

# **Transitioning towards a Movement That Accepts Children with Disabilities Just as They Are – The History of the Association of Parents of Children with Congenital Limb Defects**

Tomohisa Hori\* and Robert Chapeskie

\*Ritsumeikan University, Kyoto, Japan

## **1 Issues Addressed**

### **1.1 Research Objectives**

From the 1970s onwards, movements for the liberation of people with disabilities have appeared in advanced capitalist countries. These include the independent living movement in the U. S. and the ‘Union of Physically Impaired Against Segregation’ (UPIAS) in the U. K. In Japan the ‘Aoi Shiba no Kai [Green Grass Association]’ has been a leading force in the disabled liberation movement since the 1970s.

What has been described as the distinctive characteristic of the disabled liberation movement in Japan, in comparison with Europe and America, is its focus on not only “liberation from institutions” but also “liberation from the family” (Youda 1994:66). For example, in the context of the disabled liberation movement, Kouichi Yokozuka, a member of Japan’s “Green Grass Association,” has criticized the oppression caused by parental love, writing, “it is our destiny to cast aside the biased affection of our parents, though we may do so with tears in our eyes and while apologizing for filial impiety” (Yokozuka [1975] 1981:17). He has shown that for people with disabilities the well-intentioned actions taken by parents out of consideration for their children are not always actions to which consent should be given, and that on the contrary there are clear differences between the perspective of children and that of their parents. “In the end the things our parents do for our sake become extremely oppressive to us” (Yokozuka [1975] 1981:143).

When it comes to sociological research on Japanese people with disabilities and their families, too, the discussion has been driven by the raising of these issues. To begin with, there is the research that brought to light the oppressive state of affairs within families and led to the idea of “liberation from the family” (Okahara 1990; Tsuchiya 2002; Kasuga 2001). Masayuki Okahara, for example, in the midst of an attempt to understand the meaning of “liberation from the family,” suggests that the problem for people with disabilities is that “the extent to which they are emotionally caught up within their own families is great, a closed-off space is constructed, and they lose the opportunity to be opened up to the rest of society” (Okahara 1990:78).

Another development that can be identified is, for example, research focusing on the potential for the self-transformation of parents that arose out of assertions by the “Green Grass Association” that “parents are the enemy” (Youda 1986; Ishikawa 1995). Hiroe Youda, for instance, suggests that while “parents have dual significance as both the object and subject of discrimination,” they “will not remain stuck in a state of ‘confusion’ forever” and “will start to ‘oppose’ the validity of statements that display discrimination against people with disabilities” (Youda 1986:16). While research of the sort represented by the work of Youda can be praised for pointing out that parents are not always entities that seek to exclude people with disabilities, it has done very little

to clarify the extent to which they have actually become “parents who take their children’s side” (Ishikawa 1995:40) and the process and efficient causes of this transformation.

By focusing instead on the concrete processes by which parent activism has developed, this paper examines the question of what sort of activities lead parents to become aware of their children’s perspective. Specifically, it follows the activities, mainly on the 1970s and 1980s, of the Association of Parents of Children with Congenital Limb Defects (hereafter referred to as the “Parents’ Association”) [1]. With the current endeavors of the “Parents’ Association” to actively assert that “it is fine for children to have disabilities” as a point of reference, this paper will clarify how the parents in this group came to transform the status of this assertion.

### **1.2 Mainstream parent activism and movements critical of it during the period of rapid economic growth**

To begin with, here I would like to clarify the meaning of selecting, out of the mainstream of parent activism and critical movements that existed up to that point, the activities of the “Parents’ Association” to examine in this paper.

The “Parents’ association” was established in 1975, but the mainstream of “parents of children with disabilities” activism during this period of rapid economic growth was a movement to demand the expansion of institutions to accommodate children with severe disabilities. During this period, Japanese social services for people with disabilities, which had up to that point emphasized policies targeting those with mild disabilities for whom rehabilitation was possible, began to focus on policies targeting children with more severe disabilities. The expansion of institutions to accommodate children with severe disabilities, in particular, became the central focus of policies during this period, and within this context the lobbying activities of parents, spearheaded by the National Association for Children (Persons) with Severe Physical and Intellectual Disabilities, had a direct influence on the content of the policies adopted. With declarations such as “we are not trying to put them in an institution and escape our responsibilities as parents” and “[we do it] because our families will fall apart” ( National Association for Children (Persons) with Severe Physical and Intellectual Disabilities 1965: 29), parents of children with severe disabilities emphasized their obligations as parents while at the same time appealing to society for help in dealing with their excessive care burden and worries about what will happen to their children after they die[2].

