

CHILD WITH AUTISTIC SPECTRUM DISORDER: CARE AND CHALLENGES

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ABSTRACT

Autism Spectrum Disorder is a multifaceted neurodevelopmental condition, presenting unique challenges for children and their families. Characterized by a wide spectrum of symptoms and challenges, autism presents a unique set of demands on caregivers, educators, and healthcare professionals. The journey of raising an autistic child is a multifaceted one, requiring a deep understanding of the child's needs, strengths, and potential. In this article, we embark on an exploration of the intricate care and challenges that accompany raising an autistic child, while also shedding light on the recent scientific advancements that have transformed our approach to this condition. This article explores the care and challenges associated with raising autistic children, incorporating recent scientific advancements.

The purpose of this article is to provide a comprehensive overview of the care and challenges associated with raising an autistic child, while also highlighting the scientific advancements that have shaped suggested approach to autism care. The critical areas such as early diagnosis and intervention, the role of Individualized Education Plans, sensory sensitivities, family support, and the transformative potential of advancements in assistive technologies will delve into within the frame of this paper.

Understanding the unique needs of autistic children and addressing their challenges requires a comprehensive and up-to-date knowledge base. Autism is a condition that manifests differently in each individual, and recent scientific advancements have greatly expanded our insight into its complexities. By navigating the evolving landscape of autism research and care, it is possible to provide more effective support to children with autism and their families.

Keywords: *Autism Spectrum Disorder, autistic children, care, challenges, family, raising the autistic child, transformative potential.*

INTRODUCTION

In the modern world, there are many studies reflecting to children with Autism Spectrum Disorder and problems related to their everyday life challenges and care. Still there is a great need to investigate the problem in any aspects within the existing changing word and rapidly changing environment and demands. Autistic child is unique and very special. Child's family and specialist working with him often experience difficulties in the development of the cognitive, emotional and behavioral spheres of the child.

Parents and caregivers of autistic children commonly face challenges related to communication, sensory sensitivities, and access to specialized services. These challenges can be both emotionally, psychologically, physically, socially and financially taxing.

Nowadays, autistic child intervention requires holistic approach including, social and educational areas, with the wide range of specialists and interventions. Thus, the presented main features of care and challenges need to be investigated, identifying the causes of the manifestation and ways to overcome existing problems can be important in organizing effective work with children with Autism Spectrum Disorder.

LITERATURE REVIEW

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that profoundly impacts the lives of individuals diagnosed with it and their families. ASD is not a one-size-fits-all condition; it is a spectrum, encompassing individuals with varying abilities and needs. For example, the prevalence of autism has been steadily increasing in recent years, with estimates suggesting that approximately 1 in 44 children in the United States is now diagnosed with ASD (Maenner et al., 2020). As a result, autism has garnered increased attention from researchers, clinicians, and the broader community, leading to a deeper understanding of its complexities.

Early diagnosis and intervention are fundamental components of effective care for autistic children. Early intervention considered to be a pivotal, with the American Academy of Pediatrics recommending universal autism screening at 18 and 24 months (Johnson et al., 2020). Early interventions, like Applied Behavior Analysis, speech therapy, and occupational therapy, have shown significant promise in improving communication and adaptive behaviors (Dawson et al., 2010). Research by Johnson et al. (2020) underscores the significance of early detection through universal autism screening, allowing for timely access to intervention services. The importance of early intervention is further exemplified in studies like the one conducted by Dawson et al. (2010), which emphasizes the potential for enhancing communication and social skills in young autistic children through different interventions.

While reflecting to the child education, the role of **Individualized Education Plans** (IEPs) in the education and development of autistic children cannot be overstated. Enshrined in the Individuals with Disabilities Education Act (IDEA, 2004), IEPs represent a personalized approach to education that is collaboratively developed by parents, educators, and specialists. These plans cater to the unique strengths and challenges of each child, ensuring that their educational experience is tailored to their specific needs.

