



MANTRA: The ultimate goal of treatment and intervention is to ensure the children dealing with autism grow up to become productive members of society.

By Aney Mathew

Even if you only had a casual interest in art, chances are you've heard of Stephen Wiltshire — the celebrated, British architectural artist famed for his ability to draw from memory a landscape, accurately and in great detail after seeing it just once. Stephen can draw entire cities from memory, based on single, brief helicopter rides.

Stephen's art has won him much acclaim including an MBE. What makes his work and fascinating ability even more intriguing is the fact he has autism. Stephen's story while different is not unique; he joins the ranks of several gifted personalities who have had to deal with autism. The point? People suffering from autism can go on to lead fully productive lives given the right environment. It is believed that even the famed Michelangelo may have suffered from autism!

"A condition that has been gaining much attention in the recent times, autism is a very complex neuro-psychiatric condition and over the last decade, there has been a dramatic increase in the number of diagnosed cases worldwide," says Dr Muhammad Waqar Azeem, Chair, Qatar National Autism Working Group.

"Recent figures from the US confirm that 1 in 68 children are affected by the condition. The situation in each country is naturally different and the prevalence of autism in Qatar is currently under study. However, if we did extrapolate the figure of 1 in 68 children or even 1 in 100 children in Qatar, as suffering from autism, we could have anywhere from 3,000 to 5,000 children and adolescents in Qatar with autism," he adds.

Dr Azeem also serves as Co-Chair, WISH Autism Forum; Chair, Department of Psychiatry, Sidra Medical and Research Center; and Advisory Committee Member for Renad Academy.

Autism is a condition that can be isolating for the person who has it, and autism symptoms are tough to understand from the outside. Every person with autism is different,

and there is no single perspective regarding children with autism.

But there are some issues that are shared by many on the autism spectrum. It is characterised by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behaviour. As a result, children suffering from autism can have major challenges. They may avoid eye contact, prefer to play alone, not understand personal boundaries, have unusual mood swings, or be over-sensitive to light, sound, and touch. They form a vulnerable population and hence require significant attention depending on the acuteness of their condition.

Caring for children with autism

According to Dr Azeem, early intervention is the key to seeing success in the long run. In some western countries, therapy begins in children as young as 1 to 3 years of age; behavioural therapy, speech and language therapy, and occupational therapy have all proved to be very effective. Speech and language therapy becomes even more crucial in the case of 3 to 5 year olds. It is important that parents keep their children away from treatments offered through chelation or hyperbaric oxygen chambers, as there is no bonafide research supporting them and they can even be dangerous to the child.

The ultimate goal of treatment and intervention is to ensure the children dealing with autism grow up to become productive members of society. Encouraging examples of children growing up to become successful musicians, artists, researchers, and even scientists should offer great hope to parents.

Social awareness

As with most developmental disabilities, the stigma associated with autism is a major issue. "It's important to understand autism is a different way of thinking and acting, it is like any other condition. There is no stigma associated with diabetes or asthma, so why stigmatise autism?" asks Dr Azeem as he stresses the importance of creating awareness among the general public on this issue.

Pointing out another challenge faced by the families who have children with autism, Dr Azeem emphasises: "Schooling plays a huge role in the development of children with autism; however, we find many regular schools in Qatar shy away from taking them in. Once in school, fellow students and even teachers are often unaware of the symptoms presented by these children and the difficulties they face. As a result when confronted with behavioural issues from these children, the tendency is to label them as disobedient or rebellious. A child seen as 'acting up' could be dealing with sensory issues. The goal is to ensure these children obtain the services they require from schools. So it is important to get the schools to be knowledgeable about autism and provide the necessary services. Building awareness within the education system is a necessity."

Challenges persist outside the walls of the school, too. For instance, a child with autism experiencing sensory overloads could be disturbed by loud noises or sirens, and could react in unusual ways. Unable to understand what is going on within the child, most people tend to view the conduct as misbehaviour and expect the parents to deal strictly with the child. As Dr Azeem points out, community awareness helps people empathise with the difficulties faced by children with autism, as well

Tips for parenting a child on the autism spectrum

- Remember each child is an individual
- Family support is crucial
- Focus on the child's strengths, not only on the areas that need improvement
- Early intervention is the key
- Behavioural and occupational therapies can be very helpful
- Speech and language therapy is crucial
- Education in the right environment with right support is important
- Interacting through play is helpful
- Get support from families, professionals, and friends
- Remain hopeful and never give up.
- Remember your child is special; given time and the right environment he or she can flourish.

as their families. Social acceptance is vital to the child's success.

Family matters

One of the greatest areas of challenge and one that is often overlooked are the difficulties faced by families, especially the primary caregiver of the child. Expounding on the important role families are called to play, Dr Azeem explains, "Child is the extension of the family; when the child suffers, the whole family suffers. When you are dealing with a child challenged with sensitivities, simple everyday tasks like going to the barber or a visit to the ATM can be difficult. The situation is very challenging, and at times, mothers caring for children with autism suffer from depression. Hence support must be extended by all members and

the entire family must work together as a unit. For instance, it is imperative that both the parents attend hospital and school appointments together.

"Some families are amazing in the way they accept the situation and deal with the fact that a member has struggles, but some families take it hard. There are several parents who suffer guilt, and blame themselves for having done something wrong which could have resulted in their child having autism. It's important to understand that we are not aware of the exact cause of autism, so blaming anyone is inappropriate. They also feel guilty about neglecting the other children in the family. It's important for society to understand, empathise and be supportive; this can only be achieved through creating awareness at a nationwide level."

A journey of hope

Qatar has been taking several measures to increase national and global awareness on autism. A campaign supported by HH Sheikha Moza bint Nasser through the United Nations in 2007, resulted in April 2nd being declared 'World Autism Day' in perpetuity; additionally, all member states have been encouraged to take measures to raise awareness on autism throughout society. Qatar has been working on a National Autism Plan (first in the region). Several stakeholders including the public sector, private sector, ministries, and families came together while working on the plan. Based on their feedback, recommendations have been made in six important areas: awareness; screening and early detection; diagnosis and assessments; treatment and interventions; education (role of schools); and transition to adulthood. Qatar Foundation extends huge support to children with autism and their families. The opening of Renad Academy, a school under the QF umbrella, under the leadership of HE Sheikha Hind bint Hamad al-Thani is an example. The

academy offers a world-class programme to children diagnosed with Autism Spectrum Disorder.

The Autism Forum of WISH (World Innovation Summit for Health), an initiative of Qatar Foundation, comprises 11 experts from around the world. Best evidence-based ideas and practices are reported with strong recommendations at the WISH summits. Shafallah Center for Children with Special Needs, Rumailah Hospital, Sidra Medical and Research Center, and HMC are examples of institutions that provide help and support. Several private schools and centres — begun privately mostly by parents — are also functioning very effectively in offering remarkable services to cater to the needs of children with autism. Parents have formed a very strong organisation at a national level and are producing highly commendable results. They are fervent advocates to the cause and play a huge part in creating awareness within the community. In addition to conferences being held by the public sector, national conferences on autism are also being organised by private organisations, and parents who have children with autism.