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日本の病弱教育制度と子どもの生活: WHO・UNCRC による勧告を基に

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### 日本の病弱教育制度と子どもの生活 - WHO・UNCRC による勧告を基に-

### Special Education Systems for Children in Need of Medical Attention in Japan Focusing on the Recommendations by the WHO and UNCRC

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In this study, we examined issues regarding special education systems, which need to be resolved to guarantee the participatory right of children with illnesses in their lives, based on the recommendations concerning children's lives and participation by the WHO and UNCRC (United Nations Convention on the Rights of the Child Committee on the Rights of the Child).

To promote the daily living functions of children with illnesses, it is required, in cooperation with them, to provide education to improve social factors (e.g., systems concerning activities and participation), through guaranteeing their right to participate based on the Convention on the Rights of the Child.

To realize this, we must establish special education systems, with which children's views can be introduced for planning curricula and programs regarding education and learning.

#### 1. Background

In Japan, although the number of births shows a decreasing tendency, the proportion of children with illnesses shows a tendency to increase in the intermediate or long term <sup>1)</sup>. Therefore, it is increasingly important to establish an education system with which children with illnesses can study while receiving treatment in hospital or at home.

In Japan, such children generally undergo special education that is targeted for those with physical weakness.

This education mainly focuses on children's lives, and it is now globally regarded as important to consider children with diseases or disabilities from the aspect of their participation.

#### Objectives and Methods

Previous studies pointed out the current state and future of the management of children's lives in special education, in relation to entity <sup>2)</sup> and school curriculum guidelines <sup>3)</sup>.

キーワード:病弱教育制度、子どもの生活、世界保健機関、国連子どもの権利委員会、日本 Key words : special education systems for children with medical needs, children's lives, WHO, UNCRC, Japan

In this study, we examined issues regarding the systems of special education based on the recommendations about children's lives and participation by the WHO and UNCRC (United Nations Convention on the Rights of the Child Committee on the Rights of the Child), in order to improve the lives of children with illnesses, develop education for them, and ensure their right to participate.

We discussed the current state of children' lives under the systems of special education, and implementation items recommended by the WHO and UNCRC regarding their lives and participation. Based on this discussion, we clarified the issues regarding such systems that need to be resolved to promote their liferelated participation under special education.

#### 3. Results and Discussion

### (1) Special education systems and children's lives

Special education is provided in special support schools, special support classes, and education through home visits under special support education systems.

Special support schools include schools built together with hospitals, their branch schools, and in-hospital special support classes. Special support schools also provide education for children who require continuous medical and/or life-related management even after discharge, thereby having difficulty in attending school. Special support classes include those established in elementary, middle, and high schools, as well as those in hospitals. Special education aids children in studying with textbooks in cooperation with their previous school, and maintaining/improving their mental and physical health.

Regarding the latter, the goal of special support education (including special education) is to nurture knowledge, skills, behaviors, and habits, which are necessary for children to overcome study- or life-related difficulties due to their disabilities, and become independent.

To achieve this goal, the school curriculum guidelines for special education have stipulated the time for independent activities <sup>4)</sup>.

These activities include health maintenance, psychological stabilization, the establishment of interpersonal relationships, recognition of the environment, body movement, and communication: the details of each item are as follows:

#### 1) Health maintenance

- i. Establishment of daily routines and lifestyle
- Understanding of disease conditions, and management of the lifestyle
- iii. Understanding of the conditions of each body part, and caregiving
- iv. Maintenance and improvement of health conditions

#### 2) Psychological stabilization

- i. Emotional stabilization
- ii. Understanding of the situation, and adaption to changes
- iii. Willingness to overcome study- or life-

related difficulties due to disabilities

#### 3) Establishment of interpersonal relationships

- i. Basics regarding relationships with other people
- ii. Understanding of others people's will and feelings
- iii. Understanding of children themselves, and behavioral adjustment
- iv. Basics regarding participation in groups

#### 4) Recognition of the environment

- i. Utilization of the available sensory organs
- Dealing with the characteristics of senses and cognition
- iii. Utilization of alternative measures and aids for sensory perception
- iv. Understanding of surrounding conditions using all sensory organs
- v. Formation of concepts that are the potential cognitive and behavioral cues

