〈Others〉

Current Challenges in Inclusive Educational Support for Children Requiring Medical Care in Japan: A Focus on Pre and Post Elementary School Period

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ABSTRACT Japan's Act on Support for Children Requiring Medical Care and Their Families, which came into effect in June 2021, stipulates measures to facilitate the lives of children requiring medical care in the community and to reduce the burden on their families. Although support for children requiring medical care has progressed under this law, it is essential to verify the degree of achievement. This study examines the current situation and challenges of supporting children who require medical care in Japanese educational settings, with a focus on inclusion. First, an overview of children requiring medical care is presented, followed by a description of relevant laws and regulations. Then, the current situation before (childcare facilities and kindergartens) and after (special needs and regular elementary schools) schooling is described. Finally, we discuss support issues from an inclusive perspective.

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INTRODUCTION

The social implementation of inclusive education for children requiring medical care is one of the international issues. For example, the U.K.'s statutory guidance "Supporting Pupils at School with Medical Conditions[1)]" requires that every school enable full participation of students with medical care needs by having proper plans, trained staff, and collaborative policies in place. In the United States, the Individuals with Disabilities Education Act[2)] and Section 504 of the Rehabilitation Act[3)] guarantee the right of children requiring medical care to receive inclusive education.

In June 2021, Japan enacted the Act on Support for Children Requiring Medical Care and Their Families (Act No. 81 of 2021; hereinafter "the Act"). This legislation explicitly stipulates that national and local governments, as well as the operators of childcare facilities and schools, bear the

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responsibility of implementing a range of measures to facilitate inclusive education of children requiring medical care and alleviate the burden placed on their families.

Support systems for children requiring medical care and their families are being strengthened within the framework of this Act. It is essential to evaluate the extent to which the objectives outlined in Article 1 of the Act have been realized. To accomplish this, it is necessary to review the social circumstances surrounding children requiring medical care before and after implementation of the Act.

This study aims to examine the status and challenges of supporting children who require medical care in Japanese educational settings of early childhood and primary education, with a focus on inclusion. First, an overview of children requiring medical care is presented. The relevant legal frameworks that form the basis of inclusive support are outlined. The subsequent sections examine the status of such children before and after entering elementary school, specifically in childcare facilities, kindergartens, special needs schools, and regular elementary schools. Finally, this study discusses the challenges of inclusive educational support from policy and practice perspectives.

CHILDREN REQUIRING MEDICAL CARE

The definition of "children requiring medical care" necessitates clarification on the characteristics of "medical care." Article 2, Paragraph 1 of the Act defines medical care as "medical procedures such as respiratory management using a mechanical ventilator and suctioning of sputum." Paragraph 2 further defines a child requiring medical care as "a child for whom the ongoing provision of medical care is essential in order to live a daily and social life (referring to those under 18 years of age and those over 18 years of age who are enrolled in high schools or equivalent institutions)."

Additionally, Japan's Ministry of Health, Labour and Welfare (MHLW)[4] describes such children as "those who, due to advances in medical science, are discharged after extended stays in neonatal intensive care units, and who require ongoing use of ventilators, gastrostomy tubes, and daily medical interventions such as suctioning and tube feeding." The same source estimates that the number of Japanese children who require medical care living at home reached approximately 20,000 in FY2021. Since these forms of care constitute medical acts, they are, in principle, performed by physicians or nurses. However, in cases where such care is provided by the child or family members, these are sometimes referred to as "medical life support activities"[5].

Children requiring medical care are often capable of living at home and participating in social life, provided they receive appropriate medical interventions such as oxygen therapy through ventilators. The growing number of such children reflects advancements in medical technology, particularly in neonatal and perinatal care. For instance, Japan's National Center for Child Health and Development[6] reported that the Japanese infant mortality rate has declined sharply since 1950, reaching 1‰ in 2011. The same report outlined medical advances across decades, such as the transition from alkali therapy to artificial pulmonary surfactants that target respiratory dysfunction. Innovations in this field have contributed substantially to reduced infant mortality.

Although infant mortality has declined, it is presumed that the number of infants who would not have survived earlier has increased. Several among these children require continuous medical care from early infancy. The same report (p. 28)[6] notes that advances in medical technology have altered children's health conditions, resulting in the emergence of "children who can walk and talk but require daily medical devices and care"—the very children now classified as children requiring

medical care.

Until recently, these children were not adequately supported under the conventional disability welfare framework, making access to services challenging[7, 8]. However, the enactment of the Act is expected to improve this situation significantly.

