



# Improve Autism Rehabilitation Services by Providing Solutions Based on the Perception and Experience of Parents and Providers: A Qualitative Study

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## Abstract

**Background:** Children with autism spectrum disorder (ASD) need a variety of services. One of the most essential needs of these children with ASD is the use of rehabilitation services. However, these services pose many challenges for these individuals. Providing strategies to solve these barriers is essential.

**Objectives:** The purpose of this study was to identify strategies to overcome barriers to using rehabilitation services and improve them based on the perceptions and experiences of rehabilitation service providers and parents of children with ASD.

**Methods:** This study was conducted with a conventional qualitative approach. Twenty-seven participants were selected from rehabilitation service providers and parents of children with ASD based on purposive sampling with maximum diversity. Data were collected through semi-structured face-to-face interviews. The interviews lasted from July to December 2020 for 20 to 60 minutes and continued until the data was saturated. Data were analyzed with MAXQDA 10 software.

**Results:** After the interviews, 1057 initial codes were extracted by deleting similar codes. Strategies for using rehabilitation services for these children with ASD were classified into 5 main categories and 20 subcategories, which are: Improving the level of knowledge and attitude, creating and strengthening a systematic support system, systematic rehabilitation policies, developing a comprehensive autism rehabilitation management program and facilitating access.

**Conclusions:** In previous studies, many challenges have been identified for all services for children with ASD. The findings of this study showed that considering facilitators to solve the existing challenges in order to use of rehabilitation services for these children with ASD and their families. Therefore, policy makers, service providers and managers need to be aware of the strategies collected and pay special attention to these issues. To achieve a more favorable situation, they should adopt and implement the necessary mechanism in the field of policy and planning, so that finally lead to fundamental steps to improve the rehabilitation services needed by children with ASD.

**Keywords:** Autism Spectrum Disorder, Strategies, Facilitators, Rehabilitation Services, Healthcare, Qualitative

## 1. Background

Autism spectrum disorder (ASD) is one of the most complex and unknown childhood disorders, which is also one of the most common developmental disorders (1-3). Autism spectrum disorder is a neurodevelopmental disorder characterized by deficits in social communication and limited interests and repetitive behaviors (4, 5). Autism has the fastest growth rate of any disability since 2009 (with an average annual increase of 10.9%) (6). Many challenges of parents start when they become fully aware of their child's type of problem and become aware of the complexities

and problems of diagnosis, treatment, rehabilitation, and medicine (7). As mentioned, most of these children with ASD have significant problems in many areas, including communication skills and social interactions. As a result, they must use some form of rehabilitation service to improve their skills (8). However, according to the evidence, accessing and using these interventions and medical care is challenging for children with ASD, their parents and rehabilitation providers (9-). Some of these problems are: Lack of knowledge about how to access and use the services they need, poor cooperation between parents and profes-

sionals in the fields of planning, implementation and evaluation of health services, as well as lack of regular rehabilitation services, insufficient insurance coverage and also lack of sufficient financial support from the government (9, 12-16). Also, several solutions have been mentioned in previous studies. such as: Increasing information and appropriate education (17), cost management, social and economic support (18) and improving the insurance situation for better access to rehabilitation care (19). The purpose of this study was to identify strategies to overcome barriers to using rehabilitation services and improve them based on the perceptions and experiences of rehabilitation service providers and parents of children with ASD.

Given what has been said so far, due to the special circumstances and needs of children with ASD, one of the most urgent needs of children with ASD is the use of rehabilitation to improve their function in all areas. We want to discover a phenomenon (looking for a solution for these people to access rehabilitation services) that is new and needs to be identified. On the other hand, due to lack of knowledge, as well as dependence on socio-cultural factors, complexity of the subject and lack of study in Iran with a qualitative approach and interviews with the autism rehabilitation community, the need to identify solutions in this area is quite clear. Also, based on the studies conducted in this field and the changes made in the establishment of various autism centers in recent years, as well as the various treatment protocols used, the research team decided to find solutions for using rehabilitation services for children with ASD.

