International Journal of Psychosocial Rehabilitation, Vol. 24, Issue 08, 2020
ISSN: 1475-7192

The Role of Special Education Centers in Meeting the Social Needs of Autistic Children Parents from Their Perspective.

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ABSTRACT

This study aimed to assess the extent to which the emotional social needs of the parents of children with autism spectrum disorder (ASD) in Jordan's special education centers are met from their perspective. The researcher used a quantitative research method and an interview as a study tool. The study sample consisted of (50) parents of ASD children who were interviewed in Amman, Zarqa, Balqa, Karak, and Tafilah.

Data analysis was performed using descriptive analysis. The results indicated that the families of autistic children in Jordan are not satisfied with the services provided by the employees who worked in special education centers in meeting their social and emotional needs. The results also show that there is a positive participation from the parents and the special education centers in providing care and education to the ASD children. The results show that there is also a gap in providing medical services for ASD parents.

This study gained the confidence of ASD parents in Jordan and not only validated the existing findings but also offered insights and important information in providing them with knowledge in this specific area.

***Keywords**: ASD, parents, children, special education*

I. Introduction

Multidisciplinary studies have well established that parents are directly affected in various ways by the condition of Autism Spectrum of Disorders(ASD) in their children. In a survey conducted by CDC (Centers for Disease Control and prevention) about the occurrence of ASD amongst children, it was noted that 1 in 59 children is statistically likely to be diagnosed with ASD. Although the source didn’t succinctly expound on the precise cause for the disorder, it revealed a list of factors that put a child at a higher risk including gender (where boys were 4 times more in danger than girls), low birth weight, being an identical twin and most importantly, the genetic

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Received: 27 Mar 2020 | Revised: 20 Apr 2020 | Accepted: 05 May 2020

configuration of parents as well as their age at the point where the ASD child was conceived. (CDC, 2019).ASD was also found to exist in children across all ethnic, racial, geographical as well as socioeconomic backgrounds.

Jordan as a country has a variety of special education centers in Amman and eslewhere in which childhood disabilities and ASD are catered for. Al-Masar child development services is a great example of a special education center in Amman where children with ASD and other disorders receive special attention in education and therapeutic services. As noted by Park (2012), the rate of ASD has risen from 2006 by a rate of 25%. It was also deemed fit by CDC to expand the criteria that categorizes a child as ASD after considering that the condition includes an assortment of disorders. Notably, in earlier years, ASD was narrower in its inclusion of conditions that qualified to be named Autistic. Nonetheless, ASD is known to include disorders like social impairment, psychological retardation and learning difficulties. Much of the medical and statistical analysis on ASD placed more interest in researching on the condition and direct victims. However, in the logical reasoning that children are products of the basic unit of the society_ the family, parents are undoubtedly affected to a significant extent.

In order to objectively assess the extent to which social and emotional needs of parents of Autistic children are met from their point of view in special education centers in Jordan, the study aims to utilize existing units that will comprise the standard rule for the measurement. Having reviewed similar studies in concurring geographical regions, it was noted that studies have created benchmarks for gauging the level of satisfaction which will be applied in this study as part of the methodology approach.

II. View of literature

There are many studies that relate to ASD in many parts of the world and Jordan as well that include the perspective of parents. In Egypt for instance, a study published in 2018 by Gobrial depicted how mothers of Autistic children experienced living with Autistic children. (Gobrial 2018). The study confirmed that the main bother for mothers with ASD children was healthcare, stigma and inadequate education. At the same time, the study put forth that these mothers were negatively impacted emotionally, socially and thus had to make many sacrifices to cater for the needs of their affected children.

Another example manifesting the personal experiences of mothers of Autistic children and their decision-making process was shown in a study based in Dubai by Sopaul in 2019 . The mothers interviewed revealed that they are the primary caregivers, and the challenges they face include lack of understanding and research; family reputation; discrimination associated with stigma; and maternal stress. The study concluded that, mothers with autistic children experience several stressors and would benefit from educational workshops, including ASD-specific training.(Sopaul, 2019)

In the United Arab Emirates, a study aimed to identify the sources and the levels of psychological stresses for mothers of children with Autism Spectrum Disorder (ASD) was conducted by El Dib in 2016. The study stratified random sample consisted of (174) mothers of children with (ASD) whose children were enrolled in one of the rehabilitation of the disabled centers which were under the supervision of the United Arab Emirates’ Ministry of Society Development. The results showed a high degree of needs for the mothers, that were highly demonstrated in “Societal needs” ,“knowledge and training” ,“Social needs” and “Financial needs” respectively (El Dib, 2016) .

