CRPD holds "that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others"²⁴. Persons belonging to disabled minorities may have rare personal characteristics. Those characteristics are however inherently value neutral and should not be equated with the discriminations that are caused by public misperceptions about them. We need to change public perception, not deprive persons with disabilities of the right to life.

History provides numerous examples in which a societal majority declared a vulnerable minority fit only for extermination. Already the Nazis counted persons with disabilities among those they described as "life unworthy of life": they had no right to live. One of Hitler's first acts as Chancellor of Germany in 1933 was to pass a Law for the Prevention of Hereditarily Diseased Offspring, which allowed the compulsory sterilization of anyone suspected of having a genetic condition or disability, such as hereditary deafness, hereditary blindness, schizophrenia, or congenital mental deficiency. The law was enacted through a large number of "Genetic Health Courts". Along with the law, Hitler – an Austrian by birth –, decriminalized abortions carried out by doctors in case a foetus had racial or hereditary "defects".

It is hardly a coincidence that the term "life unworthy of life" was coined by a psychiatrist, Alfred Hoche²⁵. According to him, persons who were brain damaged, intellectually or psychosocially disabled, or autistic (though not called that at the time) were "mentally dead", "human ballast", and "empty shells of human beings". Persons with disabilities

²¹ <http://onlinelibrary.wiley.com/doi/10.1111/j.1542-2011.2011.00109.x/abstract>

²² <http://www.ncbi.nlm.nih.gov/pubmed/21910246>

²³ <http://kurier.at/politik/inland/nationalrat-beschliesst-fortpflanzungsmedizingesetz/109.421.776>

²⁴ <http://www.un.org/disabilities/convention/conventionfull.shtml>

²⁵ http://en.wikipedia.org/wiki/Life_unworthy_of_life

were among the first to be euthanized by the Nazis. Later, the killing was extended to those they considered racially inferior or impure. It is noteworthy that in some countries, such as the Netherlands, children with disabilities can be and are euthanized once more today²⁶.

The prenatal extinction of persons with disabilities is the logical continuation and consequence of the Nazis' eugenics, euthanasia, and extermination programmes and the majority's refusal to learn from history. Prevention of birth has long been recognized as a key component of genocide. Why do people shut their eyes to the eugenic genocide perpetrated against disabled minorities by way of reproductive technologies? Have not other minorities that were subjected to genocide also been pathologized? Is not describing minorities that are to be expunged from existence as diseased a hallmark of genocide? What is or is not considered "healthy" at any given point in time is socially negotiated. Jews and homosexuals are two other groups that were persecuted under the Nazis – but we would not now consider programmes to prevent the birth of Jews or homosexuals ethical. Nor would we condone any programmes to prevent the birth of dark-skinned children, or that of girls. Why can we not extend the same respect to persons with disabilities? Why are disabled persons still thought of as subhuman?

But this entire approach, seeking to employ new technologies to purify the human gene pool once and for all, is based on the faulty assumption that disability is a personal characteristic – rather than the product of social isolation and discrimination.

The 157 States parties to the CRPD are under the obligation to eliminate discrimination, not eliminate those experiencing discrimination.

The reality of discrimination can never ever justify even worse forms of discrimination.

The arguments become particularly monstrous when the fact that children with disabilities will be discriminated against is used to legally vindicate the late-term abortion of foetuses diagnosed with a disability because giving birth to or raising such a child might pose a risk to the mental health of the mother.

The negation of difference endangers vital components of humanity, such as autistic persons, that have existed for millennia and quite possibly since the beginning of mankind. Racism and ableism are equally reprehensible. Racial prejudice may be recognized as such, but ableist prejudice against persons with rare personal characteristics never is. In the case of autistic persons, it may even be argued that we form an ethnic group ourselves, based on genetic heredity and shared characteristics, culture, and identity, and should enjoy all the protections afforded to ethnic minorities under UN conventions and declarations. Some autistic persons who do not speak and use sign language to communicate belong to a protected linguistic minority also.

It may thus be easier to conceptualize research leading up to the eugenic extinction of autistic persons as preparations to an ethnic genocide against the autistic minority.

We urge the Committee to condemn, at the example of Austria, disability-selective prevention of birth, disability-selective "eugenic indication" abortion, disability-selective

²⁶ http://en.wikipedia.org/wiki/Groningen_Protocol

prenatal (genetic) testing and diagnosis, and disability-selective preimplantation genetic screening and diagnosis during IVF²⁷. Any research, in Austria and elsewhere, advancing disability-selective reproductive technologies must be prohibited and all public funding for it withdrawn.

Organizations run by and for persons with disabilities, in our case autistic self-advocacy organizations, must be granted legal standing to institute judicial proceedings against Austria, as a State party to the ICCPR and the CRPD, for disregarding and failing to protect the right to life of persons with disabilities yet to be born. We must be allowed to take legal action on behalf of any member of our minority whose right to be born has been or is to be violated based solely on disability. It cannot be that a eugenic genocide can't be challenged or stopped just because the victims have no legal status yet (or not anymore).

For us, this is a matter of life and death – the autistic community's right to survival and autistic individuals' right to life, that is, the continued right to be born.

Thank you for your consideration.

Erich Kofmel, President
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²⁷ If at all, late-term abortion of a foetus should only be permitted if the child would not be able to survive if born, such as in the case of anencephaly, or if they would be in constant unbearable and untreatable physical pain. Neither of this applies to the great majority of foetuses aborted based solely on disability and parents' fear of societal discrimination.