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Awareness Group for Parents of Children with Disability – Availability and Benefits in Saudi Arabia

Dr. Dalia Alkhoul¹

E-mail: dalia_alkhouli@hotmail.com

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Abstract

Parents or guardians of children with disabilities need to be provided with psychosocial support that will enable them to better parent their children, an advantage that can be accessed by them joining an awareness group. This study examined the availability and benefits of an awareness group for parents of children who have disabilities. The study adopted a mixed-method approach where qualitative and quantitative approaches were used in the collection and analysis of data. The qualitative data was collected using interviews while the quantitative data was collected using surveys. A sample size of 106 participants was selected using purposive sampling and snowball sampling methods. The sample size was exclusively composed of parents with children with disabilities. The findings of the

¹ Taif University. Kingdom Of Saudi Arabia

study indicated that whereas there is a need for having awareness groups for parents with children with disabilities, such groups are non-existent in Saudi Arabia at the moment. The participants acknowledged that they are facing challenges when it comes to coping with their children's mental and physical limitations and would benefit a lot by sharing their experiences with others who are handling the same difficulties. The participants also expressed the desire to attend such group forums if they were formed so that they could share ideas on how to help their children with disabilities. The study, therefore, recommended that the Saudi Arabia government should create social support group across the country targeting parents with children with disabilities to equip them with knowledge and skills on how best they can raise their children. The study also recommended parent with children with disability to take initiative and form awareness groups for themselves. Furthermore, the study recommended further research on the barriers that could inhibit the formation of social support groups for parents with children with disabilities and how those particular challenges could be overcome.

1.0 Introduction

According to the World Bank (2020), there are approximately one billion people or 15% of the world population who are living with various forms of disability, ranging from minor to severe cases. Approximately between 110 – 190 million people experience significant disability. Additionally, the World Bank report indicates that most of the disability cases occur in developing countries.

Generally, there is inadequate reliable data regarding the prevalence of disability in Saudi Arabia. However, the census data from the year 2000 indicates that there were 135,000 people living with disability; of which approximately 33% were physical disability. The census from the year 2010 indicates that the prevalence of disability in the country had slightly increased and that the number one cause of

disability was injuries from a traffic accident. Additionally, the statistics indicate a higher disability prevalence rate among men than women.

People with disability experience numerous challenges in the course of their lives, particularly from society. A study by Iezzoni and Agaronnik (2020) found that people with disability in almost every society are likely to experience some form of discrimination with respect to healthcare, education, leadership, and professional employment. Alves et al. (2016) also indicate that people with disability, especially in developing countries, are likely to experience higher poverty rates.

Namkung and Carr (2019) explored the perceived institutional discrimination among persons with disability in the United States. The study found that indeed, people with significant impairment were more likely to report disrespectful treatment, and generally be discriminated against in various aspects of the society. The study further reported that older persons with a disability were more vulnerable to disability compared to the younger ones.

Although adults are more likely to face discrimination as a result of their disability status, Hielscher and Waghorn (2017) argue that children are more vulnerable to disability challenges as compared to adults. Partially impaired adults mostly engage in various economic activities, are employed in various organizations, have families, and are generally capable of living a more ordinary life (Temple et al., 2020).

A report by the United Nations Children Fund (UNICEF) (2017) indicates that children or parents of children with disability are vulnerable to several challenges within the community. Specifically, the report indicated that approximately 45% of children or parents of children with disability have at one point experienced some form of humiliation or harassment due to disability status. The report also indicated that in approximately 24% of the families with children with disability, one of the parents had to completely give up his or her work to take care of the children.

According to the UNICEF (2017) persons with a disability, including children in the Arab region are among the most marginalized around the world. Additionally, such persons are largely excluded from ordinary societal life and activities. Nevertheless, there are significant efforts in most of these countries to improve the protection of persons with disability. Saudi Arabia is one of such countries.

