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# A proposal to activate the role of early intervention programs for the rehabilitation of mothers of children with Down syndrome, in light of the Saudi vision 2030

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## Abstract:

**BACKGROUND:** Early intervention programs are supremacy in health, psychological, social, and sports care policies in many developed countries, considering the necessity to identify the circumstances and any support required as soon as possible. Consequently, understanding the critical role of mothers of children with Down syndrome in meeting the needs of their children is crucial, as well as developing their capacity to make positive contributions to the psychosocial harmony of their children. Hence, this study aims at determining the real role of early intervention programs in the rehabilitation of mothers of children with Down syndrome and identifying the obstacles that prevent early intervention services and programs from achieving their objective and how to treat it.

**MATERIALS AND METHODS:** The descriptive-analytical approach was used. In order to achieve these objectives, an online questionnaire consisting of (88) phrases, divided into three areas, was applied to (20) mothers of children with Down syndrome.

**RESULTS:** The assessment study concluded several results from the mothers' perspective, indicating that cognitive qualifications were highest at an average of 52.66%, followed by educational qualifications at an average of 50.73%, social qualification at an average of 48.78%, and religious qualification at an average of 48.33%. Finally, psychological qualifications were lowest at an average of 45.22%. The approval rate of all these proposals exceeded 90%.

**CONCLUSION:** Based on these results, a proposal for activating early intervention programs for the rehabilitation of mothers of children with Down syndrome, in light of the Saudi Vision 2030, was set. It was also recommended to give continuous and intensive courses to mothers, in order to improve their children's skills and self-sufficiency.

## Keywords:

Down syndrome, early intervention, mothers of children with Down syndrome, rehabilitation, Saudi vision 2030

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## Introduction

Disability is a serious issue facing societies today, with many dimensions that can hinder the development and evolution of society.<sup>[1]</sup> Recently, special institutions have emerged to defend the rights of people with disabilities and provide them with

the services and rehabilitation programs they need.<sup>[2]</sup> Family plays a pivotal role in the lives of children with disabilities.<sup>[3,4]</sup> It is impossible to provide awareness and assistance to the family of a child with a disability without understanding the background of a family's behavior toward their child. Ultimately, it is a reflection of many emotions, reactions, and pressures;

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the family experiences upon the birth of a child with a disability.<sup>[5,6]</sup>

Mental disability is an educational, social, medical, and rehabilitative issue. People with mental disabilities need care and guidance; therefore, it is necessary to take into consideration their special needs and demands in all stages of economic, social, and educational planning.<sup>[7,8]</sup> Children with Down syndrome can be distinguished from others with disabilities in many areas, specifically, diseases, and health problems they can be susceptible to; Most notably, children with intellectual disability, who may cause additional stress on the family, especially the mother.<sup>[9]</sup> Every year, about 200,487 children in the world are born with Down syndrome, equal to 549 every day.<sup>[10]</sup> In the Arab world, every year between 14,118 and 16,347 children are born with Down syndrome, i.e., between 39 and 42 children are born with Down syndrome every day or one child per 700 live births.<sup>[11]</sup> According to the latest statistics in this field, there are more than 20,000 people suffer from Down syndrome in the Kingdom of Saudi Arabia aged under 17 years old. The number of Down syndrome cases in pregnancy is one in every 800 pregnancies in mothers aged 30 and up to one in every forty pregnancies for mothers aged 44.<sup>[10]</sup>

Based on the above, it is concluded that individuals with special needs, and people with Down syndrome, in particular, constitute a significant percentage that cannot be overlooked or ignored and that the condition deserves study, care, and attention.<sup>[12]</sup> If a child's disability causes him psychological, social, health, and economic problems, the family coexists with these problems and shoulders the struggles arising from the presence of a child with a disability in the family.<sup>[13]</sup> In addition, some families consider it a stigma; when one of their children is born with Down syndrome, compounded by the fact that they often perceive themselves as the cause, inducing exhaustion, anxiety, and depression.<sup>[14]</sup> Furthermore, the results of a study<sup>[10]</sup> showed that mothers of children with Down syndrome were negatively affected in terms of quality of life and mental health. The study indicated that it would be helpful to systematically assess mothers and refer them to appropriate intervention at an early stage.

Despite the development of special education programs and services provided to children with special needs in recent years, many have not provided adequate services to their mothers, exposing them to psychological and social problems and pressures.<sup>[15]</sup> A study<sup>[16]</sup> concluded that families with children with disabilities do not feel sufficiently supported by social organizations (schools and intervention Centers), as well as, they left feeling concerned and annoyed by the lack of social support (services and individuals specialized

and distinguished in practice). They are, therefore, not satisfied with those services.

