

Demands of Parents When Selecting an Elementary School for Their Children with Autism Spectrum Disorder: A Literature Review

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Abstract

Background and Purpose: Parents of children with autism spectrum disorder (ASD) experience great stress and conflict when choosing their child's pathway to elementary school. This study, through a literature review, aimed to clarify the demands of parents when selecting an elementary school for their children with ASD. **Methods:** A literature search was conducted in the Japanese literature databases J-STAGE, Ichushi-Web, and CiNii Research using the keywords "autism AND school attendance"; 2274 articles were found, from which 17 articles were analyzed. A directed content analysis was conducted based on Hohashi's Support Vectors of Family/Family Environment Intervention Model. Demands of parents when selecting a primary school for their children were extracted from the descriptions in the literature and then sub-categorized and categorized. The categories were grouped into one of three systems: family internal environment system, family external environment system, and family chrono environment system. **Results:** A total of 67 subcategories and 13 categories were extracted. The family internal environment system was comprised of three categories, such as "I want to agree with my spouse"; the family external environment system was comprised of five categories, such as "I want information to be provided"; and the family chrono environment system was comprised of five categories, such as "I have hopes for my child". **Conclusions:** It is important for medical professionals to individually evaluate the demands of parents and support them in choosing an appropriate primary school in accordance with those demands.

Keywords

Autism Spectrum Disorder, Elementary School Enrollment, Parents, Demands, Literature Review

1. Introduction

In Japan, so-called special needs education was introduced in 2007, targeting children with such developmental disabilities as autism spectrum disorder (ASD). Special needs education can be understood within the framework of inclusive education [1]. Japan's Ministry of Education, Culture, Sports, Science and Technology [2] states that, in an inclusive education system, it is important to pursue a system where children with and without disabilities can learn together at the same place and develop a diverse and flexible system that can provide instruction that most accurately meets the educational needs of children, with individual educational needs at that time, with an eye toward independence and social participation. It also states that it is necessary to prepare a variety of continuous learning environments, such as regular classes in elementary and junior high schools, part-time classes where children can partially participate in learning in regular classes, special needs classes, and special needs schools, and that a variety of learning environments should be prepared for ASD children to attend.

Regarding the selection of elementary schools for children with ASD, the Ministry of Education, Culture, Sports, Science and Technology in Japan [3] has pointed out that it is appropriate for the municipal board of education to provide sufficient information to the child and parents, respect the opinions of the child and parents to the greatest degree possible, and reach a consensus between the child and parents, the municipal board of education, and the school regarding educational needs and necessary support, with the municipal board of education responsible for the final decision. While the final decision is in the hands of the municipal board of education, it is expected that school enrollment consultations will be conducted so that the solution reached most closely approximates the wishes of the parents.

Parents of children with ASD must decide on elementary schools on behalf of their children, but it is anticipated that parents will feel stressed and conflicted as they are forced to make value judgments regarding their children's career choices. Mothers of children with ASD feel great stress about career choices, and those providing support are required to communicate to mothers, to the greatest degree possible, the likely outlook for their children's growth and future, and present appropriate career options as necessary [4]. Additionally, fathers of children with ASD may require additional support that focuses on their physical as well as their psychological health [5].

Through a literature review, this study aimed to clarify the demands of parents when selecting an elementary school for their child with ASD.

2. Methods

2.1. Operational Definition of Terms

- Demands: Subjective demands/requests/problems.
- Family internal environment system: The family environment system that exists within the family, which is the area within the family where individual

family members interact with each other [6].

- Family external environment system: The family environment system outside of the family [6].
- Family chrono environment system: A concept to indicate the process of temporal change and transformation of the family internal environment system, the family external environment system, and the family in a time frame from the past to the future [6].

2.2. Literature Search Method

The representative Japanese literature databases, J-STAGE, Ichushi-Web, and CiNii Research, were used. The search terms were “autism AND school attendance”, with the search conducted on October 3, 2024. The search found 1895 articles in J-STAGE, 296 articles in Ichushi-Web, and 187 articles in CiNii Research (Figure 1). The exclusion criteria for the literature were: 1) literature published before 2006; 2) no description of the demands of parents when selecting an elementary school for their child with ASD; 3) not a Japanese case; 4) not about enrollment in elementary school; and 5) the child’s illness was not ASD. The reason literature published before 2006 was excluded is that special needs education was introduced in 2007, and children with ASD became the subject of special needs education; therefore, it was believed that the demands of parents would differ before and after 2007. Finally, 17 articles were utilized as subjects for analysis [7]-[23].

