

## Research Article

### Autism in Saudi Arabia: Present Realities and Future Challenges

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**Abstract:** Despite improvements in the services provided to individuals with autism, some third world countries continue to struggle to provide services to individuals with autism. In this paper, the impact of culture on people's understanding of autism in the Kingdom of Saudi Arabia (KSA) is highlighted, as well as how its influence impacts the provision of necessary supports needed by individuals with autism. Using a historical context, the paper outlines the unique challenges presented by the culture and how these contribute to difficulties government agencies encounter in providing children with autism and their families with services.

**Keywords:** Autism; Disability; Special Needs; Culture; Service; Kingdom of Saudi Arabia

The social conception of disability has been a topic of discussion across many countries and cultures with one major concern and challenge being how to best meet the needs of people with disabilities. With recent developments in technology and healthcare in many developed countries, knowledge and treatment interventions for diseases and genetic conditions have increased. However, developing countries are still working to improve their health sectors in an attempt to address the challenging health issues faced by their citizens, and disability is among the many issues with which they continue to struggle.

The number of people with disabilities is rapidly growing in some countries. According to the World Health Organization (WHO, 2011), prevalence rates in low income countries was 11.8% as compared to 18% in high income countries, when measured by 2004 gross national income per capita. "The burden of childhood disability as a public health problem in these areas of the world remains relatively unrecognized" (Shawky, Abalkhail, & Soliman, 2002, p. 61).

In some cases, the development of special education in third world countries has been slow and challenging. Prior to 1958, in the Kingdom of Saudi Arabia (KSA), parents had full responsibility for caring for their disabled children (Alquraini, 2011). In 1958, some students who were blind or had visual impairments began receiving educational services in schools referred to as scientific institutes (Salloom, 1995). Later, in 1962, the Department of Special Learning was established by the Ministry of Education and has since been providing educational and rehabilitation services for individuals who are blind, deaf, and those with a range of cognitive abilities (Al-Kheraigi, 1989; Alquraini, 2011).

Cultural values and beliefs may impact the development and delivery of services for disabled children. Specifically, Al-Jadid (2013) suggests difficulties associated with research related to the current conception of disabilities in Saudi Arabia include shame, a lack of understanding of the causes of disabilities, and a reluctance to use the term disability, in

attempts to protect individuals and their families from potential stigma. In some cases, traditional and less scientific views regarding the range of abilities and needs (Alqahtani, 2012; Ravindran & Myers, 2012), can impede early diagnosis and intervention. One of the most challenging issues encountered by experts, families, and policy makers, is the growth in the number of individuals being diagnosed with autism spectrum disorders (ASD).

Similar to other socially constructed limiting conditions, individuals with ASD require special supports and services. Students with autism can exhibit “communication and language deficits, cognitive disorders, sensory processing deficits, and stereotyped behavior” (Webber & Scheuermann, 2008, p. 3). Therefore, in the current environment in the KSA, providing accommodations, services, and the necessary treatments can be demanding and stressful for family members (Zeina, Al-Ayadhi, & Bashir, 2014) and service providers (Al-Jadid, 2013).

Not only families, but, special education professionals encounter unique challenges associated with the current understanding and provision of services related to autism (Taha & Hussein, 2014). In addition to the ongoing search for causes of autism, the controversy over treatment options, and the range of services provided to individuals with autism have sparked many heated debates. There is a continuing disagreement over whether the treatment options are worthy of investment, and whether healthcare companies should cover the full range of treatments for individuals with autism. Specifically in the United States, there are debates about whether health care companies should pay for medical coverage for disabled individuals, the effectiveness of medications and other treatment options, and the specific causes of autism; while third world countries still struggle with more basic issues of services for individuals with autism (Taha & Hussein, 2014). This paper identifies issues related to the diagnosis of autism and provision of services for individuals diagnosed with autism in the Kingdom of Saudi Arabia. Additionally, we describe how services for individuals with autism have been viewed by those in the field of special education within the Saudi context.