The movement for the expansion of institutions, which had in this way grown to be quite powerful, was not, however, always a movement desired and accepted by people with disabilities themselves. One event that made the difference in perspective between children and parents at this time particularly clear was the appearance of a movement petitioning for clemency in the case of a mother in Yokohama who had killed her severely disabled child in May of 1970 and the corresponding movement which then arose in opposition to this effort.

Here it should be noted that prior to this incident the murder of children with disabilities by their immediate family, or cases of murder/suicide in families with disabled children, had not been a rare occurrence. Nor was this the first time there had been appeals for clemency in the case of a parent who had murdered their disabled child[3], and public sentiment in most of these cases tended towards sympathy for the parents without recognizing the disabled children as murder victims. At this time the Kanagawa Prefecture Alliance of Associations of Parents of Children with Physical and Intellectual Disabilities (including the National Association for Children (Persons) with Severe Physical and Intellectual Disabilities mentioned above) submitted a letter of protest to the Mayor in which they stated that “the killing of disabled children who

have been denied the right to exist by society without adequate institutions or guidance for families on their treatment and education is an inevitable outcome, and we object to this lack of social services.” In response to this statement the “Green Grass Association Kanagawa Alliance” presented the first criticisms of the movement for clemency from the perspective of people with disabilities. For example, on September 6th, 1970 the Green Grass Association’s Masayoshi Koyama, in discussions with the Kanagawa Prefecture Alliance of Associations of Parents of Children with Physical and Intellectual Disabilities held at the Yokohama City Child Education Center, criticized those on the parents’ side: “When this kind of incident occurs you point to inadequate administration of social services as the cause and say that if there were [sufficient] institutions this kind of thing wouldn’t have happened”, he said, but ‘Institutions are created at the request of parents, and not in any way created from the perspective of people with disabilities’”(Green Grass Association Kanagawa Alliance 1970:5). Through this criticism of the clemency movement, the fact that “the existence of the person in question (the person with a disability), who ought to be the most important person in this instance [the murder of a child with a disability], is being completely overlooked” (Yokozuka [1975] 1981:80) and the fact that the movement to expand institutions has been driven only by the desires of “parents, i.e., people without disabilities” were criticized for the first time from the perspective of people with disabilities.

In contrast, the activism of the “Parents’ Association” addressed in this paper has not been developed only from the point of view of parents. As I will discuss, since the 1980s the activism of the “Parents’ Association” has been moving towards activism from the perspective of people with disabilities, and the nature of its assertions has been shifting. If the mainstream of parent activism during the period of rapid economic growth can be seen as having been developed only from the perspective of parents and thus having inevitably given rise to a conflict between the perspectives of parents and children, the activism of the “Parents’ Association” warrants being considered as a movement that has developed an awareness of the differences between these perspectives on the parents’ side.

## **2 Formation of the “Parents’ Association”**

The “Parents’ Association” was formed in August, 1975 through the appeals of a full-time homemaker. The process that led to its creation began with a column, “Sentenijou no ko wo motte [Having a child with a congenital abnormality],” written by Akiko Nobe and published in the Asahi newspaper (February 6th, 1975). Following the publication of this column, Ms. Nobe continued to present the perspective of parents of children with congenital limb defects through mass media, appearing on television and being published in magazines, and on August 31st of the same year a founding meeting attended by 54 families of children with congenital limb defects was held in a rented room in Tokyo’s Saginomiya Public High School.

However, “for all of the participants to hold sufficient preparatory discussions with each other [in advance of the meeting with parents spread all over the country] was not feasible,” and the meeting was therefore organized “as common ground where, to begin with, everyone can gather under one roof and talk about how to proceed going forward” (Association of Parents of Children with Congenital Limb Defects 1975:2). As it was formed by parents and not specialists/experts, it was decided that “[the “Parents’ Association”] will consider all important and fundamental issues about what kinds of activities it will carry out in the future after the first steps [in its formation] have already been taken” and “go ahead and discuss things within the standing committee