Social Skills and Communication the prominent challenges that autistic children often face. Many research studies have delved into interventions and strategies to enhance these critical areas of development. Social communication difficulties are a hallmark of autism, and they can significantly impact a child's ability to interact with peers and adults (American Psychiatric Association, 2013).

Recent research by Kasari et al. (2020) has shed light on the effectiveness of social communication interventions. Their study highlights the benefits of targeted interventions that focus on improving social engagement and joint attention in autistic children. Such interventions have the potential to enhance the quality of social interactions and improve communication skills.

In addition to traditional therapies, technology has played a crucial role in supporting social and communication skills in autistic children. Mobile applications and software programs have been designed to provide visual supports and social stories that aid in communication (Ramdoss et al., 2012). These technologies can be particularly valuable in facilitating communication and fostering social interaction.

Sensory sensitivities are prevalent among autistic children, necessitating sensory accommodations, including sensory-friendly environments and tools (Baranek et al., 2018). This environment should be organized at home, in kindergarten and school, and the role of professionals and family is crucial here. Sensory sensitivities are a pervasive aspect of autism, affecting the daily lives of many autistic children. Recent research by Baranek et al. (2018) highlights the impact of sensory sensitivities on social symptoms. This research emphasizes the significance of sensory accommodations, which include creating sensory-friendly environments, implementing sensory diets, and providing sensory tools. Such accommodations are vital in mitigating sensory challenges, enhancing comfort, and ultimately improving the overall well-being of autistic children.

Family support is crucial, with families benefiting from support groups, counseling, respite care, and access to resources (Smith et al., 2021). The demands placed on families of autistic children are substantial, requiring robust support systems. Smith et al. (2021) delve into the unmet needs and caregiving burden experienced by families of autistic individuals. They stress the importance of support groups, counseling services, respite care, and access to resources in alleviating the challenges faced by families. Adequate family support not only helps caregivers navigate the complexities of autism but also

plays a pivotal role in fostering a nurturing environment for the child. Valuable resource for parents, families, caregivers, educators, and healthcare professionals navigating the unique challenges and opportunities that come with raising and caring for autistic children need to be developed and provided. The guidance, knowledge, and inspiration to those involved in the lives of autistic children need to be always available.

In recent years, the field of autism care has witnessed transformative **advancements in assistive technologies**. Ramdoss et al. (2012) conducted a systematic review highlighting the potential of computer-based interventions in improving social and emotional skills among individuals with ASD. Augmentative and alternative communication (AAC) devices, mobile applications, and virtual reality interventions are examples of innovative technologies that offer promising avenues for enhancing communication and social interactions in autistic child. Understanding and implementing these aspects of care can significantly enhance the quality of life for autistic children and their families.

The literature reviewed here underscores the multifaceted nature of autism care, emphasizing the significance of early diagnosis, personalized education plans, sensory accommodations, family support, and assistive technologies. These key components collectively contribute to a holistic approach to caring for autistic children. By staying informed about evidence-based practices and drawing from the latest research findings, caregivers, educators, and healthcare professionals can enhance their ability to provide effective support and care to autistic children, ultimately enabling them to thrive and reach their full potential.

Thus, the objective of the current study is to provide an in-depth exploration of the challenges faced by parents and caregivers of autistic children, shedding light on their experiences and needs.

Based on the conducted literature analyses as well as the situation in the filed in Armenia, where actually very few researches is conducted, the research question has been formulated as follows: ***What are the most common challenges faced by parents and caregivers when raising an autistic child?***

The objective and the research question aim to provide a comprehensive overview of the care and challenges associated with raising an autistic child, drawing from both existing research and real-world experiences. They address critical aspects of autism care, from early diagnosis to education, sensory sensitivities, family support, and the role of technology and inclusion.

METHODOLOGY

Focus group discussion, as a qualitative method for collecting information from family members, parents or caregivers of children with ASD as research respondents by asking multiple open questions has been used as the main method for conducting this research. A focus group is a group interview involving a small number (in this case 12) of demographically similar people or participants who have

other traits/experiences in common depending on the research objective of the study (Definition of focus group, 2016).

