

Autism in the Gulf States: a regional overview

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1. ABSTRACT

In this review, we provide a Gulf region-centric view on autism with special focus on Qatar and Oman, including a review of seminal Qatari/Omani work from the literature. In addition, we offer a summary from the World Innovation Summit for Health and World

Innovation Summit for Education autism reports as well as outline some of the main challenges, best practices and a path forward for the Gulf region from a healthcare perspective. Finally, we highlight the role of public outreach and awareness to lay the groundwork

Table 1. The estimated population and prevalence rates for autism in each of the six member states of the Gulf Cooperation Council (GCC)

GCC State	Estimated Population (in M)	Prevalence Rate per 10,000	Reference no.
Kingdom of Bahrain	1.2	4.3	6
State of Kuwait	3.1	-	
Sultanate of Oman	3.3	1.4	7
State of Qatar	2.7	-	
Kingdom of Saudi Arabia	28.4	59	8
United Arab Emirates	8.3	29	9

Note: The prevalence of autism per 10,000 is variable. The reported median in Europe is 19, USA is 22 and China is 12.

for enlightened policy for intervention and resource allocation to care for autistic individuals.

DSM-5 criteria as well as various forms of symptom checklists (2).

2. INTRODUCTION

2.1.3. Prevalence

2.1. Autism Spectrum Disorder (ASD) overview

In recent years, with the development of services coupled with the increased availability and access of novel diagnostic tools, the recorded prevalence rate of ASD has substantially increased worldwide. A recent study published in 2015 in the U.S. reported that one child out of every 68 is on the autism spectrum. As of 2010, there were an estimated 52 million cases of ASD worldwide, representing a substantial increase over the past 40 years (3). When comorbidity with other learning disabilities is factored in the calculation, such as epilepsy and intellectual disability, the diagnosis rate jumps to a range of 1:15-20 individuals having one or more of these disorders. Given the current prevalence estimates of ASD in the U.S. (*i.e.*, 1 in 68 children), approximately 50,000-70,000 youth on the autism spectrum are estimated to turn 18 years old each year (3, 4).

2.1.1. Definition of ASD

Autism spectrum disorder (ASD) represents a cluster of lifelong neurodevelopmental disorders that emerge during early childhood and interfere with a person's ability to socially relate to and interact with others. ASD is associated with a high prevalence of comorbid medical and neurological conditions including cognitive, emotional and behavioral problems. ASD and other neurodevelopmental disorders affect the quality of life of those with the conditions, as well as their families and caregivers.

As for ASD research in the Arab world, it is fairly a new investigation field. The number of confirmed cases of ASD is unknown. Prevalence studies conducted to date within Arab countries have yielded varied nationwide estimates of the prevalence (5), as shown in Table 1. More telling, ASD epidemiological investigations with an emphasis on young adults is completely lacking in the Arab world.

2.1.2. Diagnosis of ASD

Diagnosing ASD is a difficult task due to the complexity and variability of ASD characteristics and symptoms. Diagnosis of ASD subtypes requires a comprehensive profile of a child's behavioral tendencies; developmental/cognitive ability; speech, language and communication; socialization; adaptability; and sensorimotor behavior characteristics. However, ASD can be identified or distinguished from other disabilities by looking to "*the presence of a distinctive impairment in the nature and quality of social and communicative development*" (1). The most common phenotypes contributing to the diagnosis of ASD include deficits in producing spoken language, impairment in social interaction and a tendency to engage in stereotypical behaviors.

In Qatar, no comprehensive survey has yet to be completed for the prevalence of ASD, including its prevalence within the young adult demographic. Qatar has virtually no evidence-based data on health, mental health and healthcare for ASD. However, an epidemiological study by the Qatar Biomedical Research Institute (QBRI) that concluded at the end of 2017 is expected to provide an insight into this question (10). While this paper was under review, local Qatari newspapers reported that QBRI has announced its preliminary finding, indicating the prevalence rate in Qatar is 1.1%.

Presently, there are no studies clarifying the current diagnostic practice of ASD either in the Arab world in general or Qatar and Oman in particular. Yet most of the centers in the Arab world, including Qatar and Oman, usually use ADI-R or ADOS as diagnostic tools, with clinical observations based on DSM-4 and

In Oman, a prevalence estimate of 1.4 per 10,000 children was reported in 2011 (7), potentially this is an underestimation due to various social and other awareness related issues (11). A recent study mentioned that the prevalence could be as high as 8.5 cases per 10,000 children (12). Efforts are underway with input from a group of researchers from Sultan Qaboos University (SQU), and Oman Autism Society to determine the magnitude of ASD in Oman at the national level using more robust epidemiological tools.

