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The present paper examines the status of the education system for physically disabled children in Japan and its problems, based on the viewpoint of respect for children’s independence.

The education system for physically disabled children places emphasis on respect for the independence of children with physical disabilities, including the “time for independent activities”. In the field of health care, in which collaboration with the education system for physically disabled children is essential, efforts are being made to secure children’s right to participate, guaranteed by the Convention on Rights of the Child, to respect the independence of children with disorders and disabilities, and facilitate development and wellbeing.

The education system for physically disabled children is required to collaborate further with health care-related fields, including medical care, through encouraging respect for the independence of children with disorders and disabilities by ensuring children’s right to participation. It is necessary for the education system for physically disabled children to collaborate with the field of health care more closely through the promotion of respect for the independence of children with disorders and disabilities by ensuring children’s right to participate.

I. Introduction

The Japanese education system for physically-disabled children places emphasis on collaboration between education and health care.

In 1998, a “medical care model project in schools for the disabled” was introduced as part of the Japanese education system for physically disabled children. “Procedures for sputum aspiration in schools for the blind, deaf, and disabled (a request for cooperation)” was issued in 2004 based on the results of the “medical care model project in schools for the disabled”, followed by the implementation of a “project for the

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development of systems for the provision of medical care in schools for the blind, deaf, and disabled” in 2005. As suggested by the guidelines for the development of a system for the implementation of health care in schools for the blind, deaf, and disabled, collaboration between education and health care under the Japanese education system for physically disabled children primarily focuses on items related to the provision of health care.

Furthermore, the education system for children with physical disabilities and the field of health care have one thing in common: respect for the independence of children with disorders and disabilities. The education system for children with physical disabilities stipulates items related to the promotion of children’s independent activities. In the field of health care, the independence of children is respected by complying with the Convention on Rights of the Child, based on the EACH (European Association for Children in Hospital) Charter and other children’s charters established by individual hospitals. Studies have been conducted to examine collaboration between the education system for children with physical disabilities and health care, and these studies have primarily focused on the relationship between the system and medical care, including the status of school education for health care and desired school education for health care in the future. In recent years, there have been reports of the implementation of school education related to advice on independent activities in collaboration with the field of health care.  

Respect for the independence of children with disorders and disabilities is a basic right of children guaranteed by the Convention on Rights of the Child. It is significant to discuss collaboration between the Japanese education system for physically disabled children and the field of health care from the viewpoint of respect for the independence of children to promote the development and wellbeing of those children under the above-mentioned system.

II. Objective and methods

The present study aimed to promote respect for physically disabled children due to disorders and disabilities and to facilitate the development and wellbeing of those children by developing education systems for them in Japan.

The following paragraphs: review rules and regulations stipulated in the Japanese education system for those children in order to respect their independence; discuss rules and regulations related to respect for the independence of children in the field of health care; and identify problems, based on the results, to improve respect for the independence of children with disorders and disabilities by facilitating collaboration between the Japanese education system for physically disabled children and the field of health care.
III. Results

1. Respect for the independence of children in the Japanese education system for children with physical disabilities

The Japanese education system for children with physical disabilities actively promotes the independent activities of children with disorders and disabilities in relation to “advice on independent activities” stipulated in the curriculum guidelines for schools for students with special needs.

The revision of the curriculum guidelines in 1999 adopted a new subject: “advice on independent activities” to replace “nursing care and training”.

The goals for “advice on independent activities” are to: help individual children become independent, develop knowledge, skills, and habits required to improve or overcome disability-related difficulties learning and leading normal lives, and develop the basis for the harmonious development of psychological and physical aspects of children.

“Advice on independent activities” consists of elements required to conduct basic behaviors as a person, and improve or overcome a variety of difficulties due to disabilities. In the 2009 revision, “advice on independent activities” was classified into the following six categories: “Maintenance of health”, “psychological stability”, “development of relationships”, “recognition of environments”, “body movements”, and “communication”. The following paragraphs describe the details of the categories.

(1) "Maintenance of health"

Viewpoints of the maintenance of life, appropriate health management, and maintenance/improvement of health conditions required for daily lives

1) Keeping regular hours and the development of daily life habits

Thermoregulation, keeping regular hours required to maintain/improve health conditions including arousal and sleep, development of daily habits, clothing-related control, room temperature and ventilation, and development of healthy living environments including maintenance of cleanliness for infection prevention.

2) Understanding of medical conditions and life management

Understanding of one’s own medical conditions, efforts to improve them, improving understanding of lifestyle required to prevent disorders from worsening, and self-life management based on the findings.

3) Understanding of the conditions of the regions of the body and nursing care

Understanding of the conditions of injuries of nerves, muscles, bones, skin, and other regions due to diseases and accidents, and the appropriate provision of nursing care to prevent disorders from worsening.

