

Services and Supports for Individuals with Autism Spectrum Disorders in the Kingdom of Saudi Arabia

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Abstract

This paper reviews the services and supports that are available to individuals with Autism Spectrum Disorder (ASD) in the Kingdom of Saudi Arabia (KSA). The review focuses on the diagnostic process, early intervention and educational services, family collaboration/parental involvement, instructional practices, and research-based practices. Based on this review, there is need for more research in this area in order to increase awareness regarding ASD and promote better services and rehabilitation programs for people with ASD in the KSA. In addition, it is recommended that general education teachers should take special education courses in their preparation programs so that they can effectively support students with ASD in the inclusive education environment.

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Introduction

Autism Spectrum Disorder (ASD) is a developmental disorder characterized by significant deficits in social interaction, speech and nonverbal communication, stereotyped behavior, and restricted interests as well as unique strengths and differences (Alqahtani, 2012; Amr et al., 2012; Autism Speaks, 2017). ASD is a worldwide disorder, which does not discriminate based on social status or ethnicity (Kopetz & Endowed, 2012). The term “spectrum” reveals a wide variation in challenges and strengths displayed by each person with ASD. ASD symptoms typically appear between two and three years of age, but can be diagnosed as early as 18 months (Autism Speaks, 2017). Worldwide, the population of individuals with ASD has grown by approximately 67 million people in the last decade (Kopetz & Endowed, 2012).

While exact statistical data reporting the number of students with ASD is not available, anecdotal reports indicate an increase in the prevalence of ASD in the Kingdom of Saudi Arabia (KSA) (AL-Salehi & Al-Hifthy, 2009; Eid et al., 2017). Babatin, Alzahrani, Jan, Alkarimi, and Jan (2016) reported that there were 57,110 children with ASD younger than 16 years old in Saudi Arabia giving an estimated prevalence of 0.6% with a boys to girls ratio of 1:2 (Babatin et al., 2016). Given the lack of reliable information and research about ASD in the KSA, this current paper looks at the services and supports available for individuals with ASD in the country. Specifically, the paper looks at the process of diagnosis, early intervention, and educational

services. Doing so may help the authorities to take stoke of the experiences of children with ASD in the country. Also, in order to improve services and support for individuals with ASD, it is important to first review the services and support that are provided to those individuals and their families in this area (Babatin et al., 2016).

The “KSA occupies most of the Arabian Peninsula and holds the world’s sand desert and is the place of the two holiest cities of Islam: Makkah, and Madinah” (Alqahtani, 2012, p. 16). The population of the KSA is about 30.7 million people and is increasing at an annual rate of five percent (Eid et al., 2017). More than half of the population are below the age of 20 years (Alquraini, 2011). Saudi citizens derive their values from the holy book Qur’an and the tradition of their Prophet Muhammad. The values command Muslims to respect people with disabilities, as well as their families. Generally, disability is viewed in Islam as a test from God to society as a whole (Alquraini, 2011). The person with disabilities is faced with the test to show patience, while everyone else is to show support. Thus, taking care of people with disabilities is considered to be a religious obligation before it is a social issue (Alquraini, 2011).

The Saudi government has allocated more than 25% of their annual budget to the country’s educational system, which includes programs that serve people with different types of disabilities (Almousa, 2010). The government attempts to provide children with disabilities with suitable facilities in order to include them in general educational settings as well as to promote their independence. According to Alnemary, Aldhalaan, Simon-Cereijido and Alnemary (2016), due to the increasing number of people diagnosed with ASD in the KSA there is urgent need to promote awareness as well as equip and educate parents, teachers, and professionals about the disorder (Alnemary, Aldhalaan, Simon-Cereijido & Alnemary, 2016). Focusing on early diagnosis of, and intervention for, ASD is vital.