## 2. Objectives

This article is expected to show the way to improve services, living conditions and ultimately improve their quality of life by providing the necessary evidence for rehabilitation managers and policy makers.

## 3. Methods

### 3.1. Study Design

This article is a qualitative research using conventional content analysis. The purpose of this study was to identify strategies to solve the challenges of using rehabilitation services based on the perceptions and experiences of rehabilitation service providers and parents of children with ASD. Researchers often use this method in studies that aim to describe a phenomenon without the use of predetermined theoretical categories and frameworks (20). In this way, concepts are extracted directly through individual interviews and then data coding. Qualitative content analysis is used to interpret the content of data that can be identified through a systematic classification process (21).

### 3.2. Setting & Participants

Twenty-seven participants were selected. Their selection was using purposive sampling. Purposive sampling with the meaning of selection from among therapists and parents who had experience of providing and receiving rehabilitation services to children with autism, more than three years. Data collection continued until theoretical saturation. That is, until more data is no longer available. More specifically, participants included 14 therapists (7 speech therapists and 6 occupational therapists) and 13 parents of children with ASD in Tehran. We selected these interviewees with maximum variety. For example, therapists were selected in the fields of rehabilitation related to autism (speech therapy and occupational therapy).

#### 3.2.1. Inclusion Criteria

- Willingness to participate in the interview
- Parents with children with ASD aged 3 to 15
- Parents who have experienced continuous rehabilitation services for at least one year
- Therapists who have provided rehabilitation services for children with ASD for at least three years

### 3.3. Date Collection

In this article, semi-structured and in-depth interviews with open-ended questions were used. "Then, if necessary, follow-up questions were used to gather more data." In subsequent interviews, questions were set based on previously extracted categories. For example, start with the following question and then adjust the other questions based on the person's answer. For parents with an open question like: "Could you tell us your suggested strategies based on your experience that you use when facing obstacles?" Or we ask therapists, "based on your experience, can you suggest strategies for overcoming challenges in providing rehabilitation services to children with ASD?" The participants of this study were 27 people included 14 therapists (7 speech therapy and 6 occupational therapy) and 13 parents of children with ASD that 9 participants were male and 18 female. Therapists had 3 to 30 years of experience in providing rehabilitation services for people with autism and parents with 3 to 7 years of experience in receiving rehabilitation services for their children. As well as parents had from primary to university education and therapists also had bachelors and doctoral degrees.

The purpose of the study was precisely explained to the interviewee and informed consent was obtained from the participants before the interview. The interviews lasted between 20 and 60 minutes, from July to December 2020. All interviews were recorded and then written verbatim for analysis. Data were analyzed with MAXQDA 10 software. At first, several training sessions were held by the research

supervisor to use the software. Interviews, simultaneous coding and joint meetings with the research team were conducted. After conducting several interviews, the initial classification began by transferring the relevant codes and naming the subcategories. This process continued until extracting and classifying the main categories in the software. After finalizing the categories and subcategories by activating the main categories and all participants, the citations for each category were selected from the retrieval window for transfer in the article (Table 1).

### 3.4. Data Analysis

Data analysis was performed using the inductive approach of Granheim and Lundman (22). This method consists of three steps. Prepare, organize and report (23). Open coding, classification and abstraction are three stages of organization.

### 3.5. Trustworthiness of Data

Guba and Lincoln have proposed four criteria of credibility, transferability, dependability and confirmability for trustworthiness of qualitative data, which is one of the most common criteria for evaluating the quality of qualitative study data and these criteria were used in this research. "To increase the validity of the data, stay in the data for a long time." The researchers spent about a year collecting the data. Participants confirmed the reflected interviews with a check at the end of the interview. To increase compliance, all stages of the study, especially data analysis, were documented. Therefore, other interested parties had access to the documents if needed for future studies. Provide rich findings with appropriate citations to increase transferability (22, 24-27). Finally, the process of conducting interviews, coding and data collection, and categories extraction was checked in several sessions by a research team familiar with qualitative studies.

