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Saudi Parents as Advocates for Their Young Children with Disabilities: Reflections on The Journey

Sadeem A. Alolayan
University of South Florida

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Saudi Parents as Advocates for Their Young Children with Disabilities: Reflections on
The Journey

by

Sadeem A Alolayan

A dissertation submitted in partial fulfillment
of the requirement for the degree of
Doctor of Philosophy
with a concentration in Special Education
Department of Language., Literacy, ED.D., Exceptional Ed., And Physical Ed. and Physical Ed.
College of Education
University of South Florida

Major Professor: Ann Cranston-Gingras, Ph.D.
Daphne Thomas, Ph.D.
David Allsopp, Ph.D.
Robert F. Detrick, Ph.D.

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DEDICATION

I want to dedicate my work to those remarkable parent advocates who dedicate themselves to ensuring their children with disabilities have the help they need. Thanks to the advocates who participated in my study and inspired me to make a difference. I would like to acknowledge their generosity as they illuminated my academic career in the same way they have served other Saudi parents by educating and supporting them.

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My sincere gratitude to my parents, Abdullah, and Norah, for their inspiration, support, and patience, in enduring my absence from their lives while I worked on this dissertation. To my siblings, who saw me as a symbol of perseverance and, since day one at USF, insisted on calling me Dr. Sadeem. To my darling Nada, who was the sun's warmth during this dissertation winter, believed in me on those days I was full of doubt. To sweetheart, my little sister, Abeer: my soulmate and wisdom mentor. I owe it all to you; I would not have been able to accomplish my work without You. To my friend Nehal Alturkistani who has walked with me on this journey, shared ideas, supported me during this process, and made my world more colorful, thank you for your unconditional love and encouragement! I also sincerely appreciate Khulod Alrwaished 's effort, who encouraged me to be "more than just a Ph.D. student" and boosted me to new heights. I also would like to thank my classmates and now true friend, Dr. Umi Halimatus Saidah, my support system through this process.

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ABSTRACT

Although special education advocates have played an essential role in obtaining rights for individuals with disabilities, there is still much unknown about their motivations, challenges, roles, and the meaning they made from their experiences. Research into Saudi parent advocates of children with disabilities and their complex daily life issues have seldom been investigated, with rare studies that focus solely on Saudi early intervention services needs and supports. This qualitative study aimed to explore the experiences of Saudi parents of children with developmental disabilities who are special education advocates in their communities. One of the goals of this study was to obtain a better understanding of how these parents view their roles in providing support to other parents and the meaning they made from their experiences. A qualitative interview approach design was adopted for data collection. Semi-structured interviews were conducted with five Saudi participants who had been in the advocacy world. Participants were interviewed about becoming advocates in the first interview, details and challenges about early intervention services in the second interview, and what advocacy means to the parents in the third interview. Findings included a nuanced understanding of advocacy in terms of motivations, obstacles to taking steps to influence others, policies, and practices. Additionally, results highlighted barriers to Saudi parent engagement in early intervention services, defining parents' role as advocates and the meanings they made through their journeys. Finally, based on the results of this study, three levels of practical implications for policy and practice were suggested. Recommendations supported by "Saudi Vision 2030" were provided

first for Saudi policymakers, second for service providers, and third for parents. The study concludes with an overview of limitations and recommendations for future research.

CHAPTER ONE: INTRODUCTION

Background

Achieving equality and justice for children with disabilities is a vital issue in the special education field. Legislated rights for these children have undergone many developments before reaching this admissible level of relative stability that promotes the rights of persons with disabilities within a humane framework based on equality of rights and duties (Leiter, 2004). Overall, the special education field seeks to meet the needs of individuals with disabilities in accordance with the laws and legislation enacted by many countries of the world. These international policies emphasize the necessity of empowering parents' involvement in the education system (Yell, 1998). Through analyzing the cultural, political, economic, and social philosophies that contributed to the emergence of special education through different centuries in a historical context, several factors play a role in influencing special education development. Moreover, the development of special education services requires diligent work in which all segments of society collaborate, and it is not exclusive to specific parties or individuals (Winzer, 2009). One contributing factor is advocacy work (Winzer, 2009).

History indicates that advocacy work has become the essential base behind which parents and specialists have stood together, thereby leading to the emergence of many associations and institutions that defend human rights (Cunconan-Lahr & Brotherson, 1996). Hence, it is imperative for all parents of children with disabilities to effectively participate in advocacy that contributes to the development of special education programs. The experience of the United States in enacting special education laws and legislation, based on scientific research

and community partnership, is an example of efforts to establish a comprehensive, accurate, legal system to guarantee rights for individuals with special needs (Yell, 1998). The main features and distinctions of U.S special education laws and regulations, are that they can be described as comprehensive. These laws and regulations have not been limited to granting students the right to a Free Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE). Rather, they have included specific procedures for providing comprehensive special education programs that include related services, transition planning, high quality teachers and other service providers. Further, they have also expanded to include the roles of parents and their participation in decision-making related to their children's education (Yell, 1998).

Since 1975, there has been rapid development toward protecting the rights of individuals with disabilities by meeting the individual needs of infants, toddlers, children, and youth with disabilities and their families. Significant progress has been made in improving social and educational outcomes for individuals with disabilities, driven mostly by the role played by parents and non-profit associations along with social and political movements (Cunconan-Lahr, & Brotherson, 1996). As a result of lobbying over the last 40 years for the provision of services for young children from birth through five years, many federally funded programs like the Head Start program have been enacted (Butler& Gish 2003). Head Start Programs include a range of services offered in many settings including centers, family childcare or/ and the children's own homes. Head Start programs aim to support children's growth and promote school readiness for infants, toddlers, and preschoolers from low-income families (Head start programs,2022).

During the last two decades, there has been growth in the Early Intervention field. Children with disabilities are entitled to receive a Free and Appropriate Public Education (FAPE) under the Individuals with Disabilities Education Act (IDEA). Part C of IDEA is focused on early

intervention, which is a program that each state administers to guarantee children a FAPE. This began in 1986 (Mattern, 2015). Early intervention services are a range of targeted services to help young children who have developmental delays or specific health conditions. Different types of specialists work with these children. Providing services early helps children catch up and increases their chances for success in school and life overall. The IDEA Part C early intervention program aims to enhance the development of infants and toddlers with disabilities, to increase the capacity of families to meet their child's needs and to minimize the need for special education or services later in the child's life (IDEA, 1997).

Despite developments in Saudi Arabia in various areas such as infrastructure, technology, and the economy, there is a lack of early intervention services in comparison to the United States. Indeed, in the year 2000, a group of Saudi experts at the King Saud University reviewed the United States special education law, and as a result in 2001, Saudi Arabia instituted Rules and Regulations of Special Education Programs (RRSEP), which became the first policy that guarantees the rights of students with disabilities to have access to special education programs (Alquraini, 2013). This legislation guarantees students with special needs the right to free education in the LRE and to obtain support services, including early intervention, transitional plans, and individual educational programs. RRSEP also specifies the requirements and conditions which qualify a student to be served by special education services.

Overall, it can be said that early intervention services for children from birth to five years old and their families were, unfortunately, not developed when RRSEP legislation was enacted, nor have these services grown significantly (Alquraini, 2013). Consequently, early intervention services that are provided in Saudi Arabia are mainly clinical and are provided only through major hospitals or at basic governmental diagnostic/ early intervention centers.

Although Saudi Arabia occupies the largest area in the Middle East, in which there are 13 administrative regions divided into different provinces; early intervention services are not widely adequate due to the lack of number and services provided (Al-Mousa, 2010). In fact, there are approximately 35 government diagnostic and early intervention centers for girls and boys over the Kingdom's major cities. However, the centers are divided by gender with more being available for boys than girls with the emphasis on all special education centers being diagnostic rather than early intervention services (Saudi Ministry of Education, 2021). Still, despite the existence of some early intervention centers across the kingdom serving children with a variety of disabilities, these centers cannot accept and serve all children in need.

Due to limited resources, as well as the lack of human personnel responsible for providing these services at a high level of quality for the children and their families in the Kingdom of Saudi Arabia (KSA), parents have turned to other options for help (Alquraini, 2013). It is likely that the lack of national early intervention programs with trained specialists have led some Saudi parents to assume the role of educating peers, family, and others about their child's condition, while advocating for the child and the larger group to which the child belongs (Alshenaifi & Feng, 2020). Emphasis needs to be placed on the issue of advocacy and its significant impact on new parents of children with special needs seeking support. In addition, there needs to be recognition of the major efforts of those who advocate in the special needs field and their impact on new parents of children with disabilities seeking support.

The accomplishments of western parent advocacy and non-profit associations have been remarkable. They have been instrumental in passing many initiatives such as demanding governments to provide related services and guidance on federal policies and their direction (Fiedler, 2000). Advocacy in the western context has become organized, resulting in amazing

developments, based on a sense of social responsibility of individuals towards each other and towards society, with the intent of solving the problem of lack of services (Goldman, Burke, Casale, Frazier & Hodapp, 2020). Thus, it is necessary and urgent to initiate and implement legislation for individuals with disabilities through lobbying efforts of Saudi parent advocates. Furthermore, due to the ongoing political changes under the new Saudi 2030 Vision, a governmental plan which emphasizes investment in human resources, now is an opportune time for updating and implementing the RRSEP (Vision 2030). One update that should be initiated is providing early intervention services to parents and their children with disabilities because of the potential impact on the mental, physical, and emotional life of families (Rios, Aleman-Tovar & Burke, 2021).

Purpose of Study

Although advocacy work is becoming more common around the world (Burke, 2013), little is known about the advocacy experiences of families of children with disabilities (Burke, 2013; Itkonen, 2009). Many factors prevent or limit family participation in advocacy work (Burke, Sandman, Perez & O'Leary, 2018). Anticipating this, the scope of this exploratory study focused on how some Saudi parents have become advocates for their children with disabilities and a better understanding of what they do to support others on their own journeys as parent advocates. Therefore, this qualitative study's purpose was to explore a select group of Saudi parent advocates' experiences and to gain insight on how these parents understand their roles in supporting others.

It is worthwhile to identify these experiences to further understand the motivation that may be relevant to parents when seeking services and the barriers that stand in the way of parental participation in advocacy. Further, this study explored specific barriers that stand in the

parent's way of accessing early intervention services for their children in Saudi Arabia, and support that is needed in facilitating parental roles in early intervention services. Currently, early intervention services are not fully available for families to support their participation at all levels of planning, decision-making, implementation, and evaluation of early intervention services (Alotaibi& Almalki 2016).

Research Questions

The following research questions guided this study:

1. What experiences and/or motivations lead parents to become advocates for their children, and for other children with disabilities?
2. What do parent advocates perceive as barriers that prevent parents of children with disabilities from advocating for their children and other children with disabilities?
3. How do parent advocates define their role as advocates for their children and other children with disabilities?
4. How do parent advocates view the impact of their advocacy on the special education system and early intervention in particular?

Significance of Study

This study documented several key contributions to the field of parent empowerment in their children's education which are reflected in the fulfillment of positive child outcomes. Whereas early intervention is not the only area where advocacy is needed, it is a critical area because it is often the first experience that parents have with disability. Often, early intervention services can help support parents through the emotional experiences and adjustment associated with their child's disability (Girabent-Farrés, Jimenez-González, Romero-Galisteo, Amor-Barbosa & Bagur-Calafat, 2021). Early intervention services can also provide the child with a

disability or developmental delay a chance to catch up to their non-disabled peers which can minimize the need for special education later (Campbell & Ramey, 1994). Of all the potential benefits to intervention that focuses on children's early development, it is in language and communication skills, and parenting support where the most significant impact can be made (Hebbeler Spiker, Bailey, Scarborough, Mallik, Simeonsson, & Nelson, 2007). As stated in the Early Childhood Technical Assistance Centre and Center for IDEA Early Childhood Data Systems' report (2018), large percentages of children with a range of delays and disabilities continue to leave part C of IDEA programs with age-expected skills. This report analyzed data provided by each State to the Office of Special Education Programs (OSEP) in the U.S. Department of Education. According to the report, because of early intervention services, 70 percent of children with disabilities, aged 0 to 66 months, achieved functional performances similar to typical peers of the same age in individualized developmental and functional goals (Early Childhood Technical Assistance Center & Center for IDEA Early Childhood Data Systems, 2020). Clearly, it is important to understand what families need to successfully engage with early intervention services.

Moreover, parents play an integral role as active agents on behalf of their children. The family system has the most significant social impact on child development (Epley, Summers & Turnbull, 2011). Therefore, family support, training, and guidance have become a top priority. In the western context, advocacy work has led to developing the Individualized Family Service Plan (IFSP). This plan focuses on the family and on therapies that can help children with developmental delays. An IFSP is developed with input from the child's entire family, and it includes features that are designed to support the entire family (Brooks-Gunn, Liaw & Klebanov, 1992). Given the fact that Saudi Arabia has not yet commonly activated the (IFSP),

there is a need for action at the national level. Understanding the lived experiences of some Saudi parent advocates of children with disabilities should prove valuable in guiding and encouraging to other parents to urge the government to provide appropriate early intervention services for the families.

As mentioned earlier, raising a child with a disability often involves many challenges which may have a significant impact on family adaptation. When a child with one or more disabilities is born into a family or when parents receive the diagnosis of their child's disability, they experience a range of emotions (e.g., shock, grief, anger) similar to those experienced upon learning of the death of a loved one (Kandel & Merrick, 2003). This can be devastating. Furthermore, many parents experience periods of stress as they adjust to the demands of parenting a disabled child. The parents may tend to blame themselves or each other for the child's disability (Scorgie & Sobsey, 2000).

Moreover, parents face additional challenges raising a child with a disability, such as financial issues, greater feelings of social restriction, and inadequate support from the family members and communities (Vacca, 2006). The significance of this study rests in the recognition of parents' roles in helping other parents through difficult times. This study, therefore, should enable other parents to benefit from the experiences of advocates in this field, and also provide a clear, motivating definition on how to advocate, network, and support other parents in their new role of parent advocate. The findings of this study provide a profile of parental strengths, needs and opportunities towards positive adaptation (Rios, Aleman-Tovar & Burke, 2021).

Furthermore, although Saudi Arabia has made tremendous progress in addressing the issues of students with disabilities, the value of understanding the parents' experiences has not been studied before. Knowing parents' needs, support, and obstacles to obtaining early

intervention services can help to find solutions that may reduce the costs to governments for providing special education (Barnett & Escobar, 1987; Farris, Royston, Absoud, Ambler, Barnes, Hunter & Hassiotis, 2020). Also, this should enable decision-makers to solve any related problems that limit parents' involvement. This study helps to address the gap in the Arabic literature that overlooks the parent's perspectives, experiences, and their roles as advocates to support young children with disabilities and complements the drive to improve early intervention services.

The Theoretical Framework

According to Imenda (2014), "a theoretical framework is the application of a theory, or a set of concepts drawn from one and the same theory, to offer an explanation of an event, or shed some light on a particular phenomenon or research problem" (p189). Thus, holding a theory aided the researcher in analyzing the different aspects of a phenomenon based on the scientific method. Since making meaning of a phenomenon begins with individuals in the context; therefore, this qualitative research; an interviewing design was guided by social action theory.

Despite the overwhelming responsibility of parenting a child with a disability, some caregivers become self-motivated and empowered to fulfil their objectives without assistance, whereas other parents may need support and guidance. In this regard, Darling, (1988), stressed the motivation for parent's advocacy by arguing that, "Parental activism is viewed as a response to the failure of society to provide sufficient or appropriate resources to meet the needs of disabled children and their families" (p.5). Therefore, this research attempted to examine the parents' perceptions in making meaning of their role in peer-parental mentoring from a theoretical conceptual basis (Shepherd & Kervik, 2016).

In general, social movements have continuously acted as elements for political and social change, and, in this regard, significant theoretical and empirical efforts have been made to analyze them (Noble, 2000). Max Weber (1864-1920) was one of the founding fathers of sociology who worked to discover causation of human behavior. Within this broader field, this research focused on understanding some Saudi parents' social advocacy through the social action theory. The social action theoretical framework was used to explore the parents' perspectives of the influencing events and situational limitations that led them to become advocates for their children while making meaning of their role in advocacy phenomenon. As with other social roles, this role is learned through interaction with others. To gain a deep understanding of that role one must begin with individuals to understand both the intent and the context of human action.

Social action is a theory that emphasizes the need to focus on the small-scale level of social life, especially on the way individuals interact with each other, rather than to focus on the larger level (Tucker, 1965). Holding a social action view, helped the researcher to understand the motivation for parents' advocacy, and to understand the meaning attached to it. Social action theory aided in determining the answers to how and why, which dictates how this research should be conducted. Although Weber believed that societies are ultimately the result of human interaction rather than the cause of it, social action theory argues that individual actions are the basis of structures, systems, and groups (Law Alex ,2011; Tucker, 1965).

Furthermore, Weber's typology suggests the possibility of coming to a generalization about fundamental types of motivation for human action. Social action theory classified social action into ideal patterns of four fundamental sorts:

- Rational-purposeful Action, which is a rational social act associated with means and ends: it takes place with a purpose. Weber has given it other names such as the teleological or instrumental.
 - Value-rational Action, which is rational social action associated with a value; the individual chooses a course of action, using a directed social value.
 - Traditional Action, in which the individual's experiences are guided by traditions, norms, and values of the group to which he/ she belongs, where action is considered, a nature needing no prompting.
 - Affective social act, which is an act that is directed by feelings and emotions (Tucker, 1965).
- The social action theory will permit the investigation of the motivation of this social group of parents who experience similar experiences. The social action approach rests on the assumption that one group can make a positive impact in society through joint support.

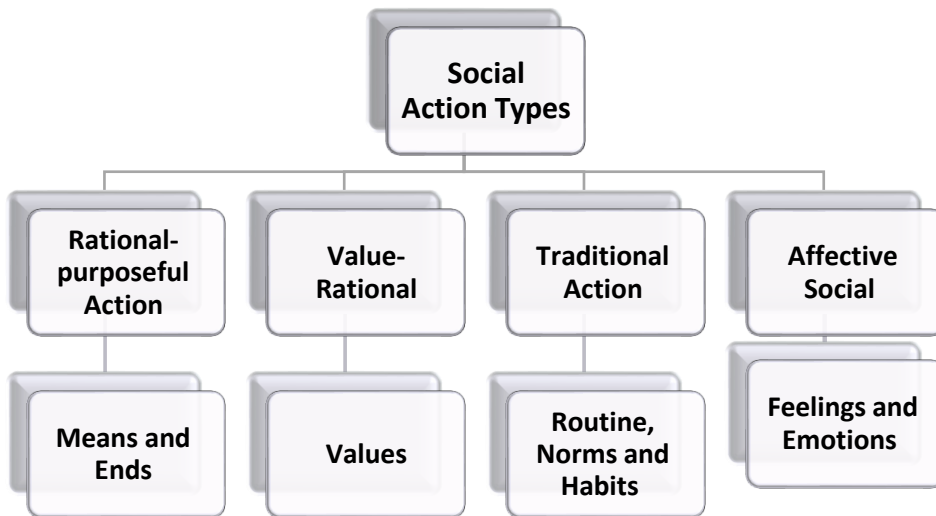


Figure1
Social Action Types

Definition of Terms

The focus of this study was to identify the parent advocates' experiences, to identify the Saudi parent's needs during the early stages of having a child with special needs, and the support appropriate to meet these needs; as well as to understand the barriers that stand in the way of advocacy. It is worthwhile to define the terms mentioned in this study:

- **Parents:** refers to Saudi mothers or fathers considered the primary caregivers for children with developmental disabilities.
- **Advocacy:** refers to engaging in any formal or informal action to educate and support other parents; emotionally, socially, and informationally; including, but not limited to, participating in conferences as speakers, contributing to producing or conveying information in any forms whether written, visual, or audio.
- **Parent Advocates:** refers to Saudi mothers or fathers who are sharing their experiences and considered socially active through their position at The Saudi Association for Special Education, which is known locally as GESTER or their social media accounts whether Twitter, Instagram, Snapchat, or WhatsApp groups.
- **Family Support Services:** are the specific services for families that enhance their child's development provided by early intervention professionals.
- **Family needs:** refer to the life skills or knowledge that need to be present to enable family members to function optimally.
- **Barriers** are any issues standing in the way of accessing or participating in early intervention services.
- **Early Intervention Services,** defined according to IDEA (1997), are early intervention services, which encompass, "developmental services that are designed to meet the developmental needs of

an infant or toddler with a disability and the needs of the family to assist appropriately in the infant's or toddler's development. The following areas are addressed: physical development; cognitive development; communication development; social or emotional development; adaptive development" (p. 101).

CHAPTER TWO: REVIEW OF LITERATURE

Families of children with disabilities often face challenges accessing services especially with regard to early intervention. Saudi parents face additional difficulties due to barriers in the diagnostic process, which might not give them access to early intervention services. Their difficulties lie with the inadequacy of intelligence quotient (IQ) tests with Saudi content, shortages of specialists in many significant areas, and out-of-pocket expenses in order to obtain an accurate diagnosis for their children within Saudi Arabia or traveling to the neighboring countries of Jordan and Egypt (Alnahdi, 2014; Alnemaary et. al, 2017). Thus, the need for empowerment and advocacy groups is increasing in Saudi Arabia to provide better services for children from birth to three years (Alkhouli, 2021).

A comprehensive review of information concerning the history of the disability advocacy movement, along with parents' experiences involving early intervention, was done to provide context for this study. The literature is presented in four sections. The first section provides a brief overview of the evolution of the disability advocacy movements. Section two addresses challenges and motivations faced by advocacy groups, their importance, and the need for a more uniform policy for action. Section three focuses on the importance and effectiveness of early intervention. The final section provides an overview of parents of children with disabilities' experience with obtaining early intervention services, their needs, inadequate support system, and difficulties.

What Is Advocacy?

Advocacy is a broad term that carries varying connotations according to the context in which it is used, whether in terms of education, society, research, and policy. According to Webster's II Dictionary, to advocate means to recommend (1999). However, there are various and frequent definitions contained in the literature for advocacy reformers that should be discussed. There have been many definitions assigned to determine the meaning of advocacy. For example, Turnbull and Turnbull (2001) state, "Advocacy is a strategy for taking action" (p. 350). While Reid (2000), firmly believes that an advocate is an individual who know how to defend thoughts and express concerns and delve into their sources. Fiedler (2000, as cited in Mitchell and Philibert, 2002) provides an expanded definition on the meaning of advocacy to "taking action that improves quality of life" and "speaking up for others who do not or can not speak up for themselves" (p. 11). Moreover, the Council for Exceptional Children (CEC), in their political advocacy handbook, suggested a simple definition, stating that an advocate stands for one who supports or defends a cause; or one who pleads on behalf of another (Bootel & Warger, 1997). Through all these definitions, it can be said that advocacy refers to a group of coordinated and integrated processes, which include planning, organizing, directing, and controlling. In short, it is setting goals and coordinating people's efforts to achieve them. Therefore, research has not established a definitive definition of advocacy.

The Evolution of the Disability Advocacy

Given the scope of this study, a brief overview of the history of advocacy among parents in The United States presented in this section. This historical analysis is fully compliant with the knowledge that examining significant events of bygone days seems vital for understanding any current or future changes, shifts, improvements in the special education system (Itkonen, 2007;

Robins & Jolly, 2013; Spaulding & Pratt, 2015). There was a time where individuals with disabilities were rejected, called names, and not allowed to have the same rights as their typical peers (Winzer, 2009). Thus, no effort to educate this group of individuals had previously been made (Winzer, 2009). For most people, a stereotype of a person with a disability was that he/ she is a burden to the community, with no education, and no ability to provide any valuable work to serve others (Spaulding & Pratt, 2015). Additionally, the perception was that they often needed financing to cover their medical care. In the middle of the last century, there were some significant attempts to understand the causes of disabilities. Some factors contributed and led to the formation of a new approach towards educating persons with disabilities, such as understanding Darwin's theory and eugenics. During the World War II, there was a vital paradigm shift that has continued to evolve. When the ideologies of Social Darwinism and Eugenics were considered acceptable, they had an adverse impact on parents with children with disabilities. Children were relegated to society's lowest strata, and forced sterilization became customary (Winzer, 2009). This negative viewpoint of the value of these said children made the formation of education opportunities for them non-existent, and this was the predominant ideology regarding special education for many decades. However, during World War II, the Measurement Movement, Braille system, and IQ, intelligence testing were used and became vital in shifting the attitude towards educating people with disabilities. The aim of the measurement movement was to objectively identify students who did not obtain any scientific benefit from staying in the classroom with their peers. Children whose academic performance was delayed were classified, and then enrolled in special education programs. It should be noted that there was a shift in ideology when one began to advocate for direct intervention and nurturing to partially or completely reverse the effects of disability (Winzer, 2009). Thus, the movement to

shift the responsibility for the education of children away from parents to the community led to the creation of common schools.

Another key factor is that the 1950's and 1960's witnessed a period of conflict and confrontation for the protection of human rights. Similarly, the passage of the 1964 Civil Rights Act prohibiting discrimination, led to further the civil rights movement in various ways. Parents of children with disabilities benefited from the movement and advocated for their children's rights. In addition, women's increased participation in the labor force and mounting concerns about poverty led to ameliorative programs for young children that inevitably spawned early childhood special education (Florian,1995). Besides the creation of common schools and legal policy, the post-World War II era brought a movement of family groups advocating the formation of social groups to protect the rights of their children with disabilities (Itkonen, 2007). The 50's and 60's saw the formation of advocacy organizations such as the United Cerebral Palsy Association, Inc., the Association for Retarded Citizens (ARC), the National Association for Retarded Children, Inc. (now The Arc), and the National Alliance on Mental Illness (NAMI). All were initially established as parent support groups and divided into diagnostic categories (disability) (Turnbull & Turnbull, 1990).

Establishment of these organizations was driven by the clear goal of supporting the parents' need to get better services for their children. Itkonen (2004) draws attention to the fact that most disability advocacy organizations began as local parental grassroots groups using advertisements as a means of recruiting and supporting each other. In fact, The United Cerebral Palsy (UCP) organization started by two families in the 1950s attempting to connect and support each other through the feelings of isolation and paucity of available services for their children. Their newspaper advertisement recruiting other parents to join their crusade demanding better

services designed to integrate their children into society has led to lasting impacts on current services for children with Cerebral Palsy (UCP, 2021).

Parents served as lobbyists and because of these indefatigable efforts, the federal government had to take significant actions. In response, the federal government began allocating funds and issuing legislation to support the development and implementation of programs to meet the children with disabilities' needs and their families as well (Itkonen,2007). During the era of President Kennedy, there were political and social trends that led to a call for more normalization, the abandonment of institutions, and the orientation towards mainstreaming in the educational setting (Dybwad 1990; Mitchell & Philibert, 2002; Trent 1994). Moreover, mental retardation and vocational education training programs occupied an important place among educators at that time. Additionally, President Gerald Ford on November 29, 1975, signed into law the Education for All Handicapped Children Act (Public Law 94-142) to support states and localities in protecting the rights of, meeting the individual needs of, and improving the results for, infants, toddlers, children, and youth with disabilities and their families (IDEA, 2021).

Despite a significantly improved recognition of the rights for children with disabilities since 1975, the ideal of full integration has not always been adequately met. For example, Spaulding and Pratt (2015) argued that the increase in these services led to creating philosophical differences regarding other issues in special education, such as including students with disabilities in the regular classrooms. Therefore, there is an urgent and permanent need of ongoing advocacy. Whatever progress occurs, there remains a need for further growth and improvement. However, through the historical tracing of parental advocacy in the passage of laws concerning special education, it appears that American parents have achieved much. Parents made a significant impact in the promulgation of legislation stemming from court cases

like *Brown v. Board of Education of Topeka* (1954), and *Mills v. Board of Education of District of Columbia* (1972) which resulted in the granting of parental rights in four major areas under IEDA which are notice, consent, participation, and compliance (Mead, & Paige, 2008).

Advocacy in Saudi Arabia

Due to the discrepancy in the advocacy definition, the advocacy work in its general sense that was previously referred to takes various forms in Arab countries and Saudi Arabia in particular. The system of government in the Kingdom of Saudi Arabia is that of a monarchy. The government in the Kingdom of Saudi Arabia is based on justice, consultation, and equality following the Islamic Sharia. Nonetheless, the king determines the final decision to arrange the country (Van Eijk, 2010).

Arab awareness groups and nonprofit associations play an essential role in communicating decision-makers' views or supporting government efforts in providing appropriate educational services. The nonprofit sector and their widespread efforts enormously contribute to society by providing needed services to support and guide families through adapting to disability by voluntarily offering information or social support. Their primary role can be seen as serving as an informational compass for responses to the complexity of parenting a child with a disability (Hadidi & Al Khateeb, 2015). However, only a few published studies documented this vital role of parental advocacy work in middle eastern countries (Burke, Rios & Lee, 2019; Alkhouli, 2021; Altamimi, Lee, Sayed-Ahmed, & Kassem, 2015).

Saudi society is a society of a religious nature and derives its practices from the principles of the Islamic religion. One of the principles of this religion is equality in rights. In addition, Islam supports the idea of social responsibility (Al-Aoufi, Al-Zayoud, & Shahminan, 2012). These religious principles support the global shift towards advocacy. (Altamimi, et al.,

2015). Over the years, special education policy has evolved from primary care and isolation in institutions to public inclusion (Almoussa, 2010). Although Saudi Arabia was established over a hundred years ago, official attention was not given to special education until about fifty years ago (Al-Ajmi, 2006). Most Saudi kings gave special attention to education, given that it is essential to the country's development. Like most countries, special education started with some personal effort for obvious disabilities like deafness and blindness. In the late sixties, the efforts of Saudi parents began to formulate a new concept to defend their children's rights to education through individual efforts. Some Saudi men have mastered the Braille language; thus, some wealthy families have taken the responsibility to hire these professionals to educate their blind children with their peers in public schools without the official supervision of the Saudi government (Almoussa, 2010). It can be said that, in Saudi Arabia, service provision for blind students started voluntarily when there was a lack of official learning institutions for the blind. These initial steps determined the Saudi advocacy path today, where parents are seeking to support each other informally or tend to pay for the services they want to obtain.

According to Merza (2012), Saudi interest in the special education system has grown due to the signing of the Convention on Human Rights and the Rights of the Child. Thus, successive developments in the philosophy of aspects of human, social and health care for Saudi citizens, as well as the affirmation of their right to obtain the services they need regardless of their age, traits, and needs, have been carried out. According to a national report issued by the Saudi Ministry of Human Resources and Social Development (2014), about 32 charity associations are concerned with disability. Establishing Saudi charitable associations specializing in all disabilities and registering them under the Ministry of Human Resources and Social Development umbrella is considered one of the most prominent advocacy activities carried out

by Saudi families. These charitable associations provide direct and indirect services to cases of disabilities of both sexes and all ages through their centers or websites and contribute to raising awareness among audiences. Also, these charitable associations urge the government and private sectors to provide better opportunities for individuals with special needs. Tracking the historical context of establishing these associations, it is evident that they are often an initiative of individuals concerned about disability with the support of professionals and donors. Often the endeavor to inaugurate them was based on a great sense of the extent of the suffering of the families in finding resources and the absence of social support, instructions and guidance in dealing with the child. Usually, with the efforts of the founding group, formal letters are sent to the Saudi Ministry of Social Affairs, which then reviews and supervises the association's activities, gives permission to establish the association, and officially registers the association in the records of charitable associations.

Alharbi and Alshammari (2020) claim that the current special education system in Saudi Arabia is rigid, which might limit the student's freedom of choice toward better learning opportunities. They also stress that the Kingdom's Vision 2030 emphasizes the importance of integrating democratic values into the education sector to empower the participation of citizens in the interest of the country's development. Anticipatingly, the 2030 vision supports the demand to improve special education services, thus, allowing parents to advocate for their children.

Advocacy Groups' Effectiveness in National Special Education Policies

The unified parental efforts to change societal perceptions of disability, and the overwhelming victories they achieved in the courts through litigation and legislation, allowed access to public education for their children. The parent groups' influence has succeeded in obtaining advanced services to better fulfill their children's needs (Yell, Rogers, & Lodge

Rodgers 1998). The value and power of parent interest groups on informing policies, the efficacy of their influence on a range of special education policies issues, and effective advocacy strategies will be briefly discussed below.

Many policies enacted, driven by parents' ideas and initiatives, drew support from influential stakeholders. Within the growing body of literature concerning education groups' role in policy-making, group effectiveness has been conceptualized in a variety of ways (Bailey & Blasco, 1990; Burke et. al, 2019; Burket et. al, 2018; Kirst & Somers, 1981; Mawhinney, 2001; Melnick, 1995; Opfer,2001). These benefits included, but were not limited to, obtaining new policies or adding items to legislative agendas (Kingdon, 1993), attracting positive media attention (Burke, Sandman, Perez & O'Leary, 2018), affecting public opinion (Browne,1998), and positively influencing child and family outcomes (Burke,Rios & Lee, 2019). Also, Goldman and his colleagues (2020) documented the efficacy of parent advocacy as an important coping strategy.

According to Cunconan-Lahrand Brotherson (1996) parents have strengthened their advocacy efforts by networking. Wang, Mannan, Poston,Turnbull & Summers, (2004) explained this concept by stating that, "parents had benefitted from their advocacy efforts through expanding and enhancing their social support network, by working with veteran parents, parent support organizations, and professionals"(p.148). Burke Rios and Lee (2019) concluded that parent advocates, by helping other parents, become the best teachers due to their experience. Advocates attend meetings with other parents and become important resources for these parents. Moreover, studies conducted by Vincent (1992), Turnbull et.al (2011), and Burke and Sandman (2017) have emphasized the importance of the deep bond and relation between parents and the child so much so that the parents become experts in knowing their children's lives. Parents can be

considered as accountability mechanisms to claim better services for their children, emphasizing the importance of their input for systemic change (Goldman et al., 2020; Kupper, 2003).

In addition, Conn-Powers, Piper and Traub, (2010) focused on the role played by stakeholders in evaluating the polices where multiple perspectives are included. The evaluation process requires representation of parents, service providers and advocating organizations for children with special needs. The results recommended that parents should be involved in making and evaluating decisions related to policy change. This creates more trust in the desired outcomes and to the service provided to their children (Conn-Powers, Piper, & Traub, 2010).

Strategies to be an Advocate

Some research sheds light on the need for parents to learn how to be advocates in order to face the challenges involved in raising a child with a disability (Burke & Sandman, 2017; Goldman et al., 2020; Nachshen & Jamieson, 2000; Wang et al., 2004). Moreover, Itkonen (2009) claimed that providing individuals who are interested in advocating with ample and sufficient knowledge, opens the doors for them to be qualified to interact directly with decision makers. Bootel and Warger (1997) offer suggestions for parents preparing to mount advocacy campaigns for effective participation in legislative advocacy based on CEC handbook guidelines. Bootel and Warger (1997) continue to point out strategies based on a CEC handbook that could be used to influence lawmakers through communication methods such as face-to-face visits, writing letters and e-mail messages, telephone conversations, speaking to parent support groups, and attending legislative advocacy events with their children. Donovan, 1986, and Burke et al. (2018) had similar strategic recommendations towards understanding legislative advocacy such as educating legislators about needs, engaging in collective advocacy, and developing relationships with legislators. These strategies were consistent with what Mitchell & Philibert

mentioned in 2002, where they argue that parents can implement specific techniques and develop essential advocacy skills. Mitchell and Philibert believe that parents have options for advocacy in multiple ways; by becoming self-advocates, representational advocates, or political advocates. These gradation levels develop according to various purposes of the parents' advocacy goals, all of which eventually fall into one category- improving the quality of services for all children with special needs and their families.

