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REVIEW ARTICLE

Study on Change in School Enrollment Status of Children with Muscular Dystrophy in Schools for Children with Special Needs in Japan; Judging from a Trend of Education Policy and Medical Technology

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ABSTRACT

In these days, children with muscular dystrophy (MD) tend to enroll in local elementary schools and junior high schools rather than the health impairment children's schools. However, it is not clear the enrollment status of children with MD in special needs schools, elementary schools or junior high schools had changed. Therefore, we considered a change in school enrolment of children with MD in schools for children with special needs focused on trend of medical technology and educational policy. According to this, it was suggested that school enrollment statue of children with MD changed after the 1980s, and the number of them in each special needs school including illness special needs schools where the most of them had enrolled have decreased. We regarded two following reasons as this change; The number of children with MD who choose local elementary schools and junior high schools have increased with the promotion of inclusive education and the progress of medical technologies, which are indicated in preceding studies. The number of children with MD have decreased with the spread of genetic diagnosis.

Therefore, we need to compare the number of children with MD enrolled in each school to clarify the enrollment status of them, and also examine trends in the medical field such as genetic diagnosis, and changes in the educational system and educational environment.

< Keywords >

muscular dystrophy, school enrollment, special needs school, prevalence, incidence

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I . Introduction

Recent globalization has increased the interaction between people of different races, cultures, and values. Along with this change, the Ministry of Education, Culture, Sports, Science and Technology described ideal persons whom our society required as those having various qualities such as the spirit of mutual understanding, value creation capability, and awareness of social contribution and language skills¹. Furthermore, education sites have promoted new learning while dealing with these needs of the changing society, that is, promotion of inclusive education. Special needs education has also aimed for an inclusive education system regardless of having disabilities and its contents.

Particularly, children with severe disability who need medical care increasingly tend to go to schools in their place of residence. In 1996, the Ministry of Education, Science, Sports, and Culture (current the Ministry of Education, Culture, Sports, Science and Technology), in 'About education for hospitalized children', and that requested necessary of cooperation of school, hospital and home, and improvement of educational environments². Subsequently, legal systems including planned barrier-free school facilities and considerate medical care were developed. Furthermore, medical technology has also advanced, which enabled children to simultaneously receive outpatient treatment and get their homes managed by themselves; resultantly, their learning opportunities have been transferring from hospitals to schools³.

Muscular dystrophy (MD) seems to be one of those diseases which are affected by changes in children's learning place. There are several types of MD based on clinical manifestations characteristics, age of onset of symptom, gene of format and so on⁴. Typical example are dystrophinopathies (Duchenne muscular dystrophy and Becker muscular dystrophy), limb-girdle muscular dystrophy, facio-scapulohumeral muscular dystrophy, Emery-Dreifuss muscular dystrophy, Fukuyama congenital muscular dystrophy, dystrophia myotonica, oculopharyngodistal myopathy. These main lesion is necrosis and playback in skeletal muscles and the main symptom is motor dysfunction. Moreover, it is a systemic disease in which many organs including skeletal muscles are invaded and the patients need management by doctors and expert staffs with different specialties. It has diverse features depending on its type and often brings on various dysfunctions—for example, contracture/deformation, respiratory dysfunction, myocardial damage, dysphagia, gastrointestinal symptom, bone metabolism disorders, endocrine metabolism disorders, eye symptoms, deafness, and central nervous system disorders. Additionally, since it may cause symptoms of spinal deformity and posture abnormality by paraspinal muscle disorder as the disease proceeds, it tends to influence Activities of daily living (ADL), Quality of life (QOL), and life prognosis. MD was recognized as a designated intractable disease because it is a progressive disease that needs long-term medical treatment and no cure is established yet⁴⁻⁶.

Therefore, many children with MD in the 1960s who had gone to the schools for

children with health impairment annexed the national clinics following medical institutions and parents' intentions. However, the number of children with MD who go to schools in their place of residence has increased because of following two reasons. First, more local educational institutions started accepting children with disabilities after the schools for children with intellectual disability and with physical and health impairment were made compulsory in 1979. Second, home ventilator therapy became popular in the 1990s⁷⁾. Nishimaki pointed out that children with MD tended to go to schools in their place of residence in the late 1980s owing to early rehabilitation and popularisation of prosthesis and mobile equipment (electric wheelchairs)⁸⁾.