4) Maintenance/improvement of health conditions

Appropriate health management in daily life to help children continue to exercise and prevent a decrease in their physical strength due to their disabilities.
(2) “Psychological stability”

Viewpoints of psychological stability, the promotion of smooth relationships, and development of bases for participation in society

1) Emotional stability
   Helping emotionally unstable children live while maintaining their emotional stability.

2) Understanding of situations and responses to changes
   Helping children reduce their feelings of resistance to specific places and situations, understand changing situations, and learn to behave appropriately.

3) Children’s motivations to become independent and overcome disability-related difficulties learning and leading normal lives
   Improving children’s motivations to reduce/overcome disability-related difficulties by understanding and accepting the conditions of their disabilities.

(3) “Development of relationships”

Viewpoints of a better understanding of children themselves and other people, the facilitation of smooth relationships, and bases for participation in groups

1) Basics of interaction with other people
   Helping children develop a basic sense of trust toward people, as well as the abilities to accept the actions of other people and respond to them.

2) Understanding of the intentions and feelings of others
   Helping children develop the abilities to understand the intentions and feelings of other people, and conduct appropriate behaviors according to the situation.

3) Understanding of themselves and coordination of their behaviors
   Helping children develop the abilities to understand their strong and weak points as well as the characteristics of their behaviors, and behave according to the situation as members of groups.

4) Basics of participation in groups
   Encouraging children to become actively involved in play and group activities: adapting themselves to groups and understanding procedures and rules for participation in groups.

(4) “Recognition of environments”

Viewpoints of the effective utilization of senses, recognition of their situations using spatial and time concepts as clues, understanding of relationships between environments and accidents, and proper judgements and behaviors

1) Utilization of the senses
   Helping children fully utilize their senses, including senses of vision, hearing, and touch.

2) Responses to the characteristics of senses and cognition
   Understanding the characteristics of the senses and cognition of individual children, helping them develop the abilities to process information and respond to individual characteristics appropriately.

3) Utilization of means for assisting or substituting for the senses
Helping children utilize auxiliary devices to understand situations by using their sensory organs, or use them to substitute for the senses.

4) Recognition of surrounding situations by utilizing the senses comprehensively

Helping children utilize their sensory organs and auxiliary or substitute means comprehensively to collect information, understand the status of the environment, and make decisions and behave appropriately.

5) Development of concepts as clues to cognition and behaviors

Helping children develop concepts, such as changes in the functions, attributes, shapes, colors of objects, sounds made by them, and space/time, and utilize them as clues to cognition.

(5) “Movement of the body”

Helping children learn basic movements required for daily activities and to perform tasks, and appropriately move their bodies in their daily lives.

1) Posture and basic skills related to exercise and body movements

Basic skills related to: improving and learning the maintenance of posture and the movements/actions of the arms and legs as the basics of body movements required in daily lives, prevention of joint contracture and deformation, maintenance/enhancement of muscle strength.

2) Maintenance of posture and the utilization of auxiliary means for performing exercise and actions

Helping children who have difficulties maintaining posture, exercising, and moving utilize a variety of auxiliary means and tools.

3) Basic actions required in daily life

Helping children learn to take care of themselves, including eating, excretion, putting on/taking off clothes, washing their face, taking baths, and basic actions required for learning, such as writing and drawing.

4) Ability of the body to move

Helping children improve their ability to move in daily life, including moving their bodies, walking, and the use of walkers and wheelchairs.

5) Actions required to perform tasks and their smooth implementation

Helping children: learn basic actions required to perform tasks, improve their skillfulness and continuousness, and develop the ability to perform tasks smoothly.

(6) “Communication”

Viewpoints of the ability for smooth communication according to situations and partners

1) Basic communication skills

Helping children develop basic skills to communicate using facial expressions, gestures, and tools according to the types and levels of their disabilities

2) Acceptance and expression of the language

Helping children develop the abilities to accept the intentions of partners and convey their thoughts using verbal language, characters, and symbols, to accept and express the language.
3) Development and utilization of the language

Helping children improve the abilities to develop language concepts that correspond to objects, phenomena, and their behaviors through communication, and learn systematic language.

4) Selection and utilization of means of communication

Helping children develop the abilities to select and utilize means and tools for smooth communication appropriately, including verbal language, characters and symbols, and devices and tools.

5) Communication according to situations

Helping children develop the ability to communicate independently according to the environment and their partner’s current situation.

2. Respect for the independence of children in the field of health care

In the field of health care, the development and wellbeing of children are being promoted through respecting their independence by securing their participation in the processes of health care-related decision-making that influence children.