Process of Diagnosis

There are many organizations for people with ASD in the KSA such as Saudi Autistic Society (SAS) located in the capital city of Riyadh, with two branches located in Jeddah in the western region and Dammam in the eastern region (Saudi Autistic Society, 2014). SAS has established a new summer program for adults with ASD and provided training in computer and other technical skills. However, there are limited opportunities for training within the program before the onset of summer vacation (Hussein & Taha, 2013). In addition, the services that SAS provides include the development and intensifying of comprehensive services and the coordination between governmental and charitable institutions for individuals with autism and their families’ needs to create an information database regarding all types of autism and existing centers of support.

Although Almasoud (2010) stated that there were no diagnostic services for ASD for children from birth to age three years, Alqahtani (2012) reported that parents in the KSA started visiting pediatricians to get their children diagnosed when the children were between 17 months to seven years old. Additionally, due to lack of knowledge and experience among professionals in the KSA, they may misdiagnose children with disabilities (Alqahtani, 2012). Further evaluation could be conducted in some private clinics, but it costs the families a great deal of money because health insurance does not cover such exams and services (Alqahtani, 2012). According to Al-Mulhim (Al-Mulhim, 2014, May 18), many Saudi families pulled out their children from

Saudi centers and transferred them to Dubai centers due to lack of services in the Saudi centers. Although the KSA had established many centers for students with ASD, they lacked some of the appropriate diagnostic, rehabilitation, and necessary treatments (Babatin et al., 2016). In addition, the centers for children with autism failed to diagnose children with ASD because of the unclear process for diagnosis. Furthermore, there was no clear methodology for how to classify students with ASD (Babatin et al., 2016). Many institutions even lacked the trained professionals needed to diagnose, treat, and rehabilitate individuals with ASD (Babatin et al., 2016). The lack of diagnostic services in the country's more rural districts created a diagnostic situation in which families had to travel to other countries in search of diagnostic services and trained professionals.

Early Intervention and Education Services

In the KSA, the accessibility of early intervention services is limited to the main cities of Riyadh, Jeddah, and Al-Dammam, and most services are provided by private organizations (Almasoud, 2010a). This adds a financial burden to families while not meeting the rising demand for their services (Almasoud, 2010a). Babatin et al. (2016) documented significant shortages of autism services and limited accessibility of services.

Early intervention starts after the age of three years in the KSA. With the exception of very few schools that provide services for students with ASD or other disabilities and charge for the services, kindergarten and preschool educational services are not available in the public school system in the country. In addition, schools in the KSA are incapable of including students with ASD because of lack of technology and other educational materials and resources (Al-Masoud, 2010). The KSA's educational system covers the following disabilities: cognitive disability, learning disabilities, autism, multiple disability, deafness, blindness, gifted, physical and health disability, emotional disorder, and communication disorder (Alquraini, 2013). According to Alnahdi (2014), there are limited institutes and classes that provide services and support for individuals with ASD. Table 1 indicates the numbers of institutes and classes where both males and females with ASD receive an educational services and support.

Table 1
Numbers of Autism Programs and Institutes by Gender

	Male	Female	Total
Institutes	40	19	59
Classes (in regular schools)	135	61	196

Source: Alnahdi (2014)

Family Supports

According to Alqahtani (2012) it is common for parents of a child with ASD in the KSA to not have proper knowledge regarding ASD. Many parents believe that as long as their children are physically fit, there is nothing for which to be concerned about (Alqahtani, 2012). Unfortunately, after the diagnosis of their children with ASD, the parents start asking many questions to which they rarely get proper and formative answers (Alqahtani, 2012). With lack of resources and

proper information about ASD, the parents resort to unproven methods and ways of treatment (Alqahtani, 2012). In addition, religion and culture have an impact on the type of treatment that is used (Alqahtani, 2012).

In the KSA services are provided in the main cities of Riyadh, Jeddah, and Al-Dammam (Almasoud, 2010). In addition, although there are some private centers for people with ASD, the total number is still small (2010). These centers fail to meet the needs of families who have children with ASD, and this failure is more obvious in areas outside of the major cities. The main focus of these centers is for the professionals to create home integrated programs, followed by the shifting of the burden of teaching and training to the shoulders of families. In terms of financial support, the government of the KSA, through the Ministry of Social Affairs, has allocated a sum of money provided to the families of those with severe disabilities. In addition, the government offers some free auxiliary equipment such as power wheelchairs as a type of financial support (King Salman Center for Disability Research, 2000).