Various researchers and the Japan Muscular Dystrophy Association have investigated the changing learning place of children with MD. According to this, they indicated that the number of children with MD who choose the schools for children with health impairment has been decreasing and that of those who choose elementary schools and junior high schools in their place of residence has increased.

However, previous studies have not clarified the number of children with MD in local elementary schools, junior high schools, and schools for children with special needs except schools for children with health impairment. Moreover, there is no information on the change in the number of children with MD, as it has been considered obvious that the decline of children with MD in schools for children with health impairment means an increase in their numbers in local elementary or junior high schools. In addition, children with MD who have impaired motor function and feel anxious about death need psychological and educational support. We believe that clarifying the school enrollment status of children with MD is essential to provide appropriate support to them in each school. It will also lead to the reconsideration of psychological issues of children with MD and educational support.

Based on the above, the target of this study is MD transferring living environment with the flow of the time, and we will attempt to consider a change in school enrolment of children with MD in schools for children with special needs judging from a trend of medical technology and educational policy.

II. Transition of the enrollment of children with MD in schools for children with special needs

In the 1990s, most children could be educated because of the promotion of, and reminder for, school enrollment by modern school system in Japan. According to 100-year History of Educational System by the Ministry of Education, Culture, Sports, Science and Technology, about 61% of children entered school in 1898, but the number of them exceeded 81% in 1900 and reached about 96% in 1905⁹⁾. However, Third Elementary School Order revised in 1900 clearly indicated that some children with disabilities were exempted from or postponed their enrollment. According to previous research, the enrollment criteria in Third Elementary School Order intended to exclude

children with disabilities from public education and keep the number of children who enter school stable, and it suggested that the nation neglected the right to education for children with disabilities¹⁰.

In 1979, however, establishment of special schools and enrollment for children with disabilities became mandatory. Moreover, it allowed school attendance of children with especially profound disabilities who had ever got eliminated or postponed their school enrollment. Later, the conventional school education for those who can go to school has changed to include dealing with children who have difficulty in going to school, such as in-facility, in-hospital, and home-visit guidance¹¹. In addition, the International Year of Disabled Persons in 1981 induced the concept of normalization to society, and children with disabilities gradually began to be accepted in the community¹².

In the case of MD, Muscular Dystrophy Clinical Station founded in 1968 has studied about basic research, rehabilitation, and so on. This caused the progress in medical technology for MD, such as spreading respiratory management method in the 1980s and myocardial disorder treatment in the 1990s, and has extremely ameliorated MD's life prognosis^{7,12}. Matsumura pointed out that the living place of children with MD has transferred from a hospital to home because of improving medical technology and a change in the public consciousness of people with disabilities⁷.

However, no studies have examined in detail the changes in school attendance in children with MD. Therefore, we will give an overview of the enrollment status of children with MD before and after the International Year of Disabled Persons.

1. Enrollment of children with MD before the International Year of Disabled Persons

Previously, children with MD could not get hospitalized or even go to school once they get difficulty in walking, because there was no cure⁸. In addition, people had deep-seated prejudices for hereditary diseases, and several children with MD were forced to live in isolation from society¹³. However, due to the effort of their parents' association, the medical systems for MD have improved, and the importance of education during rehabilitation has gradually been attracting attention¹⁴.

In 1964, when the medical policy on MD was decided, the Ministry of Health requested the Ministry of Education to educate patients with progressive muscular atrophy at the national clinics. In response to this, in 1969, the Ministry of Education notified the board of education of each prefecture about education for children with MD. National Sanatorium Nishitaga Hospital was the only educational institution at that time, and this notice led to the spread of education for children with MD in medical institutions. In 1969, children who could not walk on their own were either excluded from admission or their enrollment to school was postponed according to the school enrollment criteria. However, due to the above notice, children with MD were exempted from the application of the criteria, and the special classes at medical institutions for children with MD were reorganized in the schools for children with health impairment. School attendance for children with MD was achieved relatively quickly compared to

children with other disabilities (such as intellectual disabilities)^{8,14}.