Regarding the responsibilities associated with providing this education, Bruns and LaRocco (2017) suggested a few procedures for early intervention personnel to implement to make it easier for families to assume the role of advocates. Effective strategies include carefully listening, asking clarifying, open-ended inquiries to better comprehend a family's concerns, showing empathy, and demonstrating respect. (Bruns & LaRocco, 2017). Other strategies include teaching parents how to prioritize needs, co-planning, and solving problems. These are strategies that help families become better advocates for their kids. (Bruns & LaRocco, 2017). In this respect, Kim, Cavaretta, and Fertig (2014) add that it is the responsibility of service providers to inform parents and teach them so that they are prepared for the next phase of their lives, especially the time of transition to public schools. Furthermore, Little, Wallisch, Pope, and Dunn's work, (2018), studied the impact of the provision of early intervention services' telehealth for children with ASD and their families, which produced interesting results, indicating the effectiveness of this method as a solution for parents, especially for those living in the suburbs or urban places that are difficult to reach. Providing this type of service to children has become an essential concern for parents working with policymakers to enact.

Parent Advocates' Inspiration

Notwithstanding the importance of involving parents as agents to obtain services to achieve the best for their children, it is crucial to become aware of some of the motives behind this advocacy. As cited in Canadian Education Association (2011):

Parent advocates seem, for the most part, to be born from three distinct impetuses: a desire to fix something for their own child or children; a reaction to issues connected to special education; anger about a new policy being imposed (Kidder, 2011, p.4).

Indeed, the needs of parents whose infants or children have been recently diagnosed as disabled differ in many respects from parents of school-aged children (Gensler, 2009; Harry & Ocasio-Stoutenburg, 2020). Understanding these obligations and responsibilities from a parent's point of view is vital because parents often feel the need to receive support from other people who have had the same or similar experience (Alkhouli, 2021; Cunconan-Lahr & Brotherson, 1996; Jensen & Anne, 2000; Khusaifan, & El Keshky, 2021; Mitchell & Philibert, 2002).

Enrolment in advocacy programs appears to motivate parents to talk to other parents. An increase in motivation to affect systemic change in special education and the legislative process following participation in a parent advocacy program was first reported by Burke and Sandman (2017). In Burke & Sandman's (2017) work, the researchers intended to measure the effectiveness of enrolling in an advocacy program for the empowerment and motivation of parents. Burke & Sandman also listed several benefits for parents after leaving the program such as engaging and mounting varying forms of advocacy. According to the researchers, it was obvious that parents tend to utilize informal activities like sharing information with other parents more than formal activities (Burke & Sandman 2017).

Moreover, a study conducted to explore parents' perceptions of their role as advocates, and the impact of advocacy on their lives found both negative and positive results. To illustrate, on the positive side, parents expressed that their motivation to participate in advocacy was driven by moral obligation. Some parents believed they were fully responsible for their children's physical deficiencies; and therefore, they have vowed to compensate for this by becoming a voice for their children (Wang et al.,2004). In addition, Wang and his colleagues (2004) argued the lack of quality of the child's education services is one of the most important reasons that drives parents to be involved in advocacy activities for improvement of these services in the first place.

Given the fact that we live in a digital age, the impact of the Internet on people's lives is clear. There are large numbers of people using social media platforms, such as Facebook, to obtain social support or to access information for dealing with their disabled children. From this perspective, a study conducted by Abel, Machin and Brownlow in 2019 focused on investigating the goals of the establishment of autism groups on Facebook, found valuable information with results indicating that about 15.8% of the total count of 500 autism groups existing on Facebook were created as advocacy groups by parents to support each other.

Moreover, in a meta-synthesis conducted by Boshoff (2016) to understand parents' experiences with advocacy, it became clear that there are three stages that parents experience in the advocacy journey. Initially, parents were besieged with mixed feelings of anger, sadness, fear, discontent, and confusion regarding the diagnosis process. This led parents to request and search for more information, which was described as the second stage or the strategy of coping. After realizing the diagnosis, the third stage would come into action. This can be divided into two parts: (1) first seeking, obtaining, and using support services, and then (2) engaging the

community and educating others. As a reaction to what the parent advocates had negatively endured due lack of understanding and judgement, parents have chosen to engage with the community in various advocacy formats such as conferences/events, support groups, and the education of teachers and professional to make their and their children lives easier. (Boshoff, 2016).

Parent's Barriers to Advocacy

Although parental involvement in advocacy for their children have had positive effects and results, there are undoubtedly some impediments and obstacles that parents face to become effective advocates. Limited time and emotional stress are among the reasons standing in the family's way for being advocates for their children. Much literature supports the existence of substantial barriers for parents being advocates, most frequently reported as a lack of time and energy (Burke et al., 2020; Cunconan-Lahr & Brotherson, 1996; Gensler, 2009; Wang et al., 2004). Wang et al., 2004, studying the impact of advocacy on parents' lives, found that parents feel stressed due to a drain on family members' physical and emotional well-being. This was also noted in various studies, where researchers affirm that advocacy is emotionally draining because advocacy creates additional stress in that there is a fear for having the additional responsibilities of being involved (Cunconan-Lahr & Brotherson 1996; Burke et al., 2018). Moreover, Intagliata & Doyle (1984) cited further emotional constraints inhibiting the family's active struggle for legislative victories as, "strain resulting from the unrelieved burden of caretaking, marital conflict, social isolation, and financial burden" (p. 4).

Many parents come from impoverished or limited educational backgrounds. Financial burdens were frequently cited as obstacles to involvement in advocacy activities (Cunconan-Lahr & Brotherson, 1996). Government funding as a systemic barrier might be considered as an

obstacle among parents demanding better service. Parents are aware of the lack of governmental funding; therefore, they consider that developing any kind of advocacy activities would be ineffective (Burke et al.,2020). Moreover, Wang, and his colleagues (2004) reported that parents face several logistical barriers when conducting legislative advocacy. These logistical barriers include, but are not limited to, childcare, working time, and long- distance travel to participate in legislative advocacy.

Furthermore, Sperry, Whaley, Shaw and Brame's 1999 study of parents' perceptions of early intervention practices found barriers within the service systems that stand in parents' way of services. Despite emphasizing the importance of their participation as advocates for their children, the lack of cooperation among early intervention service providers was described as an obstacle for parents (Sperry, Whaley, Shaw & Brame, 1999). For example, parents feel they were not taken seriously by the early intervention providers when they asked questions, or when they wanted to learn more about their child's treatment plan. Actually, and from the parents' point of view, they think they know more than the specialists know and want to be respected as experts as well (Sperry et al.,1999). The lack of cooperation between service providers and parents appears to be one of the strongest barriers to parents demanding and obtaining better services for their children.

Knowledge barriers were mentioned several times in literature. Parents are unsure how to advocate for their rights. Many skills need to be obtained such as accessing trusted resources and information, documenting data and gaining self-confidence (Besnoy, Swoszowski, Newman, Floyd, Jones & Byrne, 2015; Burke et al., 2018; Cunconan-Lahr & Brotherson,1996; Kim et al., 2014; Mahoney & Filer, 1996; Okumura, Saunders & Rehm, 2015; Turnbull & Turnbull, 1990). Despite the significance of advocacy training and education, this has not been widely applied to

parents. There remains a need for exploring parent's experiences with legislative advocacy. A key problem in existing literature indicates little discussion of studies that focus on advocacy training and education programs for parents. (Baker & Brightman, 1984; Baker, Landen & Kashima, 1991; Burke & Sandman 2017; Cunconan-Lahr & Brotherson, 1996; Haynes & Hartwell-Meyers, 1978; Wang et al., 2004; Zirpoli, Hancox, Wieck & Skamulis, 1989). Thus, parents' lack of advocacy skills is a barrier to obtaining better services for their children.

Okumura and colleagues suggested providing parents with information necessary for them to acquire appropriate services for their child in addition to advising, guiding, assisting, and supporting them to facilitate their mission as advocates (Okumura et al., 2015). Cooperation to reach an agreement between service providers and parents is fundamental in order to obtain the best services for children with special needs.

What is Early Intervention?

The term early intervention refers to a broad array of activities designed to enhance a young child's development for both at-risk children and children with developmental disabilities (Ramey & Ramey, 1998). This view is shared by Douglas, Meadan & Kammes (2020) who argue the significance and effectiveness of early intervention services to support infants and toddlers with disabilities or developmental delays and their families must begin as early as possible. Also, they stress that early intervention must consist of various services such as physical, psychosocial, social, educational, speech, and occupational therapy programs for the children with disabilities and appropriate services for their families (Douglas et al., 2020). Similarly, Blauw-Hospers and Hadders-Algra (2005) emphasize that early intervention services are individually designed services that specifically support and enhance the development of children with disabilities. These services help to achieve growth geared towards all

developmental aspects which include self-help, gross motor skills, fine motor skills, social development, and language skills. In addition, according to IEDA, early intervention is a developmental service designed to meet the needs of an infant or toddler with a disability or at risk of a disability, while meeting the needs of the family to assist appropriately in the child's development, as defined by the Individual Family Service Plan (IFSP) team in any one or more of the main developmental areas. IFSP is a written document developed by a multidisciplinary team, including the parents, that aims to guide the early intervention process for children with disabilities and their families. The IFSP considers a family's unique concerns, priorities, and resources to plan, implement, and evaluate services. (Gunn, Liaw, & Klebanov, 1992).

Moreover, early intervention should be provided free of charge under public supervision in a cooperative manner with the parents (IEDA, 2021); a description that is in line with evidence-based, relationship-oriented, family-centered framework the one established by Guralnick (2011). The developmental system approach emphasizes not only the centrality of families but also the importance of relationships between early intervention providers in their activities which promote a child's development. Guralnick's approach is grounded in strengthening the quality of key family patterns of interaction that influence a child's development. This family-centered framework stresses the integration principle where professionals and family are cooperatively adopting most of the decisions on all aspects of the early intervention service process (Serrano et al., 2017).

It should be said that there is a tremendous variation of the definition of early intervention with no clear, precise, or standardized description of the practices of this intervention despite the importance of the essence of this term and its use in many political, civic, and educational aspects as well (Campbell, & Ramey, 1994). For example, Dunst (1985)

had an expanded point of view regarding the early intervention services from a social system perspective. Dunst's view of family intervention practice shifted from focusing exclusively on the child to seeing the entire family, with all members needing early interventions services so that the family unit becomes empowered decision makers. Dunst defines early intervention as "the provision of support to families of infants and young children from members of informal and formal social support networks members that impact both directly and indirectly upon parents, family and child functioning" (Dunst,1985, p. 179). Within early intervention services, the professionals provide family-centered practices to increase efficiency, ability, skills, and information to reduce the effects of developmental delays or disabilities on the child and the family (Douglas et al., 2020).

Early Intervention Importance and Effectiveness

Over the past decades, substantial evidence for the effectiveness of early intervention has been considerable enough to generate interest of policy makers and health, education, and social professionals (Little, 1999). Guralnick (1997) underlined the effectiveness of early intervention, where the intervention services have spread locally, nationally, and globally, targeted towards enhancing growth outcomes for children, parents, and the family (Guralnick, 1997). There are many rationales calling for the need to provide early infant stimulation programs for children with disabilities. In general, early intervention programs identify the factors that facilitate or hinder the growth of disabled children at an early age, especially during the first five years, helping them to catch up with their typical peers (Guralnick, 1991; Herrod, 2007).

The significance of early intervention programs was demonstrated from randomized trials that targeted children with developmental disabilities and children at risk (Ramey & Ramey, 1998). Many studies have proven the effectiveness of early intervention programs for children

with developmental disabilities and for children at biologic risk (Casto & Mastropieri, 1986; Fuller & Kaiser, 2020; Guralnick, 1997; Haskins, R. 1989). The results of these studies indicate that there are moderate to large positive effects on the child's cognitive and social competence. To illustrate, in Casto and Mastropieri's 1986 meta-analysis study that evaluated the effectiveness of early intervention for 74 pre-school children with disabilities, two major findings emerged to illustrate positive effects of early intervention. The first finding was that early intervention produces a positive effect in outcome variables like IQ, motor skills, language, and academic achievement. The second major finding was that length and intensity of the early intervention programs are associated with their efficacy. Likewise, Fuller and Kaiser (2020) found in their systematic literature review of 29 studies that early intervention for communication skills for autism spectrum disorder children aged 3.81 years were effective. They pointed out that early intervention services delivered by clinicians were significantly more effective than those delivered by parents.

Guralnick (1997) confirms the efficiency of early intervention strategies on short-term goals when provided during the five first years for children at risk and for those with established disabilities. Short-term goals mostly were targeting preventing or deteriorating the cognitive skills of children; their benefits were highly reproducible, with effect sizes in the range of .5 to .75 SD consistently found for children who received early intervention services. Guralnick claims that a developmental model that has more intensity and specificity in relation to early intervention would aid in producing long-term cognitive benefits of early intervention.

Guralnick's recommendation is in line with Haskins's 1989 finding for more research on long-term measures. Haskins discussed that evidence gathered from model preschool education, and Head Start programs are reviewed to determine what impacts the quality programs can have

on low-income children's intellectual and social competence. He concluded that Head Start produces the same results as model programs for academic performance and socio-emotional development and that these improvements are seen by the end of the year of intervention, but the impact declines over the first few years of public schooling (Haskins,1998).

According to the final report of the National Early Intervention Longitudinal Study (NEILS) (2007) study sponsored by the U.S. Department of Education Office of Special Education Programs (OSEP), young children who received early intervention programs were able to show significant progress in many developmental areas such as motor, social, and cognitive-communication skills and functioning; along with the acquisition of age-appropriate skills (Hebbeler Spiker, Bailey, Scarborough, Mallik, Simeonsson & Nelson, 2007).

Key elements of early intervention that result in a favorable outcome are timing and intensity of the early intervention services (Ramey & Ramey, 1998; Wu, Chen, Ma, & Vomočilová, 2020). Many studies have shown the ability of early intervention programs to improve a significant outcome performance later in school (e.g., Campbell & Ramey, 1994; Lazar, Darlington, Murray, Royce, & Snipper, 1982; Reynolds, Egan & Lerner, 1983). Early intervention helps children to maintain the positive effects obtained in learning process to have continued academic success. Campbell, and Ramey (1994) argue the beneficial outcome of early intervention on intellectual and academic achievement for children who receive early intervention treatment during their infancy tends to be positive and more advanced than for those who do not.

Fortunately, many developed countries have sought to adopt the early intervention system for their children with disabilities. For example, The U.S. has adopted the concept of early intervention in the late 1960's and early 1970's because of the combined efforts of parents,

advocacy organizations, and early childhood specialists. As a result, legislation was established to ensure support for the children with disabilities and their families (Butler & Gish,2003; Guralnick,2011; Ramey & Ramey, 1998). The use of IFSP, which documents the long-term outcomes for the child through the interaction of family members and service providers; thus, this document is critical. First of all, it should be pointed out that family outcomes were originally defined as the benefits experienced by families as a result of participating early intervention programs (Bailey, Hebbeler & Bruder, 2006). Epley et al., (2011) state that some positive family reported outcomes were acquiring information on how to be enhance caregivers, how to develop needed skills, and how to understand the strengths and weaknesses of their child and his/her development. Hobbler et al. (2007) and Leite and Pereira (2020) both pointed out that parents and children had enhanced quality of life and well-being through the attainment of early intervention and family support services.

The National Early Intervention Longitudinal Study (NEILS) by Bailey and colleagues (2004) aimed at gathering information which investigated the family's knowledge of the child's development and their ability to provide a developmentally supportive environment while advocating for the child's needs. After analyzing the interview data, it was found that almost all parents expressed that they were knowledgeable in caring for their child's basic needs and 85% of the participants strongly agreed that early intervention helped them to feel more competent as caregivers (Bailey et al.,2004).

According to (NEILS, 2007), families mostly reported positive outcomes when they accessed early intervention services. Parents benefit by being able to work with the early intervention professionals and being able to negotiate the service system. This is known as parent empowerment. Similar results mentioned in the National Early Childhood Technical Assistance

Centre (2011) report that working with early intervention specialists helps the parents in several ways. Collaboration between specialists and parents contributed greatly to the formation of an optimistic view of the children's future (Goode, Diefendorf, & Colgan, 2011). Also, Palmer, and his colleague (2020) point out that early intervention helps parents by giving them support and encouragement in terms of the ability to advocate for their child.

Moreover, several studies indicated that early intervention contributed to developing parental self-efficacy and to increasing the direct interaction with their children, through family-centered practices and home-based intervention models in natural environments, for the acquisition of many necessary skills during the early years of life (Hughes-Scholes & Gavidia-Payne, 2019; McWilliam, 2010; Palmer, San José Cáceres, Tarver, Howlin, Slonims, Pellicano & Charman, 2020; Schaub, Ramseier, Neuhauser, Burkhardt & Lanfranchi, 2019; Shin, Nhan, Lee, Crittenden, Flory & Hong, 2009). This is consistent with Ueda and Yonemoto (2020) who indicated the effectiveness of early intervention for Japanese families. The researcher recommended the need to improve the process of communication between service providers and parents in order to help families realize the value of early intervention. The results revealed that parents who understand and embrace the importance of early intervention get better developmental outcomes for their children than those who do not (Ueda & Yonemoto,2020).

Family Experiences with Early Intervention

The voices of parents of children with disabilities have not been well represented in the early intervention literature (Wilder & Granlund, 2015). However, results were found through the existing literature review that documents the parents' desire for services to be obtained or outcomes to be achieved. Additionally, pieces of literature that focused on identifying barriers for parents attempting to obtain services for young children with disabilities were reviewed.

Family Needs

Bailey and Blasco (1990) defined family need as the expressed desire for services to be obtained or outcomes to be achieved. The birth of a disabled child may cause an emotional crisis in the family, and a breakdown of the dreams woven by the parents throughout the pregnancy journey (Kandel & Merrick, 2003). It is very common for parents to experience a wide range of emotions when they have an exceptional child as they may experience shock, grief, anger, and perhaps some emotions like those experienced when someone loses a loved one, relative or close friend (Kandel & Merrick, 2003). The announcement of a disability diagnosis may overwhelm the family and bring about radical changes in the parent's lifestyle which may lead to an imbalance in the psychological health of the family. Obviously, maintaining psychological and mental health of the family is essential. The most prominent emotional problems have been mentioned among stay-at-home parents, working parents, single parents, married parents, mothers and fathers, parents of one child or of several children (Girabent-Farrés, et al., 2021). In other words, these emotional challenges directly impact all parents. Emotional upheaval can cause marital crises, increased aggression and depression, and feelings of guilt, anxiety, and stress (Poon & Zaidman-Zait, 2014).

Social Support. Benefits for families differ due to the various aspects of support received from their social and cultural networks. A lack of or insufficient access to key sources of social support and advice on dealing with daily living skills with an exceptional child, such as peer support programs, friends, family, and other social support networks, was a significant factor in a family's need for social support. Kim et al. continued by pointing out an important coping resource is finding alternative practical social support. Identifying the types of support that families of exceptional children need is an urgent matter.

Formal and informal social support were frequently noted as an integral part of the coping experiences of parents of children with disability (Poon et al., 2014). Disability is confusing for families, especially if the families do not have the self-efficacy to recognize the developmental concerns. Using interviews and focus groups, Marshall, Raffaele Mendez and Singleton (2020) studied the experience of parents who had a developmentally delayed child, by the specific processes the parents used to evaluate the developmental delay of their children and to determine whether specialist assistance would be sought out. helped to confirm their own appraisal regarding their child's developmental delay (Marshall et al., 2020).

In Alnemary's peer reviewed thesis (2017), the researcher sought to survey attitudes of Saudi parents of autistic children towards diagnostic services. The results of the study revealed that slightly more than a third of the total 293 parents were satisfied with the comprehensive diagnostic process however, according to Alnemary, there is an urgency in increasing the professional post-diagnostic support services (2017). Since the scope of Alnemary's 2017 study was limited to early intervention services for autistic children, further investigation of the need for support services for parents raising children with other disabilities should be explored.

By the same token, Alqahtani and Luckner's study (2021) confirmed the desire of Saudi parents to obtain support services for their children who are deaf or otherwise hearing impaired. By analyzing the results of the questionnaire, parents reported an average level of satisfaction with the services and support they received for their children. Although this study was conducted with parents of children, five years and older, this generally indicates the desire of parents of children with disabilities for official support and reflects the parents' willingness to collaborate with professionals in the interest of their children (Alqahtani & Luckner,2021).

In short, more effective formal and informal support is in demand. The invaluable need of feeling that there are people who will stand by the parents in everyday contexts and in times of distress is in demand. Therefore, more effective formal and informal support from other family members, friends, community, neighbors, and co-workers are required. These support systems would provide parents with much needed physical and emotional foundations.

Family Member Participation. Although early intervention is designed to meet both child and family needs, research indicates that families request more attention to their needs in order to effectively be involved in the practices of early intervention (Decker & Vallotton, 2016). Besides the fact that both parents need information, it is useful to note that fathers seemed to need a different method of provide information. A recent review of the literature suggests that although fathers can have a positive impact on their children with disabilities, they are noticeably absent from early intervention (birth to 3) services (Flippin & Crais, 2011; McBride, Curtiss, Uchima, Laxman, Santos, Weglarz-Ward, Kern, 2017; Mueller & Buckley, 2014). Understanding the reasons for their absence is important to solving the problem.

Despite the emphasis on fathers' participation in the progress of their child's early intervention program, mothers unfortunately continue to be the primary caregiver (Flippin & Crais, 2011). First, it should be pointed out that research concerning the needs of fathers in intervention programs is rarely found (Flippin & Crais, 2011). This is likely due to the negative stereotype of the non-involvement of fathers (Campos, 2008). Race conceptualization contributes to the neglect of broader social and ecological factors and the variability that exists among fathers of certain minorities, which has led to a lack of generalizable results. This sheds additional light on the unique challenges and perspectives faced by fathers of children with disabilities.

Through a critical ethnographic approach using focus groups and follow-up interviews with Saudi mothers of children with cerebral palsy, the researchers stress the importance of discovering the impact of disability on other family members (Mohamed Madi, Mandy & Aranda, 2019). This research opened the doors to concentration on the fathers' experiences in raising a child with cerebral palsy, and to the urgent need to conduct more qualitative research that includes the other family members for better understanding of the effect of the disability within Saudi cultural context. Generally, within the Saudi society, mothers tend to be the primary caregiver of the child. The Saudi mothers bear the responsibility for the child socially, academically, behaviorally, and physically, while the fathers' main responsibility is focused on providing the financial support (Aldosari & Pufpaff, 2014). Therefore, the thematic analysis in Al-Shammari's thesis (2019) revealed that one of the benefits of using social media platforms was increasing the participation of fathers in caring for their children with Down syndrome. Following the associations and professional's social media accounts greatly contributed to encouraging fathers of children with Down syndrome to effectively participate in becoming involved in their child's training, attending awareness seminars and early intervention sessions, and in providing emotional and logistical support to their wives (Al Shamare, 2019).

In a comparative review conducted by Al Khateeb, Kaczmarek and Al Hadidi (2019) on Arab and American parents' perceptions of autism spectrum disorder, many similarities were found regarding difficulties in raising an autistic child such as financial burdens and quality of life. Due to the traditional gender roles assigned in Arab culture, the husband speaks for his wife; therefore, the mother's experience was not received or told firsthand. This was considered a limitation of this comparative review. The researchers recommend conducting more studies that clarify mothers' views in a more direct manner. It should be noted that this comparative review

was concerned with autism spectrum disorder and included seven Arab societies in general and was not limited to Saudi society.

The circumstances of divorce or separation between parents may affect the child's life. Marital status should be stable in the parents' life so the family can live in balance thus, receive services in a satisfactory and consistent manner (Brotherson, Summers, Naig, Kyzar, Friend, Epley, and Turnbull (2010)

Family Support

A family support service is any service or support provided by an early intervention provider to help families learn more about their child and how to care for a child with a disability (Edwards, Brebner, McCormack, & MacDougall, 2017). In most cases, families are eager to acquire relevant skills and information to facilitate their work in caring for children with special needs. Many countries have laws and regulations to support children with disabilities and their parents. Therefore, it is the responsibility of early intervention providers to communicate the importance of early intervention (Edwardse et al., 2017).

Information as a Form of Support. It is important to support families in building a strong information base that can be used by all children's caregivers (Starr, Martini & Kuo, 2016) and to educate families on how to organize their children's daily and developmental activities at home (Akamoglu & Dine Bell, 2015). Providers should know how to best teach families based on their learning capacities, and since the providers are the primary and trusted source of information, they should help identify opportunities and option that families can offer to them (Akamoglu & Dinnebeil, 2015; Flippin & Crais, 2011; Starr et al., 2016).

Family's Education Background. Edwards (2016) and his colleagues discuss that parents and providers need to understand the health messages being conveyed back and forth so that parents can make informed decisions. The term 'health message' refers to a persuasive message designed to influence behavior within the field of healthcare" (p.202). Edwards et al, 2016 further points out the health message must be scaffolded based on the parent's prior and current knowledge, again with the intent of parents being able to make informed decisions regarding the use of early intervention services or not. Additionally, Bruns and Steeples point out the importance of timing and content so that the information is not only furthering the parents' education but also advancing their participation in family-centered care.

The most significant barrier parents face when searching for early intervention services are lack of information and unreliable internet sources for information (Alotaib & Almalki, 2016). Insufficient information about disability and referral systems from early intervention providers was a common complaint among parents of children with ASD in Saudi Arabia (Alotaib & Almalki, 2016). Furthermore, Al- Alnemary's thesis (2017) indicates that parents' satisfaction with the diagnosis process in Saudi Arabia was associated with providing appropriate specialized support services, which includes sufficient information. Direct instructions must be provided for the referral process since the diagnosis itself is not enough to support the family's needs for useful information.

The educational attainment of Saudi parents of autistic children was consistent with receiving ASD services without delay. To illustrate, obtaining a bachelor's degree and higher education was a catalyst for the parents' attitudes to seek medical treatment as soon as possible. In Saudi Arabia, generally, family education level determines the income. Therefore, in the Saudi context, families whose parents have a high school education or less are generally

considered low-income. Saudi parents who had a high school education or less, resorted to alternative treatments such as religious and cultural treatment (Alnemary, et.al.,2017). However, this study did not determine the relationship of the parent's educational level with their satisfaction with the services provided. The focus of this study was to determine when help was sought to access services for children with autism spectrum disorder based on the educational level among the Saudi parents.

Overall, researchers attempting to measure family satisfaction with early intervention services face additional challenges because parental reports vary in terms of education level (Pang, 2010; Leite & Pereira, 2020). A study showed that the higher the level of education, the higher the satisfaction of parents (Pang, 2010). Leite and Pereira (2020) point to the opposite view: educated parents have higher expectations of professionals and services, and early intervention providers should account for differences in education levels. More educated parents require more engagement from early intervention professionals to fulfill their needs. A recent Saudi parenting study (Alsudays et al., 2020) contradicts the study by Leite and Pereira.

Alsudays et al., discovered in their analysis and findings for 243 parents from the Qassim region that education level did not affect their expectations of attention from early intervention professionals. Their study, in fact, stated that despite the difference in parent participants demographic characteristics, all parents had limited knowledge and understanding of their children's hearing loss and audiology disabilities. However, participants indicated that they had a high level of willingness and positive attitude towards petitioning for services. Holding a positive attitude among the parents reflects the demand for raising awareness among Saudi parents and providing them with developmental information to ensure that their children receive adequate

care (Alsudays et al.,2020). To sum up, early intervention providers must take care with delivery information methods, along with the quality and quantity of services provided.

Understanding Legal Aspects. Families must participate in early intervention programs and accept the child's plan. Parents frequently served as their child's advocates in various situations. (Marshall, Adelman, Kesten, Natale & Elbaum,2017). To support their readiness to participate in decision-making for their child's future, parents may need to demonstrate their need for a better understanding of the legal system or federal and state statutory law, as well as their eligibility for IDEA, IFSP, and an Individual Educational Plan (IEP). (Mattern, 2015) Providers must educate families about the child's conditions, caring concerns, and intervention goals as well as special education laws, legislation, and rules pertaining to the child's rights (Cummings, Hardin, Meadan, 2017; Mahoney & Filer, 1996).

In a qualitative research carried out in China to investigate the experiences of families of children with impairments getting early intervention services, Zhenga, Maude, Brotherson, and Merritts (2016) discovered an intriguing finding. Researchers found that early intervention professionals seriously neglected to promote policies and their application. Parents used expressions like "We didn't know... we never knew that" demonstrating their lack of knowledge of the laws and tools pertaining to children with impairments, which delayed their enrollment in early intervention programs. (Zhenga et al., 2016, p. 442). In China, parents demand for the establishment of early intervention programs. Instead of obtaining rehabilitation services—any medical, physical, or occupational treatment services provided to a individual with disability to achieve the greatest level of independence (Zhenga et al., 2016). Like Chinese parents, there are straightforward indications among Saudi parents that early intervention programs are moving toward full involvement. (Alotaibi & Almalki 2016). However, parents continue to urge for

improved services, particularly more accessible medical and legal systems (Alotaibi & Almalki 2016).

According to Alnemary et. al, 2017 on average, children with autism began to receive early intervention and diagnosis services by 3.3 years. Many factors affect the use of early intervention services in Saudi, but the greatest factor is parents' tendency to seek religious or cultural treatments due to the lack of clear policies in early intervention, despite the existence of the Regulations of Special Education Programs and Institutes of Saudi Arabia, (RSEPI), established in 2000. These laws do not specify the age of eligible children nor the type of early intervention services they should receive (Alquraini, 2013). Thus, Al-nemary et. al, 2017, recommend the necessity of updating the policies related to early intervention in the Kingdom of Saudi Arabia.

Coaching. Many research studies have examined evidence-based strategies that have proven effective in promoting children's development. (Alquraini et al., 2018; Flippin & Crais, 2011; Gallagher, Rhodes & Darling, 2004). The child spends a lot of time with family members from birth to preschool, and because each child has different needs, parents are becoming more eager to learn these evidence-based techniques. Therefore, encouraging parents to take part on coaching roles and train their children at home is essential. (Machalicek, Lang, & Raulston, 2015). Training parents in some techniques they can use in the home environment would be promising for child development outcome, because parents can be the greatest teachers for their children.

Through an online cross-sectional survey of 446 parents of children with motor delays, about 63% of the parents reported the need for more time for coaching (Gmmash, Effgen, Skubik-Peplaski, & Lane, 2021). This quantitative study aimed to verify the relationship between

the characteristics of home activities and coaching practices provided by physical therapists and occupational therapists in early intervention with parent's commitment of time and practicing to conduct the exercises. However, the results indicated that the parents mentioned that one of the factors associated with their adherence to home activities was utilizing the five coaching practices which are planning, observation, practice, reflection, and immediate feedback in addition to using the modelling approach by physical therapists and occupational therapists in training the parents to develop their children's abilities. Thus, researchers recommended using some strategies to increase parental commitment such as: simplifying tasks, motivating parents and supporting them socially, and designing activities in a manner that involves all family members. In addition, the home activities should be designed in cooperation with parents and suited to their daily routine and their home environment since that can contribute to increasing the parental adherence in promoting their child's capabilities (Gmmash, Effgen, Skubik-Peplaski, & Lane, 2021).

Mothers highly value the knowledge of other parents as an essential resource for learning about their children's development. In addition, a case study conducted in Turkey to examine the perspectives of mothers with autistic children (Kayhan & Ozaydin, 2018) revealed that other families with autistic children were the most powerful support system for educators during the diagnosis and planning of special education services. The researchers noted that new parents favored taking the same path as the prior parents in similar situations. (Kayhan & Ozaydin, 2018).

Home Visits to Support Family Members. Early intervention personnel address the needs of the child, and they are responsible for supporting the family structure (Marshall et al., 2017). Home visits provide a great solution for mothers with more than one child. Raising other

siblings and life circumstances may hinder the mother's involvement in centers or clinics. Home visits seem to be a remedy for that dilemma (Marshall et al., 2017). Home visits have been described as a convenient and supportive process for the family so that the family is not required to arrange any meetings or make any preparations. More importantly, they offer a wonderful opportunity to include all the family members (Pighini, et al.,2014). In addition, Pighin and colleagues found that Canadian parents greatly appreciated the early intervention providers' effort in involving the siblings in the process of educating and interacting with their brother or sister with special needs. Early intervention providers, during the home visit, participated in training all members of the family to encourage family involvement. Parents felt that including siblings in the early intervention sessions contributes to further strengthening family relations (Pighini et al., 2014).

Sibling involvement was also mentioned in a study by Cummings, Hardin and Meadan (2017) conducted in rural communities with most of the parents expressing their contentment in having a sibling playmate for their child with disabilities (Cummings et al., 2017). As a result, the importance of siblings in the social and linguistic interaction with the child with special needs was noted with the recommendation that many early interventions play activities should involve siblings (Cummings et al., 2017; Marshall, Goldbart & Phillips 2007).

Home visits may be a solution for more effective parental participation in the development of their children and a resolution to early intervention scheduling failures due to their work hours. An Australian study by Hackworth et al., 2018 examined the extent of parents' involvement in three types of engagement (participant enrolment, retention, and involvement) and how this involvement was affected by individual, program, and contextual factors. The study found that providing early intervention through coaching at home visits increases the likelihood

that parents will remain active and participate in the community-based parenting program. Providing this type of home visit to the Saudi community may benefit parents much as it did the Australian parents.

The Barriers for Families' Participation in Early Intervention

There are a number of factors that influence the degree to which families can be involved in their child's development. Families seeking to enroll their children in early intervention programs face numerous issues (Williams, et al., 2013). These obstacles may be due to the family structure, the economic status, or external factors such as geographical location or culture etc. (Williams et al., 2013). These barriers need to be immediately addressed when the family tries to help their child, but families often face a shortage of specialists resulting in a lack of access to early intervention services (Williams et al., 2013).

Economic Status

Poverty. Raising an exceptional child may affect or be affected by the family's financial situation. Poverty in childhood is more common among children with disabilities than among children without disabilities. Fujijura and Yamaki (2000) reported that 28% of U.S. children with disabilities lived below the Federal Poverty Level (FPL) as contrasted with 16% of nondisabled children. A more recent study by Addy, Engelhardt, and Skinner (2013) reported that from 2006 to 2011, the overall percentage of infants and toddlers living in low-income households in the United States increased from 44% to 49%. Family involvement in children's early intervention programs may vary due to economic levels. Existing research points out that family problems associated with financial difficulties are common (Addy et al., 2013; Afolabi, 2014; Longtin & Principe, 2016). According to Afolabi (2014), poverty and illiteracy hinder parental involvement in the process of educating the child.

Excessive sensitivity due to indigence and ignorance of the educational terms used by educators may lead parents to feel that their input is not welcome resulting in reluctance to participate in their children's education (Afolabi, 2014). Longtin and Principe's 2016 study of urban African American parents of children with ASD indicated that there was a relationship between poverty and parents' level of knowledge. Parents below the poverty level have more limited knowledge and awareness of evidence-based intervention and their child's program of service in comparison to those parents above the poverty level.