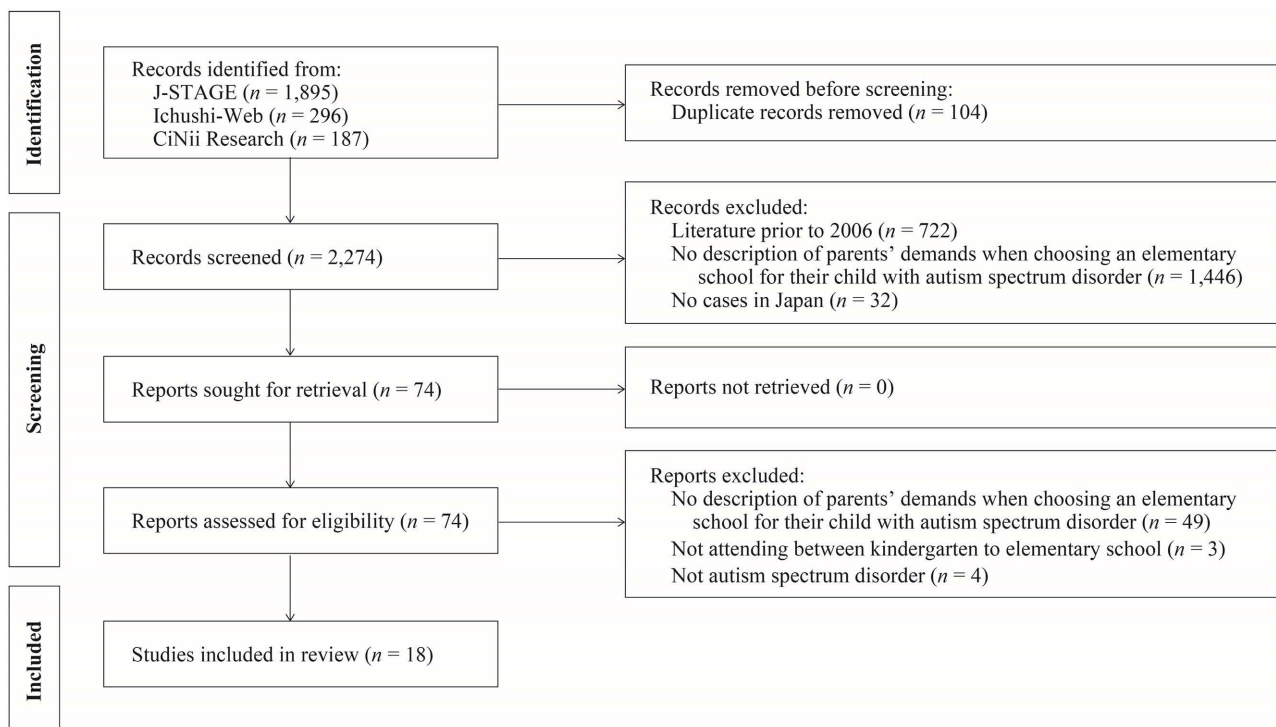


Figure 1. The flow of literature identification and selection related to the demands of parents regarding the selection of an elementary school for their children with ASD.

2.3. Analysis Method

From the descriptions in the literature, demands of parents when selecting an elementary school were extracted, and directed content analysis [24] was performed based on Hohashi's Support Vectors of Family/Family Environment Intervention Model [25]. Hohashi's Support Vectors of Family/Family Environment Intervention Model indicates the direction in which family intervention should be targeted and is suitable as a theoretical framework for classifying support for parental demands. In other words, the contents were classified into three systems: family internal environment system, family external environment system, and family chrono environment system. The extracted descriptions were expressed in one sentence without changing the meaning, and this was used as a code. Each code was compiled and classified according to the similarity of meaning, and the degree of abstraction was increased to subcategorize and further categorize. All analyses were performed independently by two pediatric nursing researchers, then differences of opinion were resolved through discussion in multiple meetings, and careful consideration was repeated until a consensus was reached. In addition, expert meetings were regularly held with the participation of 11 researchers with expertise in pediatric nursing, and refined interpretation of research results followed.

