

# Needs of Support Considered from the Free Description of the Sleep Survey for Normal Children and Disabled Children

発達障害の子どもは健常な子よりも高率に睡眠障害を持っている。それが養育者の愛着形成を妨げ、育児ストレスを引き起こすのだ。その対策は……

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## Abstract

There is a distinctive difficulty in raising disabled children. It is reported that such difficulty causes hard upbringing for their family including parents, frequently merges sleep disorders to ADHD and PDD, and is also one of the factors of abuse. We conducted a questionnaire survey in order to clarify parents' needs for support from the free description of sleep survey for normal children and disabled children, and analyzed the answers obtained from the parents of 144 disabled children (55.6%) and 68 normal children (26.0%). Among parents of disabled children, needs for support were classified into: "parental anxiety and concern," "demand for government," "problems from developmental disorder," "demand for community and society," "parents' own trouble and heartache," "cooperation and understanding of the family." Those among parents of normal children were the following: "parental anxiety and concern," "demand for government," "health problem," "demand for the family," "demand for community and society," and "others." From the above results, the differences and characteristics became apparent. Among the parents of disabled children, life security after the death of parents, demand for government or community and society, and cooperation of their husband and family were especially urgent concerns; and the parental anxiety and concern common in two groups were found to be different in detail. It is determined from these needs that the demand for government and noncooperation from the family greatly affects the mother's parenting stress and anxiety, and from the viewpoint of description about divorce and abuse, support measures are urgently needed.

**Keywords** ADHD, PDD, Sleep, Abuse, Child care stress

## Introduction

According to a survey of Japan nationwide, the number of children staying up late is rapidly increasing. In the questionnaire survey conducted in 2000, more than 50 percent of the children above fifth grade complained of trouble waking up. Particularly Japanese children tend to stay up late compared to other countries<sup>1)</sup>.

Good quality sleep is especially important for infants in the development phase of the brain<sup>2-4)</sup>. However, when the functions of parenting do not work in the background of the various causes of modern society which the environment surrounding the children is being intricately intertwined, pathology and accident have appeared as elements which form daily life, including sleep, diet, exercise,

interpersonal relationships and stress<sup>5</sup>). Various disturbances of life, such as decline in the quality of sleep, reduction in sleep time, delay of the wake-up time and bedtime, day-night reversal and withdrawing, are considered to be factors for the tendency of the night type in Japanese society which cannot be solved only by the efforts of individuals. Among disabled children whose parents have distinctive difficulty in raising, sleep disorders merge in a high rate compared to healthy children<sup>6-13</sup>), which interferes with the formation of emotional attachment of parents, and the strong parenting stress leads to maltreatment<sup>14,15</sup>). In order to put children to sleep, it is important to have a fixed order and a certain level of leisurely time, which is called “soporific action,” and for parents to have awareness of the children’s need for sleep<sup>16</sup>). However, there are not so many parents who are aware of the importance for children’s sleep and having high discipline consciousness<sup>17</sup>). In addition, the sleep disorder of disabled children is a deep problem for parents, and this problem is a “living pathology” itself, different from normal children. Rebuilding of life in general including sleep of childhood, in the formative years of basic lifestyle, in short, the “life clinical” is especially important<sup>18</sup>).

Therefore, we have conducted a survey research in order to determine the realities of sleep of disabled children and their parents (Shimomura et al, 2011-2013: Academic Research Grant Program: Foundation (C) Issue number: 23593351). Results reveal that parents of disabled children are dramatically different from those of healthy children, such as the decline in the quality of sleep of disabled children including developmental disorder, anxiety about the future of children and parenting stress.

## 1. Sleep survey for disabled children and their parents

From September to late December 2011, we conducted a self-administered questionnaire survey of the 261/1067 parents (collection rate 24.5%) in support schools and developmental disabilities facilities in O Prefecture and developmental disabilities

facilities in I Prefecture, and 262/524 (collection rate 50.0%) children in A Kindergarten and B Kindergarten, which are normal children facilities for comparison. The method of analysis was following: we performed statistical processing using the statistical software SPSS19.0J, set the significance level as 5% and analyzed content of the free description qualitatively. As ethical considerations, we have done this after the approval of the B University Research Ethics Review Committee and with the consent of the collaborators.