Despite its status as a relatively new field in Saudi Arabia, special education services have improved in the last decade. This article examines how the improvements have specifically affected individuals with autism. To provide the necessary context, we begin with a brief description of Saudi Arabia, highlighting the major social, political, and geographical aspects of the country. Next, we examine how autism is understood and defined in Saudi Arabia and how this definition impacts the ability of government agencies to provide the necessary services for individuals with autism. To understand the challenges that government agencies face in Saudi Arabia, a historical overview of the improvements that have been made, provide a context for the current state of available services for individuals with autism. We explore and critique the services available to individuals with autism in Saudi Arabia, providing insights into the pace of service development. Finally, we make recommendations based on the current knowledge and within the contextual limitations of the Kingdom of Saudi Arabia.

Autism is characterized by differences in social-emotional reciprocity such as in back and forth conversation, limited sharing of emotions, interests, affect and response, and the

apparent absence of initiation of social interaction. Children with autism may also experience differences in motor coordination, intellectual disability, attention, and physical health issues such as gastrointestinal disturbances and sleep disorders (American Psychiatric Association, 2013).

### **Saudi Arabian Context**

The Kingdom of Saudi Arabia is located in Western Asia in the Middle East and occupies approximately 80% of the Arabian Peninsula between the Persian Gulf and the Red Sea. It is bordered by Jordan, Iraq, Kuwait, the Persian Gulf, Bahrain, Qatar, the United Arab Emirates (UAE), Yemen, and Oman. It is populated by over 33 million people (United Nations, 2017), and despite its immense oil wealth still “faces enormous problems of access to health care” (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009, p. 341; Salhia, Al-Nasser, Taher, Al-Khathaami, & El-Metwally, 2014).

Due to inconsistent availability of health and specialized care in developing countries, many conditions are often overlooked that would typically be identified in developed countries (Salhia et al., 2014). This can be attributed to several factors, including a limited availability of services, inexperience with identification, lack of exposure to specific conditions, and a “lack of appropriate training among in professionals” (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009, p. 345).

### **Beliefs of Causes**

According to survey results reported by Almana, Alghamdi and Al-Ayadhi (2017), the majority of Saudis have heard about autism and have some general knowledge of it. Their results indicated that the Saudi community paid less attention to the organic causes of autism, as they believe it to be a psychiatric process. Only a few identified pregnancy complications as the cause, and most believed that with proper intervention, children with autism could outgrow it.

Research supports an association between autism and parental age, as parental age increases the risk of having a child with autism increases (Salhia et al., 2014). Delayed speech is the first noted characteristic among children diagnosed by child psychiatrists, and speech, behavioral, and pharmacological therapies are the most used therapeutic interventions for Saudi children diagnosed with autism (Al-Zaalah, Al-Asmari, Al-Malki, A-Shehri, & Al-Moalwi, & Mostafa, 2015).

While most Saudi people have some general knowledge of autism, there is much confusion surrounding its organic causes. Since the Department of Special Education and Saudi Arabian government are ensuring students with disabilities receive special education, it is important that more awareness about autism be widely disseminated to ensure more students receive special education services and parents receive necessary supports.

## Prevalence

While exact figures are not available, anecdotal reports suggest an increase in the prevalence of autism in Saudi Arabia. One recent report estimated that there were 42,500 confirmed cases of autism in 2002 and that many more remained undiagnosed (Al-Salehi, Al-Hifthy, & Ghaziuddin 2009, p. 341).

Based on a sample of 49 consecutive referrals to a teaching hospital in Riyadh, Saudi Arabia in an early prevalence study, Al-Salehi, Al-Hifthy, and Ghaziuddin (2009), determined males outnumbered females by a ratio of 3 to 1, using the 1994 DSM criteria for the diagnosis of autism. Additionally, they reported that age of onset was likely before 3 years of age, however, they were not able to substantiate this assumption due to limited available information. They did note that females were older when evaluated. A more recent systemic review by Salhia and colleagues (2014) reported prevalence rates that ranged from 1.4 to 29 per 10,000 people in the region. In a review of literature from member countries of the Gulf Cooperation Council (GCC) in the Middle East, which includes the KSA, Kelly et al., (2016) reported lower prevalence rates when compared to western countries, however, the discrepancy may be due to underdiagnosis and reporting in Saudi Arabia (p. 160).

The GCC regional prevalence estimates differ from those reported by the Center for Disease Control and Prevention which indicate that in the United States, 1 in 68 or 14.7 per 1,000 children aged 8 years or older have been diagnosed with autism. Gender studies indicate that 1 in 42 boys and 1 in 189 girls have been diagnosed with ASD (Li, Fallin, Riley, Landa, Walker, Silverstein, & Hong, 2016).