The right of children to participate is a basic right of children, including Article 12 (right of the child to be heard), a general principle of the Convention on Rights of the Child. To secure the right of children to participate related to the field of health care, the United Nations Committee on the Rights of the Child adopted General Comment No. 12 “Right of the child to be heard” and strongly recommended that Japan and other contracting countries respect these rights in 2009.7)

General Comment No. 12 defines the right of children to participate as processes in which the views of children are taken into consideration in relation to decisions that influence children, policy development, and the establishment and assessment of laws and measures, including processes in which relevant views of children and their experiences are also considered (Para. 12-13).

General Comment No. 12 suggests, during these processes, that children shall share information and interact with adults based on mutual respect as well as learn how their and adults’ views are valued and results are formed, and adults shall develop their direct relationships with children.

To secure children’s right to participate, General Comment No. 12 specifies “five steps for the implementation of participation” and “nine requirements to be fulfilled in each of the steps”.

Regarding the “five steps for the implementation”, requirements for “preparation”, “hearing”, “assessment of the abilities of children”, “information (feedback) on the validity of the views of children”, and “complaints, remedies, and redress” were pointed out.

(1) Preparation

In the first stage: “Preparation”, it is necessary for adults who are responsible for

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7) General Comment No. 12 general comment on the right of children to be heard: children’s views in relation to decisions affecting them (2009).

listening to the views of children to make decisions on: how they should explain to children, when and where they should listen to children, and what children should participate, while taking into consideration their views, to secure children’s rights to express their views and receive explanations (Para. 41). The following are listed as adults who are responsible for hearing the views of children: “social workers, care providers, and other adults who influence children”, “people in charge of final decisions in groups, such as judges” and “physicians and other professionals” (Para. 42).

(2) The hearing
In the second stage: “hearing”, adults who are responsible for hearing the views of children are required to hear and take seriously the views of children who have expressed them after making their decisions. When hearing the views of children, adults should interact with them, rather than talking to them in a unilateral way, in comfortable environments for children when possible, instead of places open to the public (Para. 43).

(3) Assessment of children’s abilities
In the third stage: “Assessment of children’s abilities”, thorough analyses of individual children shall be conducted, and, when they are able to organize their views, their abilities should be valued. Furthermore, when children are able to organize their views in rational and independent manners, adults are required to consider the views as important elements for solving problems (Para. 44).

(4) Information on the validity of the views of children (feedback)
In the fourth step: “Information (feedback) on the validity of the views of children”, it is necessary to provide children with explanations of the results of the processes and how their views were taken into consideration during the processes to listen to their views seriously, not superficially (Para. 45).

(5) Complaints, remedies, and redress
The fifth step: “Complaints, relief, and compensation”, suggests the necessity of legislation to secure children’s rights and prevent their infringement, and the provision of reliable mechanisms that children can rely on without experiencing the risks of violence and punishment (Para. 46-47).

In addition, regarding “the nine requirements to be fulfilled in each of the steps”, it has been pointed out that the above-mentioned “five steps for the implementation of participation” should be taken based on the following (Para. 133-134):

(1) “Easy-to-understand explanations” of children’s rights to participate, their scopes, objectives, and influences should be provided using appropriate methods according to their sensitivity and age.
(2) Explanations that they will never be forced to express their views against their will and that they are allowed to withdraw anytime shall be provided to ensure children's initiative.

(3) Professionals involved in the activities of children shall “respect” their participation in their social and private lives.

(4) “Subjects related to the lives of children” shall be adopted to help them associate the subjects with themselves, and view the problems as important.

(5) It is necessary to “help individual children familiarize themselves with participation in activities”, so that they can: appropriately utilize time and resources, become confident that their views make a difference, and have opportunities to express them.

(6) “Comprehensiveness” shall be maintained to secure the rights to participate for all children.

(7) Preparations shall be made to hear the views of children, conduct activities with them, and effectively encourage them to participate in activities, and “educational support” shall be provided because children require those skills and support.

(8) It is important to “ensure the safety of children and consider risks” to minimize their risks of being subjected to violence and exploitation.

(9) It is necessary to fulfill accountability about how the views of children were understood and used, and how their participation will influence the results.

In addition, General Comment 12 stipulates the following requirements to secure children's right to participate in relation to the field of health care.

In the field of health care, it is advisable to involve children in the processes of decision-making related to health care in their social and private lives. Specifically, it is necessary to: provide children with explanations of proposed treatment methods, their effects, and results (Para. 100), and introduce measures to apply children’s views and their experiences to plans for the health and development of children, their implementation, and assessment (Para. 104).

In addition, the U.N. welcomed some countries’ decisions on the age at which children are granted the right to medical consent, and strongly recommended that the views of children be respected when they are able to express their views on their treatment (informed view), even if they have not yet reached the age of medical consent (Para. 102). The U.N. suggested that age restrictions should not be imposed on children’s rights to medical counseling and advice, and pointed out that it is necessary to secure these rights for all children. They also suggested that it is
necessary to adopt laws and regulations that allow children to access medical counseling and advice without obtaining consent from their parents, or secretly, when they are necessary from the viewpoints of the safety and wellbeing of children (Para. 101).