and make decisions from there” (Association of Parents of Children with Congenital Limb Defects 1995:3). At the first meeting of the standing committee following its establishment the following concrete plans for future activities were made: “1. Activities concerning research into the causes of congenital limb defects, 2. Activities concerning research into the current state of congenital limb defects, 3. Activities concerning medical treatment for children with congenital limb defects, 4. Activities concerning issues related to the education of children with congenital limb defects, 5. Activities concerning relief compensation for children with congenital limb defects, 6. Activities to facilitate interaction with other support groups/activist groups/research groups involved in issues pertaining to (children with) congenital defects, child welfare, etc., 7. Activities concerning the planning of events to promote interaction/friendship between association members” (Association of Parents of Children with Congenital Limb Defects 1995:292-3). In other words, it was decided that the activism of the “Parents’ Association” should not only be concerned with activities addressing issues such as treatment and education, but should also be developed with appeals for research into the causes of congenital limb defects established as one of its core activities.

The distinguishing characteristic of the “Parents’ Association” is that it was started more as a movement that aimed, through appealing for research into the causes of congenital defects, to assert that “children’s disabilities are things that can happen to anyone” and “children’s disabilities are both a problem for individuals and a problem for society as a whole” (Association of Parents of Children with Congenital Limb Defects 1995:v) than as a movement whose main purpose was to engage in policy demands concerning concrete problems related to things like treatment and education. Take, for example, the “Kodomotachi no mirai wo hiraku fubo no kai [Opening up the future for children parents association]” (an association focusing mainly on parents of thalidomide children), which is also an association of parents of children with congenital limb defects and of which the “Parents’ Association” had considered launching as a subsection before its establishment as an independent organization. As Ms. Nobe asserts when she says that “[Chairman Susumu Iida] had a close relationship with the child and family department of the Ministry of Health” and “[This association] received quite a lot of money”[4], this association received a lot of donations and subsidies and engaged in welfare operations at places such as child education and treatment centers. In contrast, the “Parents’ Association” did not begin by making concrete policy requests such as “we want institutions built” or “we want treatment fees to be paid by the government”[4]. It was begun, instead, as a movement to oppose “prejudice and discrimination against parents of children with disabilities” and to seek “the understanding of family members and the general public of children without fingers or who differ from others in shape” (Association of Parents of Children with Congenital Limb Defects 1975: 1). I will discuss the question of what sort of actual effects the “Parents’ Association”’s appeals for an examination of causes of congenital defects had on parents in section 3.3.

### **3 The 1970s - The family/ expectations of science**

#### **3.1 Positioning as families of victims**

As is widely known, beginning in the late 1960s residents’ movements in various local areas arose throughout Japan to address environmental issues. Residents’ movements are movements run by residents of the area in which they are active that engage in activism to demand the protection/improvement of living circumstances (Nitagai 1976:203-7). They developed as movements that opposed, from the perspective of ordinary local residents, the rapid industrialization brought about by

high economic growth/the distortion of industrial structures brought about by regional development.

As a continuation of this trend, from the late 1970s onwards movements focused on specific minorities, such as the disabled peoples' liberation movement and the women's liberation movement, began to appear in large numbers (Kajita 1991:189). The "Parents' Association" examined in this paper can be seen as one of these minority movements, but regarding the activism it engaged in at the time of its establishment its character seems closer to that of a residents' movement raising environmental issues. For example, in 1974, the year before the "Parents' Association" was established, a settlement was reached in a thalidomide lawsuit, and around this time various environmental pollutants (SMON, PCB, DDT, etc.) began to be addressed as problematic. When it came to the children of the "Parents' Association," too, there were suspicions that their disabilities may have been caused by this collection of environmental pollutants.

For example, Keiya Nishimura has said the following regarding the suspicion within the "Parents' Association" that children's disabilities may be the result of environmental pollutants:

We wondered why such children were being born, since we didn't think it was something that would be difficult to prevent. We had the idea that somebody must be doing something bad, somebody must be destroying the environment, misusing medicines, agricultural chemicals, or detergents; somebody must be creating these children, and we were very angry. So behind the phrase "investigation of causes" there was indignation about who had stolen these children's fingers[5].