Considering the numerous challenges that persons with disability undergo, there have been several efforts, ranging from policies and laws aimed at protecting persons with a disability, to physical and psychological support programmes (Hoffman et al., 2016; Toquero, 2020). One of the psychological support programs is the awareness group for persons with disability. According to Heys et al. (2017), such an awareness group is comprised of people with similar challenges, and its purpose is often to provide a platform for such persons to share their experience with the aim of helping others to easily manage their conditions. An awareness group for persons with disability may include adult persons living with a disability, or an awareness group for parents of children with disability.

The current study focuses on the awareness group of parents of children with disability. Significant studies have since been done with respect to the impact of such an awareness group to the parents of children with disability. Peer and Hillman (2014) noted that parents of children with an intellectual developmental disability were more vulnerable and stress compared to parents of children with normal intellectual ability. Such stresses were also reported to develop into chronic levels, and impact on the wellbeing of the parent; which subsequently impacts the parent's ability to effectively meet the demands of their children with the mentioned disability. Despite the variation between the two groups of parents, Peer and Hillman (2014) noted that some parents of children with intellectual disability were significantly resilient to the stressors.

Amaya and Tomasini (2014) also contend that parents of children with disability are often overwhelmed especially upon the arrival of the child. In most cases, these parents are almost never prepared or have probably never been in a family with a person with a disability. They are, therefore, overwhelmed since they lack adequate knowledge and skills of taking care of such children. The challenge is even worse in countries with lack of related social support programmes. According to Amaya and Tomasini (2014), Mexico is one of the countries with very few support programmes for parents with children with disability. Despite the absence, the authors posit that these programs could be effective in enhancing the parents' ability to take care of their disabled children. Similar to the findings of Peer and Hillman (2014), the results indicated a positive and significant outcome of the program. Specifically, the study found that the mothers developed a positive acceptance of the status of their children, and were more willing than before, to form a network of similar parents to advocate for the protection of their children.

In a study conducted by Gould et al. (2017) found that Acceptance and Commitment Training (ACT) of parents with children with autism had a positive impact on the development of overt behaviours. Gould et al. (2017) also assert that parents with children diagnosed with autism experience chronic challenges, and as such, they require significant social support to cope with the conditions. Park (2020) found that parent's participation in awareness group with other parents whose children suffer from a given emotional disability are more likely to develop a positive attitude, and learn better, to take care of their children than those who do not participate in such.

Marshall et al. (2019) hold that cultural beliefs and practices are significant determinants of the parents' acceptance and coping with their children's disability. Some culture associate's disability with bad omen, or spirit. As a result, children with disability from such families are significantly isolated from ordinary societal life.

Additionally, such parents are less reluctant to talk about the condition of their children. Marshall et al. (2019) therefore, conducted a study to explore the outcome among parents from conservative cultures who otherwise participate in awareness group of parents with children with disability. The study found that after continuous participation, the parents were more likely to develop a rational perspective of their children's condition, more reluctant to let these children live a free life, and interact with other normal children. Further, these parents were more willing to continue participating in these groups. These findings are similar to those by Amaya and Tomasini (2014), especially with regards to the willingness to continue participating.

Alnemary et al. (2016) found that parents of children with ASD in Saudi Arabia begin utilizing the available services from the age of 3.3 years. Majority of the parents reported using a non-medical treatment. The second most used treatment was biomedical, followed by religious and cultural treatment. The study, however, found significant variation in parent use of various treatment with varied education level, age, family income, and geographic location. Generally, the study reported a low rate of treatment for children with autism. '

AlHammad et al. (2020) indicated that parents of children with ASD experiencing significant challenge with the dental health of their children, often due to lack of knowledge and awareness of how to deal with the same. This finding indicates a lack of awareness group in the country. Another study by Allala and Alzubairi (2016) also confirmed that there are less social support systems in Saudi Arabia for parents with children with disability. Furthermore, the level of income influenced the shyness level of such parents.