3. Results

As a result of the analysis, a total of 67 subcategories and 13 categories were extracted, with the family internal environment system being classified into three categories, the family external environment system into five categories, and the family chrono environment system into five categories (Table 1). In the following, the category names are enclosed in quotation marks.

Table 1. Categories of parents' demands regarding the choice of elementary school for their children with ASD.

System	Category	Reference No.
Family internal environment system	I want to agree with my spouse.	21
	I want to respect my child's wishes.	22, 23
	I want my child to attend a suitable elementary school.	19, 20, 23
Family external environment system	I want information to be provided.	7, 10, 11, 15, 16, 17, 18, 20, 22, 23
	I want help from those around me.	9, 18, 22
	I want to visit the elementary school.	11, 20, 21, 22
	I want support from the teachers.	7, 11, 12
	I want my child's disability to be made known.	8, 10, 14, 15, 16, 18, 23
Family chrono environment system	I have hopes for my child.	13, 20, 23
	I want my child to interact with friends.	8, 11, 13, 15, 17, 19, 20, 23
	I want to make requests to the elementary school after enrollment.	7, 10, 11, 16, 17, 18, 22, 23
	I want to make requests to the teachers after enrollment.	14, 16, 18, 20, 22, 23
	I want to engage in mutual assistance with others around me after enrollment.	16, 18, 22, 23

3.1. Categories in the Family Internal Environment System

“I want to agree with my spouse” represents a demand that spouses agree on the elementary school that their child will attend.

“I want to respect my child’s wishes” represents a demand that I want to choose between a regular class and a special needs class, while respecting the child’s wishes.

“I want my child to attend a suitable elementary school” represents a hopeful demand to send his/her child to an elementary school with good educational content, and a negative demand, in that I do not want to leave my child in an elementary school or not expect due to a pessimistic view of life in a regular class.

3.2. Categories in the Family External Environment System

“I want information to be provided” represents a demand for information among parents, such as advice from parents with the same disability, a demand for information to be provided to specialist institutions, such as consulting the Board of Education, and a demand for information from elementary schools, such as learning about educational content and the school acceptance system.

“I want help from those around me” represents a demand for cooperation from specialist institutions and for discussion of my feelings with a professional.

“I want to visit the elementary school” represents a demand for visiting elementary schools, such as observing and experiencing the school to observe the child’s condition.

“I want support from the teachers” represents a demand for interaction and communication with teachers and a demand for teachers to understand how to support children.

“I want my child’s disability to be made known” represents a demand for an understanding of the child’s disability from the child’s friends and the elementary school.

3.3. Categories in the Family Chrono Environment System

“I have hopes for my child” represents demands for the child’s growth after enrollment, such as growing up in his or her own way, studying hard, becoming independent, and being able to engage in group activities.

“I want my child to interact with friends” represents demands for the child’s interactions with friends—such as wanting the child to have friends and spend quality time together—and demands for opportunities to interact with the local community in order to interact with friends.

“I want to make requests to the elementary school after enrollment” represents demands for support coordination, such as coordinating after-school clubs and special-needs schools, and problem-solving demands, such as wanting an environment that suits the child’s characteristics.

“I want to make requests to the teachers after enrollment” represents demands for teachers’ ability and placement, such as wanting more teachers with special-

ized knowledge to be placed; demands for lesson content and support, such as making sure that assistants are always provided, even in special needs classes; and demands for the principal to do his/her best.

“I want to engage in mutual assistance with others around me after enrollment” reflected a demand for mutual assistance among parents, such as a desire for a network between parents and for getting along well with the parents around them.

4. Discussion

4.1. Demands of Parents in the Family Internal Environment System

With regard to “I want to agree with my spouse,” the reason why the mother and father have different opinions about the elementary school their child will attend may be attributed to differing levels of understanding about the elementary school and the child’s situation. The mother and father visit the elementary school together, and the father’s level of understanding increases, which allows them to reach an agreement [21]. It is therefore necessary to assess the mother’s and father’s levels of understanding about the child and the elementary school, and to provide support to narrow the gap in understanding through visits to the elementary school and interviews.

