紀要『人文·自然研究』第19号

Historical Developments in Ensuring Education for Children undergoing Medical Treatment: Focusing on Developments in English-speaking Countries

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2025 年 3 月 25 日発行 一橋大学 全学共通教育センター

人文・自然研究 第19号

Hitotsubashi Review of Arts and Sciences 19



2025年3月25日発行

発行:一橋大学全学共通教育センター 186-8601 東京都国立市中 2-1

組版:精興社

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1. Introduction

In recent years, mental and physical disorders and the need to address them have become social issues. They are also important issues for children and adolescents. For example, in Japan, the number of children continues to decrease, but the number of children undergoing medical treatment has not changed significantly. In other words, it can be said that overall health problems are tending to deteriorate. Two examples are to be raised in this context. The age of onset of depression is becoming lower. Furthermore, the incidence of type 2 diabetes in children, which was once thought not to be affected to children, is also increasing. The author has been working on mental health issues due to the interest in education for children with special educational needs (Murayama, 2017). In the field of education for sick children, in addition to maintaining and promoting mental health, the connection with physical illness has also been pointed out.

Historically, it can be said that education for sick children was mainly aimed at children with physical illness. It is useful to focus on psychosomatic illness as a topic that touches on the issues of both physical illness and mental health. However, when looking at ensuring education for sick children, there is very little research on the historical development of special needs education. The historical development of special needs education has proceeded according to the category of disability. For example, looking at special needs education in Japan in accordance with the School Education Act and other documents, categories such as visual impairment, hearing impairment, intellectual disability, physical impairment, and sickness have been set out. Special education schools have been established according to these five categories. Compared to other disability categories, the historical examination of the practice of special needs education for sick children has not received sufficient attention. For example, the Sage Handbook of Special Needs Education (Second Edition) edited by Lani Florian, is a representative 900-page handbook (Florian, 2013). However, there is little description of the education of sick children. One of the few notes states that advances in medicine have allowed the causes of illness to be more clearly identified as patients survive, and that knowledge became more widespread with the introduction of the first version of the International Classification of Diseases (ICD) in 1901 (Hollenweger, 2013). The paucity of references to the historical development of special needs education is also reflected in the references. In a reference list of over 30 items, Wallin (1914) is the only work on sick children. Even taking into account that the majority of the references are books dealing with the history of special needs education in general, this number is still small.

The premise for this situation is the lack of research on childhood history, not just on

sick children. Newton (2011) explored five major issues: (1) a lack of written records by children; (2) the temptation to assess authenticity of past children's actions based on the present; (3) the difficulty of assessing emotions and pain of persons in the past; (4) the urge to make ethical judgments about past practices; (5) the lack of evidence regarding poor children.

In addition, there are a number of reasons why little attention has been paid to the historical development of education for sick children. First, medical history research has been conducted as the study of the history of individual diseases or the history of specific specialized medical departments. On the other hand, education for sick children as a system has traditionally been conducted in schools adjacent to or attached to children's hospitals. As a result, it has been practiced mainly in small schools where children with various illnesses are hospitalized. There is an aspect to education for sick children that can only be developed based on medical care for children, but it has been pointed out that there is a gap between the history of medicine and the history of education for sick children sick children in that the development of medical care is oriented toward diseases and medical departments.

Secondly, there are a number of characteristics inherent in the practice of education for sick children. Learners in education for sick children learn within the system only while they are hospitalized for treatment. After treatment is completed and they are discharged from the hospital, they return to the school they originally attended, which in most cases is a school close to their home. Therefore, the period of learning in the system of the education of the sick is limited to the time of hospitalization. Unfortunately, some children may die during hospitalization. This makes learning groups such as classes prone to instability, which places constraints on systematic practice and classroom management. In other words, the instability of learning groups here includes children who are undergoing treatment for an illness being discharged from the hospital, so this in itself is not a problem. However, when examining the genealogy of education for sick children, this characteristic can be a limiting factor. In addition, when focusing on individual students, study time is also influenced by the schedule of treatment for the illness and other factors. Therefore, it is difficult to find consistency or uniformity in the practice of education for sick children (Murayama, 2021). These are thought to be constraints on the examination of the historical development of education for sick children.