One of the useful strategies that appeared in Corr, Santos, and Fowler's (2015) review of literature to support families in poverty for coping with their autistic child was to follow strict daily routines. Though this coping strategy is effective, there are barriers for parents in utilizing this strategy due to unstable housing situations, consistent low income, and inaccessibility of food (Corr et al., 2015).

Al-Khateeb et al., 2019 argue in their comparative review that financial difficulties represent a barrier to seeking early intervention services for both Arab and non-Arab parents of children with autism spectrum disorders (Al Khateeb, Kaczmarek & Al Hadidi ,2019). Saudi society is similar to Western societies in this regard. In his thesis, Alnemary (2017) mentioned that satisfaction with early intervention services for autistic children was associated with family income. Impoverished parents were unsatisfied with the early intervention services. Low income may prevent parents from obtaining better opportunities for their children's development.

Furthermore, according to Alnemary et al., 2017 Saudi parents of children with autism spectrum disorder vary in deciding the treatments they can access for their child based on the family income. Household income at or below the poverty level may be related to limiting access to biomedical treatments due to the cost of biomedical treatments compared with non-medical

treatments. The expense costs of early intervention services were also reported in a study in Arar city, Saudi Arabia, by Alenzai et al. (2020) regarding the impact an autistic child has on the quality of family life. Additionally, the analysis of the numerical data collected by a questionnaire revealed that low income affects the parents' quality of life in general. In this study, parents expressed the need for more financial support from the government to receive early intervention for their children (Alenzai et al., 2020).

Employment. A variety of variables impact the financial situation of a family. These elements include challenges in finding or maintaining employment, as well as working long hours to meet the child's needs. Indeed, parents of disabled children have lower employment rates than those without disabilities. (Seltzer, Greenberg, Floyd, Pettee & Hong, 2001). In numerous studies, parents characterized these challenges as barriers to their involvement in early intervention programs. (Campos, 2008; Pearson & Meadan, 2018; Seltzer et al., 2001). Similarly, Campos's (2008) research found that logistical challenges, such as holding multiple jobs and long work hours, clearly restricted fathers in immigrant Latino families' ability to participate in early development programs.

Working African American mothers mentioned the need for more time for implementing early intervention techniques into practice (Pearson & Meadan 2018). Mothers were unsatisfied with the time and energy demands of their employment, which prevented them from fulfilling their primary responsibility of caring for their children. (Pearson & Meadan 2018). likewise, maintaining a job affects Saudi households, unemployment harms parents' quality of life. (Alenzai et al., 2020). Working for a certain number of hours per week significantly impacts the family economically and socially. In other words, working can improve the family's finances and thus, maintain better mental health. However, scheduling appointments for the child to

receive early intervention programs may be challenging due to long work hours. (Alenzai et al., 2020). According to Cummings and his colleagues, travel times for working parents in remote areas is considered a further barrier as it prevents them from spending time with their young children and getting involved in early intervention activities. (Cummings, et al., 2017).

Geographical Location. One of the dilemmas related to parental involvement in early intervention service was reaching early intervention service center locations, especially for parents who live in villages and remote communities (Alotaibi& Almalki 2016; Cummings, et al., 2017; Zhenga et al., 2016). In a study exploring whether ecocultural features enabled or prevented parents in rural communities in North Carolina from involvement in early intervention services, the results were inconsistent (Cummings et al., 2017). Some parents indicated that they had to travel far distances to access specialty services and that traveling faraway was generally a constraint. Conversely, some parents pointed out that access to services took 20 or 30 minutes and did not negatively affect their participation (Cummings et al., 2017).

Again, Saudi and Chinese parents are in agreement with their dissatisfaction with the shortage of services in many locations. Some families from rural areas needed to travel long distances to get services and supports for their children; subsequently, parents demanded their governments increase the number of centers in the countryside Alotaibi& Almalki 2016; Zhenga). Moreover, Alnemary (2017), in his thesis, attributes the delay in seeking services for Saudi children with autism, parents to their settlement in smaller cities. It should be noted that, in Saudi Arabia, appropriate services provided to children with autism are limited to large cities. Services throughout the Kingdom are not available yet. Alyami et al. (2016) agree with Alotaibi and Almalki (2016) in their recommendations regarding the necessity of providing useful and functional intervention. Alyami et al.'s (2016) descriptive quantitative research indicates limited

access to services depending on the residential area. Alyami et al. (2016) continued by pointing out that deaf or hard of hearing children who live in the capital of Saudi Arabia, Riyadh, had priority for obtaining early intervention services faster compared to their peers in other regions of the Kingdom.

The difficulty of access to services is not only related to rural communities but also to the early intervention services' location within cities for poor parents (Longtin & Principe, 2016). Families who live in poverty often reside in poor neighborhoods with few resources, and transportation costs might affect their participation in early intervention services (Alotaibi & Almalki 2016; Corr et al., 2015; Karoly & Gonzalez, 2011). Finally, Mattern (2015) stated that families moving from one state to another might encounter barriers due to the differences in systems and policies.

Shortage of Specialists. Several studies reported that early intervention services did not meet the parents' needs due to a lack of competently trained personnel (Alotaibi & Almalki 2016; McWilliam et al., 1996). Staffing issues and shortages of occupational therapists, pediatric therapists, physical therapists, and speech-language pathologists were documented in multiple studies (Alotaibi & Almalki 2016; McWilliam et al., 1996). According to Anthony (2014):

There is a national shortage of teachers for students with visual impairments and Orientation and mobility specialists in the United States, and not all of the existing personnel have the knowledge and skills they need to adequately meet the needs of birth-through-age-5 learners and their families (p. 516).

Similar results were found in Kuwait by Alduhaim, Purcell, Cumming and Doble (2020) where early intervention providers' inefficacy issues present the same challenge for Kuwait's parents. One of the issues that Alduhaim and his colleagues discovered in their qualitative case

study on Kuwaiti hearing-impaired children found was that human resources shortages, lack of qualified professionals, caused a significant difference for better early intervention services. Parents found this shortage to be a limitation that hinder their children's participation, and parental participation, in early intervention (Alduhaim et al., 2020).

Early intervention providers may have little specialized training or experience or may have an overwhelming caseload. For example, in a study by Little, Kamholz Corwin, Barrero-Castillero, and Wang (2015), the researchers identified gaps in the early intervention system and indicated that parents were displeased with the delay in obtaining services after referral. In addition, early intervention providers expressed their professional discomfort due to lack of experience as they were young clinicians who had only recently graduated (Little et al., 2015). Similarly, Brotherson and his colleagues (2016) pointed out that the providers expressed fatigue due to the increase in workload and the number of work hours, which hindered them from achieving their best performance when working with families (Brotherson et al., 2016).

Cultural Background. Many families face challenges in obtaining adequate services for their children. Additionally, obstacles related to cultural differences frequently appear among parents (Karoly & Gonzalez, 2011; Starr et al., 2016). Cultural misunderstandings may lead to losing many developmental opportunities for children who need early intervention services. The main potential barrier to enrollment in early intervention programs is lack of understanding and cultural sensitivity among early intervention providers, which leads to ineffective response and support of the family's needs (Karoly & Gonzalez, 2011; Starr et al., 2016). Researchers suggest that vulnerable families, who may benefit most from early intervention, sometimes decline services because of social concerns, stressors, or wariness about home visits (Little et al., 2015).

Social Norms. Some hindrances to parents for enrolling in early intervention services were due to incorrect beliefs about disabilities and stigmatization associated with early intervention programs (Karoly & Gonzalez, 2011). The parents' perspective and reluctance to identify disability in many cultures due to associated stigma often leads to a delay in enrolling in early intervention services (Ijalba, 2016). The extent to which practices are appropriate for other environments should be taken into consideration. Studies highlight that some strategies may not be compatible with the prevailing parental customs in some cultures and, thus, impede the implementation of some practices used in early intervention programs (Alquraini et al., 2018; Campos, 2008). For example, in the Arab and Latino cultures, parents who rarely use affection or praise tend to be regulating authorities restricting their children's autonomy (Campos, 2008). This is contrary to the principles of reinforcement and responsive interaction with the child (Alquraini et al., 2018; Campos, 2008).

Along the same lines, in Saudi society, mothers play the role of primary care providers for their children. Previously in Al-Shammari's thesis (2019), she mentioned that the use of social media contributes significantly to changing the stereotype of lack of fathers' involvement in early intervention services. She stated that the use of social media for seeking early intervention services has had a positive impact on an amendment to the traditional norms in Saudi society regarding the role of the father versus the mother in raising the children (Al-Shammari, 2019).

Cultural pattern might significantly hinder offering the child the best services. For instance, Starr (2016) noted that in some cultures the father serves as a mediator because the mother is not permitted to speak with the early intervention specialists directly. As a result, some crucial details that could have a major effect on the child's care decisions might be overlooked.

Despite the great impact of social media on Saudi society as an easier alternative way to obtain rich and reliable information from childcare providers, there are some challenges associated with it. These issues may be attributed to the Islamic religion or to the Saudi conservative culture. Some Saudi mothers claimed that it is difficult to record themselves while training their children at home and then send the recording to the early intervention specialists to obtain feedback, without first obtaining the husband's permission (Al-Shammari, 2019). This hesitation among the Saudi mothers disrupts the child's developmental training process. In addition, some parents might ask for advice from others such as grandmothers, friends, and those who do not have the appropriate experience for diagnosis or who cannot provide specialized assistance (Ijalba, 2016; Karoly & Gonzalez, 2011). Steeley and Lukacs (2015) highly recommended further studies to investigate cultural barriers more deeply.

Beliefs. In some societies, there are widespread misconceptions about disabilities. Studies suggest that societal, religious, and traditional views may influence parents' choices. These beliefs are attributed to extrinsic factors, such as God's will and spirituality. . For instance, Islamic values, directly and indirectly, affect Saudi behaviors, including dealing with adversities. According to Madi, Mandy, and Aranda (2019) some Saudi mothers who have a child with cerebral palsy interpret the cause of having a disabled child as a test of the strength of one's faith, and full acceptance of these difficulties reflects satisfaction with God's will, which also determines their place in the life hereafter. In fact, some mothers expressed their deep-seated belief that the evil eyes, envy, and demons caused their children to be disabled. Despite the accurate medical diagnosis of their children, some Saudi mothers still attributed the disability to spiritual sources (Madi, Mandy & Aranda, 2019).

In conclusion, early intervention services within the Saudi context have not been completely investigated since the cultural norms and stigmas on having a child with disabilities are changing. The literature shows that income, accessibility, awareness and education of parents affect their involvement in advocacy for their children. Formal and informal support of families is not consistent depending on geographical location of the family and their distance to early intervention centers and services as well as child with disabilities is perceived by familial support network. Therefore, there is a gap in the literature in understanding how parents view their advocacy journey which could be used to update current Saudi early intervention systems and policies.

CHAPTER THREE: METHOD

Description of Research Method

A qualitative approach was utilized in this study. Creswell (1998) defines qualitative research as an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The section below describes the methods for developing the interview design and for gathering evidence to examine the lived experience of parent advocates of children with developmental disabilities. Given the purpose of this study, an interview design seemed appropriate to answer the research questions. This exploratory study examined parental perspectives of their experiences as child advocates, paying close attention to how they help and guide other parents toward early intervention services.

Qualitative methods are relevant in this particular context for several reasons. First, most of the existing Saudi scholarship that targets inquiry into parents of children with disabilities' life circumstances has been quantitative. However, investigating the parent's point of view in a deeper manner should help in identifying any discrepancies and gaps between current research and practices as well as aid in informing early intervention governmental policies. Second, by using a qualitative methodology, the aim is to explore and understand the parental perspectives about their experiences with advocacy work rather than to generalize the results (Merriam, 2002). Third, from the social constructionist's point of view, knowledge occurs through interaction among individuals (Merriam, 2009). Qualitative research is in line with a philosophical perspective that argues there is no single absolute reality. The truth among people is not the same (Cobern, 1993). The truth can be multiple, dynamic, and formed differently

leading to the creation of change in the thinking of individuals in the same organization. There are many ideas and facts on any one subject (Liu & Chen, 2010). Fourth, the main goal of the qualitative approach is to help build procedural knowledge by answering questions about what is happening and why or how it is happening (Shavelson & Towne, 2002, p. 99). Given the nature of the purposes of this study that strives to obtain essential information regarding the parents of an exceptional child as advocates, a qualitative approach is most appropriate.

Moreover, Brantlinger, Jimenez, Klingner, Pugach and Richardson (2005) claim that one of the rationales for qualitative inquiry is to find similarities between readers and participants and to be able to make an internal evaluation of the information provided to their own life circumstances. Finally, in the qualitative method of inquiry, the role of the researcher is vital; thus, direct interaction by interviewing the participants to construct and reconstruct the meaning occurred (O'Donnell, 2012). Also, in order to have meaningful interactions with individuals and achieve logical results, engagement with the participants to gain subjective understanding was applied (Seidman, 2006). Moreover, the purpose of applying the interviewing design in this study is to elicit information regarding the parent advocates' experiences. Gaining insight into the parent advocates' experiences, as well as the issues associated with accessing early intervention services during their parenting journeys, is critical. Meaningful conversations serve to help parents critically reflect on the significance of their experiences, thus, possibly addressing the phenomenon that other parents might experience (Seidman, 2006). This study of parent advocates' experiences mainly focused on the social, economic, and psychological aspects experienced by a parent of a disabled child and the meaning of that experience.

For the purpose of conducting this study, the potential participants were selected primarily via a non-profit association that aims to support families of children with disabilities.

Setting

The primary setting for this study was The Saudi Association for Special Education, which is known locally as GESTER. This association is non-profit, and government sponsored. It was established under the supervision of King Saud University in Riyadh. GESTER is concerned with educational studies and contributes to special education journals and bolsters the collegial partnership among all stakeholders within the community (GESTER, 2021). In addition, the GESTER Professional Program (GPP) is one of the programs under the supervision of GESTAR. This program was launched specifically to achieve the organization's vision and mission of strengthening the integration and support of families and professionals. This study conducted at GESTER for multiple reasons. First, GPP is considered one of the few programs recognized nationally as an inclusive family support program that promotes equity and equality. GPP contributes to raising awareness and educating the families of children from 0 – 21 years old, and to providing the necessary support services for them. Second, GESTER has 25 branches across the Kingdom. Due to the diverse culture in each region, parents of children who are developmentally disabled and who are involved with or work for GESTER come from various economic, cultural, and educational levels. This allowed the researcher to gain insight from hearing of their diverse experiences and perspectives.

Selection of Participants

Based on informal communication with GESTER's manager, it was ensured that the researcher would have access to participants and conduct the research. Due to the manager's experience, he was considered a valuable resource for introducing the researcher to the potential participants. The researcher utilized purposive sampling to finalize participant selection in this study. The purposive sample is a non-probability sampling selected based on the population's

characteristics and the study's objective (Patton, 2002). Merriam (2009) argues that “the logic and power of purposeful sampling lies in selecting information-rich cases for study in-depth” (p. 203). The reason for choosing this type of sampling was “to select information-rich cases whose study will illuminate the questions under study” (Patton, 1990, p. 169). The criterion-based selection was appropriate technique for this study, given the purpose of the interview method intended to achieve complex and rich data regarding each individual’s narrative of being an advocate parent for a child with disabilities and that parent’s experience with advocacy work.

To achieve a criterion-based selection, a poll survey of the essential attributes, including specific characteristics and criteria to identify potential participants, was created (LeCompte & Preissle, 1993). Then, the poll survey was sent to GESTER GPP manager via email to distribute among the potential participants (See Appendix B). The primary criteria for inclusion in this study were based on the parent's role as an advocate, defined as actively participating in advocacy events. In coordination with the GPP manager, a list of names of parents who responded to the poll survey was provided to the researcher. After the pre-screening, the researcher used a criteria checklist form to achieve the goal of selecting participants who reflected the targeted characteristics and determine the final decision regarding the potential participant.

The researcher reached out to the participants to explain the purposes of the study and checked their availability to attend three meetings. The personal emails were collected from the participants to obtain their informed consent (LeCompte & Preissle, 1993). Only participants who completed all three interviews were offered promotional coupons to access entertainment facilities for their children to show the researcher’s appreciation (Head, 2009). Sampling continued until data saturation. Given the fact that GESTER has many branches across all

regions of the Kingdom, that allowed the researcher to hear from a varied range of respondents from different cultural backgrounds (Emerson, 2015; Palinkas et. al, 2015).

Description of Participants

The literature suggests that five to seven participants are appropriate for qualitative study (Lichtman, 2012; Malterud, Siersma & Guassora, 2016; Sandelowski, 1995). Five Saudi parents of children ages 0 to 18 years with developmental disabilities, participated in this study. The primary source of data collection was accomplished through interviews since the goal of this study was not testing hypotheses or generalizing the findings. These interviews were designed to present the participants' experiences through in-depth and detailed conversations. Interviewing each parent permitted those who would read this study to feel connected to this experience and know-how to reflect on it (Seidman, 2006).

Because this exploratory study has endeavored to encourage advocacy on behalf of children with disabilities starting at an early age; priority was given to selected parents of children from birth to age six who met the other criteria. Dunst claimed that levels of parental advocacy might also relate to a child's characteristics. Considering that the special education services provided to younger children are more family-centered (Dunst, 2002). There was a low response to the poll survey within this range of age. This could be due to the fact that there are few early intervention services available for Saudi parents. Additionally, parents may not express the need for legal advice or to become advocates due to the complexity of the diagnosis process.

Regardless, given that there is a lack of early intervention services in Saudi, participants of older children with disabilities aged six to twelve years old were the majority. The reason for selecting this age was supported by Goldman and his colleagues (2020) who stated that with an

average of nine years old, the child's age at elementary school, is the most common when their families requested advocacy support.

Although parent advocates of children with special needs aged 12-18 may be beyond the scope of this study, it could be argued that parents' long advocacy experience was essential to examine. According to some studies that examined the parent advocates' experiences and identified correlates of increased parental advocacy, it can be argued that advocacy correlates with the child's characteristics (Burke & Hodapp, 2016; Goldman, Burke, Mason & Hodapp, 2017). One of the identified indicators was the child's age; a significant correlation between increased levels of advocacy the greater the age of the child was found by Burke and Hodapp (2016), where an older child needs more advocacy which is related to more outstanding advocacy. Also, a continuous action of advocacy was found among parents who have been in the field for an extended period (Goldman et al.,2017). In addition, as the parents of children above the age of 12 have had more vast experience regarding the system, these parents may be especially likely to advocate for their children.

Goldman and colleagues (2017) stress that it is well-known that prior advocacy experience and involvement with advocacy organizations predict future advocacy. Wright and Taylor (2014) mentioned that as parents increase their knowledge and capacity to serve as advocates, they may feel less stressed and more empowered. Regarding the time that parents have found themselves in the advocacy world, the parents who have been engaged in the advocacy world for an extended period and the parents who are new to the advocacy world were included in this study. Wright and Taylor also pointed out that hearing from parents in the early stages of coming to terms with their child's disability uncovered markedly different experiences compared to those who had more time to come to terms with the disability.

The parents involved in this study were five Saudi citizens: three fathers and one mother living in the capital city, Riyadh, and one mother living in Makah, a western Saudi city. Most of the parents who were located in Riyadh were originally from other Saudi regions, and therefore, they fulfilled the criteria for this study. One father was from the center, and one father was from the north of Saudi. Two parents, a mother and a father were from the south of Saudi. The kingdom of Saudi Arabia is a vast land; it has a rich culture shaped by the diversity of its tribes; the customs and traditional norms are widespread and diverse from one region to another. Each region in the Kingdom has its own identity embedded in cultural aspects such as dialects, culinary identity, clothing, songs, games, and centuries-old traditions, thus, reflected in the residents' lifestyles, such as marriage norms and the ways of raising the children. For example, the Islamic value of Mecca and Medina (cities located in the west of Saudi) permitted the citizens to integrate with delegations of pilgrims from all over the world. This opportunity for unity has influenced western Saudi residents, where individuals tend to be more open and accepting of others than the rest of the citizens. In comparison, the citizens in the center, west, and south tend to follow Bedouin culture, where tribal patterns are more evident, for instance, endogamy and being hospitable to strangers, neighbors, friends, and relatives.

Interviewing parents from both genders and culturally diverse perspectives provided a deeper understanding of the barriers they encountered and the support they needed; in addition, in-depth insight was gained as the parents reflected on the meaning they made from these experiences. All of the participants were married, and the age range of the participants was 44 to 60 years old. This study's participants' educational levels varied from high school diplomas to post-graduate studies. One parent has a high school diploma, and another has a bachelor's degree,

while two parents hold master's degrees. The final participant has a doctoral degree (See Table 1).

Table 1

Description of Participants

Participant	Gender	Marital Status	Age	Education Level	Region of Origin
1	Male	Married	60	High school diploma	Center of the kingdom
2	Male	Married	44	Master's degree	South of the kingdom
3	Male	Married	46	Ph.D.	North of the kingdom
4	Female	Married	52	Master's degree	South of the kingdom
5	Female	Married	54	Bachelor's degree	West of the kingdom

To preserve the confidentiality of the participants, the specific age of their children was not mentioned in the description of the participants. For the same reason, the exact disability types were not cited where all the children's diagnoses fall within the developmental disabilities umbrella. For this study, advocacy work is defined as sharing valuable and reliable information in various forms (written, recorded, or audible) on social networks such as Twitter, Instagram, Facebook, and Snapchat; contributing to the authoring of publications of books and pamphlets; participating in giving lectures and attending awareness events; and providing legal or social advice. Participants were selected based on two essential dimensions: their advocacy work and the category of their child's disability, especially intellectual disabilities and developmental delays because these are apparent disabilities.

Data Collection

deMarrais (2004) defines an interview as “a process in which a researcher and participant engage in a conversation focused on questions related to a research study” (p. 55). The decision to choose the interview tool was considered ideal for identifying the personal and environmental conditions related to the respondents. Given the nature of this phenomenon, it was not possible to observe the parent's behaviors, values, or feelings. Thus, interviewing parents allowed the researcher to reach accurate information about the phenomenon and its impact on the parent's life. (Merriam,2009).

The interview is an expressive and qualitative tool that provides a dynamic interaction. An in-depth interview is an experiment that provides its members with a more complete self-acquaintance and realization of their roles as parents (Benaquisto & Given, 2008).

After the criterion-based selection, the three-interview series model for gathering data was completed (Seidman, 2006). This model requires three independent interviews with each participant: (A) informal conversational interview, (B) detailed interview guide approach, and (C) standardized interview that required an emphasis on the participants' reflection on the meaning their experience holds for them (Seidman, 2006). Flexibility was taken into consideration to allow choosing the best days and times for each parent. Participants were contacted to determine the days to hold each 90-minute interview. Given the purpose of this approach, 90-minutes seemed appropriate for this type of interview, with the provision that the participants knew this in advance (Seidman, 2006). In most cases, the interviews lasted for 90 minutes, nonetheless, some were a little longer where they last for 120 minutes with two of the participants at the second interview. The first meeting was prepared in a way that highlights the

participant's experience in a frame of reference for a better understanding of their life background. The interview questions focused on reconstructing the parents' experience in the context of their lives by asking them why they became involved in this study. This stage was vital due to leading the participants to a strong self-definition of themselves and narrate a range of constitutive events that led them to become an advocate (Seidman, 2006). The purpose of the second interview was to reconstruct the participants' experiences by focusing on details and telling stories. The second interview offered a chance for giving specific and intense details through describing the relationships between the participants and people around them. Also, this interview included asking the participants to reconstruct a day in their life as being an advocate as a way of eliciting details (Seidman, 2006). The interview questions were designed in a way that supported and motivated them to speak openly which contributed to getting a profound understanding of their detailed stories and lived experiences within the context of the social setting (Seidman, 2006). The last interview revolved around making meaning of the participants' experience through reflection on the information provided in the two previous interviews. This way was fitting with the research purpose which is to reach the essential meaning of this experience and promote their future orientations (Seidman, 2006).

This process was appropriate for this study due to the nature of these interviews because each interview had a specific purpose to obtain a comprehensive and in-depth answer to the research questions (Seidman, 2006). The semi-structured questions used during the interviews with each participatory parent aided in having him/her reflect and discuss his/her advocacy work experience regarding their motivations, challenges, barriers, support, and successes, particularly in the early stages of the diagnosis process from zero to three years old. The semi-structured approach was appropriate for this study because preparing the questions facilitated analyzing the

data later (Lichtman, 2013). Before obtaining the Institutional Review Board (IRB) approval from, University of South Florida (USF) the semi-structured questions were sent to multiple experts in the field in the special education department for feedback (Amoretti & Preyer, 2011). Given the exploratory nature of the study, the interview questions were broad and flexible. (See Appendix A).

The Interview Process

First of all, engagement with parents through sharing conversations, qualitative descriptions and interpretations about the parents' experiences occurred. Since the interviews fall also under the constructionist framework, the "traveler role," which is the knowledge construction, was assumed by the interviewer in this study. Denzin and Lincoln (2011) explained the role of the interviewer as constructionist is like that of a traveler whose path is determined by the local context of the conversation, stating, "There is a focus on the how rather than the what of what emerges through the situated interaction of the interview"(p. 1012). Therefore, the "romantic" role as identified by Roulston (2007) where the interviewer "makes no claim to being objective" (p. 11), was played by the researcher, to produce valid findings through analyses and reveal subjectivities (Qu, & Dumay, 2011).

Contact with participants was made by WhatsApp or phone calls. The process of informed consent was obtained before the interview process began. The interviews were held online via Zoom with permission for recording the session (Gray et al., 2020; Lichtman, 2012). Some strategies and guided instructions implemented were considered helpful in conducting these interviews, for example, a short self-introduction was given to the participants. This introduction provided information related to:

- Identifying the purpose of the interviews in a few sentences.
- Indicating how long the interview would take.
- Giving some examples if parents needed clarification.
- Asking for follow-up/clarifications.
- Asking just one clear and short question at a time.
- Showing empathy and using active listening techniques.
- Giving enough time for parents to talk.
- Using natural pausing between questions and friendly language.
- Using the local dialect instead of the academic language.
- Staying away from sensitive conversations: religion, politics, and income.
- Occasionally verifying the recordings.
- Exchanging visual illustration by showing photos, clips or documents, used to elicit and understand thoughts / feelings or to stimulate responding.

The closing question was focused on whether the participant would like to add any further information about the topic. In the case of obtaining some significant data outside of official recording, participants were asked, in a friendly way, whether they wanted to add to what had been said in the interview. This was important for both ethical and legal reasons. Along with a recording of the sessions, a researcher's personal journal for summary commentaries were used to write down any additional information gained during the interview, like non-verbal body language, through notes, regular jottings, or sketches. After each interview, the notes from the personal journal were scanned and transferred into digital form to keep them safe. Moreover, one comprehensive organizing table was used to organize the interview processes for all the participants (See Table 2).

Table 2

Sample Data Collection Process

Names	Dates	Informed Consent	Scanned Note	Transcripts	Analyzed	Member's Check
1-1						
1-2						
1-3						
2-1						
2-2						
2-3						

Quality Criteria

This study was designed to gain insight and understanding of a particular phenomenon, the parents' advocate experience with early intervention services, instead of generalization. According to Lincoln & Guba (2013), "The relationship between researcher and respondent, when properly established, is one of respectful negotiation, joint control, and reciprocal learning" (p.19). Hence, a direct interaction with parents through a deep conversation seeking to form meanings from their experiences happened. Accordingly, the role of the researcher was active, rather than passive. To ensure the quality of this study, a set of rigorous criteria in the naturalistic sense developed by Lincoln and Guba in 1986 were applied.

To maintain the methodological rigor for this study, the following parallel criteria of trustworthiness, credibility, confirmability, and transferability were applied. Validity, or credibility, was ensured by giving the findings to the participants to validate results and generated meaning by the researcher and the participants. Lincoln and Guba (2013) supported this concept by stating that, "the meanings are best found by having research participants work together with inquirers as equals, sharing the nomination of issues deemed critical to both parties, and pursuing those topics together " (p.40). Based on this principle, joint action with the parents was imperative to achieve the purpose of conducting this study, which is to make sense of these experiences. Hence, the member check technique was used, and analysis of themes was sent to all participants after the data analysis (Amoretti & Preyer, 2011). Participants' feedback illuminated the themes which gave the researcher reason to analyze the findings from multiple perspectives (Benaquisto & Given, 2008).

Simons (2009) indicated that "triangulation is a means of cross-checking the relevance and significance of issues or testing out arguments and perspectives from different angles to generate and strengthen evidence in support of key claims" (p. 113). Thus, the peer review technique was used for the data analysis. Themes and quotes from the interviews were sent to a Saudi doctoral candidate who specializes in special education and is fluent in both Arabic and English languages, to confirm the accuracy of the analysis of the interviews.

Lincoln and Guba (2013) mentioned that "epistemology transactional subjectivism is the basic presupposition of constructivism"(p.40). Additionally, Stake (1995) argues that in case study research, "Subjectivity is not seen as a failing needing to be eliminated but as an essential element of understanding" (p. 45). From these standpoints, subjectivity through a reflexivity statement was revealed. The researcher's prior experience and current knowledge were involved

on all levels, from the early stage of designing the research questions to the methods of generating data and ending with the interpretation of that data. Moreover, to ensure confirmability, a personal reflexivity statements were written at the time of holding the interviews and data analysis process (Guba & Lincoln ,1986).

To ensure sincerity, self-reflexivity about the researcher's subjective values and biases at the beginning of this study were revealed and noted (Tracy, 2010). To illustrate, writing a reflexivity statement established a clear path to describe the awareness of the researcher's bias. According to Simon (2009), subjectivity and bias are not the same concepts, and bias could be eliminated, but the elimination of subjectivity might not be a possibility. Therefore, utilizing a personal reflexivity statement enhanced this study in multiple ways. Referring to the Lincoln and Guba (1986) definition of transferability as a direct function of the similarity or fit between settings, transferability was strengthened by presenting a comprehensive description of the data collection and analysis processes. Transferability was guaranteed by including adequate and detailed recruiting information regarding the participants. To ensure transferability, rationale for any decisions made while conducting this study and for any future study recommendations were mentioned in the discussion (Vivar et. al,2011).

Data Analysis

Transcripts were analyzed using thematic analysis to identify a set of meaningful patterns or themes and subthemes associated with the research questions. Benaquisto and Given (2008) assert that thematic analysis is primarily a descriptive strategy; an analytical framework for finding patterns within a qualitative data set. According to Benaquisto and Given (2008), "The product of a thematic analysis is a description of those patterns and the overarching design that unites them."(p.867). Using this data analysis method was in line with the purpose of this study

because it focused on capturing the critical concepts within the transcripts (Benaquisto & Given, 2008). Furthermore, thematic analysis was appropriate for this study because it offered a comprehensive, in-depth understanding of the parents' lived experience where parents were the units of analysis in this process (Gribch, 2013). Moreover, to gain a deeper insight into the parent's experiences, a set of primary standards were used during the reading process; those standards were being an open-minded reader, flexible, organized, looking for details, and linking the data to the research questions and the philosophical frameworks (Bree & Gallagher, 2016).

The data collection and analysis were simultaneous processes to give the researcher an opportunity for editing the interviews (Merriam, 2009; Ngulube, 2015). Other reasons for integrating the two stages were that each fulfilled the other and time saver which ensured sufficiency and saturation (Merriam,2009).

Open coding analysis began after the first interview and continued throughout the data collection process. This open coding process was guided by Braun and Clarke's (2006) six phases of analysis steps, starting by becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining, and naming themes, and, finally, producing the report. Each interview was recorded and was kept in the researcher's personal laptop and was kept in a password protected USB drive. All audio files were protected by setting a password.

After each interview, the audio information provided by the participants was transferred to written form by the researcher. Reissman, (1993) claimed that the process of transcription allows the researcher to become acquainted with the data. Thus, reviewing transcriptions of interviews to make sure the audio and the words match was regarded as a priority. All the transcripts were printed out. First, the data were scanned, reviewed, and read. Then the transcripts were reread several times in order to become familiar with the data. An inductive and a deductive approach

for coding the data were applied after in-depth reading of the data, which means reading line-by-line, word by word, taking into account pauses and hesitation in completing sentences. An inductive and a deductive approach were appropriate for this study because they fortified the understanding of the parents' experience (Miles, Huberman, & Saldana, 2014).

Each participant completed the three series interviews and analysis his/her data were completed before moving on to the other participant. After identifying initial codes individually, for each participant, codes were sorted into groups (categories). Categories were identified by looking for similar codes then highlighting each with one color (Sutton & Austin, 2015). Looking for categories was done across all participants' transcripts. Those categories were reviewed and resorted into groups under one larger theme. That means each theme included many categories constructed by codes. The level of abstraction of the theme was descriptive. Member checks and peer review were implemented to help substantiate trustworthiness and triangulation of the data after the thematic analysis.

Furthermore, Excel spreadsheets as codebooks were used in the analysis process for multiple reasons. First, they are cost-effective and straightforward compared to other software. Second, Excel has many features that facilitated the analysis mission, such as writing the side notes and memos beside each code (Bree & Gallagher, 2016). Memos helped the research to write down any thoughts, notes, and additional questions concerning the topic without taking grammar or spelling into consideration (Thornburg & Charmaz, 2014).

However, only quotes that reflected the themes were translated from Arabic to English due to time and cost expenditures. Direct quotes that reflected each theme were presented in the coding book. Translated quotes were included to give the reader more complete and compelling detail for authenticity of the findings. Also, participants' stories were translated from Arabic to

English. Unless there was an urgent need to change or add some sentences for better communication ideas, exact words and phrases told by the participant were used. In qualitative research, providing convincing details and rich descriptions are vital strategies to convince the reader of the correctness of the results as cited by Firestone (1987), "because they create a gestalt that makes sense to the reader" (p. 19). To prevent the loss of meaning due to the language difference, and to ensure peer review consistency, a bilingual colleague was asked to review the translated quotes and stories (Al-Amer, Ramjan, Glew, Darwish& Salamonson, 2016).

Presentation of Results

Although there is no standard format for reporting qualitative research, this study took a descriptive form sorted into representative profiles along with presentation of data derived themes. Furthermore, given the nature of this interview-based study, where interviewing was the major source of data, inserting a portrait of each participant was indispensable to better clarify the parents' background to the reader (Seidman, 2006). In addition, profiles represented a range of characteristics of the parents and offered the richest details to the audience.

Through the profile, the participants' own words were framed by the researcher into a storytelling form. The narrative form of a profile would allow the readers to reflect upon the parent advocate's consciousness and to better understand these parents and the social world around them. Seidman (2006) suggested that developing a profile consists of the following steps starting with making a copy of the transcripts: (1) identifying the important paragraphs by giving them numbers in the transcript; thus, the notations can indicate where each paragraph originated; (2) reading the transcript and underlining the important and persuasive parts that cannot be exempted from the interview; (3) cutting and pasting the paragraphs and then weaving them together into narrative form by using first-person point of view; (4) rearranging and editing

if necessary to ensure coherence and flow; and (5) coding, and disguising of identifiable materials for protecting participants' identities.

The data analysis from the interviews were sorted into themes. An overview of the themes was presented at the second section of the results (Merriam, 2009). The purpose of this overview was to serve as a road map that guided the reader to follow the research findings. Each theme was separately demonstrated, elucidated, and supported by containing some direct quotes from interviews. Braun and Clarke (2006) support Merriam's perspective with respect to including quotes from interviews since these quotes help to "make an argument in relation to your research question" (Braun & Clarke, 2006, p. 93).