With regard to “I want to respect my child’s wishes,” it is difficult for a child to express his or her wishes regarding the choice of elementary school. Therefore, parents will judge the child’s wishes and intentions based on the child’s situation at the nursery school, kindergarten, or special education center he or she is currently attending, and the child’s situation at the elementary school he or she is visiting. Consequently, it is necessary to respect the child’s wishes by informing the parents of the child’s situation and providing an opportunity for the parents to observe the child’s situation.

With regard to “I want my child to attend a suitable elementary school,” comments made by teachers and personal experiences from fellow parents are cited as factors that separate demands into hopeful and pessimistic ones. As for pessimistic views, parents’ anxiety increases depending on the way teachers respond during elementary school tours and school enrollment consultation sessions [20]. For this reason, it is necessary for teachers to interact with parents in a manner that puts them at ease. Additionally, when parents feel distrustful of the school or teachers, medical professionals should intervene and provide support in the form of an objective assessment of anticipated difficulties after enrollment.

4.2. Demands of Parents in the Family External Environment System

With regard to “I want information to be provided,” we believe that utilizing parent mentors is effective in meeting the demand for information provision among parents. Parent mentors are experienced parents who have raised children with developmental disabilities and can therefore provide information, particularly

about local resources. However, in municipalities with a mentor registration system as of 2018, the number of parent mentors varies greatly across the country, ranging from 3 to 80 [26]; therefore, we believe that awareness-raising activities for parent mentors are necessary. In response to demands for information provision, such as requests for information from specialized institutions or for details about educational content, information is required from doctors, public health nurses, and child development support centers. Parents feel a heavy burden because they do not know which elementary school is suitable for their child, so they need objective assessments of the child and advice that assumes group living. These can only be provided by experts familiar with the child's daily behavior. Therefore, we believe that medical professionals need to provide objective assessments of children, as well as knowledge of local resources and opportunities to visit schools.

With regard to "I want help from those around me," psychological support from specialist institutions is required. Because parents experience great stress when choosing a school to attend [4] [17], it is necessary for specialist institutions to build a relationship of trust that enables consultation with parents. In particular, after a child is diagnosed with ASD, parents may be at a loss as to what to do, which may lead to maladjustment, so support from medical professionals is necessary [27], and it is necessary to build a relationship of trust from this stage onwards. Furthermore, because mothers and fathers show similar levels of parenting stress [28], it is necessary to provide similar support to fathers as well as mothers.

With regard to "I want to visit the elementary school," parents need to check the format and application methods for school visits and school experiences, as they vary depending on the elementary school. We also believe that it is necessary to provide parents with information on what they should check when visiting an elementary school. It is not uncommon for some parents to want to pay multiple visits. We believe that elementary schools are required to understand what parents want to understand when they visit an elementary school and to respond flexibly.

With regard to "I want support from the teachers," parents' anxiety can increase due to teachers' comments or one-sided judgments. Four teacher values are cited as factors that can cause conflict between parents and teachers: 1) emphasis on discipline and process as a top-down organization; 2) a preference for a generic format that assumes a large number of cases rather than one individual; 3) strong individuality among teachers and a strong desire for teachers to cover all aspects of children's lives; and 4) emphasis on school life and group life [7]. We believe that it is necessary for parents and teachers to recognize the need for collaboration in support and to create a space that enables mutual understanding.

With regard to "I want my child's disability to be made known," we believe that the role of the special needs education coordinator is important. Rather than a single homeroom teacher handling the issue, it is necessary for a group of teachers, led by a special needs education coordinator, to address the issue [29]. Furthermore, with the consent of the child and his/her parents, explaining the child's dif-

facilities to classmates, parents, and the community will help promote understanding of the disability among those around the child.

4.3. Demands of Parents in the Family Chrono Environment System

With regard to “I have hopes for my child,” parents expect their children to adapt and grow in elementary school and place importance on whether an environment is in place to realize this. Elementary schools are expected to create an environment suited to individual characteristics and needs and to create individual educational plans. In addition, with regard to environmental preparation, it is important that special support provided before school entry is carried over to elementary school education [15]. For this reason, we believe it is necessary for preschool support organizations to create individual educational support plans and support books, and provide them to elementary schools.

