

Autism Spectrum Disorder: Stamping out the stigma

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Feature

Autism Spectrum Disorder is on the rise, yet it remains a largely misunderstood condition. On World Autism Awareness Day 2019, Lorna Hutchinson reports on what still needs to be done to raise awareness and provide much-needed support.



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Autism Spectrum Disorder is a complex, life-long neurological disorder that affects brain development and behaviour.

According to Autism-Europe, more than seven million people are on the autism spectrum in Europe and prevalence rates are on the increase.

Autism affects more boys than girls - one girl is diagnosed for every four boys - and the disorder can lead to stigma and discrimination due to difficulties in social interaction, learning disabilities,

repetitive patterns of behaviour and sensory issues.

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While some people with autism can live independent lives, others have severe disabilities which require life-long care and support.

There are many unknowns in autism. While there is no single isolated cause, research suggests that the condition comes from a combination of genetic and environmental influences.

Moreover, there are, to date, no clinical tests for autism; instead, psychiatrists observe behaviour and development in order to accurately make a diagnosis.

Waiting lists for public services offering autism diagnoses can be very long, which can push desperate parents, who may often be struggling with behavioural issues in their child, into seeking a private diagnosis.

“As the future European Disability Strategy is currently under consultation, it is crucial that invisible disabilities, such as autism, are not forgotten and that no one is left behind”

Aurélie Baranger, Director of Autism-Europe

Although going private can substantially cut waiting times to begin the diagnostic process, it can also be prohibitively expensive. Yet many parents feel they need answers, as well as solutions, to help their child as soon as possible.

A CERTAIN STIGMA

In 2015, the European Parliament adopted a Written Declaration on Autism, calling on the European Union and its Member States to adopt a European strategy to support accurate detection and diagnosis of autism across Europe, promote evidence-based treatment and support, and foster research and prevalence studies.

Three and a half years on, how much progress has the EU made in raising awareness of autism and protecting the rights of people with autism?

One of the main supporters of the Written Declaration, Maltese S&D MEP Miriam Dalli believes that autism still carries a certain stigma.

“As a matter close to my heart, I have been very active in raising awareness on autism, not only in

my home country of Malta, but also at EU level. Despite the various awareness-raising campaigns, there is still stigma and prejudice surrounding autism," she explained.

"Continued awareness-raising and education at EU level should provide support for removing barriers and for helping others understand what living with autism means and entails. The key message is that we seek the potential in every person, release their ability and promote an inclusive society."

Dalli explained that early diagnosis and support to families of those with autism is crucial, and that access to quality life-long education and training should be enhanced across the EU for all people on the autism spectrum.

"The key message is that we seek the potential in every person, release their ability and promote an inclusive society" **Miriam Dalli MEP**

"Under the 2010-2020 EU Disability Strategy, special attention was given to equality, participation, accessibility, employment, education and training, social protection and much more. However, challenges remain due to slow progress in society."

Dalli believes that a lack of independence and social inclusion of people with autism is a missed opportunity for both a more inclusive society and to use the exceptional skills that some people on the autism spectrum have.

Speaking of the high unemployment rate of people with autism, she said, "I truly believe that, with the skilful high attention to detail and pattern recognition skills [that people with autism can have], opportunities lie in the big data environment of the digital revolution."

DEFICITS IN AWARENESS

Fellow autism campaigner and Maltese S&D group colleague Marlene Mizzi agreed that a lot more can still be done at EU level to fill the deficits in awareness and social inclusion for autistic people.

"The causes of autism are still unknown and there is currently no cure. Nevertheless, early intervention and detection can significantly improve the life of people with autism. Autism is by no means a condition to be ignored. Regrettably, due to various misconceptions, the challenges autistic people and their families find themselves confronted with remain numerous."

Mizzi believes that many people with autism are deprived of the right to enjoy life and to actively participate in the community, experiencing widespread discrimination as well as social exclusion.

Speaking of the Written Declaration, of which she was one of the major drivers, Mizzi said, "The Declaration was our way, as MEPs, to show support and combat the stigma and prejudices against autistic people. We wanted to be the wind of change, paving the way for autism-friendly EU policies that will help improve the quality of life of people with autism and their families."

"On World Autism Awareness Day, I would like to make a poignant reminder to the EU and Member States to take action regarding the Parliament's Declaration on Autism" **Marlene Mizzi MEP**

"Unfortunately, four years after the adoption of the Declaration, the European Commission has not acknowledged our demands. There is no European Strategy for Autism and the initiatives taken to

date are far from being ambitious,” she said.

“On World Autism Awareness Day, I would like to make a poignant reminder to the EU and Member States to take action regarding the Parliament’s Declaration. A future European strategy should take into account the specific needs of autistic people in terms of accessibility, support and early detection, and endeavour to implement specific measures for the full realisation of the rights of autistic people”, she added.

'A NEW DYNAMIC FOR AUTISM'

To mark World Autism Awareness Day on 2 April, Autism-Europe, which represents 90 member associations in 38 countries, is launching a new campaign calling for “A New Dynamic for Autism” throughout Europe.

The campaign focuses on promoting a greater understanding of autism and aims to pave the way for EU policies that address the urgent challenges faced by autistic people and their families.

Aurélie Baranger, Director of Autism-Europe, said that as autism is a life-long disability, all EU Member States face similar challenges; providing timely access to diagnosis, education, employment, housing and support for life in the community.

“A holistic approach is needed in dealing with autism. The response to autism needs is, however, quite diverse across Europe, with some Member States performing better than others,” Baranger said, adding that “an EU-wide approach would help reduce inequalities”.

Baranger said that as the Parliament has “long been a promoter of the rights of autistic people,” Autism- Europe hopes to continue counting on the support of, and cooperation with, future MEPs in the next legislature.

“We have therefore released a manifesto calling on candidates to support measures for the full inclusion of autistic people in society and promoting the full implementation of the UN Convention on the Rights of Persons with Disabilities [UNCRPD] at the EU level and all its Member States if elected.”

“The EU can play a leading role in fostering inclusion and improving the quality of community support services across Europe and end segregation, notably through the use of the European Structural and Investment Funds.”

She said that the EU can also promote adequate training for professionals across sectors to develop understanding and effective support.

“As the future European Disability Strategy is currently under consultation, it is crucial that invisible disabilities, such as autism, are not forgotten and that no one is left behind,” she added.

About the author

Lorna Hutchinson is a reporter and sub-editor at The Parliament Magazine

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