



# Parents' Voices on The Advocacy of Children with Autism When Facing The Puberty

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**Abstract.** Children with autism need various accesses to health and educational support and services. Parents often face various challenges in providing these accesses, especially when their children face puberty. These challenges can have an impact on high levels of parental stress which in turn has an impact on parents' mental health and well-being. Parental advocacy is crucial in raising children with autism. Advocacy can be an active coping strategy for parents of children with disabilities. However, not all parents advocate effectively for children with autism. This study explores how parents of children with autism engage in parental advocacy, the challenges they face, and the advocacy skills that have been developed by parents especially when their children face puberty. This study employed an exploratory, qualitative study. Participants in this study include ten parents of children with autism. An interview was applied in this research to collect the data. Braun and Clarke's thematic analysis was used to analyze the data. The result showed two major themes, including (1) seeking help and diagnosis and (2) parental advocacy skills. Based on the results of this study, it can be illustrated the challenges faced by parents, the parental advocacy process, and the advocacy skills developed by parents of children with autism when dealing with puberty matters for their children.

**Keywords:** Advocacy, Children with Autism, Parents' Voices, Puberty

## 1 Introduction

Autism spectrum disorder (ASD) is manifested in early childhood and is characterized by difficulties in reciprocal social interactions and limited communication, repetitive, and stereotyped behaviors and interests [12]. ASD is experienced by 1 in 110 children worldwide [20]. When a child is diagnosed with autism, parents often experience a wide range of emotions from sadness, worry, disappointment, relief, and everything in between. Every day parents face various challenges when raising a child with autism. These challenges may stem from the inability of their children to take care of themselves, challenges from the aspect of education for children, and the stereotypes and

stigma of having children with autism [10]. These challenges can lead parents to experience a high level of stress [17] and the stress level of parents who have children with autism is higher than parents of non-disabled children or children with disabilities other than autism [11].

Parenting a child with autism emerges stress, even when the child enters puberty. In addition, children with autism have difficulty receiving verbal information and are more receptive to visual stimuli in learning [14]. This difficulty has an impact on how children express themselves sexually [13]. It is often found that children with autism express their biological needs, such as masturbating, in public places [16]. This condition can cause parents more stressed if they do not immediately seek help from others. Parents need to report their perception of their child's health condition to professionals and paramedics to receive a diagnosis and access appropriate services [19].

Research shows that psychological outcomes for parents are generally determined by coping responses with action-oriented strategies [22]. Parents explain that advocacy is an important coping strategy to get them moving forward by redirecting negative emotions into positive outcomes [3]. However, parents sometimes feel reluctant to advocate for children with autism because of the lack of essential knowledge regarding services and support for them.

Parental advocacy is an action taken by parents for children with disabilities to get services that are following the needs, strengths, and choices of children [21]. Advocacy is important for several reasons [8]. First, it is important to communicate the perceptions and concerns of parents, besides parents also need solutions. Second, parents need to be proactive to ensure that the needs of children with autism are in line with the family, school, and community. In addition, parents need advocacy for service, support, acceptance, and inclusion. It is also important that children can learn to advocate for themselves, by developing self-advocacy skills. Depending on the child's age and abilities, self-advocacy skills can be useful when children determine preferences at home, communicate coping strategies at school, and provide understanding to other employees about accommodation needs on the job. In addition, self-advocacy skills are also crucial for parents to recognize the importance of advocating for themselves and providing opportunities for self-care.

The need for advocacy may vary due to the age of the child and the need for a service. In particular, the need for parents to advocate is related to the variety of financial mechanisms, complexity, waiting lists for services, disability policies, and time lags for proving the eligibility of services [6]. Parents are natural advocates because they are committed to the welfare of their children. Advocacy skills for parents with autism include understanding autism, using clear and effective communication, being organized, and being able to manage difficult situations [19].

Several factors that influence parental advocacy include economic status, education and skills, time commitment, the severity of the child's condition, and the age at which the child is diagnosed [1]. Economic status and family income can affect the level of parental empowerment and their ability to advocate for children with autism [19]. Furthermore, to advocate effectively, parents need to educate themselves to gain an understanding of the social, and economic environment and become familiar with services for autistic children, legislation, and financial problems [9]. The severity of autistic

children also has an impact on the conceptualization of autism in parents which in turn affects their ability to advocate [7].

Not all parents are in a position to effectively advocate for children with autism. Parents explain that advocacy takes time, effort, and energy [3]. Most parents of autistic children who come from low economic status have difficulty finding services for autistic children. Even though parents from low socioeconomic backgrounds are actively involved in advocacy, they have limitations due to work schedules, lack of financial resources, language barriers, and a complete understanding of children's educational rights [15].