2.1.4. Causation and therapy

The causes of ASD are not clear-cut, but evidence suggests that a number of environmental and genetic factors are at play, and therefore the role of mutation has been speculated (13, 14). The gender gap has also emerged in the equation deciphering etiology of ASD. There is recent support for a 'female protective effect' as an explanation for males being four to five times more likely to have the disorder. Almost half (44%) of subjects with ASD have co-occurring adaptive and cognitive functioning deficits. Early diagnosis (12 to 18 months) and intervention is highly beneficial to patients. However, early diagnosis remains a challenge. Nevertheless, a team of investigators from the Cleveland Clinic Children's Center for Autism has developed what may become ASD's first objective diagnostic aid: an autism risk index based on remote eye-gaze tracking proving to be remarkably accurate (15). There is no cure to ASD, however, earlier intervention and comprehensive remedial services has been suggested to be beneficial (2). In Oman and Qatar, early intervention has been gaining momentum and some of the existing centers do have rudimental services that resembles Applied Behavior Analysis (ABA).

2.2. The ASD challenge

Most of the available research on ASD has been conducted in high-income Western countries (largely Western Europe and North America), which provides – at best - limited systematic information about the understanding and management of ASD in the rest of the world. The economic impact associated with ASD is substantial and includes direct medical, direct non-medical and indirect productivity costs. Studies estimate the lifetime cost of caring for an individual with ASD to be \$2.2 million in the US, and £1.5 million in the UK; though the figures drop to \$1.4 million in the US and £0.92 million in the UK for ASD without co-morbid conditions. In addition, if unrecognized or untreated, ASD can contribute to poor educational attainment and difficulty with employment, leading to negative economic implications (16).

Recent estimates of the total economic impact of ASD in the US in 2015, based on direct medical,

non-medical and productivity costs combined, totaled \$268 billion – ranging from 0.9 to 2% of gross domestic product (GDP). This figure is expected to rise to \$461 billion (ranging from 0.99 to 3.6% of GDP) by 2025. These figures are on par with recent estimates for 'silent epidemics' such as diabetes. Indeed the burden of ASD appears to exceed the cost of traditional enemies of health such as the likes of stroke and hypertension. However, what sets ASD apart from other non-communicable diseases – such as heart disease, cancer, stroke and hypertension – are the significantly higher non-medical costs when compared to direct medical costs (16). There is also suggestion that comorbidities of ASD tend to amplify burden to the society and afflicted individuals alike (17).

2.3. The Gulf States burden

ASD is not yet a national priority in most countries, which has led to a lack of systematic development, monitoring and evaluation of ASD efforts and to fragmented social and health services for people with ASD and their caregivers. There is a high-level interest in both Qatar and Oman to institute a national plan to address ASD. For example, amongst the Gulf States, Qatar launched its national plan in April 2017.

Outside High Income Countries (HICs), public health initiatives concerning the impact of ASD and other neurodevelopmental conditions remain poorly implemented. The knowledge gap between evidence and action in the care of individuals with ASD and neurodevelopmental disorders in Low to Medium Income Countries (LMICs) has remained considerably wide. In Oman, a study has suggested that the presence of ASD in the in the country has a net negative effect of inflating dependency ratio as well as triggering a decline in social mobility (18).

To date, 86.5% of all cases of ASD have been reported in HICs, where only 20% of the world population resides. Few population-based studies have been conducted in LMICs, which may well underrepresent the impact of ASD (16). There are also difficulties in measuring the prevalence of ASD, stemming from population awareness, selection of studies and diagnostic capabilities, as well as cross-cultural appropriateness and comparability of ASD screening, measurement and epidemiological data. The uneven rates of diagnosis have also led to variations in ASD prevalence by race and ethnicity including the MENA and Gulf regions (5, 11).

3. ASD AND OMAN

In March 2016, the Ministry of Social Development and Oman Liquid Natural Gas (Oman LNG) Company jointly signed an agreement to establish the National Center for Autism that would

act as an advocate to the welfare of people with ASD. This national facility will be dedicated to autism intervention and care addressing some of the unmet needs in terms of rehabilitation, remedial support and educational initiatives (19). Additionally, it will focus on helping individuals living with autism and generate, as well as increase, public awareness. It aims to identify, promote, treat and educate people on the welfare and acceptance of individuals living with autism. Besides, it will extend its services and support to encourage, promote and facilitate research and studies into the root causes, diagnosis and treatment of autism and associated conditions. The Oman Autism Society is a charitable society based in Muscat, established by a ministerial decree, that deals with ASD related issues and helps raise awareness and understanding of autism in the Omani society. The society goals are to

- help coordinate the efforts of the government, charity and NGO institutions
- contribute to the development and improvement of comprehensive services for children with ASD
- create a unified national (medical – psychological – educational) protocol of diagnosis
- foster public awareness and professional awareness towards ASD

It remains to be seen if such advocacy can translate into much needed educational integration for children with ASD and children with special needs and talent in particular.