Ethical Issues

Ethical issues related to human subject participation were addressed by following IRB processes and USF regulations (See Appendix C). Through obtaining consent, parents were informed of the potential risks, which were deemed minimal, and benefits of participating in the study. Although there are many foreigners working in Saudi Arabia, this study was limited to Saudi parents, fluent in Arabic, and possibly a minimal level of English language proficiency. Moreover, this study was not limited to gender or region. Fathers and mothers who are advocates from all around the cities in Saudi were asked to participate in this study. Interviewing parents from both gender and cultural diversity perspectives provided a deeper understating of their roles in the advocacy work. Any potential issues of diversity were addressed by emphasizing that participation is voluntary.

Potential Limitations

Regarding the recruitment of participants, Patton (2002) stated that "by asking a number of people to refer others, the snowball gets bigger and bigger as you accumulate new

information-rich cases” (p. 237). Thus, the planned procedure in case of inadequate response to GESTER manager's social networking was to apply the snowball sampling technique. However, that issue did not happen, and parents were not asked to recommend other parents (Merriam,2009).

Given the Saudi society culture of using general words to answer some interview questions, establishing a warm, collegial way of asking following up questions was used to encourage participants to be more specific (Al-Saggaf & Williamson,2004).

CHAPTER FOUR: FINDINGS

This study aimed to explore a select group of Saudi parent's experiences as advocates for their children with disabilities and to gain insight on how these parents understand their roles in supporting others. Parents interviewed in this study were asked to describe their experiences within their advocacy journey in terms of their inspiration, challenges, supporting roles, and impact of advocacy on their child's intervention services. The findings are presented below in two forms: profiles of the participants and themes across participants.

Profiles

A profile is a means of framing the participants' words into a story. Profiles, as developed by Seidman (1998), tell each parent's story in their own words. A participant's profile is composed based on the transcript of their interview series. Interviews were first transcribed in the participant's native language and then translated into English. For the profile, the words of the interviewer were omitted, and the participant's story was the only thing left to be heard. For reasons of clarity, exact words and phrases verbatim as stated by the participants were used unless there was an urgent need to change or add some sentences for better communication of ideas. It should be emphasized that the tone of telling stories in the Arabic language differs from western language due to cultural and dialect differences. However, since the target audiences are primarily Saudi parents, the structure was preserved as much as possible. Profiles are presented along with themes in order to facilitate readers' recognition of patterns and to enable them to draw their own conclusions. Participants reviewed their completed profiles for accuracy. The

following section presents five richly detailed stories from the parents who were interviewed for this study.

Dad One's Story

Saud was born on Down Syndrome International Day on March 21, 2009! We took the baby home, and he could have died of hunger because if he had Down syndrome, he might die of hunger as he could not breastfeed easily. However, we did not know that our child had Down syndrome! We did not know during pregnancy and even after the first three weeks of birth, we did not know! By the way, we did not know about his condition until 21 days later! We came out of the hospital. Only the neonatologist spoke to me in words that he thought I knew as if I was supposed to know about Saud's condition because he asked me, "Can you see the baby's skin?" while referring to the thickness of his skin! I did not see anything abnormal, and I did not see anything that aroused my doubt! The doctor asked me to sign the gene analysis test, but I did not know what the gene test meant at that time. It is a private hospital; the test is covered by insurance, and it is known among Saudis that hospitals sometimes make a mountain out of a molehill, so I said OK! That is all we understood from him. There were even holes in his heart, but nothing was told to us! They did not give us any information about the child's health condition. After 21 days, I mean during the appointment or the regular examination of the child, we were shocked when they informed us about the disability in a way that was worse than the diagnosis itself!

When giving birth, I was at work when my older daughter talked to me and said we were going to the hospital. When I got to them, I found my wife had come out of the operating room as the birth was a cesarean section. I saw a picture of Saud when he was born! I laughed at them and said, "where did this Filipino come from?" I mean, his facial features were Asian. When I

went to the nursery and saw the baby, there was nothing different in him, and he looked like his older brother, i.e., I mean his facial features, nose, eyebrows, and divisions. I did not see anything different!

I went home from the hospital, and no one told me anything. They just asked me at the hospital to sign the paper and that we need to check the genes, but no one explained to me what the genes are! Why did they want to test the genes? What concerns did they have? I had no fears or doubts, and the nursery doctor did not even raise my suspicions or alert me! He just asked me, "Can you see the baby?" I said, "Yes, he looks like his brother," and our conversation ended. We went home, and for 21 days, we did not know what our child had. For 21 days, we did not know that the child had two holes in the heart! Saud came to us, and I was happy with him like the rest of his siblings. These 21 days that passed were like the rest of my children, and everything is going fine. However, his mother felt something different, and the mother, of course, has a sense. She says, "I have concerns that the child has something!"

His mother suspected the child was tired, but there was no suspicion that he had Down syndrome or a disability! However, she had doubts about how long he slept as he slept a lot and did not cry. When breastfeeding, for example, if he cried, his crying and voice were weak. However, her doubts were general and were not concerned with disability! Usually, any child has a routine check-up three weeks after birth. Saud's mother went to the hospital for a routine appointment! During the examination, once the doctor heard the baby's heart at the children's clinic, he immediately told her, "Why is your child breathing like this? They did not talk to you or tell you what is wrong with him?" He said he must now be urgently referred to the pediatric consultant without explaining anything; they surprised and scared her. Anyway, she went to the

consultant doctor, and as soon as he read the papers, he said, "you do not know that your son is a Mongolian?"

I was not with her that day; I was at work. My wife called me on the phone and told me to talk to the doctor, who informed me of the heart problem and told me that the nursery doctor informed me of this, and you signed the gene sheet. I told him, "How did the nursery doctor inform me? How and when?" The nursery doctor asked me, "Do you see your child well?" I said, "Yes, I do." However, he did not inform me or hint that the child has a problem or even the possibility of being disabled. So, how can they say that he informed me?

Things went well, and it was not easy after the news that Saud had Down syndrome. We entered the shock phase, then came the denial. Our thoughts were, "no, the diagnosis cannot be correct. Surely, there is a mistake; maybe the doctor is wrong". At the same time, you get a feeling that "No, by Allah, maybe true, but why me? Why me?" You get into the whirlpool of feelings. We went through vulnerable situations and states of denial, fear, sadness, and anger! I did not know if I was afraid for or of the child. Am I anxious for my family and me to have this child? Afraid that we cannot do this duty? Am I afraid of society? I went through fears and a foggy stage!

I used to work in a well-known oil and gas company, and my work tasks put much pressure since I worked in operation in the control and security room. Our work is exhausting, and we work 12 hours a day! Due to my work in that company, I had to perform in English. Nonetheless, it is a practical professional tongue rather than an academic or general dialog. As the terms of the language used are limited only to work, my English language is a language of business because I learned and studied it in the same company. After Saud's birth, I tried and pushed myself to enter western websites and search for Down syndrome because the Arabic

sites, unfortunately, had inferior information and had more questions than answers. Hence, I tried to search the Internet and found a website called Medical Genetics, which a geneticist supervises, and they have a family support group for Down syndrome, so I joined them. The site was in Arabic, and some mothers were participating; one from Jordan and one from Kuwait, and their English was good. We were looking at the new topics that we needed as parents. I became a member of this team so that instead of receiving support from them, I learned how to support myself, and I learned how to be supportive of others. "Thank God for this doctor and his work."

Once I knew about the situation and saw the children like Saud, I looked like I was finding my way. The first thing I bypassed was denial, and I started thinking this child was my child. I am far from his diagnosis, far from his condition, and far from the results; how will our family life after Saud's diagnosis be?" As soon as I convinced myself that this is Saud, and this is, first of all, my son, I became more rational. "Saud has a condition, yes. Will it affect him? Yes, it will affect him. Will it cost us? Will it tire us out? Yes." However, we accepted all these things because he is our child, and we decided that we would give him our souls, that we would give him everything that we could while trying to minimize the effects of this syndrome on him as much as possible. We affirmed to ourselves that we would provide him with everything. After that, thank Allah, we got over the shock, and everything went well. Saud has become the focus of attention and life for the whole family!

I continued working on the medical genetics website for a while, and we did wonderful work and printed several publications. I co-published a book of nearly 400 pages called "How to Develop My Child's Skills," in which I was one of the co-authors. This book was dedicated to the family and the mother, specifically from birth to eight years old, on how to raise her child. We also participated in printing several books that the doctor wrote, and we printed thousands of

copies- thank Allah- and distributed them for free. Participation in writing and printing made me expand my academic English language acquisition, and it was not easy for me at first. However, I translated many topics so that I learned. I remember using the Arabic and English dictionary, and they are still with me. I am trying to master translation!

I continued to work for about eight years in the Down Syndrome Family Support Group on the Medical Genetics website. After that, the way of working on the website changed, and I wanted to participate on the ground, in real life, and partnerships with some government agencies. So, I searched and found an opportunity in one of the associations for special education; they offered me to work with them because they were familiar with some of my work! They said, "we have a program, and we would like to hand it over to you! What do you like to do with it?" I said, "I care about aspects of family support, and we can establish groups, i.e., teams for family support!" We have established many support teams according to the classification of disability. In 2018, I started the family support program in the association, and I was honored that I was the program's first executive director. I was the one who founded it from its inception until it became more widely known. Thank Allah, I am happy about it and am still based on it as an executive director. Of course, I have a work team as I do not work alone- the work team has a massive role-but; remember that the great responsibility lies with the leader.

Therefore, I retired early from my work in the gas company about five years ago and truly devoted myself to being influential in this field, especially in family support. I know that my voice does not have such influence on the decision-makers in special education, but our influence on parents is excellent! The truth is that I would be lying to you if I said that I am seeking tremendous and miraculous change.

Since I have translated various topics, I have had a lot of information. So, everyone around me told me "Why don't you keep it in a book? My effort was intense during my work after the birth of Saud, and thus came the material of my own book, which I published. This is, by Allah, proof of the fact that if a person has a goal, he will extract time, as they say, from the jaws of a crocodile. If you have a goal, you will create an opportunity. If you have a goal and an urgent need, you are going to do something useful. Because of these translations, I authored a 350-page book about Down syndrome called "Down Syndrome: Facts, Instructions, and Letters from the Heart" because part of the book was in letters between Saud and my thoughts and the things I was writing. So, I collected them at the end of the book and at the beginning of the book. I mean that several chapters were medical chapters and chapters for the new family, for example, about education, upbringing, behavioral problems, vision problems, dental problems, and things like that. Praise be to Allah; we succeeded, printed the book, and distributed it for free.

Naturally, and in my personal relationships, I am a person who is always in the middle circle. I am not on the opposite side, above or below. Even in my family, although I have older brothers, I am always requested in the first place, in good times and bad, needs, problems, and family matters. I am the focus of everyone's attention around me. If they need something, I will be there, and as they say, I am a mother hen; I am always there to direct everyone because I am a realistic person, and I do not make enemies with anyone. I do not rush, for example, problems with anyone, and my motto is always that I will walk alongside as long as it goes.

Saud added different dimensions to my life; with Saud's presence, I looked at life differently. I learned about a world that I would not have seen before Saud's existence: the world of disability, special education, families who suffer, children who were imprisoned and deprived of their rights, and marital problems that occur because of the presence of this individual with

disabilities. With Saud's presence, I personally changed when I accepted this child because I have a child with a disability: who will not be like the rest of the children, who will be behind his peers in some respects, who may not acquire skills like children, whose shape is different from their shapes, and who has different reactions and actions. All these things changed my perspective on life! Even in my relationships with people! My sensitivity and my compassion for people increased. I am one of those people who feels the pain of others, and I used to feel my brothers, my sisters, and my relatives. I even feel some colleagues at work and some expatriate workers. The humane feeling that I had was because I am a Muslim, whose faith urges him to feel towards others. However, the awful feeling that I experienced with my family at the beginning of Saud's diagnosis gave me the motivation to go out and lift the new families out of the impact of the shock.

A lot of times, my phone does not stop calling: WhatsApp and Twitter. I meet new families and answer their inquiries. We truly thank Allah for always getting them out of the annoying situations they are going through! I am busy with many things to offer them. First, I offer them the book, and I also have some videos translated for mothers who speak the same feeling as the new mother. This issue is not a drama series or soap opera; it is a reality and a bitter feeling that every family goes through. Moreover, I feel the rights of these children. Some of whose families may unintentionally be ignorant or unknowing may harm their child and may fall short of their rights. I feel responsible before Allah Almighty because I know that these children have rights. I must tell their families how they get them. I want to make the families themselves aware that it is realistic- away from negligence and excess, and it is far from being excessive in demanding the rights of these children or excessive emotions, protection, and fear that does not make you raise a person and does not let you do anything!

Some families exaggerate the abilities of their children; some want to make a miracle out of their children, i.e., if my child, who has a disability, is not a perfect model, then I am a failed father, failed family, or the child is a failure. Therefore, I need to warn these families not to exaggerate their emotions and overprotection. I try to protect these families from excessive pressure and negligence and protect this child from his family. I did not just adopt Saud's case, but I adopted everyone! Saud is my child. I give him everything I can, but I do not see Saud as the measure of my success. Some parents see their children, for example, as the measure of their success, "By Allah, my child memorizes a Sura of the Quran or does know how to read a book." We say, "Oh, this is the perfect mother, this is the perfect family, and this is the perfect child." Well, what can I do for the children who do not know how to read? Do we leave them and frustrate their families, or do we say that you are not good, you have nothing to give to your child?

I try to be a voice for these children and to protect them even from some of their families. I am informed that there are families who close the door on them and do not take them out of the house because, by Allah, they do not want people to see them, then their siblings do not marry!

I also protect families and warn them from charlatans. I always say, "guys watch out for fraud in advertisements on social media." For example, someone comes and offers behavior modification, gives physical therapy, occupational therapy, and a general plan for the child; even these people are swindlers. I swear I am not hostile to anyone in particular, but they see that I am their enemy personally. This is one of the problems in this field, which is the lack of clarity and credibility from the service providers. Some of them do not accept criticism, and if you tell them something or give honest criticism, they say this is slander- to the extent that five of my accounts

on Twitter were closed in a year! They closed it for me within a year, and I stayed for maybe four months without an account on Twitter.

Before Saud, I did not know anything about disability, so I did not feel responsible! But now I have knowledge, cognition, and information which I cannot hide from people. I am now committed to a moral obligation; if I know any child and I know that he needs my help, I cannot ignore it. I, of course, cannot help him financially, but I can guide the family, father, and mother or lead them where they go. Motivation and humanity form the passion that makes you always continue. I say to the people I work with, “guys, do not forget I am not one who has a temporary issue or a hobby. I am not interested in some general issues that are adopted by a passionate person, for example, in the environment or politics. My situation is different; my case lives with me and in front of my eyes daily. I am a human being who lives with my child and his issues, problems, and needs. This is a flame that cannot fade one day. I live in a renewed situation. I have passion, and I have a goal that I aspire to reach. One who has a goal cannot be stopped by roads. The person who is going to a certain destination with all the obstacles that may be in his way is looking at them as if they will stop him, and he cannot overcome them, thus giving up his destination. Or will he seek to solve them and continue his way?

I, by Allah, do not call myself an advocate, and I do not see that any human being, who does what I do, should be called an activist. I am only a father who seeks to create opportunities for my son, to correct the paths of the families who came after me, and to prevent the shortcomings from which Saud suffered from happening to other children who are still at the beginning of their lives! The first thing I want is to get the families out of the shock- which we went through and did not find anyone to take our hands-and to take the hands of the new families on the right path in accepting and dealing with their children rationally and knowing the situation

realistically and logically away from passions and emotions, and far from exaggerations and underestimating these individuals.

I always repeat and say that I raised seven before Saud. But, by Allah, it is as if I did not raise anyone before him! Although praise is to Allah, I am fair with my sons and daughters and give them their rights, but Saud is something else. Glory be to Allah Almighty! For children like Saud, their childhood means that they force you to be patient. Of course, with Saud, we thought that we were teaching him, but actually, he taught us many things while we were doing so! I mean, at first, I was seeking to educate and rehabilitate him, and I found that I was the one who learned and rehabilitated for Saud's reasons. While I was trying to teach Saud, I myself learned many things in the fields of special education, many things related to education, disability, and even the health of people with disabilities, as well as information about Down syndrome I did not know before Saud- I did not even think to learn.

Life is all about experiences and lessons, but who learns from these experiences? Why do we, for example, in school or university, have a note, write, and record the lecture? Similarly, sometimes we must write and record the lessons in life itself. The conscious person is supposed to have a note that writes down some ideas, situations, and reflections, builds on them his life perception, and evaluates himself, his experience, and these events that happened to have questions of why? When, how, and why?

If I were to evaluate myself after the experience of advocacy for Saud and others, I would say that I entered this field by force and not by choice. I am a father or head of a family that had something that made me must ask and search until I reached a stage or a point where I became aware and knowledgeable! I am like the one who lived in a new neighborhood or moved to a new country and did not know anything, but step by step, he knew where the supermarket was,

the location of the hospital, where the post office was; he knew everything, so he became aware of his needs. He started bothering himself, for example, to guide the new strangers who were coming after him, relieve them of the trouble of looking for these services, and try to guide them in the best and easiest way with the easiest shortcuts! As a person, I went through these things, and I have a quantity of information and experience in dealing with families. As a person I went through this path, my techniques to support others have evolved and shortened many efforts to convince these families to take their hands.

When I evaluate myself and ask myself what is the message I am conveying? What is the result of what I am doing? I find that I sought to reduce media exploitation in the name of disability. Now anyone who thinks of presenting something in the name of disability before doing anything knows that there are people, who will hold him accountable, who will talk about him, who will criticize his work, and who will direct and correct him. These are one of the goals that we have achieved in raising awareness in matters, ethics, and etiquette of dealing with people with disabilities. For example, at the level of voluntary and community services, we were, thank Allah, able to have an impact and achieve some goals, for example, partnership with some organizations, whether they were health or educational institutions. Even some charitable organizations had a positive impact on families; for example, if a family comes to me and they have a child, who has a medical problem, I know a lot of services to which I can direct them, and which can serve them whether if they come to me personally or informed one of the members of the teams that I work with. Thank Allah, we can now help and guide people effectively and directly through the partnerships that we have made. However, the biggest obstacle remains for me, which is reaching the decision-makers and those capable of introducing real change in

services in dealing with their files and issues. This is actually what we haven't been able to reach so far, but whoever walks the path will arrive there.

I want to inspire the stakeholders, the ones who make decisions and provide services; I want him to make sure that he hears from the people. If he really has the keenness to provide adequate, comprehensive, and satisfactory services, he will make sure that he attracts and hears from parents. As parents, even if we knock on the doors of the decision-makers and reach them and we come on dates, I mean, they are only out of courtesy, willingness, and reassurance. However, once you leave, you cannot return to the ministry and ask them what happened to the official's words because the words of willingness do not have transaction numbers, nor are they officially registered. They are merely words mentioned at that moment, and the topic is over!

However, if the stakeholders are convinced of the eligibility of people with disabilities, especially families, they hear from them (the families) directly, and (if) there is an executive order and not merely compliments, there could be advisory councils in the Ministry of Education made up of conscious families, especially since families know more about the needs of their children. Some families are already able to support decision-makers with ideas they would not have expected!

I also want to inspire families to be interested in knowing their rights and then secondly to claim them. First, you must know the rights of your child because it is impossible for a person not to know the rights he is claiming. After all, it is possible that such a person would demand other things to which he/she is unentitled! Knowledge first, then claim second, and not be silent about shortcomings! There are channels established by the government through which you can raise a complaint, present your problem, and claim the rights of your child. This is what we seek; that people would have awareness and, at the same time, have the means of claiming and staying

away from nervousness and anger. I have conviction, and I have faith in some beautiful sayings from which I started. The first of which is, "we will not change the children to fit with the world, but we will change the world for them." We talk, express, and try to find solutions, and we must look for the ways in which they learn because the problem lies even in education and special education programs. We only see the sources that we have and say, "by Allah, this is what we have. If it suits him, then it is fine, and if not, then he should not learn". Of course, most of the sources are not suitable for children. There is also a beautiful saying that I believe that "every child can learn whenever we learn how to teach him." I try to set my goals and achieve them; at the same time, I have no problem with failing. I mean, I am ready to fail, but I do not take it into my consideration (because) I mean, nothing frustrates me. The person who is always ready for obstacles, his frustration less. This is a fact that I learned and benefited from having Saud with me; I am always ready for failure and try to avoid it next time!

Dad Two's Story

Since the beginning of the year, we have been expecting a new baby! As he/she is the first child, one would always be enthusiastic, would imagine what the child would look like, and would sing to the baby! The most important thing I remember is that during pregnancy follow-up appointments, the hospital always told me that the baby was fine and okay! However, during the ultrasound examination, I saw the heartbeat, and it was irregular. I told the doctor that I wanted to make sure there was nothing wrong as I saw an irregular heart rate and asked the doctor if the baby's heart was okay. Was everything all right? She told me, "Yes, it is perfect." I felt that there was something abnormal because if you have an Apple watch and you do the CGL test, which measures the heartbeat, the lines will appear to you normal. However, when all the lines are higher or lower, there must be something wrong!

On the first of October at 9:00 AM, my wife gave birth. The hospital called me, telling me that my wife had given birth, and there was a problem; the baby had (suffered from) hypoxemia. On the way, it may be considered an exaggeration, but I felt a connection, such a strange feeling. I cannot describe the feeling that I had at the time, but frankly, I had a spiritual moment in which I felt that my child would have Down syndrome! Why did I feel that it was Down syndrome? Maybe because I always felt that all types of disabilities are acceptable to me, but the disabled who have Down syndrome! I may have considered myself a smart person, and I know that they have a deficiency in intelligence!

When I arrived at the hospital, the doctor immediately told me, “We think she has Down syndrome.” I am a person, of course, who does not have any problem in receiving bad news and always recovers from any shock, but at the same time, I was surprised by the way I was informed. We were walking with the doctor in the hallway, and she gave me the news without even telling me to sit or brace myself. I wished at least I had been sitting. I told her if you could have at least told me to sit down, it would have been better! Maybe I cannot receive news like this. To be honest, there was no psychological or informational support- even the explanation of the case was brief. She said that the baby was diagnosed with Down syndrome as she had a hole in the heart, underdeveloped ears, and short hands. I almost cried, and my feelings were mixed! These mixed feelings lasted a day or two in the same way for me. As for the baby’s mother, she was a little discreet and did not get her feelings off her chest. She received the shock as if she were in acute depression and a state of silence. She did not make any comment!

During the post-first feeling stage, it was exceedingly difficult when I conveyed to everyone that I had a disabled child. At that time, I thought as if we humans were above the level of disability and our ego was so high that it would have been impossible to have a disabled child.

It was extremely difficult for me to convey the news to my family, especially since she was the first child in the family to have a disability. It was something new to me, and I did not have any background in disability. If someone is conveying the news of someone's death, that would be the closest description of the situation. I remember then that I cried, but now I say this is from the grace of Allah Almighty, who gave us our child and let us come down a little bit from the ivory tower to understand life and people!

We then had a fierce fight with the private hospital in the first days about the baby, i.e., that she must stay in intensive care and that the night cost 8000 Riyals! The matter was merely concerned with profit; nevertheless, I knew my rights and how to claim them from the greedy world, so I fought! I know my rights, and I know that the Ministry of Health will cover the expenses; therefore, my child did not really stay long in intensive care, and I kept her in the private hospital for several days. I arranged then for my child's discharge at my own risk since I asked them, "If something would happen to her on account of the problems that she has, would you interfere?" They said, "We would not do anything!" Instead of receiving support from the private hospital, they behaved as though I had not been in a health institution nor was I supposed to receive medical care for my child." On the contrary, the situation was as if you were in a supermarket! Unfortunately, I expect this situation to be the same in the whole world, where the medical sector has become business-related in terms of pharmaceuticals or hospitals. Everything has changed from the real goal of medicine and has changed for people in general; it has become exploitation. One would rarely find someone who works for humanity's sake.

This has almost been the story since Marram's birth, which has shaped me through time until I became an advocate. Everything has literally changed in my life- even the level of optimism in life and happiness has increased. This may be owed to her laughter at home and the

happiness caused by children with Down syndrome. I also think that there is something that is difficult to prove scientifically- that it is a blessing! This was the turning point that changed my whole life! What makes me remember these is that at some point in my life, before the birth of my daughter, I was jobless, dismissed from my job, and I had tremendous financial obligations even though I am a qualified and educated person. Three days after Marram was born, I got the job of my dreams.

I spent my whole life in Riyadh until I was eighteen years old. Thank Allah, one of the things that my father had been providing us since the nineties was the internet since its entry to Saudi Arabia. Although it had not been a long time since Saudi Arabia had the internet, my father, however, provided us with computers, the internet, and everything else. This honestly opened for us the doors to the world, and we cannot deny that it expanded our perceptions.

I love knowledge. During my childhood, I loved sitting with old people and those older than me to learn from them. I used to love reading newspapers, so I have considered myself educated and smart since my childhood! Then I went to France to study and spent almost four years there. I returned to Saudi Arabia and completed my studies in the French language major.

I later took my first official job; this was my first experience working in a medical company that cares for and sells medical equipment often to the Ministry of Health. I then searched for a job with a fixed income in the field of translation as I was always looking for any way to practice my academic major, which is a translation of the French language. I took a job in one of the French companies in Saudi Arabia and then worked in an American company. In my last work experience, I had a legal problem with the company for which I worked. Since I used to work in Human Resources and have great experience in the work system through my long years of work, I filed a lawsuit against the company. Praise be to Allah! I won the case, and the

company compensated me with the due amounts. This diversity, career mobility, and job experiences frankly enriched my experience and expanded my perceptions greatly! After I won the case, I was jobless. However, after Marram was born, I directly got two job opportunities. I chose the government job even though it has the lowest pay for one reason; I said maybe my daughter needs more help, and government jobs provide more security. I can later increase my income through translation or start my own business!

When my daughter was just a few days old, one of my family members, when I showed him my daughter's picture, he expressed dissatisfaction, as if he were saying, "what is this!" I immediately defended my daughter! Praise Allah, subconsciously and instinctively. I swear I subconsciously kept defending her without even feeling it. I had this feeling of benevolence in the hospital from the first time I saw her. Allah used my wife and me for our daughter as if there was no one left for her in the world except us! This is indeed what happened. I asked myself if this is how the nearby society and closest people look at my daughter, so what would I expect from strangers and distant people? It is known, for example, in Saudi families that boys are always more desirable than girls! What I felt in my family was that they expected my baby would be a boy. Then, she was a girl, and then this girl was a disabled person, so the whole family did not welcome her! I expect that I could not judge my feelings during such a period; however, I expect that this unjust judgment towards Marram may have been, indirectly or subconsciously, a message telling me that it is only my wife and me who remain for Marram to defend her and me.

There are people; I was shocked that had children with disabilities, about whom we do not know; they are 13 or 14 years old! What was strange to me is the reaction of my acquaintances and friends; they were encouraging and supporting me. Some of them also shared

with me some of their experiences. I was shocked by the number of people with disabilities in our society. Every time I tell anyone about my daughter, they tell me stories of their own. One told me that he has a disabled brother, and one told me that his cousin has a disability. They started telling me their stories and how the children were good for the parents. There is one situation that I honestly will never forget! One of my cousins contacted me even though we did not have any close contact- we may call each other every two or three years or during the holidays, but there was truly little communication between us. However, he insisted on communicating with me by virtue of the fact that he has two children with disabilities! So, he called me and explained how his sons were really "good things" for him. It is impossible to forget this situation, which I honestly felt that it encouraged me to accept my daughter's diagnosis and made me believe that everyone should always share their stories as much as they can with families so that they would know that we all have been through the same matter. "You are not the first or last people on earth, so take responsibility!"

After the acceptance phase, Marram's medical journey began, and from there, my own journey in life also began. I consider myself born with Marram; I feel that I was born on October 1st! I did not know about early intervention. I used to hear about the term as well as occupational therapy and physiotherapy, but I did not know the differences between occupational therapy, physiotherapy, and speech therapy. We went to many clinics: ECG clinics, sleep clinics, epilepsy clinics, and children's clinics. We went to every clinic that came to one's mind! So, I thought that when Marram was seen and helped by the doctors that this was an early intervention! But after a while, I understood and started to look deeper into the subject. After six or seven months, things started to become clearer for me.

I started searching more and contacting the CEO of GESTER on Twitter. I think he saw me active on Twitter, asking, answering, and tweeting. He communicated with me and proposed the idea of joining the support groups in the first place to my wife and me to have an idea about disability. We joined them, and indeed there were things that we benefited from. There were many families with us, and many of them were already qualified. They were, for example, involved in special education and had children with disabilities or specialists in education. Every person tries to provide what he can in this field to support the new family according to their specialization. There were mothers or fathers who asked some questions about their children, even if some questions were about older children, i.e., 12 or 13 years old. It is true that they were far from our attention for our six-month-old baby, but they were giving me a vision of the future, "How will things be?" The experience was extremely good honest, and useful, especially the information. They were accurately given by active people in this society! In the groups, I used to see active people, and everyone served in his specialty!

The idea that I am in social activity seemed to emanate from support groups. I used to see people translating some articles, doing some things from time to time, and it was through personal diligence. So, I said to myself, "Why do I not work like them?" There were some who provided psychological counseling and family counseling, and activists who provided courses and lectures in special education, so why was I just watching them? I started to translate slowly, and I think that the manager at GESTER saw me as more active in the field of translation. We communicated, and the idea emerged to establish a translation team affiliated with GESTER to increase the Arabic content! However, there was a dilemma since my specialization was not in special education; I suffered as there was no dictionary for special education terms. I think that so far, there is nothing in this regard, and I have not found a dictionary of such terms in the Arab

world! Then, I established the translation team with the support of the CEO and GESTER. First, I gave them a complete outline of the work method, initial vision, and goals of the team. We started the team and thought about how we could recruit volunteers for this field! In the beginning, the goal was to translate topics about special education and disability in general, but not from the academic and scientific side, only the part that concerns the parents. The resources are, of course, either suggested by GESTER advisory team or through the questions of the families themselves when they ask about a specific topic, for example, “How I teach my son to go to the bathroom.” The ideas are collected through these questions!! They are reviewed by the advisory tea; then, the translation team starts communicating with the international institutions and associations, which issued the practical material so that we can obtain permission from them to start the process of translation into Arabic. I will not lie; there were some entities, of course, that did not cooperate, and we faced some difficulties. We did not receive from some of these institutions and associations the appropriate response, or there was procrastination in the response, and some of them did not cooperate at all for reasons that (only) Allah knows best.

Now, we are working on a massive project, and we are trying to cooperate with an entity that is an extraordinarily strong and useful organization. We concluded an agreement, and they will benefit us a lot. There are some ongoing projects, but we are still coordinating with them, and many things will then change. I think if there was a manager of the team or someone else other than me, even if he were less passionate than me, the work would be substantially completed. I will not lie; I feel that I am disrupting things! The change needs a lot of time, and I am busy. I also feel frustrated because of the lack of initiative. Yes, there are some initiatives by team members, but very few, honestly- poor response from everyone, whether from the consulting teams or translation team! One would sometimes feel that he is working alone. If I did

not look by myself or if I did not get the resource and plan and draw it myself, everything would stop. It is important that I admit my shortcomings, and I like to blame myself. I think that my role as a leader is that I should provide inspiration and action. If team members do not see you acting, inspiring, or working and be motivated by you or they try to prove themselves to you, they will not start up things! This feeling of frustration is rampant. I am even talking about some of the team members as they have the same feeling that they are working alone in a big world! The situation needs a momentous change, and no action has been taken; no one wants to do anything. Sometimes, I feel that I am making a hole in the water! “What would I get in the end?” However, what makes me act is that in the future, we may be inspiring people after us, and this activity may have a huge long-term impact!

In the field of advocacy, as far as one will do, he/she will still see himself/herself falling short. The situation is different by the way from when someone is, for example, an activist in the field or a researcher or has tendencies to defend the rights of a certain group. The matter, in reality, is completely different when someone is defending another whom he/she sees every day, and he/she is bonded to that person by blood and gives him/her unconditional love! We see how he/she interacts. It is something indescribable- no matter how much one gives. I would sit with myself every day and think, how can I serve him/her more? Someone would feel if I am not exaggerating, that he/she is falling short all the time as he/she needs that person in everything! In Saudi Muslim society, if a person sees someone in the street now who needs help, he will surely help him/her. So, how about a person in front of him /her every moment? We see him/her, he/she lives with us under one roof, we see him/her every day, he/she needs us, our presence, and our support on a daily basis, and we start asking ourselves, “How do I introduce him/her to the world? How can I make him/her like us!!”

I meet Marram for almost an hour or two a day on separate occasions. During this meeting, I always make sure that the meeting has a fruitful discussion and has good deeds and moments of education. I always ask Marram about her day. I sometimes see her at the door, and we go, for example, to the grocery store and walk a little. I try to improve her skills so that she can benefit greatly in her life. I try to teach her so that when she visits her family and talks to her uncles and aunties, she speaks in the same manner and makes some gestures, which they would be happy to see, to give her more confidence in herself. We always try to raise her in such a way that she has nothing wrong, and she is fine!

I have great ambition; I always want to accomplish more and have a lasting impact on life, as my achievements do not reach the desired level. There may be goals that I have achieved, but they are not mentioned in the list of dreams and ambitions! I may not have achieved much. I honestly do not like those who praise themselves, but I know that there are many families who do not deal with their children or think in the same way that I did with Marram.

We are a family who knows how to read and find information. Marram's mother also has a master's degree in sociology. We all come from educated families. This is what drove us to move in this direction for activity and advocacy. I believe in the importance of the family and its great role in educating children with disabilities. I personally want to translate, if I had the opportunity, a book every six months in the field of special education. I am ready, and I have no problem devoting myself to translation so that content about special education would be directed to parents who have children with disabilities or even directed to people with disabilities themselves. However, publishing companies care too much about making profits, and I haven't published any books. The content that I want is not encouraged by these publishing houses; for example, I want to translate stories for children with Down syndrome, bedtime stories that are

written in a simple format and aim to modify the children's behavior, encourage them and enhance their self-confidence. Stories like those existing in the western world! Due to low revenue projections, these publishers are not interested in publishing them."! The audience to which these types of books are targeted is considered small. For example, "How many people will the content of a book about Down syndrome be suitable for them? How many people will read the book in the first place?" Unfortunately, some families basically do not have education or the ability to access libraries; the financial situation of these poor families prevents them from buying such books.

In general, I will try in the future to be more active in establishing strategic partnerships. I am trying to make agreements with foreign associations and establish something that would last. If Allah wishes, then there would be someone to lead the ship directly. I mean, this is it; the matter no longer needs my presence. This is my dream, but we still honestly need a lot of work!

The government has protected the rights of the disabled and their families and has provided a lot of support, but the problem is not in the government! It is true that there is a dereliction from some government agencies, but the biggest dereliction lies in our society, whether from the parents or the society itself. For example, we might find someone talking in a Twitter Space (a feature in Twitter that allows a group of accounts to discuss a specific topic) about people with disabilities. We find people giving unreliable information, such as a disability is caused by bla bla bla and does not leave room for discussion, or in another Space titled "Do you agree to marry a person with a disability"? Discussing such topics has nothing to do with reality; they are silly topics or content for someone who is looking for fame or controversy. Usually, I join, engage, and correct the information and ask the host, "What is your specialty? What are the grounds you are standing on?" I sometimes have altercations with them. This is

shameful, unfortunately, but at least the message is delivered to the remaining users, i.e., this talk is nonsense!

