

# Exploring the Lives of Mothers Raising Children with Autism Spectrum Disorder in Japan

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## Abstract

**Background:** Examining the lives that mothers experience and build will allow us to deepen our understanding of children with ASD and their mothers and facilitate developing support methods. The study aimed to examine the lives of mothers raising children with autism spectrum disorder (ASD) and investigate their sources of support. **Method:** We conducted a qualitative inductive study using semi-structured interviews to identify characteristics of the lives that mothers have created. **Results:** Semi-structured interviews were conducted with 11 mothers having children with ASD. The analysis comprised three stages of coding and yielded eight categories. The lives of these mothers contained three themes: preoccupation with parenting children with ASD and their siblings; evolving mother; and using social resources. Mothers engaged in “assessing the characteristics, growth, and changes in the child with ASD”, had a “preoccupation with parenting children with ASD”, and were “thinking about the future of the child with ASD”, and “having goals and plans for parenting” while having “consideration toward the child’s siblings”. During this process, mothers experienced “changes in perspective or approach” and created lifestyles while “receiving help from people around them” and engaged in the “use of social resources”. **Conclusions:** To avoid becoming preoccupied with parenting and being burdened by their lifestyle, mothers require social support to monitor their perceptions. Furthermore, the utilization of social resources requires the supporting individuals to understand the characteristics of children with ASD, provide appropriate information, and assist in decision-making.

## Keywords

Autism Spectrum Disorder, Mothers, Raising Children

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## 1. Introduction

Autism spectrum disorder (ASD) is a brain dysfunction characterized by persistent deficits in social communication and interpersonal interaction, as well as restricted and repetitive patterns of behavior, interests, or activities [1]. Symptoms include a preference for solitary play from childhood, difficulty making eye contact, lack of interest in other people, delay and bias in verbal expression, difficulty with mutual verbal exchange, abnormal preoccupation with specific behaviors or activities, resistance to change, and obsession with specific things, which can all vary by extent [2]. In Japan, most children diagnosed with ASD at an early age are enrolled in special needs classes in elementary schools. The Ministry of Education, Culture, Sports, Science and Technology reported that 99,000 children with ASD and emotional disabilities were enrolled in special needs classes in 2019, and this number is increasing despite the declining birth-rate.

The U.S. Centers for Disease Control and Prevention reported that the prevalence of ASD in eight-year-olds in the United States increased to 23.0 per 1000 in 2018, compared to 6.7 per 1000 in 2000 [3]. In general, mothers of children with ASD feel that “something is different” from the age of 1 to 2.5 years but do not recognize it as a sign of ASD [4] [5]. A definitive diagnosis takes time because it is based on the child’s detailed growth and development characteristics. Therefore, diagnoses are typically formed at around 6.5 - 7.2 years [4] [6]. Until a diagnosis is made, mothers of children with ASD raise their children with suspicions and anxieties about their disabilities [4] [7].

As ASD children have difficulty making eye contact and sharing interests with others, their mothers experience difficulties forming a mother-child relationship; this is related to “not being recognized as a mother” and “inability to exchange words” [8]. Moreover, mothers experience panic and an abnormal preoccupation with activities, leading to difficulties with childcare (eating, dressing, using the toilet or care for excretion, etc.).

Parenting stress in mothers of children with ASD is significantly higher than those of typically developing children, children with neurodevelopmental disorders, and children with Down syndrome [9] [10] [11] [12]. The diagnostic delay in children with ASD also results in higher stress and depression levels in the mothers [13]. Previous research shows that parenting stress in these mothers is high because of behavioral characteristics related to eating and sleeping disorders in children with ASD [14] [15] [16]. Furthermore, these mothers experience stress and difficulties uniquely associated with raising children with ASD, such as the emotional experience of learning about the child’s diagnosis [17], mothers’ conflicted feelings when the child attends school [18], and challenges mothers face when discussing the disability with their children [19]. Psychological difficulties of mothers having children with ASD are a central theme in previous studies.

