EESC gives the floor to prominent Irish disability advocate Sinéad Burke



I ask you to transform the landscape for the disabled people with them, not for them. I am so grateful that you are facilitating this conversation and instigating this debate. But this cannot just be a moment. It is a movement that I invite you to join, Ms Burke tells the EESC on the eve of the International Day of Persons with Disabilities

On 2 December, the **European Economic and Social Committee (EESC)** hosted a debate with Irish disability advocate, writer and broadcaster **Sinéad Burke** in its plenary session dedicated to the empowerment of persons with disabilities and their inclusion in all spheres of economic, social and political life in the EU and beyond.

Held on the occasion of the International Day of Persons with Disabilities (IDPD), observed globally every year on 3 December, the debate was marked by an inspiring, moving and very personal speech delivered by **Ms Burke** and by powerful statements by EESC disability activists and other members.

On the International Day of Persons with Disabilities, it's important to reflect on where we have come from and the progress that we have made. For many of us, the medical model of disability is within our lived experience.

This meant that disabled people were classified by their medical condition and that they were spoken about, never spoken with or to. This framing of disability led to the perception that it was a burden on individuals, families, communities and societies. When someone was born disabled, sympathy was whispered, Ms Burke said.

Ms Burke is battling for disability rights on many fronts. Through her company, Tilting the Lens, she works towards accelerating systemic change in the perception and treatment of persons with disabilities within the domains of education and design. She has just received a literary award for her first book, Break the Mould, which encourages children to acknowledge differences and be proud of who they are, just as they are. Ms Burke is also the first little person to feature on the cover of Vogue and to attend the Met Gala.

I am incredibly proud to be disabled. My disability is one of my identities that defines me, that shapes my expertise and interests, and frames my perspective of the world. It has heightened my empathy and rehearsed my vulnerability, she told the EESC plenary session, where she had her EU debut.

Ms Burke was welcomed by the EESC president, Christa Schweng, who recalled the importance of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), a breakthrough international treaty which changed the way in which we perceive disability. It was signed by the EU in 2010 but has still not been ratified by all of its Member States.

Letting go of both a medical and charitable approach — the one in which, in Ms Burke's words, an act of inclusion is rooted in generosity, the CRPD acknowledged the rights of persons with disabilities to live with dignity and to take part in decision-making processes, particularly those that concern them. It placed the responsibility of removing the barriers on society, which has a duty to make the world inclusive and accessible to all.

The approach taken by the UN CPRD was revolutionary and represented a big step forward. Unfortunately, the situation is still difficult and further measures are needed, the EESC president stated.

I feel each of us can contribute to advancing disability rights, be it by raising awareness, advocating or engaging politically. At our level, I can ensure that in the coming years the EESC will continue to commit to this cause, one which is very close to our hearts, Ms Schweng continued.

There are about 87 million people with some form of disability in the EU. With the ageing of society, the number of persons with disabilities will continue to grow in the future.

The plenary debate focused on the burning issues that still need to be solved to achieve equality, equity and inclusion of citizens with disabilities, enabling them to live their lives to the full as active members of society.

The speakers stressed the importance of inclusive education and employment, accessible workplaces, but also of the use of language, which should make persons with disabilities feel safe and comfortable.

Involving persons with disabilities in all decisions that directly affect them is also paramount.

The spotlight was put on the devastating effect of the pandemic on citizens with disabilities, as many of the COVID-19 victims were people in homes for the elderly or in institutions, the people who paid the heaviest price. This year, the IDPD is dedicated to building back a more disability-inclusive, accessible and sustainable post COVID-19 world.

Persons with disabilities have suffered from neglect by decision makers. They have to be protected and prioritised by the EU and Member States. The health situation and lives of persons with disabilities matter too, said **Ioannis Vardakastanis**, EESC member and president of the European Disability Forum.

The EU Disability Strategy for the next decade must lead to a true paradigm shift. It can only be efficient if it considers the consequences of the pandemic and influences Member States' policies and expenditure, warned the head of the EESC's Thematic Group on Disability Rights, **Pietro Vittorio Barbieri**.

With the focus of her work on education and accessibility enabling people to live independently, **Ms Burke** saw the glimmer of a positive takeaway from the pandemic.

If there is a positive in the destruction of the virus, it is that this moment has granted us an opportunity to redesign our world. As we think about redesigning places and spaces for social distancing, let us also imagine how that could be accessible. Thinking this way will make our towns, cities and countries a safe and equitable invitation for people to be themselves, she concluded.

As a way of marking the IDPD, the EESC presented a short film, *To Be or Not to Be (in Corona times)*, produced by Theater Stap, a small Belgium-based theatre company which works with people with intellectual disabilities.

EESC IS TIRELESSLY CAMPAIGNING FOR A MORE INCLUSIVE AND ACCESSIBLE EU

The EESC has been advocating for disability rights for many years. Its Thematic Group on Disability Rights oversees the implementation of the CRPD in the EU and organises numerous hearings and country visits to assess the situation on the ground. Headed by **Mr Barbieri**, who was a member of an Italian delegation at the UN that was directly involved in drafting the CRPD in 2006, the group also provides a networking platform for many disability and other civil society organisations.

The EESC's recent work has focused on the EU's new disability agenda 2020-2030. In an opinion by Mr Vardakastanis, the EESC calls for the agenda to be fully aligned with the CRPD.

At its December plenary session, the EESC also adopted the opinion on <u>The</u> need to guarantee real rights for persons with disabilities to vote in

<u>European Parliament elections</u>. This is a follow-up to the EESC's 2019 <u>information report</u>, which found that millions of EU citizens with disabilities were deprived of their voting rights due to legal or organisational obstacles still in place in all EU countries. In its new opinion, the EESC asks for an urgent amendment to the EU's electoral law to guarantee universally accessible EU elections in 2024.