In this article, in order to obtain clues for the historical verification of education for sick children, the historical development of such education in English-speaking countries will be reviewed while taking into account the characteristics of special schools and special classes that are responsible for the education for sick children and also referring to previous research on the history of medicine and hospitals. The reason for focusing on developments in English-speaking countries in this paper is that it may be useful to note the development of the so-called "new history of medicine." According to Suzuki, traditional research into the history of medicine has focused on physicians who made important discoveries and contributions as individuals, partly because many of its bearers were medical doctors (Suzuki, 2015). However, this tendency leads to a simplification of the complex phenomenon of medicine into the limited and narrow subject of the medical

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doctor as an individual. The development of education for children in medical treatment settings is related to advances in treatment or therapy. At the same time, however, the return to school and the continuation of treatment and learning of children under medical treatment can be seen as a kind of social phenomenon. Therefore, it is necessary to pay attention to how medicine and medical treatment was related to the society, culture, and education of the same period, as well as to the relationship between supporters and the affected children. In this regard, it is thought to be useful to focus on the "new history of medicine." Although not directly cited in this paper, the problematic issue in this paper has been suggested in the works of Bynum, W. E. and Porter, R., who developed "new medical history" research at The Wellcome Institute for the History of Medicine (1968–1999) in London (Bynum & Porter, 1993, Bynum, et al. 2006). Considering that Japan has developed pediatric care while utilizing the knowledge of Western medicine since modernization, and that it has also ensured a school system and education for disabled and sick children since modernization, examining the history of education for sick children is thought to be important.

2. Historical development of education for sick children

2.1. Development of the system for the education of sick children

When considering the development of the education for sick children, it is necessary to take into account the relationship between the expansion of public education and medical insurance. It can be confirmed that private education for sick children was practiced sporadically before the establishment of public education. However, the mainstream view was that children who were hospitalized for long periods for treatment should study after their treatment was completed. This view still remains to some extent today.

There are two main reasons why children hospitalized for treatment do not engage in learning activities (MEXT, 2015). First, due to a shortage of teaching staff, there may not be enough time or sufficient opportunity for visiting guidance. Second, the children and their parents do not emphasize study because they wish to prioritize treatment. Both of these are serious problems. However, public education in most developed countries, including Japan, has adopted a grade system based on age. For example, in Japan, at the compulsory education stage, each child advances to the next grade almost automatically, even if they are absent for a long period due to hospitalization. Another advantage is that the content to be studied in each grade is determined by the Course of Study (MEXT, 2017). In the case of special schools or special classes for sick children, the curriculum is organized according to the course of study in the regular schools. For instance, when a hospitalized junior high school student studies at a special school attached to a hospital, s/he would learn the content of the junior high school course of study and self-care activities according to the characteristics or conditions of the disability or illness. The learning content of the self-care activities is set according to an individualized education plan to match the condition of the illness and developmental characteristics of each student. However, other academic subjects will be learned in the same

way as healthy junior high school students. When sick children are unable to study due to treatment, it is inevitable that there will be gaps in their learning. One of the things that is emphasized in education for sick children is to fill in these learning gaps. In addition, since the learning time is restricted in accordance with the child's physical condition and treatment schedule, the goal is to narrow down the learning content and progress. This is because it is expected that children will return to the school they attended before the onset of their illness after being discharged from the hospital, and that their learning progress will be consistent.

For these reasons, the overall practice of educating sick children tends to be smallscale and time-limited, making it difficult to conduct systematic examination or to continuously trace its lineage. Therefore, it will be necessary to start by looking at pioneering efforts in the education of sick children. As the first general understanding, it is to take a review the description by Hollenweger (2013). Hollenweger suggests that the advancement of medical knowledge and the systematization and dissemination of that knowledge by the ICD in 1901 was crucial (Hollenweger, 2013, p. 474). The ICD was originally a statistical classification created to classify the causes of deaths. In addition, it has also come to be used as a diagnostic classification.

