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Abstract

Current measures for the care of children with severe motor and intellectual disabilities that emphasize home-based support had previously not been implemented prior to the period of high economic growth in Japan. At that time, particularly when policies for the expansion of facilities were being promoted, the energetic movements by parents of children with severe motor and intellectual disabilities greatly contributed to the expansion of facilities that provide care for these children.

Although grass-roots movements by these parents can be seen starting in the 1960s, their parental affection and responsibility were emphasized in order to appeal for the need for these facilities during actual lobbying. These movements began to be successful in implementing dramatic policies starting in 1965 as a result of the expansion of such facilities being positioned as a part of social development. The fact that these policies were naturally considered to be a family function defined the stance and attitudes adopted by parents. Finally, on the basis of these considerations, this paper points that the limiting nature of the policies at that time is attributable to the fact they relied heavily on parental responsibility.

Key Words

Parents of Children with Severe Motor and Intellectual Disabilities, Lobbying Movements, A Period of High Economic Growth

I. Introduction

In recent years, in the field of social welfare in Japan, the principal concepts have related to such topics as normalization, care at home, and de-institutionalization. In the area of welfare policies for children with severe motor and intellectual disabilities (hereinafter referred to as children with SMID), the past 30 years or so have seen a shift from measures emphasizing institutional expansion to those that allowed for home care of some children with SMID.11

It must be noted, however, that revised welfare policies for children with SMID and expansion of home support services do not necessarily mean de-institutionalization and a decrease in the number of available facilities. In recent years, from the point of view of specialties in medical care and rehabilitation, and also from the point of view of home care personnel, the importance of specialized institutions has been revisited and re-evaluated. In addition, when we look at the past three decades, the fixed number of beds in facilities for children with SMID shows expansion.2) As of October 1974, the fixed number of beds totaled about 10,000 (about 6,000 of which were at hospitals designated for children with SMID and operating as national sanatoriums). By October 2004, the total exceeded 18,000, counting beds operated by public or-
ganizations, corporations, independent administrative organizations, and national hospital organizations. (The number of residents totaled 12,000 of which 80% were adults) (Cabinet Office 2004).

In the history of welfare policies for children with SMID, this paper highlights the Period of High Economic Growth that coincided with the promotion of policies furthering expansion of institutions. Furthermore, this paper especially focuses on the movements by the parents of the children with SMID in this period. Section III will describe the development of the National Association for Children (Persons) with Severe Physical and Intellectual Disabilities, hereinafter referred to as NAC(P)SPID. (It must be noted, however, that this acronym is not an authorized one with the Association.) As is well known, prior to the Period of High Economic Growth, welfare policies aimed at providing support for rehabilitation of those with minor disabilities. Throughout the Period, emphasis shifted to those children with SMID who require care at all times. During the period of transition, parents of these children with SMID appealed to society in general to relieve their excessive burden of care and their “anxiety for their children after they (the parents) become deceased.” Indeed, the parents made an extraordinary effort in their appeal for the necessity of the institutions, which led to increased development.

Needless to say, because the author is examining the parent (caregiver) movement, he recognizes past attempts to examine the history of welfare policies for children with SMID. Previous studies can be categorized into the following two main types: (1) those that focused on remedy, development, and treatment for children with SMID; and (2) those that focused on medical categorization of the children. In other words, it can be said that little light has been shed upon important elements of the caregiver movement that exists among parents of children with SMID. It should be noted that the policy measures for children with SMID made during the period are achievements directly attributable to parents who tenaciously appealed for them. This is to say that the history of welfare policies for children with SMID up to that time tended to be occupied only with the practical interests of “specialists” regarding how to provide remedies and treatments for the children and how to place them into appropriate medical categories. In other words, this mindset explains how the welfare policies for children with SMID were constructed. Because our contemporary viewpoint about children with SMID emphasizes the user’s (patient’s) perspective, the history of the welfare policies should be revisited.

In addition, the author wishes to examine the norms identified by the parents of the children with SMID during the development of the parent movement (Section IV). The author’s intention is to examine not only the development of the parent movement but also details of its forms and conditions. The reason is that, through such investigations, the author also wishes to determine the characteristics and even limitations of the parent movement during this period. Although this may be preempts the conclusions, the parents had to emphasize the specifics of their own mindset as parents in order to make their demands accepted in concrete terms. In sum, these were the characteristics and limitations during the Period of High Economic Growth, which strongly become evident during this study. Finally, in regard to the points that are made clear in Sections III and IV, the social background of each point will be elucidated (Section V). In concrete terms, the reasons for the upsurge of measures reflecting demands of the parent movements in the years following 1965 (first paragraph, Section V) and the reasons why the parents had to emphasize their affectings and responsibilities as parents (second paragraph, Section V) will be elucidated through the author’s examination of the logic behind the policies for expanding the facilities.

II. Children with SMID Becoming a Social Problem

It was in the latter half of the 1950s, when the problems of the existence and treatment of children with SMID were first recognized. The children with SMID referred to in this paper are those who have “severe mental retardation and severe physical disabilities,” and their situation had not been viewed as a social problem.
In terms of the legal system, in the Children’s Welfare Act of 1947, only “institution for physically disabled children” (Item 3 of Article 43) and “institution for children with mental retardation” (Article 42) are defined. The requirements for being placed in these institutions are physically disabled children and children with mental retardation who can be rehabilitated. In other words, children with SMID were not in these institutions.

