Report

# Literature review on realities of difficulties Japanese families with a child with developmental disabilities face and required support

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## Abstract

Purpose: Summarizing the existing research on realities of difficulties faced by Japanese families having a child with developmental disabilities (DDs) and necessary support for them, ascertaining findings of the research, and comprehensively examining specific intervention methods for corresponding families in Japan.

Methods: PubMed and CINAHL were utilized to search for English literature on the subject whereas Japan Medical Abstracts Society (web edition, ver. 5) was used for Japanese literature. The original and review articles for 2005–2014 were reviewed.

Results: Realities of difficulties were classified into six categories, with "difficulties concerning the child's behavior" being extracted the most. Overall, this category was shown to greatly affect the lives of families with a child with DDs. Such families require four categories of support. Particularly, mental and emotional support for parents was desired.

Conclusion: The review suggested that specialists needed to assess everyday difficulties of families with a child with DDs from various perspectives, using issues related to behaviors of children with DDs as a beginning. Further, parents' mental and emotional stabilities need to be supported more actively. Japanese research focusing on families with children with DDs should be continually accumulated. Based on findings from such an accumulation, support for both the parents and the child or comprehensive support focusing on the family collective should be planned.

Keyword：developmental disability, dif〵culties, family, literature review, support

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## Introduction

In Japan, the number of children with developmental disabilities (DDs) is steadily increasing (Japan League on Developmental Disabilities, 2013). The results of the National Survey on School Children with Special Educational Needs in a Regular Class reported that 6.5% of all children have "mild DDs" that cause significant difficulty in learning and behavior without mental retardation (Ministry of Education, Culture, Sports, Science and Technology, 2012).

In addition, as shown by the enforcement of special needs education and the recent establishment of the Act on Support for Persons with Developmental Disorders (Ministry of Health, Labour and Welfare, 2005), the supportive environment for DDs has improved, with a better understanding of disability emerging in Japanese society. In Japan, DDs are defined as "autism, Asperger's syndrome, other pervasive developmental disorders, learning disorders, attention deficit hyperactivity disorder (ADHD), and similar higher cerebral dysfunctions that usually present symptoms at an early age." The qualitative definition is "a disorder that typically causes behaviour, communication, and social adjustment problems during the development process" (Hiraiwa, 2009).

Children with DDs often cause (or are involved in) problems (e.g., trouble with friends, isolation from other children, and falling behind others) in the community or school one or more times (Takahashi, 2008). Parents of such children need to deal with problems caused by them due to the DD and undergo more stress associated with child rearing than other parents (Anderson, 2008; Nachshen & Minnes, 2005). The pressure of child rearing felt by these parents is considerable (Karst & Van Hecke, 2012; Raina, 2004). The presence of a child with DDs can also be a source of stress for the child's kin and siblings (Karst & Van Hecke, 2012; Schuntermann, 2007). Though a large majority of parents adjust to raising these children, some fail to adapt; the latter are said to be potential child abusers (Raina, 2004). Karst and Van Hecke reported that raising a child with DDs can cause higher stress in the family (Karst & Van Hecke, 2012).

In Japan, nuclear families comprise over 60% of the population, and their burden of child caring is substantial (Ministry of Health, Labour and Welfare, 2012). There are cases where children are abused by their parents because they do not have a person or organization that they can consult with when it is difficult for them to handle child care and when they experience depressive tendencies. (Ministry of Health, Labour and Welfare, 2014a; Ministry of Health, Labour and Welfare, 2013). In particular, parents raising a child with DDs have been reported to undergo difficulties in child caring and stress more strongly as compared with families raising a healthy child (Ministry of Health, Labour and Welfare, 2014b). Japan's Children's Charter advocates that "all children are to be raised healthily, both in mind and body, and have their livelihood guaranteed" (Ministry of Education, Culture, Sports, Science and Technology, 1951). However, to adhere to this policy, support for the entire family, and not just for the child within its perspective, is necessary for families raising children with DDs. Clarifying the everyday difficulties of members of such families and the support they require is a crucial task when providing familial support in various fields such as education, medical concerns, and welfare. Until now, several papers referring to family's difficulties and necessary support in each position and perspective were found. However, there were no literature-based papers summarizing these contents.

Therefore, this study summarizes the existing research (including case example reports) on realities of difficulties faced by Japanese families with a child with DDs and necessary support for them,

ascertains the findings of the research, and comprehensively examines specific intervention methods for corresponding families in Japan.