Early intervention is a modern concept of special education; it is an approach used by most developed countries because it provides a real opportunity to improve the abilities of children with special needs. Programs consist of two main axes: intervention for prevention and intervention for rehabilitation.<sup>[17,18]</sup> Early intervention includes the provision of a variety of medical, social, educational, and psychological services for the child who relies primarily on his family to meet his needs.<sup>[19]</sup> Therefore, early intervention programs should focus on enhancing the parents' skills and abilities to help their children grow and learn.<sup>[20]</sup> Regarding the importance of early intervention for the children, the family, and society, early intervention programs nowadays have received perceptible attention from the concerned authorities for the welfare of persons with special needs in most countries.<sup>[21]</sup> The Kingdom of Saudi Arabia, like all other countries, is aware of its role in preventing growth problems and reducing the effects of disability on children with special needs and their families.<sup>[22]</sup>

The study of El-Khatib and El-Hadidy<sup>[20]</sup> indicated that early intervention programs determine the general health and growth of children with special needs, as they reduce the financial costs of future medical and nonmedical treatments required by these children.<sup>[23]</sup> Nevertheless, mothers of children with Down syndrome do not have sufficient information or knowledge to deal with their children. Some have not recognized the idea of sending children with Down syndrome to welfare and rehabilitation institutions or centers for people with special needs.<sup>[24]</sup> Phillips *et al.*<sup>[25]</sup> confirmed that mothers need to be supported to serve and handle their children. Thus, obtaining information on mothers and their qualifications for caregiving is a substantial issue.

The study of Phillips *et al.*, Mohammed *et al.*, Sarimski, and Norouzi *et al.*<sup>[25-28]</sup> recommended the use of early intervention programs for the care of mothers of children with Down syndrome should be expanded given their serious prominence in developing treatment plans and investing in parents' capacity to care for their children through the development of their social skills. Allen<sup>[15]</sup> indicated that, despite the many advantages of early intervention programs, whether for a child with special needs or the family, reliable evidence is still urgently needed to identify the most successful forms of early intervention, whether inside the centers or at home.

Several researchers<sup>[12,25,27,29]</sup> have confirmed that focusing on early intervention results is the optimal way to grasp the effectiveness of early intervention programs and

identify their strengths and weaknesses to improve and develop them. Despite the importance of training mothers of children with Down syndrome through early intervention programs, there are many obstacles to maternal participation. Therefore, this study will seek to clarify the role of the early intervention programs in training mothers of children with Down syndrome. In addition, to identifying these obstacles in order to find appropriate solutions and make proposals for the activation of early intervention programs. Besides, develop a proposed framework for activating this role in light of the Saudi Vision 2030.

### The study problem

The study problem determined the early intervention programs as focusing on the rehabilitation of children with Down syndrome. Concerning training and supporting the mothers of children with Down syndrome; it is not entirely clear. The family, especially mothers, has an active role in assisting their children, but many obstacles prevent early intervention programs from succeeding in their role of training mothers of children with Down syndrome. Therefore, their success in improving all areas of the child's development, and giving psychological and social support to the family, cannot be guaranteed. The current study is trying to fill this gap by developing a proposal to activate the role of early intervention programs in rehabilitation mothers of children with Down syndrome, in light of the Saudi Vision 2030. By answering the following questions:

1. What is the real role of early intervention programs in rehabilitation mothers of children with Down syndrome?
2. What are the obstacles preventing early intervention programs from fulfilling their role in the rehabilitation of mothers of children with Down syndrome?
3. What are the solutions to overcoming the obstacles that prevent early intervention programs from achieving their role in the rehabilitation of mothers of children with Down syndrome?
4. What is the proposal to activate the role of early intervention programs in the rehabilitation of mothers of children with Down syndrome, in light of the Saudi Vision 2030?

## Materials and Methods

### Study design and participants

The researchers used the descriptive approach and obtained approval for this study from the competent authorities of Princess Nora University. Participants filled out questionnaires flexibly without any pressure. We use of questionnaire instead of interview schedule because is that subjects are more likely to feel that they can remain anonymous and thus may be more likely to express controversial opinions and realistic

without revealing his character. This is more difficult in an interview. Confidentiality of the information was confirmed. The questionnaire is distributed to 22 of the mothers of children with Down syndrome in Riyadh, Saudi Arabia. Mothers have completed the questionnaire in the centers for the rehabilitation of children with special needs. Two survey forms were excluded because the answers were contrary to the instructions provided with the questionnaire. As a result, the sample becomes twenty mothers. The study was applied in January 2021 for a period of 2 weeks, from January 17 to 31. The institutional ethical committee clearance was obtained from Princess Noura bint Abdulrahman University in Riyadh before application of the study; all participants completed the voluntary consent section in the questionnaire and were assured confidentiality.

### Data collection tool and technique

In the current study, after reviewing previous literature on Early Intervention Programs and Children with Down syndrome.<sup>[17,25-27,30-33]</sup> A questionnaire of three main dimensions with (88) phrases is set up. The first dimension: the real role of early intervention programs in the rehabilitation of mothers of children with Down syndrome includes 47 phrases. The second dimension: the obstacles preventing the achievement of early intervention programs in their role of rehabilitation of mothers of children with Down syndrome consists of 28 phrases. The third dimension: solutions to overcome the obstacles preventing the achievement of early intervention programs in their role of rehabilitation of mothers of children with Down syndrome consists of 13 phrases. A 3-point Likert scale was used (disagree – neutral – agree). Content validity ratio and content validity index measurements were also used in the quantitative method. The scores are distributed from 1 to 3; one for "disagree" and three for "agree." The Cronbach alpha values are calculated for the three dimensions. They were 0.95, 0.94, and 0.81, and the scale as a whole is 0.90. Self-validation was calculated as an indicator of the validity of the questionnaire as a whole, by calculating the square root of the stability coefficient. It equals (0.94), indicating that the questionnaire has a high degree of validation.