I believe that the inferior view of disability may be owed to the socio-economic level of Saudi nationals. The higher the economic situation becomes in Saudi Arabia, the more it will force parents when they have a disabled child, for example, to consider him/her below the required social standard. So, some parents would say, "If I hid this child from society and repudiated him/her, it would be better!" Parents are expected to have a healthy child of whom they will be proud! In a certain period, everyone was aiming to raise their children to be either doctors or engineers, not out of love for medicine, engineering, programming, and these things, but for prestige! My son is a doctor or an officer. My son or daughter is successful; hence, I am a successful parent! I believe that the role of parents is to be advocates for and represent their children. The problem, however, is if some parents do not believe in their child in the first place, how could we convince them? Some of them would say, "Why would he complete his/her education? What would happen? Would he become a doctor?" Therefore, I believe that a solution to this situation requires strength and rigor in law enforcement. Anyone would respect a person with disabilities not out of love or sympathy but out of fear of the law. If we reach this stage, society will reform and start accepting disability by the power of the law. If society then accepts disability by the power of the law, we can, in 20 or 30 years, reduce the penalties!

While growing up, I always admired Doctors Without Borders and humanitarian organizations. My dream was once to be a minister of health, not to be a regular doctor but to practice major administrative functions. I always thought medicine would emanate from passion and love- it was my dream. However, thanks to God, it no longer is! It was just a dream, and I think it was an innocent one to make an achievement in the humanity field.

When we talk about the impact of advocacy in my life, there are things that I do not know how to describe. Even when I pray, my feelings in my relationship with Allah have become different! On a personal level, my spirituality increased, and I developed a special relationship with Allah Almighty, not a routine relationship of prayer and fasting or concluding the Qur'an 20 times and such good deeds; there were things that a person sees in his/her life. Having this spiritual influence on me is important, but I also wish I would be known, in history, not only by Allah Almighty. I sometimes wish I were a great person and would have an impact or be an inventor like the great inventors!

Having an impact is an honor; every human being is supposed to have a mission in life! The idea may stem from the fact that I always think about it. I mean, life is not just the current life or a person takes a position... etc. A person's average age is usually 60 or, let us say, 70 years, then he says goodbye to the world! Man must live life with purpose. I always see life as a rehearsal for the afterlife, so this short life prepares a man for the afterlife! Therefore, a person must leave something behind, such as a legacy. When we talk, for example, about the impact that King Salman will leave, may Allah prolong his life; such an impact will be extraordinary!

On the other hand, some ministers worked for 20 years, but history still needs to remember them! They did not leave a substantial impact. The matter depends on a man leaving a significant impact behind. This immortalizes the human being, especially if the work left behind is good because some people may have made a bad reputation!

I had a great ambition, and now my ambition, since I have worked in this field, is to be an advocate and to work to educate families and leave an impact. I know that there are many things that we can talk about as advocates in this field; many things we know will not reflect on our children directly, but the impact may occur only after many years, and by then, our children may

even be dead. This is an honor for me, yet I also feel that I am, in reality, falling short. This may be owed to the fact that the current impact is insignificant, and we always try to shed light as much as we can on the same matter by the available means, through communication with the competent authorities or social activities available through GESTER.

I believe in our role as parents of educated youth. The KSA did spare no expense and did not fall short in providing its services to people with disabilities, and the KSA spent billions over the years. Our role lies in leaving an impact, even if it is minimal, even if planting an idea and encouraging others to move in this direction, i.e., this impact will benefit others in the future! Of the changes that I hope to see in the future, for example, during pregnancy and childbirth, all special preparations would be made to prepare parents to receive their child. There would be guidance for those who need psychological care during pregnancy, whether for the father or mother! Booklets also would be provided, for example, by the Ministry of Health or the Authority for People with Disabilities, explaining the situation with a clarification of the children's rights and explaining the services that the child needs in the future. There would be early intervention and direction for the family to intervene early. There would be medical protocols to deal with cases of disability, each case separately with specific codes in a manual, in a manner of speaking, to deal with these cases from birth to death. This manual is found in France in some of its hospitals. They call it the protocol for dealing with people with Down syndrome from the beginning of receiving the case to provide services. It is a long complete, fully detailed protocol.

I also hope families will be provided with ways to deal with their children. For example, if the person in charge of the early intervention center has a clear plan to work with during this week, he/she can give us this plan or the skills we would like to work on this week. We can work

with this plan or skills so that the child would go to the center for two or three days, and on the remaining days, parents would apply the activities at home. Such a proposal may only apply to some families. In some cases, there is an actual need for the child to attend every day, but for some families, the part-time option must be opened!

I aspire to improve the accessibility of persons with disabilities, not only now but in the long term, in the future, 10 or 20 years. “Who would know?” Saudi Arabia may one day be a pioneer in the field of disability.

I see that I represent children with disabilities and some parents whose words may fail them due to their lack of education or inability to express themselves appropriately. Such representation wants to demand their rights, for sometimes I imagine I am a person with Down syndrome, but I can talk. This feeling overcame me because I always think about my child; some things she wants, others she cannot do, and others are tiring and annoying. I learn a lot from my child, so I try to convey the image I see. I speak on behalf of my child about her problems and circumstances, going to the hospitals several times, and her physical and emotional suffering in clinics.

I voiced for my child more than anything else! I voiced for the voiceless! This voice is often a Saudi-Arabian one first and then a global one. One must initially begin with his surroundings in the KSA, then the Arab world, and globally. I attended a conference in Switzerland with policymakers in the Middle East a while ago as I was invited. I stated that they highlighted many political or social movements in the West, such as defending Black rights and feminist and homosexual movements. In contrast, no one defended or advocated for people with disabilities, and no movement was launched with an appropriate organization! This is owed to the fact that the disabled cannot even demand their rights by themselves, such as people with

Down syndrome or some cases with disorders that do not allow them to defend themselves or demand their rights. So, here comes the role of parents; they must be the voice of people with disabilities. Therefore, I invited the officials at the conference to spend more significant amounts of money and expend efforts towards research and investment in the field of disability.

Dad Three's Story

Ahmed changed the way of our lives! "Where was he taking us? What would happen in our lives? We do not know!" The needs of Ahmed determined our lives, i.e., our lives become based on Ahmed's needs. Ahmed is the first son, and he is the one with whom we discovered disability. Now, he is fourteen years old. In short, these were some questions and ideas I had when I knew my child was extraordinary.

His diagnosis was confusing and complex. The private hospital said he had autism; in America, they said he did have autism with ADHD, and at the city of Prince Sultan for rehabilitation in Saudi Arabia, they said he had mild autism. In Jordan, they said he has autism spectrum disorder with intellectual disability, which is predominant. However, I finally have come to call it intellectual disability with an autism spectrum disorder. This diagnosis comforts me, and I feel it is the closest description of Ahmed's condition. After the diagnosis, the nature of my life differed; of course, my schedule changed, and our family's daily life changed 180 degrees. One has started to make his calculations, budget, and expenses having treatments and flight tickets. I remember that I tweeted ("Now the rules of the game have changed in my life, the matter is no longer simple. It is not for me alone; there are other parties").

Ahmed's disability, of course, was caused by a medical error in childbirth, it was the doctor's fault entirely, but we did not discover that until later. We did not know about the medical error except later. After graduating from university, I was a temporary staff member in a

private school for about three months. At that time, I got engaged to my cousin, and I got married. There was a first pregnancy, but it did not continue. Then my wife became pregnant with Ahmed. When the time came to give birth, my mother-in-law was with us. After losing the first pregnancy, my wife became afraid, and the doctor always comforted her and said, "Do not be afraid; I will give you sedatives." She also said, "I will give you the mask and anesthesia to relieve the pain." As soon as we entered the hospital, the doctors gave her the mask, so she did not feel pain. Every time she felt pain, she said, "Give me the mask," based on the doctor's suggestion, and the nurses gave her the mask. When Ahmed was born, I saw an unusual movement of the medical staff; there was suspicious movement, and they ran and hurried. The boy looked blue, and I frankly said that the boy could have been dead! The situation was a total mess, and the crew was moving fast. At that time, I said oh, the child was dead; although they did not tell me anything, I expected that he was dead! Then the doctor came to me and said that Ahmed must enter the nursery for about ten days. After ten days, Ahmed was discharged, and we went home. The hospital did not tell us anything but said to come back to us later, by then, hopefully, everything would be fine.

Since Ahmed was our first child, we did not know that there was something unusual. However, my mother and mother-in-law told me the child's growth was abnormal. So, I should go and have him checked at the hospital. Then, I searched for a famous private hospital in Riyadh; I went there and arranged for imaging and an x-ray. Two days later, I went back for the appointment with the doctor to check the x-ray; he said, "I advise you to go to a neurologist to give you the complete treatment plan." I asked him what happened; he said, "I cannot talk; the neurologist is the one who will give you the details." So, I went to the neurologist immediately; he said, "I will speak with you truthfully as I want you to live the reality; the problem is that

Ahmed had a stroke at birth, which affected the brain. His entire right side and everything related to the functions was affected. This injury can impact speech or movement, and maybe on other functions that we cannot determine in this time". Honestly, the matter was far more complicated. Ahmed was my first child for me, and I was new to the world of fatherhood. Then the neurologist said, "I am telling you up to fifteen years from now. You must make your arrangements; every summer, you must travel outside the KSA for treatment". The situation at the beginning was exceedingly difficult, and his mother ultimately refused the diagnosis. We refused to call our son disabled. Then, we finally reached the stage of adaptation to the situation after about three years. We have now entered the investment stage for our son's benefit.

It is the kindness of Allah that my brother was working in Sultan bin Abdelaziz Humanitarian City (rehabilitation center). After Ahmed was diagnosed, my brother helped us to admit Ahmed for treatment and rehabilitation. Then, I submitted Ahmed's reports from Sultan City to the Ministry of Health. I was immediately told that Ahmed was to be transferred to King Fahad Medical City for early intervention. My efforts were praised, and I was told, "Excellent job that you started at this age," for we started the treatment when Ahmed was almost 11 months old. We started in King Fahad Medical City, then in Sultan bin Abdelaziz Humanitarian City. Ahmed entered Sultan City more than 11 times, of course, and it took about a month each time. Ahmed's mother accompanied him on all these visits, and sometimes, I accompanied him, too.

We, as a new family, started looking for information about disability. Ahmed's mother enrolled in a master's degree in counselling psychology, and we started getting more information and searching for the sources of disability. We knew that some associations could provide information and services for Ahmed by interacting with the families residing in Sultan City; they guided us to the centers and services. In 2011, I went to Bosnia and Herzegovina for Ahmed's

physiotherapy. After I returned from Bosnia, I started studying for a Ph.D. in Saudi Arabia. However, they opened for international scholarships, and I had the idea to get a scholarship to study for a doctorate abroad; if we were to go to America, Ahmed would benefit as he would complete his treatment during my scholarship.

Indeed, I applied for the language and doctorate. If I continued my study and were able to complete my doctorate, then it would be great, or at least I would benefit from the two-year intensive program in America. Indeed, I went to America from 2013 to the end of 2016. I studied the language there and finished my studies. I started applying for the doctorate, but for academic reasons, I was not accepted. The hospital told me that if you are not going to stay in America for a long time, we do not advise you to start the treatment with us as it would be unfair for Ahmed to learn two languages, and he will be unable to learn two languages. If you are planning later go back to Saudi Arabia and start speaking Arabic, we advise you to return now. I thought long and hard and said it was better to go back. So, I returned to Saudi Arabia in roughly 2016. After that, I had two goals: the first was to pursue Ahmed's treatment, and the second was to focus on my studies. Therefore, when I first returned to Saudi Arabia, I went to the Czech Republic and stayed for three months with my son. The doctor there advised me and said, "Why do you not go back to Saudi Arabia? There is an excellent doctor. Why don't you visit him?" In about 2017, I started my doctorate. During my studies for my doctorate, I travelled to India three separate times to treat my son. At that time, the idea of the title of the doctorate dissertation became ready; I wanted to talk about disability rights and controls in Saudi Arabia. My research, discussions with doctors, and the research proposal were all written during my travels. In late 2018, we visited Jordan for treatment, and it was effective. I did not find an appropriate program

in Saudi Arabia, and there was a difference between the services in Jordan and Saudi Arabia. Then, we thought that Ahmed must move to Jordan, for the services were incredibly special.

I took a long-term leave from work and went to Jordan for a year and a half. I stayed with my two boys, Ahmed and Tariq, my other son. Due to the working conditions, my wife could not go with us. At that time, I became my boys' father, mother, friend, and everything. Thank Allah, I could cover all these responsibilities and I learned to rely on myself, since I have experience with traveling and being alone. I was the one who cooked, washed, and cleaned. There was no one to help me. These responsibilities helped to form a second personality; I became able to manage the entire house while being preoccupied with the research and thesis. When the year and a half had ended, my leave from work ended. I only received a quarter of my salary, and I could not cover our expenses and Ahmed's. So, I thought and said to my wife, "Why do we not leave Ahmed in Jordan in the internal school, and I will return?" My wife rejected the idea that we leave Ahmed alone. She said, "Ahmed is part of the family, and either you or I am the one who should be with him, but never leaves him alone. It is impossible". Indeed, it was a difficult decision and pressure, especially on the mother, because we, as fathers, are a little intense. However, as for the mother's heart, it is difficult because she is naturally anxious.

I have other children besides Ahmed and Tariq, Ali, and Sarah. One of the doctors advised me when Ahmed was three years old and told me, "If you want Ahmed to improve and develop, you should have other children." So, in the beginning, we were frankly hesitant. When someone receives the first child with a disability, he becomes overfilled with fear that the second child can become disabled. This was one of the ideas -by the way, that is spread in families with a child with a disability. Indeed, we took the advice, and Tariq's impact on Ahmed was powerful, and vice versa. I see that Tariq has loved the leadership because of his brother, of course!

Because of Ahmed's situation, Tariq helped us a lot in taking responsibility for his brother and even with the housework at home sometimes. I believe Tariq did not live his childhood, but this reflects on his personality now. Tasks in the house are distributed to everyone, and even I was at home helping in the first place. When my son Tariq saw that his father was helping in the house, he gained this experience and became part of the schedule. He once cleaned, helped, and tidied the rooms. This is owed to Ahmed's circumstances; honestly, the whole family's life has changed!

All my family members have officially joined the treatment mission in Jordan. Praise be to Allah, as this has helped us a lot financially. These reduced expenses of Ahmed and everything related to the treatment is now, praise be to Allah, paid by the government. My family is still in Jordan, and I have been doing my work and visiting them during vacations or weekends.

These living conditions helped me have plenty of time since I am alone in Riyadh most of the time. I sought to provide things to serve the field of special education. I swear, if I were with Ahmed, I really could not get involved in advocacy for Ahmed needs 24-hour follow-up- we must be with him! If Ahmed were to be with me, it would be different. I would have a very tight schedule. Despite the difficulty of the situation in the distance of my family from me, it has a positive side because I have become more preoccupied with them. I keep remembering Ahmed and his situation. I must provide something to compensate for my distance and fill this void that I have!

I have a quality that distinguishes me. First, I am a specialist and a parent at the same time. "If I, as a parent, will not talk about disability, who will?". Second, my doctoral program, I changed my program completely. I had multiple options on the subject of control, but I

specialized in the subject of control to protect the rights of disability. I imagine Ahmed in ten, twenty, or 30 years, "What will his rights be?" Therefore, I specialized in collecting and unifying individuals with disability's rights in one place, and I faced difficulty. The rights we had in the KSA while being plenty, did not exist in one place, so I took this matter upon myself. I said if I did not tackle this matter, no one would talk about it. Thus, I combined academic matters and real-life field matters! Rights were grouped under one framework.

In KSA, rights exist, but no one has written about rights as I did. The laws are scattered and undefined in one place. For example, when someone visits the regulations of each ministry, they will find that they have specific regulations and instructions. For example, the Ministry of Education has approximately thirteen regulations to preserve the rights of students with disabilities and to activate inclusion and the student counsellor or the individual educational plan. There are many things and pieces of evidence, but no one knows! If the evidence is present and this right exists, the question remains, "Why do we not apply this right?". This was one of my motivations for advocacy. Some rights exist, but you want someone to instruct people about them. So, I found myself taking this role, even describing myself in my Twitter bio as a coach specializing in protecting the rights of people with disabilities. I used the word trainer, or coach in general, because I present more than one educational course, including a training course I offer to instruct people on the rights of disability. I chose the word coach since the word advocate may be taken negatively. Advocacy is a beautiful and universal word, but the situation in our culture may mean something else. Many understand that when a person is a social activist, it may mean that he is a person who opposes the regime or seeks to stir up confusion. So, through my training courses, I advise the parents and tell them, "The rights exist, you just look for them for they exist. Claim your rights from the responsible entities. Do not be silent, file the

letter to the responsible party". In other words, I started teaching the parents how to assert their rights and the joint mechanism followed in demanding rights.

There are tremendous efforts present in Saudi Arabia, but they only need an official who understands and is familiar with the situation to make executive decisions. Now thank Allah, the Authority of Persons with Disabilities exists and is a direct reference for citizens. I always used to ask the parents or anyone complaining about the current situation, "Did you contact the official?". The answer was almost 90% "No." Therefore, I told them to file a letter and express their complaints. A letter is supposed to be filed by one; two to five officials will look at the letter so that they profoundly look at the issue. I know there is a shortfall, and even the official authorities say there is a shortfall; however, respecting the regimes and the officials is significant in writing speeches. No offensive letters should be written, and we must know how to address the officials. We have at least performed our part of the responsibility.

I know the situation will not change completely, and I always ask myself, "Have we achieved what we wanted?" Of course not, but I see we are moving in the right direction. In two years or less, many things will be changed, hopefully for the better. However, I still say that we want a specialized regulatory body! People need to learn their rights and where to go. In addition, people do not adapt to their child's disability quickly, and our early intervention services are fragile. If I did not go and asked about such services, I would not know about them. If there were guiding messages from the ministries or an order by the Ministry of Health for follow-up, it would have been better. I hope the Ministry of Health will force the parents to follow up. The Ministry of Health forces parents to get vaccinated. However, I also hope they force the person to be vaccinated and follow up with a speech-language pathologist, physiotherapist, and audiologist, "Is there another health problem or not?". If we had compulsory

programs and activation of early intervention from three years old, it would be preventive treatment! I also hope that the ministries will play their role in providing awareness as NGOs are more effective than government ministries; even globally, this is known that often the role of specialized associations through courses and the media is more significant. So, I try to deliver a message to people with disabilities "You are a complete person, and you have full capabilities, but you only need services!"

The role of the media is feeble in the subject of awareness. There should be films that educate and raise awareness and convey the correct picture of disability. I once saw an Indian movie that I liked about a student with a specific syndrome and depicting the details of his life with his family. I swear I was significantly affected by the movie, for I have a child with a disability, so I felt it. The idea of the movie was how the student adapts in the classroom and how the teacher makes him one of the best students. Sometimes we need guidance through movies or series since we, as parents, live in suffering, and we become delighted when we see a specific drama about reality. The day will come when I act or tell Ahmed's story, and I am ready to make it a movie. Consequently, when there is a character who has a disability or a specific syndrome, I always watch it.

Some families suffer and may divorce due to the lack of guidance since the wife or husband becomes busy with the child; the psychological side is essential for families. Most of the services are provided to the child, but it is also essential to pay attention to the families. They must have special programs, such as support and training programs and even recreational trips so parents can strengthen through. This matter is exceedingly difficult and expensive financially, mentally, and socially; the view of people and society is brutal, "Everyone looks at you with compassion and mercy." Under the difficulties and pressures of life, I was hoping that there

would be all-expenses-paid trips, so I could travel outside the KSA to relax! In one of the meetings with parents in an association, I suggested that there should be a care home that accepts the disabled child for a whole week. For example, if I must travel or leave, or have a social event and I cannot take my child with me, I want to place him in this house, which would be a business but supported by government agencies! I will be assured that my son is in a safe and secure place for a certain period of time; hence, I will be able to travel and renew my energy. The family needs support on the psychological side, recreational, touristic, and therapeutic care so that we can be resilient and do our part with our children. "Indeed, I travel recreationally, but this is necessary in order to be able to provide myself with the strength to be patient to take care of my child!"

Traveling has changed a lot in my personality. For example, during my stay in America and Jordan and through my travels for Ahmed's treatment, traveling has helped me to think profoundly and increased my relationship with Allah. When one stays in foreign countries alone, he has two options: strengthening or losing his faith! The alienation affected me a lot, thank Allah, and to not lose myself, and I filled my free time with something useful; I was concerned with reading. I started spending much time in libraries to research and read to fill any free time. My relationship with travel started early. I have seven brothers, and my father spared no expense, as our financial situation was good. So, as a result, there was continuous travel for tourism with the family; we were traveling outside the KSA. This travel contributed to the formation of my personality, and I became familiar with overseas experiences. This helped me to constantly search for and have solutions since I have a love of knowledge and curiosity. With time, I have developed a culture of abundance, i.e., I take and give information from and to you. There are

two types of mentalities: an abundance mindset and a scarcity mindset. I have an abundance mindset since I like to share and give others the information I have.

Also traveling, whether in the past or currently, has made me gain life skills such as respecting the cultures and differences of others. I engage with everyone, regardless of their religion, nationality, or race; in the end, we are all sons of Adam, and there is a link between people: humanity. I am open with other people to the extent that everywhere I go, no one asks me, "Where are you from?" I am still determining where I am from! I am like a sponge, according to the last person I sit with; I imitate his/her words. I took this habit from traveling as I try to adapt to people.

I also have a habit, which has helped me with being an advocate, that when I get excited about a topic, I try to explore as much as possible and deal with it with the highest possible quality. My quality standard is between average or particularly good and less than excellent. I cannot reach excellence at once, but I try to reach excellence! I naturally tended to self-education from a young age, and I used to enroll in development courses early in middle and high school. I am passionate about learning and have participated in English language courses. While growing up, one of my uncles was interested in computers, educated, and familiar with the courses, so he encouraged me to enroll in computer courses. As a result, I had an early conception about Windows, Black Screen, and C. I am not a technical expert, but I have loved technology, browsing websites and being able to access the Internet for a long time ago. My passion for technology a long time ago helped me to access global information. I was familiar with everything new; I am honestly addicted to computers and software and applications. I spend most of my free time on YouTube as I am short on reading. Thus, in return, I make up for reading with documentaries because I like things that have pictures with sound.

In the end, frankly, my conscience is noticeably clear, thank Allah. This is owed firstly to the fact that I wrote my experience with my son's treatment in my blog, and I collected the rights of the disabled in one place for I felt that this was my duty, honestly. Maybe, Allah will hold me accountable from the side of Sharia and morals, and this is zakat on knowledge (one of the Pillars of Islam). "If I did not talk, who will?" Finally, I covet to reap the rewards that, Allah willing, will come out to society and Ahmed in the future.

Mom One's Story

Fahad's pregnancy, birth, and diagnosis of autism were all in America. Fahad's birth was difficult. Thus, Allah blessed my soul and Fahad's soul, and we both entered intensive care, and it was a case of a rescue. However, Allah gave us a second chance, and we lived. All medical errors happened in America, and I was hiding that the diagnosis for Fahad was from America until after I started teaching courses and lectures, telling the public my story in America as a motivation for the parents, who insist that if their child were in America, he/she would have been diagnosed correctly and treated better. I wanted to show people that whether in America or the remaining countries, mistakes happen in all places in the world. A medical error happened to me in America, and my son was misdiagnosed in America. All these complicated things were in America.

What happened is that the doctor recommended inducing labor, so I had medical complications, and the boy was in the abdomen, drank water, and had hypoxemia and diabetes. The doctor gave me a back needle, and the anesthesiologist was not satisfied; so, against the doctor's recommendation, the anesthesiologist gave me a second needle, i.e., a second anesthesia! I, at once, felt that my stomach became bitterly cold, and then I could no longer feel myself. They told me I had entered a semi-coma, and I woke up. When I first woke up, I was tied

up, and my mouth was closed with the ventilator. I was in no condition to do anything. I even felt that I was calling and saying, "Oh, Saleh (her husband's name)," and he was not answering me as the devices and wires were attached to me, my hands were tied, and I could not ring the emergency bell. The devices were attached to me from my head to my legs. The first time I asked, when I woke up of course, about my baby, the nurse said, "Do not be afraid. Your baby is fine, and there is nothing wrong with him," and she said, "You are in intensive care while he is in the nursery."

I was alone, and my husband was not with me because he did not have the bracelet that allowed him to reach me. He was waiting for the translators, anyone, to let him know about my condition! They told him that if he came out of the waiting room, they would kick him out. The poor man came back, sat alone, and used the phone. Later, the nurse approached and told him, "Your wife had a boy, and they were all fine." The nurse did not tell my husband that his wife and the baby were in critical condition! She only told him that we were okay. My husband called my mom, who was in Saudi Arabia, to tell her that I had given birth and was okay. After a couple of hours, my mother rang my husband and said, "Saleh, let me talk to my daughter; I want to speak to her" he told her, "I did not see her yet!". She said to him, "What? Strange?". He said, "Yes, I swear I have not seen her yet." It was 6:00 AM on the second day after giving birth! The wires were still attached to me for breathing, and I could not speak. After noon, my husband was finally able to see me, and he immediately told me that "The first thing you must do is talk to your mother." He said, "Your mother is anxious. She says if my daughter dies, bring her body here and not to bury her in America!".

During that time, I was psychologically tired, and whenever I told anyone that the situation was terrifying, they would tell me, "You were drugged. You should be thankful. We

were terrified of the situation more than you know because we did not know if you would survive or not!”

Now, I am strongly affected when I see anyone in the emergency room or an intensive care room. My family says, “Why are you affected? We are the ones who felt the situation more than you, and you were drugged!” I tell them, “The problem is that you thought I was drugged and did not feel anything.” I was indeed drugged, but my heart was sensing everything and what was around me. On the contrary, I sensed everything strongly!

When a mother and her child transition to the stage of death, and a second chance is given, this feeling gives one goosebump! They took me then to another palliative care room, not the intensive one. Every time one of the medical staff entered, I found them celebrating me and saying this is the miracle we saved with her child! The Americans mixed it all up and registered my case in their records; they congratulated the doctor who saved me. Indeed, he did not save me; it is the opposite! I did not sue them! Although the Saudi embassy’s lawyer told my husband, “If you want, I can file a case. I will file it for you for free, and I will not take any fees from you and will receive at least USD 100,000 since it is a medical and known error”. However, my husband told him, “I do not accept compensation for my wife and child. The most important thing is that they are alive and safe, thank Allah”. During that time, my family still did not know about me and did not see me, but they knew I was alive; I started talking to them daily on FaceTime. So, I admire the means of communication and the internet.

Indeed, I did not have anyone in my family while I was in America, but the most extensive support was honestly from the Saudi neighbors. I had neighbors, who, during my postpartum period every day, each would make me breakfast, lunch, and even Arabic coffee! I wanted to breastfeed my son as I am one of the supporters of breastfeeding and love its

outcomes. Every time I started breastfeeding the boy, he turned blue, and his breathing stopped. I took him to the children's hospital; when he got hungry, I gave him a feeding bottle. As soon as I put the bottle in his mouth, the devices started ringing, and the nurses came running and yelling, "WHAT DID YOU DO TO THE BOY?" threateningly as if I were to kill him. They examined the boy and diagnosed that he had a "Choking." Two weeks later, when they discharged me from the hospital, the doctors told me I should perform an MRI on the child in six months to ensure that the brain was functioning well!

When Fahad was born, we were concerned with his health because he chokings during breastfeeding to the point of dying. There was no oxygen, and he used to turn blue as if he were dying! I kept monitoring and watching my son well; I never neglected him. Is it possible for any mother other than me to say, "I do not know that my child has autism" up to a year and nine months; I observed him due to his choking condition. However, as I said, I kept monitoring and watching Fahad every day, all the time, so that he did not have a choking. I can confirm that my child was normal!

My mother used to tell me, "When you were young, you made the same move during breastfeeding? Your father and I had trouble with your choking. We took you to the emergency hospital three times and handed you over to them, thinking they would give us a dead body. However, glory is to Allah, you come back after they revive you, and you go home with us. I did not know what the reason was!"

After Fahad was diagnosed with autism for a while, my personality changed, and I rebelled, "Hahahaha "As my husband's said, "What did the Americans do to you? Did they transfer blood to you to rebel?" (He means when I entered intensive care in America). He asked

me, "Whose blood did they give you to make you change? Hahaha! I told him, "It is not the blood, but dark moments teach me!"

After Fahad's birth and after the intensive care, I succumbed to depression, and I saw a psychiatrist who gave me sleeping pills. After the third month of visiting the psychiatrist, he told me, "What are you doing?" I said, "Nothing; I take the pills and sleep!" He said, "No, what have you changed in your life?" He said, "I give you the pills to help you with your battle, not to sleep" He then said, "You must focus on something new in your life," He said, "Go back to your studies," I said, "I cannot, my children need me," He said, "Your children do not need you dead like this! Your children need you strong". The psychiatrist was the one who was influencing me; he affected me, and he was the only person who supported me during that period! So, after the birth of my child, I got excited; I joined for a one-year computer diploma and learned how to design websites. My passion was in the computer, and the diploma was the breakthrough that got me out of this state of death!

When Fahad was young, everyone loved him during the first two years, although he did not laugh in your face, kiss you, or do anything. He was quiet and calm! During routine follow-up visits, I asked the doctor, "Do you notice that Fahad is not talking? I mean, we visit you every time, almost every month, and he is not talking!" He said, "No, I thought he was a shy child" When I told the pediatrician my son was not talking, he immediately transferred him for diagnosis, x-rays, and tests. We got him an MRI and a hearing test. We did everything for him, and everything was fine! The doctor gave us a referral for diagnosis, saying there must be an IQ test. We went to perform the IQ test, but they did not have translators. The specialist said it was a non-verbal test and that we would not need a translator. I was with Fahad at the time of the test and diagnosis, and the boy did not understand her. The specialist gave him a book, which was the

first time he had seen a book in his life, and I told her the boy had not seen a book in his life; she said, “How has he not seen a book?” She was an American, of course, and I spoke English. I said, “I never gave him a book at home. How do you want him to deal with the book?”. Then she gave him a shoelace and said, “Let him tie it!” She refused to let me hold my son, so I was sitting away from him, and she was sitting with the boy! She told me you are a negligent mother. In the end, Fahad was diagnosed in America at the age of two years as having severe autism, hyperactivity, and distraction with severe Intellectual disability, unteachable and untrainable. He will remain in this case his whole life, or I could put him in an accommodation center if I cannot take care of him. Alternatively, if I wanted, I could just put him in day-care in the severe disability classroom in the middle of a government school close to my area, and this was up to me. My husband and I decided that Fahad would go to day-care in an inclusion school and be in classes with severe disabilities. They asked us to write a pledge that he must go to the center because Fahad has an American passport and that we would not also refuse that he would come and go by bus!

It is true that they explained everything to us, but everything was done in a threatening tone. We were prevented from going with him the first day he took the bus. I went in our car with my husband, and I was crying. This was the first time someone had taken my child from me; I did not know where he would go. When we arrived at the center and wanted to enter with him, they prevented us from entering. Then we went to the administration, and the administrator said it was forbidden to enter with him in the classroom! I said, "How is it forbidden! I see that my son is going to a new place for the first time, and he is two years old". She said, "all the children are safe. We cannot let you enter and let him see you in the first place because we do

not want him to get attached to you. So, I cannot let you enter, but I promise you that your child is safe".

I felt at that time of Fahad's diagnosis that there was an injustice to my child: first, because my son's diagnosis was quick, and second because the difference in culture had a role that my son had an unfair diagnosis! The diagnosis was critical in changing my personality when I knew that Fahad had autism. I said, "I should change my way of dealing with him." I said, "It is unfair how they dealt with my son because I have spoiled my child." I would at least stop spoiling him; I would watch my actions and find out what he could not do because of my spoiling! I wanted to see the limit that I would reach with Fahad!

I felt injustice by the presence of Fahad in the center. When he concluded the semester , and during the home visit, Fahad's teacher confirmed that my son's level was advanced and that he did not need to be in the care center. However, due to the threats we were receiving, we should refrain from making any decision regarding education of Fahad. We decided to return to Saudi Arabia! At that time, the matter placed us under pressure since they threatened us extensively about the pledge. We became afraid and terrified that someone would take our son from us! Indeed, we returned to Saudi Arabia and needed to receive the appropriate services; there was a deficit and shortage.

There was no one offering courses or family support! I searched for any courses or anyone to hold a session or teach me about autism, but no one offered this course. There was only a female doctor who offered courses in Riyadh. She offered such courses for 3000 riyals. As a mother, I thought, "What is better? Should I pay 3000 riyals for my son's speech sessions, or should I go and take the course?" Then I said, "No, I will pay the money for my son's speech sessions." The choice was difficult, and we lacked education, unlike these days! When I knew

that my child had autism, I did not find anyone to guide me; there was no family counselling after diagnosis or educational courses for autism. I was motivated to learn and offer courses to others!

Then, my husband had a chance to work in Bahrain, and once I found out, I applied for a fellowship in the Department of Business Administration. However, when I arrived in Bahrain, they told me there was an autism program in Bahrain! I said, "Transfer me to the program." They told me it has no future, no jobs. I said, "I do not care. Transfer me to the program because I want to understand my son". This was my goal now: to understand my son. I did not want anyone to play him or me for a fool! In the centers in Saudi Arabia, each one was throwing me at the other as if I were a ball and the child's years were wasted. No one talked or told me this was science, nor that this was how to deal with autism.

All my life, I have been a peaceful person. My voice was not heard; I only carried out the orders of others. I used to follow, not lead; all my words were "Okay, yes, as, as you wish and done" without asking, inquiring, or even thinking. There was an order from those around me that I had to enforce, but after I started studying for the master's, I rebelled! While initially studying for the master's degree, I had my own decisions! For example, my husband used to tell me, "Do not go today; Fahad is tired!" I started saying, "No, I will go because I have a class." Consequently, when I saw that this was okay on the day, I told him, "I do not care anymore" I knew that the word "No" was not fearful.

The decisions that I made during my master's degree were the ones that seemed to open my mind. If I made up my mind and expressed my personality, it did not mean that I hated my family, my children, or my husband, that I was a rebellious woman or a negligent mother, or that I was supposed to be a follower all my life to someone. On the contrary, my children needed me

to be strong. I mean, for myself, I needed to be vital to defend them; I needed to be, as they say, a brutal woman who attacks, demands, and takes her rights!

After I studied for my master's degree, I began to understand my son Fahad, and I became the one who trained and taught him everything because I understood and studied his case! I acted with him and dealt with him according to his abilities. I treated him in many situations as if he were a three-year-old child, and in other situations, I treated him as if he were a man. Besides that, thank Allah, my son is now almost more independent than his normal brother. Fahad is the one who knows if something hurts me or bothers me; he comes to tell me then, "Mama, what happened?" Do you believe that Fahad is the most affectionate one at home?

