

Autism services in low-resource areas

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ABSTRACT

الأهداف: البحث عن الخدمات التأهيلية المختلفة والمقدمة للأطفال المصابين بأطياف التوحد بالأردن.

المنهجية: تم استخدام استبيان جمع المعلومات من أولياء أمور عينة مناسبة من الأطفال الذين تتراوح أعمارهم بين 2.5 و 17 عاماً والذين تم تشخيصهم باضطراب طيف التوحد ويتم معينتهم في عيادات طب الأعصاب للأطفال في ثلاث مستشفيات جامعية.

النتائج: تمت مقابلة ما مجموعه 274 من أولياء الأمور. تمكن 196 (71.5%) طفل من الاستفادة من خدمات مراكز التأهيل. كان متوسط العمر لتلقي الجلسة الأولى 3.9 سنوات. كانت الخدمات الأكثر شيوعاً التي تم تلقيها هي العلاج السلوكي (182; 66.4%). كان متوسط الساعات الأسبوعية الأعلى في علاج النطق 6.25 ساعة والسلوك 6.64 ساعة. كانت المراكز الخاصة للإعاقات التطورية هي الأكثر استخداماً تلبيها المراكز الخاصة بالتوحد. كانت العوائق الأكثر شيوعاً هي التكاليف (138; 58%) والنقل (88; 37.5%). معظم الاهالي (198; 72.3%) ابدوا رغبتهم بأن يتلقى طفلهم التأهيل في مركز متخصص بالتوحد، ومعظمهم لم يرغب في تلقي تدريب لتدريب أبنائهم بأنفسهم.

الخلاصة: يعاني معظم الأطفال المصابين بالتوحد في الأردن من فجوات كبيرة في الوصول إلى الخدمات التأهيلية. في المستقبل يجب أن يأخذ بعين الاعتبار تطوير التدخلات التأهيلية وبما يتناسب ويراعي احتياجات أولئك الذين يعيشون في مناطق محدودة الموارد

Objectives: To explore access to intervention services for children with autism spectrum disorder (ASD) in Jordan.

Methods: We used prospective cross sectional design and survey methodology to collect information from the parents of a convenient sample of children with ASD aged 2.5-17 years and who attended pediatric neurology clinics in 3 different university affiliated hospitals in 3 geographic areas in Jordan from February to December 2018.

Results: We interviewed parents of 274 children with ASD. One hundred ninety-six (71.5%) received

rehabilitation services. The average age at first session was 3.9 years. The most common services received were behavioral therapy (182; 66.4%). The average weekly hours were highest for speech and behavioral therapy; 6.25 and 6.64 respectively. Private centers for developmental disabilities were the most commonly used followed by private centers for ASD. The most common barriers were costs (138; 58%) and transportation (88; 37.5%). Most parents (198; 72.3%) prefer to receive rehabilitation in a specialized center for autism, and most did not want to receive training to train their child themselves.

Conclusion: Most children with ASD in Jordan have limited access to recommended autism services. The development of future interventions must consider the needs of those living in limited resource regions.

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Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder characterized by deficits in social communication and restricted repetitive behaviors.¹ Recent reports from the United States indicate that one in 44 children have autism.² Accurate data of the prevalence of autism in Jordan are not available. The prevalence figures from other Middle Eastern countries range from 1.14 per 100 to 29 per

10,000.³⁻⁶ This wide range may have resulted from the varying methodologies and inclusion criteria used in these studies.⁷

Healthcare for children with ASD is complex, and requires an individualized approach and the use of specialized behavioral, speech, educational, and medical therapies based on each child's particular deficit profile.⁸ These interventions are costly, labor-intensive, and require lengthy periods of provider training. The National Research Council recommends that children with ASD receive "structured, therapeutic activities for at least 25 hours per week."⁹ A few studies have addressed the specifics of meeting this recommendation, and more information is needed on the uses of different therapies across a broad geographic range.¹⁰

Specialized interventions for children with ASD is lacking worldwide. A 2020 review of barriers to autism therapy access in the United States and Canada concluded that most individuals with ASD do not have access to the services needed to address their various needs.¹¹ The review added that the common obstacles to access include inadequate screening and diagnostics, and unclear referral pathways. This may be due to the shortage of specialized providers, such as developmental behavioral pediatricians, and child and adolescent psychiatrists as well as the lack of training and perceived competence of general pediatricians in diagnosing and managing ASD.

Global data show significant disparities in the resources available for addressing behavioral disorders in children and adolescents.¹² In low-resource settings, several access barriers to these resources have been identified. These include an insufficient healthcare system capacity and a lack of evidence base for cultural and contextual factors affecting diagnosis and help-seeking behaviors pose significant challenges to the development of effective and accessible interventions.^{13,14}

Reports from lower-middle-income countries (LMICs) point to underdeveloped systems and considerable delays in service and resource provision.¹⁵ Some studies have revealed limitations in availability, including the lack of community-based and ASD-specific interventions.^{16,17}

In Jordan, care for children up to 6 years is provided free of charge through the government healthcare system.

