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Qatar and Autism

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Historical Background

Similar to most countries within the region, autism spectrum disorder (ASD) awareness and programming in Qatar have been changing rapidly throughout the past years. Despite ASD being recognized by medical professionals and cases are detected at an estimated similar rate to international trends, ASD was not documented as a separate disability category in Qatar's national statistics until 2012 (Ministry of Development Planning and Statistics 2013). Nonetheless, the country's leadership has shown special interest in ASD as there is a recognition of its growing prevalence and the need to provide services for the affected individuals and their families. Hence, on April 2, 2008, Qatar officially joined the United Nations in announcing April 2 as the world's "Autism Awareness Day"; an event which was proposed to the UN by Her Highness Sheikha Moza Bint Nasser (United Nations Meetings Coverage and Press Releases 2008). Yet, ASD and general special needs services were operational years before this event. In fact, the history of ASD services and policy developments in Qatar

are all linked back to initiatives launched by HH Sheikha Moza Bint Nasser.

The first unit designated to serve children, adults, and elderly with special needs was opened in 1982 at the country's main healthcare provider: Hamad Medical Corporation (HMC) – Rumailah Hospital. However, the buildings and organizational structure changed rapidly until 2012, when the Child Development Center was opened to provide services for children with different disabilities including ASD. Children with ASD (3–6 years) started receiving early intervention by the multidisciplinary team of professionals within the Autism Program: assessment, diagnosis, and early intervention.

In 1999, a significant development in Qatar for ASD service provision was the establishment of the Shafallah Center for Children with Disabilities (formerly known as the Shafallah Center for Children with Special Needs). It was established under the guidance of HH Sheikha Moza Bint Nasser to meet the increasing demands for services to children with special needs. The Shafallah Center is currently servicing a large number of individuals with ASD in the country. Most recently, in 2016, Qatar Foundation opened the "Renad Academy" to join in the venture of providing services to children with ASD and their families. Many private centers' programs have also been developed during these years to meet the increasing demands. These centers are all licensed by the ministry of Public Health and the Ministry of Education.

Programs to assist in transitioning children with ASD into mainstream education were not functional until the Additional Educational Support Needs (AESN) policy was passed by the Ministry of Education (formerly known as the Supreme Education Council) in June of 2009 (Supreme Education Council 2009). To support and enhance the process of academic and social inclusion, the Ministry of Education also established the Evaluation Institute in 2009. This institute started offering individual student evaluations to serve the needs of diverse learners, including children with ASD who are attending mainstream schools. To further support this process of inclusion, Qatar Assistive Technology Center (known as “MADA”), a nonprofit organization was established in 2010 by the Ministry of Information and Communication Technology to provide assistive technology support to children, adults, and families of individuals with special needs.

“Best Buddies – Qatar chapter” was founded in 2007 under the umbrella of the Shafallah center. It is a nonprofit organization dedicated to enhancing the lives of individuals with intellectual disabilities by providing opportunities for one-to-one friendships and integrated employment. This organization is another example of the inclusion movement and change in societal attitudes and perspectives towards individuals with disabilities.

Legal Issues, Mandates for Service

In Qatar, Autism was not reported as a separate disability category until 2012, as it used to be reported within the intellectual disability classification (Ministry of Development Planning and Statistics 2013). In 2004, the first law that regulates the rights of persons with disabilities was issued (Law No. 2) (Qatar Legal Portal 2004). The 14 articles within this law reinforced the social view of disabilities and paved the way for the succeeding mandates in the years to follow. Rights of persons with disabilities are also included in the sustainable development plan which is part of Qatar National Vision 2030

(General Secretariat for Development Planning 2008).

ASD in Qatar has affected families from all ethnic backgrounds and different socioeconomic status; it became a disability that has increasing awareness and concern in Qatar and the region. As mentioned previously, in 2007, Qatar joined the UN member states in marking April 2 as the world’s “Autism Awareness Day.” This event came in conjunction with increased involvement of Qatari authorities to expand healthcare and social services provision to those affected with ASD. In 2007, the social security act provided monthly benefits to persons with disabilities which included a monthly cash allowance for domestic help (Committee on the Rights of Persons with Disabilities 2015). In 2008, Qatar ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and adopted all the rights contained within this convention by April 2015 (Committee on the Rights of Persons with Disabilities 2015).

On the educational and health care level, the country continues to make more government-funded services available for both nationals (Qataris) and expatriates (other nationalities). This includes evaluation clinics to diagnose and assess children with special needs that comes in line with the country’s decision on inclusion of children with disabilities into the public school system, through either full or partial integration.