Picardi et al (2018) conducted a study aimed at quantifying the subjective (related to caregiver) and objective (time, finance) burden of ASD in mothers and fathers. The study sample consisted of 359 parents of children with ASD. The study and in consistent with the previous studies confirmed that parents of children with ASD carry a huge caregiver burden, where the results clearly revealed that the parents of children with ASD reported higher objective and subjective burden, more frequent psychological distress, lower social support. Particularly, mothers reported greater subjective burden than fathers.

In France 2015, a study aimed to explore the needs of parents of children with ASD to provide recommendations for support. The study found that six dimensions of need emerged: material, information, guidance, daily management, relational support, and emotional support (Cyrielle, et al, 2015). Remarkably, the parent’s responses showed that needs priorities were different for parents with a child with ASD involving the transmission of knowledge and skills as well as emotional and relational support. The study highlighted the need to develop support programs focused on the needs of the parents that reflect educational, behavioral, and psychological dimensions.

Few studies have shown that participating in parental support groups was associated with less mental health problems. Alibekova et al (2019) conducted a study that aimed to explore the association of participation in support groups with stress and mood disorders in parents of children with autism in Kazakhstan. The results of this study indicated that 44.4% of parents reported experiencing stress, and almost half of the sample had elevated depressive (53.7%) and anxiety symptoms (47.4%). 45.3% of participants were members of parental organizations; there were no significant differences in the prevalence of stress and mood disorders among members and non-members of parental support groups. Results of the multivariate logistic regression showed that parents with older autistic children (OR 1.37, p-value 0.001), less family support (OR 0.894, p-value 0.044) and higher income (OR 3.01, p-value 0.025) were more likely to be members of support groups.

The study indicated the need to increase support groups to under-served populations of Kazakhstan’s families with autistic children and strengthen the role of support groups in meeting the emotional needs of the parents.

Another study focused on the role of social centers in supporting families who have a children with ASD was performed in the resource center of the Regional Rehabilitation Center for Disabled Children "Nadezhda" in Volzhsky, Volgograd Region in 2019. The Regional Rehabilitation Center provided families with psychological and pedagogical support that includes diagnostics, informational support, teaching parents of competencies in raising and educating of children, involving parents in everyday correctional and development process, leisure activities. The study successfully concluded that the role of interaction between specialists and parents, as well as role of the “School of Effective Parenting”, held in the “Nadezhda” Center emphasized in improving the quality of life of the family (Voloshchuk, Karpova, Kazachkova, 2019).

A pilot study was designed to evaluate the family-focused psychoeducational therapy (FFPT) for autism spectrum disorder (ASD) family. In Phase I, 64 parents of ASD children (ASD-group) and 63 parents of typically development children (TD-group) were invited to investigate parenting self-efficacy and emotion at baseline. In Phase II, the 4-week of FFPT was offered for the ASD-group. Date was collected at baseline, post-intervention and one-month follow-up, using the parental self-efficacy, Self-Rating Anxiety Scale and Self-Rating Depression Scale.

The results showed that ASD-group significantly lower levels of parenting self-efficacy and worse emotion than TD-group ($p < 0.05$); And after attending the program, ASD-group had significant improvements for all outcome measures and these changes maintained over a period of time ($p < 0.05$). This preliminary study suggests that the FFPT may effectively improve parenting self-efficacy, reduce anxiety and depression for parents of children with ASD.(Yating,Huaying,Minjian,Wang,2019)

In 2007, another study that main goal was to determine the relationship between Autism and parental stress was undertaken. The study concluded that parents of ASD children with recent special service needs was linked with unique stress. (Schieve, Blumberg, Rice, Visser, & Boyle 2007).Notably, the research measured the aggravation range for parents of ASD children paying close attention to parents of children who recently needed special services.The study successfully established that there was a difference in the aggravation range score for parents of children who recently required special services vis-à-vis parents of children having other developmental complications. An interesting revelation from the study was that ASD was more likely to be found in children of 4 to 10 years old and were male. It was not precise as to whether ASD children raised by single parents or raised together with other children of the same family were more prevalent to ASD even if their economic status was considered.