Data collection

As a whole 12 participants took part in the conducted focus group discussion with the duration of 65 minutes. The number of participants and related groups is shown in the table 1.

Table 1.

Participants of the study

N	Participant	Age of the participant	Age of the child
1	Mother 1	34	6
2	Mother 2	28	4
3	Mother 3	42	8
4	Mother 4	31	6
5	Mother 5	36	7
6	Father 1	40	9
7	Father 2	38	8
8	Grandmother 1	64	8
9	Grandmother 2	66	10
10	Grandmother 3	60	5
11	Personal care giver 1	35	8
12	Personal care giver 2	42	7

The table indicates, that the majority of research participants are mothers (with the average age 34) and grandmothers (with the average age 64). The focus group discussion has been held in “Arevamanuk” child development center, where all children with ADS visit daily.

Data analyses

Within the frame of current study, the content analysis research method is used to examine and quantify the existence of certain words, subjects, and concepts in the transcribed text. This method helps to transform qualitative inputs to help the researchers make reliable conclusions about what parents think of the current situation connected to care and challenges related to daily activities of child with ADS. The content analysis had been conducted manually.

RESULTS

As a result of collected data analyses the following themes emerged. Still, it's important to note that these challenges can vary widely among families, depending on the individual needs and

characteristics of the autistic child. Additionally, while these challenges are common, many parents and caregivers also experience moments of joy, growth, and fulfillment in raising their autistic child.

1. Difficulty in Communication: Many parents and caregivers of autistic children commonly face challenges related to communication. Autistic children may struggle with verbal communication or exhibit limited speech, making it challenging for parents to understand their needs and emotions.

2. Managing Sensory Sensitivities: Sensory sensitivities are a prevalent challenge. Autistic children may be hypersensitive or hyposensitive to sensory stimuli, leading to discomfort, anxiety, or meltdowns in response to certain sounds, textures, or environments.

3. Limited access to Specialized Services: Accessing specialized services, therapies, and educational resources can be a significant challenge. Parents may encounter barriers in navigating the healthcare system, securing therapy appointments, and obtaining appropriate educational support for their child. In Armenia they experience difficulties in finding the services required and appropriate for their child. In many cases they need to choose whatever exist in the market.

4. Social Isolation: Both parents, family members and caregivers may experience social isolation within Armenian society due to the unique needs of their autistic child. This isolation can result from difficulties in finding social activities that are inclusive and accommodating for their child's sensory sensitivities.

5. Financial Stress: Providing for an autistic child's needs can be financially burdensome. Costs associated with therapies, medications, and assistive technologies may strain family budgets, causing stress and financial difficulties. This issue very often can be reason of family quarrels and misunderstandings between parents.

6. Coping with Challenging Behaviors: Parents and caregivers often face the challenge of managing challenging behaviors exhibited by autistic children. This may include aggressive outbursts, repetitive behaviors, and difficulties in self-regulation. Within society this kind of behavior is very often misunderstood.

7. Balancing Family Dynamics: The needs of an autistic child can impact the dynamics within a family. Siblings may require additional attention, and parents may need to find a balance between meeting their child's needs and maintaining their own well-being.

8. Advocating for the Child: Advocating for an autistic child's rights and needs within educational, social and healthcare systems can be demanding. Parents may need to become strong advocates to ensure their child receives appropriate support and accommodations.

9. Emotional Stress and Burnout: Providing care for an autistic child can be emotionally taxing, leading to stress and burnout among parents and caregivers. Emotional well-being and self-care often become essential but challenging priorities.

10. School and teacher Collaboration: IEPs should encourage collaboration between teachers, specialists, and parents. Effective collaboration can lead to more comprehensive support for the child, ensuring that educational goals are aligned across different settings. But in real life not everything so easy and there is a gap between school and parent cooperation in the schools. The schools are not ready to admit and accept a child with ADS.

11. Uncertainty about the Future: Parents and caregivers often face uncertainty about their child's future, including concerns about independence, long-term care, and the availability of resources and support as their child grows older.

