THE PAST, PRESENT AND FUTURE OF A COMMUNITY SUPPORT SYSTEM FOR CHILDREN WITH DEVELOPMENTAL DISORDERS IN MIYAKE TOWN: FOCUS ON LESSONS LEARNED AND NEEDS FOR THE FUTURE

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Abstract Introduction Support for early detection and intervention for developmental disorders in children as well as support that provides assistance for their families is vital for the establishment of community support systems for children with developmental disorders. We investigated the structure of a community support system in Miyake Town, Nara Prefecture, based on these two perspectives and examined the needs that may arise in future.

Methods Using a participatory action research framework, we interviewed community health nurses involved in establishing community support systems for children with developmental disorders, collected records of past community support activities and observed participants.

Results The community support system for children with developmental disorders in Miyake Town included the following 4 phases: 1) health examinations for infants; 2) first-stage intervention classes; 3) second-stage intervention classes, and 4) a network of people as a part of the community support system. Infants specifically suspected of a developmental disorder were screened during medical examinations when aged 1.5 years. Children subsequently participating in first-stage intervention classes were observed in second-stage intervention classes during kindergarten, if needed, and received continual support after entering elementary school. Of the children who participated in second-stage intervention classes, 75% were found or suspected to have developmental disorders when aged 1.5 years, and 62% had participated in first-stage intervention classes. Families of such children communicated problems in daily life associated with these disorders to a community support staff member, which promoted the establishment of a community support system.

Conclusions 1) Medical examinations of 1.5-year-old infants and children participating in first-stage intervention classes are important for the early detection of developmental disorders and for establishing community support systems for such children. 2) Families of such children are strengthened through the community support system. The bond formed between parents during first- and second-stage intervention classes has been a factor.

Key words : developmental disorders, community support system, early detection and intervention for developmental disorders

INTRODUCTION

Early detection and intervention for children with developmental disorders are extremely important issues concerning mother and child health. The results of Sugiyama's research in 1996 on the effects of early intervention for autism showed that disorders in children have become milder because medical examinations of 1.5-year-old infants are conducted more frequently[1]. These results indicate that early detection and intervention are extremely effective for children with developmental disorders. However, various problems associated with the detection of disorders at an early stage and conducting early intervention need to be resolved. Other problems, such as differences between husbands and wives in terms of acceptance of the child's disabilities, deterioration of affection between parents and chronic sorrow experienced by most families with children who have intellectual disabilities, have also been reported[2-4]. Therefore, it is important not only to detect developmental disorders at an early stage but also for families to have the strength to deal with the conflicts that may arise from developmental disorders suffered by the children, accept the fact that their children are disabled and make appropriate decisions in order to receive proper support[5]. Parents of disabled children also need to make adjustments so that they do not lose their autonomy and instead can decide which path to follow[6].

Therefore, support for early detection and intervention for children with developmental disorders as well as support that provides assistance for families with children who have developmental disorders is absolutely necessary for the establishment of a community support system for such children. The objectives of this report were to verify the structure of a community support system in Miyake Town in Nara Prefecture for children with developmental disorders based on the above-mentioned two perspectives and to examine the needs that may arise in future.

METHODS

Study design

In the present study, we used participatory action research. Researchers using this approach typically work with groups or communities that are vulnerable to control or oppression from a dominant group or culture. Researchers and study participants collaborate to define a problem, select an approach, analyse the data and determine the usefulness of the findings[7].

To address the challenge, we used participatory action research and developed a project in partnership with Miyake Health Centre, Nara Prefecture, which serves children with developmental disorders in a community care setting.

Data gathering

Community health nurses involved in forming community support systems for children with developmental disorders were interviewed. Records concerning past community support activities were collected. Participant observations were conducted.

Research period

Data were collected from September 2008 to August 2009. Analyses were performed from September to December 2009.

Analysis method

We clarified the structure of the community support system for children with developmental disorders in Miyake Town at first. We performed analyses to assess early detection and intervention for children with developmental disorders and strengthened the families of such children. Needs that may arise in future were examined.

Ethical considerations

The interviewees were provided with a verbal explanation of the objectives and methods of the research and were asked to give their consent to participate in the study. They also approved the public disclosure of the research results through media such as theses.