## Methods

### Participants

PubMed and CINAHL were used for searching English papers on the subject, and "developmental disorders," "families," and "Japan" (in Japanese) were used as keywords to search for original and review articles published between 2005 and 2014. The Japan Medical Abstracts Society (web edition, ver. 5) was utilized to search for Japanese literature using "developmental disorders," "families," and "Japan" as keywords to search for original and review articles published between 2005 and December 2014. Therefore, 38 pieces of English literature and 33 pieces of Japanese literature were found. Excluding literature that did not have

Table 1. Literature list

| Literature Number | Title | Year | Author(s) | Publication | Study type |
|---|---|---|---|---|---|
| 1 | On familial support of mild development disabilities through cases where the acceptance of the disabilities was difficult | 2005 | Ogata, A. | Japanese Journal of Family Therapy, **22(3)**, 230-235 | case study |
| 2 | Effects of study seminars for guardians who have a child with a high-functioning pervasive development disorder: Holding a high-functioning autism/Asperger's syndrome study session for the guardians who have a child attending an elementary school or kindergarten or not attending kindergarten | 2005 | Namiki, N., Asai, T., Sugiyama, T., Koishi, S. & Azuma, M. | Journal of Clinical Psychiatry, **34(9)**, 1229-1236 | small intervention study |
| 3 | Examination of school-aged child with a high-functioning pervasive development disorder adapting to schools and rehabilitation | 2008 | Hayashi, Y. | Official Journal of the Japanese Society of Child Neurology, **40(4)**, 295-300 | case study |
| 4 | The analysis of needs of infants with autism and their family before attending school through case examples | 2009 | Sakai, H., Nakayama, K. & Takada, T. | The Japanese journal for public health nurse, **65(8)**, 670-675 | case study |
| 5 | The tasks of regional livelihood support toward children with developmental disorders based on an awareness survey of guardians from City A, a regional nucleated city | 2010 | Takahashi, M. | Association of Disability Sciences, **34**, 189-204 | questionnaire study |
| 6 | An outline of the stress and related factors that a child on the autism spectrum and their family experience | 2011 | Tamaki, A., Matsuoka, J., Hatsuda, M. & Nishiike, E. | Bulletin of the Faculty of Nursing Science, University of KinDai Himeji, **3**, 9-15 | questionnaire study |
| 7 | Parent training for parents of a child with developmental disabilities: Examination of efficacy through 29 case examples | 2011 | Itani, T. & Uebayashi, Y. | Japanese Journal of Child and Adolescent Psychiatry, **52(5)**, 578-590 | small intervention study |

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| 8 | The effect of parent training on mothers who feel difficulties toward raising a child with developmental disorders | 2012 | Honyama, K., Matsuzaka, T., Nagaoka, T. & Matsuo, M. | Official Journal of the Japanese Society of Child Neurology,**44(4)**, 389-294 | small intervention study |
| 9 | Support for developmental disability: From the perspective of mental health support for guardians | 2012 | Inoue, M. | The Journal of Child & Brain Development, **3(2)**, 80-83 | questionnaire study |
| 10 | On the state of support given to a child and people with developmental disabilities during a disaster: Examination based on a seminar on developmental disability support | 2012 | Sugahara, S., Shimizu, M. & Fujiwara, K. | Bulletin of the Tohoku Bunka Gakuen University Faculty of Medical Science & Welfare, Department of Rehabilitation, **8(1)**, 33-42 | interview study |
| 21 | Developmental disorder parenting stressor index (DDPSI): Reliability and validity | 2013 | Yamane T. | Shinrigaku Kenkyu., **83(6)**, 556-565. Japanese. | questionnaire study |
| 22 | High incidence of sleep problems in children with developmental disorders: Results of a questionnaire survey in a Japanese elementary school | 2014 | Matsuoka, M., Nagamitsu, S., Iwasaki, M., Iemura, A., Yamashita, Y., Maeda, M., Kitani, S., Kakuma, T., Uchimura, N. & Matsuishi, T. | Brain Development, **36(1)**, 35-44 | questionnaire study |
| 23 | Professional caregiver's view on mental health in parents of children with developmental disabilities: A nationwide study of institutions and consultation centers in Japan. | 2012 | Kobayashi, T., Inagaki, M. & Kaga, M. | ISRN Pediatrics,:121898 | questionnaire study |
| 24 | Measurement of family-centered care: Translation, adaptation, and validation of the measure of processes of care (MPOC-56 and -20) for use in Japan. | 2012 | Himuro, N., Kozuka, N., & Mori, M. | Child Care Health and Development, **39(3)**, 358-365 | questionnaire study |
| 25 | Factors associated with the empowerment of Japanese families raising a child with developmental disorders | 2011 | Wakimizu, R., Fujioka, H., Yoneyama, A., Iejima, A. & Miyamoto, S. | Research on Developmental Disabilities,**32(3)**, 1030-1037 | questionnaire study |
| 26 | Empowerment process for families rearing children with developmental disorders in Japan | 2010 | Wakimizu, R., Fujioka, H. & Yoneyama, A. | Nursing and Health Sciences, **12(3)**, 322-328 | interview study |

families with a child with DDs as the subject or does not mention everyday difficulties of families, a total of 26 pieces of literature were used as analysis participants (Table 1).