Significant progress has been made in establishing services for people with disabilities. However, the gaps between the needs and care received for individuals with ASD in Jordan have rarely been studied before, thereby making the planning, development, and provision of these services challenging. Furthermore, there is neither any clear pathway for management and referral, nor any clear national guideline or regulation for these services.

This study aim was to assess access to quality of intervention services for children with ASD in Jordan, types of services available, and the barriers to access and unmet needs from a parental point of view. This information is required to guide the development of programs for improving the care and functional outcomes of these children in future. A matched group of children with global developmental delay (GDD) was used to compare services for other developmental and behavioral conditions.

Methods. We used prospective cross-sectional research design and survey methodology to collect data from parents of children with ASD who received care at 3 pediatric neurology clinics in Jordan from February to December 2018 (10 months). The neurology clinics covered 3 geographic regions in Jordan and served as referral centers for surrounding rural areas in the north, central, and southern parts of the country. In Jordan and many other LMICs, child neurologists provide most diagnostic and subsequent neurodevelopmental management for children with ASD.

Parents of children 2 years or older who were diagnosed with ASD 6 months or more before to the beginning of the study were recruited to participate in the study. A control group was selected from children with other developmental delays or disability who also were diagnosed 6 months or more before the onset of the study. Children accompanied by caregivers other than their parents were excluded.

Research assistants who were trained in the conduct of research methods interviewed the accompanying parents at the time of presentation to the clinic. The survey consisted of 3 parts: The first part of the survey collected demographic data including age, educational level, and average monthly income. In the second part, information was collected about the services the child had received including their age at the first session, interval between their age when diagnosed, and their age at the first session, number of autism service facilities tried, whether the services were provided by the private or governmental centers or at home, and whether the facilities were specialized for ASD. The

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third part explored the parental preferences regarding the location of services and any obstacles encountered in accessing them.

The services received were divided into 4 categories: physiotherapy, speech therapy, occupational therapy, and behavioral therapy. Each subcategory was assessed in terms of age at the first session, average number of hours per week, monthly cost, average distance between home and provider, and degree of parental satisfaction.

A five-point Likert scale was used to assess parents' satisfaction with each service.

A pilot study on 10 parents was conducted before the beginning of the study which resulted in minor modifications to the survey.

We conducted a Medline database search using PubMed to identify related articles that have been published on this subject. We incorporated the information from these sources in the planning of the study as well as in the discussion and cited the articles in the reference section.

Data analysis and statistical methods. We used Statistical Package for Social Sciences (SPSS) version 17 (SPSS Inc., Chicago, IL, USA) to analyse our data. Chi-square test was used to test for statistically significant differences, when applicable. A p -value < 0.05 was considered to be statistically significant.

Table 1 - Parental demographics of ASD and GDD Groups.

Demographics	Autism n (%)	GDD n (%)
<i>Age of parents</i>		
<i>Father</i>		
20-29	5 (1.8)	6 (2.3)
30-39	113 (41.2)	108 (42)
40-49	121 (44.2)	117 (45.5)
≥50	30 (10.9)	22 (8.6)
Deceased	5 (1.8)	4 (1.6)
<i>Mother</i>		
20-29	34 (12.4)	47 (18.3)
30-39	160 (58.4)	144 (56)
40-49	75 (27.4)	59 (23)
≥50	4 (1.5)	5 (1.9)
Deceased	1 (0.4)	2 (0.8)
<i>Level of education</i>		
<i>Less than high school</i>		
Father	43 (15.8)	65 (25.3)
Mother	29 (10.6)	42(16.3)
<i>High school or above</i>		
Father	231 (84.3)	192 (74.7)
Mother	245 (89.4)	215 (83.7)
<i>Monthly family income</i>		
100-300 JD	51 (18.8)	81 (31.5)
301-500 JD	157 (57.29)	130 (50.6)
> 500 JD	66 (24.3)	46 (17.9)

ASD -Autism spectrum disorder, GDD - global developmental delay

Ethical approval. This study was approved by the Institutional Review Board of the Jordan University Hospital and the University of Jordan and is in accordance with the ethical standards of the 1964 Helsinki Declaration of Human Rights and its later amendments. Parents who agreed to participate in this research signed a consent form indicating voluntary participation in the study before the onset of data collection.

Results. A total of 274 parents of children with autism were interviewed. Two hundred and fifty-seven parents of age matched children with developmental delays and disabilities other than autism were also interviewed and served as a control group.