### (1) *The basic attributes of respondents*

The average age of parents was 40.2±5.6, and mothers and fathers account for 93.4% and 4.9% respectively. Mothers’ occupation was following: stay-at-home mother 64.3%, mother with part-time job 19.9%, and mother with full-time job 10%. The average age of children was 9.1±4.6, and male-to-female ratio was 3:1. Disorders were classified as pervasive developmental disorders that include autism, autism spectrum, Asperger syndrome (PDD) (53.3%); mental retardation due to hereditary, congenital disease (intellectual disability) (28.4%); attention deficit hyperactivity disorder (ADHD) (0.4%); developmental disorder not otherwise specified (0.4%); disorders due to heart disease, etc.; and no answer (11.1%). This data includes not only children with developmental disabilities but also those with other disorders.

## 2. Purpose of research

The purpose of research is to clarify needs for support and thoughts of parents from the contents of the free description through the sleeping survey of disabled children.

## 3. Approach

Subjects: Parents of support schools and facilities in the region K.

Period: From September to late December 2011

**Method:** We conducted a self-administered anonymous questionnaire. We explained the research in advance to the person responsible, asked the person to distribute the questionnaire to the parents and collected it by using the return envelope.

**Content:** General attributes of the disordered children and families, life rhythm of the children, questionnaire and free description of sleep realities.

**Methods of analysis:** Free description was obtained from 145 parents (59.7%) out of 243 parents of disabled children (total response rate of 95.48%, and from 68 parents out of 257 parents of normal children (response rate 49%). We repeated analysis of the two descriptions until there was agreement between the researchers, and finally we ensured reliability by categorizing the contents of each description.

**Ethical considerations:** We obtained approval of the B University Research Ethics Review Committee, with the consent of the subjects regarding the purpose of the study, methods, freedom of participation, protection of personal information, strict storage of data, and publication of results.

## 4. Results

We listed randomly the examples of the actual analysis process of free description obtained from parents with disabled and normal children.

### *Disabled children Description Case 1*

I feel anxiety about the future when I die and nobody can look after my child. Currently there is no anxiety because my husband, my parents, and my brother cooperate with me very well, but I feel anxiety when I think about the years ahead. In addition, I am also anxious about disasters because my child cannot get used to places different from the house, and we do not have contact with people in the community.

### *Analysis*

Researcher A	1. The fear of life of children in the future 2. The anxiety for the duration of cooperation among family members 3. Anxiety at the time of a disaster
Researcher B	1. The fear of life of children in the future 2. The anxiety for the duration of cooperation among family members 3. Anxiety at the time of a disaster
Researcher C	1. The fear of life after the death of the parent in the future 2. The anxiety for the duration of cooperation among family members 3. Anxiety at the time of a disaster
Integration	<b>Parental anxiety and concern</b> 1. The fear of life after the death of the parent in the future 2. The anxiety for the duration of cooperation among family members and at the time of a disaster

### *Disabled children Description Case 2*

Lack of cooperation of the husband. I consult him, but he imposes all the responsibility to me, saying that he is busy and I am the mother. Ultimately we divorced. In the end he tried to cooperate, but it was too late. It is quite tough for parents to have a disabled child. I am supported by my parents and sister who are close to me and consult and cooperate with me. I think it would be painful to be in a place with no acquaintances around me.

### *Disabled children Description Case 3*

I'm always frustrated by the behavior of my disabled son (first grade in junior high school). During the daytime I am supported by support school and helpers, but when he comes home I feel absolutely fed up with his behavior, and it is tough to suppress my emotion. I become desperate when I think this situation will continue. The only salvation is that my husband understands my feelings and looks after our child after he comes home, but it is painful when he is not at home. There is no fun.

### *Disabled children Description Case 4*

My child is already an adult. When he goes for a walk or shopping or is walking to the bus stop to go to the work station, he gets curious glances from

the general public. In worse cases, stones are thrown against him. I want the world to be a place where this kind of things doesn't happen. I want the society to become friendly to the weak. Then the incidents of kidnapping children and injury cases will not happen anymore.