Mr. Nishimura's belief that at the time the view within the "Parents' Association" was that "children's disabilities are man-made" and "we are the families of victims" is in no way deluded. If we look at materials released by the "Parents' Association" at the time, for example, they assert that children's congenital defects are "a fear inherent in modern society," and that "the causes of children's defects lurk within the state of modern society in which industrial development is given priority over people's lives". And, as the following statement implies, this view can easily be understood as having been shared by the entire association: "in order to prevent the next misfortune from occurring, while bringing citizens onboard we must continue to think about how to declaim, decry and inform people about the real state of these fears" (Association of Parents of Children with Congenital Limb Defects 1978:1). Similarly, as the "warning to humanity" theme often employed by the "Parents' Association" in joint symposia with organizations such as the "Kikeizaru mondai kenkyu kai [Monkey deformity problem research association]" indicates, the claim being made was that "almost all of our children's disabilities have some kind of external cause". It can be established that, based on the belief that "the problem of children's disabilities we are dealing with is not a problem that belongs to each of us [parents] as individuals...it is a problem that concerns the survival of humanity itself" (Association of Parents of Children with Congenital Limb Defects 1982a: 16), these parents worked to create an understanding of children's disabilities as a problem belonging to society as a whole by actively positioning themselves as the families of victims.

### **3.2 The development of activities related to the investigation of causes**

The "Parents' Association" was thus established, in an era in which various issues were being raised concerning environmental destruction, as a movement advocating the investigation of the causes of disabilities in children. In the organization's founding document, for example, they demand that the state/ministry of health conduct

“thorough epidemiological studies and investigations of the causes/current state of congenital limb defects,” with the aim of designating/eliminating teratogens that are environmental factors. Through these efforts they explicitly sought to ensure that these sorts of children would not be born in the future, so that “the suffering and sadness of the families and the children themselves will not be repeated” (Association of Parents of Children with Congenital Limb Defects 1995:341). In concrete terms the activities of the “Parents’ Association” to appeal for the investigation of causes [of congenital defects] developed as follows.

The parents’ first activity was to gather the medical records of the association’s members. The purpose of gathering these records was to examine external influences on the mothers during their pregnancies, and, in this era in which it was plausibly being asserted that the number of children with congenital defects was increasing as a result of teratogens, collecting records was something useful the parents could do right away. They asked their doctors to provide their medical records covering the duration of their pregnancies. In cases where it was difficult for the parents to do it themselves, Mitsushiro Kida made the request for documents in their stead [6]. A history of the usage of medical treatments such as prescription medication, x-rays, and vaccines by members of the association during their pregnancies was compiled, and an analysis of this data was conducted. One of the trends this analysis revealed was a high rate of hormone drug use [7], and this fact was later connected to one of the demands made of the state/ministry of health.

Appeals to the state/ministry of health by the “Parents’ Association” were carried out through many specific initiatives. For example, on October 6th, 1978, a “list of questions and requests concerning the issue of children with congenital limb defects” was submitted to each political party and all of the members of the social labor committee, and a response to this document was then demanded. This “questions and requests document” contained the following items that illustrate the main demands of the “Parents’ Association” at the time: “1. Take measures to supervise the safety and side effects of pharmaceutical products and deal with the problem of the use of progesterone drugs, 2. Comprehensively examine all teratogens, 3. Establish congenital defect centers and conduct epidemiological studies, 4. Improve the system for research into human genetics and establish courses on human genetics within university faculties of medicine, 5. Establish an advisory committee on congenital defects, 6. Address issues concerning thalidomide recognition and continue recognition efforts.”[8] In other words, broadly summarized their main demands were: 1. Strengthen the inspection system for teratogens including hormone medications, 2. Establish institutions specifically to deal with congenital defects, and 3. Continue the work of recognizing the damage caused by thalidomide.

In addition, symposia and photography exhibitions were also held in each region in an effort to increase local understanding of these issues. At symposia held in areas all over the country, for example, various speakers, including doctors, environmental protection activists, and educators, were invited to give presentations, and the issue of congenital defects was addressed from various angles. These symposia spread the idea that “congenital defects are not just someone else’s problem” and “someday this problem could affect me directly.” As a result, the view that “it is not an issue that can be left up to politicians and experts; we must each think about it in our daily lives from a variety of perspectives, and we must take action” (Association of Parents of Children with Congenital Limb Defects 1978:2) and a sense of proximity to the problem through an awareness that children’s disabilities could occur in any family was promoted.