After my studies, I began to deal with him better. Nothing forces me to say this, but I am not exaggerating when I say I got 85% better. The 25%, as they say, I was dealing with him instinctively; I believe the mother can provide even if she did not learn, know, study, read, or even attend courses!

When I was in Bahrain, and after I finished my master's degree, I offered courses to one of the affiliated charities concerned with autism. I used to offer them morning courses when my children were in school; I sometimes offered them a course once a week or a month!

I only pay attention to the specialist who attends and cooperates, not the statistician who scapegoats the parents and blames them for the failure of educational plans! We, as parents, see one side of the coin; I see the two swords and the palm tree, and you see the face or the writing. The coin has two sides: a picture and writing, right? Parents always look at the picture, and the specialist looks at the writing or vice versa; there is no one looking at both sides. If the specialist does not help or stand by the parents' side so that both agree on the same direction, the whole picture will be different and incomplete.

After graduation I went back to Saudi Arabia, I was not an employee. My friend suggested I start a little bit and record clips on Snapchat, as it was widespread those days, like TikTok is now. I started working on all social media: Twitter, Snapchat, Instagram, Telegram, and YouTube! I became an advocate and pledged to serve the parents- not the specialists- the parents whom I cared about! I launched these accounts, as I said, because I felt that many mothers were lost like myself. Therefore, I said, if there is a distortion of the thought about autism, I have to modify the idea about specialists; I want to help mothers understand autism, and this is how the idea came! For example, they google autism, find commercials for autism treatment in minutes, or that urine or milk is a cure for autism; they do not understand what autism means. When they search on YouTube, they see a boy who breaks, destroys, beats, and sheds blood, or they see clips where the child is tied to a chair and is even uncatchable.

I started sending the link to my channel to relatives and mothers I met in Bahrain and anyone I knew who had an autistic child. My colleagues who were with me at the university sent my link to other mothers who had an autistic child, and my colleagues who were with me, some of them were from Kuwait or the UAE, not only Saudi women. Then, I turned to Twitter and started searching in the hashtags of autism or people with disabilities, and I followed the doctors whose names are known in special education. I started following them if a book was issued or if they offered a course and saw what centers or conferences they would visit! Through following and mentioning, one account leads to another; a Tweet that drags me to another or a comment under a Tweet, and people discuss me, then follow me. Even the Tweet pinned to my account attracts people to me and makes them follow me, and so on. Little by little, I became well-known on Twitter, which is the reason that made me famous quickly.

In my tweets, I began to write that I would be online on Snap and talk about something; on my YouTube channel, you will see topics about this thing. Twitter is the most important thing that made me famous or helped me reach people. I have two thousand seventeen thousand followers on Twitter. From Twitter, people and centers started calling me, "We want you to offer courses with us," or they say, "We liked your elocution, we liked your style," or I offer to associations that I speak for them, teach courses, or propose to them that I attend events with them. Then, I became a member in the associations when I knew that there were memberships!

After I started offering courses and became a member of the associations, I was nominated and attended more than one meeting with the Authority of People with Disability in Saudi Arabia. I attended two meetings with them and attended several meetings in special education centers for development. I attended meetings with GESTER, where I was also offering with them courses and presented a couple of meetings with them. I am a member now in more than one voluntary association, and all my activities are ,of course, voluntary for Allah's sake.

I am working and offering courses because my goal is to educate the parents. Advocacy is not based on business or money. Gain must only sometimes be money or consideration. I see the results of my voluntary work reflected in me as a relief of distress, push-back to calamities, or blessing in livelihood, and I believe in this thing and deal on its basis!

I took a course to be a life coach, so I can deal with and teach people how to overcome some difficult situations in their lives and to get to safety with the least number of losses. So, I feel, or I wish that I am always the hook that saves anyone who is drowning! I am happy after I provide service to any human who is in need. I reach a state of joy, happiness, and euphoria that I help improve anyone's life—an indescribable feeling when you feel that you are (really) valuable

in society. O Lord, praise be to you, I have role and status, and I can serve and change the lives of others. I changed from Abeer who was only following people to Abeer who leads others!

Indeed, I do not wait for a reward or applause from anyone, but it does not mean I do not like the appreciation for my effort. If someone one day said, "Mrs. Abeer, she is my teacher," "she helped me," or "she gave me a hand." This makes me happy and motivates me to complete and continue.

I came from a family who has lived their whole life in Riyadh, and our house was hospitable. No servants, hotels, or restaurants spread like now; everything was prepared at home.

From the day we were young, my sisters and I were raised as housewives, i.e., we helped my mother in raising my siblings, and we helped her when we had guests. The guests came and slept at our house, and some of them lived with us for years. For example, young people from the village would stay with us during their studies, so we were responsible for them. These events all refined my personality. This thing made me learn that giving has no limits.

I remember a situation that affected me a lot when I was in the sixth grade; my mother accompanied my sister in the hospital for a whole month, so I took responsibility for the entire house and my siblings in addition to the guests who were staying with us. I was forced to assume the responsibilities of the whole house; my brother was 3 years old, and the rest of my siblings at that time were infected with Varicella zoster virus! I took care of the sick children and cooked for the adult guests. I was concerned about my father because he was nervous, and we used to think that our father is strong, yet in the end, I saw my father's personality: how cooperative and kind he was. In this situation, I got to know my father more in that period when I got close to him and dealt with him directly.

Also, staying abroad refined and changed me. It taught and changed me. The first thing I started to do was to accept everyone and believe in people's differences. Even before I gave birth to Fahad, I was traveling abroad. I travelled with my husband to several countries by virtue of his work, and this taught me that our differences from each other do not mean that there must be a disagreement between us or that someone is right while the other is wrong. When I entered the field of volunteering, these experiences did not make me think hard. Volunteering and accepting others are in my blood, as they say. I do not know; I feel that all these things also affected and changed my personality!

I would like to draft a book; I have the idea in my mind, but I do not like to read, and I do not like to write. Therefore, what is in my head is final, I will not write by myself, but I would really like the story of my life to be written in a book or at least the story of my struggle with Fahad and his condition! I want to author a book, and I feel that now the trend of parents' books is more than before. Now, whoever authors a book, as long as he/she is one of the parents of people with disabilities, you will find the book more popular than if the writer was a specialized scientist. As I said, my tragedy is that I want someone to author my story; I would talk, and someone would draft my story.

My view of my role as an advocate is crucial in that I have become influential in the lives of others. When I hear that someone has taken me as a role model, it gives me a marvelous feeling and the motivation to continue! In the world of volunteering, we offer and forget that we offered service, or those around us forget that we helped them. Sometimes, from time to time, we feel frustrated and wish to stop. I sometimes ask myself, "Why do I bother myself? There is no need", or even if I sometimes sit for a while without working, it is normal. There is no one behind me who will encourage or remind me of the work, so I feel tepid for a few moments.

However, when someone suddenly comes to excite me, or I find a mention in my account on Twitter, for example, saying she was helpful, or a post of my account on Snapchat saying that my account is one of the accounts that benefited them, the same thing if there is someone posts my channel in YouTube or Telegram, I feel like this gives me gasoline to complete the journey.

People benefit from me, pray for me, and remember me in a good way. If someone criticizes me about my advice or claims that I am too arrogant, I just leave them alone. Instead, I focus on knowing I am helping those mothers: the ones who are in a state of shock and on the verge of collapse because of receiving news of their child's diagnosis. I talk to them and advise and instruct them. o. Then, two or three years later, when I see her opening a social media account that benefits families provide services and helps parents. Wow! Here I am in heaven! I delivered the message until she became an active person in (our) society; I see her providing service instead of asking for it!

Even in my family, this (my volunteering activity) has affected my brothers and influenced them to join volunteering. My older brother started volunteering because he got cancer. So, the first thing he started was the Saudi Cancer Foundation for cancer fighters, but he did not tell anyone. Little by little, he entered the world of volunteering and expanded. He liked it. Somehow, I believe I encouraged him because I have become a famous advocate.

As for my little brother, he is a pharmacist and follows in my footsteps as he wants to become like me. He always says that "You are always my role model, and you let me walk in this field." He has also left a great impact on many people in his field, and they have entered volunteering because of him. I am happy that my brothers and I are engaged in the world of volunteering and advocacy for helping others.

I can proudly say my voice is heard, but it is heard by whom-only parents. I hope that it is also heard by the officials, and I hope that we see some progress more seriously. The main problem lies with the officials. When the person in charge of special education has no background in special education, and at the same time, he is the person responsible for making decisions, we get down as parents! He is making decisions, but he does not understand our reality, or he is sometimes sticking to the plan that the officials before him devised since he has no background about what is happening, which results in him floundering.

In general, I am certainly satisfied with the impact that I leave on the parents; first, they demand the rights of their children, and they have learned how to deal with their children. My message is always to the parents, "Understand your child and deal with him as a child and as a special case." These things, praise be to Allah, have reached a large segment of society, and, Allah willing, I will reach a larger segment yet!

The only thing I wish that Saudi mothers these days would find is family guidance after the diagnosis. I wish that there was a case manager who would take control of the family after their son is diagnosed. This case manager would know about the details of the son's condition and what he would need to learn while guiding the parents on where to start and where to go; this case manager would have a list of names of the centers and inclusion schools and would not only say "Go visit an intervention center or a day-care center" in general and say that was it. He (the case manager) is supposed to have a list of the names of the centers that exist in each region, hospitals, support services that are available, associations, supporting families, and even government services for people with special needs and their rights. This individual would tell the parents where to go and assist them, parents, in applying for them, if necessary. For example, the case manager would say, "Go open a social development account for the child and register him at

the specified age." In short, a case manager who would do the job that I am doing now. I hope that there is a qualified case manager in every diagnostic center who would approach every father and mother the first time they know about their child's diagnosis and would tell them, "This is not the end of the world, but your child needs 1,2,3 come on the go, and you can ask me any question at any time!"

Fahad is the best thing that has happened in my life. He changed many things for the better in my life! Fahad taught me a slogan that I always repeat (I will be patient until patience is unable to be patient. I will be patient until the Most Merciful looks into my matter. I will be patient until patience knows that I have patience for something that is better than patience).

This is the story of me: the story of Abeer who turned from Abeer behind the pressure cooker and the coffee pot into Abeer today, who is behind the means of communication from Zoom and Teams to all social media- except TikTok as I still have not created an account.

Mom Two's Story

I am the mother of a twelve-year-old child with Down syndrome, to whom I gave birth after all my children had grown up. I am educated, and all my family members have been educated: my mother, father, and sisters. I lived with my mother, who is separated from my father, so I grew up first in my grandfather's house with my aunts. I stayed with my maternal grandfather; he was the one who raised and taught us. He always told my mother that girls must learn and have a university degree to be independent. I graduated a long time ago. Then, I moved to live with my mother's husband, and my mother was rigorous and did not fool around. My mother was responsible for us; she was the one who provided for and managed our affairs. My mother strictly raised us to have strong personalities. She used to distribute tasks among us three girls as if we were men! It was genuinely like we were men! My order was the middle among my

sisters; we are all daughters, as my mother did not have boys! We used to do everything ourselves. For example, when my mother was at work, she came home to find us having made lunch and completed our homework. Each of us had a role in the house; each one would take care of something while being independent, and everyone had her homework. Everyone

would finish their studying, then move to the tasks at home. We were raised on order and discipline. We went to the university, researched ourselves, and travelled independently to Riyadh. There was a time when we used to visit our father and come back; we used to book our trips, travel, and do everything independently. I graduated from high school, and my mother was in the education field, but she used to say, "Come on, move your feet and apply by yourself to the university. Go and attend your lectures by yourself. Forget that I am in the education field, will come after you, and will apply, on your behalf, to the specialization you want. I am no longer responsible for you. You have grown up now". Indeed, I submitted my file at the university and entered the Sharia department!

When I graduated, I got married immediately and refused to work. Frankly, I would not say I like working and am not inclined to work. When I married, I was not particularly eager to distract myself from my children. I should invest in my children so they would support me instead of me and their father going out, leaving them, and staying away from them as my mother did, so I refused to work. "You Reap What You Sow" is what I found with my children, thank Allah. I made every effort with my children: I taught, taught, and spent time with them. I felt overwhelming joy in investing in my children before I gave birth to my son Mohammed. Although my oldest son applied for engineering at my desire, I used to instruct and spend time with him to discover his ambitions. Thank Allah, he succeeded and applied for engineering. The same story applies to my second son.

In the field of disability, we have no one in our family who has a disability; no one is disabled in the family, neither mine nor my husband's. When I gave birth to Mohammed, my eldest son was in his early twenties, he asked me, "Do you intend to raise Mohammed as you did with me? Will you do with him like what you did to me to be an engineer?" I said directly, "Yes, but this time I will not do it alone; you will help me too." I said, "It is shameful that you are an engineer, and your brother becomes marginalized and does not know anything." This is an inappropriate image for society, uncivilized, and unsuitable for us as an educated family, as I have always focused on this point. Although on that day, when I spoke to my son, I did not know what society's view or look of disability was. I was looking for how I should be a source of strength for my son, regardless of his disability. I was not looking at the disability itself. Instead, I looked at how I could adapt and provide a safe life for my son.

I loved early intervention in Mohammed; I treated him with affection and love in the early years. I used to play on the swings and slides with him, go out to the gardens, and spend time with him. I immersed myself in early intervention to the extent that my husband used to say, "It is like you did not give birth before." Even my mother used to say, "You are like a little girl who has never given birth!". My mother even said, "My daughter, you are now a grandmother; you cannot do this." However, I believed that nothing prevented me from tutoring my son regardless of everything, and the young is like the old. I do not believe in borders; I am a mother and must provide! I am convinced my son can aid himself in being a leader, so I proceeded with my plan!

The first thing I noticed when I gave birth to Mohammed was that his looks and features were strange and different from my children. I looked at the doctor when she brought him and told her, "His features are different from those of my children" she said, "This is whom you gave

birth to," and she kept silent! Then at 9:00 AM, the pediatrician called loudly, "I WANT TO SEE THE MOTHER OF THIS CHILD." The way he was approaching and calling in the hallway made me feel like he was my enemy; even his high voice tone indicated that I caused a disaster, as if I brought or found my child in the streets; that was the image the pediatrician provoked! To be honest, I got scared!

I had just given birth and was annoyed by him, so I sent my daughter to see the situation in the coordinator. She returned and said, "Mother, the doctors are talking about my brother. They say that he is abnormal!" I asked her, "What do you mean by abnormal?" She said, "It means insane." My daughter was in high school, and she was still young. I grabbed and removed the blanket from above my bed with all my strength. At that time, I had given birth 5 or 6 hours ago; I wore my hijab and went out to meet the doctor. While outside, I met a pediatrician who said, "Are you this boy's mother?" I said, "Yes, I am. What is wrong with him?" He said, "Come to the room!" He took me into the room as if I were a criminal and asked me, "Do you know what you did? You brought a developmentally disabled boy at the age of 40!" I controlled myself and asked him, "From a medical point of view, is there something wrong with my son?" He started angrily and accused me, "Do you know that this boy was going to be mentally retarded?" I replied, "I did not ask you about anything else. I asked you from the medical point of view. So, answer the question!" He said, "You have a strong personality and refuse to hear my words!" I told him, "Again, shush. I am warning you that this is my son, and I am his mother!" He kept uttering inappropriate words. Then I asked the nurses, "Why was the doctor attacking me?" At that time, I felt so attacked and not supported, especially by the medical personnel. At that time, I decided to transfer my son and go to our government hospitals, so I would hopefully find good

(medical support) there. A doctor talking to a patient who has just given birth for 6 hours in this manner is someone I do not trust for my son's health at all!

My husband's family is from a small village, and they do not know Mohamed's condition. They used to tell me the boy was deformed! One of my daughters asked me, "What is the meaning of deformed? Why do they say that he is deformed?" I told her, "A deformed is someone who does not have beautiful features," She said, "But Mohammed is wonderful?" I said, "Then he is not deformed. Mohammed has a case called Down Syndrome!" From the beginning, I was concerned about teaching people the correct word they call my son because I did not want to bother and upset myself, and I did not want society to treat him with the marginalized culture of the disabled. I want to introduce my child to my community correctly. I need to educate society so that when my son grows up and says, "I have Down syndrome.", he will not be ashamed or disgraced. I read about children with Down syndrome telling their success stories. I want my son to grow up and talk about himself: "I have Down Syndrome!" I used to go to the pediatrician and ask him, "What should I do?" Of course, he says, "I do not have anything for you!" and "I do not know much about this group. All I know is that it is very mentally retarded, and no matter how much you give it, it does not give you the results you wish for" so he used to say. Therefore, I started saying to my children, call your brother from afar; call Mohammed. I found out that he communicates and hears to the same degree. I used to switch the on and off the light, and I found him paying attention. I put the light in front of him, and he would open and close his eyes. His brothers were also making voices from the right and left, and he would look at them, babble, shout, and cry!

Since we had a desktop computer, I told my children, "I want to browse the internet." I looked for Down syndrome, and I first started reading success stories. I was drowning in the

ocean and looking for a way out! A mother was filming her son while training him to exercise at home. I used to do the same exercises with simple ones; I would stretch and clench his leg with my hand about less than half, for example. I fix the upper torso, tilt the lower trunk, and then repeat the same action as a kind of activity. I did not know that these were all exercises to strengthen the muscles.

The time of Mohammed's birth coincided with the birth of my first grandson. When I grabbed my grandson after the birth, I immediately found him pulling himself, stretching his leg, so I said Glory be to Allah! There is a considerable difference between him and Mohammed when I first held him. Glory be to Allah, as if my Lord brought him to me to make it easier to compare. I used to see all the things in which Mohammed was late and compare him to my daughter's son! We did not have intervention centers in Mecca, and I do not know about the centers. However, I used to see some mothers having children with Down syndrome in the malls, hospitals, and gardens, so I asked them, "Where does your son go to receive services? Where did you admit him?" They would reply, "In an X... association" So, I would take the number of such associations. Then I communicated with a specific association and admitted Mohammed at one year and four months. This was the first time I had admitted him to an intervention center.

My husband was a leader and an official, so I used to manage and arrange everything in his life. For example, if he had meetings, I would assume the responsibility for such meetings, arrange his papers for him, distribute tasks, and even manage the financial affairs inside the house. I was like a private secretary but working at home! So now, most of my work is from home as social media and technology have developed highly. Things are fast. People access information with the click of a button. We can present, receive, ask, and use information immediately and effortlessly. It is free, no travel or courses or money. With the click of a button,

we find the search results, information, and help. I was helping others by building up and passing on the information.

Many things have affected my personality and made me another person! Even my sons used to tell me, "Mom, if Mohammed were your first child, would you expect to reach success with him like this?" I replied, "No!" They ask, "Um, why, mom?" I said, "Just like you did give me another personality, and I succeeded with you, so I continued the journey with Mohammed!" Things are complicated for any new mother to be accepted with any child since she feels lost. Motherhood at the beginning of life for any mother is difficult in the first place; she is confused. So, when a mother gives birth to a child with Down syndrome after having other children, she has at least gone through many life challenges and had educational experiences!

I received support from my sisters the first time I gave birth. They searched and read about Down syndrome online and gave me the information immediately after childbirth. They said, "We read about it (Down syndrome), and its features are such and such." I did not particularly appreciate being preoccupied with the features at that time. I only wanted to be reassured that the boy was healthy since the doctors had filled me with fear that my child had holes in his heart and all the treatments, medicines, and so on! My mind was confused and tired as I had just given birth a few days ago.

Later, I searched YouTube and found an Egyptian woman named Um Mahmoud, whose son has Down syndrome. Since she has a channel, she talked at length in a way one cannot imagine; she was a conscious mother. For example, she used to say, "The first time I gave birth to my child, I informed the neighbors and my family, and I purchased all books about people with special needs. I understood everything about my son". She used to walk the streets with the child to develop his senses. She told people, "Watch out for my son; he is nice and sensitive. If

you do not want to see him, it is fine, do not come near him!". Her strong character influenced me, and I started to understand my son and know more about him. I started teaching his brothers how to carry him and deal with him! I even started to excel in his training and exercises due to my need. I started to visit libraries to the extent that they started telling me, "Did you go back to raise children?" I replied, "This is a beautiful world." living in a world of childhood is truly a beautiful world. Unfortunately, many people are ignorant of this fact. When someone enters this stage, he/she forgets people and reality. He/she starts creating, entering his/her world, and producing ideas. If they work out, he/she looks forward to the next idea! I watched my progress and felt incredibly happy. My husband used to tell me, "You are living in another world" I replied, "Leave me in my world," which lasted for a year and three months, then my son joined the first center. Dr. N.Q. She was the center's director and had a son with autism. However, her son has grown up to be a big young man. She used to say, "Special education does not need slow cooking, heat, and working iron. You will always be encouraged once you accomplish a stage, accomplish another one, then move to the next, and so on!" These were the most beautiful moments of my life in early intervention: I lived with Mohammed, and I enjoyed every minute with my son!

My first supporters, after Allah, are my children; if I am busy, they would play with, feed Mohammed, and prepare his meals, and he eats and play with them. My husband, however, was the first frustrated. He used to say, "Leave him be he is the blessing of the house, whom Allah gave us; leave him just like this" I would reply, "Fine, that is your point of view!" One of my best friends, Um Fahad, is the mother of a child with Down syndrome. Her son is 20 years old, and she is the president of the Autism Society. I talked to her, and she used to tell me, "We are all the same; our husbands are all the same," and tell me, "I even do not tell him about the

diseases that my son has; I go to the doctors and do everything! This is why we do not want to hear the more negative talk!". Fahd's mother was managing a group of mothers to teach, train and educate them, so I joined them. We exchanged cell phone numbers, and we became friends. Um, Fahad was helpful to her because she was easy to talk to and give advice. Whenever we met, she would listen, advise, and encourage us by telling us, "It is normal to feel tired, do not listen to the words of frustrated people," and then tell me, "Get the frustrated people out of your life, do not see them."

At that time, we used to attend the center, listen to lectures, and have training (sessions). Then, we would go back home and apply, and we would continue to go back and forth! Then we, mothers, started meeting every few months. We considered, according to the age of our children, for example, the ages of ten years, what we need to develop their skills. Thus, we agreed and recruited a specialist. We learned and started recruiting the Egyptian specialists employed in private centers. We would meet somewhere. For example, we would rent a hall and recruit specialists to train us. Therefore, we used to rent a hall, and they would visit us on Thursday and Friday; we would take and apply for these programs. We did practical duties, and we used to do roll play.

Furthermore, during these meetings, there was venting (session). We would sit with the specialist and talk; she would direct us about the things that we should give to people to deal with our children, what the red lines that people are supposed not to cross with our children are, and how to control our nerves and actions with people appropriately so that they would not cause us more psychological problems. The journey and the training stage are long; teaching the skills requires concentration and attention since it is full of details and effort. At this stage, every new

mother used to tell me, "I do not see my family except for every two or three months; I swear I do not find the time!"

We started a new chapter with Saudi specialists in special education who would be recruited from specific centers affiliated with NGOs to train our children on speech or behavior modification and hyperactivity. We sometimes recruited a certified Saudi trainer from the University of Jeddah or a visiting trainer from Riyadh University. The information provided was, of course, more accurate and more profound. We then finished that stage and closed the story of the Egyptian specialists.

Moreover, we mothers made WhatsApp groups, and most of the mothers added me. I have never established a group, yet the mothers always said, "Mohammad's mom, we created a group and added you." There was no Twitter then, but we had WhatsApp groups divided according to age. For example, the old ages, who are eighteen years old, had their mothers grouped. When my son was young, I did not communicate with old ages because I did not like to hear about big problems that were unsuitable for the age of my son, and I used to say to mothers, "Stay in the age group in which your son is. It is normal to be two years older. However, when your son is six years old, for example, and join a twelve- or thirteen-year-old group, you will be distracted or hear problems that have not occurred to your son yet." I am a participant in almost twelve groups. During Coronavirus and quarantine, we did workshops and some activities through Teams. I did activities about environments and activities to teach them how to tutor their child at home and play with them through cartons. I did the environment of grocery, animals, fields, and farm animals!

As for adding to the group, if the members of each group knew someone who needed advice or support, they would ask to be added and join us. I do not have the mood for

commitment. Many mothers told me to create a YouTube channel, but I was not excited. I participate in twelve groups, and the mothers talk to me directly. I am not benefiting from the followers as much as they benefit. YouTube is full of channels for education. I am nothing next to them, but I need to communicate with mothers directly when they complain about a problem or ask about a specific problem. I want the mother to stay calm and focused in the episodes on YouTube. She should ask in the group, and I will respond to her directly. Providing in-person courses are even more difficult for me as it needs time and effort, but providing information in groups is easy.

Even in the markets, I find mothers who approach me when they see me with my son and ask me, "How do you go out with him like this? How did you teach him?" I say, "Ok, I am now in the market, so I cannot explain but give me your mobile number, and I will talk to you back home." I then added her with us in the groups and communicated with the group administrator to add her. After a while, I find the new mother has learned, understood, strengthened her personality, and interacted.

Since I often go to the heart hospital for my son, people would consistently approach me and question me in awe about well Mohammad's behavior. I wish they would not question me in the hospital but instead give me their phone number so I can talk with them honestly and openly. I remember the first thing we started in the association, and during training days, we formed groups of mothers; we thought that we would put our names in hospitals so that mothers would benefit from us; however, it was difficult to distribute our numbers to people for it is possible to see the number, but they will not communicate except when they see us in person with our children behaving. They feel encouraged- then talk and ask. I participated in the big carnival during Coronavirus, which the Autism Society supervised. My goal was to instruct mothers, so I

participated in presenting activities and had a corner. I presented the means of teaching primitive methods, for example, the design of the city model, the aquatic environment model, the desert environment model, etc. Visitors used to ask me, "What is this?" Even special education teachers said that it did not occur to them to make models. I also took and distributed gifts to the visiting mothers and children! I also presented at the conference supervised by the Autism Society. Since I have experience with them, they said, "We want to have mothers speaking and a booth

where they would present simple things that attract visitors." So, I must give them strong words through which they would understand who our children are to convey this idea to society! My friend, Fahd's mother, was with me, and another mother of two autistic young men was with me. Dr. N.Q., the founder of the Autism Society, was with us. As an association, it has excellent awareness areas, and it is interested in applying them practically, being the face of the association, but I work directly with families.

I support families directly and spread awareness that disabled children must not miss the golden stage, i.e., the stage of early intervention. Not recognizing its importance as a crucial stage could lead to disorientation and loss for all family members. I always used to tell my husband, "We must work with Mohammed until we reach a stage of stability, or we, the whole family, will be lost."

A while ago, the director of comprehensive rehabilitation called me to give a speech to the mothers who refuse to take their children to visit them at home! I saw things that tired me psychologically. So, when I am responsible and go to do awareness activities for the community, the demands from me are too much. I am happy and proud that I gave my voice as a mother while sitting in my place. I taught, instructed, heard the stories and tragedies, and I taught them how to face pressures and resist, but when saw cases of moms abandoning their children affected

me. No one is entitled to deprive this child of education; No one is entitled to deprive this child of opportunities!

I remember a story once about one of the mothers who gave birth to a boy with Down syndrome and refused point-blank to receive him. So, one of the specialists, a group administrator, said, "O Mohammed's mom, help." She directed me to the director of the GESTER, who spoke to me and said, "I will add you to a family support group." As a result, I participated with them.

For example, when we buy a cell phone, we look for its features. Sometimes, when my kids want to buy perfume because an actress used it, they keep looking for it! I do the same thing; I must look for any service I will provide to my son. Sometimes, they tell me, "Why do you tire yourself and take your time to search?" I reply, "You are now looking for perfume and not a useful product; now, you do not want me to look for a better life for this child? this son?" It is my right, as well as Mohammed's. It is my son's right to look for a decent life for him. I do not deny that research, early intervention, and support from the groups have honestly helped me and given me support. Sometimes even when I go to the centers to give a speech, some mothers approach me, asking, "Are you Mohammed's mom? and telling me, "We are your audience from this group."

There was once a specialist who asked in the group about someone who could communicate and remarkably deliver speeches. The group members responded and nominated me. They said, "There is no one but Mohammed's mom." She did speak to me, and I went and attended. It was about general success stories, including success stories of adaptation. I spoke for half an hour; it was a message to the community on adapting to disability. I was surprised that there was an attendance from the school of Mohammed. They attended and honored me as an

ideal mother, and it was something incredible, frankly, something that comforted me; I opened up gradually and received support and appreciation. Since these events are straightforward, they quickly reach the heart of people!

I feel happy that I am helping a mother to talk to and accept her child; I feel proud. Many mothers call me, "O Mohammed's mom, I went to a specialist, and she said such and such, but what you said is easier to understand." So, I talked and told her where to start. You do not know what it means that a mother sees her child suffering, and she does not know how to do anything! As a specialist, he/she gives instructions, go home, and your work is done, but he/she does not know about the feeling of this mother who suffers from her pain and sorrows". However, I know, and I tried it. I join the groups, educate and tutor the mothers, and tell them they must instruct their children. The role of an experienced mother with a child with a disability is to educate the newer moms since we have discovered our "mistakes" We have learned from them, so we must educate others about the potential mistakes they could make with their children. Many people suggested that I author a book about my experience with my son, but I do not know; I am hesitant because I need to figure out what to write, how to write, or what book to write. Should I author and sell small stories? My son and I are now entering adolescence, and I have physical therapy for him, so I want to overcome this obstacle, and then I will think about the book and authorship.

Themes

According to Braun and Clarke (2006) analysing qualitative data with a thematic approach involves identifying, analysing, and reporting repeated patterns across a data set. For the analysis of the data, the researcher followed Braun and Clarke's guidelines (2006). Patterns were generated by the researcher through a rigorous process of data familiarisation, data coding,

and theme development and revision across all participants to address the research questions. A cross-examination of the participants transcripts during the thematic analysis revealed four overarching themes with sub themes. The four common themes were: becoming and being an advocate, parent's barriers to advocacy, defining parents' role as advocates and effectiveness and impact of advocacy.

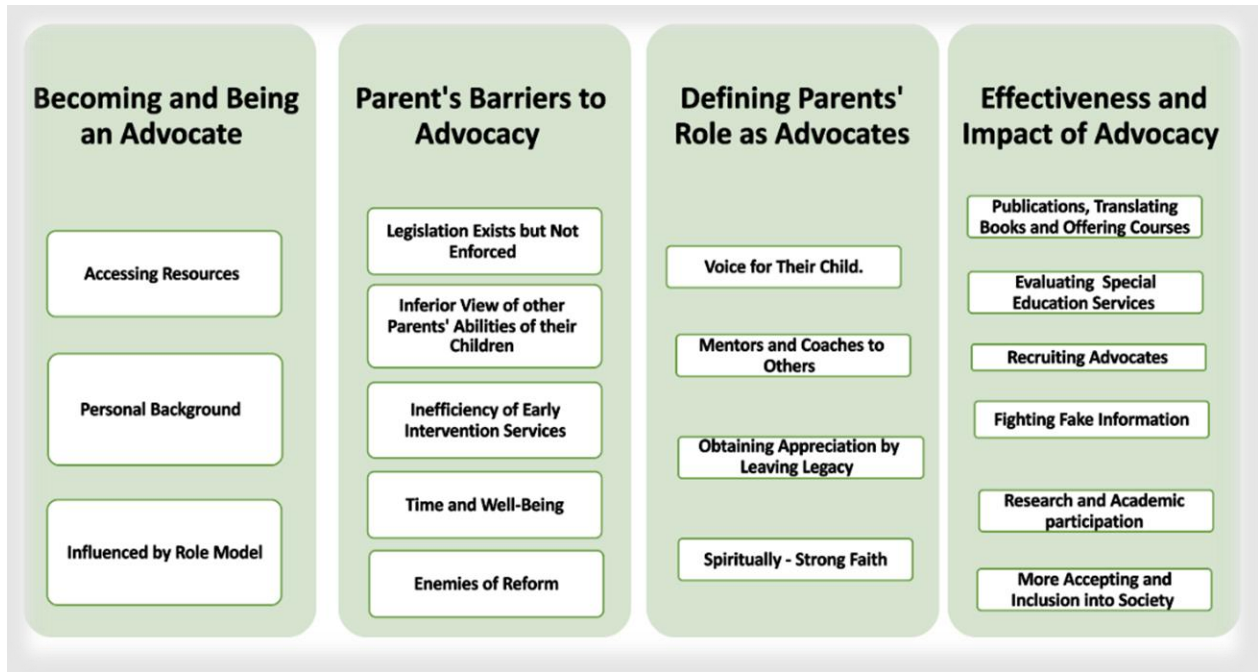


Figure 2

The Four Primary Themes and Associated Subthemes

Parent's Motivations, Barriers, Meanings, and Impacts of Advocacy

This section of the thematic analytical findings of semi-structure interviews includes selected translated quotes because of their support of code development. The names of each parent and his/her child have been changed to ensure their anonymity. The discussion of these rich examples will be done in Chapter Five.

Becoming and Being an Advocate

Becoming and being an advocate refers to any motivation or experiences that led or facilitated the way for a parent to become an advocate. Most parents attributed the reason for becoming an advocate in the first place to the lack of accurate, practical, and reliable information in the Arabic language, whether from the pediatrician or other resources.

Accessing Resources

Within the theme of becoming and being an advocate is the sub-themes of accessing resources. This refers to the participants' attempts to gain information about their children's disabilities and assistance with finding services. Dad One said:

My first advice to a new parent is to beware of searching in Google. When they search, they will be frightened by the diseases children with Down syndrome might have while they are still in shock. The best thing to do is to talk to another parent who has gone along the same path.

Dad Two further expounded on Dad One's observation by stating that:

When I tried to inform my family about my child's condition, I did not know anything about disability, nor could I obtain any information from doctors. All the information on Google or Wikipedia was old, shallow, misleading, socially terrifying or from the medical point of view.

Mom One gave another example of misleading information on YouTube. She stated that:

“Because I felt that every mother and father needed to know what I knew. Parents were lost; all they could find when searching on YouTube were misleading short clips regarding treating autism in ten minutes, treating autism with camel milk, or seeing the complex cases tied to chairs, all that got them scared.”

Difficulties with information found through the Internet prompted participants to search for other information sources to help raise their child, which in most cases meant joining parents' support groups. Mom One and Dad Two both connected with others on Twitter, but Mom One expanded her social media to Snapchat and YouTube, "where I would upload videos to reach the largest scale of society." Mom Two echoed the importance of connecting with others through social media; however, she preferred WhatsApp as 'with one click, I receive and answer parents' questions and concerns.' Mom Two also pointed out that social media could be done anywhere, at any time, and with no monetary charge.

Personal Background

Parents also talked about personal characteristics from their life experiences or qualities credited to their family of origin. Their proficiency in the English language, either because of their job, education, or travel experiences, helped them obtain or translate reliable information.

“During my childhood, we received so many guests and took care of them. Giving, as a value, has existed for a long time in our culture. Giving was also called generosity for relatives and strangers so that helping others and being a volunteer to teach others I can say it is in my blood system.” (Mom 1)

Mom One also shared, “Living in many countries changed me and refined my personality, taught me that difference does not mean disagreement, and I began to accept diversity and be more open-minded.”

Dad Two pointed out his experience:

After I finished high school, I got a scholarship to learn another language in a European country. I learned about their traditions and values, which affected my personality and expanded my perception. Upon returning to Saudi, I also worked in many foreign

companies, and I was exposed to inclusion and diversity greatly enriched my life experience; thus, I want to leave a lasting impact on others.