2.2. Ensuring education for sick children in the United Kingdom

In developed European countries, children's hospitals expanded rapidly after 1865. As a result, many children became long-term hospitalized patients, and volunteer teachers' responded to their educational needs. However, as the word "volunteer teachers" suggests, it is important to note that education for sick children was not systematized as public education was, but was merely a sporadic effort by highly conscious teachers. The need for more formal educational facilities was recognized in the 20th century. For example, looking at developments in the United Kingdom, the Education Act of 1918 made schooling compulsory for all disabled children, not just the blind and deaf. By 1921, there were more than 300 facilities for the blind, deaf, and physically disabled, as well as children with tuberculous, and epilepsy. It is noteworthy that children suffering from tuberculosis and epilepsy were included as targets, along with those suffering from other disabilities. However, as it was often thought that disabled children should be separated from their families, only a small number of disabled children remained in regular education. Many children with disabilities left home to attend boarding schools. Sick children lived away from home to receive hospital treatment.

The idea of "open-air schools" was then introduced to England from Germany. Sick and disabled children studied in outdoor classrooms (Quinn, 1946). The open-air school initiative is important in considering the classroom environment, but outdoor learning can be understood as including the meaning of what we now call a change of scenery for treatment. Further, improvements in diet and other factors cannot be overlooked.

The earliest school for sick children was Bostall Woods, Woolwich, opened by the London County Council in 1907. By 1939, 150 open-air schools had been established, providing places for approximately 20,000 children to attend. It is said that by moving away from unhealthy and crowded home environments, the health of children began to improve. The 1933 Education Act stated that "all LEA [Local Education Authority] s are obliged to arrange suitable education for all children of compulsory school age who are out of school because of illness or injury" (Government of United Kingdom, 1933). It also gave LEAs powers to provide appropriate full-time or part-time education for children outside compulsory school age.

The 1944 Education Act and the 1946 Health Service Act allowed health and education authorities to work together to provide education for sick children both in long-term hospitals and at home. These included schools for hospitals with sufficient pediatric facilities to run such institutions, and "out of school education" by home and hospital teachers where formal schools were not appropriate. The expansion of hospital facilities with the establishment of the National Health Service in 1948 led to the establishment of a committee under Sir Harry Pratt to investigate arrangements for the welfare of sick children in hospital. Its report noted that a normal daily life, including education, was important for all hospitalized children, and that hospitals and education authorities should work together to ensure that suitable opportunities and facilities were made available. In 1978 the Warnock Committee stated that "Education whilst in hospital is the right of every child over the age of five...we recommend that arrangements should be made for all children to receive education as soon as possible after their admission to hospital" (Warnock, et al. 1978).

2.3. Guaranteeing education for sick children in the United States

In this section,: developments in the United States are surveyed. In the U.S., it is stipulated that educating students with chronic illnesses is a legal obligation of the public school system. Most students with chronic illnesses are classified by one of two legislative acts that protect individual rights and give students the right to a quality public education. School districts are well aware of the laws that stipulate and protect the rights of all students. Most school districts therefore have programs and teachers that are specially trained to educate students who qualify for an Individualized Education Program (IEP) or 504 Plan, as outlined in the Rehabilitation Act of 1973. Another law that potentially protects the rights of students with chronic illnesses is the Americans with Disabilities Act of 1990. Before the law was enacted, the needs of most students with disabilities were not met. These students had no opportunity or right to a public education and were usually excluded from learning. It was the responsibility of the family to place their child in such a way that individual services and needs were met. These needs became a financial obligation for the families without assistance from local school districts or the federal government (Kirk et al., 2005).