Children with SMID became a social problem for the first time in May 1957, triggered by an appeal made by Dr. Teiju Kobayashi of the Japan Red Cross Maternity Hospital. In an opinionated report titled “On Discrepancies Not Covered by the Children’s Welfare Act,” Dr. Kobayashi decried that “the Children’s Welfare Act is supposed to cover measures for children under 18 years of age but there are some blind spots in reality” (Zenkoku Shakai Fukushi Taikai 1957: 45). Indeed, what he pointed out was the existence of children with SMID who had been neglected by the legal system in Japan. This was followed by a newspaper article titled “Hikari no nai kodomo (Child Devoid of Light)” (Asahi Shimbun, evening edition, December 26, 1957), which took up the same social issue. Stimulated by the article, newsletters and journals of various welfare-related organizations also reported on the problem. On June 20, 1958, a meeting was held by the Jusho Kekkanji Taisaku Inkai (Committee for Establishing Countermeasures for Children with Severe Physical and Intellectually Disability) at the Tokyo Council of Social Welfare. The meeting resolved that the children who used to be called “Jusho Kekkanji (a child with severe disability)” and “Fuchi Eikanji (a child with incurable or permanent disability)” should be called “Jusho Shinshin Shougaiji or Jushoji (a child with SMID).” Then, four days later, Zenkoku Shakai Fukushi Taikai (All Japan Meeting for Social Welfare) was held, where a resolution was passed for the “Establishment of Jusho Shinshin Shougaiji Taisaku Inkai (Committee for Establishing Countermeasures for Children with SMID).” At the first committee meeting, the following major tasks were established to deal with the social problem of children with SMID: “(1) revise the Children’s Welfare Act for establishing institutions, by applying new concepts; (2) conduct surveys to clarify actual conditions as a foundation for establishing concrete measures; and (3) disseminate the basic principle of the measures as “resident care in an institution,” which means a special institution providing medical care, and increase budget allocation for the measures ” (Inclusion Japan 1958:34).

The matter of children with SMID became known to the general public in the 1960s, not only to those in the field of social welfare. In November 1958, Nihon Shinshin Shogaiji Kyokai (Japanese Association for Physically and Intellectually Disabled Children) (which is a managing organization for Shimada Ryoikuen) was established. In May 1961, Shimada Ryoikuen, the first Japanese institution for children with SMID, was established at last. With the establishment of Shimada Ryoikuen as the trigger, the social problem of children with SMID began to be covered widely by general mass media. In July 1963, Tsutomu Minakami, a popular writer, wrote an article titled Haiki Ikeda Soridaijin-dono (Dear Prime Minister Ikeda) in Chuo Koron (Central Review, a monthly magazine), which was an open letter addressed to the Prime Minister. The article became a sensation and triggered various media campaigns to establish measures for children with SMID, by major newspapers and NHK.

Against the backdrop of various media campaigns to establish measures for children with SMID, a movement by the parents of children with SMID surfaced, which openly promoted activities and developments. As the matter of children with SMID, which had been kept in the closed circle of welfare professionals, became known to the general public, the parent movement began to take its own initiatives, beyond their activities within various groups and organizations, as described below. Especially, the NAC(P)SPID movement, which was established in 1964, exerted a strong influence on the content of various measures for children with SMID.

In the next section, the author reconstructs how the parent movement developed, using what can be seen in the Ryoshin no Tsudo (Gathering of Parents), a magazine issued by NAC(P)SPID. The purpose is a historical one, to clarify how the parents of children with SMID appealed for the necessity of institutions dedicated to children with SMID, beginning in 1957.
when children with SMID were recognized as a social problem and continuing throughout the Period of High Economic Growth. In order to facilitate analysis, the time frame is divided into four: Period I “Period of activities within other groups (1957-1960)”; Period II “Period of activities below the surface (1961-1964)”; Period III “Period of drastic reflection of movements to measures (1965-1967)”; and Period IV “Period of facing new problems (1968-1973).” Thus, the author will proceed with an analysis based on these periods.

III. Developments in the Parents’ Movement for Children with SMID

1. Period of activities within other groups (1957-1960)

As explained above, the remarks by Teiju Kobayashi at the All Japan Meeting for Social Welfare opened society’s eyes to the presence of children with SMID. This awakening turned the matter of their treatment into a social problem for the first time and the problem came to be widely known among people concerned with social welfare. However, the parent movement did not surface until the 1960’s. Before this decade, no associations of parents of children with SMID existed; such parents had to continue their activities within associations of parents of children with mental retardation and physical disabilities. Within these circles, it was inevitable that children with SMID who had no prospects of recovery were always marginalized.

For example, Zen-Nihon Seishin Hakujakusha Ikuseikai (Inclusion Japan), which is an association of parents with mentally retarded children, had not conceived the possibility of serving children who were mentally retarded since birth and had no prospects for improvement. Ever since its founding in 1952, this association had focused on its primary goal: “Promotion of movements for a law about the education of children with mental retardation and realization of relevant applications of the Welfare Act.” As another example, the Articles of Incorporation of Inclusion Japan at the time of its founding in 1959 state: “This corporation has as its objective supporting the mentally retarded, who need to have measures for support, development, and rehabilitation, without infringing upon their spirit of independence. In other words, the objective is to support the mentally retarded so that they can lead lives as normal persons in society.” The key words here are “rehabilitation” of the mentally retarded as “normal persons living in society” (Inclusion Japan 2001).