## Support for Autism

In 2004, the Saudi government began developing special education services by investing in research and encouraging universities to open special education programs to train professionals capable of providing services to those in need (Prince Salman Center, 2004). While this has been the case, all disabled individuals have not received the same levels of attention in Saudi Arabia, with those diagnosed with autism among them. In fact, in 1993, private individuals initiated the first program for individuals with autism (Al-Aoufi, 2011, p. 9). It was not until 2004 that the government started its first program serving those diagnosed with autism.

Within public schools in Saudi Arabia, the special education department has opened special schools which care for children diagnosed with mild to moderate intellectual disabilities. Other students included in the program include those with autism and hearing impairment (Aldabas, 2015). Such schools provide students with special education services and resources. Moreover, the government has passed several laws to ensure that disabled students receive an appropriate and free education (Aldabas, 2015). Although serving individuals diagnosed with autism has recently received more attention, it remains a major challenge the government, special education professionals, service providers, and families must address.

With the initiation of government-sponsored programs, policy makers created an avenue for families to receive services for their autistic children with centers specifically designed to provide diagnosis, intervention, and support. As demonstrated in the literature, the impact and importance of early diagnosis and intervention is critical for children with a variety of disabilities, including autism (Corsello, 2005). When detected at an early age, early interventions that address the symptoms and characteristics of autism are incredibly fruitful. Al-Aoufi (2011) states, “Children with developmental delay who are exposed to early intervention programs are more likely to gain more coping strategies than later in life” (p. 72). Early intervention programs are useful for providing both diagnoses and strategies that promote a more positive long-term outcomes for children.

## **Benefits of Governmental Programming**

### **Early Intervention**

One of the Saudi government’s most significant efforts related to autism, was to create early intervention programs. Recognizing the importance of early intervention, the Saudi government established intervention programs to help both individuals with autism and their families. As with any new initiative, there are supporters as well as critics. Supporters applaud the interdisciplinary nature of services, early diagnostic services, and benefits of parental training, which are addressed in the following sections.

#### *Interdisciplinary service*

Those in favor of early intervention programs for individuals with autism tout their interdisciplinary nature. Al-Aoufi (2011) notes, “Early intervention is multi-disciplinary service, where more than one intervention approach or service could be provided for the child and the family as required” (p. 71). The interdisciplinary nature is meant to address the range of abilities related to autism by providing, “psychological services, diagnosis and assessment, consultations, transportation, family training, occupational therapy, speech therapy, dietary therapy, medication therapy, behavioral modification therapy and play therapy” (p. 71).

#### *Diagnosis*

The early intervention programs established by the Kingdom of Saudi Arabia also provided increased access to diagnostic services. The availability of these services ensures the detection of a range of disabilities at an early stage. Once a diagnosis is made, professionals can begin to develop an individualized strategy designed to support the individual’s unique needs. Proponents are hopeful the government will expand its programming to address the needs of more individuals and disabilities across all parts of the country (Alotaibi & Almalki, 2016; Alquraini, 2011). As proposed by Al-Aoufi (2011), the Saudi government must continue to establish additional special education programming that would provide services to individuals with special needs in general, and individuals with autism in particular (p. 50).

#### *Parent training*

Another beneficial service related to autism provided by the Saudi government is that of parent training. Supportive of findings from Alotaibi and Almalki (2016), who reported

parents' primary concern was a need for information, early intervention programs in Saudi Arabia contain a component to help train parents of children with autism to address their range of abilities and develop strategies to support their children's development. These programs also provide children with therapies, "to remedy current developmental problems, in order to stop its re-occurrence and to provide the families with an action plan in order to help these children" (Al-Aoufi, 2011, p. 7). Interestingly, the 80 parents who participated in the Alotaibi and Almalki (2016) study, rated a need for information greater than a need for support or community services.

## **Challenges of Governmental Programming**

As previously mentioned, there has been some criticism of the development of government-sponsored services for individuals with diagnosed conditions. Criticism focuses on a lack of access to services, limits on the number of individuals that can be served, delays in diagnosis, and limited knowledge which are addressed in the following sections.