## Analysis methods

Each selected piece of literature was classified according to "year published," "subject" (i.e., children, family), "the disability of the child," "the state of

difficulties," "support and needs," and "familial support given." Thereafter, an analysis form was developed, and each piece of literature was read intensively, with its content summarized—the points of analysis being realities of difficulties, required support and needs, and familial support being performed for families with a child with DDs. These analyzes were promoted by researchers continuous discussing.

## Results

### Research contents

#### 1. Realities of difficulties

As a result of the analysis, the difficulties that families having a child with DDs face were classified into six categories as follows. Each category was further classified by focal themes (Table 2).

Table 2. Realities of difficulties

| Types of difficulties | Focal theme | Content of difficulties (literature number) |
|---|---|---|
| Everyday difficulties | Work | Having to quit work (14) |
| | Mental and physical health | Having physical health complaints (14, 22)<br>Having mental health complaints (14, 21, 23) |
| | Increase in exhaustion from child caring and housework | Housework and taking care of the siblings became more difficult. (16)<br>Becoming tired from spending both time and physical energy (16)<br>Have to assist with homework (16)<br>Life becomes stagnant if the child goes to or becomes admitted in a hospital or when the mother becomes physically ill. (16)<br>Having to make small adjustments with child caring (16) |
| | Life rhythm | Leading a life in which the day and night are reversed (14, 22)<br>Disruption of the life rhythm (14, 22) |
| Difficulties related to the child's behavior | Impact on daily life | Tantrums (15)<br>Panic (14)<br>Hyperactivity (6)<br>Breaking things in the house and/or being physically attacked (14)<br>Rough, aggressive, and impulsive activities (6, 15)<br>Anxiety and fixation (14, 15)<br>Being fussy about food (14) |
| | Dealing with the child | I myself do not know what to do when a delay in the child's development has been pointed out. (5)<br>I do not know how to deal with behaviors characteristic to disabilities. (5, 14)<br>I do not know how to deal with changes that occur in puberty. (14)<br>I do not know how to deal with sexual curiosity and interests. (14)<br>I do not know how to get involved with or predict how to deal with the child's growth.<br>Worrying about the difficulty in interacting with the child (5)<br>I do not know how to raise the child. (15)<br>Difficulties with forming attachment (6) |
| | Social activity | Actions that causes harm or annoyance to the surrounding (15)<br>Negative expressive actions (15)<br>Difficulty in sustaining concentration (15)<br>Difficulties in understanding the state or standpoint (15)<br>Difficulty in attempting new things (15)<br>Reluctance in attending the kindergarten after a long-term break (15)<br>Using original words (14)<br>Prematurity in verbal expression ability (14)<br>Issues with group activities (15)<br>Difficulties in communication (6, 7, 15) |