MD had met the admission criteria of the special school for children with physical impairment or health impairment by School Education Law Enforcement Ordinance article 22-3 (before revision). The educational contents of physical education/functional training (later care and training) prepared within each subject in the 1958 version of 'Handicapped Children's Elementary School Curriculum Guidelines for Physically Handicapped Education' had been judged to be suitable for the education of children with MD. Similarly, the educational contents of care and physical education (later care and training) in 'School for Special Needs Elementary School Curriculum Guidelines for Illness Education' did not diverge from that of education for children with MD. Therefore, for the education of children with MD, education for children with physical impairment or illness had been considered appropriate¹⁴.

However, in actuality, educational placements of most children with MD in the 1960s and 1970s were in the schools for children with health impairment. Most children with MD who attended the schools for children with health impairment could walk, but did not change the school even if the symptoms progressed. In the schools for children with health impairment, there had been constraints on the number of teachers and class hours; moreover, the establishment of curriculum had not been enough. However, after adopting care/training in the curriculum guidelines in 1971, the educational contents and teaching methods were substantially improved and school facilities and information equipment were developed⁸. In addition, the board of education, which was the right holder of educational measures, rarely decided on educational measures for ill children except for some physically weak children; enrollment of ill children was mostly decided by medical institutions or parents at the time of 1969¹⁴. Therefore, it is thought that the tendency for children with MD to attend illness education institutions in national clinics responsible for MD patients increased.

Some children with MD had to enter a medical institution away from their home because not all prefectures had medical institutions for MD patients. For that reason, they applied a criteria of enrollment in schools for children with physical impairments in areas without schools for children with health impairments⁸. It is thought that the advantages of schools for children with physical impairment in terms of the number of teachers and cost also contributed to this.

2. Enrollment of children with MD after the International Year of Disabled Persons

Following the notification issued by the Ministry of Education, Culture, Sports, Science and Technology in 1994, 'About education for children undergoing medical treatment for illness', the board of education reviewed the conventional correspondence for ill children. Moreover, the board of education endeavoured to grasp the actual situation of children undergoing medical treatment, securing appropriate educational measure, and establishing educational institutions for ill children. Furthermore, patients with respiratory equipment such as those with MD got to live in the region

because of the revision of medical insurance in 1990 and 1994, development of portable medical devices, and expansion of home support services such as home-visit nursing¹³⁾.

The gradual decrease in the number of children with nervous system diseases including MD attending schools for children with health impairment from the 1990s to the 2000s was due to the above effects¹⁵⁾. It was suggested in 'History of education for MD' published by the Japan Muscular Dystrophy Association that the number of children with MD has slightly decreased in many schools for children with health impairment from 1988¹⁴⁾.

Meanwhile, with the improvement of medical technology during these days, it is presumed that children with MD were attending other special schools instead of sticking to schools for children with health impairment where the ward was established. Especially, more children with MD attend schools for children with physical impairment than schools for children with health impairment⁸⁾. In addition, children with MD may have intellectual disabilities, and some of them have chosen schools for children with intellectual disabilities rather than schools for children with health impairment or physical impairment¹⁶⁾.

However, it can be seen that the number of children with MD attending not only the schools for children with health impairment but also other special schools has decreased. Figure 1 shows the transition in the number of children with MD attending a school for children with health impairment (school A) and a school for children with physical impairment (school B) in X prefecture. School A was built next to a hospital where there was a ward for MD that managed not only sick and frail children, but also children with multiple disabilities including intellectual disabilities. School B is the only school in X prefecture for children with physical impairment which has a high school section and school dormitory. Children attending school A or B choose between a course with the regular curriculum, a course with a curriculum for children with intellectual disabilities, and a course centred on independent activities, based on their wishes.

As can be seen from Figure 1, 10 children with MD enrolled in both schools A and B in 2013, but the number of enrolled students has dropped significantly in both schools in 2018. The declining trend seen at School A, which is a school for children with health impairment, is consistent with conventional knowledge. The same tendency is also seen in school B, which is a school for children with physical impairment, and it is considered that the number of children with MD may be decreasing in all special needs schools, including schools for children with health impairment.