According to the literature presented in this section, it is evident that a number of studies have been done with regards to group awareness of parents of children with disability. However, there is barely a similar study in Saudi Arabia that specifically focuses on parents of children with disability. Also, most of the studies

in Saudi Arabia have focused more on autism. The current study was, therefore, designed to explore the availability of awareness group of parents of children with disability, and their benefits in Saudi Arabia. The following section details the methodology used in the study.

2.0 Methodology

2.1 Study Design

The study used a mixed-method approach; that is both a qualitative interview and quantitative survey designs. The survey design was appropriate, considering that there is little information regarding the awareness group of parents of children with disability in Saudi Arabia and the perceived impact of the same. A survey study is often preferred in cases where there is a need to establish more information about a given research phenomenon (Park, & Park, 2016). Considering the ambiguous nature of the topic, it was necessary to use a qualitative interview. According to Prasad (2019), qualitative studies are often preferred in capturing information that cannot be effectively expressed quantitatively. Parents of children with disability have a different experience with their children. As such, it is not possible to uniformly capture their perception. However, through an interview, it is was possible to probe and gain more insight regarding the experience of such parents with regards to children with disability and social support.

2.2 Participants

The participants were purposively selected. Purposive sampling is the selection of study respondents based on pre-determined conditions or criteria (Campbell et al., 2020). In this study, all the participants were parents with children with some form of disability. Also, snowball sampling was used to get the specific participants. Snowball sampling involves the use of respondents with who the researcher has some kind of acquaintance (Etikan, 2016). In this study, family friends, relatives and colleagues were the initial contact persons. Only contacts with

children with a disability were contacted. The initial contact persons were asked to refer or recommend the researcher to yet other participants with children with disability. The procedure was repeated until all the respondents were reached. A total of 106 participants were selected, of who, 6 participated in the qualitative interview, and the remaining 100 participated in the survey study.

2.3 Instrument and Data Collection Procedure

For the qualitative study, the unstructured interview was used. This technique is usually preferred in cases where the responses are less anticipated and may vary from one participant to another (Adhabi, & Anozie, 2017; Prevett et al., 2020; Roulston, & Choi, 2018). It was deemed prudent that the researcher initiate interview based on the prevailing situation of the parents. This decision was based on the fact that different parents could have children with a significantly different disability, and as such, their experience and challenges were unique.

For the quantitative survey data, structured close-ended questionnaires were administered online to the respondents. Since 100 respondents were targeted for the quantitative data, it was necessary to use an online survey to avoid frequent interpersonal contacts following the constraints caused by the coronavirus pandemic.

3.0 Results

3.1 Quantitative Results

3.1.1 Demographic Data

Table 1

Gender

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Male	16	16.0	16.0	16.0
Female	84	84.0	84.0	100.0
Total	100	100.0	100.0	

According to table 1 above, majority of the respondents (84%) were women, and the remaining (16%) were men. More women than men were expected to respond, given their close contact and knowledge of their children's disability needs.

Table 2

Age

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 18 - 24	14	14.0	14.0	14.0
25 - 34	54	54.0	54.0	68.0
35 - 44	32	32.0	32.0	100.0
Total	100	100.0	100.0	

Table 2 above indicates that majority of the respondents (54%) were of the age of 25 – 34. Also, (32%) of the respondents were of the age of 35 – 44 years. The remaining (14%) were of the age of 18 – 24. None of the respondents was of the age 45 years and over.

Table 3

Education Level

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Primary	7	7.0	7.0	7.0
Secondary	53	53.0	53.0	60.0
University	40	40.0	40.0	100.0
Total	100	100.0	100.0	

According to table 3 above, majority of the respondent (53%) had secondary education qualification. Another majority (40%) had university qualification. Only (7%) had less than primary education qualification.

Table 4

Type of Disability

	Frequency	Percent	Valid Percent	Cumulative Percent
Mental	14	14.0	14.0	14.0
Visual	8	8.0	8.0	22.0
Multiple disability	8	8.0	8.0	30.0
Valid Motor	8	8.0	8.0	38.0
Autism	29	29.0	29.0	67.0
Down syndrome	33	33.0	33.0	100.0
Total	100	100.0	100.0	

As indicated in the table above, the majority of the parents had children with down syndrome (33%). Another majority (29%) had children with an autism spectrum disorder. Also (14%) had a mental disability. An equal number of cases of visual, multiple disabilities, and motor disability were also reported at (8%) each.