The researchers applied descriptive and inferential statistics to analyze the data. These were analyzed using SPSS Statistics V21 (IBM Corp., Armonk, N.Y., USA). The real role of early intervention programs in rehabilitating mothers of children with Down syndrome has been identified. In addition, obstacles and solutions proposed through average, standard deviation, and percentage. The participants' response to each dimension of the questionnaire was analyzed through frequency, percentage, average, and standard deviation.

### Ethical consideration

The institutional ethical committee clearance was obtained from the Centre for Promising Research in Social Research and Women's Studies at Princess Noura bint Abdulrahman University in Riyadh before application of study tools. Participants in the sample voluntarily filled out the questionnaire without any pressure, ensuring the confidentiality of information.

### Results

The study axes were analyzed to extract its results according to its various questions, and the results were as follows:

The first question answers What is the real role of early intervention programs in the rehabilitation of mothers of children with Down syndrome? Frequencies, relative weight, and percentages of responses in the study sample were calculated.

Table 1 shows the results.

Table 1 shows that the overall degree of the responses from the study sample regarding the real role of early intervention programs in the rehabilitation of mothers of children with Down syndrome is 49.29%. The degrees are intermediate proportions, reflecting the weakness and ineffectiveness of early intervention programs in the rehabilitation of mothers of children with Down syndrome. These programs are ineffective and low impact from the mothers' perspective, i.e., the individuals of the study sample. Overall, the degrees of phrases for each dimension are all medium to low in effect, according to the study sample.

### The second question answers

What are the obstacles preventing early intervention programs from achieving their role in the rehabilitation of mothers of children with Down syndrome? Frequencies, the relative weight, and the percentage of responses of the study sample were calculated, and the results are illustrated in Table 2.

As shown in Table 2, the most prominent obstacles preventing early intervention programs from achieving their role in the rehabilitation of mothers of children with Down syndrome, from the mothers' perspective, are portrayed in the following order: In the first place, obstacles caused by Down syndrome legislation with an average of 89.99% are represented as follows: existing legislation does not cover the care and rehabilitation of mothers of children with Down syndrome – lack of legislation and laws that help to provide the required rehabilitation mothers of children with Down syndrome. In the second place, obstacles caused by institutions

involved in the training and care of mothers of children with Down syndrome with an average of 87.21% are represented as follows: insufficient number of experts and specialists involved in the training process – Absence of specialized institutions in the training of mothers of children with Down syndrome. In the third place, obstacles caused by mothers of children with Down syndrome with an average of 85.92%: are represented as follows: declining interest of mothers to participate in training, as they are convinced that this program is useless – mothers abstinence from participating in rehabilitation program because of the distance between the institution and their homes). In the fourth place, obstacles caused by the surrounding community with an average of 85.33% are represented in: (disregard for the geographical location of mothers of children with Down syndrome – Inadequate community services provided for the care and rehabilitation of mothers of children with Down syndrome).

The third question answer: "what are the solutions to overcome the obstacles preventing the achievement of early intervention programs in their role of rehabilitation of mothers of children with Down syndrome?" Frequencies, the relative weight, and the percentage of responses of the study sample were calculated, and the results are illustrated in Table 3.

As shown in Table 4, all solutions to overcome the obstacles to achieving early intervention programs in their role of the rehabilitation of mothers of children with Down syndrome have been accepted by a sample of experts. The degree of acceptance of all proposals exceeds 90%.

### Discussion

Study results indicated that the real role of early intervention programs in the rehabilitation of mothers of children with Down syndrome is 49.29%. The degrees are intermediate proportions, reflecting the weakness and ineffectiveness of early intervention programs in the rehabilitation of mothers of children with Down syndrome. In other words, these programs are ineffective and low-impact from the mothers' perspective, showing by the phrases of the first dimension; the most prominent of these phrases were as follows:

Cognitive qualification ranked highest with an average score of 52.66%: the most prominent phrases according to this dimension were develop mothers' knowledge to help them identify their children's strengths and weaknesses, develop mothers' knowledge of how to measure the progress of their children's development, as well as, provide mothers with knowledge of educational centers and institutions that can offer support. This clearly



**Table 1: The reality of the role of early intervention programs in the rehabilitation of mothers of children with Down syndrome**