In terms of ASD specifically, it has been recognized within the health, education, and labor sectors. Thus, individuals with ASD are protected by the local and international laws on the rights of individuals with special needs. Autism remains as a separate category in the mandates of the Ministry of Education, and the support system specified involves individualized planning tailored to each students’ abilities and areas of need. In line with this, every independent (government-funded) school in the country includes a department for students with special needs and has support staff who have the necessary qualifications to support the student’s learning on a daily basis.

At the postsecondary educational level, Qatar University established a center known as the “Inclusion and Special Needs Support Center,”

to ensure that the proper accommodations are provided based on each student's needs to succeed and fully participate in all aspects of university life.

In 2016, the World Innovation Summit for Health (WISH) issued a report on Autism with recommendations for improvement of service provision internationally (Munir et al. 2016). In 2017, the National Autism Plan was launched in collaboration with the World Health Organization (WHO). The working group included stakeholders from around the country. This group was charged with creating a National Autism Plan based on six pillars: awareness, early recognition and screening, diagnosis and assessment, interventions, school services, and transition to adulthood. Lastly, a report is currently being developed by the World Innovation Summit for Education (WISE) and is going to be presented in December 2017. The WISE report will have reviewed ASD services provision in Qatar.

Through this brief review of the trends in Qatar's legal recognition and support service provision for ASD, it demonstrates a continuing strive to improve the lives of individuals affected with ASD.

Overview of Current Treatments and Centers

The current ASD programs in Qatar include:

- Diagnostic services:

The diagnostic services usually involve a multidisciplinary team of professionals that includes a developmental pediatrician, child psychiatrist, psychologist, and other relevant specialists. The main diagnostic tools used are the DSM-5 criteria, ADOS-2, and ADI-R, in addition to the use of the main ASD screening tools such as the Red Flags Checklist (RFC) in well-baby clinics which is recommended by the Ministry of Public Health, M-CHAT, SCQ (which has been translated into Arabic language and validated by a research team in Qatar (Alshaban et al. 2015)),

and others. ASD diagnostic services are available mainly at Rumailah Hospital, HMC's Behavioral Clinic, Shafallah Center for Children with Disabilities, and Sidra Medical and Research Center.

- Intervention services which include:
 - Child and family medical and social support services
 - Multidisciplinary early intervention services
 - Family training and counseling
 - Mainstream education inclusion support
 - Transition planning; independent living and employment services

These intervention services are offered at a public and private sector basis. The first government-funded and the country's largest center servicing more than 150 individuals with ASD is the Shafallah Center for Children with Disabilities. Meanwhile, early intervention programs for ASD are mainly offered by Rumailah Hospital as well as some other private centers such as the Child Development Center which provide a comprehensive multidisciplinary early intervention programs that include; behavioral, speech, occupational, and physical therapy, and other relevant services. Recently, Qatar Foundation has joined this venture with the opening of Renad Academy. All of the intervention service providing center foster a curriculum based on evidence-based practices. These practices include Applied Behavior Analysis, Pivotal Response Training, Verbal Behavior, Discrete Trial Training, Treatment and Education of Autistic and Communication related handicapped Children (TEACCH), etc.

The Shafallah Center for Children with Disabilities is the only center offering services from early intervention to employment and independent living training. The Ministry of Education also provides curriculums and programs consisting of 2-year preparation, and then a 6-year vocational training. It also provides 4 years of vocational qualification training such as "carpentry, book binding, painting, agriculture, and poetry for boys; sewing, embroidery, and home economics for girls" (Ministry of Education

2007). All of the public and private programs offered are conducted by a multidisciplinary team of professionals that require the licensing of the Ministry of Public Health and the Ministry of Education.

The National Autism Plan (2017–2021) includes 44 recommendations to be implemented by 2021. It contains some short-term targets which should be applied within the first year of the plan. It aims at improving the quality of the offered services and continues the development of care, education, and community participation. These initiatives will further enhance the quality of the present services and align all services with Universal Best Practices for ASD intervention programming and education in Qatar.

Overview of Research Directions

Despite minimal publications about ASD in Qatar, it has been increasing in the past few years. To date, ASD research included investigations about: the quality of life of caregivers (Kheir et al. 2012), social robotics for ASD (Qatar University 2016), clinical case reports (Al-Sarraj et al. 2014; Ahram et al. 2017), and an overview of Autism and Applied Behavior Analysis in the GCC (Kelly et al. 2016). Most recently, QBRI published the first paper about clinical characteristics of ASD in Qatar with factors including consanguinity, gender, socioeconomic status, comorbidities, etc. The study was titled “ASD in Qatar: Profiles and Correlates of a Large Clinical Sample” which described the clinical characteristics of ASD for 171 cases enrolled in Shafallah Center (Alshaban et al. 2017). Moreover, there is currently a country-wide prevalence study which started in 2013 and is also being conducted by QBRI. This research, which is in its concluding phase, involves the collection of data about all diagnosed cases from 2013 to 2017, as well as screening more than 100 mainstream primary schools in Qatar (both public and private schools). The screening process included using the Arabic translated Social Communication Questionnaire (SCQ) in detecting cases of ASD. Those who scored above the cutoff were invited for

assessment to confirm or exclude the ASD diagnosis through using clinical observation, DSM-5 criteria, and ADOS-2 diagnostic tools. Moreover, QBRI is also planning a research project in collaboration with Cleveland Clinic (USA) and Autism Speaks, to validate the use of eye tracking technology as an objective tool for the early diagnosis of ASD. This is considered as an ambitious and pioneering project for Qatar and the region.