LEGISLATIVE FRAMEWORKS FOR EDUCATIONAL INCLUSION

Article 3 of the Act outlines its basic principles, with Paragraph 2 emphasizing the rights of children requiring medical care to receive education alongside their peers without such needs. Articles 6 and 7 clearly establish the responsibilities of childcare and school administrators to provide appropriate support to these children. These legal provisions reflect a commitment to inclusive education.

The concept of inclusion has emerged in European social policy as a countermeasure to exclusion, a condition in which individuals are unable to access the benefits of social welfare[9]. Individuals experiencing exclusion, such as institutionalized children, individuals with mental illness, and homeless individuals, often lack strong social ties and access to resources. Inclusion, therefore, represents a policy approach to integrate such individuals into society.

Inclusion in education was first internationally recognized in the 1994 Salamanca Statement issued by UNESCO[10]. This statement asserts that children with special educational needs should attend regular schools that employ child-centered pedagogy that is responsive to their needs. Such inclusive schools are vital for combating discrimination and realizing education for all. Furthermore, the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD) emphasized inclusive education in Article 24, requiring states to ensure that persons with disabilities are not excluded from the general education system and can access quality education within their communities supported by reasonable accommodations[11]. The ratification of the CRPD helped institutionalize inclusive education globally.

Japan ratified the CRPD in 2014 and subsequently revised several domestic laws[12]. The 2011 amendment to Japan's Basic Act for Persons with Disabilities (BAPD) mandated that children with disabilities should, wherever possible, receive education together with children without disabilities. The 2013 Act for Eliminating Discrimination against Persons with Disabilities in Japan includes medical care as part of reasonable accommodation[13], which is expected to be implemented in educational settings unless it imposes an excessive burden[14].

In 2016, Japan's Child Welfare Act was revised for the first time to legally define children requiring medical care. The revision emphasizes that their educational needs should be met through inter-institutional collaboration, respecting the preferences of the child and their family (Japan's inter-ministerial notification: Isei-hatsu No. 3, Kōji-hatsu No. 4, Shō-hatsu No. 2, Fukushi-hon No. 377, and Monka-hatsu No. 372; all dated June 3, 2016). In 2021, the Act reaffirmed this principle by mandating the provision of appropriate educational support for peers without disabilities.

Thus, the notion of inclusion, originating in the Salamanca Statement and further reinforced by the CRPD, has informed domestic legislative efforts, culminating in the 2021 Act.

CURRENT STATUS OF CHILDREN REQUIRING MEDICAL CARE BEFORE SCHOOL ENROLLMENT: Childcare Facilities and Kindergartens

Prior to the enforcement of the Act on Support for Children Requiring Medical Care, various legislative measures were implemented to promote inclusive support for these children. However, the actual situation in the educational setting remains unclear.

This section examines the status of children requiring medical care in early childhood education settings, namely childcare facilities (including daycare centers and certified childcare institutions †1 and kindergartens, prior to enrollment in elementary school. As the number of children who attend the preschool departments of special needs schools is limited, they have been excluded from this discussion †2.

According to the MHLW[15], 768 children requiring medical care will be enrolled in childcare facilities in 2021. Additionally, a survey conducted by Japan's Ministry of Education, Culture, Sports, Science, and Technology (MEXT)[16] reported that 254 children were enrolled in kindergartens in the same year. Meanwhile, MHLW estimates place the total number of children requiring medical care aged 0-19 years at approximately 20,180 as of 2021[4].

Based on these data, it is estimated that among the 20,180 children requiring medical care, approximately 6,000-7,000 belonged to the preschool age group (0-5 years), considering that advances in neonatal care have significantly improved survival among younger children. Among these, 768 and 254 children were enrolled in childcare facilities and kindergartens, respectively. Assuming some overlap in enrollment with certified childcare institutions †3, the total number of children in these settings is approximately 900-1,000. This suggests that only about 15% †4 of preschool-aged children requiring medical care were enrolled in childcare facilities or kindergarten in 2021.