3.1.2 Awareness/Support Groups of Parents of Children with Disability

Table 5

General Awareness of Groups for Parents with Children with Disability

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Yes	76	76.0	76.0	76.0
No	24	24.0	24.0	100.0
Total	100	100.0	100.0	

According to table 5, more than half the majority of the respondents (76%) were aware of the existence of awareness group, or social groups for parents with children with disability. The remaining (24%) were unaware.

Table 6

Source of Knowledge of Awareness Groups

	Frequency	Percent	Valid Percent	Cumulative Percent
Internet	33	33.0	33.0	33.0
Friends/Peers	15	15.0	15.0	48.0
Parents/relatives/siblings	23	23.0	23.0	71.0
Institutional centers	15	15.0	15.0	86.0
None	14	14.0	14.0	100.0
Total	100	100.0	100.0	

As table 6 above indicates, the majority of the respondents (33%) knew about the awareness or social support groups for parents through the internet. Another (23%) reported having heard from parents, relatives, or siblings. Also, (15%) indicated to have heard this information from friends and peers, as well as institutional centres. Another (14%) reported never to have heard of such information from anywhere.

When asked about the awareness of an awareness group, or social support group for parents with children with disability within their communities, all the respondents reported to be unaware of the same, as shown on table 7 above.

Table 7

Presence of Awareness Group within the Community/City

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid No	100	100.0	100.0	100.0

Table 8

Attendance of Awareness/Social Support Groups

	Frequency	Percent	Valid Percent	Cumulative Percent
yes	16	16.0	16.0	16.0
Valid No	84	84.0	84.0	100.0
Total	100	100.0	100.0	

According to table 8 above, majority of the respondents (84%) reported to never have attended any awareness/social support groups for parents. The remaining (16%) reported having. However, those who reported with affirmative probably had attended the same elsewhere other than their community. Table 7 indicates that none of such groups exists within the respondents' respective communities.

Table 9

Willingness to Attend Awareness/Social Support Group

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Yes	100	100.0	100.0	100.0

Despite the majority reporting to never have attended such support groups, all of them showed a willingness to attend such awareness group if they existed within their community (table 9).

3.1.3 Perception Of Awareness/Support Groups

Table 10

Challenge Level for Parents with Children with Disability

	Frequency	Percent	Valid Percent	Cumulative Percent
Very difficult	67	67.0	67.0	67.0
Valid Difficult	33	33.0	33.0	100.0
Total	100	100.0	100.0	

According to table 10 above, majority of the respondents (67%) reported that they experience very difficult challenges with their children. Another (33%) reported that the challenges were difficult.

Table 11

Saudi Arabia Policies on Supporting Children with Disability

	Frequency	Percent	Valid Percent	Cumulative Percent
very poor	45	45.0	45.0	45.0
Valid Poor	55	55.0	55.0	100.0
Total	100	100.0	100.0	

Based on the challenges experienced by parents with children with disability, they were asked to rate the various support offered by the Saudi Arabia government. As shown in Table 11 above, majority of the respondents (55%) reported that the support was poor, while the other (45%) reported that the support was very poor.

Table 12

Need for Awareness/Social Support Groups for Parents with Children with Disability

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid yes	100	100.0	100.0	100.0

The respondents were then asked whether they needed awareness of social support groups for parents with children having a disability. As table 12 above indicate, all the respondents agreed.