Also, as measures focused more closely on specific regions, photography exhibitions were staged at places such as department stores, community centers, and city galleries. Most notably, “deformed monkey exhibitions” were held in conjunction with “Kikeizaru

mondai kenkyu kai [Monkey deformity problem research association]”, raising the question of whether “the deformities of children could, like those of the monkeys, perhaps be the result of the sacrifices of economic development.” Through the “deformed monkey exhibitions” [it was suggested that] “deformities are increasing among wild monkeys that are given food,” and this “was happening because monkeys were consuming the same food eaten by humans.” As a result, it was asserted that “monkey deformities are emblematic of human deformities and the danger of humanity’s downfall” (Association of Parents of Children with Congenital Limb Defects 1995:175).

### **3.3 The effects of science (investigations into the causes of congenital defects)**

So what kind of meaning did the appeals for an investigation of the causes of congenital defects made by the “Parents’ Association” during the 1970s have for the parents involved? For example, Ichiro Nebashi says the following about the motivation behind his taking part in the appeals for an investigation of causes made by the “Parents’ Association” at that time.

I went to see deformed monkeys on Awaji Island. Mr. [Minoru] Nakahashi was the Director [of the Awaji Island Monkey Center], and I went there. What I am going to say is strange, but I approached them thinking that I might be able to see, even among deformed monkeys, these things being inherited. At the time, I was hoping that congenital defects had appeared even among monkeys. Because if so it would make it very easy to understand. [The relationship between] environment and inheritance. That mutations arise suddenly as the result of damage caused by drugs. This was explained to me by Dr [Mitsushirou] Kida; the environment and heredity are closely connected and inseparable issues, and genes are expressed through an interaction with materials in the environment. When I talk about prejudice concerning genes, I don’t mean in a moral sense, but in a universal or scientific sense, because there is little understanding of the fact that disabled children are born this way, that everybody is born, that we are all created by genes. This unscientific perspective is unacceptable. When I heard this [Dr Kida’s explanation of the fact that mutations arise suddenly through interactions between genes and the environment] it was as though my world had been turned completely upside down[9].

Mr. Nebashi is a parent of a child with a disability that was determined to be hereditary. In the above quotation, while distancing himself with the phrase “what I am going to say is strange,” he relates how he approached the Awaji Island monkeys hoping that “hereditary disabilities had appeared even among monkeys.” This was because, as can be understood from his account, if hereditary disabilities appeared even among the monkeys of Awaji Island (an issue that at the time was viewed from the perspective of environmental pollution), then “the environment and heredity are closely connected and inseparable issues,” and hereditary disabilities arise not only because of genes themselves but because of how “genes are expressed through an interaction with materials in the environment,” i.e., it would be possible to confirm that genes are not the determinative cause of these disabilities. He sought to oppose prejudice and discrimination against parents regarding their children’s disabilities by attempting to find a fundamental cause of these disabilities outside of family lineage and bloodlines.

This move towards opposing prejudice and discrimination against parents by finding the cause of their children’s disabilities outside of family lineage and bloodlines was by no means unique to Mr. Nebashi. For example, “Parents’ Association” founder

Akiko Nobe has also said that at the time she started the organization she had “a desire to get rid of prejudice and discrimination by scientifically investigating the causes [of children’s disabilities].”[4] It was thought that by scientifically uncovering their causes it could be established that children’s disabilities could potentially happen to anyone and that these disabilities were neither the result of family lineage or bloodlines nor something caused by the decisions or judgment of the child’s parents. As is related in Mr. Nebashi’s account of the “world changing” experience of learning that even in the case of heredity environmental factors play a role, the appeal for investigation of the causes of disabilities was itself something that brought a certain kind of liberation to parents by confirming that children’s disabilities were “not something caused by family lineage or bloodlines” and “not the parents’ fault.”[10]

#### **4 The 1980s - The person concerned (parents and children) / a perspective focused on daily life**

##### **4.1 Investigating causes reaches an impasse**

As we have seen thus far, the activism of the “Parents’ Association” in the 1970s addressed children’s disabilities from the perspective of environmental pollution, and developed as a movement seeking the designation/abolition of teratogens. Entering the 1980s, however, this appeal for the investigation of causes gradually reached an impasse.