### 3.6. Ethical Considerations

In this study, all relevant ethical principles such as: Obtaining informed consent from participants before the interview for interview and recording them, considering the right of participants to leave at any stage of the study and keeping information confidential were fully observed. This article is extracted from the master's thesis and has an ethics code approved by the ethics committee of the University of Social Welfare and Rehabilitation Sciences (USWR) (code: IR.USWR.REC.1399.144).

## 4. Results

Data analysis shows the results in the form of five main concepts and twenty sub-categories as facilitators of rehabilitation services in Table 2.

### 4.1. Improving the Level of Knowledge and Changing Attitudes of Stakeholders

The solution to the lack of knowledge, which is one of the challenges found in the field of autism rehabilitation in my previous study, is to improve the level of knowledge and attitude. Improving the level of knowledge and attitude should be considered in all people involved in the rehabilitation process, family and rehabilitation service providers, as well as other people in the community, to improve the quality of these services and increase public awareness. Therefore, this category has four subcategories: "Family awareness", "community awareness", "specialized training of service providers" and "use of specialists in autism". According to the findings discovered in this research, people can be informed in the following ways. For example, according to the results discovered in this study, increasing the level of public knowledge of the society is easily possible through media and social networks. But this awareness for service providers can be done in the form of courses and workshops. One of the rehabilitation service providers explained this solution as follows: "In fact, we should increase the awareness of families regarding the important role they play in treatment. In this way, we can advance the treatment of autism towards family-based treatments. Holding group meetings helps families a lot." (Participant 4)

### 4.2. Establish and Strengthen a Systematic Support System

Findings indicate that one of the important strategies proposed by many participants is to create and strengthen a systematic support system. This category has three subcategories: "Comprehensive insurance coverage", "providing financial support to the family" and "family psychosocial support".

Children with ASD and their families need a variety of support, such as financial support, for example expanding insurance coverage, and a variety of psychosocial support services, such as counseling, to reduce the harmful effects of the disorder. In this regard, one of the parents stated: "It is better if it's possible for the rehabilitation to be covered by special insurance, or the costs are such that the family pays them with special conditions (for example, in installments) or in a way that puts less pressure on the family. The cost to these children with ASD is very high, and in addition to the daily costs, the costs of treatment and rehabilitation are also very high." (Participant 3)

### 4.3. Systematic Rehabilitation Policies

Systematic rehabilitation policies are another effective way to help improve the quality of rehabilitation services for children with ASD. This category has 4 sub-categories: "Determining the structure and trustee of rehabilitation

**Table 1.** Examples of Codes, Sub-categories, Categories and a Topic of Narration Content Analysis

Meaning Unit	Condensed Meaning Unit; Description Close to the Text	Condensed Meaning Unit; Interpretation of the Underlying Meaning	Sub-theme	Theme
1. When parents come to me, they should know what my job is, what my specialty is, and know how productive and how effective my work is for their child.	It is important for parents to be aware of the role of the therapist and how to treat and the effects. It is also important that they are aware of their role and importance in treatment.	1. Contribute to the rehabilitation process of a child with autism spectrum disorder by increasing family awareness of the treatment process	Family awareness (family associations education, media culture, university education, family therapist counseling)	Improving the level of knowledge and attitude
2. In fact, we have to increase the awareness of families that they play an important role in the treatment, so that by increasing their awareness, we can move some treatment towards family-centered therapies.		2. Increase awareness of families about their role in the process of rehabilitating their children		
		3. The effectiveness of the family if the therapist provides sufficient information and shows the right way		
		4. Increasing parents' awareness of the therapist's specialty		
		5. Increasing parents' awareness of the effectiveness of therapist work on children with autism spectrum disorder		
		6. Lower family anxiety levels by getting the right information from the therapist		