The Ministry of Health in Oman has started a national-level screening program that, in turn, has necessitated the need to validate screening so that evidence-based early intervention could be instituted. Further, as part of this initiative healthcare providers training on “Training of Trainers Method” on surveillance, screening, instruments interpretation, risk assessment, etc. has been contemplated (20). As per Al-Mamari *et al.* (12), this is the first routine developmental screening program utilizing an Arabic tool in the Middle Eastern region. It is anticipated that this modality will help to measure the prevalence rate in Oman.

3.1. Research on Omani people with ASD

Research on Omani ASD patients covered largely three areas: genetic, biochemical and behavioral aspects. Below we provide a summary of key published papers.

3.1.1. Genetics

Rajab *et al.* (21) demonstrated a genetic defect, an autosomal recessive splice acceptor

mutation in DEAF1 gene in a consanguineous Omani family, in which three children were affected with autism, intellectual disability and epilepsy. Udayakumar *et al.* (22) reported the chromosomal region 7p21.1 involvement in ASD subject showing the topographies of a 7p duplication phenotype. The duplication was detected by conventional G-banded karyotype analysis/fluorescence *in situ* hybridization and confirmed by array comparative genomic hybridization (CGH). Al-Mamari *et al.* (23) investigated chromosomal copy number changes using CGH in a cohort of patients with ASD from a highly consanguineous Omani population and discovered that copy number variants is seen in 27% of the studied patient cohort. On the other hand, Al-Futaisi *et al.* (24) reported the synchronicity of ASD with Tuberous Sclerosis Complex (TSC) in three children. Patients had confirmed TSC genetic/clinical diagnosis and fulfilled the DSM-V diagnostic criteria for ASD.

3.1.2. Biochemistry

Early work by Ali *et al.* (25) using enzyme immunoassays showed that homocysteine levels were increased in Omani ASD subjects along with reduction in the folate and vitamin B₁₂ levels when compared to controls. Similarly, significantly reduced folate and vitamin B₁₂ levels were reported by Al-Farsi *et al.* (26) in Omani ASD subjects. These findings suggest that there is a need to manage the intake of essential nutrients for ASD children to overcome nutrition deficiencies in ASD. Both investigations were a case control study done in 3- to 5-year old of preschool children. Eventually, the studies point to the prominent involvement of folate and vitamin B₁₂ metabolism in Omani ASD children (27). In a follow up study with the same cohort utilizing high-performance liquid chromatography serum analysis found that these Omani ASD children (< 5 years) has low serum levels of docosahexaenoic acid (DHA, an omega-3 fatty acid that is a primary structural component of the human brain) than control children (28). Ultimately, serum tests could be used as clinical biomarkers for an early diagnosis and management of ASD. In another controlled study, Al-Farsi *et al.* (29) corroborated findings on Omani ASD children that toxic levels of heavy metals and low levels of essential minerals play a critical role in the pathogenesis of ASD. Analysis of heavy metals and essential minerals was carried out by inductively coupled plasma mass spectrometry using hair samples. Omani ASD children had significantly higher levels of heavy metal toxicity sulfur, sodium, magnesium, potassium, zinc, and iron, but depleted mineral levels of calcium and copper in their hair samples. Hodgson *et al.* (30) shown in an Omani ASD cohort that exhibits significant nutritional deficiencies in serum folate and vitamin B₁₂, elevated levels of mercury in their hair, and reduced glutathione serum levels (which is even lower in males than females) and decreased methylation capacity indicative of oxidative stress. Scientific evidence

argues that oxidative stress play an important role in disease pathology in ASD. Essa *et al.* (31) reviewed the importance of oxidative stress and tryptophan catabolism in ASD. In short, studies suggest that oxidative stress-induced mechanisms and reduced antioxidant defense, mitochondrial dysfunction, and impaired energy metabolism (NAD⁽⁺⁾, NADH, ATP, pyruvate, and lactate), are major causes of ASD. Also, neuroinflammatory mediators have been implicated in ASD pathogenesis where tryptophan degradation pathway is activated. Essa and colleagues found altered tryptophan catabolism (kynurenine pathway) along with dysfunction in glutamatergic systems in age-matched Omani ASD samples. Their study proposed that elevated quinolinic acid could be linked to 16p11.2 mutations leading to abnormal glutamatergic activity associated with ASD pathogenesis (32), which may help rationalize the efficacy of sulforaphane treatment in ASD (33). Essa *et al.* (34) observed that plasma oxidative stress indicators were altered in more Omani ASD subjects than in age-matched controls, which coincide with mitochondrial dysfunction in ASD. Specifically, high levels of nitric oxide (NO), peroxidation by products of macromolecules such as malondialdehyde (MDA), protein carbonyl, and lactate to pyruvate ratio were observed. In 2011, interesting findings were reported by Essa's group suggesting the involvement of leptin and adiponectin in age-matched Omani ASD plasma samples (31, 34). In Omani ASD children, leptin levels were elevated while adiponectin levels were reduced. Leptin, a peptide hormone mainly secreted by adipose tissue, is involved in the regulation of body weight and energy expenditure. Leptin also plays a role in regulation of neuroendocrine functions, immune system and inflammatory response. On the other hand, adiponectin is a protein produced by adipose tissue and is involved in the control of energy homeostasis. It also provides insulin sensitizing, anti-inflammatory and anti-atherogenetic properties.