### **Lack of Access**

While many individuals have been able to take advantage of government-sponsored diagnostic services, others have been critical of the limits associated with these services related to autism. Al-Masoud (2011) points to an inability to accurately diagnose autism due to classroom teachers and parents' inability to recognize the hallmark characteristics of ASD. Additionally, even though efforts have been made to provide diagnostic services through early intervention programs, the process can still be confusing which limits its effectiveness. Moreover, with the increasing number of individuals being diagnosed with autism, additional challenges can be anticipated.

### **Limited Availability of Services**

Unfortunately, once an individual is assessed and diagnosed, there is no guarantee services will be available. Al-Aoufi (2011) reports, "The number of individuals accommodated is minimal compared to the existing number of individuals with autism" (p. 51). Despite the best intentions of policy makers, limited access to services has posed a challenge and has been one of the major barriers for early intervention programs (Alotaibi & Almalki, 2016; Salhia et al., 2014). With the increasing numbers of people diagnosed with autism and continuing issues of access to services, there is a need to expand capacity and expertise to provide services to ensure the success of special education intervention programs for individuals with autism and broaden their reach.

### **Delayed Diagnosis**

As previously noted, the earlier a diagnosis is made, the more positive the outcomes, due to professionals' abilities to identify key issues and develop a clear plan of action to mitigate or eliminate the negative impacts. Seif Eldin, Habib, Noufal, Farrag, Bazaid, Al-Sharbati, Bader, Moussa, Essali, and Gaddour (2008) describe autism and the long-term

challenges delays in diagnosis can cause. They posit these delays “in many Arab countries has led to excess impairment and burden to affected children and their families” (p. 281).

In addition, early intervention services can also be complicated by inaccurate diagnoses. Autism is often misdiagnosed in Saudi Arabia when compared to other physical and mental conditions (Alqahtani, 2012, p. 15) which can lead to delayed or ineffective interventions. Additionally, the diagnosis process is not always clear. Al-Aoufi (2011) reports that, “participating mothers expressed specific concerns about the confusion over diagnosis” (p. 291). Such confusion can also lead to delays in the provision of services, resulting in less than optimal progress for children diagnosed with autism.

### **Limited Knowledge**

A lack of informed public regarding autism can be challenging and have adverse consequences. Alqahtani (2012) asserts that, “The lack of information about autism among parents may contribute to a failure to provide appropriate treatment and help” (p. 15). With no or even limited knowledge about autism, parents may rely on a cultural (i.e., unscientific) understanding of physical and mental disabilities. Frequently, a lack of information also leads to a reliance on informal treatments. For instance, Alqahtani reported that many of the females interviewed in his study believed the causes of autism to be cultural, resulting in treatments based upon cultural beliefs. In these cases, culturally-based treatments are viewed as the appropriate way to treat autism because of a lack of parental knowledge regarding autism. To these individuals, “Informal treatments are chosen because they are perceived as healing the source of symptoms rather than the symptoms themselves” (p. 21).

Additionally, as is still the case in many western contexts, it is clear from the language used in the literature that the KSA still holds to a medical model of disability. Disabled individuals (Barclay, 2017) are still considered in need of medical intervention. Until social conceptions of the range of abilities within the disabled community are addressed, true inclusive approaches and alternative perspectives will have limited traction.

### **Limited Resources**

While government-sponsored intervention programs are purported to help educate families with individuals with special needs, a lack of available professionals in these intervention programs has been a major challenge. While professionals are supposed to provide support in this regard, Al-Aoufi (2011) found the “internet was the parents’ first choice to obtain information about autism and its treatment” (p. 290).

Finally, Al-Aoufi (2011) outlined additional challenges that face early intervention programs in Saudi Arabia. Such challenges included the (a) limited collection and use of accurate statistics on the number of individuals with disabling conditions, including those with autism; (b) shortage of experts and qualified professionals to develop effective services and the ability to work efficiently with individuals with disabling conditions; (c) limited programs for raising the general public’s awareness about disabling conditions, their causes

and methods of prevention and remediation; (d) lack of local research within the disability field; and (e) the lack of an organized training and counseling program that offers education and support for families of individuals with disabilities.