Table 13

Desired Assistance/Help from the Awareness/Social Support Group

	Frequency	Percent	Valid Percent	Cumulative Percent
Independence	63	63.0	63.0	63.0
Social Skills	21	21.0	21.0	84.0
Educational development	16	16.0	16.0	100.0
Total	100	100.0	100.0	

Assuming the existence of awareness/social support groups, the respondents were asked of the kind of support that they would want to get from the same. As table 13 indicates, most of the respondents wanted assistance to enable their children to become independent (63%). Another (21%) wanted their children to have social skills, while the remaining (16%) wanted their children to attain educational development.

3.2 Qualitative Results

A thematic analysis was used to explore the interview transcripts. Codes were generated, which were then used to generate the relevant themes for the study, which are outlined below.

3.2.1 There are Almost no Awareness/Social Support Groups for Parents with Children with Disability

All six respondents agreed unanimously that there are no awareness groups or social support groups for parents with children who have a disability. All the six respondents were actually aware that elsewhere, there are support groups for such parents. One of the respondents was offered to join a support group, although she turned down

I wouldn't. I was offered to join many support groups in Canada, but I am a person that doesn't believe in support groups.

According to the respondent, joining a social support group makes her feel as if she admits that she has a sick child, and is therefore afraid that the family could be alienated on the same basis.

I am against support groups because I feel that it can alienate the family member

3.2.2 Awareness/Social Support Groups are Necessary

All five respondents unanimously agreed that awareness groups for parents with children with disability are absolutely necessary. Two of these respondents had actually been members of the same elsewhere other than Saudi Arabia, and they admit that the groups had really been helpful.

There were a lot of religious and spiritual speculations since all the hospitals I had attended, including some in Jordan, could not establish the cause of my son's seizures. Eventually, I found a support group for parents with children suffering from epilepsy in the United Kingdom.

I had an experience with a support group of parents with children having autism. From this group, I learned a lot on how I could help my son, especially with educational development; which had really been a problem.

Although one respondent was sceptical about the social support group, she admitted that similar government programs in Saudi Arabia would be effective, which concurs with the findings of the literature.

3.2.3 Most Parents Would Prefer Independence

Most of the respondents reported that they would prefer if their children could be independent. Below are some of the responses.

I am getting old, my wife passed away, and my son is currently 28 years of age, but I am afraid he cannot live without me. I am always worried who will take care of him when I die.

I would like my daughter to have an independent life, travel the world. My sister and I were able to travel by the time we were 15 and 16. If only she could have the same life, like her other twin sisters.

If my son could be independent, he could even learn some apprenticeship and earn a living, and probably have his own family. However, I don't know how I can achieve it.

4.0 Discussion

The qualitative results complement the quantitative results with respect to lack of awareness or social support programs in Saudi Arabia, awareness of the same, and the preferred benefits. Generally, the study found that most respondents are aware of the existence of awareness or social support programs for parents with children with disability. Despite the awareness level, the respondents report of lack of knowledge of similar groups in Saudi Arabia, which is consistent with the findings in the literature. Mohamed et al. (2019) reported a lack of social support programs for mothers with children suffering from Cerebral Palsy. Alwhaibi et al. (2020) also reported a lack of community and institutional support for mothers with children having a disability in Saudi Arabia. Similar findings were also reported by (Alenazi et al., 2020; Al-Kandari et al., 2017; Alqahtani, & Luckner, 2019).

The lack of adequate awareness group, or social support programs for parents with children with disability in Saudi Arabia can be associated with cultural and religious practices and beliefs. Balubaid and Sahab (2017) reported that despite adequate knowledge of coping with children with disability among mothers of children with Cerebral Palsy, religiosity is a significant obstacle, especially with regards to sharing and interacting with the society. Alsharif (2019) found that religion interacts with other factors such as education level and geographic location to negatively influence the society's view of disability in Saudi Arabia. Another study by Sharak et al. (2017) found that religious beliefs regarding child disability in Saudi

Arabia were associated with increased stress levels and poor coping behaviours. A negative relationship between religion and perception of child disability were also reported by (Hassanein et al., 2020; Mahson et al., 2020).