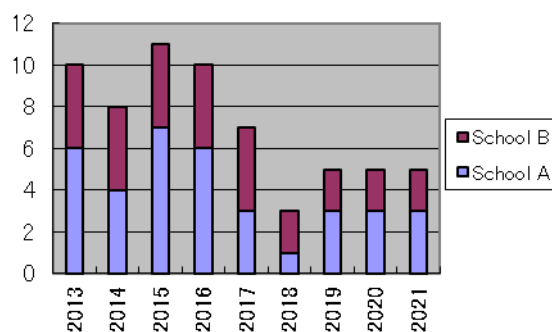


Figure 1. Transition in the number of children with MD enrolled in school A and B

III. Factor of changing in the number of children with MD enrolled in schools for children with special needs

As mentioned above, although almost all children with MD had enrolled in schools for children with health impairment, a few of them had enrolled in other special needs schools. However, from the 1980s, it is indicated that the number of children with MD enrolled in not only the schools for children with health impairment but also others has decreased.

We will explore some factors which resulted in a decrease in the number of children with MD in special needs schools.

1. Promotion of special needs education in ordinary schools

One of the possible factors is that more children with MD have been learning at schools in the region. Nishimaki pointed out that the learning place for children with MD has transitioned from special needs schools to elementary, junior high, and high schools in the region⁸⁾. Suzuki et al., who asked the parents of children with Duchenne muscular dystrophy (DMD) living in home about their choice of school, indicated that 95% of the respondents chose local elementary schools when they entered elementary school, and 40% chose junior high schools when they entered junior high school¹⁷⁾.

Figure 2 shows the number of children with MD enrolled into the elementary school, junior high school, and high school in Schools A and B. Most of the children with MD enrolled in Schools A and B are high school students, suggesting that even at the earliest time in this data, they had already chosen a local primary school when they entered primary school. However, at the junior high school stage when the disease is expected to progress, there seems to be a tendency to choose a local junior high school. According to the teachers at schools A and B, most of the students chose special needs classes at elementary and junior high schools, and each subject was studied in regular classes.

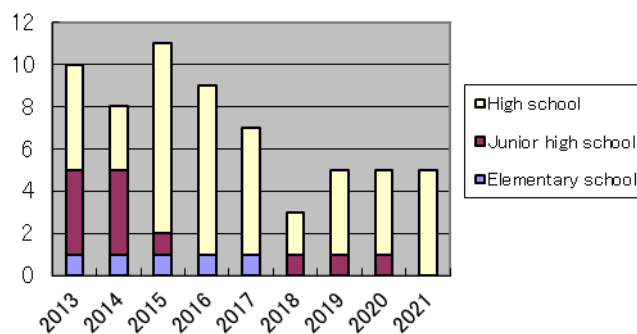


Figure 2. Number of children with MD enrolled in the elementary school, junior high school, and high school in Schools A and B

The promotion of education aimed at building an inclusive society may have affected the increase in the number of MD children enrolled in local elementary and junior high schools.

In 1979, schools for children with disabilities became compulsory in Japan. Subsequently, the concept of normalization spread throughout the International Year of Disabled Persons in 1981 and the number of children with disabilities learning in the community increased¹³. Furthermore, in 2002, the ‘School Education Law Enforcement Regulations’ were partially revised, and the ‘certified admission system’ was established¹⁸. This allowed children with disabilities to enrol in local elementary and junior high schools and receive appropriate education if the Board of Education admitted them under special circumstances. The policy that children with disabilities should be enrolled in special needs schools in principle was later revised into getting the children with disabilities enrolled in local elementary and junior high schools. The school destination is now decided from a comprehensive perspective such as disability status and educational needs. The opinions of children and parents are emphasised, and that of experts in pedagogy, medicine, psychology, and school and community situations are also respected¹⁹.

In 2012, it was shown that the concept of an inclusive education system based on the Convention on the Rights of Persons with Disabilities is important. Japan's inclusive education system seeks ways to learn in the same place with or without disabilities, and prepares a diverse and flexible system that can provide education that meets the individual educational needs of children¹.