In the case of Nihon Shitai Fujiyuji Kyokai (Japanese Society for Disabled Children), which has been in support of parents of physically disabled children, the term “children with SMID” first appeared in an article written by Matsuwaka (1961) in 1961 (as far as the present author can determine). The term “children with SMID” was categorized by Nishikawa and others the following year, however. Children with SMID are divided into two groups: “incurably and permanently disabled” who have no prospects of improvement “no matter what treatments are performed on them; and “comparatively severely disabled” who recover in a relatively short period” (Nishikawa 1962). Within the Association, therefore, children with SMID are those “comparatively severely disabled” but not the “incurably and permanently disabled.” Thus, among parent associations at that time, the children of interest were mainly moderately disabled children who are capable of rehabilitation, and so children with SMID who had no hope for rehabilitation were outside their scope.

2. Period of activities below the surface (1961-1964)

When children with SMID became well-known to the general public, their parent movement was openly seen, which began to happen in the 1960’s. In March 1962, a new Jusho Shinshin Shogaiji Taisaku Sokushin Kyogikai (Association for Promotion of Countermeasures for Children with SMID) was established, aiming to transform the requests of parents of children with SMID into concrete countermeasures to serve them. In October 1962, The Basic Requirements on Countermeasures for Children with SMID was submitted to the Director, Children and Family Bureau, Ministry of Welfare as a petition by concerned parents.

The actual conditions surrounding these children
are yet to be clarified. There is not a single counter-
measure for children cared for at home and, even
if there were some, they are only known at two or
three exceptional places which serve these children
[such as Shimada Ryoikuen and Biwako Gakuen].
Besides, the contents of the measure are not applied
to severely disabled, children with double burdens,
and children with triple burdens. This means that
the treatment of such children is very minimal. It
is a pity that the parents of these children depend
on the benign and philanthropic will of institutions.
The mental and financial burdens on families with
these children are beyond description by means of
words. Because the actual conditions of these
families are totally helpless, not a few tragedies are
induced, such as suicides of parents or children and
disrupted homes. (Jusho Shinshin Shogaiji Taisaku
Sokushin Kyogikai 1962)

The Jusho Shinshin Shogaiji Taisaku Sokushin Kyogikai (Association for Promotion of Countermeasures for Children with SMID) is composed of 12 organiza-
tions, with the Zenkoku Shakai Fukushi Kyogikai (Ja-
pan National Council of Social Welfare) taking the lead
along with such organizations as Zen-Nihon Seishin
Shogoisha Ikuseikai (Inclusion Japan) and Zenkoku
Shitai Fujiyuji Fubo no Kai (National Federation of
the Physically Disabled and Their Parents Associations).
The petition made by the Jusho Shinshin Shogaiji Tai-
saku Sokushin Kyogikai (Association for Promotion of Countermeasures for Children with SMID) expressed
for the first time the point of view of parents, reveal-
ing to the government the fact that there had been no
measures for children with SMID. At the same time,
the tragedies of families with children with SMID were
appealed to the administration. After receiving the peti-
tion, the Ministry of Welfare issued a notice by the Vice
Minister on the “Implementation Requirements for
Remedies and Treatments for Children with SMID (July
26, 1963, Jihatsu 149).”

In the Notice, the Ministry defined children with
SMID as “those children for whom rehabilitation is
extremely difficult due to high level of physical disability
along with mental retardation or due to high level of
physical disability along with difficulty in providing
appropriate remedy and treatment at home.” This defi-
nition almost exactly accepts the definition of children
with SMID included in the Basic Requirements on
Countermeasures for Children with SMID submitted by
the parents. The Notice also disclosed that institutions
for children with SMID (above-mentioned Shimada
Ryoikuen and Biwako Gakuen) would be operated as
enterprises subsidized by the national government and
that the expenses for remedies and treatments for these
children would be paid by the national government as
well as Tokyo Metropolitan and prefectural govern-
ments (including designated municipalities).

In 1964, the NAC(P)SPID was established at long
last, as an association restricted to parents of children
with SMID. The Japan National Council of Social
Welfare worked as an intermediary between two orga-
nizations that were already operating in this field: Zen-
Nihon Seishin Hakujakusha Ikuseikai (Inclusion Japan)
and Zenkoku Shitai Fujiyuji Fubo no Kai (National Federation of the Physically Disabled and Their Parents
Associations), forging a new association composed
entirely of parents of children with SMID, which inher-
ited the Nisseki Ryoshin no Tsudo (Parents Gathering
at Japan Red Cross Maternity Hospital). In June 1964,
a meeting celebrating the founding of the Association
was held at Toranomon Hatsume Kaikan in Tokyo.
Many parents of children with SMID gathered along-
side social welfare people and politicians.

Regardless of whether one belongs to Zen-Nihon
Seishin Hakujakusha Ikuseikai (Inclusion Japan) or
Zenkoku Shitai Fujiyuji Fubo no Kai (National Fed-
eration of the Physically Disabled and Their Parents
Associations), all parents share the same objective
of caring for unfortunate children. Therefore, the
pre-requisite is essentially mutual understanding
and cooperation to promote measures for the wel-
fare of disabled children and to respect the true feel-
ings of the local community. The NAC(P)SPID will
emphasize the protection of children with SMID,
who tend to be left out of society and need special
efforts to bring them into our circle. We will work
to promote mutual friendship among all members,
to appeal to people in society to understand the realities of these children, and to extend our loving hands to the children. (NAC(P)SPID 1964)

The founding spirit of the NAC(P)SPID was "protect every single child, even the weakest." The primary goal was establishment of a special law concerning children with SMID. This was necessary because the existing Children's Welfare Act could not be applied to people 18 years or older, even if it was amended. In order to avoid the likely situation where certain children would be left unprotected in the future, it was thought that a drastic change in legislation was needed. Two days after its founding meeting, the NAC(P)SPID expressed its opinion that "a special law needs to be enacted so that the law will cover comprehensively from newborn to elderly" (NAC(P)SPID 1964). Then, petitions were made to the Chief Cabinet Secretary, the Labor Committees of the Upper and Lower Houses of Parliament, and other political players. In this manner, parents of children with SMID began to initiate their own activities in the 1960’s.