#### 5) Body movement

- i. Basic skills for posture, exercise, and movement
- Postural maintenance, and the utilization of measures to aid in exercise and movement
- iii. Basic movements necessary for daily life
- iv. Ability to move the body
- v. Movements necessary for work, and smooth implementation

#### 6) Communication

- i. Basic abilities for communication
- ii. Linguistic perception and expression

- iii. Linguistic formation and utilization
- iv. Selection and utilization of measures for communication
- v. Communication according to the situation

In sum, regarding children's lives, special education focuses on health maintenance, the establishment of daily routines and lifestyle, understanding of disease conditions, and management of the lifestyle. Psychological stabilization involves the willingness to overcome study- or life-related difficulties due to disabilities, and body movement involves basic movements necessary for daily life.

Thus, the systems of special education place importance on the establishment and management of children's lifestyles to achieve the maintenance of their health. The education also stresses the importance of their willingness to overcome difficulties, and basic movements that are necessary in their lives.

# (2) Lives of and participation by children with illnesses

Concerning the lives of children with diseases or disabilities, it is globally required to improve daily living functions from the aspect of their participation.

In the general assembly held in May 2001, the WHO adopted the ICF (International Classification of Functioning, Disability and Health)<sup>5)</sup>, which is an international classification regarding individuals' daily living functions, disabilities, and health. The ICF was published as a revision of the ICIDH (International Classification of Impairments, Disabilities, and Handicaps), which had been released as a supplementary classification of the ICD (International Classification of Diseases) in 1980 by the WHO.

The ICF, which includes the aspect of daily living functions, characteristically covers health- and life-related domains. As such, the international classification regarding disabilities and health was revised from a medical model covering individuals' internal influences to a social model covering external influences as well.

Along with this transition, the ICF stated the following to improve daily living functions: Firstly, it is required to integrate mental/ physical functioning and body structures, and focus on activities and participation. Concerning activities and participation, it is required to efficiently improve these functions from the aspect of skills and state of performing them. The items regarding skills and the state of performing them include the following wide range of domains (including those of social activities and participation) that are required to be evaluated: learning, the application of knowledge, general issues and requirements, communication, exercise, movement, self-care, household life, interpersonal relationships, primary liferelated fields, community life, social life, and citizens' lives.

Secondly, as the ICF includes environmental and personal factors as components partly contributing to daily living functions, it is necessary to focus on the environment, which is an external influence, as well as each individual's characteristics, in order to improve such functions. The environmental factors are divided into personal and social factors. The former represents personally familiar environments (e.g., home and school), including a physical environment in which there is contact with other people. The latter, on the other hand, represents formal/informal structures, services, general approaches, and systems, all of which are factors influencing individuals in communities and society: these items include organizations and services regarding the following: working environment, community activities, administrative agencies, communications, transportation, informal social networks, law, regulations, formal/ informal rules, people's behaviors, and ideology.

Thirdly, to improve daily living functions, it is required under the ICF to focus on the mutual and complex relationships between health-related components, such as mental and physical functions, body structures, activities, participation, and environmental factors. Through specifying the relationships between these components, the ICF suggests that changing one component may influence some or all other components.

Thus, it is required under the ICF to improve daily living functions through reducing social factors hindering activities and participation according to personal factors, based on the above-mentioned characteristics of the ICF.

In addition, in 2007, the WHO adopted the

ICF-CY (International Classification of Functioning, Disability and Health - version for Children & Youth)<sup>6</sup>.

It is necessary under the ICF-CY, which points out issues regarding participation by children and youths, to improve their daily living functions in keeping with the Convention on the Rights of the Child.

# (3) Children's right to participate and their lives

Participation is the fundamental right of children, which is protected mainly by Article 12 (Respect for the Child's Will) of the Convention on the Rights of the Child. Concerning the right to participate, in 2009, the UNCRC adopted "General Comment No. 12: The right of the child to be heard" (Comment No. 12)<sup>7)</sup>, targeting the understanding and efficient fulfillment of Article 12.