However, it has been pointed out that it is difficult to continue attending local elementary, junior high, and high schools. According to a survey by Suzuki et al. ¹⁷, some children were transferred to a special needs school while in elementary school, and 60% of the children with MD and their parents chose a special needs school when they entered junior high school. The reason for the transition was the lack of facilities related to the use of wheelchairs and the securing of assistant teachers and supporters.

Regarding school facilities, maintenance guidelines in 1992 firstly showed basic

matters regarding barrier-free access, and guidelines on facility development and basic ideas for promoting special needs education were presented in 2007²⁰). In addition, the elementary school facility maintenance guidelines revised in 2009 stated that it is important to meet the condition or characteristics of disabilities and educational needs; showed consideration for extending the barrier-free access to the entire school facilities, such as slopes, railings, and elevators; and mentioned important matters regarding specific planning/designs depending on the characteristics of children with disabilities²⁰). As a result, according to an investigation by the Ministry of Education, Culture, Sports, Science and Technology, the installation rate was over 70% in elementary and junior high schools where children and students who needed support attended, and 50% or more in total²¹). In this way, although barrier-free measures are being promoted, having to give up attending local schools because of a lack of with facilities and equipment is still an issue.

The reason may be that the elevator installation rate is low and the support staffs are not sufficient. According to a report by the Ministry of Education, Culture, Sports, Science and Technology, the allocation of support staff seems to be increasing year by year, but the allocation rate of the support staff was only 59.9% in 2010. In many cases, it is necessary to clarify in advance the number of support staff and the budget amount required and to make an early allocation plan for the placement of support staff²²). This may affect the percentage of support staff placement. Similarly, if a child with disability wishes to enrol in a local high school and wants the school to be barrier-free, it should be requested beforehand, such as when enrolling in junior high school. In addition, going to a local high school has many educational challenges; therefore, it is said that many children with muscle dysfunction and their parents often choose a special needs school or a well-equipped private school for attending high school.

As mentioned above, even today, when the promotion of inclusive education and medical technology has advanced, enrolling in local elementary, junior high, and high schools is not easy. The increasing tendency to enrol in local elementary, junior high, and high schools may be one of the reasons for the decrease in the number of children with MD enrolled in the elementary and junior high schools in special needs schools, but explaining the background of such a decrease is difficult.

2. Decline of children with MD

The overall number of children with MD seems to be declining; the decreasing number of children with MD enrolled in special needs schools may be a reflection of this. According to the Ministry of Health, Labour and Welfare, the number of MD patients is estimated to be 25,400⁴). In addition, it has been reported that there are 21,000 patients aged 18 years or older with progressive muscular atrophic disease, including amyotrophic lateral sclerosis (ALS), and 1,500 of them live at home²³). Studies have been conducted to determine the total number of MD patients, but these are either estimates or include ALS patients. Therefore, it is difficult to know the exact number of children

with MD and the transition.

This may be related to the history of the support system for MD patients. The total number of intractable illnesses specified should be kept as the sum of the number of people who have received a medical expenses beneficiary certificate and the number of people who are not eligible for medical expense subsidies but are registered²⁴⁾. The number of people with MD receiving a medical expenses beneficiary certificate gradually increased from 2016 to 2020, reaching 4,510 by 2020²⁵⁾. MD was designated as an intractable disease in 2015 due to the enforcement of the Act on Medical Care for Patients in 2014, compared to other diseases according to the guidelines on measures for children with MD issued in 1964. MD-specific support measures were already implemented. It may be difficult to estimate the number of MD patients from the number of designated medical expenses beneficiary certificates because those with MD who have not received the certificate may obtain them later.

Prevalence and incidence are often indicators of the number of patients with a disease. These are basic methods of indicating the outbreak of a disease within a particular group. Prevalence indicates the percentage of people in the group who are affected by the disease at any given time, whereas incidence show the percentage of new illness cases in a group within a specific time period. According to reviews based on overseas reports, the prevalence of Duchenne muscular dystrophy (DMD) which is typical types of MD in men is 4.78 per 100,000 population, and the incidence of DMD in men ranges from 10.71 to 27.78 per 100,000 population²⁶⁾. Based on domestic and overseas reports on the number of MD patients, the prevalence of MD in Japan is estimated to be approximately 17 to 20 per 100,000 population, and that of dystrophinopathy is estimated to be four to five per 100,000 population⁵⁾. In the case of the incidence in Japan, it is only an investigation by each group. It is estimated that the prevalence of MD in Japan increased due to the life-prolonging effect of respiratory management, and the incidence decreased owing to the effect of genetic counseling²⁷⁾.

