

## Op-Ed: Safeguarding the wellbeing of families living with autism

*Dr. Sharifa Noaman Al-Emadi, Executive Director of Doha International Family Institute – a QF member – on how Qatar is supporting people with autism and their loved ones, and why everything it has done so far is just the start.*

According to the American Psychiatric Association, Autism Spectrum Disorder (ASD) – a neurodevelopmental disorder that lasts for a lifetime – accounts for one percent of the global population.

People with autism tend to experience difficulties with social interactions and communication, often displaying repetitive behavioral patterns and defined interests. Research has shown that the psychological wellbeing of parents can affect the way they interact with their children, such as the development of a child in social, emotional, linguistic, and cognitive aspects of their lives.

As a way of targeting this growing trend, Qatar has placed great emphasis on providing treatment and rehabilitation services to people with autism, including raising awareness about ASD on a global scale. One way in which it has done this is World Autism Awareness Day which was first proposed by Her Highness Sheikha Moza bint Nasser, Chairperson of Qatar Foundation, to the United Nations (UN) in 2007, and was adopted without a vote by the UN General Assembly. As a result, the first World Autism Awareness Day was celebrated on April 2, 2008

In an effort to contribute to Qatar’s national development strategy, the Doha International Family Institute (DIFI) – a member of Qatar Foundation that aims to be a global knowledge leader on issues facing the Arab family – conducted a study on the wellbeing of families living with ASD. Using a mixed-methods approach, this study collected both qualitative and quantitative data through in-depth interviews and surveys with parents of children who have ASD.

We found that families who have children with ASD face difficulties in accessing quality and timely services. In addition, not only do parents of children with autism face challenges related to social and emotional support and respite care, but the relationships between spouses and siblings are also adversely affected.

And these concerns do not stop there. Parents also bear extra financial strain in trying to secure the wellbeing of their children. Finally, DIFI’s study found that many parents expressed strong concerns about their children’s future.

The challenges that families face highlight the importance of having widespread awareness of the disorder. Some of the challenges mentioned above were clearly expressed by the parents. One mother stated “When we go out, my daughter suffers because no one respects her rights. When she is out playing, she sometimes screams, and people stare. I then have to explain that she has special needs.” Another parent said “people sometimes look [at my daughter] and walk away. Of course, it hurts. I’m human. I’m a father, and it hurts to see such a situation.”

In fact, some parents have highlighted the extremes that strangers have gone to express their concerns, one stating that “[my daughter] was once sitting and screamed two or three times, and a man in his fifties or sixties got up and said ‘you are not able to raise your daughter well’.”

Nevertheless, some recommendations from the study were discussed and shared by DIFI in a research forum last February. This forum included key stakeholders such as the Ministry of Public Health, the Ministry of Education and Higher Education, Shafallah Center, the Family Department of the Ministry of Administrative Development, Labor and Social Affairs, as well as some families of children with ASD.

Participants recommended making diagnostic procedures simple and clear, ensuring immediate and high-quality services and support, providing psychosocial support, building coping skills for parents and siblings of children with autism, reducing financial burdens on families, and raising public social awareness of autism and its different manifestations and challenges.

And Qatar's efforts do not stop there.

Over the years, Qatar has established several public facilities that provide diagnosis and treatment, in addition to providing healthcare and education to people with autism. The Child Development Center at Rumailah Hospital, part of Hamad Medical Corporation, was established in 1982 to provide assessment, diagnosis and early intervention for children with special needs from the ages of 3-6 years.

Under the directive of Her Highness Sheikha Moza bint Nasser, the Shafallah Center for Persons with Disability was established in 1999 to provide more specialized services to children with special needs. And in 2016, Qatar Foundation established Renad Academy, which currently provides specialized education for children with mild to moderate autism, and accepts children aged 3-7 years. Every year, it is adding a higher grade level, to ultimately reach the point where it serves students of all ages.

Simultaneously, the Ministry of Education and Higher Education established the Roua Center, which provides assessment, guidance and support services for students with special needs. Mothers of children with autism have also established the Qatar Autism Families Association - an informal association for families living with autism. In support of these public facilities, there are private centers that provide medical care and education to individuals with autism.

Although all of these efforts are part of the Qatar National Autism Plan (2017-2022), aiming to support individuals with autism and their families through awareness, early diagnosis, treatment, and education, they are just the beginning.

DIFI's work, for example, doesn't just stop at conducting research and proposing evidence-based policies, but it also actively works with stakeholders and partners to advocate for the well-being of families of children living with ASD and for the necessary support and care to be provided.

**ENDS**