Regarding factors influencing children, Comment No. 12 states that: most articles of the Convention, mainly Article 12, require and promote children's participation, and it is required under the entire Convention to make plans, exercise management, and achieve development in cooperation with children (para.86). Comment No. 12 also suggests that children, including those in a certain group (e.g., children with illnesses), and their interests (e.g., health, economy, education, and environment) become the focus of the above requirements (para.87).

Comment No. 12 places emphasis on children's lives in understanding and fulfilling

their right to participate.

Firstly, Comment No. 12 stresses that the concept of participation should be the basis of efforts that are made between children and adults, who are involved in the development of policies, plans, and measures in any situation concerning children's lives (para.13). Based on this concept, it is necessary under Comment No. 12 to consider children's views as potentially helpful viewpoints and experiences in decision- and policy-making processes, as well as the preparation and evaluation of regulations and/or measures (para.12).

Secondly, Comment No. 12 specifies that Article 12 particularly concerns the rights to express views regarding matters of children, and participate in acts and decisions that influence their lives (para.81). Also, Comment No. 12 stresses that Article 12 mandates the signatories of the convention to establish legal frameworks and systems necessary for promoting children's spontaneous participation in any act and decision making that influence them, and respect their views.

In addition, Comment No. 12 points out that children's right to access information, which is stated in Article 17 (Access to Information) of the convention, must be fulfilled to better understand their right to express their opinions in a broad sense (para.82). As Comment No. 12 states that children have the right to access appropriate information on any matter concerning them according to their age and abilities, the school education curricula of the signatories are required to include children's right to access information in line with Articles 17 and 42.

Thirdly, Comment No. 12 states that it is also required to focus on children's lives to fulfill their right to participate (para.134d). The details of this requirement are that children should have the right to express their views about issues concerning their lives, for which they are allowed to use their knowledge, skills, and abilities, and children should be allowed to stress and work on issues that they regard as important and related to themselves.

Regarding education and school in particular, Comment No. 12 specifies that it is fundamental to respect children's right to express their views in educational settings to fulfill Article 28 (Right to Receive Education) of the Convention (para.105). It is required under Comment No. 12 to promote children's spontaneity through providing participatory settings in any educational environment (para.107), and respect their opinions about planning school curricula and programs, because their living conditions and ideas should be taken into consideration in education and learning. For this purpose, it is required in Comment No. 12 to allow children to freely express their opinions about the formulation and execution of school policies/ rules in class meetings and school conferences (para.110), and talk with children about various perspectives concerning regional and national educational polices (para.111).

Based on the above recommendations regarding participation, to improve the daily

living functions of children with illnesses, it is necessary to establish legal frameworks and systems, and then reduce social factors hindering activities and participation in cooperation with children while introducing their views, particularly because it is necessary to ensure their participation in line with the Convention on the Rights of the Child. To meet these requirements, it is essential that children can use their knowledge, skills, and abilities, and they are guaranteed to be able to access necessary information on participation.

It is also required to reflect the views of children with illnesses when planning curricula and programs regarding their education and learning, because their living conditions and ideas should be considered in education and learning. To achieve this, it is necessary to ensure opportunities for discussions with children about the formulation and execution of school policies, as well as national and municipal educational policies. This measure is also important to guarantee the Objectives of Education (Article 28), which are stipulated as the child's right in the Convention on the Rights of the Child.

#### 4. Conclusion

In this study, we examined issues that need to be resolved to ensure the participatory right of children with illnesses in their lives under the systems of special education.

To promote the daily living functions of children with illnesses, it is required in cooperation with them to improve social factors (e.g., systems concerning activities and participation), through guaranteeing their right to participate based on the Convention on the Rights of the Child.

To actualize this, it is necessary to establish special education systems for children with illnesses, with which their opinions can be introduced for planning curricula and programs regarding education and learning.

Concerning the lives of children with illnesses, in Japan, the EACH (European Association for Children in Hospital) Charter<sup>8)</sup>, and hospitals' original charters for children<sup>9)</sup> stipulate that it is required to adhere to the Convention on the Rights of the Child (including the right to participate) even in special education, in order to protect their participatory right in their general lives, which involve staying in hospital and receiving medical services at home.

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