| | | |
|---|---|---|
| Difficulties related to the familial relationships | Husband | The husband does not understand how difficult it is. (14)<br>The husband does not understand the disability. (14)<br>The husband cannot accept the disability. (14) |
| | Family | The understanding of disability by the entire family is poor. (6) |
| Education-related difficulties | School/facility selection | Agonizing when selecting the primary or high school to advance to (14)<br>Unsure which facility or class is suitable for the child (5)<br>Difficulty in selecting a living environment suitable for the child (16) |
| | Educational institution | The school or the kindergarten does not listen to requests. (14)<br>Unable to voice dissatisfaction toward the school (16)<br>Inability to attain the continuity of teaching staff members (14)<br>The response of the teaching staff members differs depending on the quality. (14)<br>The teaching staff members do not understand the disability and respond coldly. (14)<br>It was painful that the delay in development caused by the child's disability was attributed to his/her interaction with the parents. (5)<br>Not receiving any information at all on lectures related to developmental disabilities at a private kindergarten (5)<br>Not receiving any information related to developmental disability education at each school (5) |
| | Academic support | Having difficulties with assisting learning (14)<br>Taking too much time assisting the child with homework (15) |
| | School life | Not knowing effective methods for supporting the child's school life (16)<br>Not fitting in within a group (6)<br>Concerns over bullying and secondary disability (6)<br>Not being able to keep up with the learning (6, 16)<br>Wanting the children in the same grade to know about the state of the child as well as how to approach and interact with the child (5)<br>Not knowing the state of the school life (16)<br>Not going to the bathroom at school and having a tantrum when being asked to persistently (5)<br>Not being able to concentrate on tests (7) |
| | Other guardians | Other guardians give me cold glances. (14)<br>Feeling melancholic when meeting other guardians for the first time because of being unable to become close with them (14)<br>Cannot gain any compassion from people around (7) |
| Rehabilitation-related difficulties | Rehabilitation | Lack of information on rehabilitation methods (16, 17, 18, 19, 26)<br>Feeling of burden or conflicts toward continuing with the rehabilitation (16, 19)<br>Rehabilitation is expensive. (16)<br>It is for reducing behavior issues and does not cure autism. (7) |
| | Medical institution | Specialized hospitals are far. (14, 17)<br>There are few specialists, and reservations are difficult to make. (14, 17, 26)<br>There are few doctors specializing in developmental disabilities. (16, 17, 26)<br>Receiving reliable medical treatment is difficult (i.e., due to difficulties in transportation and long waiting time). (16, 26)<br>It is difficult to get a correct diagnosis or receive an appropriate treatment. (7, 26) |
| | Specialized institution | Feeling of distrust regarding how specialized institutions are handling such cases (14, 19)<br>There is a possibility that one cannot reach an autism specialist easily. (7) |

| | Support | The public assistance did not match with the child's disability. (16) |
|---|---|---|
| Psychological burden | The child's future | Long-term psychological anxiety (16)<br>Concerns regarding whether the child can have a job and lead an independent life in future (16)<br>Worried whether the child will commit a crime after becoming an adult (16) |
| | On the child and the other children | Concerns about the child not being able to keep up with the studies (16)<br>Concerns about the child having difficulties in friendship and group activities (16) |
| | Accepting disabilities | Difficulties in accepting disabilities (14)<br>Wishing to hide the disability (14)<br>Feelings of guilt toward rejecting the child (14) |

*Everyday difficulties*

Regarding everyday difficulties, it was first indicated that the participants had to quit their work to prioritize taking care of their child. Furthermore, even in cases where they did not quit their job, the results demonstrated a reality in which taking care of their child affected their jobs, such as being called away while working or having to take leave from work.

Next, it was shown that there was deterioration in participants' mental and physical health because of issues such as concerns related to problematic behaviors of their child. There have been statements by participants complaining about their physical problems (e.g., "I feel that my body is aching" and "my weight is decreasing") as well as an increase in psychological stress and the development of psychological illnesses.

The results also indicated the reality in which spending their daily lives with a child with DDs increased the participants' exhaustion from child rearing and household chores. This included instances such as the parents having to carry their child home after grocery shopping because the child did not want to go home and the child making the younger brother cry by teasing him without considering his feelings. Moreover, the analysis revealed causes of participants' exhaustion, such as having to spend considerable time helping with their child's homework or having to spend many hours looking after their child every day at home. Furthermore, interview results showed that participants felt that their lives stopped during periods when their child or they themselves were ill or during pregnancy. An awareness of difficulties was discussed regarding raising their child, including having to communicate visually using pictures and charts in light of the child's development or constantly having to make small adjustments.

There have also been reports on the participants' life rhythms being disrupted because of reasons such as having to remain awake through the night for children whose night and day is reversed.

*Difficulties associated with the child's behavior*

Impacts on one's lives included families falling into a confused state when their child threw a tantrum, having a panic attack, or child caring becoming difficult because of their child's behavior. In addition, there have been reports of things in the house getting broken or family members being physically attacked because of the child's rough or aggressive and impulsive behaviors. The anxiety and fixations of such children are strong. To be specific, there have been cases where families have had to stock specific food products in their refrigerator, and remove all mirrors in their house because of their child's strong drive to lose weight, and because they could not go out with their daughter who would pursue a perfect appearance. As such, the

characteristics of the child's disorder also affected the families' lives.

The participants worried about dealing with their child (e.g., "I do not know how to deal with the delay in development," and "I don't know how to deal with my child's problematic behavior") and also about the child's growth and changes (i.e., "changes that occur during puberty" and "sexual interest and concern"). The state in which participants worried about their relationship with their child (i.e., "difficulties in interacting with their child," "difficulties in raising the child," and "difficulties in feeling an attachment [to the child]") was also indicated.