This raises a significant question: How do the remaining preschool-aged children requiring medical care spend their daytime hours? Fig. 1, based on a diagram from the MHLW[17], illustrates the daily schedule and service use of a three-year-old child requiring medical care. This indicates that, in addition to formal childcare, several children receive disability welfare services such as developmental support, home-visit nursing, and in-home care. A fact-finding survey of children requiring medical care and their families conducted by Mitsubishi UFJ Research & Consulting (p. 36)[18] reported that children aged 0-6 years were particularly likely to utilize developmental support services. These findings suggest that several children who are not enrolled in childcare facilities

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
	◎	◎	◎	◎	◎	◎	◎
6：00	Wake up	Wake up	Wake up	Wake up	Wake up	Wake up	Wake up
	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎
8：00							
	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎
12：00	Daycare center	Child development support	Child development support	Daycare center	Child development support		
	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎
17：00	In-home care	Home-visit nursing	In-home care	Home-visit nursing	In-home care	Home-visit nursing	
	Tube feeding, medication ◎	Tube feeding, Medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎	Tube feeding, medication ◎
19：00	Bathing		Bathing		Bathing		Bathing
	Bedtime	Bedtime	Bedtime	Bedtime	Bedtime	Bedtime	Bedtime
22：00	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎	Tube feeding ◎
	◎	◎	◎	◎	◎	◎	◎

Fig. 1. Conceptual illustration of the daily life of a child requiring medical care: Case of a 3-year-old prior to entering elementary school

Note: The symbol "◎" denotes suctioning. This figure was developed by the authors based on a diagram published by the MHLW[17].

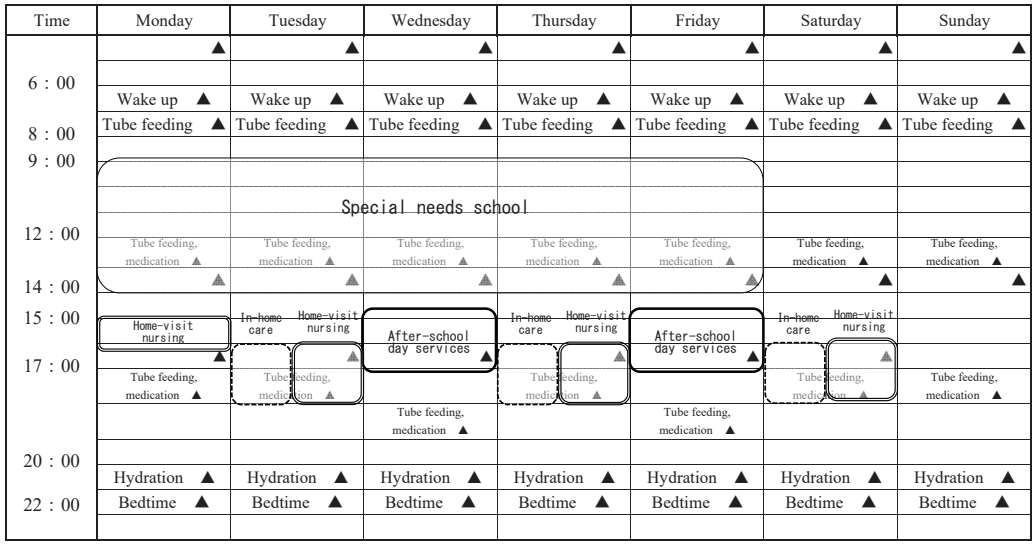

Fig. 2. Conceptual illustration of the daily life of a child requiring medical care: Case of a 10-year-old subsequent to entering elementary school
Note: The symbol "▲" denotes suctioning and postural change. This figure was developed by the authors based on a diagram published by the MHLW[17].

or kindergartens spend their days receiving support from disabled welfare services.

CURRENT STATUS OF CHILDREN REQUIRING MEDICAL CARE AFTER SCHOOL ENROLLMENT: Special needs and Regular Elementary Schools

This section examines the status of children who require medical care after entering elementary school. Several among these children either attend special needs schools or are enrolled in special needs classes with regular elementary schools. A special needs school is defined as "an institution that provides education equivalent to that of an elementary school while offering instruction aimed at overcoming learning and daily life challenges stemming from disabilities and fostering independence"[19]. In contrast, special needs classes are established within regular elementary schools to support students with disabilities in overcoming challenges in learning or daily life"[19]. These schools and classes are often equipped to provide medical care, making them more accessible to children requiring support.

According to data from MEXT[16], 4,295 children requiring medical care were either attending or receiving home-based instruction from the elementary departments of special needs schools in 2021. An additional 769 participants were enrolled in special needs classes at regular elementary schools. In contrast, only 506 students were enrolled in general education classrooms in regular elementary schools. These figures suggest that only approximately 9% of children requiring medical care after entering elementary school were placed in regular classes (506 / [4,295 + 769 + 506]).