We also explored the life structure of siblings of children with ASD in previous research. Siblings experience difficulties in building relationships because it is not easy to understand the unique world of children with ASD. However,

mastering a sense of “reasonable” distance allows siblings to avoid getting caught up in this unique world and build their own lives while “protecting” themselves [20] to ensure safety and security related to the presence and respect of family members. The stress experienced by mothers of children with ASD is assumed to reduce their ability to raise children. Nevertheless, it can be inferred that mothers also strive to protect themselves. Previous studies have clarified mothers’ parenting process with children having pervasive developmental disorders [21], but no studies have explored the parenting process in mothers of children with ASD. Family goals during parenting and educational periods include providing healthy childcare for infants, assuring school attendance considering the children’s abilities and aptitudes, and maintaining family unity [22]. Examining the lives that mothers experience and build will allow us to deepen our understanding of children with ASD and their mothers and facilitate developing support methods. This will help improve mothers’ parenting abilities, strengthen family function, and improve the quality of life.

## **2. Methods**

### **2.1. Research Objective**

We aimed to examine the lives of mothers having children with ASD and investigate their sources of support.

### **2.2. Research Method**

We conducted a qualitative inductive study that analyzed semi-structured interview data pertaining to the lives that mothers have created. We defined mothers as subjective beings, who, while being influenced by their surrounding environment, act according to their own will and judgment.

### **2.3. Recruitment and Enrollment of Study Participants**

Participants included nurturing and educated mothers living with a child diagnosed with ASD. Participants should communicate linguistically in Japanese.

Participants were recruited with the cooperation of an education and support facility for children with disabilities attended by children with ASD. First, we asked for their willingness to cooperate in an interview during the preceding questionnaire survey. Then, their contact information was obtained, they were contacted, the interview survey was explained, and mothers who were willing to cooperate were enrolled.

### **2.4. Data Collection**

We focused on the developmental status of children with ASD, the process of interaction between mothers and children with ASD, and the parent and child environment to understand the lives that mothers created. This comprised the relationship and environment between the mother and surrounding people, including the mothers’ perceptions, thoughts, and responses in this context. The

interview collected data on: 1) the basic lifestyle of children with ASD, how to respond to them, and ideas and policies for responding to them; 2) the communication development status of children with ASD, how to respond to them, and ideas and policies for responding to them; 3) emotional ties with children with ASD; 4) family relationships and emotional ties; and 5) the support that mothers receive. Interviews were conducted in quiet private rooms, and care was taken to avoid visits by others. The interview was recorded with the participant's consent; field notes taken during the interview recorded keywords spoken by the mother and their facial expressions. The data collection period was from December 2016 to October 2018.

### 2.5. Data Analysis

We transcribed the recorded interviews verbatim and attempted to grasp participants' words comprehensively. We used NVivo software (Japanese version) to code for a meaningful context and develop labels that appropriately expressed the content. When we were unsure about coding and labels, we consulted the interview field notes. Open-coded subcategories (two levels) were set according to label similarity. Subsequently, we determined the relationships between subcategories and extracted categories (three levels).

The collaborating researchers had experience with research on children with developmental disorders and their mothers and pediatric nursing. All researchers confirmed the analysis content and agreed on the analysis results. Furthermore, we asked the mother of a research participant, who was also a representative of an association of parents of children with ASD, to check the analysis results. We made this request based on the judgment that, as a representative of the parents' association, they understood the situation, possessed information on many mothers, and could offer an objective opinion. Regarding parental involvement role subcategories, they stated that there is flexibility in parent roles in each family, but they believed that the compiled results were convincing.

The research was approved by the institutional review board of the affiliated university. Prior to the interviews, we explained the objective of the research in writing and verbally and informed potential participants that their research cooperation was voluntary. They could withdraw at any stage in the research and were assured that their personal information would be protected. Participants then provided written consent to participate.