	Phrase	Frequencies			Relative weight	Percentage	Rank	Dimensions average
		Agree	Somewhat agree	Disagree				
Social qualification	Raise awareness and understanding amongst mothers of the needs and abilities of children with Down syndrome	1	4	15	26	43.33	7	48.78
	Increase the ability of mothers to alleviate the difficulties children with Down syndrome experience	3	3	14	29	48.33	6	
	Develop the listening and speaking skills of mothers for communication with their children	3	6	11	32	53.33	3	
	Enable mothers to offer the activities their children love	2	6	12	30	50	5	
	Train mothers to provide a natural environment full of love, compassion, and tolerance for their children	0	5	15	25	41.66	8	
	Achieve a positive relationship between mothers, their children, siblings, and other relatives	3	3	14	29	48.33	6	
	Develop the ability of mothers to provide excellent care for their children whilst continuing their own jobs	1	4	15	26	43.33	7	
	Facilitate improvement of the relationship between mothers of children with Down syndrome and their husbands	3	5	12	31	51.66	4	
	Assist mothers in the decision-making process regarding their children	0	5	15	25	41.66	8	
	Enhance mothers' understanding of their children's abilities and strengths	5	4	11	34	56.66	2	
Psychological qualification	Increase the confidence of mothers of children with Down syndrome when they go out in public	5	5	10	35	58.33	1	45.22
	Contribute to reducing feelings of guilt mothers have regarding their children's condition	2	5	13	29	48.33	2	
	Develop the self-confidence of mothers of children with Down syndrome	2	5	13	29	48.33	2	
	Relieve psychological stress for mothers as they care for their children	4	2	14	30	50	1	
	Strengthen feelings of gratification among mothers despite the burdens they carry whilst caring for their children	2	4	14	28	46.66	3	
	Reduce the negative thoughts mothers have towards their children	2	4	14	28	46.66	3	
	Contribute to improving the focus of mothers in their family lives	0	4	16	24	40	7	
	Contribute to improving mothers' feelings of happiness	1	4	15	26	43.33	5	
	Increase the optimism mothers have for the care and treatment of their children	2	1	17	25	41.66	6	
	Develop the emotional stability of mothers	0	7	13	27	45	4	
Educational qualification	Provide mothers with ways to develop their children's sensory and motor skills	3	0	17	26	43.33	6	50.73
	Provide mothers with programs to integrate and educate their children alongside other children	0	6	14	26	43.33	6	
	Teach mothers to protect their children from the difficulties they encounter as a result of their condition	6	3	11	35	58.33	2	
	Teach mothers ways to increase their children's ability to remember	5	4	11	34	56.66	3	
	Organize seminars and meetings for mothers to guide them inappropriate treatment of their children	0	5	15	25	41.66	7	
	Teach mothers to detect possible complications arising from their children's condition	2	5	13	29	48.33	4	
	Teach mothers ways to enhance their children's responses	6	4	10	36	60	1	

Contd...

**Table 1: Contd...**

	Phrase	Frequencies			Relative weight	Percentage	Rank	Dimensions average
		Agree	Somewhat agree	Disagree				
Cognitive qualification	Teach mothers how to explain the educational curricula to their children	1	5	14	27	45	5	52.66
	Enable mothers to acquire a curriculum of communication skills that can be used with their children	6	4	10	36	60	1	
	Enable mothers to acquire information on how to diagnose their children	3	7	10	33	55	3	
	Develop the knowledge of the mothers so that they have the means and tools to care for their children	0	5	15	25	41.66	5	
	Develop the knowledge of the mothers to help them identify the strengths and weaknesses of their children	8	2	10	38	63.33	1	
	Identify the legislation, laws, and training resources that mothers can use in the upbringing of their children	3	7	10	33	55	3	
	Provide mothers with the knowledge that helps them to identify and manage the difficulties their children face	0	3	17	23	38.33	6	
	Provide mothers with knowledge of educational centers and institutions that can offer support	4	6	10	34	56.66	2	
	Develop mothers' knowledge of how to measure the progress of their children's development	6	6	8	38	63.33	1	
	Provide mothers with knowledge of how to teach their children to interact with others	0	6	14	26	43.33	4	
Religious qualification	Provide mothers with information on ways to develop the abilities of their children to become self-reliant	3	7	10	33	55	3	48.33
	Advise mothers of activities appropriate for their children	4	5	11	33	55	3	
	Increase mothers' confidence that God will help them through trials and hardships	1	2	17	24	40	6	
	Strengthen mothers' belief that their children are the key to their paradise	5	5	10	35	58.33	1	
	Strengthen the will of mothers to accept God's will and their destiny	3	7	10	33	55	2	
	Make clear to mothers that their children are a gift from God and therefore he must be thanked	0	4	16	24	40	6	
	Facilitate participation in religious seminars for mothers to strengthen their spiritual side	4	4	12	32	53.33	3	
	Develop mothers' feeling that caring for their children is primarily a religious duty	1	5	14	27	45	5	
	Strengthen mothers' certainty in the ability of God to heal their children	1	5	14	27	45	5	
	Reduce mothers' discontent and guilt for their children's condition	3	4	13	30	50	4	
Total		1390	49.29%					

implies that the fact that a mother's lack of knowledge and awareness of her child's condition could pose a potential threat to her child's future development. More specifically, if the mother is unaware of the diagnosis of her child, and cannot realize that the changes are an indication of her child's progress; in order to reinforce their conditions; It would be necessary to identify centers and institutions for mothers to help her identify the strengths and weaknesses of her children, and early intervention programs should focus on this aspect during the qualification process.

Educational qualification scored second, with an average of 50.73%: the most prominent phrases according to this dimension were teach mothers how to enhance their children's responses, enabling mothers to acquire communication skills that can be used with their children. This clearly implies that the fact that early intervention programs focus on the behavioral and communicative aspects of the child with Down syndrome. For this reason, early intervention programs should pay particular attention to these during child rehabilitation, given the importance of educating mothers on how to interact and

**Table 2: The obstacles preventing early intervention programs from achieving their role in the rehabilitation of mothers of children with Down syndrome**