The National Council for Special Education in USA sought to examine how well information relating to ASD was disseminated to affected parents. In this study where 11 fathers and 27 mothers were interviewed, there was found a gap in how positively education was delivered to equip parents of ASD children with know-how relating to providing services and caring for their siblings. A sense of empowerment for parents of ASD children was found needing which would help them advocate for their children.The focus of this study was largely on parents of ASD children as well as professionals in the field with a close insight on the service providers. The study established that there was lack of collaboration between professionals and service providers to Autistic children, a factor that led to parents of ASD children discovering the needs of children themselves (Murphy & Tierney, 2009).

Additionally, another focus on parents with ASD childrenfocused on parents' conceptualisation of autism as well as the public perception. It was noted by the research that one dissatisfying factor for parents with ASD children was how the general public associated Autism with failures on the parent's side (Barnes, Hall & Graff, 2009). The study was conducted in 2009 with 9 mothers and 2 fathers who were notcouples.A crucial discovery by the comprehensive study affirmed that major causes of stress for parents was not only based on outsiders but also how the parent reacted to that kind of stimuli. The publication argued logically on why it was viewed as a parent's failure when their child wasidentified as Autistic, putting forward that in the professional circles, Autism was known to emerge from a variety of causes and thus parentscould not be directly blamed. Social workers were seen by the study to be the unifying factor particularly where the members of the extended family blamed parents for Autism.

In Jordan, other studies conducted on parents with ASD children confirmed the existence of social and emotional dissatisfaction. Rayan and Ahmad (2016) sought to measure the nature and magnitude of psychological suffering in parents of Autistic children living in Jordan. The study focused on trait mindfulness where it was discovered that depression, anxiety and stresswere common in the parents. The study was administered on parents of 104 ASD children and concluded that in order to curb the level of depression in parents of ASD children, mindfulness-based intervention could be applied. In another study by Iftikhar and Butt (2013), it was concluded that on a gender scale, mothers of ASD children were more depressed, anxious and stressed than their male counterparts. This was majorly due to lack of finances, lack of facilities, lack of professionals, and social and family pressure. The survey was on the psychological well-being and parental concern of children with ASD. It was administered on 40 ASD children of ages between 2 and 10 years and their parents.

Lastly, Hyassat, Akhayat & Alzyoud (2015) did a similar research in Jordan in which they put forward that parents are better placed in assessing the progress of their autistic children for the fact that they are more aware of them. Their perspective on the effectiveness of special education centers in Jordan would be critical in assessing the objectivity and justification of those services. The source also put forth that a harmonious collaborative efforts between the special education centers and the parents would enhance the services and remain relevant in the fight against ASD. The study also developed a scale for measuring the degree to which parents of Autistic children and other disordersare satisfied with available special needs for the children. They created an instrument that outlined 5 dimensions which were a suitable representational of satisfaction in the parents of children with ASD and other disorders. The dimensions were:

- Medical attention services
- Access to services
- Special education organizations
- Parental participation
- Accessible support

The study problem

Considering the importance of tackling the social needs of the parents of children with ASD, many researchers have sought to stand on these needs in the modern era. General speaking, such families often encounter various obstacles and stress in meeting the needs of their ASD children which reflected negatively on their children well-being. Many children with ASD require intensive educational, behavioral, and healthcare services, which require significant financial, time, and care from their families who at the same time experiencing different kinds of stress, social burden and depression which result in negative impacts on both the parents and their ASD children. For this reason, the researcher aimed to investigate the role of special education centers in meeting the social needs of autistic children parents from their perspective.

The study questions:

What is the role of special education centers in meeting the social needs of autistic children parents from their perspective?

These sub questions are stemmed from the general question

1. To what extent are parents of ASD children satisfied with medical care, accessibility to services, care and support provided to their children by the special centers in Jordan?
2. To what extent are parents of ASD children satisfied with the Special education institutions that catered their children in Jordan?

Received: 27 Mar 2020 | Revised: 20 Apr 2020 | Accepted: 05 May 2020

3. To what extent are parents of ASD children satisfied with their involvement in the Special education institutions that catered their children in Jordan?

The study objectives:

This study aimed to assess the extent to which the emotional social needs of families of children with autism spectrum disorder (ASD) in Jordan's special education centers are met from their perspective.

Study limitations:

This study is limited to the special education centers in Amman, Zarqa, Balqa, Karak, and Tafilah in (2019).

