

The availability of services for children with autism spectrum disorder in a Saudi population

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ABSTRACT

الأهداف: لتقييم مدى توافر الخدمات المختلف لمراكز التوحد في منطقتنا .

الطريقة: أجريت هذه الدراسة المقننة المستقبلية خلال الفترة ما بين مارس إلى مايو 2015م بواسطة استبيان مكون من 30 سؤال تم توزيعها على عدة مراكز حكومية وخاصة للتوحد في مدينة جدة تشمل العاملين في هذه المراكز لتقييم مدى توفر الخدمات المقدمة للأطفال المصابين بالتوحد .

النتائج: تم إدراج 12 مركزا للتوحد و قد أكمل 136 موظف الاستبيان . ذكر ثمانية وسبعون (57%) من المشاركين أن مركزهم يعاني من نقص في بعض الخدمات المهمة لمرضى التوحد ومنها برامج العناية المنزلية والتواصل (59%) ، برامج لتحفيز الأسر للمشاركة في تحسين الحالة وتقديم الجوائز للمتميزين منهم (51%) ، برامج تعليمية خاصة لدمج الأطفال (39%) ، وبرامج العلاج الوظيفي ومتوفرة في (16%) . مع العلم أن كثير من التخصصات الغير متوفرة في المركز يمكن تحويلها لخارج المركز في (24%) فقط من الحالات لعدم توفرها في معظم الأحيان . وقد ذكر المشاركون عدة عقبات رئيسية في تقديم الخدمات بصورة مقبولة بما في ذلك مشاركة الأسر (24%) ، مشاكل الأطفال السلوكية (13%) ، أعداد الاطفال المتزايدة (9%) ، وبيئة العمل (5%) .

الخاتمة: توجد نقاط واضحة في الخدمات المتوفرة لمرضى التوحد في منطقتنا مع العلم أن التحويل الخارجي في مثل هذه الخدمات محدود وقد تتمكن من تحديد عدد من الخدمات والنواحي العلاجية التي يجب تطويرها وتحسينها للأطفال الذين يعانون من التوحد .

Objective: To assess the perceived availability of various services provided by Autism centers in our region.

Methods: A cross sectional study was conducted from March to May 2015 involving health care workers at various governmental and private autism centers in Jeddah, Kingdom of Saudi Arabia. A structured 30-item questionnaire was designed to assess

their demographics, training, experience, and the availability of various services at their centers.

Results: Twelve autism centers were included and 136 employees participated in the study. Seventy-eight (57%) participants indicated that their center lacked important and essential services. These included programs for home care and outreach (59%), family recognition incentives and rewards (51%), integrative educational programs (39%), and occupational therapy (16%). Access for outside referral for these services was available in only 24% of cases. They cited several major obstacles in providing adequate service including; family involvement (24%), child's behavioral problems (13%), increased number of students (9%), and work environment and space (5%).

Conclusion: Significant deficiencies exist in the availability of autism services in our region. Access for referrals for important services is also limited. We identified several areas that can be targeted to help develop, promote, and improve the provided services for children with autism spectrum disorder.

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Autism spectrum disorder (ASD) is characterized by impairments in communication and social interaction, and the presence of repetitive and stereotyped behavior, interests, and activities.¹ Population-based epidemiological studies have reported a steady increase in the prevalence of ASD reaching up to 10 per 1,000 with limited geographic variations.² Managing children with ASD requires individualized intensive programs that includes behavioral, educational, and psychological interventions, usually provided in specialized autism centers.³ Once these children are diagnosed with ASD, they should be assessed and managed using these specialized programs. Beginning such multidisciplinary treatment early increases the likelihood of a favorable outcome, however, this is not always possible.⁴ Autism centers are under pressure to accept an increasing number of children and required to recruit specially trained personnel to educate and effectively modify challenging behaviors. Authors from developing countries reported considerable delays in the provision of such services, mostly due to the under-developed service systems.⁵ On the other hand, caregivers of children with ASD often report difficulties in using available services, inadequate financial coverage, and lack of shared decision making and care coordination.⁶

Readily available autism services are of paramount importance in order to provide adequate rehabilitation of affected children and their families, and improve their quality of life.⁷ These issues have received limited study in our region with a critical gap in ASD research

in developing countries.⁸ There is a lack of previous studies from Saudi Arabia addressing this issue. Such information is needed for planning adequate autism services and future development and improvements. The purpose of this study was therefore to assess the perceived availability of various services provided by Autism centers in our region. We hypothesize that certain services are lacking or of limited availability including behavioral modification and psychological counseling.