Passed in 1997 and reaffirmed in 2004 and 2011, the Individuals with Disabilities Education Act (IDEA) is a federal law that dictates the educational services public school districts are to provide to all students with disabilities. A free and appropriate education (FAPE) is a central priority of the act (Zirkel, 2007). The scope of services includes early intervention, inclusive practices, and therapeutic support for students identified as having disabilities. Special education and student services are guaranteed in the section of the Individuals with Disabilities Education Act titled "Other Health Disabilities." Ac-

cording to the Act: A student has limited ability to pay attention to the educational environment due to limitations in strength, energy, or attention, including heightened attention to environmental stimuli; (i) due to a chronic or acute health problem, such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, heart disease, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, or sickle cell anemia; or (ii) that adversely affects the student's academic performance. (IDEA Final Rule - 34 C.F.R. & 300.7 (b) (9)). Section 504 of the Rehabilitation Act of 1973 provides further protections for students with chronic conditions who are ineligible to receive special education services under IDEA. This federal law requires that no entity receiving financial funds, including public schools, may exclude, deny access to, or discriminate against a student with a disability (29 U.S.C. 794 (a) 1973). Students with 504 plans thus have the right to the same educational opportunities as their peers, and it is the school system's duty to ensure those opportunities. Although there is no specific funding to support 504 plans, school systems are obligated to provide the necessary support to chronically ill children who have 504 plans. The rights of chronically ill children have also been upheld in the courts. The U.S. Supreme Court (Cedar Rapids Community School District v. Garrett F., 1999) ruled in favor of parents whose children. required medical services during school hours and believed that the school system had an obligation to pay for those services. This decision was consistent with a federal court decision (Timothy W. v. Rochester School District, 1989) that ruled in favor of the parents, holding that the school district must pay for all educational programs for children with disabilities, regardless of the severity of the disability.

At the intersection of IDEA and Section 504 in public schools is the Americans with Disabilities Act of 1990 (ADA). This act has two main purposes: a national law to eliminate discrimination against people with disabilities and a national law to establish enforceable standards to address institutions that discriminate against people with disabilities. The ADA in public schools provides a foundation for the IEP and Section 504. It supports both the school and community planning and helps students improve their access to facilities and resources. The education of students with chronic illnesses has evolved over time, and the role of schools has changed with the passage of federal laws protecting the rights of students with disabilities. Before the passage of IDEA and the Rehabilitation Act of 1973, students with chronic illnesses were typically educated at home by their parents (Kirk et al., 2005). Advances in science and medicine have improved the academic performance of children with a variety of chronic illnesses (Sexson and Madan-Swain, 1993, 1995; Clay et al., 2004). As a result, more students with chronic illnesses are being educated at home. This situation has been suggested to be the double-barreled situation. On the one hand, it is the promotion of the educational rights for the sick children even if they cannot commute to the schools. On the other hand, it shows the lack of development of the hospitalized school. This double-barreled situation has not been changed significantly nowadays.

2.3. Developments at Toronto Children's Hospital, Canada: Wright (2016) as a clue

In Canada, Wright's historical study of Toronto Children's Hospital is noteworthy (Wright, 2016). Wright focuses on the historical circumstances and social diversity of the time in which Toronto Children's Hospital was being operated. It is said to reflect diverse social customs and cultural interests (p. 367). He describes the development of Toronto Children's Hospital in the context of developments in science, pediatric medicine, and surgery, changes in the way child psychology is thought to be viewed, and many medical advances since the 20th century. The hospital, which was specially established in Toronto, and the development of orthopedics, which was important in hospitals being seen as treatment facilities, are also the basis of this development. According to recent Japanese categories, orthopedics is closely related to the education of children with physical impairments, but considering the physical deformities of children with chronic diseases, severe cases such as scoliosis, and cases of so-called bedridden children, the development of not only internal medicine but also orthopedics is important.

