

Geneva, 12 June 2015

Written contribution to the Half Day of General Discussion on the "Right to Life" of the Human Rights Committee

## **RIGHT TO LIFE AND PRENATAL GENETIC TESTING FOR AUTISM**

This is a joint contribution by Autistic Minority International and Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (Germany).

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, 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).

Enthinderungsselbsthilfe von Autisten für Autisten (und Angehörige) (ESH)<sup>1</sup> is a German DPO run by and for autistics (and their relatives). It was founded in 2006, which makes it the oldest autism self-advocacy organization active in the entire German-speaking region. Representing autistic interests, ESH has dealt extensively with the German political system, public administration, and courts at all federal levels. In 2013, ESH received the Canadian "International Naturally Autistic People Award".

We greatly appreciate the opportunity to be able to provide our input 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).

We will limit ourselves to discussing and stressing just one issue of particular importance to autistic persons, namely 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). We consider ongoing research in this direction, 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.

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<sup>1</sup> <http://autisten.enthinderung.de>

Many of the points we will be raising are applicable to existing reproductive technologies and persons with other 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. 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>2</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."

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>3</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<sup>4</sup>: "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

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<sup>2</sup> <http://www.un.org/en/events/autismday/2013/sgmessage.shtml>

<sup>3</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>4</sup> <http://daccess-ods.un.org/access.nsf/Get?Open&DS=A/HRC/FMI/2013/2&Lang=E>

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>5</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. [...] When available, services are too often far from human rights friendly or evidence-based. 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 relying on the over-prescription of psychotropic medications, their placement in psychiatric hospitals and long-term care institutions, the use of physical or chemical restraint, electro-impulsive therapy, etc. 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.

"More investment is needed in services and research into removing societal barriers and misconceptions about autism. Autistics 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. [...] 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."

With regard to the right to life and prenatal genetic testing for disabilities such as trisomy 21 (Down syndrome) and, potentially, autism, we should listen to what actually autistic persons have to say, such as this autistic woman (Katharine May Cunningham aka Anastassia Charity Marie Florine) posting in an autism forum online about a highly controversial US autism "charity" run by non-autistic persons<sup>6</sup>: "They support eugenics. Alongside salaries, most of their donations go to research to create a genetic test for autism so that parents can abort their children or fetuses when they test positive for

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<sup>5</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)

<sup>6</sup> <http://wrongplanet.net/forums/viewtopic.php?t=279558>

autism in the womb. Yes, the test can be useful to plan for a child's life, but let's admit that with society's attitude right now, most women would abort an autistic fetus. They just want to wipe us from the gene pool. One woman who worked for [a government-run centre for persons with intellectual disabilities and/or autism in Montréal, Canada] told me she wouldn't abort a kid because he didn't have the right color eyes, but that it's a woman's right to abort an autistic fetus because it is autistic. When I told them I considered boycotting the facility, they told me I needed to work on agreeing to disagree. However, I say that agreeing to disagree does not mean letting the opposition walk all over you and giving in to them."

The world has changed considerably since the adoption of the Committee's General Comments Nos. 6 and 14 in 1982 and 1984, respectively. 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.

Preimplantation genetic screening and diagnosis during in vitro fertilization (IVF) may show an embryo's genetic predisposition for a disability or impairment and lead to the destruction of the embryo solely because of this. 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 terminated<sup>7</sup> –, and the same is true for foetuses 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.

Large sums of money from both public and private sources are expended on research trying to find a prenatal genetic test that would allow the abortion of foetuses "at risk" of autism or, alternatively, the manipulation of such foetuses in the womb to prevent autism from developing. 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.

At the same time, we know today that disability is a social construct. The 154 States Parties to the Convention on the Rights of Persons with Disabilities (CRPD) agree "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"<sup>8</sup>. 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.

Article 10 of the CRPD thus reads: "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others." With regard to the legality of late-term abortions of foetuses diagnosed with a disability, the Committee on the Rights of Persons with Disabilities found in its Concluding Observations on Austria:

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<sup>7</sup> <http://onlinelibrary.wiley.com/doi/10.1111/j.1542-2011.2011.00109.x/abstract>

<sup>8</sup> <http://www.un.org/disabilities/convention/conventionfull.shtml>

"While the Committee recognizes women's right to reproductive autonomy, [...] [t]he 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."<sup>9</sup> We believe that any laws allowing for and easing the abortion of fetuses based solely on disability must be deemed discriminatory.

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 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 Hoche<sup>10</sup>. 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 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 today<sup>11</sup>.

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.

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<sup>9</sup> <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnzSGolKOaUX8SsM2PfxU7s9lOchc%2bi0vJdc3TEt6JuQH6d6LwuOqunaiCbf0Z0e%2b%2fWMB4CH5VprCrZY%2bNACxgG%2b3FQ4iHroX8O6TU68Yogo>

<sup>10</sup> [http://en.wikipedia.org/wiki/Life\\_unworthy\\_of\\_life](http://en.wikipedia.org/wiki/Life_unworthy_of_life)

<sup>11</sup> [http://en.wikipedia.org/wiki/Groningen\\_Protocol](http://en.wikipedia.org/wiki/Groningen_Protocol)

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 fetuses 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 disability-selective prevention of birth, disability-selective abortion, disability-selective prenatal (genetic) testing and diagnosis, disability-selective preimplantation genetic screening and diagnosis during IVF, and euthanasia of disabled children. Any research advancing disability-selective reproductive technologies must be prohibited and all public funding for it withdrawn.

We recommend that the Committee pay attention to research seeking to manipulate fetuses in the womb in order to prevent autism from developing, as it 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. While in such a scenario birth would still take place, we believe it would not be the same person that is being born. 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.

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 States Parties to the ICCPR that disregard or fail 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.

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Enthinderung