With regard to “I want my child to interact with friends,” parents believe that elementary school is the only time they can guarantee their child the experience of coexisting with healthy children of the same age [20]. While some parents choose regular classes or special needs classes for the sake of interacting with friends, even if their child proceeds to a special needs school, they still have interactions and collaborative learning with special needs classes. For both children with and without disabilities, interaction and collaborative learning are of great significance in broadening experiences, cultivating sociality, and nurturing rich humanity toward the creation of a symbiotic society, which can also foster respect for diversity [2]. For this reason, we believe that it is necessary to provide information about interaction and collaborative learning with special needs classes when choosing a school to attend. On the other hand, because the learning content and pace in regular classes are advanced, there are concerns that children with ASD may not be able to keep up with the environment and that they may be forced to bear an excessive academic burden. To alleviate such concerns, it is important to provide careful information in advance concerning the availability of a support system tailored to the child’s characteristics and the specific content of educational considerations.

With regard to “I want to make requests to the elementary school after enrollment,” children with ASD often have obsessions and sensory disorders (hypersensitivity and hyposensitivity); therefore, environmental improvement is important. The Ministry of Education, Culture, Sports, Science and Technology in Japan [2] states that consideration is needed for the unique senses of children with ASD, according to their cognitive characteristics, and according to behavioral characteristics and emotional disorders. It is necessary to improve facilities with consideration for sensitivity to sound and temperature, reduce indoor stimuli, and ensure space to promote cooling down when panic occurs. Some elementary schools are unable to secure a place to cool down due to a lack of empty classrooms, but some schools have responded by creating partitions in the classroom with curtains or cardboard and placing them around the seats [30]. It is necessary to secure the

necessary financial resources and improve the environment, while at the same time thinking about and devising ways to take into consideration the environmental improvement situation at each elementary school.

With regard to “I want to make requests to the teachers after enrollment,” the extent to which behaviors resulting from ASD characteristics may pose a risk in life at a regular school is highly individualized and depends largely on the teacher’s understanding of the child and the attitude of the surrounding healthy children, so no matter how much information is collected or how many experiences of experienced parents are heard, the actual outlook is uncertain [20]. In addition, in special needs education, support workers and teachers are required to provide support that is more tailored to the child than before, but the number of support workers and teachers remains the same, and the shortage of schools and inadequate facilities within schools are difficult to resolve quickly [14]. Even in such circumstances, there are teachers who conduct classes with a consistent approach throughout the school, create an atmosphere that is accepting of disabilities throughout the class, and create an environment where it is easy to provide support and consideration even with a shortage of human resources [30]. From this, it is believed that support that is tailored to the individuality of children will be possible.

With regard to “I want to engage in mutual assistance with others around me after enrollment,” examples of interactions with other parents include interacting with parents of classmates after enrollment; participating in local or municipal social events; making use of parent mentors; and communicating through social networking services (SNS). For parents of children with developmental disabilities, parent meetings provide a place where they can vent about their child’s troubles or sorrows [31] as well as a place to change their mood [32], and to obtain the support needed to relieve family stress [33]. By interacting with each other at parent meetings, they can form friendships to provide mutual support [34]. In this way, participation in social events such as parent meetings is extremely important, and we believe it is important for elementary schools to provide opportunities for parents to gather after events such as school tours and provide information about social events.

4.4. Limitations of This Study

While this study consisted of a comprehensive literature search through the inclusion of gray literature, the literature quality varied. In addition, this study addressed the demands of young children regarding the selection of elementary schools, but children with ASD may consider changing classes or transferring schools after enrollment. It will therefore be necessary to consider the demands of parents regarding their choices and decisions not only during the early stages of childhood.

5. Conclusion

In this study, a directed content analysis was conducted based on Hohashi’s Sup-

port Vectors of the Family/Family Environment Intervention Model on Japanese literature regarding the demands of parents in the selection of elementary schools for young children with ASD. Seventeen literature articles were analyzed, and 13 categories were extracted. The family internal environment system was classified into three categories, such as “I want to agree with my spouse”; the family external environment system into five categories, such as “I want information to be provided”; and the family chrono environment system into five categories, such as “I have hopes for my child”. It is important for medical professionals to support parents in making appropriate elementary school selections based on these demands.

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Conflicts of Interest

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

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