The way services are provided to the families of individuals with ASD is via centers of autism and these centers are scarce and barely meet the families' needs (Babatin et al., 2016). As such, there are many individuals with ASD who do not receive the minimal level of service, including diagnosis (Alqahtani, 2012). Such centers also lack highly qualified staff, doctors, and other professionals. In addition, most of the higher education institutes neither contribute nor support programs for families regarding ASD. Thus, this impacts the quality of life for children with ASD. Furthermore, even though the KSA offers families who have children with ASD financial support, and this support seems to be relatively accessible, the amount and type of services vary from family to family (Al-Mulhim, 2014, May 18) While annual budgets should be directed towards individuals with severe ASD, these funds are not even meeting their basic needs including costs of treatment, traveling to and from centers, and purchasing the necessary materials (Al-Mulhim, 2014, May 18). Finally, in the KSA, individuals with ASD and their families should be granted access, with appropriate accommodations, to public places like parking places and park areas. In the KSA, these services are not available in most parts of the country due to lack of awareness from policy makers within The Ministry of Municipal and Rural Affairs (Almasoud, 2010).

Instructional Practices and Research-based Pedagogy

In terms of instructional practices in the KSA, as Almasoud (2010) reported, the field of special education only begun recently; consequently, students with ASD are still excluded from public schools, and students with high functioning autism are at a high risk of being undiagnosed due to the untrained teachers in the public schools. However, there are a few private specialist centers that provide professional services in treating students with ASD. The specialists who work in these centers have rich experiences in the field of autism that allow them to work effectively with both children and their parents from onset to intervention through adulthood. The approaches and interventions that they use to support children with ASD are useful in terms of teaching and educating students. For instance, the division (TEACCH) Treatment and Education of Autistic and Related Communication Handicapped Children provides private centers for use as a foundation of diagnostic techniques and educational intervening for children with autism speech patterns (Almasoud, 2010).

Additionally, although the KSA uses the TEACCH approach for children with ASD, all students with ASD who attend private centers receive TEACCH as a comprehensive educational program, which is not suitable for all of them (Almasoud, 2010). Besides, autism centers in the KSA cannot accept an increasing number of children with ASD and need specialists to effectively educate and modify challenging behaviors (Babatin et al., 2016). In addition, there are three research centers in the country that study ASD disorders namely, the ASD Research Center, the Research Department of the Saudi Autistic Society, and the King Salman Center for Disability Research (KSCDR). The KSCDR aims to encourage research related to disability issues in order to improve the quality of life for people with disabilities (Almasoud, 2010b). KSCDR also supports and coordinates, manages, and finances research and academic activities deemed useful to the community and to humanity in general. It also seeks to be up-to-date with the latest scientific research and processes through the pooling of resources of scientific, technical, and human-scale methodology domestically and internationally. The center's research focus is applied rather than theoretical, in attempt to have direct solution for the difficulties of medical, psychological, educational, and social problems facing people with disabilities (Almasoud, 2010). It is obvious that the KSA has several needs in terms of instructional practices and research-based pedagogy. Although the KSA has some research centers for autism, the number of centers is very limited and the types of existing research studies only focus on disabilities in medical concepts (Hussein, Hanan, & Ghada, 2013).

Inclusive Classrooms

The inclusion of individuals with special educational needs in the general education setting is a major concern (Abed, & Alrawajfh, 2017). In terms of inclusion in the KSA, there is legislation for people with special needs to access services throughout the education system as life-long learning experience (Al-Mousa, 2010; Alquraini, 2013). However, there are many calls to embrace inclusion (i.e. mainstreaming) for individuals with special needs (Aldabas, 2015). According to Al-Mousa (2010):

Mainstreaming refers to the temporal, instructional, and social integration of eligible exceptional children with normal peers based on an ongoing, individually determined, educational planning, and programming process and requires clarification of responsibility among regular and special education, administrative, instructional, and supportive personnel. (p.17)