Issues that made the participants concerned included the conspicuous behavior of their child that caused annoyance to the people around them. Furthermore, difficulties within the child's social life were also raised, including the difficulties in sustaining concentration, prematurity in verbal expression, and the child's attendance or non-attendance at school. The issues that the child faced in interpersonal and social aspects, such as difficulties in communication, were perceived as difficulties on the part of both the child and the families.

*Difficulties related to family relationships*

There were many complaints from mothers regarding their husband's lack of understanding, such as "my husband does not understand our child's disability and cannot accept it" and "my husband does not understand the difficulties of child caring." Furthermore, the review showed the state in which the entire family left the responsibility of dealing with the child with DDs to the mother without attempting to understand the child's disabilities.

*Difficulties related to education*

The analysis result showed that participants faced many concerns and anxieties when selecting schools and facilities because of the inability to identify schools and classes suitable for the child.

Furthermore, participants felt that "our requests are not being heard" and "we cannot voice our dissatisfaction" regarding educational institutions. There were also concerns such as the teaching staff at school did not understand the disability and the participants could not receive continuous support. Complaints were also made stating that the school could not ascertain the support needed by children with DDs or their families.

There were complaints of difficulties faced in providing learning support for the children at home and spending too much time helping them with their homework.

In association with the child's school attendance, the participants' source of concerns gradually changed to "being unable to fit with the group" and "bullying and secondary disabilities." Parents were concerned because they were unaware of effective methods of supporting the child's school life. The participants wished that classmates would know how to interact with their child. Though there were participants who knew the specific state of their child's school life, there were also those who did not know the state of their child because of the lack of status reports provided by the school.

Participants also mentioned difficulties in establishing a positive relationship with other guardians.

*Difficulties related to rehabilitation*

Participants had a sense of difficulties in carrying on with the rehabilitation of the child because of the lack of information related to rehabilitation. Furthermore, they were experiencing financial, physical, and time-related burdens and emotional conflicts for the continuation of such rehabilitation. In addition, they possessed the understanding that the disabilities of their child could not be cured with

their care.

Concerning the treatment of their child, there were families who could not receive treatment, despite desiring treatment, because of limited resources, such as doctors and hospitals (e.g., "there are few doctors who specialize in developmental disabilities," "the special hospital is far away," and "it is difficult to secure a reservation").

There were also cases where the participants felt suspicious toward the specialized organization they attended for rehabilitation and cases where the participants could not find an appropriate specialist to deal with their child's disability.

In addition, there was a situation where public assistance was unsuitable for the participant's child.

*Psychological burden*

The participants had a long-lasting anxiety concerning their children. Specifically, they had worries such as "Will my child be able to become self-sufficient in the future and hold a job?" and "Will my child commit a crime?"

Moreover, there were participants who became pessimistic by comparing their child with other children, wondering "whether my child can keep up with studies" or "whether my child is having difficulties interacting with friends or being part of a group."

Furthermore, there were participants who felt guilty for being unable to accept their own children's disabilities despite being mothers and being unable to tell the people around them about the disabilities.

Table 3. Support and needs

| Types of support/needs | Specific details (literature number) |
|---|---|
| Physical support/needs | Financial support (9)<br>Provision of information related to social resources (15)<br>Teaching smooth social resource utilization skills to guardians (9)<br>Support by specialists who possess both knowledge and skills (15)<br>Support that enables appropriate understanding of the child's behavior and characteristics (14)<br>Informing the child's development state and future vision as accurately as possible (14)<br>Support from the spouse and other family members (9) |
| Emotional support/needs | Proactive support for parent's mental and emotional stability (14)<br>Consultation and treatment for guardian's psychological disorder (9)<br>Application of specific support for guardians who have a child suffering from a mental/developmental disorder (9)<br>Support that provides understanding and consolation for parents' feelings (14)<br>Support for mothers that provides a listening ear to them on a regular basis (15)<br>Provision of a place that enables guardians to consult at ease with each other than with families or friends (15)<br>Continuous psychological support for mothers (15)<br>Exchange among guardians (9)<br>Support that enables mothers to secure time for relaxation (15)<br>Being supported by exchanges with and advice from mothers with a child with DDs (16)<br>Being supported by the understanding and cooperation from husbands and parents (16)<br>Being supported by the support of those who understand within the community (16)<br>Wanting support where one can talk to someone on a regular basis (6)<br>Wanting a place where one can consult with ease and feel secure (16, 26) |

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|---|---|
| Support/needs focused on children | Further enhancement of welfare support for the child (9)<br>Support for the child and family that focused on the strengths and positive aspects of the child (15, 23, 25) |
| Measures at facilities and specialized institutions | Strengthening the link with external specialized institution (9)<br>Strengthening the training of teaching staff members (9)<br>Allocating a designated specialist (9)<br>Providing support that notices the strength and development of the child and builds on them (16)<br>Wanting the strength and the development of the child to be mentioned specifically (16)<br>Necessity of having the family's state being ascertained objectively (19, 21, 23) |

## 2. Support and needs

Support required by mothers and families having children with DDs includes physical support, psychological support, and support focused on the child. There were also needs for appropriate measures at facilities and specialized organizations (Table 3).