In 1965 and afterwards, the activities of NAC(P)SPID evolved to their full-scale. On June 26, 1965, the second all-Japan meeting of the NAC(P)SPID was held at the Kubo Lecture Hall at Toranomon in Tokyo. As a guest of the meeting, Chief Cabinet Secretary Tomisaburo Hashimoto made the following remarks, prefaced by his heart-felt comment that "he did not have the courage to read the clichéd and insensitive remarks prepared by bureaucrats."

I do not have the courage to read the words of greeting prepared by the ministry for me to deliver to you. It could be that we as politicians did not have sufficient affection for you to feel your sadness as our sadness and to receive your misfortunes as our misfortunes. I take it that the Minister of Welfare means to do so this time. As for myself, although I could not all of a sudden produce the requested measures, as a person representing the Prime Min-

ister, expressing my feelings in simple language would be a means to reward your efforts to take drastic measures in terms of the public budget. (Hashimoto 1965)

This national meeting of the NAC(P)SPID in 1965 was a threshold or turning point, and it has been said that “favorable winds” were blowing for the new Association. Several days after the meeting, a round-table conference was held, including the Chief Cabinet Secretary and various officials involved in the Cabinet and the Ministry of Welfare, as well as Tsutomu Minakami, Chieko Akiyama, and representative parents of the NAC(P)SPID. Promises were made about the budget, affirming it would cover measures for children with SMID during the next fiscal year. Also around this time, the matter of children with SMID began to attract public attention and various incidents were taken up by newspapers, radio, and television. For example, just within 1965, then-Minister of Welfare Suzuki visited the Shimada Ryoikuen in July and the Colony Roundtable Meeting was established in October. In December, the Colony Concept was made public, with the announcement that "the Colony should be a resident community which is also a comprehensive medical institution.” As if responding enthusiastically, all areas of Japan became active within the respective branches of the NAC(P)SPID. At the same time, support groups for the NAC(P)SPID (such as the Student Federation for Remedies of Children with SMID, and local volunteer groups) were established.

The heightening of social interest in children with SMID was directly reflected in the fixed number of beds in institutions for such children. Because it was assumed in 1965 that the number of children with SMID was about 30,000 throughout Japan, the fixed number of beds totaled only 368 and there were only three facilities: Shimada, Biwako, and Akitsu. By 1975, the number of beds increased to 11,000. At the same time, when we look at the national budget allocation for measures for children with SMID, it was only 101.8 million yen in fiscal year 1965, but immediately increased to 800 million yen in the next fiscal year 1966.
Furthermore, in August 1967, institutions for children with SMID were placed under the national legal system, a dream come true for their parents, realized by the revision of the Children’s Welfare Act (Item 4 of Article 43). According to Kamimura (1987), who was then Section Chief, Bureau of Children and Family, this revision was a direct legalization of the Notice by the Vice Minister and the Opinion Paper addressed to the Minister of Welfare by the Special Division on children with SMID of the Central Child Welfare Council (December 23, 1966). This influential Opinion Paper actually took up the points that the NAC(P)SPID had been requesting (NAC(P)SPID 1967). Thus, the Revision of the Act was a direct replica of the parents’ appeals. At the same time, an additional resolution was passed for the children who had been left out of the legal system, about whom NAC(P)SPID was concerned. This resolution was submitted under the title of “Concerning the Enactment of Revision of a Part of the Children’s Welfare Act (August 24, 1967, Jihatsu 101)” and it confirmed that the “unification of a child and an adult” or “continuation of resident status and approval for new resident status can be given for those children with SMID who need to continue to receive remedy and treatment.” Thus, one can see during this period that the appeals of parents of children with SMID came to be reflected in legal and administrative measures for them, opening up possibilities for residence in institutions for the children with SMID.


After the revision of the Children’s Welfare Act in 1967, construction of institutions for children with SMID began in many locations throughout Japan. This did not mean, however, that all the children with SMID were able to reside in the institutions. Although children with SMID with relatively lighter mental problems could obtain resident status, it became apparent that so-called “children with mobile severe motor and intellectual disabilities” were not able to obtain resident status. The latter were severely intellectually disabled persons who often put a heavy burden on the institutions. In concrete terms, those severely intellectually disabled who tended to destroy objects and harm themselves, as well as those who reached adulthood, could not obtain resident status. (In 1973, employees of an institution went on strike appealing that they suffered from lower back pain.) Inside the NAC(P)SPID, a special committee for resolving the situation was established and petitions were submitted.