Methods. A cross sectional study involving health care workers at various autism centers across Jeddah, Kingdom of Saudi Arabia was conducted from March to May 2015. Jeddah is the second largest city in the country with a population exceeding 4 million people. Various governmental and private autism centers across the city were identified through the national Saudi Autism Society, Ministry of Education website, internet search, and local directories. Multiple private/public autism centers were identified from all city regions (north, center, south west, and south east). All included centers were purely designated for children with autism of 3-12 years of age. The study protocol was explained to the directors of the autism centers through an official letter followed by telephone communication. Their approval was obtained before visiting the centers.

A structured 30-item questionnaire was designed to include the demographics, training, and experience of the participants (Table 1). Key questions were included to assess the availability of various services and the need for additional programs and specialties (Table 2). Open-ended questions were also included to assess the best and worst aspects of the provided services and how the provided services could improve (Table 3). Assigned coauthors visited the centers to conduct the

Table 1 - Characteristics of healthcare workers at various autism centers in Jeddah, Kingdom of Saudi Arabia (n=136).

Variables	n (%)
Age (mean±SD)	20-54 years (29±6.7)
Saudi nationality	83 (61)
<i>Specialty</i>	
Special education	48 (35)
Psychology	34 (25)
Speech and language	23 (17)
Social services	9 (7)
Physical therapy	7 (5)
Administration	6 (4.5)
Computer technology	5 (3.5)
Nursing	4 (3)
<i>Educational level</i>	
Master degree	4 (3)
Bachelor	118 (87)
Diploma	7 (5)
Lower degree	6 (4.5)
Duration of training (mean±SD)	(17±35)
Duration of experience	(58±62)

Table 2 - The availability of various autism services and programs at various autism centers in Jeddah, Kingdom of Saudi Arabia (n=136).

Available services and programs	n (%)
Training and educational workshops for workers	127 (93)
Utilization of educational computer programs	125 (92)
Tools to teach and promote self-care	125 (92)
Referral access for services outside the center	111 (81)
Family educational workshops	106 (78)
Public educational campaigns	105 (77)
Programs for home care and outreach	80 (59)
Family recognition incentives and rewards	70 (51)
Integrative educational programs	53 (39)
Adequate sources of financial support for families	17 (12.5)

Table 3 - Summary of the most common responses to the open-ended autism service questions among autism center in Jeddah, Kingdom of Saudi Arabia (n=136).

Question and responses	n (%)
<i>Best services provided by the center</i>	
Physical and occupational training	24 (17.5)
Speech and language therapy	16 (12)
Special education	12 (9)
Behavioral modification	9 (6.5)
Computer training and utilization	7 (5)
Other / not specified	68 (50)
<i>Most important obstacles in providing adequate service</i>	
Family involvement	32 (24)
Child's behavioral problems	18 (13)
Increased number of students	12 (9)
Work environment and space	7 (5)
Poor child's hygiene	4 (3)
Other / not specified	63 (46)
<i>Suggestions to improve the autism services</i>	
Increased parental involvement	22 (16)
Increased manpower	18 (13)
Improving work space and environment	11 (8)
Reduce number of children per classroom	7 (5)
Increase number of services	4 (3)
Other / not specified	74 (55)

interviews in a private meeting room and individually assisted the participants to complete the questionnaires. King Abdulaziz University hospital ethics committee approved the study design and questionnaire. Informed consent was obtained from the participants before voluntarily participating in the study. Data were collected in Excel sheets and the statistical analysis was performed using Statistical Package for the Social Sciences 17 (SPSS Inc, Chicago, IL, USA). Descriptive analyses were performed.