RESULTS

Community support system for children with developmental disorders

A community support system for children with developmental disorders in Miyake Town was established in 1994 with the enactment of the Community Health Act at a time when municipalities were playing a key role in public health activities concerning mothers and their children. The activities performed under this system included the formation of an early detection and intervention system for children with developmental disorders in Miyake Town (Fig. 1).

Midwives provided home guidance for nearly every newborn infant and mother in Miyake Town so that the mother could be involved in the development of the child from the early stages of infancy. Health examinations and screening were performed in about 90% of infants for problems such as delays in motor and intellectual development together with counselling support. Infants suspected of a developmental disorder were specifically screened during medical examinations conducted at 1.5 years of age. Children subsequently participating in first-stage intervention classes were placed under observation in second-stage intervention classes during kindergarten, if needed, and received continual support after entering elementary school. Diagnoses, evaluations and intervention for developmental disorders were usually performed from the time second-stage intervention classes began until

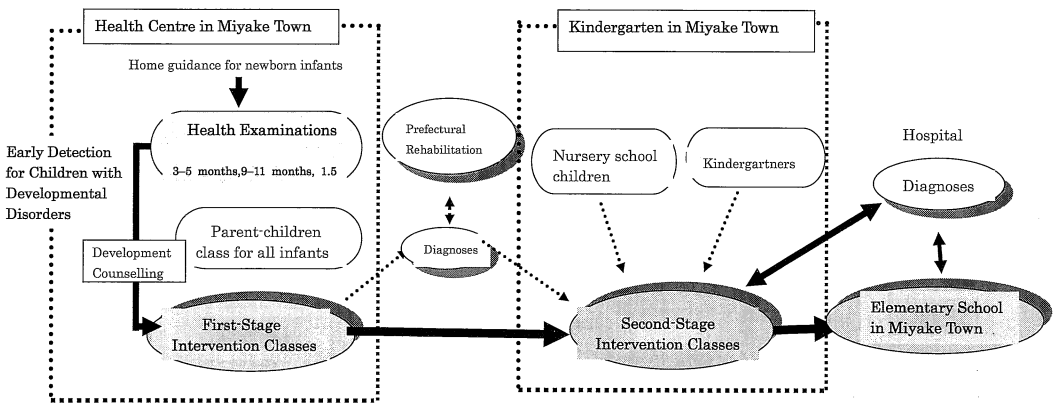

Fig.1. A Community Support System for Children with Developmental Disorders in Miyake Town

the time the children entered elementary school. Diagnoses were often made at healthcare facilities when the children were aged 4 years on average. The families started to sense that their children were different from other children, and therefore, decided to have their children participate in second-stage intervention classes and be examined thoroughly. Some children underwent examinations by a specialist physician while attending first-stage intervention classes and received specialized treatment at a prefectural rehabilitation centre, but this occurred for fewer than 1 person per year on average.

The community system for the support of children with developmental disorders in Miyake Town included the following 4 phases: 1) health examinations for infants; 2) first-stage intervention classes; 3) second-stage intervention classes, and 4) networks comprising the community support system.

Health examinations for infants

Health examinations for infants were implemented to detect problems such as developmental delays and illnesses in infants at an early stage and to provide appropriate guidance. Miyake Town distributed maternal and child health handbooks after notification of pregnancy and provided support, such as health examinations, for pregnant women. Midwives then visited the mothers after delivery and provided health guidance together with information concerning child raising. Health examinations were performed in 90% of children aged 3–5 months, 9–11 months, 1.5 years and 3.7 years. The staff consisted of physicians, dentists, community health nurses, clinical nurses, nutritionists and dental hygienists.

Possible developmental disorders were usually detected during health examinations of children aged 1.5 and 3.7 years. However, prior to this age, developmental disorders were suspected in infants aged 3–5 months and 9–11 months who showed delays in their development on examination and when mothers experienced difficulties raising their children. Hence, efforts were made to detect developmental disorders in children at an early stage, to provide health examinations and child-raising guidance to the parents of every child during the examinations performed at each period and to constantly monitor each child's growth and development.

First-stage intervention classes

Prior to first-stage intervention classes, community health nurses confirmed with the parents by phone and through visits the development of children who required observation based on the results of medical examinations conducted at 1.5 years of age, and referred them to places such as healthcare and intervention facilities. In several cases, the parents were told by community health nurses that their children were underdeveloped, leading to biases towards disorders and loss of motivation to receive intervention. In addition, there were cases in which mothers and their children found it difficult to attend an institution for children with disabilities because of long distances to travel, and some in which attendance had to be delayed for nearly a year, further increasing the parents' anxiety.