There were 294 items of needs of parent of disabled children, and were classified into 9 categories. Figure 1 shows the results of analyzes of these contents.

The categories of the disabled children in descending order are as follows. "Parental anxiety and concern" 113 (38%), and the main contents were life after the death of the parent, growth and development, self-reliance of children, children's courses, social adjustment, symbiosis with healthy people, and night-type of sleep. "Demand for government" was 86 (29%), and the main contents were panic, sleep disorders, involvement with people, behavior, hypersensitivity of sensory organs, withdrawal and

others. "Demand for society" was 19 (7%) and the main contents were understanding of the specific developmental disorder, society in which people can live normally, assistance to people with developmental disabilities and others. "Parents' own trouble and heartache" and "understanding and cooperation of the family" were both 16 (6%), and the former main contents were childcare fatigue, parenting stress, conflict of mother, and the despair for the current situation. The latter was mainly about husbands; childcare cooperation, lack of understanding of childcare, demand for coming home early, disturbance of life, childcare cooperation of grandparents and brothers/sisters and others.

"Demand for schools and educational institutions" was 10 (3%) and the main contents were the understanding and quality level of teachers, and support education. "Health problems of the parents themselves" was 6 (2%), and the main contents were sleep disorders, peace of mind and others. "Others

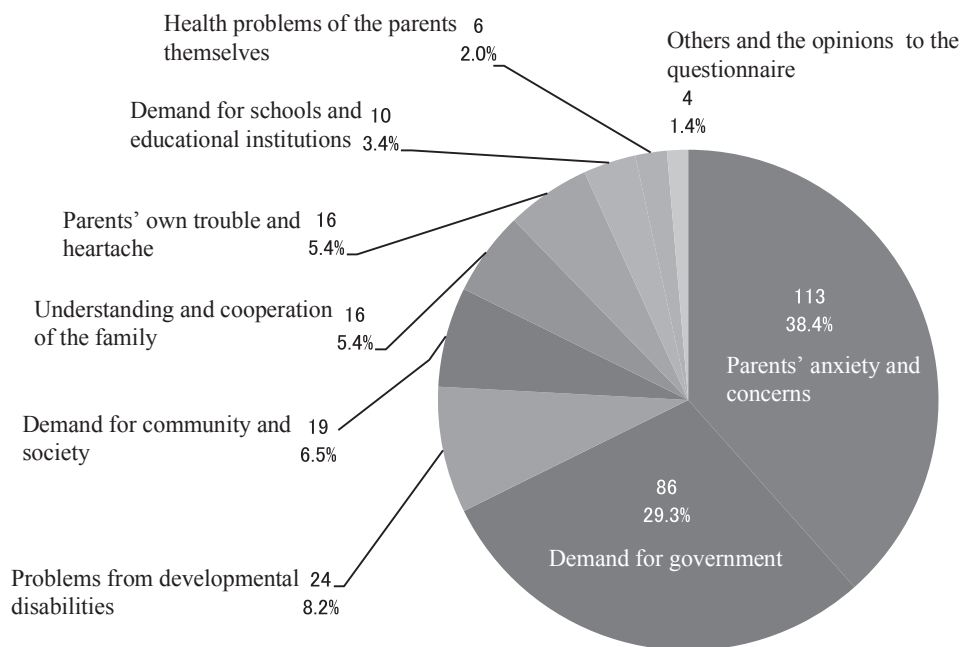


Fig. 1 Needs for support of parents of disabled children

and the opinions to the questionnaire” was 4 (1%). It was classified into 9 categories above.

Next, we again analyzed some description contents of normal children randomly in order to compare the needs of parents of disabled children and normal children.

### ***Normal children Description Case 1***

I want to let my children play safely. I want to let them go to lessons. Kick the children out because of the declining academic abilities and parents’ circumstances.