3.1.3. Social and behavioral aspects

In a case-control study Al-Farsi *et al.* (35) noted the association between suboptimal breast-feeding practices and ASD in Oman. The results imply that ASD is potentially associated with the late initiation of breast-feeding, a non-intake of colostrum, pre-lacteal feeding, and bottle-feeding. They also suggested that the ASD risk tends to be reduced in a dose–response fashion over increasing periods of exclusive breast-feeding and continued breast-feeding. Al-Farsi *et al.* (18) also investigated whether socioeconomic status has a direct bearing on perceived challenges arising from available remedial and rehabilitation, utilization and perception of psychiatric services, and constraints on being a caregiver with children with ASD. The authors described the challenges of ASD caregivers in Oman, noted the absence of multidisciplinary team catering to the need of children with special needs,

and stated that the caregivers felt that there is a lack of adequate attention to resource allocation and the quality of services need to be improved. Furthermore, the authors reported that the socioeconomic burden was highly affected in the caregivers of ASD subjects in Oman with low-income caregivers suffer a disproportionate burden. Caring for children affects the mental health status of caregivers. Parents of Omani children with ASD control study the caregivers had marked levels of stress, anxiety, and depression when compared to the control group (36). A cross-sectional study was conducted to evaluate school teachers' awareness about ASD in an urban region in Oman (37). Misconceptions about ASD were found to be common among mainstream teachers in the country. Moreover, ASD knowledge was comparatively low and inconsistent between male and female teachers. The authors recommended the need for increased awareness programs amongst teachers to overcome misconceptions and negative attitudes toward children with ASD.

4. ASD AND QATAR

In December 2007, the United Nations General Assembly unanimously passed the resolution proposed by Qatar, designating April 2nd as World Autism Awareness Day (Autism Speaks at the UN, 2007). In Qatar, ASD was added as a disability category after 2012, where previously it used to be included within the intellectual disability reporting (Ministry of Development Planning and Statistics, 2016). Presently, there are no studies clarifying the current diagnostic practice of ASD in Qatar. However, most of the centers in Qatar usually use the ADI-R or ADOS as diagnostic tools, typically in tandem with the DSM-4 and DSM-5 criteria for diagnosis.

So far, no comprehensive survey has been completed for the prevalence of autism in Qatar. A study is currently underway by QBRI with the cooperation of the Cleveland Clinic and Oregon Science and Health University to find the prevalence of autism in Qatar (10). The recently published study on ASD by QBRI was designed to describe the clinical characteristics of ASD and their correlates in Qatar (38).

4.1. The Qatar National Autism Plan 2017-2021

The Qatar national plan is based on the research and proposals of six taskforces, and recommendations from autism experts from the WHO. The plan was launched in April 2017. The plan provided an overview of services for persons with ASD and highlighted constraints in care. Focused on improving the lives of persons with ASD, it had clear recommendations for the provision services for both their wellbeing and that of their families. The national plan is based around this core idea: “*Individuals on the*

Table 2. Overview of the key recommendations

Recommendation	Goal
Short-term	<ul style="list-style-type: none"> • Raise awareness • Parent support and information resources • Service development • Training and education • Expand educational options
Medium-term	Integrated pathways and guidelines Data and future service planning
Long-term	Quality monitoring Transition planning

autism spectrum have the right, now and in the future, to receive the right care and support and to have the same opportunities as their peers, within a society that accepts them.” (39).

Support for individuals with ASD should be multidisciplinary in nature. The plan addresses an array of issues, including:

- Awareness
- Early Recognition/Screening
- Diagnosis and Assessment
- Intervention
- Education
- Transition into Adolescence, Adulthood and Elderhood

A range of stakeholders has been involved in the development of the plan and therefore they will play a vital role in ensuring the recommendations are implemented. Key recommendations are executed at intervals. The timing of the deliverables will be dependent on the availability of resources of responsible stakeholders. Summary of goals is presented in Table 2 below.

4.2. Social robotic

A pioneering work is taking place at Qatar University in the area of social robotics “Humanoid Robots for Children with ASD”. Socially assistive robotics is aimed at addressing the gaps in care given to humans by providing assistance in the form of social interaction (40). We elaborate on the utility and value of social robotics below.