	Obstacles	Total sample					Relative Percentage weight	Ranking	The average of dimensions
		Frequencies			Disagree	Agree			
		Agree	Somewhat agree	Disagree					
Obstacles caused by mothers of children with Down syndrome	Low interest amongst mothers to participate in training, as they are convinced that this program is useless	9	9	2	47	78.33	1	85.92	
	Negative attitudes of mothers towards their children's development	13	2	5	48	80	7		
	Mothers abstinence from participating in the training program, because of work commitments	16	3	1	55	91.66	3		
	Mothers abstinence from participating in the training program, because they are ashamed of their children's condition	11	4	5	46	76.66	8		
	The financial burden denies mothers the freedom to participate in the training program	16	4	0	56	93.33	2		
	Mothers' poor health hindering the training process	15	4	1	54	90	4		
	Mothers' abstinence from participating in the care of their children due to psychological stresses	13	5	2	51	85	5		
	Convincing mothers that the social worker is the responsible party for the rehabilitation, care, and education of their children	13	4	3	50	83.33	6		
	Mothers' abstinence from participating in the training program because of the distance between the institution and their homes	17	3	0	57	95	1		
	Obstacles caused by institutions concerned with the training and care of children with Down syndrome	Lack of willingness from the institution to cooperate with the mothers	11	8	1	50	83.33		5
Routine and complex procedures of services for training mothers		11	7	2	49	81.66	6		
The scarcity of training programs for workers and professionals specialized in training processes at the institution		14	5	1	53	88.33	3		
The lack of appropriate methods and devices needed for training mothers		13	6	1	52	86.66	4		
Absence of institutions specialized in the training of mothers of children with Down syndrome		15	5	0	55	91.66	2		
The an insufficient number of experts and specialists involved in the training process		17	3	0	57	95	1		
Lack of follow-up from the institution with mothers after the completion of the training program		14	5	1	53	88.33	3		
Deficiency of the competence and experience of people involved in the training process		11	8	1	50	83.33	5		
The lack of financial support for institutions to continue to provide outstanding training qualifications for mothers of children with Down syndrome		13	6	1	52	86.66	4		

Contd...

**Table 2: Contd...**

Obstacles		Total sample					Relative Percentage	Ranking	The average of dimensions
		Frequencies			weight				
		Agree	Somewhat agree	Disagree					
Obstacles caused by the legislation for people with special needs (with Down syndrome)	There are no legislative institutions specialized in the field of caring for mothers of children with Down syndrome	14	5	1	53	88.33	3	89.99	
	Outdated legislation is unsuitable for sources of care and rehabilitation mothers of children with Down syndrome	14	5	1	53	88.33	3		
	Existing legislation does not cover the care and rehabilitation of mothers of children with Down syndrome	16	3	1	55	91.66	1		
	Absence of legislation and laws that help to provide the required training to mothers of children with Down syndrome	15	4	1	54	90	2		
	There is no mechanism to implement legislation and laws relating to the care and rehabilitation of mothers of children with Down syndrome	16	3	1	55	91.66	1		
Obstacles caused by the surrounding community	The negative perception of society towards mothers of children with Down syndrome	10	5	5	45	75	4	85.33	
	Inadequate community services provided for the care and rehabilitation of mothers of children with Down syndrome	16	3	1	55	91.66	2		
	Disregard for the geographical location of mothers of children with Down syndrome	18	2	0	58	96.66	1		
	Society ignores the rights of the mother and her child (ren)	15	3	2	53	88.33	3		
	Government restrictions limiting the rehabilitation activities of the institution	10	5	5	45	75	4		

communicating positively with their children. Social qualification scored third, with an average of 48.78%: the most prominent phrases according to this dimension were increase the confidence of mothers of children with Down syndrome when they go public, as well as, enhance mothers' understanding of their children's abilities and strengths. This clearly implies that most of the mothers preferred not to let their children go public due to their unpredictable and embarrassing behavior, especially when those around them do not appreciate the situation. Consequently, the important role of these programs is to increase mothers' confidence when going public with their children, so they feel less concerned and embarrassed.

Moreover, Scoring next was the Religious Qualification with an average of 48.33%: the most prominent phrases according to this dimension were strengthening mothers' belief that their children are the key to reinforcing mothers' will to accept God's will and destiny. This clearly implies that one of the biggest problems faced by

mothers of children with Down syndrome is the difficulty of readjusting to family life after their child's birth; they are often embarrassed and ashamed. Therefore, early intervention programs should be concerned with supporting and promoting religious restraint and consent obtained through Allah's Divine Decree. Psychological qualification scored lowest, with an average of 45.22%: the most prominent phrases according to this dimension were reduce psychological stress on mothers while caring for their children, contribute to reducing mothers' feelings of guilt about their children's condition, as well as, develop the self-confidence of mothers of children with Down syndrome.

The study suggests that psychological stresses arise when mothers cannot overcome difficulties they face because of their limited capabilities. More specifically, mothers may suffer from psychological tension, provoking feelings of instability, discomfort, fear, and pessimism about different aspects of life. Thus, early intervention programs should take this into account during psychological



**Table 3: Solutions to overcome the obstacles that prevent the achievement of early intervention programs in their role of rehabilitation mothers of children with Down syndrome**