Demographic characteristics. As shown in Table 1, the average age of parents of children with ASD was 36 for mothers and 41.25 for fathers. Monthly income in most families (197; 72%) ranged from 301 to 500 JD (423–700 USD). Most parents (89% of mothers, and 84% of fathers) completed high school or higher education (Table 1).

Approximately half of the families (132; 48.2%) owned a car, but only 41 mothers (15%) had a driving license. Among the mothers included in this study, 33 (12%) reported a need to adjust or reduce their working schedule or stop working to accommodate the care needs of their child diagnosed with autism, while 23 fathers (8.4%) had to increase their work schedules to manage the additional expenses related to autism services.

The age range of the children with autism ranged from 2.5 to 17 years. Most patients (228; 83.2%) were aged <3 years. Male-to-female ratio of 2.8:1.

Healthcare services received by children with ASD. Of the 274 children studied, 196 (71.5 %) received rehabilitation services. The most common service was behavioral therapy (182; 66.4%), whereas the least common was physiotherapy (18; 6.6%). As shown in Table 2, The mean age at the first session was 3.9 years. Average age at the first physiotherapy session was 3.8 (range: 0.25 to 9 years), while average age at the first speech therapy session was 4 (range 1.25 to 9 years). The average interval between diagnosis and age at the first session varied according to the service type. Private centers were the most common types of facilities where children received services for developmental disabilities, followed by private centers specializing in ASD treatment. The mean number of hours spent per week on services was the highest for the behavioral and speech therapies, at 6.64 and 6.25 hours/week respectively.

Table 2 - Overview of Services.

Overview of services	Autism	GDD	P-values
	n (%)		
Total number of children included in the study	274	257	
Average age at first session for those who attended	3.9	3.7	0.798
<i>Total number of centres tried by parents</i>			
Average	1.65	1.65	0.729
Range	(1-6)	(1-10)	
<i>Type of services received</i>			
Physiotherapy	18 (6.6)	103 (40.1)	0.000
Speech therapy	177 (64.6)	87 (33.9)	0.000
Occupational therapy	37 (13.5)	59 (23)	0.005
Communication/behavioral therapy	182 (66.4)	61 (23.7)	0.000
<i>Degree of parental satisfaction: satisfied or very satisfied</i>			
Physiotherapy	11 (61.1)	62 (60.2)	0.000
Speech therapy	87 (49.1)	55 (63.2)	0.000
Occupational therapy	20 (54)	36 (61.0)	0.089
Communication /behavioral therapy	97 (53.2)	40 (65.6)	0.000
<i>Parent believes their child may go to school if they attend rehabilitation services</i>			
Yes	103 (37.6)	104 (40.5)	0.041
No	158 (57.7)	141 (54.9)	
Don't know	13 (4.7)	12 (4.7)	
<i>Barriers to services</i>			
Cost	138 (58)	172 (72)	0.001
Distance /transportation	88 (37.5)	110 (46)	0.045
Not helpful	75 (31.5)	51 (21.3)	0.012
Parents are trained to provide services	7 (2.9)	10 (4.2)	0.464
<i>Preferred location of services</i>			
Home	37 (13.5)	48 (18.8)	0.10
Specialized center	198 (72.3)	181 (70.7)	0.691
Online courses	1 (0.4)	3 (1.2)	0.283
Hospital	14 (5.1)	11 (4.3)	0.659
Receive training to provide services themselves	21 (7.7)	30 (11.7)	0.114

Parents often reported attendance at more than one facility, ranging from one to 6. A total of 103 (37.7%) parents believed that therapy would eventually allow their children to attend regular school (Table 2).

The most commonly reported barrier to service access was cost (138, 58%), followed by distance or issues with transportation (88, 37.5%). Most parents (198; 72.3%) preferred that their children receive services at specialized centers for ASD (Table 2).

Approximately half of the parents indicated that they were satisfied or very satisfied with the services they received (Table 3).

Differences between the ASD and GDD groups.

Children with ASD received more behavioral and speech therapies, whereas those with GDD received more physical and occupational therapies. Parents of children with developmental delays other than autism reported higher satisfaction rates than those of children with ASD. More parents in the former group believed that rehabilitation was useful. Although both groups identified cost and distance as hindrance to access,

more parents having children with GDD cited these as obstacles. Parents in both groups preferred that their children receive therapy at specialized facilities rather than in hospitals, at home, or through Internet modules or online courses that would allow them to train their children themselves (Table 2).

Discussion. In this study, we found that there were substantial barriers to access to autism services in Jordan. While our study showed improvement in early detection compared to our 2013 study,¹⁸ access remained suboptimal, with approximately a third of children never having received the services at the time of study. Additionally, for those who received the services, the available services fell markedly short of the recommended intensity in terms of the number of weekly hours dedicated.¹⁹

Large gaps in access to autism services, especially behavioral interventions, have been documented worldwide, including in high-income countries, such as the United States, Canada, and the United

Table 3 - Details of services for children with ASD.