## 3. Results

Interviews were conducted with 11 mothers who provided consent to participate. We determined that 10 participants would be sufficient for a homogenous population; therefore, 11 participants were considered appropriate [23]. The ages of children with ASD ranged from 3 to 12 years. **Table 1** shows the attributes of mothers, family context, and characteristics of the children with ASD. All interviews were conducted by the same researcher. The interview duration ranged from 28 to 73 minutes, with an average of 52 minutes.

**Table 1.** Mothers' attributes, family context, and characteristics of children with ASD.

Mother	Age (years)	Family members other than mother ( <b>ASD child is in bold</b> )	ASD child characteristics
<b>a</b>	30	Mother <b>Young daughter</b>	Delayed speech, restless
<b>b</b>	40	Husband Baby boy <b>Pre-school son</b>	Delayed speech, hyperactive
<b>c</b>	30	Husband Father Mother <b>Pre-school son</b> Elementary school age daughter	Child says only what they want to say
<b>d</b>	30	Husband Father Mother Young twin daughter <b>Pre-school son</b>	Delayed speech, interacts with friends only when there is a need
<b>e</b>	40	Husband Pre-school (son) <b>Elementary school age son</b> Junior high school age daughter High school age son	Does not sustain conversations, interacts with friends only when there is a need
<b>f</b>	30	Husband <b>Pre-school son</b>	Delayed speech, interacts with friends only when there is a need
<b>g</b>	30	Husband <b>Pre-school son</b> Elementary school age daughter	Child says only what they want to say, interacts with friends only when there is a need
<b>h</b>	40	Husband <b>Pre-school son</b>	Does not sustain conversations, hyperactive, no interest in other children
<b>i</b>	30	Husband <b>Pre-school son</b> Two elementary school age daughters Junior high school age son	Does not sustain conversations, restless, interacts with friends only when there is a need
<b>j</b>	30	Husband <b>Pre-school son</b>	Does not sustain conversations, restless, interacts with friends only when there is a need
<b>k</b>	30	Husband Young daughter <b>Pre-school son</b>	Delayed speech, restless, interacts with friends only when there is a need

ASD, Autism Spectrum Disorder.

We extracted 37 subcategories from 542 codes, and eight categories were derived from their relationships, which were further clustered into three themes: 1) raising children with ASD and their siblings, 2) evolving mother, and 3) using social resources. **Tables 2-4** show the categories, subcategories, and examples of mothers' narratives.

### 3.1. Preoccupation with Parenting Children with ASD and Their Siblings

In the following section, categories are indicated with “ ”, subcategories with < >, and codes with ‘ ’. Through comparisons with siblings and surrounding children, mothers developed concerns about the children's developmental delays and began to <suspect a disorder>. After their children were diagnosed with ASD, mothers continued <using trial and error in parenting> while experiencing a <parenting strain> and <struggling desperately with parenting>. Meanwhile, they could not sufficiently care for their other children, which they indicated in comments such as ‘I am so busy with my older child that I have no time to take care of their brother who is 4 years younger than them’ and <concern and empathy for the child's siblings.>, wondering whether they are burdening the siblings. The mothers considered growth and schooling of the children with ASD, im-

pacts on siblings, and their future lifestyles. Consequently, they parented using trial and error, relying on the aspects they valued in their current lifestyles. The categories and definitions are given below.