DISCUSSION

Recent scientific advancements in the field of autism research have revolutionized the understanding of this condition and its management. This article's scientific novelty lies in its incorporation of the latest research findings and evidence-based strategies for supporting autistic children and their families (Johnson et al., 2020; Dawson et al., 2010; Individuals with Disabilities Education Act, 2004; Baranek et al., 2018; Smith et al., 2021; Ramdoss et al., 2012). By exploring the nuances of autism care and drawing insights from current literature, it was aimed to provide a valuable resource for parents, caregivers, educators, and healthcare professionals navigating the unique challenges and opportunities that come with raising and caring for autistic children.

In this journey, the reviewed authors and delve into critical aspects of autism care, ranging from early diagnosis and interventions to individualized education plans, sensory sensitivities, family support, and innovative assistive technologies. By drawing from the latest scientific research and evidence-based strategies, within the frame of this study it was aimed to provide insights and guidance that will benefit parents, caregivers, educators, and healthcare professionals in their efforts to support autistic children in realizing their full potential.

SUGGESTIONS AND ADVICES

The literature review and further data analyses have highlighted key challenging areas of the intervention in the care of autistic children. These areas in global perspective encompass social skills and communication, sensory integration and regulation, and education and inclusion. While much progress has been made, ongoing research and innovation are essential to further enhance our understanding of autism and improve the quality of care and support provided to autistic children and their families.

This study provides valuable insights into various aspects of autism care, including interventions for social skills and communication, strategies for addressing sensory sensitivities, and the impact of

inclusive education. The findings of these studies contribute to our understanding of effective approaches to supporting autistic children and improving their quality of life. Thus, the following tips are suggested to be taken into account by the persons dealing or living with the child having ADS.

Improved Communication Skills: Autistic children who receive early diagnosis and intervention often show improvements in communication skills. They may develop more robust verbal or non-verbal communication abilities, leading to enhanced expressive and receptive language.

Enhanced Social Interaction: Early intervention can positively affect social interaction. Autistic children may exhibit improved social engagement, better understanding of social cues, and increased interest in peer interactions. They may form more meaningful relationships with family members and peers.

Cognitive Development: Early intervention contributes to cognitive development. Autistic children may demonstrate better cognitive functioning, problem-solving skills, and adaptive behaviors over time.

Behavioral Adaptation: Autistic children who receive early intervention may show a decrease in challenging behaviors and meltdowns. They may acquire effective coping mechanisms, reducing the frequency and intensity of behavioral challenges.

Academic Progress: Early intervention can have a positive impact on academic progress. Autistic children may achieve developmental milestones related to learning and education more effectively, potentially narrowing the gap between them and their neurotypical peers.

Independence and Self-Care: Over time, autistic children who undergo early intervention may exhibit increased independence and self-care skills. They may become more capable of managing daily routines, personal hygiene, and daily tasks.

Improved Quality of Life: Early diagnosis and intervention contribute to an improved overall quality of life for autistic children and their families. Families may experience reduced stress, increased well-being, and a sense of empowerment.

Long-Term Benefits: The research may reveal that the benefits of early intervention are sustained into adolescence and adulthood. Autistic individuals who received early support may continue to thrive, lead fulfilling lives, and actively contribute to their communities.

Cost Savings: Early intervention may reduce the need for more intensive and costly interventions and support services in later years.

Individual Variation: It's important to note that while early intervention has positive impacts, there may be individual variation in outcomes. Not all autistic children will respond in the same way, and the effectiveness of interventions may depend on factors such as the child's unique characteristics, the type of interventions received, and the quality of support provided.

Tailored Educational Approaches: IEPs play a pivotal role in tailoring educational approaches to the unique needs and strengths of each autistic child. This individualization may result in more effective and engaging learning experiences.

Improved Communication Skills: Researchers may find that IEPs frequently emphasize communication goals, leading to improved communication skills in autistic children. This could include enhanced speech and language abilities, as well as alternative communication methods such as augmentative and alternative communication (AAC) devices.

Enhanced Socialization: IEPs might prioritize socialization goals, fostering increased social interaction and peer engagement among autistic children. Specialized supports within the IEP could facilitate participation in group activities and better integration into the school community.