III. Study methodology

Study population:

The study population was majorly comprised of participants from Amman for the reason that as a rule of thumb, it was the largest geographical region with specialized special education centers and professionals in particular those with ASD.Referring to the study by Hyassat et al (2015), Jordan is a small country with only 6.2 million citizens. The prevalence of disability in general is not exactly defined but it’s known to be with 2% of the total population. The deliverance of special services to ASD and other disabilities within children is practiced in Jordan by many different institutions, serving ministries as well as the private and voluntary sectors. In this light, the researcher settled on a research population of 50 participants who were parents of ASD children receiving special care within special education centers in the abovementioned regions. The focus groups were organized into clusters of 10 participants with 3 groups in total for those in Amman. There was a focus group of 6 participants and 5 participants in Al-Balqa and Al-Karak respectively. 9 participants in As Zarqa and At Tafilah were individually administered by the use of semi structured interviews.

Participants were gathered in a convenient and private location in Amman for the focus group. They had earlier identified Sunday afternoon as the appropriate time for the activity in which every group was interviewed separately on its own day. Reminders were sent via text messages and a follow-up call was made on the eve of the data collection day. Names have been protected for confidentiality purposes. At the time when a participant arrived, the researcher gained informed consent after which they filled a demographic form. It is important to note that challenges encountered with data gathering ranged from language, time, geography, and finances and planning. The official language of Jordan is Arabic and for the purposes of publishing this research, translation to English for some significant findings was consistently applied. Privacy, ethical considerations, procedural and safety concerns were highly maintained.

Data analysis was approached through thematic analysis method as portrayed by Braun and Clarke (2006). This included a process of arranging the responses from study participants into categories based on key words that appeared regularly in the data. Carefully selected recurring themes formed the basis for which conclusions were derived. In the consideration that the nature of the research was qualitative, a fitting data analysis method was applied.

Study sample:

The study sample consisted of (50) parents of ASD children who were interviewed in Amman, Zarqa, Balqa, Karak, and Tafilah.

Study tool:

In this research, a mix of approaches were applied in gathering data from respondents. The study included a qualitative survey with focus groups on parents with ASD children based in Amman, Az Zarqa, Al Balqa, Al Karak and At Tafilah. Semi-structured interviews were applied to the focus groups as well as one-to-one interviews with parents of ASD children who did not physically appear in the focus groups. Questions that ranged from “Yes” or “No” answers to those of detailed explanations were used. As noted by Morgan (1997), over the years, guidelines on the use of focus groups in social science researches have been summarized into 4 derivatives as follows:

- They use homogenous outsiders as contributors
- They depend on moderately structured interview with high moderator participation
- They have 6 to 10 members per group
- They contain 3 to 5 groups for every project

The study recognized the existence of hurdles in perfecting the 4-criteria “rule-of-thumb” for the reason that special cases may call for specialized focus groups (Morgan 1997).The survey applied this framework in the formation of focus groups. The table (1) below is an extract of semi-structured interview questions that were posed to respondents.

Table (1). Examples of interview questions

- How did you discover that your child is Autistic?
- What did you first think about ASD when you heard of it?
- Were you aware of the prevalence of ASD in Jordan before your child was diagnosed?
- How did you learn about the existence of special education centers in Jordan that offer ASD care services?
- How would you rate the services offered to your child at the special education center?
- How often do you stay with you child and offer education and care yourself?
- Are you able to reach information that already exist about ASD?
- How do your family members say about the ASD condition in your child?
- What about the members of your society?

IV. Discussions of the results

Using the instrument developed by Hyassat et al (2015), the 5 dimensions of gauging the extent to which parents are satisfied with special care for their Autistic children in Jordan brings the following into attention:

The result of the first Sub question: To what extent are parents of ASD children satisfied with medical care, accessibility to services, care and support provided to their children by the special centers in Jordan?

(i) Medical care services

Parents of ASD children in Amman raised concerns that although medical services for their special needs' children existed, communication barriers with professionalized care is seen as a challenge. It was noted that making phone calls to the centers asking for medical guidance was not constantly helpful.

> "I have to administer medication to my Autistic child every now and then but sometimes am not sure how. I think of calling the education centers for help but am not sure if they would answer the question "Participant 11.

(ii) Access to services

It was noted that for parents with ASD children attending Amman based special education centers, there was a well-established through way to access special care services. The staff were generally welcoming and there was a perceived ease of applying for the services. 79% of participants gave a 3.8 score on a 5-scaled interview question that asked,

> "On a scale of 0 to 5 with 0 being the least and 5 being the highest, how would you say accessing the services in special education centers is in your location?"