Measures for children with SMID by the national and local governments are making progress each year. Institutions for children with SMID have been built in various locations and the number of resident children has increased. There are, however, still some children who cannot obtain resident status in these institutions. For example, in the selection process to determine resident status, so-called “children with mobile severe motor and intellectual disabilities” tend to be cut off, with denial explained in terms of the conditions and building structure at the institution being inappropriate. …We should give ample thought to such problems experienced by “children with mobile severe motor and intellectual disabilities” and we should listen to the opinion of experts regarding the most appropriate remedies and treatments of these children and the capacity of the institutions. We must make an appeal so that countermeasures to solve such problems can be established urgently. (NAC(P)SPID 1969)

In addition to the difficulty of obtaining resident status for “children with mobile severe motor and intellectual disabilities”, which became apparent and was discussed openly, there is a more opaque problem in terms of public enlightenment about preventive abortion of children with SMID, which has been discussed by policy makers. During the period in question, there seemed to be more intensified awareness of this problem inside the NAC(P)SPID, which was noteworthy. For example, President Omura of the National Pediatric Hospital, who maintained a close relationship with policy makers, wrote as follows: “Due to recent progress made in obstetrics, …It is now possible to conduct abortion specifically to prevent births of children with SMID” (Omura 1970). This was an appeal to people such as NAC(P)SPID members, advocating for pre-
natal diagnosis and selective abortion. This means that, during the period, in spite of the drastically improved likelihood of children with SMID obtaining resident status, policy makers had a growing awareness of the financial burden of operating the institutions. In other words, members of NAC(P)SPID were being “pitched” with suggestions about the possibility of preventive abortions, which would mean less financial burden for everyone (Matsubara 2000).

IV. Emphases on Affection and Responsibilities of Parents

How did the parent movement for children with SMID evolve through awareness of parental norms? In the previous section, it was noted that since 1965, there has been a drastic increase in measures that reflect parent appeals on behalf of children with SMID. As the forces behind petitions by these parents to the government strengthened, President Kitaura of the NAC(P)SPID commented that the following postures among parents would facilitate making parent appeals more effective. He was then president of the Association and he himself was the father of a child with SMID.

What will be important here is not to forget our responsibilities as parents. In concrete terms, this means adopting a way of thinking that “I am doing everything I can as a parent. But some of the child’s needs are far beyond my capabilities. For these, I would like to have public assistance.” When we appeal to the government with this kind of thinking and “this attitude,” which everybody understands, we know it works. We have experienced this many times in our various petition attempts (Kitaura 1965).

What must be noted here are the phrases “we are doing everything we can as parents” and “but some of the child’s needs are far beyond my capabilities. For these, I would like to have public assistance.” Because these concepts are considered to be expressive of the self-awareness of parents of children with SMID. Expecting self-awareness and the right mental attitude from parents of children with SMID is an ideal of the NAC(P)SPID that has been emphasized continuously to the present time. Concerning this, Kitaura and Niwa have commented as follows: “The happiness of children with SMID depends on the affection of the general public. …Whatever hardships we face, we must help each other without forgetting gratitude” (Kitaura 1968). “This is pure love of the parents toward their children and this is born out of devotion in our way of life with our children. ‘Care for the children’ is not something we can leave to a third party” (Niwa 1974). Indeed, the affection and responsibilities of parents have always been emphasized in order to strengthen the bonds within the Association and find ways to break through the hardships faced by the Association. 4

However, it should be noted that emphasis on mental attitude did not originate with the founding of the Association and then become reflected in their movement. Rather, this ideal is an outgrowth and continuation from what existed before. The original ideal so-to-speak was that of Nisseki Ryoshin no Tsudoi (Parents Gathering at Japan Red Cross Maternity Hospital, hereinafter referred to as the Gathering), which had been held since 1955. The Gathering was originally a consultation meeting to develop remedies as a group, conducted by Dr. Teiju Kobayashi who was a pediatrician at the Japan Red Cross Maternity Hospital. The NAC(P)SPID was established in 1964 as a continuation of the ideal of the Gathering. Thus, the Gathering already had taken the stance of emphasizing the importance of the mindset of parents of children with SMID.

Parents of children with SMID sometimes agonize about how to bring up their children. They should never forget that their attitudes as parents of these children take priority to learning methods about how to educate and train their children. …There may be many occasions where you learn new skills and techniques of child rearing, but there are few where you learn proper attitudes as parents of these children. The meaning of this Gathering is learning from our own experiences. We not only learn with
our heads but we also pioneer a new way of life through our learning. (Kobayashi 1961)

One can see clearly from Kobayashi’s words that, although the Gathering was considered as consultation meeting for finding remedies as a group, it also had the function of being a locus to “learn proper attitudes as parents of these children” rather than learning only “skills and techniques of child rearing.” Such a meaning and purpose of the Gathering was a reflection of Teiju Kobayashi’s ideas and practices. Kobayashi (1968) states: “One could see more psychological unhealthiness and pain among the people around the children with disabilities than in the children themselves. Small children are united with their mothers and they are really attached to their mothers. For this reason, it is the mothers themselves who need to acquire a firm and positive attitude toward bringing up the children” (Kobayashi 1968: 7). In his consultation he always stressed the “mental health of the family.” In his guidance and practice, Kobayashi instructed even the expression of affection by the parents. On this point, he states: “Expressions of affection toward the children should be appropriate in terms of quality, quantity, methods, and strength. The expressions of affection should reflect the reasons for the feeling and, if the time is short, then the expressions should be strong ones” (Kobayashi 1965: 209).

Mothers should be deft at expressing their affection. In front of two children, they must be absolutely equal to both. But when a mother is with a child alone, then she should firmly hold him/her like a baby. Moreover, she should praise the child for being good or not being angry and also use reasoning. When a child is satisfied in this manner, he/she would not lose his/her temper when with his/her brother/sister because a bad temper is a behavior of dissatisfaction. (Kobayashi 1965: 166)

In addition, Kobayashi makes certain strong statements about the physician-mother relationship in his practice: “Mothers naturally give guidance to their children, so the physician can guide the mother rather than guide the child directly” (Kobayashi 1965: 12). In other words, a physician supports a mother’s nurturing of her child in the emotional aspects and this is what he means by “a physician’s guidance of the mother.” Looking at this from a different angle, a physician becomes a part of the strategic apparatus for maintaining the family (function) (Donzelot 1979). The mechanism of this is clearly shown in the fact that Kobayashi’s guidance extended to a mother’s expressions of affection to her children. Thus, the emphasis on the parental attitudes of the members of the NAC(P)SPID, which permeated the activities of the Association, was a fundamental ideal of the Gathering that existed prior to the founding of the Association, especially in the thoughts of Kobayashi.