To begin with, as a problem within the organization, around the end of the 1970s the activities that been undertaken by the “Parents’ Association” on its own in an attempt to investigate the causes of birth defects eventually arrived at a state of affairs in which “while several suspicious substances had come to light, specific causes could not be determined” (Association of Parents of Children with Congenital Limb Defects 1989a: 75). To take hormone drugs as an example, these medications are prescribed to women who have a heightened risk of miscarriage and thus already belong to a category with a higher chance of giving birth to a child with a limb defect. There was also a real sense that even if the teratogenicity of hormone drugs could be established, because they were not nearly as powerful as thalidomide it would remain difficult to clearly prove a causal relationship.

As a result, confronted with the difficulty of determining causes, the activism of the “Parents’ Association” began to turn in part towards problems children faced in their daily lives, such as the issue of recorders used in music class (some activities concerning educational issues had in fact been conducted since the organization’s founding, and activities addressing the recorder issue had begun in 1978). For example, activities dealing with the issue of recorders included demands for the creation of special recorder programs, public funding, and the use of other instruments being made of local governments/school boards (Association of Parents of Children with Congenital Limb Defects 1993: 11). On the other hand, there was also a movement which maintained that, since suspicious substances still existed, advocacy for the investigation of causes should continue even if causation could not be definitively established. Activities related to the investigation of causes regarding various substances continued, including efforts focusing on the progesterone drug Doginon, the anti-nausea drug Bendectin, and Agent Orange. These efforts too, however, ground to a halt by the late 1980s without having been able to obtain any significant results. Also, as an example of influence from outside the organization, the fact that the movement to promote fetal screening and selective abortion as a secondary preventative measure had become prominent at that time made it impossible for parents to avoid becoming sensitive to the dangers inherent in advocating for the investigation of causes.

To begin with, in 1979 a congenital defect monitoring research group (hereafter

referred to as the “monitoring group”) was formed within the ministry of health in the name of “fully engaging in the construction of a congenital defect monitoring system.” When the “Parents’ Association” first learned of the monitoring group’s creation, they expected its activities to simply reflect the appeals they had been making for more research. Later it became clear, through discussions with this group and the reports it issued, that the monitoring group’s research placed an emphasis on genetic and fetal diagnosis, and over time the “Parents’ Association” became increasingly wary of it. In particular, when the “Parents’ Association” learned of efforts to submit a proposed Maternal and Child Health Act in September of 1985, as a result of the fact that one of the legislation’s main principles was the promotion of genetic counseling and fetal screening (secondary prevention) under the name of a “newborn monitoring system for the monitoring of the births of children with congenital defects (primary prevention),” the organization directly opposed its passage and submitted a written statement of its contrary views (Association of Parents of Children with Congenital Limb Defects 1989a: 117-24).

Another development that was also related to this effort to promote secondary prevention was the “Parents’ Association”’s appeals for the investigation of causes becoming a major target of criticism from the disabled people’s liberation movement, a movement that was in conflict with the movement against pollution/harmful medication. For example, in November of 1984 the “Parents’ Association” had a meeting with the “National Green Grass Association”[11]. The “Parents’ Association”’s push for the investigation of causes, “presumably comes from the idea that the birth of children with disabilities is ‘something that should not happen, a special case, an unfortunate event’. Assuming this is the case, is the potential for discrimination not inherent in this starting point?” This kind of assertion was the main thrust of the criticism leveled against the “Parents’ Association”.

Of course, it was possible to respond to this criticism from the “National Green Grass Association” by saying, “no, these children’s disabilities are not simply natural disabilities; they are man-made disabilities, or “damage”. This being the case, isn’t it necessary to thoroughly pursue the causes and perpetrators of this damage?” (Association of Parents of Children with Congenital Limb Defects 1989a: 112-4). In other words, it was possible to respond by reaffirming the distinction between primary prevention and secondary prevention. The statement opposing the Maternal and Child Health Act submitted by the “Parents’ Association,” for example, asserted that “monitoring is fundamentally something done in order to watch for and eliminate harmful substances, and is distinct from questions concerning the treatment and welfare of children with disabilities” (Association of Parents of Children with Congenital Limb Defects 1989a: 125), and the importance of censuring those who cause harm was recognized. It was also argued during discussions with the “National Green Grass Association” that “the matter of these children being born and living as children with disabilities is a separate issue; [the “Parents’ Association”] has been engaged in investigating the causes [of disabilities], not preventing the birth of children who have them.”[11]

These sorts of responses aside, however, going forward the parents of the “Parents’ Association” were no longer able to develop their appeals for causal investigations without facing criticism. They developed a considerable understanding of the danger of appeals for the investigation of causes being understood as something different from what they intended.