4.2.1. Diagnosis and therapy

The use of social robots offers quantification methods free of observer bias. They are capable of detecting, measuring and responding to social behaviors. Unlike with humans, they allow for the design of repeatable interactions with subjects, in order to quantify social responses effectively. Robots used for autistic children have been shown to have made tremendous amount of difference in 4 different

areas of therapy. Specifically, social learning, imitation skills, communication and interaction with society. The humanoid robots, being similar to a human, showed better results than other robots. The use of humanoid robots presents a unique opportunity for early diagnosis, screening and early intervention particularly in a cultural context (40).

4.2.2. Social and cultural context

Arbitrarily adopted western ASD practices negate cultural context. This is especially relevant to therapy and intervention practices for ASD, which are largely child-specific in nature and can have their efficacy affected by minute details. Therefore, in such cases, including culturally relevant features in therapy practices can potentially improve results. Robots generate a high degree of motivation and engagement in subjects including those who are unwilling to interact socially with human therapists. This may be attributed to the fact that interactive robots can be programmed to exhibit exactly the right amount of social behavior, best suited to the subject. Culturally relevant interactions also present us with the opportunity to further our understanding of ASD, and evaluate just how deep-rooted the impact of culture can be on the behavior of a child with autism. Using culturally adaptive robots for ASD therapy is truly a unique idea with potential to play a transformative role for children with ASD (40).

4.3. Research on Qatari people with ASD

There is a paucity of studies on ASD in Qatar; mostly investigations are either in the form of clinical case reports and studies on genetic causes or quality of life of caregivers (10). A recently published study was designed to describe the clinical characteristics of ASD and their correlates in Qatar (38). The aim of the investigation was to describe cases within one of the country’s largest special needs centers in Qatar, the Shafallah Center for Children with Special Needs, which is a government-supported institute that accepts both citizens and expatriates. Recruited individuals from the Shafallah Center were evaluated for ASD clinical profiles and their correlates. Within the sample of 171 individuals with ASD, 47% were

ethnic Qataris, while 53% were non-Qataris (Arabs and other nationalities). The clinical study analysis included the following factors: nationality, age, gender, socioeconomic status, consanguinity, prenatal/postnatal complications, and comorbidities.

The clinical investigation results revealed that about 80% of the identified cases were male, with a 4:1 male to female ratio. Additionally, 83% of the families had one proband, 9.9% with 2 probands, and 7.1% with more than two. Co-morbid conditions included: intellectual disabilities (ID) in 83% of cases and epilepsy in 18.8%. About 76.6% of subjects were nonverbal. There were 3 (1.8%) children with Rett's syndrome, 3 (1.8%) with Fragile X syndrome, and 1 (0.6%) with tuberous sclerosis. There are currently no publications that clarify the mean age of diagnosis in Qatar, however, the present study showed that more than half of the diagnosed cases were among the ages of 7–14 years (56%).

The enrolment of subjects from the Shafallah Center is thought to yield a representative sample of ASD in Qatar. However, the sample under discussion may not be representative of the broader population in Qatar due to the fact that most of the cases referred to Shafallah Center are older than 5 years of age (only 4 cases were 0–4 years of age). The male to female ratio is similar to other reports in the literature (4:1). Additionally, most of the cases with high functioning ASD attend mainstream schools.

Interestingly, relevant to the discussion, the clinical sample included the age groups 15-19 (28.6%) and >20 (12.2%). In other words, young adults represent approx. 41% of the sample size. Almost half of the samples studied were ethnic Qataris, which is not reflective of the fact that out of the estimated 2.7 million people living in Qatar, only ~ 12% are citizens. Further studies are needed to evaluate whether the prevalence in Qatar is proportionally higher than Western countries.

4.3.1. WISH engagement

The World Innovation Summit for Health (WISH), an initiative of the Qatar Foundation for Education, Science and Community Development (QF for short), brings together a community of policymakers and healthcare leaders to help solve the most urgent global health challenges while capturing and disseminating the best evidence-based ideas. Generally, WISH convenes a summit every two years on various topics highlighting key areas for research and collaboration, including autism spectrum disorder (ASD).

With regards to ASD, WISH organized in Doha, Qatar the “WISH Autism Forum 2016”, chaired by Kerim M Munir, Director of Psychiatry, University

Center for Excellence in Developmental Disabilities, Division of Developmental Medicine, Boston Children's Hospital and Society Fellow & Associate Professor of Psychiatry & Pediatrics, Harvard Medical School, and produced “*Autism: A Global Framework for Action*” report (16). Later, WISH was present as a leading panelist during World Innovation Summit for Education (WISE) - WISE Panel 2017 (41). In the WISE meeting a report on autism led by Karen Guldberg from University of Birmingham was published “*Meeting the Needs of Pupils with Autism in Qatar: Moving Forward*” (42).