During first-stage intervention classes, families whose infants were suspected of having developmental disorders during medical examinations conducted at 1.5 years of age and were worried about developmental delays, those that were not worried about developmental delays even though their children were suspected of having developmental disorders but decided to

participate anyway, and those whose children were not suspected of having developmental delays but were nonetheless anxious, were provided with childcare in an established programme which allowed the infants to play freely and parents to learn about development. Parents were encouraged to participate mainly by providing them with explanations for delays in their children's development and areas of slow progress during medical examinations conducted at 1.5 years of age, followed by an explanation that intervention classes may enhance their children's development. Based on the observations made in first-stage intervention classes, participation in second-stage intervention classes during kindergarten was suggested if needed.

First-stage intervention classes were conducted 8 times per course with 2 courses per year. The staff consisted of three nursery teachers, one community health nurse and one development counsellor. The objective was to show parents how to interact with their children by having pleasurable experiences by playing games and to realize the challenges that their children face. During a 30-minute free-play session, teachers looked after the

Table 1. First-Stage Intervention Class

Content

① **Schedule**

9:30～Free Play session
10:00～:Roll-call followed by contact play between the child and the mother
10:15 Snack
10:30 Established program
11:00 Picture-story show
11:15 Going back home

② **Established Program**

- Physical play (Balloon play etc.)
- Touch play (Water・Flour・Paste etc.)
- Walk
- Cooking

③ **Lectures**(Theory of development)

Participant's development problems n=15 (2008)

- Language development problems 9/15 children
- Social relationship problems 6 /15 children
- Behavioural problems 6/15 children
- Child-rearing anxieties 4/15 children
- Mother and child relationship problems 3 /15 children
- Neuromotor development problems 1/15 children

children and the parents spoke freely among themselves. The parents could express their worries and anxieties while building relationships with other parents before their children entered kindergarten. Thus, problems that were often seen in follow-up classes after medical examinations of 1.5-year-old infants, such as isolated mothers and an atmosphere in which they refused follow-up classes, were rarely seen in first-stage intervention classes (Table 1).

A total of 15 groups of families participated in 2008. Of these groups, seven were families that were worried about developmental delays in their children, four were those that were not worried about their children's developmental delays but decided to participate in first-stage intervention classes anyway and four were those of children with no developmental delays but who were nonetheless anxious.

Activities performed during the first-stage intervention class were detailed in a town report describing the activities of parent–children class, which was directed at all infants. This report was offered to all families in Miyake Town regardless of whether the family included any children with a developmental disorder, so that the general town citizens could understand them.

Parents with children who have developmental delays feel psychologically burdened when children from parenting classes play with each other. When they see their own children not being able to do things that other children can do, they may raise their voices and tell them to do better or they may pick up their children and stop them from playing. However, when parents learn how to interact with their children who have developmental delays during first-stage intervention classes, they see how their children's development changes while changes occur within themselves (Table 2).

Second-stage intervention classes

Approximately 90% of the children in Miyake Town enter kindergarten. Therefore, children who enter kindergarten after first-stage intervention classes include those with only moderate degrees of intellectual disabilities, and some of them require temporary nursery

Table 2. Parent-Children Class for All Infants

Content
1) Baby classes : 3–to14-month-old babies 3 courses are held during each year by one course 4 times
2) Infancy classes: 1.5-year-old to 3- or 4-year-old infants 3 courses are held each during year by one course 4 times
Participants (2008)
① Baby classes: 25 groups (Total number 88 groups)
② Infancy classes: 26 groups (Total number 98 groups)

teachers to look after them upon entering kindergarten.

However, two years after first-stage intervention classes began, mothers started to approach the community health nurses at health centres with concerns, such as whether the teachers would be able to understand their children's disorders, whether they would be able to understand the weaknesses of their children and whether developmental counselling would continue after their children entered kindergarten. Hence, second-stage intervention classes commenced in 1997 as a form of intervention after the children entered kindergarten. The classes were initially held at health centres but were later held at kindergartens.