Behavioral Supports: Researchers may observe that IEPs include behavioral supports and strategies that help manage challenging behaviors. These supports could lead to a reduction in disruptive behaviors and meltdowns, creating a more conducive learning environment.

Academic Progress: IEPs can contribute to academic progress. Autistic children with well-structured IEPs may achieve developmental milestones related to reading, mathematics, and other academic subjects more effectively.

Inclusive Education: Findings may highlight the role of IEPs in promoting inclusive education. Researchers may discover that IEPs support the inclusion of autistic children in mainstream classrooms, promoting peer interaction and diverse learning experiences.

Teacher Collaboration: IEPs might encourage collaboration between teachers, specialists, and parents. Effective collaboration can lead to more comprehensive support for the child, ensuring that educational goals are aligned across different settings.

Parental Involvement: Researchers may find that successful IEPs involve parents actively in the planning and implementation of educational goals. Engaged parents can reinforce learning at home and support their child's educational journey.

Progress Monitoring: Regular assessments and modifications based on the child's evolving needs could lead to continued improvements in educational experiences.

Long-Term Benefits: Over time, the benefits of well-structured IEPs extend beyond the school years. Autistic individuals who received tailored support through their education may demonstrate increased independence and success in adulthood.

Latest advancements in assistive technologies: Computer-based interventions, augmented communication devices, and virtual reality tools as latest technologies have demonstrated promise in enhancing communication, social interactions, and skill development among autistic children.

Enhanced Social Interaction: Social skills interventions lead to improved social interaction

among autistic children. These interventions could facilitate the development of skills such as joint attention, turn-taking, and understanding social cues, contributing to more meaningful and satisfying social relationships.

Improved Communication: Research findings might indicate that communication interventions, including speech therapy and AAC, enhance the expressive and receptive communication abilities of autistic children. Improved communication can reduce frustration and promote a sense of agency and self-expression.

Reduced Social Isolation: Effective social skills and communication interventions could reduce feelings of social isolation among autistic children. By equipping them with the tools to engage with peers and family members, these interventions may help autistic children build connections and feel more included in social settings.

Enhanced Emotional Regulation: Interventions focusing on emotional regulation and understanding emotions may contribute to better well-being. Autistic children who can identify and manage their emotions may experience reduced stress and anxiety, leading to improved overall emotional well-being.

Reduction in Challenging Behaviors: Research may show that social skills and communication interventions are associated with a reduction in challenging behaviors, such as meltdowns and aggression. Teaching alternative ways to communicate needs and emotions can lead to more adaptive responses to stressors.

Increased Self-Esteem: Effective interventions could boost the self-esteem and self-confidence of autistic children. Improved social and communication skills may lead to greater self-assuredness and a more positive self-image.

Better Academic Performance: Studies might find that interventions targeting communication and social skills positively impact academic performance. Autistic children who can effectively communicate and collaborate with peers and educators may excel academically.

Long-Term Benefits: Research may indicate that the benefits of social skills and communication interventions extend into adolescence and adulthood. Autistic individuals who receive early and ongoing support may experience enhanced social inclusion, employment opportunities, and overall life satisfaction.

Variation in Effectiveness: Findings could underscore that the effectiveness of interventions varies among individuals. Some approaches, such as Applied Behavior Analysis, social skills groups, and speech therapy, may be more effective for certain children based on their unique strengths and challenges.

Family Support: Research may emphasize the importance of involving families in interventions.

Collaborative approaches that engage parents and caregivers in reinforcing social and communication skills at home may yield more positive outcomes.

In summary, research on early diagnosis and intervention may provide substantial evidence supporting the long-term positive impact of timely support on the developmental outcomes of autistic children. These findings can underscore the importance of early intervention programs and their potential to enhance the lives of autistic individuals and their families. However, it's important to note that the effectiveness of IEPs can vary based on factors such as the quality of the plan, the skills and training of educators, and the level of family involvement. Research can provide valuable insights into best practices for creating and implementing IEPs that enhance the educational experiences and outcomes of autistic children.