**Table 2.** Preoccupation with parenting children with ASD and their siblings.

Category	Subcategory	Example codes	
Assessing characteristics, growth, and changes of the child with ASD	Assessing child's growth and changes	Their range of interest expanded, and it feels a little easier to play with them. (b)	
	Comparing with other children	Compared to their sisters, they were slower to respond to language. I think it was their understanding of language rather than the production of it that was delayed. (d)	
	Assessing child's characteristics	There are problems, like how they become fixated on things; thus, they have considerable trouble sharing their toys and sometimes shoves others. Things like that. (b)	
	Struggling desperately with parenting	I feel like it is my job to teach my children to become independent and take care of themselves. I am really struggling to do this. (e)	
	Parenting techniques that do not work well	It really hurts, is really hard, when they do things like cover their ears. (b)	
	Parenting techniques that work well	They will try a little bite of the coating on fried chicken, for example. Now they will try eating things they choose themselves. (h)	
	Getting angry with the child	I know that it is good to praise them when they do even a single thing right, but I feel conflicted. I compare them to other kids, and I get sad and become angry at them. (b)	
Preoccupation with parenting children with ASD	Doubting the disorder	It was when they were 3. They could not say even a single word and played differently from other kids, so I looked it up online and thought they probably have ASD. (j)	
	Using trial and error in parenting	I'll say, "it is the rule," and sometimes, maybe once in a hundred times, they'll follow the rules easily, but they just will not do it every time. (k)	
	Parenting strain	I feel like I have failed at things like communicating with the daycare and I have to accept it. (d)	
	Effects on siblings	I am so busy with my older child that I have no time to take care of their 4-year old younger brother. (e)	
	Concern and empathy for the child's siblings	Concern and empathy for the child's siblings	It is nice when they help out, but I do not want it to be a burden on them. (c) They stay calm when their brother steals their toys. (b)
		Getting help from siblings	They will take care of them, for example, waiting for them. (c)
	Thinking about the future of the child with ASD	Worry about entering school	There are several things, like whether to put them in a special needs class or a regular class. In daycare, I can talk to the teacher when I pick them up and hear how they are doing, but I cannot do that in elementary school, and I worry about that. (d)
Anxiety about the child's growth and development		I hope that as they grow, their developmental age gradually comes closer to their actual age. (a)	
Having goals and plans for parenting	Respecting the child's feelings	I really want to prioritize self-esteem, but I cannot seem to do it well. (g)	
	Setting role for interaction	I get angry at them when they do something bad, but I have a rule that only I am allowed to get angry. I told my husband that they are never allowed to get angry at them. (f)	
	Teaching daily living skills	As long as they have life skills, such as going to the bathroom and eating by themselves, studying is secondary. (h)	

Letters in parentheses indicate narratives of the study participant. ASD, Autism Spectrum Disorder.

**Table 3.** Evolving mother.

Category	Subcategory	Example codes
Changes in perspective or approach	Worrying alone and dwelling	It is easy to dwell on it all alone, and about a year and a half ago, I developed insomnia and depression for which I now take medicine. (e)
	Questioning perspective or way of thinking	From raising them, I have begun feeling like it is not necessary for kids to do things all together, like singing and sports day. (g)
	Changing perspective or way of thinking	One time I stopped everything, stopped saying, “they cannot do that,” and I found they could do certain things really well, like their amazing memory, and they often really surprise me. (j)
	Creating distance with the child with ASD	Their primary care doctor told me that it is much better for them to be around other kids than with parents all the time, so I decided to send them to daycare. (f)
	The child is irreplaceable	Certainly it is a lot of work, but I would be lonely without them, and they are definitely irreplaceable. (i)
	Reflecting on themselves	I think I was always trying to make them more normal. (h)
	Feeling it is difficult to keep living	When I got the diagnosis, I felt it was too hard to continue living in this family and that maybe I would be better off dead, but their older sister was also there, so I realized I could not die. (g)
	Husband does not understand	They see things totally differently, and sometimes I am a little shocked when they do not understand what I am feeling at all. (b)
	Someone present who does not understand	Their grandparents discriminate against disabilities (have a discriminatory attitude) and do not really accept it, so I do not talk about my son to them. (f)
	Some things they could not do alone	We can generally work to create a daily routine at home, but we cannot do some things alone. (i)
Receiving help from people around them	Getting help from people around them	We were out, and I took them to a corner to wait for them to calm down, and an older person said to me, “You can do it.” I felt like (what I was doing) was right. (c)
	Getting help from their parents	About parenting, I get better advice when I ask my parents than when I ask my husband. I talk to my mother more often than my father. (i)
	Talking to others	Sometimes I feel better when I talk to my older sister. (g)
	Getting help from their husband	The one who helps me is my husband, I think. For parenting too, he loves kids and plays with them quite a bit. (g)

Letters in parentheses indicate narratives of the study participant. ASD, Autism Spectrum Disorder.