In addition, the development of the nursing profession during this period was noted. Wright gives high praise to the achievements of Alan Brown, who served as medical director from 1921 to 1951. Brown's contributions to improving child welfare in Toronto, reducing infant mortality in the wards, and developing pediatrics as an academic field are exemplified. Similarly, Wright also mentions the milk pasteurization plant and the strong connection between the hospital and the burgeoning public health movement.

Wright's original perspective includes a description of the "Visiting Hours" for hospitalized children (p. 167). Brown is said to have felt uncomfortable with parents being in the wards, and it is pointed out that parents' visits to their children were restricted or excluded in the hospital. He then describes the process by which the hospital gradually transitioned to a "newer family-friendly model of institutional care" (p. 188). A simple comparison cannot be made because the current situation differs in the way children's rights and hospital management are perceived. However, the significance of restricting contact between children undergoing medical treatment and their parents could be the subject of historical consideration from the perspective of public health, in relation to contemporary understandings of the infectiousness of disease and the issue of parental separation and parental absence in institutions, a problem that would later be called hospitalization in the second half of the 20th century.

3. The impact of COVID-19 in modern history

With regards to consideration of the historical development of school education, especially the education of children undergoing medical treatment, it is necessary to consider the impact of COVID-19, which has been felt across school education in general. However, the impact was particularly noticeable for children undergoing medical treatment through hospitalization or outpatient care. There are two main factors that can be cited. First, restrictions on access to hospitals and hospital rooms meant that teaching staff were restricted from entering hospital rooms. Second, distance learning using ICT devices was encouraged, which opened up the possibility of students remaining at their original schools while hospitalized, thus eliminating the need to transfer to schools attached to the hospital.

Schools should be thought to remain open as much as possible while taking appropriate public health and social measures. An international expert group established by the World Health Organization's European Regional Office pointed this out in its recommendations on school education during the COVID-19 pandemic. The revised recommendations come against the backdrop of rising infection rates in some countries, driven primarily by a combination of relaxing public health and social measures, increased social interactions, and vaccine inequalities across regions. "The summer months offer a valuable window of opportunity for governments to put in place the right set of measures that will help keep infection rates down and avoid resorting to school closures, which, as we have seen, have such a harmful effect on the education, social and mental well-being of our children and youth," said Dr Hans Henri P. Kluge, WHO Regional Director for Europe. "The spread of new variants, coupled with the presence of pockets of unvaccinated people in school settings, means that there is no time to lose. The time to act is now. We can't allow the pandemic to rob children of their education and development" (World Health Organization. Regional Office for Europe, 2021).

The updated recommendations indicates that society must emerge from the education and health crisis brought about by COVID-19 with more resilient education and health systems, and pursue the ambitious goal of restoring and transforming education, so that all students learn better, have stronger social and emotional skills, and enjoy better health and well-being (World Health Organization. Regional Office for Europe, 2021). The following eight points were identified as overarching goals. First, the use of PCR or rapid diagnostic antigen tests in school settings. Second, the need for research to evaluate the effectiveness of risk mitigation measures on infection control was noted. Third, the importance of protecting educational outcomes, as well as mental and social well-being was raised. Fourth, it was stated that children living in vulnerable situations need to be taken into account. Fifth, schools were urged to promote changes in the school environment that will benefit children's health and infection control. Sixth, it was stated that it is important to include children in all decision-making. Seventh, it was suggested that there was a need to proceed with vaccination strategies in school settings. Finally, eighth, it was advocated that schools remain open. It was stated that school closures should be considered as a last resort only "in the event of large-scale transmission or when community transmission cannot be controlled by other means."

Across the WHO European Region, the pandemic also had a disastrous impact on schooling in the 2020–2021 academic year. According to UNESCO monitoring of countrylevel distance learning solutions, 44 out of 53 countries in the WHO European Region closed schools at the national level in April 2020, when the pandemic was at its peak (World Health Organization. Regional Office for Europe, 2021). School closures had serious consequences for children and adolescents' education, development, and well-being. In addition to depriving them of the social interactions necessary to support and promote mental well-being, school closures led to distance learning regimes that did not

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provide the same educational outcomes. Moreover, even under the best circumstances, socially disadvantaged children and those who need more educational support have fallen behind, widening social inequalities between and within countries.