Minami et al. investigated the number of patients with DMD who are currently in hospitals and clinical departments specialising in neurological disorder in Hokkaido and calculated the prevalence of each age group in Hokkaido to understand the actual situation of DMD²⁷⁾. By reckoning the prevalence of 7–11 years as the incidence, they compared the data obtained to conventional reports. Table 1 shows the number of patients with DMD, the prevalence in each age group, and previous reports on the prevalence and incidence in Japan. Comparing the results in Table 1 to past reports, the incidence is not always accurate because it depends on the investigation method and number of subjects, but the prevalence has increased and the incidence has decreased from 1965 to 1992.

Table 1 Reports on the prevalence and incidence of DMD

Survey area	Survey year	Prevalence ($\times 10^{-5}$)	Incidence (male birth $\times 10^{-5}$)	The number of patients	Report
Chiba	1965~74	2.50	21.7	46	Yasuda, Kondo (1980)
Kagoshima	1980	2.55	22.8	45	Norimatsu et al. (1981)
Hokkaido/Hokuriku/Kyusyu	1979~82	3.55	29.2	384	Kanamori (1988)
Kumamoto	1983	1.7	-	31	Araki et al. (1984)
Okinawa	1989	3.44	-	42	Nakagawa et al. (1990)
Hokkaido	1992	2.73	18.18	131	Minami et al. (1993)

Partially modified by quoting from Ryoji Minami et al. Epidemiology of Duchenne muscular dystrophy in Hokkaido. *Ministry of Health and Welfare Psychiatric and Neurological Disorders Contract Research "Research on Clinical Pathology, Genetic Counseling and Epidemiology of Muscular Dystrophy" 1992 Report.* 1993, 7-10²⁷⁾

The increase in prevalence is due to the year-by-year improvement in medical technology such as ventilators. In the medical setting in Japan in the early 1980s, there was hesitancy regarding ventilator treatment for patients with neuromuscular disease because ventilators were expensive and hospitals could not have enough of them, and there were communication issues about tracheostomy. However, after that, effectiveness of ventilator which do not tracheostomy have been shown in reports from abroad and a breathing method with a nose mask (NIPPV) was introduced in 1990, which contributed to life prolonging by five years on average²⁸⁾. In the cause of death statistics published by the International Statistical Classification of Diseases and Related Health Problems (ICD), it is also suggested that the number of deaths from primary muscle disorders (ICD code G71 classification) including MD have increased about three times from 1980 to 2020. Improvement in medical technology such as ventilators might relate strongly to the long life of patients with MD because the number of deaths has increased in especially patients with MD over the age of 50 years. Many relationships between the increase in prevalence and use of ventilators have been reported abroad²⁹⁾. In addition, clinical trial is underway in recent years so that a treatment which will suppress the deterioration of motor function for specific DMD can be established. It is regarded that improvement in medical technology tends to affect the life-prolonging of patients with DMD which has symptoms of muscle weakness from childhood and is easily susceptible to not only diseases invading skeletal muscles but also systemic diseases invading multiple organs.

What is more, the decline in incidence likely relates to birth refrain because of the effect of genetic counselling and spread of information about MD. MD is a hereditary disease. Therefore, a few families were worried regarding whether to give birth when they came to know about the pregnancy. The Japan Muscular Dystrophy Association

accepted genetic counselling of 47 cases in 1994 which were mostly related to issues of blood relatives rather than issues of patients. The clients worried mostly about the possibilities of a future onset of MD in a child, and many clients especially requested a carrier diagnosis for sisters with siblings diagnosed with DMD³⁰.