WISH has been active in advancing the ASD agenda in Qatar. To address ASD in a comprehensive way, the WISH Autism Forum Framework presents five pillars predicated on a foundation of health, education and social services (Figure 1) that leads to improved outcomes for economies, society and individuals living with ASD. The five primary themes to consider are the following:

- Increase awareness and rates of early diagnosis
- Provide evidence-based therapies and delivery of services
- Implement family support systems
- Support access to public education, vocational training and assisted employment
- Participate in high-quality research and surveillance

The report presentation outlines key issues in understanding the ASD journey captured in Figure 2 and the need to tackle the burden globally. The report presents goals, challenges and describes opportunities for action. It looks at solutions that are currently available and makes three key recommendations to policymakers to coordinate ASD response (16).

The policy recommendations described in this report aim to achieve improved outcomes for individuals living with ASD, for economies struggling to pay for the cost of care and for society at large, facing the increasing prevalence and burden of ASD. The following recommendations are directed at policymakers, outlining what can be done today to decrease the present and future burden caused by ASD.

- Create an interagency coordinating commission to address ASD nationally
- Launch interdisciplinary training and research centers for excellence in ASD and neurodevelopmental disorders across the lifespan
- Establish a global partnership framework to address ASD and neurodevelopmental disorders across the lifespan

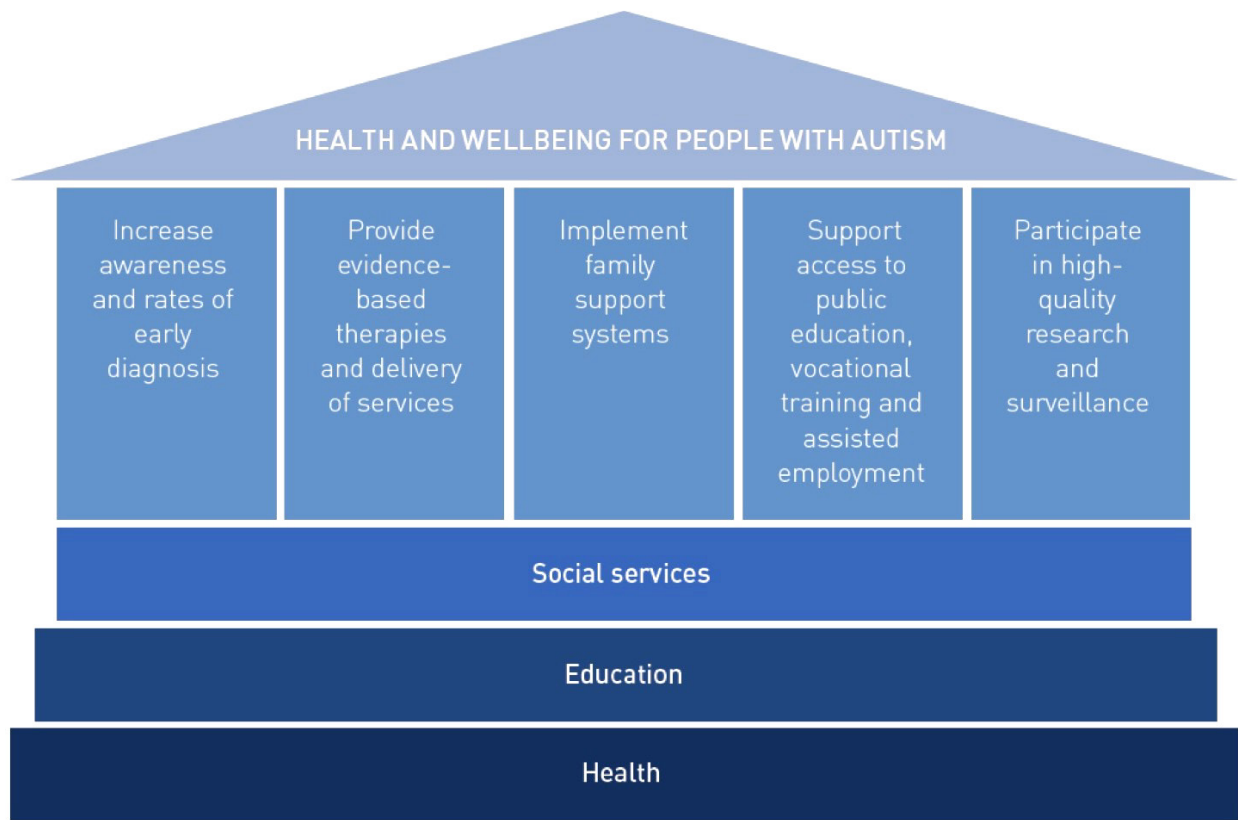


Figure 1. ASD framework foundation and pillars. A pyramid for health and wellbeing for people with autism.