According to Alquraini (2012), most individuals with severe intellectual disabilities are educated in special institutes with lack of necessary services to meet their needs. Thus, there is no interaction between the individuals and their typically developing peers in inclusive settings where the social, communication, and academic skills could be improved. One reason behind this is teachers' perceptions about inclusive education for those individuals. Educators in the KSA have somewhat negative attitudes towards the inclusion of individuals with disabilities in the general education system. There are several factors that impact this negative view toward inclusive education, such as "their current teaching position, previous teaching experience with students who had any kind of disability in inclusive settings and the teacher's gender" (Alquraini, 2012, p. 170).

Alamri (2016) examined teachers' attitudes regarding individuals with ASD and found that there were disagreements regarding the inclusion of students with ASD. The teachers' responses also showed anxiety related to potential problems of behaviors from those students and a lack of education on their part regarding the characteristics of individuals with ASD. Also, Haimour and Obaidat (2013) examined 391 general and special education teachers' knowledge regarding individuals with ASD from various segregated and inclusive schools within Jeddah. The results indicated that the teachers had a weak level of knowledge about autism and showed significant differences in their knowledge about the disorder based on position, education level, and teaching experience. However, special education teachers showed more advanced experience and education of teaching individuals with autism. This is because general education teachers are unprepared to support student with ASD. Therefore, special education courses need to be provided for general education teachers in the country since they currently do not take any such courses in their preparation programs (Aldabas, 2015; Alquraini, 2011). In addition, professional development focusing on awareness of disabilities should be provided for general education teachers by the schools (Aldabas, 2015). Since the trend in the KSA is towards inclusion of students with ASD, "more research is needed to examine the attitudes of teachers and other stakeholders regarding inclusive education and the factors that affect these attitudes" (Alquraini, 2011, p.154).

Conclusion

With the increasing number of individuals with ASD in the world, more efforts should be made in terms of providing services and supports to this population. This paper highlighted the current situation for individuals with ASD in the KSA regarding available services and supports. The paper highlighted that even though the special education services, including services for individuals with ASD, are developing more still needs to be done. In terms of the diagnostic process, the children are being diagnosed at the age of three years and the health insurance does not cover the diagnostic services, leading families to assume responsibility of the cost. In addition, the availability of the diagnostic services is readily accessible in only the main cities. Regarding the early intervention and education services, the KSA does not have an Individualized Family Services Plan (IFSP) or individualized educational programs (IEP) to assist children with ASD and their families to receive appropriate services and support in the classroom and home environments.

Furthermore, the classrooms are not ready to include students with ASD in terms of materials and the necessary equipment. Even though there are financial support systems for families of children with ASD, the amount of support does not fully cover the necessary services and the quality of services that are provided by the public sector do not meet the families' needs, while the private sector's attempts to provide appropriate services that meet families' needs are expensive. Since there are two types of schools, regular schools and schools for students with special needs, the teachers' attitudes toward inclusive classroom environments are varied, and a significant number of teachers do not support inclusion. General education and special education teachers do not implement the instructional practices and evidence-based practices to serve students with ASD, since there is limited research and resources in the Arabic language.

Recommendation

Based on this literature review of the current situation in the KSA, it is recommended that more specialized services should be established to serve students with ASD and their families in every region of the country. Several studies should be conducted in the field of autism to cover educational needs and raise awareness in the community regarding the issues of students with ASD in the country. These authors suggest that the greatest needs of families of children with autism are as follows: recognizing and providing programs for home care and outreach, family recognition incentives and rewards, integrative educational programs and occupational therapy. Additional services and supports that children with ASD and their families need include increasing financial support for children with ASD, colleges and universities contributing to the awareness of ASD, adequate sources of learning supplied to each school, and the average classroom size in KSA being minimized.

Finally, future research should investigate the needs of individuals with ASD and their families in order to provide the best services and support. Also, future research should address the assessment process, public services, transition services, and the use and development of assistive technology for children with ASD.

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