Mom Two had to say:

My mother was tough; she taught my sisters and me to depend on ourselves. I was responsible for educating them and helping them with their homework without asking her for help. As a result, her way of raising me gave me a strong personality, and I knew how to search for information on my own; I used to teach my sister with homework, so now I love to teach others.

Dad Three mentioned:

During my childhood, every summer, my father made sure that we traveled outside Saudi Arabia for tourist reasons. Travel formed my personality and made me aware of external experiences and obtained soft skills such as respecting other cultures, being a talkative person, and exchanging knowledge.

Most parents find a way to link their hobby or express their passion to advocacy work.

Participants believed that practicing advocacy through activities that they usually enjoy doing drives them to keep working. Dad Three and Mom One expressed their passion for technology and how they linked it to their advocacy work:

My father was keen to provide us with the Internet since its beginning in the 90s; I turned my focus on self-education and to the technology field until it became my passion. I can say that I am addicted to my laptop. Therefore, I developed an application that connects parents with service providers. (Dad 3)

When I was in the United States, I registered for a computer course to help me escape depression upon my child's diagnosis, and I felt it rescued me. Since then, computers

since, design, and PowerPoint have become my passion. When I returned to Saudi Arabia, I did not get a job, so I started designing online courses to present them to local disability organizations. (Mom 1)

Through advocacy, Dad Two was able to practice his specialty in a helpful way, he said:

I would love to translate; if I had the opportunity, I would translate a book every six months. I am ready to dedicate the rest of my life to translating. First, other parents could benefit while I practice my passion and express my love for my specialty, translation.

Mom Two's interest was doing physical exercises and creating and designing instructional materials to help her child. She elaborated by stating:

I learned early intervention strategies; they became my passion, and I applied them to my son. I noticed amazing results. I did all the physical activities at home; I started to design means and tools to support my child's development from home environment and share them with new mothers.

The writing was Dad One's way to express his feelings. He shared:

I used to write reflections, poems, and thoughts. When my son was born, I returned to writing my feelings and letters between him and I. By imagining what he would want to say to the world, I published them as a chapter in my book. My son's disability encouraged me to improve my writing aptitudes.

Influenced by Role Model

Due to insufficient information regarding disability, parents' resort to searching for help. As a result, they often connect with those who inspire or trigger something inside them to become advocates. For instance, Dad Two illustrated how some people would, by chance, inspire others to act. He said:

I was shocked when my daughter was born and could not accept the situation. One of my cousins insisted on speaking to me even though we were not close. He explained the situation to me about the disability and helped me to accept my child's disability.

Honestly, I owe him because what he did encouraged me to share my story with the new families.

The same participant also pointed out the positive influence of advocates parents where he stated that, “My real inspiration was the CEO of GESTER, he contacted me and motivated me to join them.”

Some parents were affected by international influencers, Dad One mentioned that:

When I started to translate videos, an elderly Mexican mother grabbed my attention; she was making videos talking about Down syndrome and giving advice on preparing her child for life when she dies. She also advised mothers about the importance of caring for themselves to take care of their children. Because of these video translations, I wrote a book of 350 pages about Down Syndrome.

While another participant, Mom Two, said “I found a YouTube channel for an Egyptian mother filming videos on how to deal with her child with Down syndrome. She spoke in-depth about how to tell others about her child's disability and how she defends him from negative stereotypes. She taught me the necessary skills to defend my son.”

Parents' Barriers to Advocacy

As presented in the next section, parent’s barriers to advocacy refers to any issues that limit and or negatively affect the parents' advocacy activities.

Legislation Exists but Not Enforced

The significant obstacle parents expressed was the legislation's lack of enforcement. Everyone agreed on the existence of regulations contained in the official constitution, but activating the executive authority for these laws by officials specialized in special education was an apparent demand among parents.

Dad One had a straightforward opinion when he asked a direct question:

The main dilemma is that law exists, but we have issues applying it. Decision makers often have no background in special needs and do not seek to hear from parents, and if it happens, it is a matter of courtesy; these meetings are not officially documented. There is a budget of billions to provide a comfortable life for the disabled. Where is that money spent?

Dad Three held a similar view, where he mentioned that:

In Saudi Arabia, human rights are reserved for everyone. I collected these rights and regulations from separate ministries in one document. The problem lies in the overlap between Saudi ministries; each has its systems, so parents need to search for these rights to know about them, and it is not an easy mission. I know that some government agencies have a defect, but with the 2030 vision, I have hope.

Mom One concurred with Dad Three. She elaborates on the theme by stating:

The main issue is that the responsible person, usually, does not have a background in special education, and he is the one who makes the decisions, which result in ill-thought-out decisions; thus, we as parents suffer.

Dad Two said that “The government ensures to give everyone their rights, but there is no fulfilment of the application of these rights. The law activation is flawed and needs to be closely monitored.”

Inferior View of other Parents' Abilities of their Children

The advocates interviewed stressed that one of the most prominent obstacles they face in uniting the parent's efforts are negative attitudes regarding disability. Unfortunately, some families still feel shame about their social status, which would hinder the enrolment of their children in early intervention centers or special education institutions.

One parent painfully stated: “If the parents do not believe in their child in the first place, in this case, how will you convince them to advocate for their child or claim for better serves?” (Dad 2)

Dad One speaks similarly:

Through my advocate experience, some families have children in their twenties, but they keep them isolated because they think their siblings will not get married if someone knows. The weird thing was that some of these families have high academic degrees; for example, I remember a mother complaining about her husband (who is a professor) by saying that his son does not need an education; all he needs is eating and sleeping.

Sometimes, to avoid negative peer judgement, other parents with a child with disability would keep the child hidden. Mom One recalls other mother, “highly educated one” wishing for an accident to kill both her and her child in order to avoid being a parent to her child. Mom One clearly claims, “The stigma is real”. Mom Two also shared how other parents would give negative advice to others in the group. “They (the other mothers) would tell each other not to take the child outside and let him stay with the babysitter to avoid negative judgment. Mom Two

states that questioned those mothers and their actions "... how do you expect society to accept your child if you do so?"

Inefficiency of Early Intervention Services

One of the most complex dilemmas facing parent advocates for improving early intervention services is the scarcity of early intervention centers and the difficulty accessing those that exist. Various factors were described as deterrents to accessing early intervention services, such as poor communication between the parents and the specialist, the absence of eligibility criteria, high cost, and limited locations. For example, a parent declared:

I feel impractical. I always raise awareness about early intervention's importance, and parents ask me where these centers are. I do not know how to respond to them. I wish there were government centers that would receive cases and be compulsory. Not everyone can afford private clinics; they are pricey. (Dad1)

Mom Two had to educate herself due to the poor communication between the parents and the specialists, she shared that: "I had to have a master's degree because the specialists did not know how to teach my child, so I wanted to become a specialist and advocate simultaneously. I wanted the center's staff to take me seriously."

She also added:

When I wanted to enroll my child at the center, there were no clear criteria for acceptance or rejection; they refused him because he was wearing diapers. Well, he was two years old. How do you want him to know to go to the toilet if you do not teach him?

Dad Three described a similar instance of inconsistent acceptance criteria. "They refused to receive my child because they say we only receive those whose IQ is high." Another parent offered insight regarding the location. She truthfully described the situation, "We do not have

any early intervention centers here in Makkah. If they are any, they are located in the capital, Riyadh. However, these centers are primitive.” (Mom 2)

Time and Well-Being

Upon discussing specific content regarding the impact of advocacy on family wellbeing, participants described a broad range of factors they found pertinent to reflect on the energy-draining and energy-giving nature of advocacy work, such as lack of physical and emotional welfare (frustration and lack of some agencies appreciation for their efforts because they are voluntary and free): marital frigidity, neglect of other children, and lack of time.

Parents talked about unhealthy behaviors and attitudes. Mom Two shared:

“Honestly, there are some events or mothers who take away your health and energy; you will find that they will drag you toward their negativity. Mom One stated:

I went through a hard time when I reached an unhealthy stage of being attached to my social media accounts. I had my phone in my hands for twenty-four hours and was afraid I would miss a D.M. or a comment. However, I realized how this affected my marriage and family, so I calmed down a bit.

Dad Two explained how he felt frustrated and at his breaking point but felt like he had no options. " I felt like I was at a breaking point, but what could I do to get or leave?"

Dad One described the side effect as feeling severely fatigue due to his lack of sleep for preparing awareness activities, which resulted in, “I fell, and my colleague had to call 911 to help me out.” (Dad1)

Moreover, Dad Three shared his realization that he had given his other children appropriate level of attention when, “During the quarantine due to COVID-19, my second son was so happy and said: dad, it has been a long time since you and I talked together. (Dad 3)

Enemies of Reform

Some parents described their experiences with classical media channels and social media; they provided selective experiences describing how they did not get any support through media. For instance, some classical media channels negatively responded to the parent's request to take part in raising awareness through public events. Dad Two said, "I contacted one of the broadcasters in one of the sports channels to advertise a short clip prepared by the association where I work. At first, they agreed; then, they called and informed me that there would be publicity of other social issues more important than disability." Dad One said, "I have been on a TV show with other specialists, and the greatest attention was given to talk by the professors and not to me (the parent)."

Moreover, some advocates were disturbed by unknown enemies who tried to steal their content, re-publish it, and hack their social media accounts for personal revenge or to exploit access to many followers for their interests. Mom Two said, "My account on Snapchat was hacked, and the hacker started asking my followers to transfer money to his/her bank account. They trusted him/her, thinking that I needed that money." This same parent mentioned that:

I do not mind finding some topics that I worked hard to prepare have been re-published under another name other than mine because what I care about is delivering the correct information to the parents; thus, I do not care if my content was stolen as long my goal has been achieved.

Finally, Dad One shared his experience by saying, "Up to five Twitter accounts have been banned; it may have been because I always created hashtags demanding improvement in services, and they often become a trend. I can say that someone does not want my voice to be heard."

Defining Parents' Role as Advocates

The meaning that parents derived from their advocacy journey was expressed through how they defined their role as advocates. The emergent subthemes were revealed in the way each parent expressed the meaning of becoming an advocate and were represented through remarkable descriptions of being a voice for their child and the families that will come after them, serving as mentors and coaches for others, obtaining appreciation from others by leaving a good legacy, and finally embracing spirituality and strong faith. Dad One outlined his role by stating that:

The decision to advocate was not one you make on your own. It was something that happened to me. Life circumstances combined with your values as a Muslim, where we have principles guiding our behaviours such as wishing the best to others as you wish for yourself, so I find myself morally obligated to help other parents to avoid the pain of informing them of the disability diagnoses, guide them, educate them, and to be a voice for my child and their children.

While Mom One said:

I rejoice and reach a state of euphoria and happiness when I help someone or when I aid to improve families' quality lives; I feel I am valued in society. Sometimes, I am the rescue hook that has lifted the family from drowning and brought them to the shore with minimal losses.

Mom Two talked about her role in this way:

I must pay motherhood forward would be better.; I coach others as other mothers supported me at the beginning of my child's diagnosis. I also feel proud of myself when a parent tells me I went to the specialist, and she taught me, but your coaching is better

because you are a mother like us, and you know more details. I guess that is kind of why I do what I do.

Dad Two, however, saw himself in a multifaceted way as a “Saudi, Arab, and international voice.” He continued by stating he needed to be the voice for those who were voiceless due to “lack of education” or had an “inability to express themselves properly”. He felt that “Through my advocacy, I seek to settle a minute change or influence others to continue my path.” Dad Three, a father and a professional at the same time, described his role as unique. He explained:

I believe what makes me an esteemed advocate is that I am a father first and a specialist simultaneously. My message is clear: I demand equality for people with disabilities. I feel it is my duty to play this role for two reasons, as a Muslim who is required to accomplish benefaction or charitable work in return for the knowledge he gains, and from a human and moral side that encourages me to help others who are in need.

In summary, the underlying reasons that propelled each participant to devote their energy were shaped by being the voice of their child, being supported by other parents or religion, and/or being grounded in moral convictions.

Effectiveness and Impact of Advocacy

The theme of effectiveness and impact of advocacy refers to the impact of their advocacy on the special education system and early intervention services. In this study, most parents were engaged in many advocacy activities which resulted in providing further opportunities to help parents of children with disabilities. They were able to make a positive impact on special education services and on providing accurate resources. They helped in providing publications, translating books and offering courses. They participated in the evaluation of special education

services at the state level, recruited local advocates to work in the field, fought against fake information on social media accounts and helped close the gap between research and reality to assist in changing the stereotype of children with disabilities for more acceptance and inclusion into society. The following section will selectively present what parents had to say about their contributions in these areas.

Publications, Translating Books and Offering Courses

All parents were dismayed at how their doctors informed them of their children's disabilities. Thus, they seemed to agree that supporting other parents through such experiences was the core effect of advocacy among all the parents. For instance, Dad Three said, “I became more active in the Twitter spaces, communicating with parents directly, answering their questions, and giving them legal advice on how to obtain their child's rights.”

Also, Dad One proudly said, “our mission in the association has become apparent, and the effect of our work is oriented and easier; now we have strategic partnerships with some agencies and health faculties; therefore, we can direct the people to services faster.”

Four of the five participants agreed that their significant impact on the advocacy was the publication or translating of documents or the offering of educational courses either online or face-to-face. Dad One states, “The first thing I do when I communicate with a new family is to give them a copy of my book because it contains everything related to diagnosis, acceptance, and dealing with the child.” Dad Two stressed that “I became the head of the translation department in an association, and I hired many translators with me to serve the parents and solve the problems of their children.” Mom Two described her contribution:

I present many awareness and education courses to the parents through the associations of which I am a member, either online or face-to-face, and all of them are free. My goal

is never business. I aim to serve people and deliver content to them without money.

However, I wish the organizations could cover the logistical expenses.

Another participant indicated that, “I started offering training courses for parents to teach them about their children's rights and then legally demand them.” (Dad 3)

Evaluating Special Education Services

Parents talked about the experiences of collaboration between parents and professionals at the state level regarding evaluating the services provided to individuals with disabilities. Mom One expressed her feelings that, “I am now a member at more than one organization so that I participated in the Parents' forum to evaluate the special education services through sharing my vision.” Dad Three, on the other hands talked about his distinguishing work “After I obtain my Ph.D., The ministries began to contact me asking for my vision on some topics, and I began to send them copies of the handbook I collected containing all regulations and providing some recommendations.”

Nonetheless, perhaps the low advocacy for early intervention services is due to misinformation given during the diagnosis and lack of clear decision making since so many official stakeholders overlap in responsibility. For example, one father said:

I met the minister of Health and showed him my application that I created to link the family with the service providers. He welcomed the idea and got excited, but I have not obtained an official permit because I need approval from three different ministries; I do not know which one should give me the final permit to launch my app. (Dad 3)

Dad One offered a similar opinion:

At the association, we requested a meeting with the Ministry of Health, Education, and Human Resources, but we are still waiting for a response. Because there is still

confusion, who the early intervention specialist should be? Is it the health practitioner or the special education teacher? This overlapping is our problem.

Recruiting Local Advocates

Participants have committed to advocacy and focused on being prepared for the future. Whenever the parents perceive a possible new advocate, they pursue those individuals to not only increase their numbers but also to promote more advocacy. A parent elaborated on this:

When I see new mothers- when they first join a WhatsApp support group collapse and cry- and after a few months, I find them more assertive, and they have started to help other new mothers; at that time, I thank God because I believe that somehow, I have assisted in the growth in the number of advocates. (Mom 2)

“Through the association's activities and support groups, I can see due to my experience that if there is a parent who can become an advocate, I then approach and get to know his/her skills and develop them.” (Dad 1)

Fighting Fake Information on Social Media Accounts

The participants in this study recounted some experiences when fighting impostors and rectifying misleading information were an important part of their advocacy roles. Dad One pointed out the positive outcomes of advocacy; he believes:

I am pleased with the great results we have achieved in the association; parents have come to distinguish between charlatans taking advantage of their children's disability and real specialists. Parents usually ask me about the credibility of some social media accounts, and they warn each other of impostors and non-specialists.

Dad Two understood his impact as an advocate would constantly change and increase due to society's demand that individuals with disabilities be marginalized and discriminated against. He said:

Some people give unreliable information in a Twitter Space or in another Space titled 'Do you agree to marry a person with a disability?' Typically, I participate, engage in the discussion, correct the information, and ask the host, 'What is your specialty?' Sometimes, I am in an altercation with them. Even though this is shameful, at least this message is conveyed to the remaining users, this is nonsense!

Research and academic participation

Participants also pointed out the disconnect between the academic field and family conception of involvement in the special education system and what it would entail. One Mom said, "as an advocate and a mom, usually, researchers contact me to review their questionnaires and provide feedback, and I always visit the universities classes to help prepare the pre-service teacher to deal with parents." (Mom 1) Another participant pointed out, "I believe you are the 100th researcher with whom I participated. Scientific research and practical recommendations are the way to change. Who else will participate if I do not participate with you in this research?" (Dad1).

More Accepting and Inclusion into Society

Parents reveal their desires in developing values regarding inclusion in community to have further acceptance for their children. A mom related:

I began to teach mothers on the WhatsApp support group to pronounce the right name of their child disability; that he/she is Down syndrome, not a disabled child, and I

encouraged them to take him/her everywhere with them from a young age so that people know about them and for the child to know people and places. (Mom 2)

Dad Two added:

I make sure to talk to my daughter about trending topics so that she can communicate with those around her. I noticed it reflected more acceptance of her among my family and even in our village. People have become more accepting when we visit during the holidays and have included her in their conversations. I wonder if this would have happened if I had not become an advocate.

Summary

It is clear that the participants entered the world of advocacy when they became parents of a child with disabilities. Their advocacy became a reflection on their need to educate themselves and others and to find and collaborate with other parents going through similar experiences. Regardless of the painful starting points in their advocacy journey, all the parents felt thankful to have a meaningful purpose and the ability to help others.

CHAPTER FIVE: DISCUSSION

Overview

This qualitative study aimed to explore a select group of Saudi parent advocates' experiences and to gain insight into how these parents understand their roles in supporting others. The focus was to learn about their journeys, support systems, conflicts, resolutions, and what they believed to be the impact of their role on other families and the special education system. Five Saudi parents with children who are developmentally disabled were interviewed to gain a deeper understanding of their experience and the impact of their role as advocates on the system. In this study, parents of a child with developmental disabilities responded to questions in a series of three interviews. Interview data were then qualitatively coded and sorted into four major themes that revolved around the parents' motivations and challenges, definitions of the parents' role as advocates and the impact of advocacy. Understanding the life circumstances of these parents could enable other parents to become advocates and enhance the services for children with disabilities and their families in Saudi. This chapter focuses on interpreting the results obtained by reviewing the findings as they relate to the literature and their connection to the social action theory by Max Weber. This study's findings offer some implications, present some of the study's limitations, and provide recommendations for future research.

Interpretation of The Results Through Review of The Findings in Relation to The Literature

This discussion will be presented based on the themes mentioned in chapter four: parents' motivations and experiences, barriers faced, defining parents' role as advocates and the impact parents believed they might have made on the special education system.

The Advocates' Motivations and Experiences

This section describes how parents explained what drove their advocacy. All five participants in this study expressed their need for information regarding the disability and were annoyed with how they received the diagnosis; parents experienced mixed feelings of anger, sadness, fear, discontent, and confusion during and after the diagnosis. The initial trigger for all participants to become advocates was a sense of hopelessness from the lack of pediatrics support and trusted information.

Turning Points to advocacy

In response to the negativity parents' advocates have endured due to a lack of understanding and the pessimistic prognoses from the pediatrician, parents have chosen to advocate by joining local associations, social media, and support groups to improve the lives of their children and themselves. The lack of information and trust issues between advocates and providers of services led them to be advocates. This result supports Boshoff's 2016 point of view where he claims that as parents go through the coping stage, they seek, obtain, and use support services and then engage the community and educate others.

As a result of the bad experiences with the diagnosis process, parents have a specific demand, especially at the private hospitals (all participants had their children at private hospitals). Each parent was motivated to devote their energies to ensuring that other parents

would not experience the negative feelings resulting from their children's diagnoses. Three of the participants revealed how determined they are to ensure assigning a case manager or a social worker to inform parents of the disability diagnosis. This matter reflects the urgent need in Saudi for accountability over health institutions in the ministry. This is in line with what has been mentioned by researchers, Akamoglu and Dinnebeil (2015) and Flippin and Crais (2011), about parents' need for information as a supportive source, especially at the diagnosis stage by service providers.

All five participants in this study seemed to agree that having access to the internet and support groups as helpful resources aids shaped their goals towards helping others. Moreover, they cited numerous examples of role models in the special education field, especially in early intervention, through real person examples, social media accounts, or websites, whether Arabic or foreign influencers. These participants follow in the footsteps of these pioneer parent advocates. Three participants shared stories in which an influencer in the virtual world inspired them to start some advocacy activities. This point is supported by the results of Abel, Machin, and Brownlow (2019) who argue that the internet profoundly impacts people's lives. In addition to social support, many users use social media platforms, such as Facebook, to find information about how to deal with their disabled children.

One unexpected finding was the extent to which the participants expressed the beneficial influence of movies they watched about disability in general or about prominent persons in the field of disability as a motivation for them to emulate and make similar outcomes on families' lives and leave an unforgettable legacy. Two participants pointed out their desire to produce realistic films of their daily life with their children and post them, but financial obstacles prevented them. The participants draw attention to their dissatisfaction with the shortcomings of

the Saudi media in shedding light on disability issues. This finding is an excellent point towards improving awareness, most especially in audiovisual media production. In other words, painful living experiences that participants went through, which were embodied in movies and cinema, could play a role in turning a parent toward advocacy. In reviewing the literature, data were not found on the association between movies and advocacy motivation. Prior studies related to advocacy have yet to report such results.

Highlight the Reality Kingdom of Saudi Arabia

Given the fact that all the advocates were Saudi parents, the desire to shed light on the efforts of the Kingdom of Saudi Arabia in supporting disability initiatives and empowering people with disabilities locally and globally was evident. Four participants were keen to reveal the educational and financial rights given to individuals with disabilities in many ways as in other nations. Participants stressed the importance of national centers that serve people with disabilities through national transformation programs, which is one of the Saudi Vision 2030 realization programs. Most participants in this study agreed that the Saudi vision of 2030 carries hope for improving early intervention services. However, there must be a broader philosophy embedded in all disability aspects and personal beliefs among the other parents to achieve this outcome.

The Kingdom's Vision 2030 emphasizes the importance of integrating democracy into the education sector to empower citizens to participate in the country's development (Alharbi & Alshammari, 2020). Parents will be able to advocate for their children because the 2030 vision supports a growing demand for improvements in special education services. From this perspective, one of the motives of Saudi's advocacy activities is to highlight the Saudi effort toward human rights. Also, it responds to the claims that Saudi society has adopted the concept

of inequality in the positions of individuals with a disability as a disadvantaged group (Mustafa, 2018). As a religious society, Saudi society is based on Islamic principles. This religion emphasizes equality in rights as one of its principles. Al-Aoufi et al. (2012) assert that Islam also prescribes social responsibility, and Altamimi et al. (2015) believed these religious principles support advocacy.

Personal Characteristics

As a child and an adult, participants described experiences where personal life experiences by interacting with other cultures or supporting others played a crucial role in their identities. The findings suggest that they are innately willing to fight for a cause or to volunteer provided information due to a sense of human or moral responsibility. Some early encounters during growing up expanded their background and assisted them in significant ways in becoming more aware of accepting differences. Some examples of these incidents were taking responsibility for raising siblings, traveling, and mixing with other civilizations and cultures. There seems to be an agreement among four of the participants' importance of personal background in sharpening their efforts to become advocates and sustaining a motivational reason to continue advocating on the acts of continual discrimination in society and a desire to improve the quality of life for their child's future. Such a result has yet to be explicitly reported in the literature, and it may be due to the lack of qualitative studies on Saudi individuals as a study sample.

One exciting finding was that advocacy was a way of practicing a hobby or passion for the majority of the participants in this study. They tried to link their hobbies or passion to the advocacy activities. The participants felt that practicing something they love would reduce the advocacy stress. For instance, one parent went so far as to say he recalls the reason for writing a

book: to get back to writing as he used to write before his son was born. He finds that writing is his way of coping. Since this motivation has yet to be found elsewhere, it is probably due to the limited free time available to them outside their parenting duty. The probable explanation for this result is that they cannot entertain themselves and pursue hobbies that require money or the presence of friends. Therefore, the findings of this study claim that linking advocacy with a hobby means continuing to gain more knowledge. This matter provides an opportunity to restore balance and correct the cognitive, professional, and social paths.



Figure 3

Parents' Motivations Led to Advocacy

The Advocates' Battles-and Barriers

The findings in the study indicate that while the parents desired a role as an advocate for their child, they faced barriers such as complaining that existing legislation is not enforced, lack of understanding of parents' perspectives by decision-makers, a stigmatizing view of other parents' abilities of their children, and the inefficiency of early intervention services. Time and well-being, health issues, and having reform enemies like hackers and plagiarizers were likewise barriers documented by participants.

Policies – The Regulations in Their Right Place

It is noteworthy that all participants were in explicit agreement about their satisfaction with the governmental effort, pointing directly to their desire to guide other parents on how these rights can be obtained effectively. However, all the participants in this study were annoyed by the inefficiency of some ministries in applying the law. For example, three participants reported that, in most cases, private and public early intervention centers have no united criteria that are suitable for enrolling a child with a disability. However, they stress the child's rights that government ensures to him/her to FAPE.

Participants' reactions varied regarding their role in reaching decision-makers. Reaching out to the decision-makers was accessible; however, finding common ground or following up with the topic discussed was an obstacle that participants had. Those advocates needed help communicating with decision-makers, including but limited to lack of meeting documentation, not receiving follow-up calls, or exchanging courtesy instead of making implementation plans. In contrast, three participants expressed their opinions about their participation as members of associations related to special education in evaluating services by the Authority for Persons with Disabilities. Two participants were not satisfied and withdrew from attending the meetings, and

only one participant expressed his enthusiasm and was satisfied with the meeting's outcomes. This odd result may be due to the solid educational background of that participant, as he obtained a Ph.D. and his position as a faculty in a university, in addition to being the father of a child with a disability. A possible explanation for this disappointment might be that Saudi Arabia is not a democratic country as its constitution is a monarchy. Saudi Arabia's government works upon the principles of justice, consultation, and equality, but the king ultimately determines how the country is arranged. This finding is consistent with Van Eijk (2010), who argues that a monarchy governs Saudi Arabia.

The Impact of Shortcomings of Services on their life

What seems to be the core of the barriers to accessing early intervention services was one finding related to the impact of advocacy on early intervention when participants asked about the difficulties of enrolling their child in early intervention services and what they did do to overcome these challenges. Participants were unanimous in the view that there were shortages and insufficient early intervention centers in all cities of the Kingdom. These views surfaced mainly concerning the location of the centers as they are mostly limited to the capital of Saudi. If they exist, the admission requirements and the eligibility criteria vary. This result further supports the ideas of Alyami et al. (2016), indicating that children who live in Riyadh, Saudi Arabia's capital, have priority over their peers in other regions for obtaining early intervention services.

In this study, the participants agreed that there is collaboration and understanding of their children's disabilities among employers. This outcome is different from that of Alenzai et al. 2020 who found that scheduling appointments for an early intervention program may be challenging if the employee has long work hours. In this study, a dissenting opinion is held by

three male participants who believed that they were supported emotionally and financially by their employers. However, the researcher could not explore or discover this side from the female perspective, as the two female participants were housewives.

It is also noteworthy that all participants were in explicit agreement about the negative impact on their well-being due to “disability” more than the impact of advocacy on their life. However, lack of time, health, feebleness in marital relationships, and paying less attention to the upbringing of other children were expressed by participants as hindrances standing in their way of having contentment and prosperity. These findings broadly support the work of other studies in this area linking advocacy with living a full life. There is substantial literature supporting the idea that parents face significant barriers when it comes to advocating, mainly the lack of time and energy (Burke et. al, 2020; Cunconan-Lahr& Brotherson, 1996; Gensler, 2009; Wang et al.,2004).

Undesirable Personal Conflicts

Advocacy in the Saudi context is not confined to educating others to meet their children's individual needs alone; it extends to other activities like calls for the quality and quantity of services provided. Accordingly, the most surprising finding to emerge from the analysis is the animosity attached to participants, especially those advocates who have been in the field for more than ten years by some individuals or organizations. Indeed, only some people are good at receiving criticism effectively, and some need clarification on the person himself with the act. Instead of rejecting or criticizing the act, the criticism and rejection become directed at the person himself, which may contribute to creating hostility or avoiding inviting the participant to important social events or forums. Moreover, despite the value of guaranteeing individual property rights in Saudi, there were some violations, such as re-posting the same content under

another account through social media channels like Twitter, Snapchat, etc. Nevertheless, two of the participants were not disturbed by these violations and expressed that what is important is the spread of correct information among parents who need such information. As long as other parents benefit from the content, property rights do not matter. This discrepancy could be attributed to the common assumption that Arab societies are less concerned with individual property rights; this is in direct contrast to other countries who have strict attitudes toward individual property rights.

Defining Parents' Role as Advocates

According to Fiedler (2000, as cited in Mitchell and Philibert, 2002), *advocacy* is defined as "taking action to improve quality of life" and "speaking up for others who cannot or do not want to speak up" (p. 11). In discussing the impact and meaning of their journeys, most participants mentioned their own experiences and successes as motivating factors for making a clear difference in parents' lives and their children. Because of their knowledge and understanding of how to successfully surpass the diagnosis stages, they perceived they had the privilege of educating and supporting other parents. With this privilege came the obligation to use it to help others.

In their reflections, the participants reflected on what advocacy means to them. Most advocates continue to help other families based on their initial motivation drive. Defining the role participants play can be seen as a voice for their children and other children. Being a voice was a social action in nature and the concoction of the integrity of the subjective meaning (a moral obligation) they made through their journey. Further, the results of this study indicate that religion and faith enabled participants to gain strength, stability, and clarity in their lives and generate meaning and purpose. This point is consistent with Madi, Mandy, and Aranda's (2019)

results in that Saudi mothers believe having a child with a disability is a test of faith and completing the process of accepting these obstacles is a sign of satisfaction with God's will, which also decides their place in eternity.

Effectiveness and Impact of Advocacy

Regarding the impact on the special education system, the participants agreed that they achieved a noticeable effect on parents while their effect on decision-makers was slight. Even though the parents share their evaluative opinions and participated in events, three of the participants felt like nothing has changed; participants feel that officials do not value their opinions. These findings are surprising given that other research shows parents as accountability mechanisms. They can be considered as scrutineers of good service for their children, emphasizing the importance of their input in affecting change at the system level (Conn-Powers, Piper, & Traub, 2010; Goldman et al., 2020; Kupper, 2003). These results are likely related to what Hadidi and Al-Khateeb (2015) argued that Arab awareness groups and nonprofit associations have limited impact, but that impact is strengthened through networking. To put it another way, their central role is to serve as an educational and emotional support resource for parents dealing with the complexity of raising disabled children.

The participants also agreed that there is a disconnect between the theoretical side and reality, and the parents emphasized their role in reducing this gap. Some participants attended university classes as guest speakers or in evaluating and arbitrating the research questionnaires and distributing them among the parents through their networks. In general, parents felt the importance of training pre-serves-teachers to deal with families practically instead of theoretically. However, this result has yet to be described in previous literature.

Understanding the Advocates' Motivation Through the Theory of Social Action

Various reasons have been offered throughout history to explain why social change occurs. In his social action theory, Weber believed that human motives and ideas are behind any social change and that opinions, values, and beliefs can contribute to social transformations. The individual can also - according to Weber - act freely and determine future destiny. (Tucker, 1965) Social action theory gives researchers a better understanding of actions behind human behavior, which may be traditional, affective, value, or rational. Thus, this study sought to associate the findings regarding the motives of advocacy to the social action theory concerning the four factors underpinning the theory. The following section focuses on how the findings of this study could be used to understand the behavior of advocates and how it could lead to an increase in the value of advocacy to other parents in terms of encouragement to enroll in advocacy and increased opportunities toward positive adaptation with disability. In the context of this study about motivations to become an advocate, the elements can be understood as follows:

Table 3

Theory of Social Action and Advocates' Motivations

Theory Elements	Advocates Motivations Context
Traditional Action	The traditions and norms of the families play a role in shaping the advocates' identity.
Affective Social Action	Feelings and attitudes about helping other parents.
Value-Rational Action	Advocates evaluate their choice to initiate advocacy based on a social value orientation mainly from religion, education, and the country.
Rational-Purposeful Action	Participants set broader goals and use ways or means to achieve them without specific plans.

In this exploratory study, through the interviews, parents were asked what the motivations of advocacy within the Saudi context were. Priority was given to identifying individuals' external and internal motives that affect their attitudes towards advocacy and exploring the effect of socio-cultural demographic factors on beginning their journey. Through analysis, the Saudi advocate's behavior was motivated and directed mainly and clearly by three out of the four social theory types; the fourth one, rational purposeful action, was not so evident. These conclusions are likely related to the dominance of traditions, values, and feelings within Saudi culture (Van Eijk, 2010). Saudi society is like other Arab and Islamic societies; culture in Saudi society has traditionally been shaped mainly by Islam, which shapes traditions, social norms, patterns, obligations, privileges, and practices to which every member of society is brought up from birth and is keen on adhering to it because it meets the needs of the individual and the group to which he/she belongs. As Saudi is the most conservative of the Arab states; Saudi society attaches great importance to these customs and traditions because they contribute to the cohesion and unity of society and cannot be dispensed with it.

The findings suggest that the traditions and norms of the families to which participants belong drove advocates' choices of supporting other parents. The custom of Saudi families is to take care of siblings, help neighbours, and serve guests. The participants found themselves motivated to follow the same pattern in serving other families. The results also support the second type of theory; that some participants grew their advocacy from emotions. Parents' advocacy is directed chiefly by their feelings to often protect other parents from the five stages of coping with emotions associated with the diagnosis process. Participants also apply rational action given the value; their advocacy was accomplished from three core values: religious principles, education, and nationalism. Religious principles and strong faith were mentioned as

helping them overcome difficult times, so the parents wanted to help others overcome them. Second is education, where participants were knowledgeable, had a high degree of awareness, and thus linked it to educating others as a human and moral obligation. Parents emphasized the need to educate themselves about disability as most of them enrolled in university seeking degrees as they express "knowledge is power." The third value is national. Most participants were committed to defending the Saudi government's efforts toward individuals with special needs. The participants mainly wanted to fix the national institutional system defects, rectify their shortcomings, and show the Kingdom at its best.