It should be noted, however, giving respect to the points of view of the parents, that the emphases on affection and responsibilities were made more practical and spontaneous through the parents’ petitions. This means that, the parents did not merely emphasize affection and responsibilities in a passive manner (as judgmental dopes who passively receive the social meaning of the vocabulary (Garfinkel 1967)), but rather attempted to change the meaning of the affection and responsibilities in an active manner.

It goes without saying that the affection between parents and children is precious and strong. Therefore, it would be natural for the parents to think that they do not want to let the children leave their home. But what does it really mean, in reality, to love the children? ...I take the point of view of the children with SMID and make a judgment about “what would be happier for them.” I think not to “let them go away from home” would be a kind of one-way affection felt by the parents and it would be a good demonstration of the responsibility of the parents to let the children take resident status without hesitation. (NAC(P)SPID 1966)

One might think that letting children leave home is a negation of affection and responsibilities. Some of the parents argue, however, that letting the child have resident status truly indicates the affection and responsibility of the parents. What is really happening here is
that the parents are not simply emphasizing their affections and responsibilities but also finding new meaning in them. By evolving the meaning of the vocabulary, they are positioning the necessity for institutionalization (Gubrium and Holstein 1990). On the one hand, parents thus had to point to the norms of parenting such as affection and responsibilities in the petitions. But, on the other hand, they have been actively attempting to justify the necessity of institutions. This means that parents can find the basis for accepting the necessity of institutions.

V. Social Background of Parent Movement for Children with SMID

In this section, the author will examine the social background that led to the aforementioned movement by the parents of children with SMID as well as the limiting factors. In concrete terms, the activism by parents of children with SMID rapidly came to be reflected in policy measures of the national government after 1965 (Section III), and so one is justified in asking “What was behind it?” (first paragraph, Section V) And, in consideration of the fact that the parents had to emphasize their mental attitudes in their social movement (Section IV), one ought to ask “What was the rationale behind the shift in attitudes?” (second paragraph, Section V) These two questions inquire into the social backgrounds of Sections III and IV, respectively, and will be addressed in separate parts of this section. They will be elucidated from the point of view of policy logic for expansion of institutions and, for judgment based on them, the available guidelines and reports will be used.

1. Logic of Social Development

Early in the 1960’s, policy measures for the severely disabled began to be promoted full-scale. In the periods before that, as can be seen in Shintai Shogaisha Fukushi-Ho (Physically Disabled Welfare Act) of 1949, welfare measures were limited to those with minor disabilities who could be rehabilitated to engage in occupations. In other words, there were no considerations for the severely disabled, and their parents were certainly out of the scope of such measures. It is no wonder that only those children who can be rehabilitated were considered subjects at that time among the parent organizations for mentally retarded and physically disabled children.

From about the middle of the 1960’s to the middle of the 1970’s, the welfare budget of the national government kept on increasing, supported by a natural increase in the national budget due to rapid economic growth. Under these circumstances, the system of the social welfare policies was established by the six basic welfare laws and institution building for severely disabled people was socially spotlighted. For example, in a report by the Central Child Welfare Council titled “Concerning the Urgent Improvement and Development of Social Welfare Institutions” (November 25, 1970), the following comments were made concerning measures for expanding facilities in the 1960’s: “In spite of our economic prosperity, phenomena that could be called social discrepancies are emerging in various parts of society. Especially, there are remarkable lags in social welfare institutions” (Central Child Welfare Council 1970: 249). The report and its recommendations pointed to critical lacks of facilities and institutions. As noted in Section III, in 1965, the Roundtable Study Group on the Colonies (Colony Roundtable Meeting) was established within the Ministry of Welfare, which lead to the Colony Concept, aimed at building large-scale institutions for accommodation of the mentally retarded in general.

As far as the Colony Concept is concerned, Shakai Kaihatsu Kondankai (Roundtable Meeting for Social Development, established in July 1965, hereinafter referred to as the Roundtable) played a major role in the direct promotion of the Colony Concept. The Roundtable was a private council for then-Prime Minister Eisaku Sato. The Roundtable established the Colony Roundtable Meeting within the Ministry of Welfare and a resolution was passed for establishing a network of Colonies all over Japan by 1974.

The vision of social development is the creation of a society rich in humane characteristics, which
ubiquitously promotes healthy and civilized life for the whole nation. In turn, this means that human capabilities will be furthered while social conditions will be improved, matching the human development. In the background of the emergent social development concept in Japan is the necessity for correcting the “discrepancies” that arose because of rapid economic expansion. We feel that social development will play a major role in the economy’s stable growth into the future. (Shakai Kaihatsu Kondankai 1965)

From this report by the Roundtable, it is possible to surmise that the Japanese Government at that time had a unified notion related to improvement of qualities of the population and enlargement of social welfare policies. The reason behind such an understanding was that, from the international point of view, Japan was still a country that had only a medium level of development, struggling to reach the level of advanced countries. It was considered necessary, therefore, for Japan to cope not only with maladies resulting from very rapid economic development but also to raise the levels of welfare, healthcare, and hygiene, which were not on a par with advanced countries. The Sato Cabinet, which came into being in 1964 after the Ikeda Cabinet, amended the sole prioritization of the economy and established a policy direction toward emphases on social welfare and security as well as continued economic growth.