Moreover, since it is necessary to obtain informed consent from children when conducting medical and scientific research or clinical trials involving children, it is necessary for physicians and facilitators to provide them with explanations so that they can easily understand their rights related to participation (Para. 103).

IV. Discussion

The Japanese education system for physically disabled children has the following two problems in relation to collaboration with the field of health care:

The first problem is that the independence of children with disorders and disabilities is respected in only limited situations. The Japanese education system for physically disabled children stipulates that the independence of children shall be respected in relation to “advice for independent activities” provided with the aim of “helping children become independent, develop knowledge, skills, and habits required to improve or overcome disability-related difficulties learning and leading normal lives, and develop the basis for the harmonious development of psychological and physical aspects of children”. Under the current system, the independence of children is respected only when they attempt to become independent and overcome disability-related difficulties learning and leading normal lives.

On the other hand, in the field of health care, the independence of children is respected by securing their rights to participate to allow them to become involved in various processes of solving their problems. The areas in which the independence of children is respected include “processes of decision-making related to health care in social and private lives” such as “the introduction of measures to apply children’s views and their experiences to plans for the health and development of children, their implementation, and assessment”, or social issues related to their lives and pediatric health care. In fact, some activities of pediatric patients’ associations, including activities to support: interaction among children, learning from each other among children, and children’s approaches to their own independence and society, are conducted by children with disorders and disabilities themselves, and physicians and other health care professionals actively provide support for these independent activities of children.

As for the Japanese education system for physically disabled children, the necessity of ensuring children’s participation in the processes of the development of study plans and their assessment has been pointed out. Collaboration between the education system for physically disabled children and the field of health care shall be conducted so that the independence of children with disorders and disabilities will be respected by ensuring their
rights to participate not only in learning and their daily lives, but also in their social and private lives.

As the second problem, collaboration between the system and the field of health care is not sufficient to respect the independence of children with disorders and disabilities.

In this field of health care, the independence of children with disorders and disabilities is respected by securing children’s right to participate. Children’s participation is positioned as follows: “Processes in which the views of children are taken into consideration when: decisions that influence them are made, relevant policies are adopted, laws and measures are established or assessed, and processes in which the related views of children and their experiences are also considered”. During this process, children share information and interact with adults based on mutual respect, and learn how their and adults’ views are valued and results are formed. Therefore, children’s participation should be respected as an event in which adults can develop their direct relationships with children. The implementation of children’s participation consists of the following five steps: “preparation”, “The hearing”, “assessment of the ability of children”, “information on the validity of the views of children (feedback)”, and “complaints, remedies, and redress”. Regarding the above-mentioned five steps, the following nine requirements should be fulfilled: “the provision of easy-to-understand explanations for children”, “encouragement of children’s initiative”, “respect for children’s participation by professionals”, “relationships with the lives of children”, “helping children familiarize themselves with participation”, “comprehensiveness for all children”, “educational support for children’s participation”, “ensuring the safety of children and consideration of risks”, and “fulfilling accountability by explaining to children”.

The Japanese education system for physically disabled children is required to collaborate with the field of health care by respecting the independence of children with disorders and disabilities as well as providing medical care.

V. Conclusion

In the present study, challenges and problems related to collaboration between the Japanese education system for physically disabled children and the field of health care were discussed.

Under the Japanese education system for physically disabled children, “advice for independent activities” is provided with the aim of “helping children become independent and overcome disability-related difficulties learning and leading normal lives”, to respect their independence. On the other hand, in the field of health care, the independence of children is respected by “promoting children’s active involvement in the processes of solving their problems”, which is associated with the “processes of decision-making related to health care in social and private lives”.

The Japanese education system for
physically disabled children has problems in that the independence of children with disorders and disabilities is respected in only limited situations, and that the education system does not effectively collaborate with health care professionals to respect the independence of the above-mentioned people.

Therefore, the education system for physically disabled children should collaborate with the field of health care in order to respect the independence of children with disorders and disabilities by securing children’s rights to participate in their social and private lives, while taking into account positioning of “the processes of their participation”, “the five steps” in the implementation of participation, and “the nine requirements” to be fulfilled in the five steps.

Notes

1) Notification issued by the Health Policy Bureau of the Ministry of Health, Labour, and Welfare “Procedures for aspiration of sputum in schools for the blind, deaf, and disabled (a request for cooperation)” October 20, 2004 (Notification No. 1020008)


3) The following hospitals stipulate in their original charters for children that the Convention on the Rights of the Child shall be complied with in the hospitals.