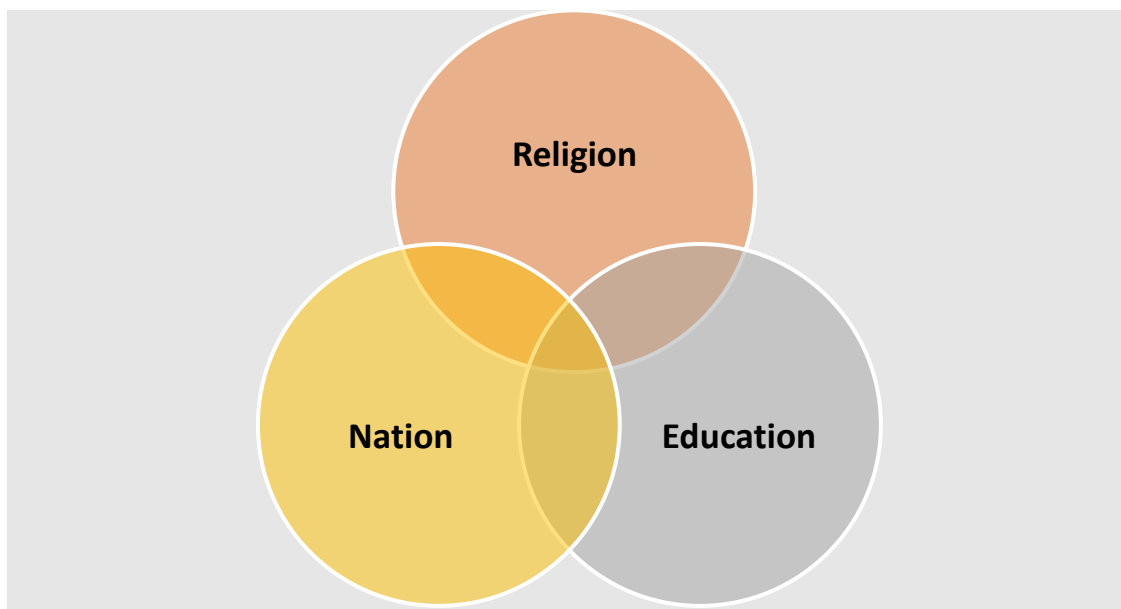


Figure 4

The Main Three Value Guided Participants to Advocacy

As for the fourth type of social action theory, it is difficult to relate this type to Saudi context, but it might be seen as a long goal that the participants want to achieve. Due to the lack of early intervention services, the participants desired to improve the services for their children and the children to come. In comparison, some of the participants expressed their desire to make history. However, for the participants, there was no specific plan or date to achieve the participants' "making history" goal. According to social action theory, action can only be meaningful if it is goal oriented. Thus, a critical weakness of this argument of the social action theory through this study is that any rational goal needs to be effectively measured to be observed.

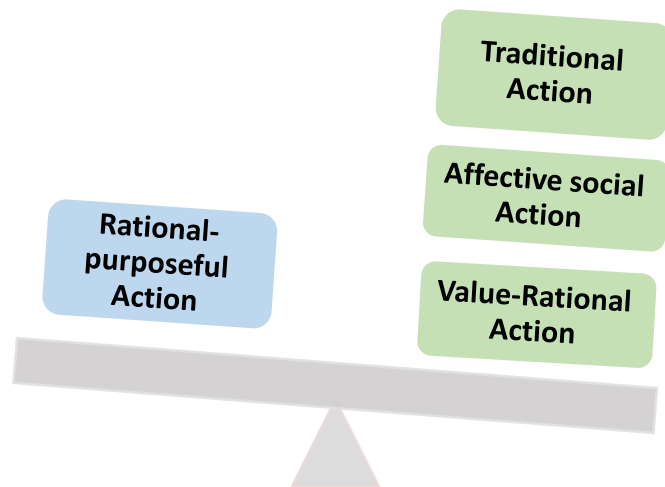


Figure 5

The Three Type Affect the Saudi Advocates more than the Fourth Type

Potential Implications of Findings

The results of this study, which are considered qualitative by investigating the perspective of advocates, aim to improve the quality of services provided to children with disabilities and their families. Despite the small number of participants, many issues of value and direct relevance to extending the advocacy and early intervention services were discussed. This section will cover some recommendations at four different levels. One is for policymakers, the second for service providers, the third for teacher preparation and early intervention specialists, and the fourth for parents of children with disabilities to implement high-quality early intervention services. The researcher has made suggestions that build on findings such as some motivations participants hold to become advocates, barriers or challenges that limit families' advocacy or access to services for at-risk or disabled children, the roles played by the participants, and the impacts they believe they make. The following are specific recommendations related to these themes.

Recommendations for Saudi Policy Officials

Through Vision 2030, the Saudi government seeks development approaches for society members. This study would enable decision-makers to understand barriers and thus seek to develop appropriate solutions for better-serving individuals with special needs. Although the Saudi legislation RESEP stresses the parents' involvement in IEP and evaluating the service; however, reconstruction, updating, and implementation of the policy was a demand among the participants. The findings of this study show that for participants, the current parent's involvement policy could be more optimal and requires some reconsideration.

There was a complete agreement among the participants that officials are unwilling to support legislation protecting the rights of persons with disabilities due to poor attitudes about

parents' involvement or having minimal special education backgrounds. The policymakers and other relevant stakeholders should make concerted efforts toward recruiting qualified officials through human resources that help overcome the need for more understanding of issues related to special education, thus enhancing early intervention services. Many steps should be applied to reach a high level of family involvement in a child's IEP. For example, policymakers should listen carefully to the parents' questions and respond to them in a realistic and non-exaggerated manner. Moreover, documenting the meetings between the officials and parents may help supervise and control the development advocates seek in the field of disability.

The lack of information or knowledge about early intervention in Saudi society cannot be denied. To date, there has yet to be any trustworthy information that there are official resources that might help parents understand the importance of early intervention services or how to immediately and directly access them. Nonetheless, the concerned ministries should intensify efforts on their websites and update data and means of communication to ensure that parents get the reliable information they are looking for to understand disability. Participants in this study highlighted the effectiveness of communicating directly with some government accounts via Twitter. The findings illustrate that when parents filed complaints with the government, they would sometimes not receive a response or may receive a late reply. By activating communication channels like hotlines between citizens and the government, parents' demands with case numbers can be conveyed to the official authorities, who can respond promptly.

Saudi drama has often presented people with special needs as either comedians or as a source of pity. Rarely has any director dared go through the experience of producing balanced movies in which the disabled play a realistic role. Some participants expressed that their motivation for advocacy was due to watching inspirational films. The Saudi media ministry may

consider paying close attention to raising awareness to inform the public of early intervention services. The officials at the media ministry should focus on addressing the stereotype against disability issues, especially thoughts related to stigmatization associated with inclusion. Collaboration opportunities might be considered with networks, and nongovernmental organizations could hold informational support campaigns on the legal rights of special needs children and their families. Producing realistic movies and/or short clips as well as holding TV talk shows with advocates, would encourage parents to seek out options and services, weigh the options and make decisions with trusted professionals.

Although participants in this study were not asked about problems with everyday life challenges, almost all participants agreed that the airport facilities and traveling experience were complicated. Ticketing procedures and going to security are very difficult for families with children with disabilities because of the interactions with untrained staff. Therefore, the parents advocated for close mentoring on these issues. This study's finding reveals that participants are concerned about the accomplishment of full accessibility for families with disabled children in the travel industry. Thus, all government officials and officials from relevant ministries should pay special attention to updates and travel rules for disabled people.

Recommendations for Services Providers

Results obtained in this study stress the need for reforms in the diagnosis procedures. The first, perhaps most meaningful, conflict was early encounters with pediatricians. The findings suggest that participants' willingness to stand up and advocate was primarily driven by the painful experience of receiving their child's diagnosis.

Even though the Ministry of Health provides individuals with disabilities health services, including screening for disabilities in newborns, the most prominent pain that the participants

complained about was the way in which they were informed of the disability diagnosis. Some suggestions for hospital administrators need to be taken into consideration. For example, informing parents of their child's disability should be done in a private room, with emphasis on training specialists on professional methods of reporting disability. The researcher also suggests that informing families about disabilities should be carried out by social workers or psychologists at hospitals and doctors' offices. Providing therapy services to support parents online may provide a suitable means of communication and expressing feelings. Moreover, supporting parents with some strategies of informing others about the diagnosis of disability, such as siblings and the rest of the family members, seems to be an urgent matter that Saudi families need.

Since some parents might be impoverished and ignorant of educational terms used by professionals, the parents might be reluctant to participate in their children's development. Additionally, the language used by the professionals may make the parents feel unwelcome to give their input. Again, this could have adverse consequences such as a child not receiving or participating in early intervention services. Overall, most participants expressed the need and desire to build trusting relationships between the service providers and themselves. Likewise, service providers should give considerable attention to the professional language they use with parents. This will allow for successful two-way communication, an essential characteristic of effective interaction. A profound understanding of parental needs will help identify the forms of support the children and families need to be successful.

Recommendations for Teacher Preparation and Early Intervention Specialists

Participants' responses indicated a need to refine policies, initiatives, and practices related to special education teacher preparation such as building a curriculum that promotes positive relationships between families and preservice teachers by positioning parents and students as

collaborators as well as opening the doors for teamwork opportunities in numerous forms. For instance, hosting parents as speakers and arranging home visits for observations may contribute to pre-service teachers' ability to gain a realistic picture of the family's life circumstances.

Moreover, to address the problem of the shortage of early intervention specialists, recording some short videos for early intervention strategies and posting them through social media accounts under the supervision of the health/ education ministries would allow parents to follow up at home. Recording actual mothers with experience with disabilities to present such clips may result in delivering more practical and implementable exercises. Parents indicated that they preferred to follow the same path as the parents who were in the same situation. From the female participants' perspective, the mothers value the expertise of other parents as a critical resource for learning about their children. Additionally, training parents in some strategies they can implement in the home environment would benefit child development.

In summary, ultimately, effective communication is the key to positive outcomes for the family. Furthermore, providers should be aware of the benefits of partnerships with the parents and learn how to best support them to help their children.

Recommendations for Other Parents

The findings from this study shed light on the meanings and effects of advocacy built upon the power that parents must change the trajectory of their children's lives. The purpose of advocacy in general is to influence the policy system and social context of individuals with disabilities. The stories of the participants might lead to empowering parents and taking action to advocate. Thus, they might encourage parents to tap into the formidable power of other parents to follow a similar path, resulting in enhanced early intervention services for children with disabilities and their families.

Even though the government ensures the protection of the rights of individuals with disabilities, the reality of the beneficiaries of these rights and their level of awareness of them are still subpar. Participants emphasized a need for a deep understanding of the rights of their children with disabilities and the best way to obtain them. To address this issue, parents need to join support groups and discuss the available national platforms to submit requests for these rights with experienced parents. Parents might also seek legal consultations and ombudsman to become knowledgeable of these rights.

Considering themes from the data, an enhanced appreciation of advocates' barriers was gained and some areas for improvement in parents' quality of life. Parents who are seeking to become advocates must be aware and able to evaluate and reflect upon their values to decide how and what to compromise on for advocacy. Indeed, getting a sense of what makes advocates feel good as well as knowing what challenges the advocacy is essential because it can aid potential advocates in learning some strategies to reduce the stress levels associated with advocating. Examining advocates' roles, barriers, and effectiveness may also inform potential advocates of the significance of developing skills such as distributing tasks and defining responsibilities with others, improve wellness, creating personal time, and developing practical communication skills.

Advocates played a significant role in supporting other parents besides explaining how to adapt to the disability aspects in daily life in a trusted way. However, participants face several problems, including feeling frustrated by parents who spread information on social media regarding old folk tales and traditional cures that may be incorrectly recommended and hurt their children. The area that appears to need improvement is addressing the negative social attitudes toward children with disabilities. Although the Saudi 2030 vision emphasizes rights and inclusion, parents should promote this vision's values by accompanying their children on the public social

level; this would mean, for example, taking their children to attend public family gatherings or going out while running errands. These actions could alleviate and counter society's stigmas. The findings of this study suggest that there is a need to incorporate all family members within the inclusion context. Some parents, particularly fathers in general, believe their children with disabilities are worthless. Fathers who see their children negatively are not accustomed to being questioned about their judgments and might need to be educated through success stories, which might inspire parents to have higher aspirations for their disabled children.

To sum up, several recommendations of how advocacy could empower a 'voice' to those whose needs are often marginalized in both early intervention service provision and broader special education were provided.

Strengths and Limitations of the Study and Recommendations for Further Research

A vital strength of this study is the sharing of detailed stories of the participants' experiences through their profiles and the power of parents' networking. The sharing of stories provides avenues to address the common problems expressed especially with regard to diagnosis and allows for connections with other parents who have similar experiences. Despite the exploratory nature, this study offers some insight into parents' acceptance of their child's disability and how parents can benefit from sharing their stories to help younger families. Especially for new parents, these stories can provide information about what to expect and help ease the process of acceptance. The study's strengths included in-depth analysis of the meanings that potential and veteran participants can gain from hearing other participants' stories and contributions. Moreover, it can be said that the clarity of defining the motives, barriers, meaning, and impacts of advocacy in terms of its goals and results may help other parents to identify the ways and means to follow that same path and evaluate the costs and consequences of this action

concerning their emotions and values.

Indeed, this study is limited to the perspective and experiences of a restricted number of participants who advocate for their children, so the findings cannot be generalized. Despite the small sample size, this research provides an in-depth qualitative analysis of advocacy in the special education field. This topic has yet to be addressed or studied in the Saudi context. The results of this study have led to a better understanding of advocacy in the special education process by investigating the perspective of advocates. However, the study sample was limited in that the two female participants were both housewives. Additional research could be done with females who have jobs to see if they have different concerns related to their roles as mothers, employees, and advocates.

One limitation that should be noted was that two of the participants ignored the request to use their camera while being interviewed. This could be due to the impact of social customs and traditions that impede participants from freely showing their faces in public, especially women. Though the researcher assured the participants of their anonymity, they could not be persuaded to show their faces. Despite the importance of observing facial expressions and body language in the interviews, lack of such observations was not a major obstacle to conducting the research.

Since most of this study's sample participants have had their children at private hospitals located primarily in Riyadh, where none of the children were born at public hospitals, this study could not provide a complete picture of the motivations and barriers of advocacy. Private hospitals usually require cash/credit for medical services, and sometimes there are exaggerations in payment procedures. In contrast, the government financially supports public hospitals, so medical procedures are often more objective and accurate. Therefore, further investigation for

advocates of children born in public hospitals might be exciting and produce different results that would have important implications for services provided in public hospitals.

Some participants illuminated the important role of local associations to which they belong as members in reaching a larger audience. Future studies might investigate the role played by civil associations in providing educational resources to support the various Saudi communities. A better understanding of this matter could develop into a greater collaboration between the nonprofit sector and government educational institutions. Joint work may result in more trustworthy and credible scientific literature that could be distributed through the media and special education sphere. In general, the advocacy needs and challenges of parents with children on the disability spectrum, outside of intellectual and/or developmental disability, remain relatively under-researched in the Saudi context. It is also imperative that future research explores parents' perspective with children on the disability spectrum, whose experiences may be different than the parents who were interviewed in this project. Finally, political solutions that directly address barriers to the activation of legislation protecting families with disabled children from their entitled rights need to be devised.

Conclusion

Advocacy in Saudi appears to follow various tendencies commonly noticed in a western context. Advocacy is primarily driven by context, and the context of life for individuals with disabilities and their families differs significantly from country to country based on political and cultural contexts. The family system is the most important social factor influencing child development. Advocates persist in educating other families about effective practices for supporting infants and children with disabilities, meaning any information or skills needed to facilitate the parents' role. Due to the deficiency of early intervention services in Saudi, some

parents continue to build on their knowledge about supporting other parents, especially in the early stages.

Consequently, family guidance and training are a priority. The study sought to explore advocates' perceptions of their experiences considering inspiration, challenges, supporting roles, and advocacy impact on their child's intervention services. This study focused on recognizing these experiences and finding the meanings by determining the motivations and conflicts that stand in the way of advocacy and understanding how parents define their role as advocates. Additionally, this study attempted to understand the barriers parents may face when seeking to be active participants in their child's development and access to early intervention services. Qualitative interviews of a semi-structured nature were conducted with five parents of children with developmental disabilities who discussed their experiences as advocates /primary caregivers. Overarching themes emerged from the data demonstrating parents' motivations as the expressed desire for services to be obtained or positive outcomes to be achieved in their communities. The findings in this study revealed that the concept of advocacy has emerged as increasingly significant through social media accounts. Advocates' motivations were highly influenced by aspects that were often related to accessing online information and to personal characteristics. These personal attributes were prominent from their previous experiences, such as traveling, and family circumstances pulled heavily from the cultural context. Significant issues related to advocacy barriers were discussed, for example, the weakness in activating legitimate aspects regarding special education policies. Also, the hopeless perspective of the potential benefits of early intervention among other parents focuses on the need for more benefits for Saudi children in existing centers.

Moreover, in this study, the advocate's major issue falls within the health and educational institutions, where the effectiveness of professional collaboration was questioned. Advocates felt their roles were defined by their commencement as a "voice" to their children and mentor others. They felt united with others through shared values like religion, humanity, and bright visions for the future. Advocates negotiated the conceptions of their impact and their values on society that were highlighted through many remarkable advocacy activities, such as developing resources and creating a positive attitude toward accepting disability and inclusion into society. Therefore, recommendations were suggested that would enable critical stakeholders: the decision-makers, services providers, and engage other parents, to become advocates for betterment in implementing early intervention services in the Kingdom of Saudi Arabia.

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APPENDIX A: SAMPLE INTERVIEWES QUESTIONS

The first interview questions will aim to build a strong foundation and become familiar with the participants.

- Can you please tell me about yourself including any details you would like to share regarding your family, educational background, and your work?
- Can you tell me why you decided to participate in this study?
- Can you please tell me about a significant incident that happened in your life?
- When talking about family, you mentioned that you have a child with a disability, can you tell me more about your child?

The second interview questions will focus on eliciting details about the parents' experience with early intervention and being advocates.

- Did you know that your child would be born with a disability? If not, when did you know about it, and how did you find out?
- Can you talk about the birth of your child and the available sources of support that you had when you first learned about your child's disability?
- Have you been aware of early intervention services? If you had experiences with such services, what were the obstacles to accessing them? Could you tell me about a time when you faced difficulty in terms of accessing early intervention services?
- How did you deal with having difficulties getting access to early intervention services?
Was there anyone who helped?
- What were your motives to get involved in advocacy work?

- Can you describe some specific advocacy activities you have participated in on behalf of your child or other children with disabilities?

The third interview questions will focus on finding meaning given what parents have reconstructed in the previous two interviews,

- How would you describe your role as an advocate to another parent? Does it have meaning for your life?
- What meaning does your role as an advocate for children with disabilities have for you?
- Do you think you have accomplished your goal to help other parents who have children with disabilities? Do you believe you can make special education services better in Saudi? If not, what are some obstacles you are facing?
- How do you balance a day in your life with your child and being an advocate?
- How would you describe the future ideal care for a parent of child with disability from zero to three years?

APPENDIX B: SCREENING CHECKLIST FOR SELECTING PARTICIPANTS

Saudi Parents as Advocates for Their Young Children with Disabilities: Reflections on The Journey.

by
Sadeem ALolayan

if you are a Saudi Arabia parent who engaged in advocacy and a parent of a child with a developmental disability, you are invited to participate in this study to share your experience related to your experience in the advocacy world. For more information, or to volunteer for this study, please contact: The Saudi Association for Special Education, which is known locally as GESTER, GPP manger.

Are you a Saudi parent?

- ❖ Yes
- ❖ No

Do you have child with a disability?

- ❖ Yes
- ❖ No

Do you have a child with a developmental disability?

- ❖ Yes
- ❖ No

Are you currently engaging in advocacy work? *

- ❖ Yes
- ❖ No

Your Gender:

- ❖ Male.
- ❖ Female.

How old are you?

- ❖ 18-28 years.
- ❖ 29-39 years.
- ❖ 40-50 years.
- ❖ 51-60 years.
- ❖ Older than 60 years.

How old is your child with a disability?

*Advocacy work refers to sharing valuable and reliable information in various forms (written, recorded, or audible) on social networks such as Twitter, Instagram, Facebook and Snapchat; contributing to authoring of publications of books and pamphlets; participating in giving lectures and/or attending awareness events; and providing legal or social advice to other parents. (Donaldson,2007).

- ❖ 0-6 years old.
- ❖ 7-12 years old.
- ❖ 13-18 years old.
- ❖ Older than 18 years old.

How many children with a disability do you have?

- ❖ One.
- ❖ Two.
- ❖ More than two.

What is your marital status?

- ❖ Married.
- ❖ Divorced.
- ❖ Widower- Widow.
- ❖ Other.

What is your education background?

- ❖ Middle school.
- ❖ High school.
- ❖ Two-Year College degree.
- ❖ Four-Year College degree.
- ❖ Graduate.

How long you been engaging in the advocacy work?

- ❖ Less than 6 months.
- ❖ 6 -12 months.
- ❖ 1- 4 years.
- ❖ 5-10 years.
- ❖ More than 10 years.

APPENDIX C: CONSENT FORMS

Informed Consent to Participate in Research Involving Minimal Risk
Information to Consider Before Taking Part in this Research Study

Title: Saudi Parents as Advocates for Their Young Children with Disabilities: Reflections on The Journey.

Study # 004560

Overview: You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask her to explain any words or information you do not clearly understand. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below. The information in this document should help you to decide if you would like to participate. The sections in this Overview provide the basic information about the study. More detailed information is provided in the remainder of the document.

Study Staff: This study is being led by Sadeem ALolayan who is a doctoral student at the University of South Florida. This person is called the Principal Investigator. She is being guided in this research by Dr. Ann Cranston-Gingras, USF, professor. Other approved research staff may act on behalf of the Principal Investigator.

Study Details: This study is being supported/sponsored by the University of South Florida. The purpose of this qualitative study is to explore a select group of Saudi parent advocates' experiences and to gain insight on how these parents understand their roles in supporting others. If you take part in the study, you will be interviewed three times, and each time might take up to 90 minutes. The interviews will be online through zoom or Microsoft. The interviews will be recorded, and you will be notified and your approval for recording will be received before the interviews. Recordings will remain in electronic format and will be deleted after the final report is presented to the IRB or 5 years later. After 5 years, images, recordings, and transcripts will be deleted.

Subjects: You are being asked to take part because you have a child with a developmental disability, and you are a parent advocate.

Voluntary Participation: Your participation is voluntary. You do not have to participate and may stop your participation at any time. There will be no penalties or loss of benefits or opportunities if you do not participate or decide to stop once you start.

Benefits, Compensation, and Risk: There is no cost to participate. If you complete all three interviews, you will be offered a gift card of 30 dollars. This research is considered minimal risk. Minimal risk means that study risks are the same as the risks you face in daily life.

Confidentiality: Even if we publish the findings from this study, we will keep your study information private and confidential. Anyone with the authority to look at your records must keep them confidential.

Why are you being asked to take part?

The purpose of this qualitative study is to explore a select group of Saudi parent advocates' experiences and to gain insight on how these parents understand their roles in supporting others. You are being asked to take part because you have a child with a developmental disability, and you are a parent advocate.

Study Procedures:

If you take part in this study, you will be asked to complete three online interviews individually. Each interview will take approximately 90 minutes. The interviews will mainly inquire about your experiences as a parent advocate. The interviews focus on three aspects: the first interview revolves around background information. The second interview will revolve around giving specific details regarding your advocacy journey. The third interview emphasizes the reflection on the meaning your experience holds for you. The interview protocol will consist of open-ended questions. The interview will be recorded for analysis processes. The researcher will take your permission to record the interview.

Total Number of Subjects

Up to 7 individuals from Saudi Arabia will take part in this study.

Alternatives / Voluntary Participation / Withdrawal

You have the right to not take a part in this study and to withdraw from the study at any time. You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

Benefits

The potential benefits of participating in this research study include:

- Participating in this study will help you to reach the essential meaning of your experience and promote your future orientations.
- The findings generated from this study will be valuable in guiding and encouraging other parents to urge the government to provide appropriate early intervention services for their children.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

If you complete all three interviews, you will be offered a gift card of 30 dollars.

Costs

This study will not cost you anything.

Privacy and Confidentiality

We will do our best to keep your records private and confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Certain people may need to see your study records. These individuals include:

- The research team, including the Principal Investigator, study coordinator, and all other research staff.

- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes: the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, and staff in USF Research Integrity and Compliance.

Your information or samples collected as part of the research, even if identifiers are removed, will NOT be used or distributed for future research studies. We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

You can get the answers to your questions, concerns, or complaints.

If you have any questions, concerns or complaints about this study, call Sadeem Alolayan at 7276232245. If you have questions about your rights, complaints, or issues as a person taking part in this study, call the USF IRB at (813) 974-5638 or contact by email at RSCH-IRB@usf.edu.

Consent to Take Part in Research

I freely give my consent to take part in this study: and authorize that my health information as agreed above, be collected/disclosed in this study]. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent and Research Authorization

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

Signature of Person Obtaining Informed Consent Date

Printed Name of Person Obtaining Informed Consent

الموافقة المستنيرة للمشاركة في البحوث التي تنطوي على الحد الأدنى من المخاطر

معلومات

العنوان : الآباء السعوديون كمدافعين عن أطفالهم الصغار ذوي الإعاقة: تأملات في الرحلة

الدراسة: Y004560

نظرة عامة: يُطلب منك المشاركة في دراسة بحثية. تشمل الدراسات البحثية فقط الأشخاص الذين يختارون المشاركة. تسمى هذه الوثيقة نموذج الموافقة المسبقة. يرجى قراءة هذه المعلومات بعناية وخذ وقتك في اتخاذ قرارك. اطلب من الباحث أو طاقم الدراسة مناقشة نموذج الموافقة هذا معك، يرجى مطالبتهم بشرح أي كلمات أو معلومات لا تفهمها بوضوح. يتم سرد طبيعة الدراسة والمخاطر والمضايقات وغيرها من المعلومات الهامة حول الدراسة أدناه. يجب أن تساعدك المعلومات الواردة في هذا المستند على تحديد ما إذا كنت ترغب في المشاركة. توفر الأقسام الموجودة في هذه النظرة العامة المعلومات الأساسية حول الدراسة. يتم توفير معلومات أكثر تفصيلاً في الجزء المتبقي من المستند.

طاقم الدراسة: تقود هذه الدراسة سديم العليان وهي طالبة دكتوراه في جامعة جنوب فلوريدا. يسمى هذا الشخص الباحث الرئيسي. يتم توجيهها في هذا البحث من قبل الدكتورة آن كرانتون غينغراس، أستاذة جامعية في جامعة جنوب فلوريدا. يجوز لموظفي البحث المعتمدين الآخرين التصرف نيابة عن الباحث الرئيسي. تفاصيل الدراسة: يتم إجراء هذه الدراسة بالمملكة العربية السعودية بدعم / رعاية جامعة جنوب فلوريدا. الغرض من الدراسة النوعية هو استكشاف مجموعة مختارة من خبرات الوالدين السعوديين المدافعين (ناشط اجتماعي) عن أطفالهم واكتساب نظرة ثاقبة حول كيفية فهم هؤلاء الوالدين لأدوارهم في دعم الآخرين. إذا شاركت في الدراسة، فستتم مقابلتك ثلاث مرات، وقد تستغرق كل مرة ما يصل إلى 90 دقيقة. ستكون المقابلة عبر الإنترنت من خلال برنامج زوم أو مايكروسوفت. سيتم تسجيل المقابلات وسيتم إخطارك وسيتم أخذ موافقتك على التسجيل قبل المقابلة. ستبقى التسجيلات بتنسيق إلكتروني وسيتم حذفها بعد تقديم التقرير النهائي إلى مجلس الهجرة واللجوء أو بعد 5 سنوات. بعد 5 سنوات، سيتم حذف الصور والتسجيلات والنصوص.

الموضوعات: يُطلب منك المشاركة لأن لديك طفلاً من ذوي الاحتياجات الخاصة وتعتبر ناشط اجتماعي..

المشاركة الطوعية: مشاركتك تطوعية. لا يتعين عليك المشاركة ويمكنك إيقاف مشاركتك في أي وقت. لن تكون هناك عقوبات أو خسارة في المزايا أو الفرص إذا لم تشارك أو قررت التوقف بمجرد أن تبدأ. الفوائد والتعويضات والمخاطر: لا نعرف ما إذا كنت ستحصل على أي فائدة من مشاركتك. لا يوجد أي تكلفة للمشاركة. فقط المشارك الذي يكمل الثلاث مقابلات سوف يحصل على كوبون هديه بقيمة 120 ريال. يعتبر هذا البحث الحد الأدنى من المخاطر. يعني الحد الأدنى من المخاطر أن مخاطر الدراسة هي نفس المخاطر التي تواجهها في الحياة اليومية. السرية: حتى إذا نشرنا نتائج هذه الدراسة، فسنحافظ على خصوصية وسرية معلومات دراستك. يجب على أي شخص لديه سلطة الاطلاع على سجلاتك الحفاظ على سريتها.

لماذا يطلب منك المشاركة

الغرض من الدراسة هو استكشاف مجموعة مختارة من خبرات الوالدين السعوديين المدافعين (ناشط اجتماعي) عن أطفالهم واكتساب نظرة ثاقبة حول كيفية فهم هؤلاء الوالدين لأدوارهم في دعم الآخرين. الخاصة يُطلب منك المشاركة لأن لديك طفلاً من ذوي الاحتياجات الخاصة وتعتبر ناشط اجتماعي.. إجراءات الدراسة:

إذا شاركت في هذه الدراسة، فسيُطلب منك إكمال ثلاث مقابلات عبر الإنترنت بشكل فردي. ستستغرق كل فترة 90 دقيقة تقريباً. ستناقش المقابلات بشكل أساسي عن تجاربك كوالد مؤيد. تركز المقابلات على ثلاثة جوانب: المقابلة الأولى تدور حول المعلومات الأساسية. ستتمحور المقابلة الثانية حول إعطاء تفاصيل محددة ومكثفة فيما يتعلق برحلة المناصرة الخاصة بك. تؤكد المقابلة الثالثة على التفكير في المعنى الذي تحمله تجربتك بالنسبة لك. يتكون بروتوكول المقابلة من أسئلة مفتوحة. سيتم تسجيل المقابلة لعمليات التحليل. سيأخذ الباحث إذنك لتسجيل المقابلة

إجمالي عدد المواضيع:

سيشارك ما يصل إلى 7 أفراد من المملكة العربية السعودية في هذه الدراسة.

البدائل / المشاركة الطوعية / الانسحاب

يحق لك عدم المشاركة في هذه الدراسة والانسحاب من الدراسة في أي وقت. يجب أن تشارك في هذه الدراسة فقط إذا كنت ترغب في التطوع. يجب ألا تشعر بوجود أي ضغوط للمشاركة في الدراسة. أنت حر في المشاركة في هذا البحث أو الانسحاب في أي وقت. لن تكون هناك عقوبة أو خسارة في المزايا التي يحق لك الحصول عليها إذا توقفت عن المشاركة في هذه الدراسة

الفوائد:

- تشمل الفوائد المحتملة للمشاركة في هذه الدراسة البحثية ما يلي:
- ستساعدك المشاركة في هذه الدراسة على الوصول إلى المعنى الأساسي لتجربتك وتعزيز توجهاتك المستقبلية.
- ستكون النتائج المستخلصة من هذه الدراسة ذات قيمة في توجيه وتشجيع الآباء الآخرين لحث الحكومة على توفير خدمات التدخل المبكر المناسبة لأطفالهم.

المخاطر أو الانزعاج:

يعتبر هذا البحث على أنه الحد الأدنى من المخاطر. هذا يعني أن المخاطر المرتبطة بهذه الدراسة هي نفس المخاطر التي تواجهها كل يوم. لا توجد مخاطر إضافية معروفة لأولئك الذين يشاركون في هذه الدراسة.

تعويضات:

إذا أكملت جميع المقابلات الثلاثة ، فسيتم تقديم بطاقة هدية بقيمة 30 دولارًا لك .

التكاليف:

هذه الدراسة لن تكلفك شيئاً.

الخصوصية والسرية:

سنبذل قصارى جهدنا للحفاظ على سرية وسرية سجلاتك. لا يمكننا ضمان السرية المطلقة. قد يتم الكشف عن معلوماتك الشخصية إذا اقتضى القانون ذلك. قد يحتاج بعض الأشخاص إلى الاطلاع على سجلات الدراسة الخاصة بك. هؤلاء الأفراد هم:

- فريق البحث ، بما في ذلك الباحث الرئيسي ومنسق الدراسة وجميع موظفي البحث الآخرين.
 - بعض الأشخاص الحكوميين والجامعيين الذين يحتاجون إلى معرفة المزيد عن الدراسة. على سبيل المثال ، قد يحتاج الأفراد الذين يشرفون على هذه الدراسة إلى إلقاء نظرة على سجلاتك. يتم ذلك للتأكد من أننا نقوم بالدراسة بالطريقة الصحيحة.
 - يحتاجون أيضاً إلى التأكد من أننا نحمي حقوقك وسلامتك.
 - مجلس المراجعة المؤسسية (IRB) التابع لـ USF والموظفين المرتبطين به الذين لديهم مسؤوليات إشرافية لهذه الدراسة ، والموظفين في USF Research Integrity and Compliance.
- لن يتم استخدام المعلومات أو العينات التي تم جمعها كجزء من البحث ، حتى إذا تمت إزالة المعرفات ، أو توزيعها للدراسات البحثية المستقبلية. قد ننشر ما تعلمناه من هذه الدراسة. إذا فعلنا ذلك ، فلن نقوم بتضمين اسمك. لن ننشر أي شيء من شأنه أن يتيح للناس معرفة من أنت.

مخاوف أو شكاوى:

إذا كانت لديك أي أسئلة أو مخاوف أو شكاوى حول هذه الدراسة ، فاتصل بسديم العليان على + (699) 505241230 . أو إذا كانت لديك أسئلة حول حقوقك أو شكاوىك أو مشكلاتك بصفحتك شخصاً مشاركاً في هذه الدراسة ، فاتصل بـ USF IRB أو تواصل عبر البريد الإلكتروني على (813) 5638-974

RSCH-IRB@usf.edu

الموافقة على المشاركة في البحث والتفويض بجمع المعلومات الصحية واستخدامها والكشف عنها

أمنح موافقتي بحرية للمشاركة في هذه الدراسة وأصرح بجمع / الكشف عن معلوماتي كما هو متفق عليه أعلاه في هذه الدراسة أنا أفهم أنه من خلال التوقيع على هذا النموذج، أوافق على ذلك. لقد تلقيت نسخة من هذا النموذج لأخذها معي.

التوقيع
التاريخ

الاسم

بيان الشخص الذي حصل على الموافقة المستنيرة والتفويض البحثي:

لقد شرحت بعناية للشخص المشارك في الدراسة ما يمكن أن يتوقعه من مشاركته. أؤكد أن هذا الشخص يتحدث اللغة التي تم استخدامها لشرح هذا البحث ويتلقى نموذج موافقة مستنيرة بلغته الأساسية. قدم المشارك في هذا البحث هذا موافقة مستنيرة فعالة من الناحية القانونية.

التوقيع

التاريخ

الاسم

APPENDIX D: IRB EXEMPT DETERMINATION LETTER



EXEMPT DETERMINATION

September 21, 2022

Sadeem Alolayan
[REDACTED]
[REDACTED]

Dear Ms. Sadeem Alolayan:

On 9/21/2022, the IRB reviewed and approved the following protocol:

Application Type:	Initial Study
IRB ID:	STUDY004560
Review Type:	Exempt 2
Title:	Saudi Parents as Advocates for Their Young Children with Disabilities: Reflections on The Journey.
Protocol:	• sadeem- Social-Behavioral Protocol

The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

Sincerely,

Gabriela Plazarte
IRB Research Compliance Administrator

Institutional Review Boards / Research Integrity & Compliance
FWA No. 00001669
University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813-974-5638