The stigma about children with autism received by parents made them feel guilty about their autistic child's condition and masked the diagnosis of autism in children [19]. It also happens to parents who have autistic children who have reached puberty. Parents and families face many problems such as constant pressure, a greater need to care for children who are entering puberty, providing support and accommodation in education [12], as well as in terms of sexual education for children. Moreover, autistic adolescents tend to develop inappropriate sexual behavior, such as masturbating in public areas, touching private body parts of themselves or others in public places, or commenting using inappropriate sexual connotations [2]. Therefore, parental advocacy skills are increasingly crucial for parents to have. This study aims to explore parents' voices in advocating for children with autism when they face puberty.

## **2 Methods**

An exploratory qualitative study was used in this study. Participants in this study consisted of ten parents of children with autism who had entered puberty (4 fathers, and 6 mothers, aged 40 to 50 years old), who were selected using a purposive sampling strategy. The data collection technique used was interviewing through face-to-face focus group discussions. Participants were asked to describe the experiences faced when children with autism went through puberty, the advocacy that the parents had done, and the advocacy skills the parents had mastered. The interviews conducted were recorded by audio and transcribed verbatim. This verbatim transcript was analyzed using thematic analysis using Braun and Clarke [5], consisting of stages of identification, analysis, and description of the themes.

## **3 Results**

Three major themes were identified in this study, including (1) seeking help and diagnosis and (2) parental advocacy skills. Two major themes and sub-theme can be seen in Table 1.

**Table 1.** Main themes and sub-themes identified from transcribed verbatim

Main themes	Sub-themes
Seeking help and diagnosis	Challenges faced by parents; seeking help and diagnosis; raising awareness
Parental advocacy skills	Active involvement; self-aware in advocacy

### 3.1 Theme 1: Seeking help and diagnosis

#### Challenges faced by parents.

All participants stated that they faced challenges when children with autism began to enter puberty. Participants feel worried when children face puberty, such as how parents communicate about the changes that occur during puberty, how children communicate about their puberty experiences, children's behavior when outside the home, children's emotions are still unstable, and the possibility of children hurting him/herself.

"When my child faces puberty, if the child has a wet dream, the child should tell me so that he can take a shower immediately. But sometimes the kids don't tell us so we have to look at the sheets." (Participant 1)

"My son is 18 years old, but until now his emotions are still very high. If he hears noises he doesn't like, such as the sound of birds, or the sound of chickens, he gets angry and sometimes immediately slams the door or sometimes crashes into the door. Sometimes he banged his head against that door, and it still happens today." (Participant 5)

The emergence of maladaptive behavior in children also makes participants worry about their future, such as children rubbing their genitals in public places. In addition, there is one participant who is worried about the future of their children, especially related to marriage and building relationships with the opposite sex.

"My son went through puberty after entering school, he looked like he was on his stomach and then he rubbed his genitals. Then the sheets were stiff and wet with water. If his emotions tend to be the same, yes, but I shiver because sometimes he suddenly bumps into me and kisses my breasts." (Participant 2)

"I dare not imagine that he is attracted to beautiful girls. For example, I have a daughter-in-law, my son is married, then I do not dare to imagine, whether my child will marry or not, it is hard for me." (Participant 4)

#### Seeking help and diagnosis.

The advocacy process is initiated by parents when they seek help and diagnose their child.

"My son is now diagnosed with autism from the age of 2.5 years, from the age of zero to 2.5 years is normal. Around the age of 2.5, everything is gone. Eye contact is lost, and all communication is lost. Now he is almost 15 years old." (Participant 6)

One of the participants sought help from doctors and foundations for children with disabilities, even though the family did not believe in the child's diagnosis and assumed that his child was being abused by someone else.

“So at that time my son was normal at first, and was able to speak, but then he got bronchitis and after coming home from the hospital he was silent, there was something different from my son. I was a little suspicious of the condition of my child, so I was advised to go to the Foundation for Education for Children with Disabilities (YPAC), but I didn't do it because my husband and in-laws believed that my son had been cursed.” (Participant 2)

The diagnostic process is a struggle. Participants felt that they were struggling alone because of their distrust of the diagnosis, their husbands did not believe them, and their families did not support them.

“At that time I was struggling alone, only after the child was 14 years old, my husband wanted to take the child for therapy in the hospital.” (Participant 2)

### **Raising awareness.**

Parents want to increase awareness, especially in recognizing the signs of autism, including when children enter puberty. Participants recognized the signs when their child would be sexually aroused.

“If my child is aroused, he will play with the ball. And the ball was raised and swayed so.” (Participant 10)

In addition, participants also studied the characteristics of autistic children and how to communicate effectively with them.

