Joint statement

United Nations Human Rights Council joint statement shows greater need for rights-based disability-specific approach to autism

The undersigned DPOs call on UN member states to cover sufficiently the rights and needs of autistic people when raising awareness on autism and disabilities at large.

To mark the upcoming World Autism Awareness Day (WAAD) 2021, Qatar and Poland sponsored a joint statement supported by 151 UN member states among them 23 European, incl. Spain. The statement was read out today, 9 March 2021, during the 46th session of the United Nations Human Rights Council (UNHRC). WAAD is celebrated every 2 April as established by the United National General Assembly resolution 62/139 tabled by Qatar on 18 December 2007. This resolution marks one of only a few official United Nations Days on a specific disability. Every year it brings the world’s attention to the rights and needs of autistic people. We, the supporters of the following statement, have a long history of advocacy for the rights and needs of autistic people and those with disabilities at large.

We take note of the joint declaration to mark World Autism Awareness Day 2021 at the United Nations Human Rights Council, but regret that the following rights and needs of autistic people are not sufficiently covered: the right to quality of live, to live independently in the communities considering individual lifestyle preferences, to inclusive quality education and employment, to treatment without force (currently endangered by the additional protocol to the Oviedo Convention of the Council of Europe as highlighted by the European Disability Forum at the UNHRC), to legal capacity, to sexual and reproductive rights and to accessible access to justice, the need to end violence by law enforcement officials, to eradicate poverty and social exclusion, for evidence-based COVID-19 treatments, COVID-19 vaccination prioritisation as well as for diagnosis and interventions on co-occurring conditions.

We appreciate the important track record of some of the sponsors and supporters of the joint statement, and would like to highlight the following positive elements:

1. We welcome very much the attention paid to autistic people and their families at the UNHRC in general. We strongly endorse the reference of the joint declaration to the 2007 initiative establishing WAAD thanks to Her Highness Sheikha Moza bint Nasser of Qatar.

2. We strongly concur that the joint statement highlights the continuous discrimination faced by autistic people and their families as well as the need for respect, protection and fulfilment of the rights of people on the autism spectrum to ensure their full and effective participation in society.

3. We appreciate that the joint statement highlights the rights and needs of autistic children in general.

4. We especially concur that the joint statement highlights the impact the COVID-19 pandemic has on autistic people and their families in terms of lack of access to needed services, medical supplies,
employment, adequate standard of living and social protection as well as the barriers autistic people and their families (will) face during post-COVID-19 pandemic recovery.

5. We especially approve that the joint statement emphasises the importance of WAAD to in order to stand up for the rights of autistic people and speak out against their discrimination and ensure they have the necessary support to be able to exercise their rights and fundamental freedoms. We also express our deep appreciation that the joint declaration endorses World Autism Awareness Day as a call to action for better access and opportunities for people on the autism spectrum, training for public administrators, service providers, caregivers, families and non-professionals to support the integration of autistic people into society so that they can realize their full potential for the benefit of all.

We also take this opportunity to outline some concerns that we have with the statement:

6. We are very concerned that the joint statement does not sufficiently reflect the principles and standards of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as well as the valuable work of the Committee on the Rights of Persons with Disabilities (CRPD committee). In that regard, we remind the sponsors and supporters of the joint statement that the United Nations General Assembly resolution establishing World Autism Awareness Day specifically recalls the UNCRPD.

7. We regret the limited scope of the joint statement and the language used to refer to people on the autism spectrum.

8. We especially deplore that the joint statement makes use of medicalised language when referring to autistic people. Autism is a life-long neurodevelopmental disability. The autistic communities prefer to use person-first ("person on the autism spectrum") or identity-first ("autistic person") language.¹

9. We express our regrets that the joint statement does not devote sufficient attention to the rights and specific needs of autistic adults as well as ageing on the autism spectrum.

10. We especially take note of the joint statement finding the options of autistic people and their families expanded considerably in recent years. We remind the sponsors and supporters of the shortcomings in access to evidence-based early intervention for autistic children as well as provisions of accessibility and support services in education and employment for people on the autism spectrum. We recall that these interventions and supports services have been interrupted ever since the COVID-19 pandemic.

When raising awareness on autism and disabilities at larges, we strongly recommend UN member states and other stakeholders involved in the process to engage with independent disability and autism experts such as the representatives of the Committee on the Rights of Persons with Disabilities (CRPD committee), more specifically with disability organisations at large like the European Disability Forum as well as autism-specific disability association like Autism-Europe Confederación Autismo España, and many others representing the autism communities and their families themselves.

¹ Please refer to acceptable language guidelines by Autism-Europe: https://www.autismeurope.org/about-autism/acceptable-language/
Undersigned:

**Autism-Europe** is an international association whose main objective is to advance the rights of autistic people and their families and to help them improve their quality of life. Based in Brussels, it ensures effective liaison between its 90-member autism organisations from 40 European countries, including 26 Member States of the European Union, national governments, as well as European and international institutions. AE represents an estimated 7 million people throughout Europe.

**Confederación Autismo-España** is a national confederation. It represents 141 entities that provide support and specialised services to autistic people and their families. Autismo-España works for and on behalf of people on the autism spectrum in the promotion of the effective exercise of their rights and in the strengthening of the autism association movement in Spain.

**European Disability Forum** is an umbrella organisation of persons with disabilities that defends the interests of over 100 million persons with disabilities in Europe. EDF is an independent non-governmental organisation (NGO) that brings together representative organisations of persons with disabilities from across Europe. It is run by persons with disabilities and their families. EDF is a strong united voice of persons with disabilities in Europe.