### ***Analysis***

Researcher A	A safe environment, education for children, neglect of the parent
Researcher B	A safe environment to play, education for children
Researcher C	A safe environment to play, education for children
Integration	<b>Thoughts of parents</b> (Safe environment: playing, education for children)

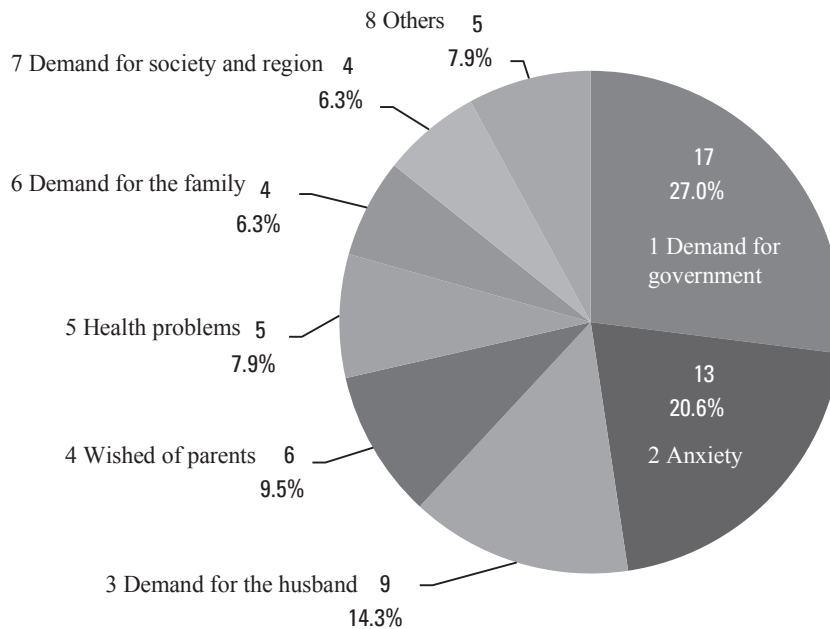
### ***Normal children Description Case 2***

I want the municipal governments to increase large parks where children can play with confidence. I want more parks in which children can play with balls. I want the control over the bicycles to be tightened because we cannot walk on the sidewalk with confidence due to them because cyclists ignore the signals and listen to music through earphones.

### ***Normal children Description Case 3***

I have anxiety about the difference in grades of children which occur from the difference between the economic powers of the parents.

We analyzed the description of 168 parents of normal children in the same way as those of disabled children. As a result, their needs were classified into 63 items and 8 categories. The category of the normal children in descending order is following: “demand for government” were 17 (27%), and the main contents were the improvement of child care



**Fig. 2 Needs of support for parents of normal children**

support and institutional, making the medical costs and vaccination free, security measures, structure and enhance of the education level, reduction of tuition, measures of children on waiting lists and others. “Parents’ own trouble” was 13 (21%), and the main contents were growth and eating behavior of children, the future of children, radioactive contamination, climate, politics, economics, education of children, education gap, educational expenses, changes in the educational environment, school life, relationships with friends and others. “Demand for husband” was 9 (14%), and the main contents were about discipline (too strict or too spoiling), non-smoking, staying up too late, the time of returning home and others. “Wishes of parents” were 6 (10%), and the main contents were relationships with friends, growth of children, independence, happiness of children, improvement of the rhythm of life and others. “Health problems” were 5 (8%), and the main contents were childcare cooperation, discipline and spoiling of grandparents and others. “Demand for society” was 4 (6%), and the main contents were enforcing traffic rules and safe driving, urban development where girls can walk with confidence: patrolling, and others. 5 items of “others” (8%) were parenting stress, concern to the net social, behavior problems of children, and others. Figure 2 below shows the analysis of these contents.

## 5. Discussion

There was a big difference in priorities and needs of support between the categories of parents of disabled children and normal children. The top category among parents of disabled children was “parental anxiety and concern,” and the most common concern was “life security after the death of the parent,” compelling concerns of parents about the life of children’s future including economic anxieties. The independence of children (wages) and social adjustment also account much for parents’ anxiety, and demand for educational support for children with developmental disorders, vocational training, employment, etc. rep-