Details of services	Physiotherapy	Occupational therapy	Speech therapy	Behavioral therapy
Number of children receiving service	18 (6.6)	37 (13.5)	177 (64.6)	182 (66.4)
<i>Age at first session</i>				
Average	3.8	3.7	4.0	4.0
Range	(0.25-9)	(1.25-9)	(1.25-9)	(1.25-9)
Average weekly hours	3.6	3.1	6.25	6.64
<i>Type of treatment center</i>				
Public autism center	0	0	2 (1.1)	1 (0.5)
Public developmental delay center	4 (22.2)	1 (2.7)	6 (3.4)	2 (1.1)
Private autism center	8 (44.2)	18 (48.6)	65 (36.7)	67 (36.8)
Private developmental delay center	4 (22.2)	13 (35.1)	81 (45.8)	86 (47.3)
Home	2 (11.1)	4 (10.8)	8 (4.5)	10 (5.5)
School	0	1 (2.7)	10 (5.6)	11 (6)
Other	0	0	5 (2.8)	5 (2.7)
<i>Average monthly cost</i>				
Jordanian dinar	99.50	113.50	107	113.74
(US dollar)	(140.3)	(160)	(151)	(160.4)
<i>Distance from home to center in minutes</i>				
< 15 min	4 (22.2)	12 (32.4)	33 (18.7)	34 (18.9)
15-30 min	9 (50)	19 (51.4)	100 (56.4)	103 (56.5)
30-60 min	4 (22.2)	6 (16.2)	34 (19.3)	35 (19.4)
> 60 min	1 (5.6)	0	10 (5.7)	10 (5.6)
Degree of parental satisfaction: satisfied or very satisfied	11 (61.1)	20 (54)	87 (49.1)	97 (53.2)

Kingdom.²⁰⁻²⁴ Studies from other Arab nations similarly point to significant disparities; for example, the mean age at first service access is 3.3 years in Saudi Arabia²⁵ compared to 2.2 years in the United States.²⁶

Our data are consistent with the above research and indicate that services are rarely delivered by autism-specialized centers. This may explain parental dissatisfaction and the perception that services were not helpful. This was why parents tried multiple sources or gave up when the perceived cost-benefit ratio seemed unfavorable. This may contribute to the higher rate of complementary and alternative medicine use in the families of children with ASD, as we found in a recent study of the same population.²⁷

The study reports considerable financial burden on such families as the most common challenge, followed by transportation-related difficulties. The average monthly cost of therapy sessions is reported to be between a quarter and a third of the total monthly family income. Additionally, the study shows that the caregivers often must stop working or reduce their working hours,²⁸ thereby compromising the family's financial situation further.²⁹ In our study, 12% of the mothers reported making changes to their work schedules; however, this may simply reflect the proportion of mothers who worked outside the home, which is approximately 22% in Jordan.

Most parents preferred their children receive services at specialized centers rather than in hospitals, at home,

or through online training; few were willing to be trained to deliver the services themselves. This finding should be considered when planning strategies for improving similar services.

Other studies have reported that parents in LMICs tend to have lower expectations and that this could be related to their knowledge and beliefs about ASD or mistrust in the available services.³⁰⁻³³

Finally, parents of children with ASD encounter challenges and difficulties similar to those encountered by parents of children with other developmental delays, necessitating a comprehensive review of all services currently provided to the children with developmental disorders.

In anticipation of a greater demand for childhood developmental services, global networking to help develop more user-friendly services must be considered. With the development of artificial intelligence, cooperation with experts in this field could help meet these challenges and improve expected outcomes.

Limitations. This study was conducted at the child neurology clinics at 3 academic hospitals. This may have limited the generalizability of the data. Children with autism who live in rural areas outside of urban centers may have a more restricted access to diagnostic and treatment services, as has been documented in the studies from the United States and other countries.¹¹

While we focused on the services for children with ASD, adolescents and adults with this disorder may face

greater obstacles to service access. Future studies should explore services for older individuals.

Conclusion. Children with ASD in Jordan, an LMIC in the Middle East, experience significant challenges to access quality autism services, similar to what has been reported in high-income countries. Over the past 2 to 3 decades, the prevalence of ASD has increased exponentially worldwide; however, most research on the diagnosis and treatment of this condition come from the developed countries with advanced medical systems and different patient demographics than their developing counterparts. Therefore, research on LMICs is critical to optimize the care of ASD patients in these countries.

This study examines a large representative sample from across Jordan and provide valuable information on the availability and types of autism services in low-resource settings.

In the absence of comprehensive epidemiological data on ASD in LMICs, parents' perceptions of gaps in access to services for and of their children's unmet needs may provide the only available information necessary for planning future research and service programs.

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