### Physical support

Physical support includes financial support for the families, including rehabilitation fees. Furthermore, participants sought services in which options would be given to guardians and families raising the child, such as providing information related to social resources and notifying them about how to use such resources. In addition, the participants also required support from specialists, such as "explanations in which parents can appropriately understand the developmental state and behavioral characteristics of the child" and "support that can depict the future state as much as possible." Moreover, participants wished for physical support from their spouses and other family members.

### Psychological support

Psychological support required by the participants includes more active support for mental and emotional stability of parents and families. The need for diagnosis and treatment of mental illnesses concerning psychological complaints that were manifested has been indicated. A support that understands participants' emotions and consoles them by becoming involved with families facing difficulties in a sympathetic manner was also sought. Furthermore, the analysis result suggested the importance of providing mental health support for the participants in a long-term and continuous manner. An assistance method that provides a place for interaction among guardians and enables them to consult regarding their concerns and support one another, thus helping them gain emotional support, is required. Another method mentioned was to provide time during which mothers can leave housework and child caring behind, leading to emotional support. Literature 16 reported situations where participants were supported by those around them (e.g., "I am supported by the understanding and cooperation from my husband and my parents," "I am supported by the help of those who understand in the community," and "I am supported by the interaction and advice from mothers who also have a child with DDs.")

### Support focused on the children

Concerning support focused on the children, the participants wished for further enhancement of welfare support toward children. In particular, they desired support that focused on the strength and positive characteristics of those with DDs and further strengthened these characteristics.

*Support sought from facilities and specialized institutions*

From facilities and specialized institutions, participants desired support such as the enforcement of connections with external specialized institutions, the enforcement of DD-related training of staff members, and the allocation of designated specialists. In addition, when the child could do more things with training, the participants felt that their child was slowly growing and moving forward. The participants stated that being informed of the positive aspects and development of their child verbally by the members of the institution and the specialists became a source of encouragement and support for child caring.

3. Support focused on families

Among the examined literature, there were some that conducted research with the aim of providing familial support (Table 4).

Table 4.  Familial support being provided

| Literature number | Familial support details | Results and reported details |
|---|---|---|
| 1 | School advisor's intervention Familial support that promotes acceptance through consultation with guardians | Participant is in a conflicting relationship with the school party concerning the aspect of assistance. It is important to provide familial support by interacting with guardians in a psychoeducational manner. |
| 2 | High-functioning autism/Asperger's syndrome study seminar | The seminar advanced the parent's understanding of their child. The effects of the study seminar were seen after some time. |
| 7 | Training for the parents of a child with DDs Examination of efficacy via 29 cases | Functional improvements were seen as a result of training, with reduction in the severity of noticeable inattention, movement, and impulsivity. |
| 8 | The effects of training for mothers who experience difficulties regarding caring for a child with DDs | Training reduced the secondary disability of the child. Generalization of training effects requires developmental support coordinated with educational institutions. Training is also significant from the perspective of early rehabilitation support. |
| 16 | Camp activities that stimulate sensory perception and movements | Stabilization of autonomic nervous system activity and stress reduction Promotes the activation of the frontal lobe restraint function |
| 20 | Effectiveness of the group-based Positive Parenting Program with Japanese families raising a child with developmental disabilities: A longitudinal study | The rearers' perception of the child's behavior and child caring became positive, improving their emotional state and child caring skills. The problematic behavior of the child decreased, significantly increasing the sense of empowerment of the families. |

Literature 1 discusses an intervention that promotes acceptance by school advisors and doctors in a case involving difficulty in the acceptance of disabilities. However, it was ineffective and instead reported that the family was rather in conflict with the school and medical team concerning the aspect of support.

Literature 2 involved conducting a study seminar on high-functioning autism and Asperger's syndrome for families. Consequently, the understanding of the families toward their children was promoted. Furthermore, the effect of the study seminar was sustained even after some lapse of time.

Literature 7, 8, and 20 reported that, as a result of examining the efficacy of parent training, the sense of difficulties parents felt toward dealing with their children with DDs was alleviated, and their mental health improved. It was also suggested that the secondary disability of the child was reduced due to the training. Moreover, it was reported that the training was also important from the perspective of providing an early rehabilitation support before consulting a medical institution.