Second-stage intervention classes serve to diagnose developmental disorders and evaluate intervention while this intervention is being conducted on children with developmental disorders, and if needed, on those who are suspected of having disorders based on observations made during first-stage intervention classes. The classes were mainly organized by kindergarten nursery teachers in charge of coordinating for special needs education, and the staff included one nursery teacher, one developmental counsellor and one community health nurse who had been involved since first-stage intervention classes. The goal of second-stage intervention classes was to form small groups in which the children can think for themselves and build social skills for self-help as well as ability to control their own emotions and actions. Details of the activities included in these classes are as shown in Table 3.

A total of 24 five-year-old children participated in second-stage intervention classes between 2005 and 2009. Eighteen of the 24 participants were suspected of having developmental disorders during their medical examinations conducted at 1.5 years of age,

Table 3. Second-Stage Intervention Class

Content
Morning Intervention Class (MIT) : Mainly 3-years-old
①Number of children:10
Afternoon Intervention Class(AIT) : Mainly 5-years-old
②Number of children:10
Schedule
MIT
(9:00)→ **MIT**(9:45)→Regular class(11:15)→Lunch→ Activities at regular class→Going Back home (14:00)
AIT
(9:00)→Activities at regular class→Lunch→**AIT** (12:45~14:15) →Going back home (14:00)
Staff
Nursery Teachers (Special need education coordinator) ,Community Health Nurse and Development Counsellor

Table 4. Number of 5-year old children in Second-Stage Intervention Classes, Method for Screening and Status at Follow-up

Year	Number of 5-year-old children in second-stage intervention classes		Methods for screening			Number of children identified who required welfare service	Number of participants in special-needs class
	Number of 5-year-old children in second-stage intervention classes	Five-year-old population	Number of participants aged 1.5-years health checkups(Numbers of participants in first-stage intervention classes)	Number of participants of age 3-years health checkups	Parent's report and detections by nursery teacher		
2005	1	61	0	0	1	1	1
2006	1	63	1 (1)	0	0	0	0
2007	10	51	7 (7)	2	1	2	4
2008	7	59	5 (4)	2	0	0	3
2009	5	55	5 (5)	0	0	0	2
Total	24/289 (8.3%)	289	18 /24(75.0%)	4/24 (16.67%)	2/24 (8.33%)	3/289 (1.04%)	10/289 (3.46%)

and 17 of the 24 had participated in first-stage intervention classes (Table 4).

These children participated in second-stage intervention classes once a week while receiving conventional education in classes at kindergarten on having completed first-stage intervention classes.

An intervention class newsletter was issued each month. During each term, child care visits by parents and meetings between the staff members and parents involved in the intervention were conducted. The goals of the meetings included looking at future child care activities to be conducted in the kindergarten and how to interact with children at home in the light of changes in children's development as conveyed by staff members, while also considering how the children were doing at home after the intervention. Instead of being held privately, these meetings were held with all parents who were concurrently participating in second-stage intervention classes. The parents could share information about the daily activities of their children who had the same disorders as those of other children, thus creating bonds between different families.

Nursery teachers have reported that by participating in second-stage intervention classes, children gain confidence and become able to play freely. Based on these results, we consider that interacting with children while focusing on an intervention for individual developmental issues in an environment where integrated child care is implemented is important.

Network of people from various occupations as a part of the community support system

Children who participated in initial first-stage intervention classes are now in high school. Some of them are receiving welfare services in the same areas under the Services and Support for Persons with Disabilities Act but they have needs arising from disorders that they did not have before. Networks are being formed among people from various occupations, ranging from those consisting of the initial community health nurses, development counsellors and nursery teachers to those consisting of elementary school teachers of special needs classes and even medical practitioners.

Sharing changes in children's development and having a deep common understanding of how to provide them with support are the basis of these collaborations formed in first-stage intervention classes. For example, when a mother expresses how a child's crying is irritating

her, people with different viewpoints coming from different occupations examine how they can provide her with proper support.

In second-stage intervention classes, the nursery teacher can have a deeper understanding of developmental disorders, detect new cases of suspected developmental disorders in children, consult with development counsellors and examine concrete ways of providing support through collaborations with people from various occupations.