“Our child is already communicative, but not as optimal as Mrs. M (child of Participant 7), so we have to look into her eyes, sit on the same level, then we can talk.” (Participant 8)

“But my child's condition is still very limited communication. In other words, we have to use gesture language, this is not allowed, it has to be like this.” (Participant 10)

One way to increase awareness is to provide understanding for family members (wife/husband, siblings) about the condition of autistic children.

“So far, I have no idea what the future will look like, nor can I go too far. Next, suppose one day we die, who will the child be with? Even his siblings do not necessarily want to be included in the care. So all this time, I got used to communicating with his wife and siblings, treating him (autistic children) well, indeed his condition is like that, but let's assume this child is normal.” (Participant 6)

“At home, we have a habit, we have deliberations and sitting together discussing anything. The first one, of course, discusses the condition of Mas M (autistic child), we give an understanding that when we come out, God has given us an angel. He will help us later, now we help him. So if we love him, Allah will also love us.” (Participant 8)

### 3.2 Theme 2: Parental advocacy skills

#### Active involvement.

Parents are active in seeking insight into the signs of their child's puberty. Parents also provide understanding regarding appropriate sexual behavior and what is inappropriate in public spaces.

"Indeed, I got used to it from the start, children have been given freedom, if you want to do something like that (sexual behavior), you can do it in your room, not in public spaces." (Participant 6)

Parents are actively involved in caring for their autistic children and involve other family members to accompany their children when they need help.

"When he had signs of pubic hair growth, we asked his twin sister to accompany him to bathe. So he can't be 100% independent so he still needs assistance. We involve siblings to accompany our autistic child and when Mas F (his autistic child) has started to grow pubic hair, then we give him some understanding." (Participant 8)

#### Self-aware in advocacy.

Parents have learned the skills essential to be able to advocate effectively. One of them is having the self-awareness to know their rights, children's disabilities, and available services. Parents seek help from school teachers and therapists.

"I am very active in seeking help for children. I'm sure if I try there will be a way." (Participant 9)

"Initially last month my son was circumcised, I then counseled the teacher at the school. My child wants to be circumcised, what should I do? Then the teacher gives advice, try to give the child information first, then be given an idea of what the process will be like." (Participant 7)

"We often talk to our therapists about how to deal with a child like this. When asked by the therapist, our child was very obedient, he was told to do this and that he wanted. But when asked to eat fruit at home, my child vomits. Even though at the therapist's place he wanted to eat fruit. I don't know what the difference is in the knowledge the therapists have, how come my child can eat fruit." (Participant 2)

## 4 Discussions

The purpose of this study was to explore parental advocacy efforts in the journey of raising children with autism when facing puberty. Based on the results of the study, it was found that the stages of parents in advocating for children, namely (a) facing challenges and obstacles when caring for autistic children who are in puberty; (b) seeking help and diagnosis; (c) raising awareness; (d) develop advocacy skills, including active involvement and self-aware advocacy.

The challenges faced include concerns about their future, concerns about building relationships with the opposite sex, children's behavior outside the home, unstable emotions, and inappropriate sexual behavior in public spaces. Facing these challenges, par-

ents then seek help and diagnosis, including teachers and therapists. Parents also increase awareness by recognizing the signs when a child enters puberty, recognizing when a child is sexually aroused, recognizing how to communicate effectively with children, and providing understanding about the child's condition to other family members. Furthermore, parents develop advocacy skills including being actively involved in seeking insight into the condition of their child's puberty and providing understanding to children regarding appropriate and inappropriate sexual behavior in public spaces. Parents also begin to have the self-awareness to fulfill their rights, disabilities, and services available for their autistic children.

The results of this study are supported by other studies. Parents identify the obstacles faced in their advocacy efforts including the lack of knowledge and support from service providers and others [4]. Understanding the advocacy process and the steps that need to be taken can help parents prepare and develop their advocacy skills [19]. Raising awareness about autism, educating others, and supporting other parents are important things for parents to follow [18]. In facilitating the role of parents' advocacy, service providers need to encourage parents to get social support.

## 5 Conclusions

This study explores parents' voices in advocating for autistic children when facing puberty. Every parent of an autistic child must face obstacles and challenges in raising their child, especially when their autistic child is facing puberty. After identifying the challenges and obstacles faced, parents seek help and diagnosis from other parties. Parents also increase their understanding of the signs that appear when children experience sexual arousal and contribute to providing understanding for other family members so that they can jointly accompany children with autism through puberty. Along with increasing parental awareness, parents also develop advocacy skills, such as being actively involved in finding out the signs of puberty in children and how to deal with them and parents having the self-awareness to seek support services and better understand their rights and children's disabilities.

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