Literature 16 stated that a camp was held to stimulate the sensory perception of children with DDs and promote exercises, providing comprehensive familial support. The literature reported that through the camp activities, the autonomic nervous system activities of the children were stabilized and their stress was reduced along with the promotion of the activation of the frontal lobe's restraining function. However, no intervention was implemented for parents or other family members, and the literature did not mention any changes in the outcome with families before and after the camp.

**Discussion**

Research trends and participants

The amount of literature focusing on families with a child with DDs has been increasing in recent years. This can be attributed to the impact of the Act on Support for Persons with Developmental Disabilities (Ministry of Education, Culture, Sports, Science and Technology, 2004), the 2005 revision of the Child Welfare Act (Ministry of Health, Labour and Welfare, 1947), and the 2011 revision of the Child Welfare Act (Ministry of Health, Labour and Welfare, 2011). However, such literature is sparse, and further accumulation of results is required.

The majority of participants in the research considered were the main rearers. Given that Schuntermann reported the burden on the siblings of children with DDs, findings on each family member's reality of life and on the support required by them need to be accumulated in Japan as well (Schuntermann, 2007).

Research contents

1. Realities of difficulties

As a result of the analysis, the difficulties of families with a child with DDs were classified into six categories: everyday difficulties, difficulties related to the child's behavior, difficulties concerning the familial relationship, education-related difficulties, rehabilitation-related difficulties, and psychological burden.

Among these categories, difficulties related to the child's behavior were mentioned most frequently. Most of the child's behaviors mentioned as problematic were symptoms of DDs. The participant family felt great difficulties with the child's problematic behavior pertaining to DDs and also indicated it as the fundamental cause for everyday difficulties, education-related difficulties, and psychological burden. In general, it was observed that the difficulties related to the behavior of the child greatly impacted the lives of families with a child with DDs.

The content of difficulties related to familial

relationships, education-related, and rehabilitation-related difficulties reported in Table 2 infers a situation in which participants do not have a person or lack opportunities to consult their household or school, thus becoming isolated in terms of childcare. In particular, there were many statements that indicated the isolation of mothers, such as "my husband does not understand how difficult childcare is" and "my husband does not accept the child's disability." There was also a case of conflict between a participant and the school officials concerning the guidance and support provided to the child. To prevent the isolation of participants with regard to childcare, it is crucial to hold seminars on disabilities for parents and family members as well as set up a regular place for discussion that provides a connection between each specialist and other parents.

Based on the fact that Table 2 shows "the lack of specialists on developmental disorders" regarding rehabilitation-related difficulties and "the lack of the understanding of developmental disorders in educational institutions" regarding education-related difficulties, the participants experienced difficulties in raising the child without being able to rely on specialists or public institutions. However, these rehabilitation-related and education-related difficulties that parents face are believed to also decrease the qualities of the child and not just the parents. The analysis showed that there are discrepancies in the content of rehabilitation and the quality that the participants received depending on their residential area because of the lack of specialists and specialist institutions on DDs in Japan. It is necessary to develop a system in which participants can attain services of a certain level, irrespective of where they live.

2. Support and needs

Literature 8 had a case of a mother who attended sessions at a psychosomatic medicine and psychiatric practice after having lost her confidence because of having a strong sense of rehabilitation-related difficulties. Literature 9 reported on parents' depression, neurosis, personality disorder, schizophrenia, and alcohol dependency based on survey results. It was believed that the behavior and conduct of children with DDs affected the state of parents' health, including mental health. Thus, the literature suggested that providing psychological support and intervention for families that have a child with DDs is indispensable.

What is considered most important is support that understands parents' emotions and provides accompaniment. In reality, the evaluation and understanding of parents who have a child with DDs were different than those of specialists. Literature 11 showed that specialists evaluated children based on observation and research conducted in one setting whereas parents evaluated their children over a long period of time. Therefore, the parents' evaluation was higher than that of the specialists. In contrast, parents also felt that specialists did not understand the difficulties of raising their child. Specialists should consider the possibility of there being discrepancies between their judgment and parents' perception of their children and their sense of difficulties in child caring. Thereafter, such specialists should actively provide support to further stabilize parents' mental and emotional aspects. Providing an opportunity for guardians to interact is one way in which specialists can support them in a feasible manner within a community.