For example, Tokyo’s then-Governor Ryutaro Azuma stated in the “Gathering of Parents” magazine of the NAC(P)SPID, concerning the basis for promoting measures for children with SMID:

As one of the goals of the Metropolitan Government policies to be emphasized during the next fiscal year, I have selected stability and improvement in the lives of our citizens. In other words, “building up daily life of the people” should come first so that all 10 million people living in the Metropolis can have a bright and happy life. Included in this vision are housing, city water and sewage systems, rubbish collection, welfare, and public health and hygiene. I would also like to inform you that these policies include the promotion of policies for children with SMID, about which you are most interested. (Azuma 1965)

From the words of then-Governor Azuma, it can be understood how the slogan of the NAC(P)SPID, “protect every single child, even the weakest,” came to be included in the policy measures of governments. In his words, the policies for children with SMID were discussed on the same level as the public policies for housing, city water and sewage systems, and rubbish collection. This indicates that the measures for children with SMID were considered significant measures for overall social development, which “has the meaning of future-oriented policies for coping with fluctuations in the social and economic spheres” (Shakai Kaihatsu Kondankai 1965). This also means that the policies for children with SMID were discussed as a key part of “building up daily life of the people”, which is the point of view of improving the lives of all the people. It must be noted that, such discussions mean that this issue was promoted as something much more concrete than a humanistic ideal, such as the one held by the parents of children with SMID, namely “protect every single child, even the weakest.”

2. Measures for Children with SMID that Encompass Parental Responsibility

The policies enlarging institutions that included policies for children with SMID had, from the point of view of national policies toward families (family policies), the function of remedial policies for those households that could not achieve ordinary family life. For example, in the recommendations of the Shin-Keizai Shakai Hatten Keikaku (New Development Plan of Economy and Society, April 1970) by the Keizai Singikai (Economic Council), which was a continuation of the previous year’s Shin-Zenkoku Sogo Kaihatsu Keikaku (New Comprehensive National Development Plan, April 1969), the measures for expansion of various facilities, including institutions for children with SMID, are positioned in regard to public assistance in the following manner.
As for the standard of provision of livelihood assistance etc., appropriate improvement measures will be provided in consideration of increases in the consumption levels of the average worker’s household. At the same time, investigation will be made to determine changes in standards in view of the tendencies for increases in elderly households and households containing the physically disabled and mentally retarded among all the households that receive livelihood assistance. As for social welfare institutions for the non-adaptive stratum of society such as households of the physically disabled and mentally retarded, the elderly, and single mothers, these will be made an urgent task, especially in view of the current situation where their development is extremely delayed. (Economic Council 1970)

In this recommendation, we can see an assertion of expansion of institutions mentioned from the point of view of public assistance. Furthermore, the lack of institutions is decried: “these will be made an urgent task, especially in view of the current situation where their development is extremely delayed.” The recommendation states that, as for the reason why the shortage of institutions became problematic, there are “tendencies for increases in elderly households and households containing the physically disabled and mentally retarded among all the households that receive livelihood assistance.” It can be confirmed that an increase in non-adaptive households having deficient family functions prompted the measures for increases in the institutions.

As symbolized by the Kokumin Shotoku Baizo Keikaku (Plan to Double National Income, 1960), extraordinary economic growth was achieved during this period. In the middle of the 1960’s, Japan achieved the world’s second largest GNP (after the U.S.A.). In stark contrast to this new prosperity, the structural changes and functional weakening of families unquestionably came to the fore. The workers became more fluid in terms of employment due to the economic development and consequently there were shrinking families and the local community collapsed. Employment of married women as an additional source of labor undoubtedly weakened the function of nurturing dependent family members, which had long existed prior to that time. For example, the recommendations given by the Kokumin Seikatsu Shingi-kai (Social Policy Council) titled “Shorai Kokumin Seikatsu: 20-nenko no Vision (The Future of the Nation’s Life: The Vision of 20 Years Hence) mentioned that “the fluidity of labor should be increased along with development and improvement of housing and traffic systems” (Social Policy Council 1966). The necessity for supplementing and strengthening family functions was also mentioned in regard to securing necessary labor power. Thus, measures for expansion of institutions for the disabled were promoted in order to supplement and strengthen the family functions for the sake of sustaining economic growth into the future.

From a different point of view, however, it could be said that the measures for expanding these institutions during this period were rooted more deeply; namely, the administration considered family functions to be axiomatic and used them as the basis for its reasoning. As noted above, rapid economic growth in the 1960’s brought about, along with income increases per household, shrinking income differences between urban areas and rural areas. As a result, a standardized family came into being and, concomitantly, thinking of oneself as a middle-class person permeated the attitude of the entire nation, which in turn unified public conception of the family image (Sakamoto 1997). For example, as symbolized by the expression “my home-ism” (or way of life oriented toward comfortable life in one’s own home) in the middle of the 1960’s, in the unified image of the family, specific family composition and shadow work of the housewife were presumed, and so the responsibilities of nurturing by the family members were considered self-evident. Thus, when promoting the above measures, the administration assumed as a prerequisite (or axiom) certain family functions. The measures therefore were remedies for those who were outside the standardized family image. In concrete terms, these people were “non-adaptive strata including the physically and mentally disabled, the elderly, and single mothers” (emphasis added by the author).