Results. Twelve autism centers (2 governmental and 10 private) across the Jeddah region were approached and a total of 136 employees participated in completing the study questionnaires. All approached workers happily agreed to participate. Characteristics of the study participants are summarized in Table 1. The majority were females (92.5%) as a result of the set up of these centers with variable specialties and experiences. Table 2 summarizes the availability of various services and activities related to children with autism and their families. Deficiencies were identified in the availability of several services including programs for home care and outreach, family recognition incentives and rewards, and integrative educational programs (Table 2). Seventy-eight participants (57%) indicated that there

are some important and essential services that are not available in their center including occupational therapy (16%), educational integration programs (14%), sensory integration (9%), and behavioral modification (6%). Access to outside referral for these services was available in only 24% of cases. In addition, only 12.5% of the participants believed that their center provides adequate sources of financial support for families. Table 3 provides a summary of the most common responses to the open-ended questions related to the best services provided by the center, most important obstacles in providing adequate service, and suggestions for further improvements. They mainly refer to more parental involvement, work environment, load, and space (Table 3).

Discussion. Raising a child with ASD puts a tremendous strain on families due to competing commitments, often leading to initial social withdrawal with later reintegration into social networks.⁹ Providing adequate autism services is therefore critical for supporting these children and their families. Our study documented significant deficiencies in the availability of autism services in our region with limited access to outside referrals for deficient services, as perceived by the professionals working in these centers. Up to 57% of the study participants identified important and needed services that were not available at their center. A recent study from a developing country identified similar limitations in service availability with difficulties in community-based services and in the provision of ASD specific interventions.¹⁰ In our study, major defects were recognized in providing programs for home care and outreach, family recognition incentives and rewards, integrative educational programs, and occupational therapy. Another study documented that evidence-based practices for students with autism are rarely incorporated into community settings, and little is known about the quality of implementation.¹¹ Starting to integrate these children with public school systems is urgently needed in our region. Teachers in public school special education classrooms can learn to implement evidence-based strategies; however they require extensive training, coaching, and time to reach and maintain moderate procedural implementation fidelity.¹¹

Another important deficiency that was identified by our study is the lack of provision of adequate sources of financial counseling and support for families of children with ASD. This may be related to the nature of the included autism centers that were mainly private

(10 out of 12), however, other studies documented similar problems.^{12,13} The most common out-of-pocket expenditure types, even with private medical insurance, were medications, outpatient services, and dental care.¹² These families are frequently faced with significant financial and employment difficulties resulting from the increased demands for services required for their autistic children.¹³ Caregivers of children with ASD were more likely to report financial difficulty, cutting work hours, and stopping work. This area needs urgent attention in our region as there is no doubt that having a child with ASD carries a negative impact with a significant financial and employment burden on the family. In addition, professionals in these centers cited several obstacles to providing adequate services, particularly related to parental involvement, child's behavior, and hygiene. This may be related to the cultural, educational, and socioeconomic backgrounds of the affected families. Focused educational campaigns and parental training should be developed to target this area.

There are some limitations to our study. Our sample was not large enough, and with female predominance. However, it was representative of the autism workforce as it involved a wide range of governmental and private centers with variable ages, training, and experience. Reporting bias may have affected the results since the questions on the availability of services are predisposed to subjective judgments and recall bias. Finally, our questionnaire was not previously used or validated in other studies. We conclude that significant deficiencies exist in the availability of autism services in our region. Access for referrals for important services is also limited, as perceived by the professionals working in these centers. We identified several areas that can be targeted to help develop, promote, and improve the provided services to children with ASD. Future research is needed to address autism services across the whole country and try to identify barriers to the availability of deficient services. Such efforts should focus on confirming the availability of such services through means other than

employee inquiry, and also examining the utilization and efficiency of the available services.

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