**Table 4.** Using social resources.

Category	Subcategory	Example codes
Use of social resources	Using social resources	I visit the hospital about once every half a year, and I get advice at these sorts of places. (b)
	Learning about education and support for children with disabilities and having consultations	I studied about support from private organizations, and I use what I learned; I use a careful approach for early childhood according to their stage of mental development. (h)
	Sending the child to daycare	I talked about their disability during the daycare interview, but they just sort of smoothed it over, saying, “do not worry about it, they are welcome here.” (b)
	Sending the child to an education and support facility for children with disabilities	About my son, the doctor said, “on a scale of 1 to 5, with 5 as the highest level and 1 as the lowest, they are a 2.” After watching them for some time, we decided to start sending them to the education and support facility for children with disabilities. (g)
	Confusion about education and support facilities for children with disabilities	Education and support facilities for children with disabilities are only for early childhood; thus, many mothers are at a loss after that ends. (h)

Letters in parentheses indicate narratives of the study participant.

1) “Assessing the characteristics, growth, and changes in the child with ASD” refers to the content captured by the mothers’ perception of the extent of development in children with ASD and changes in language and reactions obtained through observing them and comparing them with other children. This becomes possible through the mother understanding the characteristics and changes in children with ASD.

2) “Preoccupation with parenting children with ASD” refers to mothers’ involvement with children with ASD, as well as their daily parenting efforts and thoughts regarding those efforts. Given the narratives on trial and error and desperation, this was described as a preoccupation.

3) “Consideration toward the child’s siblings” refers to mothers’ perception and involvement with siblings of children with ASD, the impact on the siblings due to greater attention toward the child with ASD, and the siblings’ response.

4) “Thinking about the future of the child with ASD” refers to the mothers’ thoughts and ideas about the growth and future life of their children with ASD.

5) “Having goals and plans for parenting” refers to the methods and ideas that mothers consider important in the process of parenting children with ASD.

### **3.2. Evolving Mother**

The mothers experienced <feeling it is difficult to keep living> as they were <worrying alone and dwelling> on thoughts of parenting and because their husbands or surrounding people lacked an understanding of ASD. Mothers also consulted with and received support from their husbands and surrounding people, such as their parents, when there were <some things they could not do alone> or when there were issues relating to parenting. The mothers were aware of their own changes (evolution), as the psychological distance from their children gave them the opportunity to develop a new perspective on their children's existence; moreover, their relationships with the people around them changed the way they perceived and contemplated about life. Mothers were also aware of their own changes in how they saw and thought about things. The categories and definitions are given below.

1) “Changes in perspective or approach” refers to mothers looking back on themselves and considering changes in the way they perceive things, their own ways of thinking, and the way they think about the existence of their children while facing the pain of living and surrounding people’s awareness of the disability during the parenting process.

2) “Receiving help from people around them” refers to the responses of surrounding people and the mother’s perception of these responses when problems occur during parenting, such as issues that parents cannot resolve alone or when events occur that require consultations.

### **3.3. Using Social Resources**

Mothers used social resources that they considered appropriate in parenting children with ASD, such as attending support facilities and daycares. Mothers sent



their children to “daycare” and “education and support facilities for children with disabilities”. Mothers used social resources such as “learning about education and support for children with disabilities” provided by rehabilitation facilities and private organizations. Some mothers were confused about “education and support” when their children’s attendance at education and support facilities was terminated due to their children’s age.