Regarding the support focusing on the children, the analysis demonstrated that participants' need of support also extended to the future of the child (i.e., school attendance and employment) and not just the child's current phase of life. In particular, they sought support that focused and built on the strength and positive aspects characteristic to DDs. Many concerns were raised on how school teaching staff lacked the understanding of DDs and did not comprehend how

to deal with them. Furthermore, based on statements that stipulated that the child's quality of life differed depending on the teacher's qualities, the improvement and support sustained at school, where children spend their time outside the household, was considered indispensable. It is essential for all teachers to support children with DDs during their school life and deal with their families. Moreover, promoting the teachers' understanding of DDs for such support to continue in future was deemed to be an issue.

Participants viewed hospitals and rehabilitation institutions as essential support resources. They perceived the growth and progress of their child when their child could do more things through rehabilitation. Furthermore, they obtained encouragement and support by having the strength and development of the child pointed out objectively by staff members. On the other hand, there were participants who could not receive specialized support despite wanting to proceed with rehabilitation (Literature 13). First and foremost, an institutional environment is required for rehabilitation support. Thereafter, the improvement of specialized support (i.e., rehabilitation) needs to be planned, along with increasing its quantity and quality, such that more children and parents can receive such services.

3. Support focusing on families

It is crucial to ascertain the needs of the families when providing support. Literature 15 mentions such situations where information does not reach families. These scenarios include the participants not receiving any information at all at their kindergarten (such as lectures related to DDs) and on the education of children with DDs in schools that the participants have to select for their children. The literature also discusses a situation where the public assistance provided varies from the needs of the participants. It is necessary to conduct preliminary research on the types of disabilities suffered by the

children who are the target of the assistance and the type of assistance they need.

In addition, it is crucial to plan the support to be provided in conjunction with society's events. Literature 11 reports the support for children and adults with DDs during the Great Tohoku Disaster that occurred on March 11, 2011 and proposed "registered evacuation sites," in which evacuation sites are to be determined in advance. Planning support for unusual events in such a manner may lead to reducing the family's anxiety as well as providing psychological assistance to them.

It is inferred that alleviating the symptoms of children with DDs (Literature 16) will also alleviate the difficulties of dealing with a child with DDs in everyday life (Table 2). Parents themselves attending seminars (Literature 2) to develop the acceptance and understanding of disabilities and acquiring specific childcare skills in parent training (Literature 7, 8, 20) are believed to be able to alleviate the difficulties in dealing with their child in daily life. On the basis of these findings, it can be concluded that familial support should be provided to both children and family members and not just either one of them. Some of the literature consulted in this study also discussed support given to only one party. However, the findings from the analysis suggested the necessity of providing comprehensive support to both parents and children or focusing on the family collective.

**Conclusion**

In this review, difficulties in families' daily life were classified into six categories, and support that families required was classified into 4 categories. The results suggested that specialists need to assess everyday difficulties of families with a child with DDs from various perspectives, using issues related to the behaviors of children with DDs as a

beginning. Furthermore, they also suggested that parents' mental and emotional stabilities need to be promoted more actively. Though the review clarified the overall picture of the realities of life of Japanese families having children with DDs, the support they want, and the actual assistance they receive, the research is still inadequate. Further research needs to be conducted in Japan in future. Based on the findings of such research, support for both the parents and the child and comprehensive support focusing on the family collective should be planned and executed.

## Acknowledgments

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**報　告**

# 発達障害児をもつ日本人家族が直面する困難実態と必要とされる支援に関する文献検討

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【要　旨】本研究では、発達障害児をもつ日本人家族が直面する困難実態と必要とされる支援に関して現存する研究を要約し、その所見を明らかにし、同様の家族に特異的な介入方法を包括的に探索することを目的とした。英語の文献に対しては Pubmed 及び CINAHL を用いて、日本語の文献に対しては医学中央雑誌を用いて、検索した。2005年から2014年まで刊行された原著及びレビュー論文を対象とした。その結果、困難実態は 6 つのカテゴリーに分類された。中でも、「児の行動に関する困難」では多くの内容が抽出された。このカテゴリーの内容は総じて発達障害児をもつ家族の生活に大きな影響を与えていた。家族が必要としている支援については4つのカテゴリーが明らかになった。特に、親に対する心理的情緒的支援が切望されていた。本レビューは、専門職者が発達障害児をもつ家族の日常的な困難について、発達障害児の行動に関することをはじめとして様々な視点から評価する必要があることを示唆した。更に、親の心理的情緒的安定を図るためにより積極的に支援する必要がある。日本では、発達障害児の家族に焦点をあてた研究を絶えず蓄積していく必要がある。そのような蓄積からの所見をもとに、親子双方への支援や家族全体に焦点をあてた包括的な支援を計画していく必要がある。

キーワード：発達障害，困難，家族，文献検討，サポート