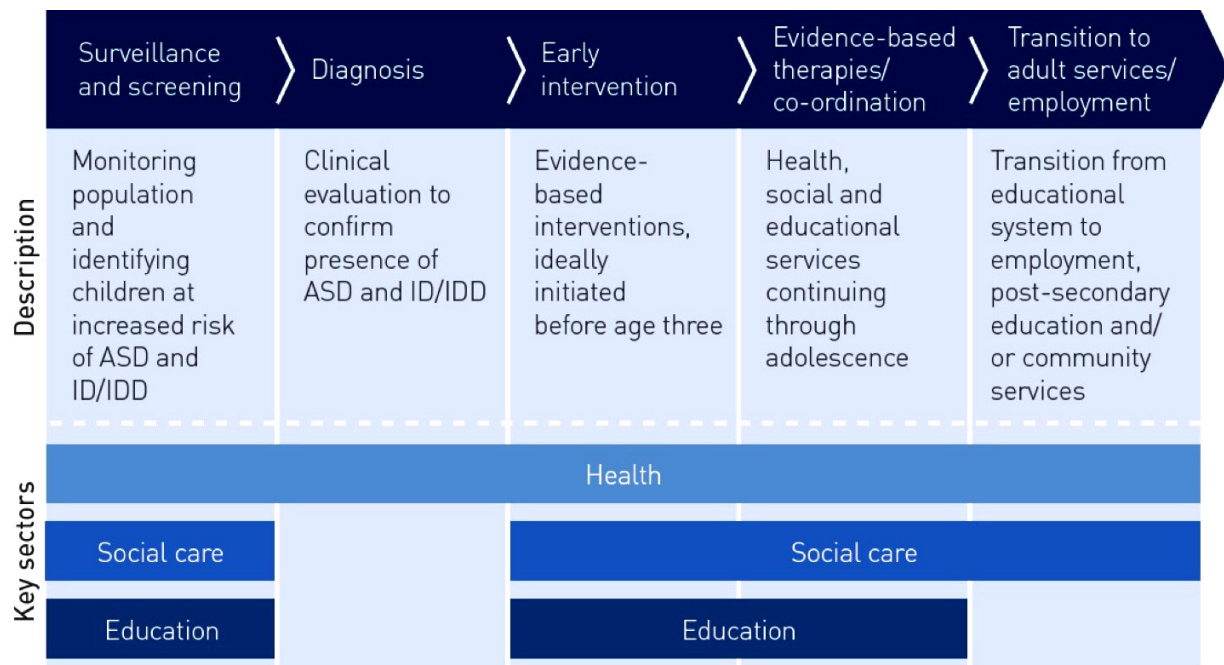


Figure 2. ASD pipeline and three sectors involvement. Modified from reference (43).

4.3.2. WISE report

Recently, WISE commissioned a research report that is both contextual and empirical in nature to address how to strengthen the education pillar of the Qatar National Autism Plan (NAP) 2017-2021, given the importance of the role of education in social inclusion and quality of life for autistic people and their families. Three overarching themes emerged from this research, as indicated below, with clear policy recommendations (42).

- Awareness, Knowledge and Understanding
- Policy, Provision and Practice
- Personal and Professional Development

These themes align well with the aspirations outlined in the Qatar's NAP 2017-2021 and with the themes identified in the WISH 2016 report.

5. THE PATH FORWARD REGIONALLY

The WISH ASD forum and WISE report served to foster an increased awareness of the public health challenges posed by ASD in the region and to support development of an ASD response through policy and social innovation. It also served to highlight the good progress made in ASD planning and service delivery within the region, in particular providing a platform for information exchange on national and regional initiatives, ideas and strategies such as best practices regarding ASD (16, 42).

There is a critical need to strengthen national capacities in caring for children, young people and adults with ASD and other neurodevelopmental disorders. To accomplish this objective, policymakers should address a variety of areas. The following were identified as next steps to move the ASD agenda forward within the region as well as globally:

- Personal and professional development;
- Increase awareness, knowledge and understanding of ASD;
- Encourage early detection and diagnosis, allowing children to access services as early as possible;
- Ensure that children with ASD have access to evidence-based therapies by providing additional training to parents, teachers and clinicians around the most effective interventions;
- Provide those with ASD and neurodevelopmental disorders access to public education, with the goal of inclusion;
- Ensure that families of those with ASD and neurodevelopmental disorders have the appropriate support and information to care for their family members; and

- Foster participation in high-quality research and health surveillance to obtain a full and accurate picture of the challenges we face in treating ASD and neurodevelopmental disorders.

Here, we offer three key recommendations for regional policymakers to coordinate the response to ASD and other neurodevelopmental disorders. While specific initiatives will differ in countries and regions, we believe that these recommendations will promote collaboration between disciplines and encourage global partnerships regionally and between nations.