These numbers indicate that the majority of school-aged children requiring medical care attend either special needs schools or special needs classes within regular elementary schools. A limited number of children have been integrated in to regular education classrooms. Based on the MHLW[17], Fig. 2 presents the weekly schedule of a 10-year-old child who required medical care. This indicates that several children attend after-school day services, receive in-home care, or utilize other

disability welfare services during school hours. The findings of the fact-finding survey by Mitsubishi UFJ Research & Consulting (p. 36)[18] support this pattern, showing that children aged 7-12 years commonly use after-school day services and in-home care. These trends confirm the continued reliance on welfare services along with school-based support.

FUTURE CHALLENGES: Toward Inclusive Support for Children Requiring Medical Care in Educational Settings

Data from the MHLW and MEXT indicates that only approximately 10% of children requiring medical care attend childcare facilities, kindergartens, or regular elementary school classrooms alongside their typically developing peers. This suggests that the current educational environment is far from fully inclusive of these children in Japan.

To realize the inclusive support envisioned in the Act, it is necessary to consider how inclusive education can be implemented more effectively. Laws and frameworks inspired by the Salamanca Statement emphasize the significance of reasonable accommodations to enable the participation of persons with disabilities. In the current societal framework, the realization of inclusive support is generally premised on children requiring medical care and participating in settings designed for typically developing children. This approach emphasizes adaptation to the environment to accommodate these children.

However, inclusion can also be achieved through the participation of typically developing children, including children requiring medical care, in educational settings. For example, if children without disabilities attend the elementary department of a special needs school, children requiring medical care can receive the necessary care while benefiting from peer interaction and inclusive learning opportunities.

Since the 2004 revision of the BAPD, the Japanese educational system has promoted "exchange and collaborative learning" between children with and without disabilities. Such programs provide opportunities for mutual understanding and personal growth by enabling joint activities, fostering social development, and cultivating empathy and respect[20]. These interactions can take several forms[21]:

1. Inter-school exchanges, where students from kindergartens or elementary schools engage with peers from special needs schools;

2. Local school exchanges, where students from special needs schools attend schools in their residential communities; and

3. Intra-school exchanges, where students from regular and special needs classes interact within the same school.

In all these formats, inclusion is not unidirectional. It involves both children with disabilities participating in regular classrooms and children without disabilities engaging in special needs settings. A notable example is the "invited exchange," where students from regular classes are invited into special needs classes. Research has shown that such practices can enhance the quality of the learning experiences for both groups[22, 23].

The design of these exchange and collaborative learning sessions is becoming increasingly influenced by the principles of Learning Universal Design (LUD)[24]. According to CAST[25], LUD is defined as an approach that "provides multiple means of representation, expression, and engagement in order to reduce instructional barriers, offer appropriate support and challenges, and maintain high expectations for all learners—including students with disabilities and those whose first language is not the language of instruction." LUD provides an educational framework that supports all learners, regardless of their disability

status, as they develop motivation, learning strategies, and readiness to engage in educational content. Importantly, LUD shifts the focus of educational objectives from merely acquiring knowledge and skills to the processes through which such learning occurs. By emphasizing "learning how to learn," the framework fosters inclusive instructional design applicable to diverse learners, including both children requiring medical care and their typically developing peers.

In Japan, if exchange and collaborative learning, invited exchanges, and LUD are systematically implemented in classrooms that include children requiring medical care, inclusive support can be expanded and improved in a sustainable and effective manner.

PRESENTATION HISTORY

Parts of this study were presented at a symposium on inclusive support for children requiring medical care sponsored by the Hashimoto Foundation's 2022 Welfare Research Grant Program and at the 59th Annual Conference of the Japanese Association for the Study of Developmental Disabilities.

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NOTES

† 1 It is called Nintei Kodomoen in Japan, which refers to a certified center for early childhood education and care.

† 2 According to MEXT[16], as of 2021, 40 children requiring medical care were attending preschool departments of special-needs schools, and one child was receiving home-based instructions.

† 3 The data provided by MHLW[15] refer broadly to "childcare facilities", which likely include certified childcare institutions. In contrast, the MEXT[16] survey included children enrolled in certified kindergarten-type childcare institutions.

† 4 Assuming the number of children requiring medical care aged 0-5 is approximately 6,000 to 7,000 and that about 900 to 1,000 of them are enrolled in childcare facilities or kindergartens, the estimated enrollment rate is approximately 15%. This calculation was based on a midpoint estimate of 6,500 children in the age group of 950 enrolled in childcare/kindergarten settings.

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