“Use of social resources” refers to the measures mothers took to promote their children’s development and measures taken against various social resources (environments).

## 4. Discussion

### 4.1. Preoccupation with Parenting Children with ASD and Their Siblings

In this section, alphabetical letters in parentheses refer to participants. The mothers lived their lives “assessing the characteristics, growth, and changes in the child with ASD”. The mothers understood the growth of their children with ASD by recognizing delays in speech and intense obsessions compared with other children. Although the children faced difficulties with other children, it became easier for mothers to play with them (b). From infancy, children with ASD typically avoid eye contact and do not share interests with others. They also have language delays, although the extent of the delay is variable [2]. Mothers’ understanding of their children’s characteristics facilitates understanding them. Capturing children’s changes and growth based on this understanding is assumed to bring the mothers joy. However, until this understanding is formed, mothers would be <doubting the disorder> of their children by comparing them with other children (j). Japan’s health examination system for infants examines children at one year and six months and at three years. Even when developmental delays are indicated in these health examinations, the diagnostic age can range from 2 to 8 years [24] because it takes time to identify the characteristics and make a diagnosis. Consequently, mothers experience a “preoccupation with parenting the children with ASD” while <doubting the disorder>.

When children received an ASD diagnosis, mothers developed a deeper understanding of ASD and attended medical and nursing institutions to learn about and practice treatment methods. However, as symptom severity varies and is highly individualized, mothers began <using trial and error in parenting> and viewed the children’s independence as their responsibility (e), resulting in them <struggling desperately with parenting>. The situation where the mother is at the center of parenting results in <parenting strain>. Additionally, predicting the development and future of children with ASD is difficult for mothers <using trial and error in parenting> and having no time to spare. Therefore, they begin to <worry about entering school>, the issues regarding school attendance that they will face, such as “whether to put them in a special needs class or a regular class”, the extent of support they can receive, and whether their children will receive

such support. Anxiety surrounding not knowing how children are doing, given their speech delay and poor expressiveness (d), leads to worry and stress regarding school life in mothers of children with pervasive developmental disorders [25].

These worries lead to mental and physical exhaustion [17] associated with difficulties in dealing with the characteristics of developmental disorders. This, in turn, makes it difficult for mothers to establish a good relationship with their children. Itai reported that mothers of children with disabilities have closer psychological distance with their child than those of healthy children [26]. It is considered that this kind of relationship formation influences the close psychological distance between mothers and children with ASD. However, there is a risk that these mothers will become psychologically involved in the situation. This differs from their sense of “reasonable” distance with their child’s siblings [20]. Not getting caught up in the situation assures objectivity toward the relationship, which leads to the “protection” of the mother, and will allow an objective understanding of the child’s situation. Mothers who maintain psychological distance and have sufficient mental bandwidth to prioritize themselves occasionally have an appropriate relationship with their child. Therefore, it is necessary for surrounding people to take interest in the distance between the mother and child and provide support so that the mother can become aware of the distance or lack thereof. Ensuring objectivity and understanding the child’s growth and changes facilitates “having goals and plans for parenting”. Hence, an appropriate psychological distance between the child and mother is important.

Mothers recognized the burden on the siblings of children with ASD, such as not being able to care for them sufficiently (e) and making them endure the difficulties (b). Mothers also felt that <siblings are being helpful> and were considerate toward them. In previous research, we clarified that siblings of children with ASD were considerate toward their parents [20]. This was influenced by siblings’ awareness of mothers’ fatigue in caring for children with ASD. Both mothers and siblings bear the burden of caring for children with ASD. Emotional ties are strengthened by being considerate toward one another, but there were concerns that such consideration may collapse, depending on the extent of caregiving.

## 4.2. Evolving Mother

The mothers’ perceptions changed by the values of surrounding people and their understanding of disabilities, their personal questions toward those values and understanding, and the support of surrounding people.