- Create an interagency coordinating commission to address ASD nationally
- Launch interdisciplinary training and research centers for excellence in ASD and neurodevelopmental disorders across the lifespan
- Establish a global/regional partnership framework to address ASD and neurodevelopmental disorders across the lifespan of people with ASD

6. PUBLIC OUTREACH AND AWARENESS

Public awareness and education are key to ASD communication. It is important to inform, sensitize and draw the attention of the public to enhance awareness of ASD societal issues and value of research (e.g., exhibitions, seminars, brochures, posters and videos). Equally important is to educate the public to impart knowledge and know-how (conferences, workshops, group discussions, training and courses). Community involvement and engagement brings collaborative groups to address issues that impact the well-being of these groups and provides the power to bring positive, measurable change to achieve long-term and sustainable outcomes, processes, relationships, discourse, decision-making, or implementation.

Oman. Within the context of Oman, Oman Autism Society (OAS), a charity organization established in February 2014 acts as the pioneer center to provide awareness and support to community. There are various types of activities conducted by the center including entertainment, parents' training, autistic's training, and awareness, to mention but a few. One of the recreational activities includes a program in cooperation with Marah Land in Al Qurum Natural Park, Muscat with free games for the autistic children and their families that was held in March 2016. In addition, a delegation from the May Institute National Autism Center (Randolph, MA), in cooperation with the Ministries of Health and Social Development in Oman, visited the OAS in May 2017 with the aim to develop the services that would help rehabilitate people with autism. The organization is one of the largest and most well

respected providers of services and special education schools for children and adults with autism and other special needs in Massachusetts and in the U.S. It has a set of standards for effective, research-validated educational and behavioral interventions for children on the spectrum. OAS provides training support for specialists and teachers in the education sectors. In addition, there is special training for parents of children with ASD in order to apply care programs at home. Regarding the awareness programs, so far, there have been two public outreach meetings held in 2017 in order to provide awareness to the communities (19).

Qatar. In the spirit of public outreach and education, WISH organized in 2017 an interactive public event at Education City a summer community program for children with autism to address the challenges faced by Qatari families of children with ASD, benefiting children from the Qatar Autism Families Association (QAFA). A six-week swimming program was the first time WISH and QF Recreation Services had collaborated on such a community program. The horse-riding program ran for three weeks with the support of the Equine Education division at Al Shaqab with children enjoying the chance to improve their motor and balance skills, as well as experience the sensory and emotional benefits that come from riding a horse.

Recently, in October 2017 WISH collaborated with the LFC Foundation, the official charity of Liverpool Football Club (LFC), to host a week-long football training course that addressed effective ways for people working in sport in Qatar to engage with children who have autism, or sensory or physical impairments. The training program, titled *'Respect 4 All, Qatar'* took place at Education City, Doha. It focused on giving sports coaches targeted practical training in helping children with autism reach their potential, socialize, and pursue a healthy lifestyle through participation in football-related activities. The course included both classroom sessions and practical outdoor workshops, the latter of which saw coaches work directly with local children who have autism. The sessions discussed topics such as the evolution of working practices and language, how people with additional needs engage in sport, and best practice. The training culminated in a festival day that brought together the participating coaches and children for a range of fun activities alongside coaches from LFC Foundation.

7. CONCLUSION

Research into ASD is new in the Arab world and most of the research attention is related to etiology. ASD prevalence studies conducted within Arab countries have yielded varied country-wide estimates; prevalence in the MENA region has not been determined accurately. ASD epidemiological

research in the Gulf States is relatively new as well, and the actual burden of ASD in the GCC similarly is still unclear. GCC ASD data analysis indicated that the prevalence rate range from 1.4 to 60 per 10,000 children. To date, not only is there little to no research documented in the Arab world on the prevalence of ASD, but also the services provided and support given to families, treatment outcomes, or the economic costs incurred. More revealing, ASD public health studies with an emphasis on young adults is completely lacking in the Arab world. Under-diagnosis and underreporting are attributed to the limited availability of quality specialized healthcare services for children with neuro-developmental disorders. Some of the under-reporting can be also attributed to cultural attitudes regarding disability, due to the stigma attached to most neurodevelopmental disorders. The shortage of specialists to diagnose ASD properly and the lack of parents' awareness to reorganize symptoms and seek diagnostic clarification are also contributing factors. In this perspective, we provided a Gulf region centric view on ASD with special focus on Qatar and Oman including review of seminal Qatari/Omani work from the literature. In addition, we offered a summary and direct excerpts from the WISH and WISE autism reports as well as outlined some of the main challenges, best practices and a path forward for the Gulf region from a healthcare perspective. Finally, we highlighted the role of public outreach and awareness to lay the groundwork for enlightened policy for intervention and resource allocation to care for ASD individuals.

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