Furthermore, an Autism Genetic Research Program in Qatar started in 2007 through joining the Autism Genome Project; an International Consortium for Autism Genetic research. The Shafallah Medical Genetics Center (now part of QBRI) took the lead with more than 160 families participating in that project. QBRI continues to lead the Autism genetic research program together with Sidra Medical and Research Center, in collaboration with other Qatari and International institutions. QBRI scientists will be undertaking another QNRF funded research project titled “Defining the Epigenetic and Environmental Etiology of Autism Spectrum Disorder” QBRI Autism research team will also be investigating the effect of Hyperbaric Oxygen Therapy on a representative sample of children with ASD in Qatar. Moreover, the research team will also investigate the clinical characteristics of all ASD cases diagnosed through the ongoing prevalence project, examining the effect of parental age as a risk factor in ASD prevalence. In addition, QBRI Autism research team plan to evaluate the quality of ASD services in Qatar.

Overview of Training

Professional training for individuals working with children with ASD in Qatar occurs at different levels; postsecondary training, ongoing professional training, and training workshops, conferences, and symposiums by both the public and private stakeholders. Regarding postsecondary training, Qatar University’s college of education offers three programs: Bachelor, Diploma, and Master programs in Special Education. The programs have US accreditation, and the curriculum ensures that graduates leave with knowledge

about the best universal practices in ASD intervention. These programs include mandatory supervised field training.

Ongoing training of teachers and specialists is offered by two entities; the Evaluation Institute (known as Ro'a center) and the National Center for Educator Development (NCED) at Qatar University. These institutions provide training workshops as well as ongoing support through field visits to the mainstream schools.

Recently, QBRI organized ADOS-2 and ADI-R training course for healthcare professionals in association with Beginning with Autism Consultancy and Training group, UK; a total of 24 professionals from the Shafallah Center, Rumailah Hospital, QBRI, and Al Tamakun school were trained and licensed in administering the ADOS-2 and ADI-R diagnostic tools.

Lastly, training conferences, symposiums, and workshops take place throughout the year by different organizations and centers. These training events are offered either free of charge, or for a cost accompanied with Professional Development (PD) hours or Continuing Medical Education (CME) hours. The target audience is usually professionals, healthcare providers, and families. Some centers, such as the Child Development Center (a private center offering early intervention services for children with ASD and other developmental delays), hosts an annual training symposium targeting professionals and families. Meanwhile, HMC, Sidra Medical and Research Center, QBRI, and other private centers have training workshops throughout the year, to raise awareness and knowledge about ASD and other related disabilities.

Social Policy and Current Controversies

ASD awareness is evidently higher within the Qatari society. With the government's support for outreach events, the impact is noticeable during each annual Autism Awareness Month of April, as more organizations take the initiative, come together to raise awareness and collaborate to offer different activities for individuals with ASD and their families. Moreover, local nonprofit

organizations, such as Qatar Autism Families Association (QAFA) and the Qatar Autism Society, are examples of social movements that serve as a unified voice of the families' demands and offer ongoing community support. Past and current debates about ASD continue regarding the need for the increase in the provision of diagnostic and intervention services. Nonetheless, the government's efforts continue to expand ASD services provision to accommodate the increasing number of diagnosed cases. Meanwhile, some of the private centers compete to provide quality services at a high cost that some families cannot afford. Debates also revolve around the need for more educators and other specialists to successfully include students with ASD and other disabilities into the mainstream schools. Some families seek to hire a private therapist, tutor, or instructional assistant (shadow teacher) to help in the provision of certain needed services. Support in transitioning individuals with ASD through "education to employment to independent living" is a process which has been improving with the existing services offered by the Adult Training Unit in Shafallah Center, Ro'a Center (Evaluation Institute), and the Inclusion and Special Needs Support Center at Qatar University. However, the center at Qatar University is only equipped with staff and resources to serve specific physical and learning disabilities, and ASD is not listed as one of the disabilities that the center can provide services for. Moreover, the Adult Training Unit at Shafallah Center cannot cope with the needed transition services for all ASD cases within Qatar.

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