Suggestions	Frequencies			Total sample			Overall average of suggestions
	Agree	Somewhat agree	Disagree	Relative weight	Percentage	Ranking	
Amend society's perception of mothers of children with Down syndrome	18	2	0	58	96.66	3	97.81
Establish disciplines and mechanisms to implement laws and legislation concerning to qualify mothers of children with Down syndrome	18	2	0	58	96.66	3	
Provide a database of training services and locations for mothers of children with Down syndrome	18	2	0	58	96.66	3	
Provide specialized professional cadres in early intervention for rehabilitation of mothers of children with Down syndrome	18	2	0	58	96.66	3	
Provide appropriate means, devices, and tools for the early intervention processes	19	1	0	59	98.33	2	
Develop community services provided for the care and rehabilitation of mothers of children with Down syndrome	19	1	0	59	98.33	2	
Organize training courses for all social workers and mothers of children with Down syndrome in order to consolidate and support cooperation	18	2	0	58	96.66	3	
Provide different activities that ensure the effective participation of mothers in rehabilitation their children, rather than limiting their participation in meetings and events	20	0	0	60	100	1	
Provide adequate financial support to continue providing qualifications to mothers of children with Down syndrome	19	1	0	59	98.33	2	
Organize workshops and training courses for mothers and workers in the early intervention programs, to educate them about children's and families' rights	19	1	0	59	98.33	2	
Open a special department for early intervention in every institution to initiate the early intervention program in the rehabilitation of mothers of children with Down syndrome	18	2	0	58	96.66	3	
A continuous assessment process should be carried out at each stage of the early intervention program to determine the extent to which the training objectives have been achieved	20	0	0	60	100	1	
Provide means of transport to mothers who must travel a great distance from their home	19	1	0	59	98.33	2	

rehabilitation processes, to promote admission and improve mothers' social skills. Consequently, mothers will be able to carry out their main functions effectively. Although cognitive Qualification has been ranked first, mothers are still looking forward to providing better and more effective qualified services. Hence, other less qualified types need to deliver their services more effectively. This finding is consistent with the study findings of Al-Fawaer, Allen, Parrish and Phillips, Summers *et al.*, and Turnbull *et al.*<sup>[22,31,34-36]</sup>

Concerning the obstacles preventing early intervention programs from achieving their role in the rehabilitation of mothers of children with Down syndrome, ranking as follows: Laws and legislation for people with disabilities. Then, obstacles caused by the institutions concerned with the training and care of mothers of children with Down syndrome, after that obstacles caused by mothers of children with Down syndrome. Finally, obstacles caused by the surrounding community.

The emergence of obstacles, maybe since the rehabilitation of mothers of children with Down syndrome, has only recently enticed the attention of early intervention programs. They suggest that the proposed should have objectives to address obstacles or challenges to achieving early intervention programs from training mothers of children with Down syndrome. They also suggest that the proposed should include policies and procedures to overcome these obstacles. This finding is consistent with the study of Badghaish and Tsibidaki and Tsamparli.<sup>[13,16]</sup> emphasizing constraints on early intervention programs and the necessity to propose solutions to reduce them.

This finding is consistent with the study findings of Badghaish<sup>[13]</sup> emphasizing the need for proposals for early intervention programs. They are also consistent with the studies of Phillips *et al.*, Mohammed *et al.*, Sarimski, Al-Qamish and Al-Ma'ayta, and Khayal<sup>[25-27,37,38]</sup> emphasizing the need for expansion of early intervention programs for the care of mothers of children with Down syndrome.

**Table 4: Model of the proposed framework of the early intervention program for qualifying and supporting mothers of children with Down syndrome**

Type of qualification	Title of the session	Session's objectives
Cognitive training	Down syndrome (concept and causes)	Introduce the concept of Down syndrome to mothers Discuss the causes of Down syndrome Provide mothers with methods of preventing Down syndrome Introduce mothers to legislations, laws, and training courses related to Down syndrome
	Mental and social abilities of people with Down syndrome	Introduce the mental abilities of people with Down syndrome to mothers Inform mothers of the effect of these abilities on their children's education Illustrate the social characteristics of people with Down syndrome Inform mothers of the individual differences between children
	Physical and linguistic abilities of people with Down syndrome	Train mothers in methods that help them treat speech impediments in their children Educate mothers on the linguistic abilities of their children Inform mothers of the physical abilities of their children
	Psychological and social needs of people with Down syndrome	Inform mothers of the psychological needs of their children Inform mothers of the impact their children's social needs have on the formation of their personality Train mothers to use different methods to satisfy the needs of their children
	Managing the behavior of people with Down syndrome	Train mothers in methods of behavior management for children with Down syndrome (in particular, reinforcement and extinction)
Social training	Daily life skills for people with Down syndrome	Inform mothers of the capacity and potential of their children Encourage mothers to give their children independence in (clothing, food.) Train mothers in various methods and techniques to help their children overcome feelings of isolation, difficulty in verbal and nonverbal communication, and lack of enjoyment of typical activities
	Outside social situations for people with Down syndrome	Raise mothers' awareness of how to enhance their children's basic social skills and their impact on their social acceptance Train mothers in ways of dealing with situations that occur in public places
	Family and social relationships	Inform mothers of ways of dealing with their husbands Inform mothers of the necessity to strengthen their relationships with the rest of their children Introduce mothers to ways of developing human relationships based on love, respect, and appreciation of their children, which can only be achieved through close relationships with people surrounding the child such as, parents, brothers, sisters, and family
Psychological training	Psychological problems of mothers of children with Down syndrome	Help mothers to overcome the trauma they experience on discovering their child has Down syndrome Train mothers to use models for overcoming feelings of (shyness- sadness- distress-fear for the child's life- frustration- self-isolation- guilt- self-censure and mutual accusations-fear of child's rejection- discontent)
	Stressful situations that face mothers of children with Down syndrome and ways of dealing with them	Introduce mothers to the difficulties they will face bringing up their children Develop mothers' skills in dealing with difficult situations, such as (self-confidence -psychological strength-decision-making-problem-solving-time management) Mothers should be advised of the necessity to give their children time; listen to them, answer their questions, be patient while talking to them, and consider them in need of support and help
Educational training	Community services provided to children with Down syndrome	Mothers should be made aware of the community services available to children with Down syndrome Provide clarification and explanation to mothers on the entities that provide services to children, the costs, and location
	The educational and vocational future of children with Down syndrome	Inform mothers of the potential professional future of their children Encourage mothers to highlight and safeguard the development of the positive characteristics in their children Train mothers in ways to enhance their children's interactions Train mothers how to explain educational curriculums to their children using different teaching methods
Religious training	Religious guidance for mothers of children with Down syndrome	Provide help for mothers to accept themselves and their children's condition, and build their confidence to face life's challenges and crises Organize meetings for mothers with religious scholars, sheiks, or religious leaders in order to strengthen their beliefs and increase their faith in fate and patience
Finally: the assessment of the early intervention program for training mothers of children with Down syndrome		Assess the early intervention program Encourage mothers to continue practicing the skills they acquire during the program