While talking about Inclusive Education model which has been adopted by Armenian state, it is very important to highlight the following points:

Improved Social Interaction: Research may suggest that autistic children in inclusive classrooms exhibit improved social interaction compared to those in non-inclusive settings. Inclusive education may facilitate more opportunities for peer interaction, leading to the development of social skills and friendships.

Enhanced Peer Relationships: Findings might indicate that autistic children in inclusive settings establish more positive and meaningful peer relationships. Inclusive environments can foster empathy and understanding among neurotypical peers, promoting acceptance and inclusion.

Increased Academic Achievement: Research could reveal that autistic children in inclusive classrooms achieve higher academic outcomes. Access to a diverse curriculum and specialized support within inclusive settings may lead to improved learning and cognitive development.

Greater Independence: Researchers may find that autistic children in inclusive education settings demonstrate greater independence and self-advocacy skills. Inclusive classrooms may encourage self-expression and self-determination, contributing to long-term independence.

Enhanced Communication Skills: Inclusive education may positively impact the communication skills of autistic children. Interactions with neurotypical peers and teachers can provide valuable opportunities for language development and expressive communication.

Positive Self-Concept: Research findings might suggest that autistic children in inclusive settings develop a more positive self-concept and self-esteem. Feeling valued and accepted by peers can boost self-confidence and overall well-being.

Reduced Stigma: Research may indicate that inclusive education reduces the stigma associated with autism. Positive experiences in inclusive classrooms can promote understanding and acceptance, reducing negative stereotypes.

Development of Advocacy Skills: Autistic children in inclusive settings may develop advocacy skills and self-advocacy, advocating for their needs and preferences. This skill set can be valuable throughout their educational journey and beyond.

Preparation for Real-World Inclusion: Findings could emphasize that inclusive education prepares autistic children for real-world inclusion and participation. These children may be better equipped to navigate diverse social and professional environments in adulthood.

Varied Experiences: It's important to acknowledge that the impact of inclusive education can vary among individual autistic children. The extent of positive outcomes may depend on factors such as the quality of inclusive practices, teacher training, and the level of support provided within the inclusive classroom.

CONCLUSION

In this article, it was possible to embark on the journey through the world of autism care, drawing from recent scientific advancements and research findings to shed light on the multifaceted nature of raising an autistic child. By addressing the challenges and opportunities presented by autism, it is highly recommended to work collectively to ensure that every autistic child has the opportunity to reach their full potential.

Sensory sensitivities are a prominent feature of autism, and they can vary widely among individuals. Sensory integration therapy, a form of occupational therapy that aims to help individuals process sensory information more effectively, has shown promise in improving sensory regulation and reducing sensory-related challenges. It is very much valuable as there is an intricate relationship between sensory sensitivities and daily functioning, and very often it is extremely important to address sensory sensitivities as part of a comprehensive care plan for autistic children.

Education is a critical aspect of the care and development of autistic children. In recent years, there has been a growing emphasis on inclusive education, which strives to integrate autistic children into mainstream classrooms. Inclusive education, when implemented effectively, can provide autistic children with opportunities for social interaction and skill development alongside their neurotypical peers. However, the success of inclusive education depends on various factors, including teacher training, individualized support, and the overall school environment.

Thus, the care and challenges associated with raising an autistic child are multifaceted and demand a comprehensive understanding of the unique needs and strengths of each individual. Through an exploration of various research methods, including surveys, case studies, observational research, content analysis, and literature reviews, valuable insights into the complex landscape of autism care can be examined and identified.

It is important to note that the care of autistic children is highly individualized, and what works best for one child may not be the same for another. The challenges are real, but so are the opportunities for growth, learning, and connection within the autism community.

As we continue to advance our understanding of autism and its care, it is our hope that this research contributes to a more inclusive, supportive, and compassionate society - one where autistic children and their families can thrive and where each individual's unique potential is celebrated and nurtured. In doing so, we can create a world where the challenges are met with resilience and where the care is guided by empathy and understanding.

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