

Including autistic kids benefits us all

The UAE turns its focus towards enhanced therapeutic and societal support for those living with autism, writes **Inga Louisa Stevens**

PHOTOS BY AIZA CASTILLO-DOMINGO

As we approach the eleventh annual World Autism Day on April 2, hundreds of thousands of communities around the world will be turning light blue in appreciation of people living with autism. This day is all about increasing understanding and acceptance and fostering worldwide support for inclusion for those who have an autism spectrum disorder (ASD).

According to the World Health Organization, ASD refers to a range of conditions characterised by some degree of impaired social behaviour, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively. ASDs begin in childhood, in most cases during the first five years of life, and tend to persist into adolescence and adulthood. It is estimated that worldwide, 1 in 160 children has an ASD, although no official statistics are currently available for the UAE.

Amidst rising awareness of the condition in the UAE, children with autism and their carers now have an increasing number of avenues to turn to for therapeutic support in coping with their condition and learning skills to help them assimilate into mainstream society. According to the World Health Organization, because of the significant emotional and economic burden on people with these disorders and their families, the empowerment of caregivers is increasingly being recognised as a critical component of care interventions for children with ASD. Enter the Al Jalila Foundation, a global philanthropic organisation dedicated to transforming lives through medical education and research, founded by His Highness Shaikh Mohammed Bin Rashid Al Maktoum, Vice-President and Prime Minister of the UAE and Ruler of Dubai, to position Dubai and the UAE at the forefront of medical innovation.

Ta'alouf is Al Jalila Foundation's flagship programme, which equips teachers and parents with knowledge and skills to better manage

children with disabilities and special educational needs. Ta'alouf means 'harmony' in Arabic and brings this spirit to life by working in unison with strategic partners, including parents, educators and the community to empower what they call children of determination. Instead of being weighed down by their disorders, these children can rise above their disabilities and discover abilities.

Since 2013, the Ta'alouf programme, in partnership with the British University in Dubai and Zayed University, has trained over 500 parents and 206 teachers in the UAE.

According to Professor Eman Gaad, dean of the faculty of education at The British University in Dubai, the key skills and topics covered during the Ta'alouf programme include behaviour analysis, acquiring practical intervention, inclusive education and behaviour management, communication strategies and individualisation of intervention (IEP), as well as abuse-related behaviours.

'The acquired practical skills and knowledge through Ta'alouf definitely helps parents to manage the challenging behaviour of their children and, through this empowerment,

'As a family with children with special needs, we have been socially isolated through lack of awareness. But Ta'alouf was extraordinary'

parents have become more aware of the difference between form and function of behaviour,' explains Professor Eman. 'This particular knowledge helps them to understand their children's requests and find out the reasons for throwing tantrums.

'Parents also became aware of inclusion laws and regulations, which in turn could increase the number of included students in mainstream schools.'

152 parents and teachers graduated from the fourth Ta'alouf programme in November 2017 at a ceremony in Dubai Healthcare City, among

them Sultan Siddique Ali Qadri, from Pakistan. Sultan lives in Sharjah with his wife Syyeda, their three boys, Muhammad, 16, and 13-year old twins Mustafa and Faizan, all of whom have autism and are non-verbal, and their daughter Zawanah, 16, who is Muhammad's twin.

Syyeda and Zawanah look after the boys, without the assistance of external carers, helping them with daily tasks.

'My day starts around 4am, when I wake up to prepare food for the boys and help them get ready for their daily activities,' Syyeda explains. 'They need help with the most basic skills, such as dressing, showering and going to the bathroom. I often do not stop until 10pm once everyone is in bed and the house is clean.'

'I do find it very difficult and challenging. When I get sick, I not only have to take care of myself but also the house and the boys. At that juncture, I feel helpless and dejected. I have not taken a holiday for seven years as I know that it would be very difficult for even my brother, sisters and in-laws to accommodate my boys,

even for a few days. However, my biggest dream and wish is that one day I get to perform Ummrah with my family.'

Sultan was introduced to the Ta'alouf programme by the staff at the Shaikh Rashid Center for Disabled in Dubai where his sons attend daily rehabilitation, which includes behavioural, speech and occupational therapy.

'There is a very limited number of schools or centres in the UAE for children with complex needs and there are very long waiting lists for their enrollment,' Sultan says. 'Even if we did get a space for the boys, we would have to arrange

for Dh130,000 in annual school fees, which is almost equal to my total annual income.'

'As a family with children with special needs, we have often been socially isolated through lack of awareness. Ta'alouf was an extraordinary experience, all the way from the trainers, the course materials, the supportive atmosphere, to meeting other parents with the same problems,' Sultan explains.

'The most wonderful thing about Ta'alouf is that the trainers truly understand our day-to-day issues and gave us practical solutions to resolve them. Ta'alouf is life-changing and our life, and that of our children, has become so much easier and we hope to be an encouragement to other parents. We have special children, but we are also special parents.'

'The UAE is making great leaps and bounds in including and bringing out the best in People of Determination, a term created by Shaikh Mohammed when he launched the National Strategy for Empowering People with Disabilities. All of us here today are the embodiment of this initiative and actively uphold and deliver on the strategy to support them' said Dr Abdulkareem Al Olama, CEO of Al Jalila Foundation, while speaking during the Ta'alouf graduation ceremony. 'At the heart of Ta'alouf is social inclusion and we will continue to champion it in our classrooms, playgrounds and our communities.'