Special needs teachers at elementary schools, and kindergartens are also trying to form collaborations through observations made during second-stage intervention classes in order to help preschool-aged children with preparations. Although there are only a few such instances, parents and teachers sometimes make use of developmental counselling services at health centres for consultation on how to handle problems concerning needs at home and school arising from issues and disorders in daily life, such as the child getting irritated and inflicting violence on others. This suggests that developmental counselling corners at health centres are not simply consultation centres for follow-up of infants after their health examinations but are rather services that people rely on for continual and consistent developmental support for children with developmental disorders.

Furthermore, these collaborations include not only community health nurses from health centres, development counsellors, kindergarten nursery teachers and special needs elementary school class teachers, but also other teachers. The sharing of daily needs arising from disorders seen in various cases serves as the basis for people of different occupations to collaborate. Others, including a child psychiatrist, have joined this network since around

Table 5. Lecture on Children with Developmental Disorders

・2008 **Subject:** Understanding and Support for Children with Delayed Development **Content:** 1)Features of Delayed Development 2)Diagnoses and Intervention of Pervasive Developmental Disorders 3) Individualized Support in Kindergarten and Elementary School **Participants:** Parents ▪ Nursery Teachers ▪ Teachers ▪ After-School Care Staff ・2009 **Subject:** Lecture "About Children with Slow Development" **Discussion** : (Parents Group) **Participants:** Parents **Subject:** Understanding and Support for Children with Slow Development **Content:**1) Diagnoses and Intervention of Pervasive Developmental Disorders 2) Individualized Education Support **Participants:** Elementary School Teachers

2008.

In 2008, families that had children with developmental disorders, nursery teachers, and elementary school teachers as well as others gathered to attend a lecture titled 'Understanding and Supporting Children with Delayed Development' presented by a child psychiatrist (Table 5). A questionnaire survey was conducted before the lecture to identify the topics families wanted to discuss during the lecture. Many families expressed a need for counselling about how to interact with their children on a daily basis, particularly when it came to discipline and how to scold them.

Secondary disorders, such as psychological symptoms, including sleeplessness, panic and anxiety, are expected to arise in children with age. Medical care, especially through collaborations with child psychiatrists, will become an important factor in handling these secondary problems. New study groups and systems are now being formed so that families can send distress signals when they fear disruption in their daily lives due to such secondary disorders. The response to these distress signals can include collaborations between concerned bodies in the relevant areas so that needs arising from secondary disorders can be met.

DISCUSSION

Support for early detection and intervention for developmental disorders

Evaluation of the community support system for children with developmental disorders in Miyake Town shows that there were 24 participants in second-stage intervention classes between 2004 and 2009. Of the 24, 18 (75%) were suspected of having developmental disorders during medical examinations conducted at 1.5 years of age and 17 (70.8%) had participated in first-stage intervention classes. Of these, six children participated directly in second-stage intervention classes once they were enrolled at a child care centre, and four of them participated on the basis of results of medical examination conducted at three years of age.

A national survey conducted by the Ministry of Education, Culture, Sports, Science and Technology showed that 6.13% of the children who attended regular classes had developmental disorders, such as LD, ADHD and high-functioning autism. According to the Annual Statistical Report of National Health Conditions of 2009, children who attended special needs schools or special needs classes at elementary or junior high schools and those who were receiving guidance from other special classes accounted for 2.17%[8]. In Miyake Town, 8.3% of the children born attend second-stage intervention classes and continue to do so in elementary school.

Shimizu stated that the objective of early intervention for children with developmental disorders is to establish some degree of improvement before they enter school and to prepare them in such a way that they receive education effectively[9]. With these objectives, Miyake Town is successfully detecting cases of developmental disorders or the possibility of disorders before the children are sent to kindergarten and providing them with timely support.

Evaluations of the effects of early detection and intervention for children with developmental disorders have not yet been conducted. Some elementary school teachers have

stated that handling children who have already attended second-stage intervention classes is easier for their schools, but it is necessary to gather more information from nursery and elementary teachers in order to fully understand the effects of early intervention while also considering the risk of the development of secondary disorders. Gathering information from families and conducting evaluations from a long-term perspective should also be considered in future evaluations.

Support for strengthening families

The statements made by the parents of children with developmental disorders were the main factors that promoted the formation of the system.