Mothers who played a central role in parenting the children were driven into a situation where they were <worrying alone and dwelling> and even <feeling it is difficult to keep living>. Nagata and Sano found that mothers of children with ASD were highly depressed, and their perceptions of their competence as parents affected the intensity of their stress [27]. It is considered that <parenting

that does not work well> despite desperate efforts affects parents' perceptions of competence and leads to feelings of depression. Furthermore, the diagnosis of the child's disability may lead to a sense of hopelessness regarding the child's future (g) and reduce the mother's ability to regulate her emotions. This may stem from the following: a perception that it is important for children to be normal (h), situations where they are expected to do things together with others (g), and a lack of understanding of the disability in surrounding people. A lack of understanding of children's disabilities among their closest relatives, such as husbands and the mothers' parents, also contributes to negative thinking.

Self-monitoring is essential for correcting self-perception [28], and cognitive monitoring plays an important role in leading an adaptive lifestyle [29]. Having the children attend daycare can help mothers maintain a physical and psychological distance from them. <Talking to others> and <getting help from their parents> allowed mothers to monitor (inspect/evaluate) their relationship with their children, allowing them to correct their perceptions, such as perceiving that <the child is irreplaceable>, and change their perspectives and ways of thinking. Furthermore, changes in perception are affected by the environment surrounding the mother, such as <getting help from their husband> and <getting help from people around them>. Expanding children's range of activities allows mothers to recognize that there are limits to what can be done at home. This allows them to grasp the situation objectively by recognizing <some things they could not do alone>, and <talking to others> is an opportunity to receive support and change the situation.

### 4.3. Using Social Resources

Mothers used social resources such as support facilities, hospitals, and daycares for parenting their children with ASD. Crucially, early and appropriate diagnosis is important because it leads to early initiation of treatment. Mothers also used private organizations and support facilities to learn about parenting methods and have consultations. However, mothers also had <confusion about education and support facilities for children with disabilities>. Some mothers were also at a loss because of the reduced number of visits to support facilities or interruptions in the use of such facilities resulting from sending their children to school (h). Matsuoka *et al.* stated that mothers of children with pervasive developmental disorders desired support that focused on children's strengths and growth. Attending support facilities supports children's growth and facilitates the mothers' psychological stability by providing venues for consultation [25]. The Act on Support for Persons with Developmental Disabilities came into effect 17 years ago. Although there have been improvements in support measures, many private support facilities continue to emerge, and these measures remain insufficient. Appropriate use of social resources requires mothers to obtain and consider information on such resources. Therefore, it is necessary to provide adequate information that corresponds to children's disability characteristics and indivi-

duality and supports the mothers' and families' decision-making.

As this study targeted mothers living in the same area in Japan, regional circumstances regarding the social welfare system may have influenced the results. Furthermore, we did not investigate the extent of the abilities and characteristics of children with ASD or their impact on the mothers' lives. This is a potential topic for future research.

## 5. Conclusion

The lives of mothers parenting children with ASD are built around three themes: 1) preoccupation with parenting children with ASD and their siblings, 2) evolving mother, and 3) use of social resources. When children are diagnosed with ASD, mothers learn about ASD to support their children adequately with treatment. However, as the children have various individual characteristics, parents end up <using trial and error in parenting> and <struggling desperately with parenting>. The situation of desperately struggling with and becoming preoccupied with parenting is related to a close psychological distance from the children and becomes a burden in life. Through this process, mothers develop their own policies regarding parenting and experience changes in their personal views and ways of thinking. For mothers to change their views and ways of thinking without increasing the burdens on their lives, they need the support of people around them to help them objectively view parenting and monitor their perceptions. Furthermore, for mothers to use social resources in parenting, the supporting individuals must understand the characteristics of children with ASD, provide appropriate information, and assist in decision-making.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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