The study concluded that, according to the proposals presented by mothers and those presented within the theoretical framework, as well as, findings of the study, and in light of the Saudi Vision 2030, the following proposal could be presented to initiate early intervention programs for rehabilitation of mothers of children with Down syndrome: The proposals are illustrated in Table 4.

## Conclusion

Disability is not the responsibility of the state only but a shared responsibility between the state, social institutions, and the family; In particular, mothers are within the family. All bodies, institutions, and centers involved in the care and training of people with disabilities should work together to assist them and their families. Institutions should encourage, support, and admit people with disabilities, improve their social status, and encourage them to become prominent and productive members of society. For this reason, we presented a proposed framework to initiate the role of early intervention programs used to train mothers of children with Down syndrome, believing that early intervention and training in its different forms are important in supporting mothers of children with Down syndrome.

## Limitation and recommendation

The limitations of the present survey are to be viewed with following key points. This study was done in the city of Riyadh in Saudi Arabia; hence, it needs to be cautious to generalize the results. Similar research needs to be conducted in other cities of Saudi Arabia, as sample sizes were small. This study would yield better result if more participants were recruited.

In light of the study findings, the following is recommended: Implement the activities, events and strategies planned in early intervention programs for mothers of children with Down syndrome. Provide mothers with continuous, intensive courses to help them improve the skills in how to deal with their children. Adopt practical methods to initiate the early intervention program for the rehabilitation of mothers of children with Down syndrome. In addition to organize cultural courses and educational guides, aimed at mothers of children with Down syndrome, to deal with their children and the difficulties. Training centers should undertake home visits to increase the interaction between mothers and their children. Increase mothers' participation in the Boards of Directors of training centers for people with disabilities. Facilitate the participation of mothers of children with Down syndrome in monitoring and surveillance of the quality of training at training centers.

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## Conflicts of interest

There are no conflicts of interest.

## References

1. Rajati F, Ashtarian H, Salari N, Ghanbari M, Naghibifar Z, Hosseini SY. Quality of life predictors in physically disabled people. *J Educ Health Promot* 2018;7:61.
2. Pakjouei S, Aryankhesal A, Kamali M, Seyedin SH. Experience of people with physical disability: Mobility needs during earthquakes. *J Educ Health Promot* 2018;7:80.
3. Ahmed Hammad M, Shaaban Awed H. Prevalence of cyberbullying and traditional bullying and their relationship to self-esteem among hearing-impaired adolescents. *Humanit Soc Sci Rev* 2020;8:167-78.
4. Sheidanik S, Savabi-Esfahani M, Ghamarani A, Erfani A. The association of psychological well-being and fertility intention in parents of children with intellectual disability: A foundation for reproductive education. *J Educ Health Promot* 2021;10:13.
5. Ogwezzy-Ndisika AO, Solomon T. Knowledge, attitude and practice of hand washing among mothers of children 0-59 months of age in Lagos Nigeria. *Univ J Public Health* 2019;7:52-8.
6. El-Beblawi E. *Development of Community's Awareness of the Disability, Categories, Causes and Prevention*. Riyadh: Rushd Bookstore; 2013.
7. Fatim DH, Jacques HM, Kouakou B. Early intervention in any diabete undiagnosed patient suffered from ocular and cardiovascular diseases in cardiology. *Universal Journal of Public Health* 2019;7(6): 227-232.
8. Shrit AA. *Behaviors and Fears of Children with Intellectual Disabilities*. Egypt: Horus International Foundation for Printing, Publishing and Distribution; 2009.
9. Abbas SA. Strategies for tackling the psychological stresses of mothers of children with Down syndrome, field study in damascus governorate. *J Study Sci Stud* 2019;41:641-63.
10. Sandra CK. *The Relationship between Family Functioning and Adjustment in Families with a Child with a Developmental Disability*. New York: City University of New York; 2016.
11. El-Sewedy A. *Down Syndrome Statistics Saudi Arab: Down Syndrome Family Support Group, Medical Genetics Site*; 2018. Available from: [http://www.werathah.com/down/awareness\\_campaigns/ds-statistics/](http://www.werathah.com/down/awareness_campaigns/ds-statistics/). [Last accessed on 2021 Jan 02].
12. Al-Kubaisy NF. Down syndrome: Causes, symptoms and most important methods of functional treatment. *J Educ Psychol Res Facult Educ Univ Baghdad* 2017;54:132-49.
13. Badghaish MK. *Obstacles of Early Intervention Programs in Arab Countries and Constraints that Face Persons with Special Needs Saudi Arabia: Blogger*; 2014. Available from: [http://etec9.blogspot.com/2014/03/blog-post\\_2913.html](http://etec9.blogspot.com/2014/03/blog-post_2913.html). [Last accessed on 2021 Jan 10].