### **External Obstacles to Governmental Efforts**

The shortcomings of intervention programs in Saudi Arabia have been identified and delineated, however there are additional factors that may play a role in the effectiveness of government-sponsored programs that are outside of its control.

#### **Cultural Issues**

It is common for each culture to have its own response to unfamiliar conditions, disabilities, and diseases (Alqahtani, 2012; Zeina et al., 2014). Some within the Saudi culture, being less familiar with the causes of autism, have attributed autism to superstitious causes, which has impacted efforts to improve the quality of special education services. The beliefs and practices regarding the potential and treatment of individuals with autism are different from one culture to another and change over time (Ravindran & Myers, 2012). Culture influences key aspects of the diagnosis and treatment process and affects the likelihood that individuals seek help, what treatments to use, available resources, and relationships between families and professionals. Daley (2002) suggests the treatment approaches that work and are culturally accepted in the West may not be the same approaches accepted and used to treat children (or adults) with ASD in other parts of the world.

In the West, potential causes of autism are identified based on science, and various treatments are available which include behavioral, cognitive, pharmaceutical, sensory, relational, vitamins, and diet therapy. However, in other cultures, the causes of autism might be still regarded as 'Karma, 'Allah's will,' or 'the will of God' which results in non-scientific treatments such as acupuncture and/or herbal medicine (Kelly et al., 2016; Ravindran & Myers, 2012).

#### **Lack of Research**

Improvements in intervention programs require research exploring the effectiveness of these programs. In Saudi Arabia, a lack of research contributes to the lack of quality services provided to individuals with autism (Kelly et al., 2016). Al-Salehi and Ghaziuddin (2009) found that deterioration in the quality of services provided to individuals with autism can be attributed to an under-representation of topics such as autism, addressed in child psychiatry publications. The lack of research on ASD has created a major challenge in efforts to evaluate and improve the services provided to individuals with autism. With additional research, the government could generate accurate prevalence rates, analyze effective interventions, and provide suggestions for how intervention programs can be improved and expanded, thereby achieving their stated goal of improving outcomes for individuals diagnosed with autism.



## Recommendations

The Saudi government has experienced challenges in providing supports and services to individuals diagnosed with autism. Despite recent efforts, there is a need for more research and improved services. Without research into the efficacy of supports and services, the ability to make evidence-based decisions and recommendations is limited. Research evaluating the system of supports and services can identify shortcomings of intervention programs and support new developments addressing the needs from those most closely involved.

There is also a need for more investment in the recruitment and training of professionals to ensure that individuals with autism are receiving timely and appropriate services. Additionally, intervention programs can make use of new technologies to improve services. Creating a database of information regarding the characteristics, potential causes, available services for individuals with autism, and advice for parents whose children have been diagnosed or may be at-risk for autism, can help educate the general population about autism.

The Internet has been useful in supplying information about other physical conditions and disabilities. Abo El-Soud, Hassan, Kandil, and Shohieb (2010) describe websites that “are especially developed for disabled persons. Some of these websites are e-learning application for the disabled people” (p. 56). Additional recommendations include the distribution of an “e-learning module that was developed to support library staff training in disability awareness” (p. 56). Technology would also be beneficial in this regard to facilitate training for both professionals and family members.

Finally, to address the social construction of disability which underpins attitudes towards individuals diagnosed with autism and perpetuates conditions that serve to disable rather than enable, the KSA should adopt a more aggressive stance and promote inclusive environments and practices. Principles of Universal Design for both the environment (Iwarsson & Ståhl, 2009) and for learning (Rose & Meyer, 2006) should be adopted and implemented across the Kingdom, combined with an informational, social media blitz to increase understanding of the range of abilities that exist in society and how individuals can encourage full participation of all citizens.

## Conclusions

Despite the efforts of Saudi Arabian government-supported programs and the support such programs have provided to individuals with autism and their families, these programs still have a long way to go. Experts have criticized governmental programs for delayed diagnoses, misdiagnoses, limited availability of services, and a lack of knowledge of the general public. Despite the criticisms, anecdotally, government-sponsored intervention programs still provide some positive outcomes for those who are able to access their services and are worthy of praise. Addressing their shortcomings coupled with the adoption and encouragement of a more inclusive approach to the full range of abilities, will enhance the available services and subsequently improve outcomes for individuals diagnosed with autism

in Saudi Arabia and their families.

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