The positive perception of the respondents towards the awareness or social support groups is directly related to the perceived benefits of the participating in the same, which was demonstrated by studies in the literature review (Amaya, & Tomasini, 2014; Peer, & Hillman, 2014; Park, 2020). Nemati et al. (2020) argue that the primary challenges of mothers with children with disability are often accepted. Similar sentiments are also confirmed by (Behrani, & Shah, 2016; Di Renzo et al., 2020; Wheeler et al., 2018). Participation in the awareness programs, therefore, helps the parents to at least interact with other parents with a similar situation, and they learn from them how to cope. Although religion is portrayed as a negative determinant of coping behaviour, Qureshi et al. (2020) argue that it can sometimes play a major role in acceptance among parents with children with disability.

The awareness groups for parents with children having disabilities functions in an almost similar manner to social support groups for people recovering from drug addiction, or trauma. The social rings for addicts are meant for sharing experiences, stories, and creating networks to help with recoveries. Often, when one is overwhelmed, he or she can call a trusted member from the ring to assist with the current situation (Abdollahi, & Haghayegh, 2020; Bliuc et al., 2020). The awareness groups for parents with disabled children also function in similar manners. It provides an opportunity for parents with children of similar disability to establish a network of support (Haynes et al., 2020). An inexperienced parent can interact and learn from other parents who have experienced similar challenges; which ultimately makes coping easier (Felizardo et al., 2016; Halstead et al., 2018; Islam, 2020).

The results also established that most parents would like their children to become independent. Dorothy Orem's self-care nursing theory can be used to explain

this finding. According to Orem's self-care theory, optimum wellbeing of an individual is achieved when one is capable of independently taking care of him, or herself (Vayalil, 2016). The theory posits that nursing care or any form of healthcare treatment is always geared towards restoring self-care autonomy, except for extreme cases of significant incapacitation with regards to the same (Younas, & Quennell, 2019).

In the context of children with disability, the parents' major concern is always the survival of the child after they can no longer take care of their disabled children; that is when they grow old, or die (Hattori et al., 2019). As one of the respondents reported, his main concern was who would take care of his son when he dies. It is also man's natural instinct to survive by procreation. Most parents and the society at large are always concerned with their children's capacity to be independent enough to raise a family of their own (Gilson, & Carter, 2016; Tyrer et al., 2020). According to Erevelles and Nguyen, (2016), female disabled children are significantly vulnerable to abuse, particularly sexual, which is yet a major concern for the parents. When such children grow up, they are more likely to get pregnant; which is yet another source of independence concern among the parents. There is always the concern about whether they will be capable of adequately taking care of the babies.

The results also indicated a great concern among parents regarding their children's social skills. Children with down syndrome, and autism spectrum disorder; which formed the major proportion of reported cases often experience significant challenges with social interaction with others at school, and within the society (Hekal et al., 2017; Milojevich et al., 2020). Yet, studies indicate that social development among such persons is important for their overall cognitive growth (Jacobs et al., 2020; Kim et al., 2016; Yatapratama, & Syamsi, 2019). The social support groups could, therefore, be used to educate the parents on how they can improve or promote the development of social skills among their children.

5.0 Conclusion and Recommendation

From the findings of the study, it is evident that there is almost no awareness group for parents with children having a disability in Saudi Arabia despite their perceived, and evidence-based importance. Parents of children with disability are certainly experiencing significant difficulties in coping with their children's condition. The awareness, or social support groups, therefore, could help such parents to learn how to effectively cope with their varying children's conditions by learning and sharing among parents with similar challenges. The study also found that despite the absence of such awareness groups in Saudi Arabia, most parents are generally aware of their existence, have a positive perception towards them, and would most likely attend the same if they existed within the community. Based on these findings, the following recommendations are made:-

- 1- Parents in Saudi Arabia communities should take the initiative of forming awareness or social support groups for parents of children with disability
- 2- The government of Saudi Arabia should develop social support programs for parents with children with disability especially in rural areas
- 3- More studies should be conducted to determine the potential barriers to formations of such groups in Saudi Arabia, and how such challenges could be overcome.

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