(iii) Available support

Participants of the survey showed a gap in how often and effectively the support for Autism in special centers in all the 5 regions was helpful. Although 45% of the study population agreed that they were aware of the formal support bodies including the nature of support that is offered, well over 47% of the study population had not applied for aid other than financial.

4. **The result of the second Sub question:** To what extent are parents of ASD children satisfied with the Special education institutions that catered their children in Jordan?

Special education institutions

The researcher considered varied subjective responses by participants from the regions and summarized the theme of special education institutions as follows: Amman-based special education institutions had proper staff, machines and suitable environment for ASD children but with a slightly higher cost. Special centers in Al-Balqa and Al-Karak did not have resources that matched those in Amman, but their costs were justifiable. As for the participants in As Zarqa and At Tafilah, the result met differing uncertainty as to the nature of "professional" care. However, respondents from these latter regions were fulfilled that the services they received from the special educational institutions were worthy. The following extract is a response by a respondent from At Tafilah to the interview question:

> "Do you believe that the special center where your ASD child is usually catered for has qualified staff and that the environment is suitable for the child?"

> "Well, when I went there for the first time, I met a young lady_ I can't recall her name, but she was good-hearted. I knew that somehow she would help me with my child. The place didn't have big machines for massage, but it was not as expensive" Participant 46.

- **The result for the third question**: To what extent are parents of ASD children satisfied with their involvement in the Special education institutions that catered their children in Jordan?

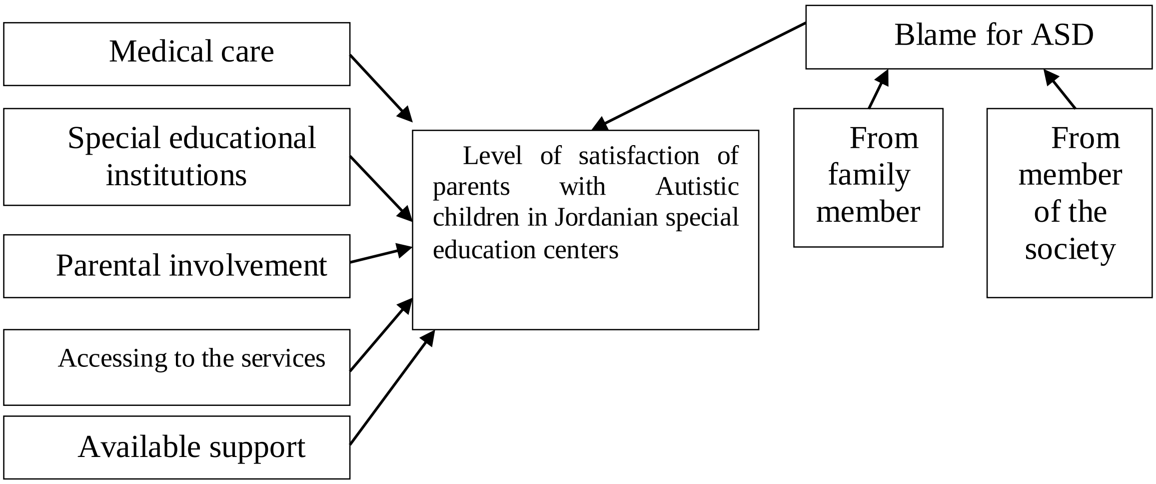
Parental involvement

In the conduit of the survey, participants were asked if the centers for special education in their respective regions contacted them for any enquiries about their children. Again, for those based in Amman, at times they were called on phone when something about their child needed to be confirmed. The data tested positive for parental involvement.

V. Conclusion and recommendation

Autism in Jordan is an issue worth of research with particular focus on parents' view. Areas that perform well with regards to findings in this research are staff who work in the special education centers (for Amman-based special education centers) and availability of formal information. Areas that could be improved are public awareness of Autism and special meetings with affected parents including follow-up on medication and directory assistance. The instrument of measuring parent's satisfaction in this research did not include the factor of blame from family members and members of the society as discussed byBarnes et al (2011).The figure (1) below is an illustration of the conceptual formation for which the satisfaction of parents with ASD children was done and how it could be improved:

Figure (1). The conceptual units for measuring parental satisfaction for ASD



However, the study recommends another study to be administered paying much attention to the point of view of teachers in special education in Jordan. An instrument to gauge how teachers would assess their extent to which they meet the satisfaction of families with Autistic children would need to be developed.

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