For example, the influence of mothers resulted in the establishment of second-stage intervention classes. Parents of infants and elementary school students can now receive developmental counselling at health centres for problems in daily life caused by developmental disorders. This is believed to be responsible for the formation of the network of community support for children with developmental disorders, with the influence of parents of such children being at the core. The foundation for this network is collaboration among community health nurses at health centres, developmental counsellors, kindergarten nursery teachers, teachers of special needs classes at elementary schools and other teachers, who could by means of this collaboration share their experiences of problems faced in daily life caused by various disorders suffered by the children.

Preventing secondary disorders and taking care not to disrupt the lives of either the children who have developmental disorders or others, such as their families, is important in early detection and intervention for children with such disorders. The network in Miyake Town has been formed for children with developmental disorders so that families

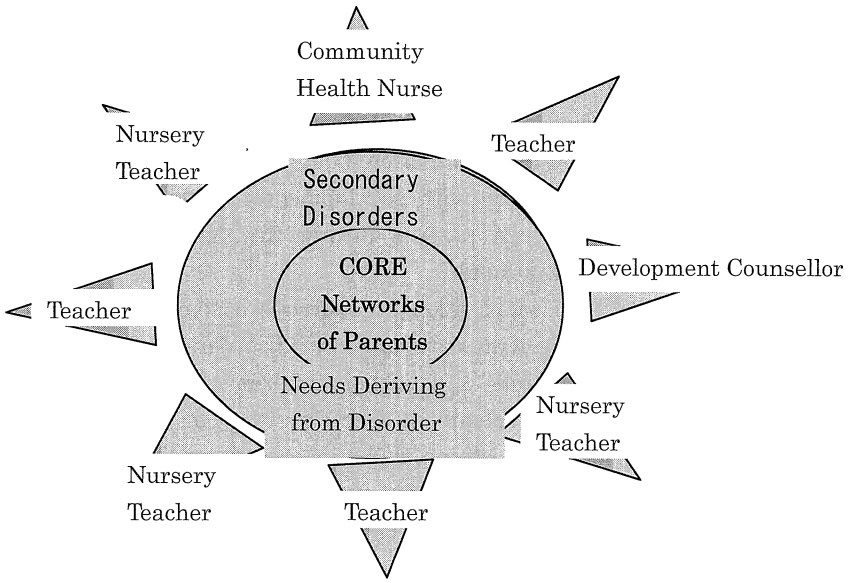

Fig. 2. Network Consisting of Parents and Collaborations with Individuals from Various Occupations Involved in the Community Support for Children with Developmental Disorders

transmitting distress signals concerning such problems arising in daily life can be examined by concerned bodies that can offer solutions (Fig. 2).

Efforts are currently being made to take the individuality of disorders into consideration through collaborations of various bodies that handle distress signals from families facing problems in daily life caused by disorders. A family's ability to cope is believed to be strengthened through its ability to transmit such signals, even though they may be small in number.

The bonds parents form between themselves is believed to have an effect on the strength of the family. Parents have stated that they acquire strength from the bonds that they have formed with other parents, and that they support and get support from other parents because they feel that the only parents who can understand their situation are those with disabled children. This is believed to be the result of parents who have children with disorders getting to know each other during first- and second-stage intervention classes where they form bonds with each other through daily interaction. This network among parents is thought to have a mutually beneficial effect and may be responsible for increasing the parents' strength.

CONCLUSION

Two points have become clear upon verifying the structure of the community support system for children with developmental disorders described in this report.

First, 92% of the children who participated in second-stage intervention classes were found to have developmental disorders or were suspected to have developmental disorders during medical examinations conducted at 1.5 years of age, and 62% of them had participated in first-stage intervention classes. Therefore, medical examinations of 1.5-year-old infants and attending first-stage intervention classes are believed to play an important role in the early detection of developmental disorders and the provision of a community support system for children with such disorders in Miyake Town.

Second, the communication of problems in daily life caused by disorders to concerned bodies by families of children with developmental disorders has promoted the establishment of a community support system. Families have been believed to be strengthened through the community support system for children with developmental disorders in Miyake Town. The bond that has been formed between parents during first- and second-stage intervention classes has also been a contributing factor.

This report does not verify the steps taken to establish a community support system for adolescents, adults and the elderly with developmental disorders, and the results discussed in this study are focused on infants and school children with developmental disorders. Collection of data on infants and school children involved in the support system, their parents and people from various occupations, including health, medical care and welfare, that concern developmental disorders is planned for future, so that community support systems aimed at the above-mentioned groups with developmental disorders can also be verified.

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