**Table 2.** Strategies for Using Rehabilitation Services for Children with ASD

Categories	Subcategories
1. Improving the level of knowledge and changing attitudes of stakeholders	1. Family awareness
	2. Awareness of the community
	3. Specialized training of service providers
	4. Use of specialist therapists in the field of autism
2. Establish and strengthen a systematic support system	5. Comprehensive insurance coverage
	6. Provide financial support to the family
	7. Psychosocial support of the family
3. Systematic rehabilitation policies	8. Determining the structure and custodian of rehabilitation in the country
	9. Expansion of tele rehabilitation services
	10. Establish a systematic monitoring system
	11. Integration of autism rehabilitation policies in trustee organizations
	4. Develop a comprehensive autism rehabilitation management program
13. Changing the rehabilitation approach towards family-centered	
14. Establishment of comprehensive centers for autism	
15. Provide an autism rehabilitation program	
16. Team work promotion	
17. Establish systematic screening, diagnostic and evaluation systems	
5. Facilitate access to services and Proportional distribution of providers	18. Facilitate access to rehabilitation centers
	19. Proportional distribution of therapists and centers among the population
	20. Adaptation of community structure and rehabilitation clinics

in the country", "expansion of tele rehabilitation services", "establishment of a systematic monitoring system" and "integration of autism rehabilitation policy in the trustee

organizations".

The explanation of systematic rehabilitation policies brings these policies to the attention of legislators in dif-

ferent fields, which leads to the improvement of the overall situation of autism rehabilitation services in the country.

One therapist put it this way: "There must be a macro policy, and some of the macro-policy institutions of the country should come together and allow one of their own to do so." (25 participants)

#### 4.4. Create a Comprehensive Rehabilitation Management Program for Autism

Developing a comprehensive autism rehabilitation management program is one of the factors that can be effective in using rehabilitation services for children with ASD. This category includes 6 sub-categories: "Development of a comprehensive autism rehabilitation protocol", "change of rehabilitation approach to family-centered", "establishment of comprehensive autism rehabilitation centers", "presentation of autism rehabilitation program", "promotion of teamwork" and "establishment of screening systems with systematic diagnosis and evaluation". One of the service providers said: "Indeed, the Ministry of Health should have an autism spectrum disorder management program in the country in line with its policies. It should definitely be managed and planned throughout the country." (Participant 10)

#### 4.5. Facilitate Access to Services and Proportional Distribution of Providers

Facilitating access and adaptation of rehabilitation centers and the community can help families use rehabilitation services for children with ASD. One of the solutions suggested by many participants is to facilitate access. This category has three subcategories with the following titles: Facilitate access to rehabilitation centers; proper distribution of specialists and centers among the people; adaptation of community structure and rehabilitation clinics.

This requires environmental planning and adaptation in all places that children with ASD and their families use, including rehabilitation centers and other public places to attend. Therefore, the competent institutions should gather all the facilities in such a way as to facilitate the access of the families to the centers and the rehabilitation clinics should be suitable in such a way that the clients can easily use its facilities. Adaptation of the physical structure of society is very important for all people with disabilities, including children with ASD. Regarding the proper distribution of therapists and centers among the people, one of the participants from the group of therapists said:

"My other suggestion is to create distribution. Services should be distributed equally to all deprived areas and all places." (Participant 1)

## 5. Discussion

### 5.1. Strategies

The Morris et al. study in 2019 showed that due to the knowledge gap that exists between the knowledge of service providers and the knowledge of people with autism spectrum disorders, there is a need to inform, increase information and also educate these people (17). Hayat et al. survey found that there is a lack of knowledge about autism spectrum disorder among health care professionals in Saudi Arabia, and experienced professionals working with children with ASD can provide training nationwide (28). A study conducted in 2018 to determine the level of awareness of autistic parents showed that unfortunately there is a lack of knowledge and awareness about autism, and to fill this gap, awareness programs should be conducted to improve parents' knowledge about autism. Fortunately, most parents were willing to treat their children with ASD if diagnosed. However, only a few participants knew about autism rehabilitation centers (29). Doherty et al. also considered education and raising awareness about medical care as a facilitator of health care for people with ASD and other people with disabilities (30). The findings of all the above researches are consistent with the present research.