In addition, preimplantation genetic diagnosis from 1998 also seems to have affected the decline of children with MD. Preimplantation genetic diagnosis involves the genetic analysis of fertilised eggs in vitro, and if there are no abnormalities, the fertilised eggs are implanted in the uterus to establish pregnancy. The cases of preimplantation genetic diagnosis are limited; for example, one condition is being a couple who have a high risk of giving birth to a child with a serious hereditary disease. Preimplantation genetic diagnosis for MD started in 2004. Kaiya conducted a questionnaire survey for preimplantation genetic diagnosis for the members of the Japan Muscular Dystrophy Association. According to this, the number of proponents in the family is decreasing, although its rate is low, and the number of proponents in patients is increasing slightly. Kaiya pointed out the narrowing gap between patients and their families year by year and said that this result is due to the spread of knowledge about preimplantation genetic diagnosis and that the patients and their families thought deeply about preimplantation genetic diagnosis³¹. In addition, there are patients and families who have a negative opinion on reproductive medical practice including preimplantation genetic diagnosis. One of them said, *‘Certainly, when I see my son who suffers from the disease, I feel responsible for having my baby. However, I am horrified that humans are also selected, just as products are selected, as good or bad. I hope that the study is focused on making gene therapy possible for a child born with the disease’*. In contrast, there are positive opinions such as *‘I have a Duchenne type son and I feel painful looking at his dire situations such as dyspnea, sputum clogging, and other pain. Some parents want to raise a child even with disability, but when it comes to this disease, I think that this is an exception. I wish the genetic screening will be known to many people and promoted to be utilised well’*³¹. MD is an intractable disease that is hereditary, degenerative, and has no cure. Preimplantation genetic diagnosis can mentally help people who have patients with MD as their relatives and parents who have an eldest son with MD. Improving each diagnosis seems to affect birth refrain for children with MD.

However, as Kawai et al. pointed out that genetic diagnosis affects to give birth a child positivity, each diagnosis does not always cause birth refrain³². In addition, since there are many negative opinions of preimplantation genetic diagnosis for MD, which is a hereditary disease in Japan, and there are few cases compared to other countries owing to its huge costs, it needs to consider the relevance to the incidence and birth refrain by each diagnosis.

As described above, it is considered that the number of births of children with MD has decreased due to the decline in the incidence. This may have caused the decline in the number of children with MD attending special needs schools.

IV. Discussion and Conclusion

It is said that the number of children with MD in special needs schools, including schools for children with health impairment, is declining in elementary and junior high schools. It has generally been thought to be related to the increase in the number of children with MD enrolled in local elementary and junior high schools.

We reviewed related previous studies and recent findings on the total number of children with MD which are thought to be related to changes in the school attendance, and education of children with MD. We also conducted a small-scale survey on changes in school attendance.

The results certainly suggest that the number of children with MD in special needs schools is decreasing, especially in elementary and junior high schools. It is assumed that such a decrease may be due to the increase in the number of children with MD enrolled in elementary and junior high schools. This is thought to be influenced by the advances in inclusive education and medical technology; in the educational field, barrier-free and education supports have been provided due to the spread of normalization in the International Year of Disabled Persons. In these days, inclusive education system has been promoted. Such changes in law, system and technology seem to relate to the school enrollment of children with MD. Additionally, in the medical field, medical technologies for patients with MD, such as ventilators, have improved in the 1980s in Japan.

However, it is difficult to explain the trends in the enrollment of children with MD based on the above reasons alone. This is because it was thought that many issues still remain for children with MD to enrol in local elementary, junior high, and high schools. In other words, although the educational environment and medical technology are improving, barrier-free school facilities and the placement of support staffs are not yet sufficient, which is a barrier for children with MD to learn at local schools.

In addition, most of the studies on the school enrollment status of children with MD are targeted only at schools for children with health impairment. Therefore, it has once again become clear that the actual school enrollment situation of children with MD is not known.

Hence, we need to compare the number of children with MD in local elementary and junior high schools and that in each special needs school, and to understand a trend of school enrolment for children with MD. We believe that understanding it will be useful when examining whether the laws and systems related to school education are contributing to the realization of the school enrollment that children with MD want.

It is also necessary to consider the factors of changing the number of children with MD in each school and to prompt solution for the issues related to school enrolment in the context of a trend of their birth and education support.

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