14. Hammad MA, Alqarni TM. Psychosocial effects of social media on the Saudi society during the Coronavirus Disease 2019 pandemic: A cross-sectional study. *PLoS One* 2021;16:e0248811.
15. Hassan MA. Psychological Stress and Its Relation to the Needs of Untypical Parents (People with Motor Disabilities in Khartoum). Sudan: Khartoum University; 2009.
16. Tsibidaki A, Tsampanli A. Support networks for the Greek family with preschool or school-age disabled children. *Electronic Journal of Research in Educational Psychology* 2007; 5(2):283-306.
17. Al-Qamish MN, Al-Khawalda MA. Early Intervention for Children at Risk. Oman, Jordan: Dar Al-Thaqafa for Publishing and Distributing; 2014.
18. Lingeswaran A. Assessing knowledge of primary school teachers on specific learning disabilities in two schools in India. *J Educ Health Promot* 2013;2:30.
19. Tavakol K, Karimi M, Salehi K, Kashani F, Shakour M. Spiritual experiences of family members to cope with the challenges of childhood disability: A qualitative study in Iran. *J Educ Health Promot* 2018;7:121.
20. El-Khatib G, El-Hadidy M. Early Intervention, an Introduction in Special Education in Early Childhood. Oman, Jordan: Dar El-Fikr for Printing, Publishing and Distribution; 2009.
21. Azizifar A, Salamati M, Mohamadian F, Veisani Y, Cheraghi F, Alirahmi M, *et al.* The effectiveness of an intervention program -barton intervention program- on reading fluency of Iranian students with dyslexia. *J Educ Health Promot* 2019;8:167.
22. Al-Fawaer AG. Evaluate early intervention services of children with special needs in Oman by their parents. *J Arab Child* 2015;65:35-53.
23. Shirazikhah M, Mirabzadeh A, Sajjadi H, Joghataei MT, Biglarian A, Shahboulaghi FM, *et al.* Health services coverage: Physical access to rehabilitation facilities in Tehran compare with the country. *J Educ Health Promot* 2021;10:4.
24. Sadek FM. Towards more Integrated Programs of Caring, Educating and Qualifying Children with Down Syndrome Workshop of the Iraqi Frameworks Working in the Field of Intellectual Disability; 13-16/7/2008. Damascus, Syria: Damascus University; 2008.
25. Phillips BA, Conners F, Curtner-Smith ME. Parenting children with Down syndrome: An analysis of parenting styles, parenting dimensions, and parental stress. *Res Dev Disabil* 2017;68:9-19.
26. Mohammed AS, Eliwa SM, Zaki RA. Relationship between psychological well-being and coping strategies among family caregivers of children with Down syndrome. *Egypt J Health Care* 2020;11:155-72.
27. Sarimski K. Parenting stress in mothers of children with Down syndrome in preschool age/erlebte belastung von muttern von kindern mit downsyndrom im vorschulalter. *Prax Kinderpsychol Kinderpsychiatr* 2017;66:672-87.
28. Norouzi S, Moghaddam MH, Morowatisharifabad MA, Norouzi A, Jafari AR, Fallahzadeh H. Examining social-cognitive predictors of parenting skills among mothers with preschool and early elementary school-aged children. *J Educ Health Promot* 2015;4:96.
29. Mohamed HG. Learning Theories. Oman, Jordan: Dar Al-Thaqafa for Publishing and Distributing; 2007.
30. Al-Arar MH. Mental Health of Mothers of Children with Down Syndrome in the Gaza Strip and Its Relationship with Some Variables [Master's ]. Palestine: Islamic University, Gaza; 2014.
31. Allen G. Early Intervention: The Next Steps, an Independent Report to Her Majesty's Government by Graham Allen MP. London, UK: Cabinet Office; 2011.
32. Al-Zoubidy MS, Al-Shugairi OK. The effect of early intervention program 'Portage' to reduce stress among mothers of mentally handicapped children (Down syndrome). *J Univ Anbar Humanit* 2014;2:611-64.
33. Yehia KA, El-Sayed M. Activities for Ordinary Children and Children with Special Needs: Pre-School Education. Oman, Jordan: Dar Al-Massira for Publishing, Printing, and Distribution; 2014.
34. Parrish D, Phillips G. Developing an Early Childhood Outcomes System for OSEP: Key Considerations. Washington, DC: American Institutes for Research; 2003.
35. Summers JA, Marquis J, Mannan H, Turnbull AP, Fleming K, Poston DJ, *et al.* Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programmes. *Int J Disabil Dev Educ* 2007;54:319-38.
36. Turnbull AP, Summers JA, Turnbull R, Brotherson MJ, Winton P, Roberts R, *et al.* Family supports and services in early intervention: A bold vision. *J Early Interv* 2007;29:187-206.
37. Al-Qamish MN, Al-Ma'ayta KM. The Psychology of Children with Special Needs. Oman, Jordan: Dar El-Fikr for Printing, Publishing and Distribution; 2013.
38. Khayal MA. The effectiveness of early intervention program in developing receptive language and expressive language of children with Down syndrome. *Fac Educ J Menoufiya Univ* 2009;19:203-38.