Sultan and Syyeda (RIGHT) say Ta'alouf has provided them the skills to manage the issues their kids face



Meanwhile, the Autism Spectrum Disorder programme at the Al Jalila Children's Specialty Hospital in Dubai provides comprehensive multidisciplinary assessments for children with ASD based on Gold Standard clinical tools, and evidence-based management of comorbid psychiatric diagnoses.

Dr Ammar Al Banna, who is the head of the Child and Adolescent Mental Health Centre of Excellence at Al Jalila Children's Specialty Hospital, explains some of the most common reason for referral to the Autism Spectrum Disorders programme.

'Many parents are looking for a comprehensive assessment of their children using standardised assessment tools, with a multidisciplinary team, in order to more accurately diagnose their child, rule out important comorbidities [additional diseases related to the primary condition] that warrant treatment and to identify strengths to build on. More importantly, parents seek accurate information about the diagnosis, causes, and treatments of ASD, and for support and guidance when navigating health, social and educational systems.'

Dr Ammar adds that autism has unfortunately been a magnet for fad treatments and myths, such as the study that linked ASD with vaccines, so it is extremely important to follow scientific evidence-based practices that have been subjected to rigorous research standards, otherwise, he says, we risk negatively

affecting the well-being of individuals with ASD and their loved ones.

'When it comes to community inclusion, it is extremely important to be reminded that this is every child's right. Since autism is a spectrum, and affected individuals have different needs and strengths, there is no single recipe for integration but improving public awareness to better understand individuals with ASD and their families goes a long way,' Dr Ammar says. 'Programmes that are tailored for typically developing children should also take into account individuals with ASD, and there are guidelines to help with this. Teaching all members of society to accept and value individual differences and to treat others with the golden rule of empathy is crucial.'

One key intervention that helps with integration is early identification and intensive behavioural treatment that aims for mainstreaming and integration. For instance, studies have consistently shown that children who receive early intensive behavioural therapy (defined by at least 25 hours per week of specialised treatment) are more likely to be integrated into regular schools. It is also important to address the public stigma and lack of tolerance of people with differences.

i *The next five-week Ta'alouf programme will start on April 7. It is free of charge and parents can apply by contacting the Al Jalila Foundation on taalouf@aljalilafoundation.ae.*

Understanding ASD

WHAT IS AUTISM?

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Autistic people see, hear and feel the world differently to other people. It is not an disease and cannot be 'cured'. Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. While some have learning disabilities, others have mental health issues or other conditions, meaning they need different levels of support. All people on the autism spectrum can learn, develop and live a more fulfilling life with the right kind of support. In most cases the conditions are apparent during the first 5 years of life. While some people with autism spectrum disorder (ASD) can live independently, others need life-long care and support.

HOW MANY PEOPLE ARE AFFECTED?

Globally, 1 in 160 children has ASD. Some well-controlled studies have, however, reported figures that are substantially higher. The prevalence of ASD appears to be increasing globally. There are many possible explanations for this increase, including improved awareness, expansion of diagnostic criteria and better diagnostic tools.

WHAT CAUSES ASD?

Available scientific evidence suggests that there are probably many environmental and genetic factors that make a child more likely to have an ASD. However, there is no evidence of a causal association between measles, mumps and rubella vaccine or any other childhood vaccine, and ASD. Previous studies suggesting a causal link were found to be filled with methodological flaws.

DO OTHER CONDITIONS AFFECT ASD PATIENTS?

Often, epilepsy, depression, anxiety and attention deficit hyperactivity disorder (ADHD). They may be more vulnerable to developing noncommunicable conditions because of physical inactivity and poor diet.

HOW IS ASD TREATED?

Intervention during early childhood is vital to promote optimal development and well-being. It is important that children with ASD and their families are offered relevant information and support.

HOW ARE PEOPLE WITH ASD TREATED?

They are at greater risk of violence, injury and abuse, are often subject to stigma, discrimination and human rights violations. Globally, access to services and support is inadequate.

Sources: WHO; The UK National Autistic Society

Autism black book

DUBAI

Autism Rocks Support Centre

UK-based charity Autism Rocks has opened a support centre to provide therapy for children on the autism spectrum and training to teachers and parents to help them learn how to address challenging situations; visit autism.rocks.

Autism Trust Foundation

The Autism Trust Foundation (ATF) is a non-profit organisation registered in the UK and the United Nation Department of Economic and Social Affairs. In the UAE, the ATF works to provide support, ambition and hope to the community, leading the way to create a society that wholeheartedly accepts and welcomes those with autism; visit autismtrustfoundation.com.

Dubai Autism Center

Dubai Autism Center is the largest nonprofit organisation in the UAE serving children with Autism Spectrum Disorders; visit dubaiautismcentre.ae.

Stepping Stones

Stepping Stones is an internationally recognised organisation that uses evidenced-based practices to treat and educate individuals diagnosed across various areas of developmental and learning difficulties such as ASD; visit steppingstonesca.com.

ABU DHABI

Emirates Autism Center

This is a private centre specialised in autism spectrum disorders with state-of-the-art classrooms specifically designed to meet the sensory and environmental needs of its students; emiratesautism.ae.

Future Rehabilitation Centre

The Future Rehabilitation Centre is dedicated to the empowerment of children with various disabilities, including autism, by providing them with therapy services and education that specifically address their individual needs; visit future-centre.org.

The New England Centre for Children Abu Dhabi

NECC-AD provides intensive educational services for UAE national kids with autism and related disorders ages 3-9 utilising the principles of Applied Behaviour Analysis; neccabudhabi.org.