Therefore, measures taken for children with SMID...
during this period primarily had as prerequisite society's expectation of family functions. The measures were intended to secure a relatively normal standard of living and lifestyle for families with functional disorders. During the period, this very fact prescribes the actual condition of the parental movement for children with SMID, as described in Section IV. In other words, in the activities of NAC(P)SPID, certain mindsets were emphasized: “We are doing everything we can as parents” and “We want assistance only in the areas where we cannot do it by ourselves.” In turn, as the administration promoted measures that had parental responsibilities as a prerequisite, parents had to emphasize their mindsets.

VI. In Lieu of Conclusion

In this paper, the development of the parent movement for children with SMID was examined, mainly in regard to the period of rapid economic growth in postwar Japan. As detailed in Section III, this movement showed unique development in the 1960s. It directly influenced the content of government measures, from “Implementation Requirements for Remedies and Treatments for Children with SMID (July 26, 1963, Jihatsu 149)” (included in the Notice by the Vice Minister of Welfare) to the revision on the Children’s Welfare Act of August 1967 (Item 4 of Article 43). The extent of progress indicates that measures for children with SMID are not feasible without considering the degree of influence exerted by the parent movement. This fact, in turn, suggests a need to revise one-sided historical analyses of the welfare measures that had previously been implemented for children with SMID.

It is also true that the parent movement for children with SMID during this period appealed for the necessity of institutions by emphasizing a certain mindset among parents, which has been described in Section IV. What this very fact makes clear is that, even though parent appeals were rapidly reflected in governmental measures in 1965 and afterwards, society continued to see parental responsibilities as self-evident, which forced the parents to indicate their own norms during their appeals for changes in laws. In other words, the parent movement demonstrates that remedy measures only came about with expectations for maximal parental responsibilities; thus, measures for children with SMID during the period of rapid economic growth were “remedy measures and still remain only remedy measures” which is one of their limitations.

After the sustained economic growth, a period of low economic growth occurred. Then, how did the parent movement develop after that point? Especially, what changes were brought on the parental norms that had been expressed during the period of rapid economic growth? The author would like to touch upon these points.

At the start of the 1980s, paradoxically, there were increasing moves within NAC(P)SPID to set down or verbalize the mindset of parents and to make it into an ideology. That is to say, arguments for returning to the original mindset and principles cropped up repeatedly within the Association. In 1981, for example, Oya no Kensho (Parents’ Charter) was passed as a resolution, and slogans were created to express the way of life and responsibilities of parents and bonds with institutions and local communities. In 1976 and subsequent years, “Three Basic Principles of NAC(P)SPID” were frequently cited within the Association, which may have given the mistaken impression that they had been passed down since the founding of the Association. A series of such moves related to the fact that they were on the verge of budget crises that threatened to reduce or even eliminate funds for children with SMID. For example, in 1981, a zero increase ceiling was set for the budget of the Children and Family Bureau and a negative ceiling of 10% reduction was set for the next fiscal year.

These verbalizations, however, do not mean that parents had actualized the norms and furthered the self-realization achieved during the period of rapid economic growth. For example, President Kitaura (1981) of NAC(P)SPID, who had spearheaded the movement ever since the Association’s founding, stated as follows: “each child seems to have found their niche in life, which signifies that each is living a happier life, and that is something which makes me feel happiness
and loneliness at the same time." This is what she said about parents who were seemingly not so enthusiastic about the movement as before. This is to say that the standard of life of children with SMID and their families had become so much better than before. As a result, the parents have paced themselves with the self-realization of their mindsets as parents. This would suggest that there is a certain distance between the discourse level and actual conditions concerning the mindset of the parents. In the period of low economic growth and subsequent years, how did the parents develop their movement? The author hopes to write about that part of history in another paper.

Notes

1) For example, currently there are various home service care services provided, which include: home help service, visiting care service, respite service, etc. In recent years, due to progress in medicine and the changes in social conditions, the number of semi-extraordinary children with SMID (children with SMID that require respirators and oxygen inhalation) have increased. Furthermore, beginning with fiscal year 1996, the day-care program for children with SMID has been put in the category of general enterprises. In the New Government Action Plan for Persons with Disabilities of December 2002, which planned for placements of 280 day-care facilities for children with SMID by the end of fiscal year 2007, and for improvements in service qualities.

2) The fixed number of beds in the facilities for children with SMID all over Japan within the past 40 years was 368 as of 1965, 11,879 as of 1975, 14,047 as of 1985, and 18,137 as of 2004. As can be seen from these rising figures, the upturn was sharp in the 10 years before 1975 but the upward slope was mild after 1976 (NAC(P)SPID 2004: 62-70).

3) These were not necessarily clearly categorized but, there are as (1) Egusa 2005, Okada 2001, Hosobuchi 2003 and as (2) Oshima 1971, Some 2001. As for (2), the idea of children with SMID itself had been categorize in institutions. There have been, therefore, studies to define the concept in medical terms as a new category.

4) These were calls to members and the former was a quotation from Sadao Kitaura, at the time when problems of children with mobile severe motor and intellectual disabilities surfaced and the latter was a quotation from Masaharu Niwa, the vice president of the Association at the time of an emergency of the employee strikes over Japan. Because of the strikes, emergencies occurred in that resident children with SMID had to return home.


6) Refer to the homepage of the NAC(P)SPID (http://www.normanet.ne.jp/~ww100092/newpage2.htm) for details.

7) Then Secretary General of the All Japan Social Welfare Council, Kenbo touched upon the Three Basic Principles of the NAC(P)SPID at its 13th All Japan Meeting. He also spoke about the anxiety for decreased budgets for children of SMID in the context of reconsideration of welfare debate and he emphasized the norms of parents (Kenbo 1976: 8-10).

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