resent the inadequacy of welfare policy and support system current in Japan. On the other hand, the top category of normal children was “demand for government” which includes the improvement of childcare support and institutions, making the medical costs and vaccination free, security measures, structure and enhance of the education level, reduction of tuition, measures of children on waiting lists and others. Subsequently the parents’ own troubles including growth and eating behavior of children, the future of children (radioactive contamination), education of children, education gap. In addition, in the demand for family, that for the husband was especially strong. In these cases, mothers are often supported by grandparents and brothers/sisters nearby, rather than husbands, and because this description was seen in both disordered and normal children, the need of child care support for both parents has been suggested. In the end, the most notable and serious description of disabled children regarded the lack of understanding and correspondence of people in general who support daily life toward developmental disorders. This has been largely responsible for child-care fatigue, parenting stress and emotional attachment formation of parents, especially mothers. In the field of education like kindergartens, nursery schools, schools and support schools, parents’ needs including the lack of understanding of teachers and other caregivers, deficiencies of facilities and systems, education content, education system qualities of teachers have become apparent. In addition, because there was a description of “night-type of sleep” obtained only from the parents of disabled children, the result of this study which supports the research report that the sleep disorders occur at high rates among disabled children, especially children with autism. Strengthening of the sleep-wake rhythm, which is a major base to adjust the lifestyle, leads to improvement of developmental disabilities<sup>19)</sup>, and is linked to improvement in the degree of fatigue of disabled children, the activation of cerebral, and prevention of malaise, sleep disorders, obesity, and truancy. In the rebuilding of life, including lifestyle, external factors involved in

complex life in general of parents and disabled children greatly affect, so there is a limit to the personal effort of parents. However, when the sleep of the parent is regular, that of children is also regular, so it is pointed that sleep consideration of parents affects the falling asleep, sleep maintenance and sleep health index<sup>20</sup>. In addition, Hayama et al (2011) says in the behavioral science approach to sleep problems in children under 5 years of age that behavioral insomnia in children of “discipline-deficient” (Diagnostic criteria for behavioral insomnia of childhood of American Academy of Sleep Medicine, 2010) has a relationship of reinforcement positive between parental nurturing behavior, and that avoiding child support action enhancing the behavioral insomnia in children leads to the prevention of sleep disorders and improves sleep<sup>21</sup>, which shows the need for sleep education for parents. For the preventive parent education methods for sleep, there is a behavioral science approach by sleep problems in children by the American Academy of Sleep Medicine intended for healthy children. Soporific action includes bathing, brushing the teeth, change of clothes, picture-book reading as aggressive ritual, and lullaby, as a program. It has been reported that there is a protective effect only by distributing documents written appropriate preventive action to prevent sleep problems<sup>21</sup>, so a sleep improvement program that is based on the individuality of the child is required. Other descriptions seen only among children disabled was the panic, sleep disorder, hypersensitivity of sensory organs and withdrawing of disabled children specific which could be the cause of parenting stress and childcare fatigue of parents, and conflict of the mother, despair for the status quo. These show not only the anxiety and concerns of parents, especially mothers of disabled children, but also the lack of clear mental and physical; and occurrence of mal-treatment and abuse is predicted. There is a need of support which does not place an excessive psychological burden on the mother, the early diagnosis and treatment by specialists, providing information necessary for the guidance of parents, adjustment of the environment, in

which mothers can engage in childcare with ease by cooperation of husband and family, parenting class, child-care support, support system such as making a “development support center & secure call center at the time of trouble” 24-hours a day by specialists (Japan Federation of developmental disorders<sup>16</sup>), guardian system when necessary, and provision of information such as “life insurance trust type.”

## 6. Conclusion

Enhancement of such facilities and systems required by the parents leads to the reduction of fatigue from child-care and excessive parenting stress of mothers. In addition, there is an urgent need to promote the dissemination of correct knowledge of the sleep education<sup>17, 22</sup>. These efforts will lead to prevention of aggravating factors of developmental disabilities and mal-treatments<sup>23</sup>. However, in order to promote the program of sleep improvement in accordance with the level of understanding and action of developmental disorders specific, it is necessary to consider the actual situation and countermeasures of more detailed sleep disorders. I want to deepen the research further in the 2014-2016 fiscal year Academic Research Grant Fund Foundation (C) Issue number: 26463436 “Research on life clinical based on sleep improvement program for children of developmental disorders.”

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