Most countries reopened schools in the late summer of 2020, but as infection rates rose through the autumn and winter, dozens of countries took stricter measures and some closed schools. However, studies conducted in some countries in the winter of 2020 showed that SARC-CoV-2 infection rates among students were lower than in the general population, with secondary transmission in schools accounting for less than 1% of infections.

According to a UNICEF press release, the 2020–2021 fiscal year saw the biggest education disruption in history. At the same time, these experiences have provided evidence and tools to help children and young people safely return to face-to-face learning (Islam, 2021).

4. Discussion and Further Research

In this paper, a literature study was conducted to obtain a historical perspective on the guaranteeing education for children undergoing medical treatment, focusing mainly on English-speaking countries. In the UK, it is confirmed that educational guarantees for sick children were institutionalized from an early stage along with the development of children's hospitals. In the US, it is also confirmed that educational guarantees for children who require medical care have been established at the federal level, and that the scope of the guarantees has been expanded, sometimes accompanied by litigation. In Canada, it is confirmed that the development of the Toronto Children's Hospital, based on previous research (Wright, 2016), is a noteworthy example. The impact and influence of COVID-19 in the recent past is also outlined.

It is considered necessary for children undergoing medical treatment to learn in a special environment due to their health and medical constraints. Discussions on inclusive education have become active, and the goal is for all children to learn in the same place. On the other hand, children undergoing medical treatment must be treated as an exception. If that is so, then the need to maintain and develop a system that continues learning in parallel with treatment should be universally explored. It is necessary to continue to consider this question.

There are four main issues to be considered in the future. First, it is necessary to conduct an examination based on the practice of pediatric hospitals, such as the Toronto Hospital for Sick Children. It is thought that a content analysis of the expertise of the teaching staff and the curriculum will be useful. In particular, it is important to examine the learning tasks related to self-understanding of illness. Second, it is necessary to explore the relationship between the development of pediatrics as a specialized field and the development of education for children undergoing medical treatment. This can also be positioned as a kind of medical history research. It is necessary to aim to develop the history of education for sick children based on the development of medical history. Third, it is necessary to consider the international development of education for children undergoing medical treatment and its impact on Japan. As symbolized by COVID-19, medical care and school education, as well as the perspective of public health including schools, require attention to global standards. Consideration should be given to the development of WHO activities. Fourth, there is the issue of so-called dual school enrollment. For example, in Japan, hospitalized patients are required to transfer from the school they were attending and to enroll in the school attached to the hospital. On the other hand, there are also countries that temporarily allow dual school enrollment during hospitalization. The establishment of these systems can be effectively verified through comparative historical research. Future studies should be based on these points.

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Abstract

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Taku Murayama

In this article, in order to obtain clues for the historical verification of education for sick children, the historical development of such education are reviewed to obtain a historical perspective on the guaranteeing education for children undergoing medical treatment, focusing mainly on English-speaking countries. The reason for focusing on developments in English-speaking countries in this paper is that it may be useful to note the development of the so-called "new history of medicine." In the UK, it is confirmed that educational guarantees for sick children were institutionalized from an early stage along with the development of children's hospitals. In the US, it is also confirmed that educational guarantees for children who require medical care has been established at the federal level, and that the scope and scope of the guarantees has been expanded, sometimes accompanied by litigation. In Canada, it is confirmed that the development of the Toronto Children's Hospital, based on previous research is a noteworthy example. The impact and influence of COVID-19 in the recent past is also outlined. It is considered necessary for children undergoing medical treatment to learn in a special environment due to their health and medical constraints. Discussions on inclusive education have become active, and the goal is for all children to learn in the same place. On the other hand, children undergoing medical treatment must be treated as an exception. If that is so, then the need to maintain and develop a system that continues learning in parallel with treatment should be universally explored. It is necessary to continue to consider this question.

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