The results of the Kuru and Piyal study in 2018 showed that providing support and understanding to families of children with ASD as well as professionals can have a positive impact on children with ASD's health outcomes. Specialists must focus on meeting the needs of the family in order to plan and implement appropriate programs accordingly (31). In another study by Joyce et al., The complex needs of people with autism spectrum disorder were identified, which led to the need for regular use of services, and the financial resources supporting autism spectrum disorder services were identified (32). The concordance of the results of the above studies with the findings of the present study is evident.

Given the challenges in access, a 2020 study found that telemedicine provides an opportunity to facilitate early detection and referral for intervention for children with ASD (3, 33). Mosadeghrad et al. also pointed out: Health managers and policy makers should take special measures to control and prevent autism. Treatment, cost management and its social and economic support (18). The findings of the above studies somehow refer to the solution obtained in the present study regarding systematic rehabilitation policies.

A 2020 study by Liu et al. highlighted the importance of early screening for autism spectrum disorder. In this study, it was noted that early intervention clearly confirms a significant improvement in functional social behaviors



in toddlers (34). A study by Franz et al. in 2018 showed that early detection and intervention improves the outcome of child and family interventions and reduces long-term costs (35). The above researches point to the importance of screening, diagnosis, early intervention and overall planning of a comprehensive rehabilitation program in children with ASD and are consistent with the strategy obtained in the present study.

The Medford-Davis et al. study showed that insurance status affects access to rehabilitation care, which may also affect health outcomes (19). A 2020 study by Calleja et al. on adult access to health care for people with autism highlighted the importance of access to appropriate health care not only in meeting the needs of a person with autism, but also in better health care management (36). The concordance of the results of these studies with the results of the present study is clear.

### 5.2. Conclusions

Finally, the findings of this study showed there are solutions to solve the challenges of using rehabilitation services for children with ASD. Knowing these strategies will enable rehabilitation policy makers and planners to take more effective steps in providing autism rehabilitation services. The existing capacities of the country must be taken into account. In order to achieve the desired situation, the necessary mechanisms in the field of policy and planning must be adopted and implemented. These mechanisms lead to fundamental steps to improve autism rehabilitation services. We hope that the results of this study will pave the way for policy makers and managers to improve these services, so that they can modify their executive structures and develop comprehensive programs to achieve the human rights of these children with ASD, like other people, in the field of health and rehabilitation. Also, the findings of previous research showed that the executive structures as well as information in the country in the field of rehabilitation and treatment programs for children with ASD face many problems. Establishing a systematic monitoring system was the solution proposed in response to this challenge. On the one hand, the challenge of neglecting the structure and policy of rehabilitation puts the solution of systematic rehabilitation policies in front of the implementers of the project.

### 5.3. Limitations

In this qualitative study, participants were purposefully selected from rehabilitation service providers and parents of children with ASD. The following groups were not interviewed: Policy makers, managers, NGO officials and others. Service providers, such as specialist physicians, psychologists, and psychiatrists. It can be very useful to

consider it in future studies. Also, due to the prevalence of coronavirus and the prevailing conditions in the community caused by this disease, access and face-to-face interviews with all interviewees were among the limitations of the study.

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### Footnotes

**Authors' Contribution:** Study concept and design: K. A. and M. A.; acquisition of data: M. A.; analysis and interpretation of data: K. A. and M. A.; drafting of the manuscript: M. A.; study supervision: K. A. and M. K.

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**Informed Consent:** The purpose of the study was precisely explained to the interviewee and informed consent was obtained from the participants before the interview.

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