#### **4.2 Differences between the perspectives of parents and children**

Entering the 1980s, the appeals for investigation of the causes of disabilities that parents had been making while positioning themselves as the families of victims had

thus seemed to have reached a dead end. Ultimately, the result of this was that going forward the “Parents’ Association” movement became one in which the difference in perspective between parents and children was accepted; in specific terms, it transitioned into a movement within which the assertion “it is fine for children’s disabilities to exist” could be made.

#### 4.2.1 The parents’ perspective

Here, to begin with, I would like to establish the assumptions/impetus behind the “Parents’ Association”’s shift towards the assertion that, from the parents’ perspective, “it is fine for children’s disabilities to exist.” As my space is limited, I will make only the two following points.

First, it must be said that a substantive reduction in the various burdens born by the parents of disabled children in the “Parents’ Association” was a prerequisite for the transition that would result in these parents coming to believe that “it is fine for children’s disabilities to exist.” In addition to a) the fact that in the case of the “Parents’ Association” the children’s disabilities were minor to start with and thus did not present serious burdens for their parents, b) around that time, the maturation of children and advice from adult members began to reduce parents’ concerns about the future. Also, c) through the activities undertaken in the 1970s these parents had to a certain extent been freed of their prejudice and discrimination against disabilities. Furthermore, d) according to Yoko Matsubara around that time a sense of taboo concerning “eugenics” began to permeate the public consciousness (Matsubara 2000: 223-4); understood in a different way, prejudice and discrimination against disabilities ceased to be socially justified. In other words, for parents disabilities were no longer disabilities (defects/inconveniences); disabilities became (or got closer to being) nothing more than attributes that had arbitrarily been given negative value, and along with d) this indicates a state of affairs in which it was easier to call out prejudice and discrimination where it existed in society.

Second, against the backdrop of the movement to promote secondary prevention and the emergence of “eugenics” as a controversial social issue, parents acquired a new awareness of prejudice and discrimination towards disabilities. In the course of actively asserting that “it is fine for children’s disabilities to exist,” the “Parents’ Association” came to oppose secondary prevention measures. For example, through the decision of whether or not to give birth to a child with a disability being left up to the parents, or through others viewing this kind of decision as possible, the responsibility of parents in giving birth to children with disabilities once again began to be considered.

Through techniques such as fetal testing, the science I had been counting on entered, on the contrary, an era of choosing between lives that should not be born and lives that should be selected; this is what the 1980s were for me. As a mother who had given birth to a child with a disability, my shame and feelings of guilt and self-blame were further compounded through the spread of these new technologies which had already begun to plant in the minds of ordinary people the idea that children with disabilities should not be born: “Why did you give birth to such a child now that we are in an era in which it is avoidable?” I felt that through science I was once again being marked with a label[4]. [Emphasis is the author’s].

If appeals for the investigation of causes in the 1970s can be seen as having brought some measure of liberation to parents by scientifically confirming that children’s disabilities were “not caused by family lineage or bloodlines” and were “not the parents’ fault,” then in the 1980s “the spread of [scientific] technology” conversely increased this blame and suspicion of wrongdoing. Parents of children with hereditary

disabilities were particularly sensitive to this movement towards the promotion of secondary prevention measures. This sensitivity was the result of the fact that the spread of technologies such as fetal testing was directly connected to various issues such as the birth of second children or grandchildren and was thus not something these parents could ignore or view as having no connection to their own families.

The key events behind the “Parents’ Association” fully engaging, as an organization, in these issues concerning parents of children with hereditary disabilities were Watabe’s essay in October of 1980 [12] and the movement to reform the Eugenic Protection Law in 1982[13]. Watabe said that it is desirable for people with hereditary disabilities to autonomously choose sterilization, and parents of children with hereditary disabilities criticized this as an inexcusable assertion. Around this time parents also learned that diseases found within the “Parents’ Association” were included among the “undesirable offspring” cited in article 1 of the Eugenic Protection Law and that there had been a movement to include a provision for fetuses; as a result they were once again forced to acknowledge prejudice and discrimination against people with disabilities (Association of Parents of Children with Congenital Limb Defects 1995:259-67).

#### **4.2.2 The children’s perspective**

So what about the children’s perspective? How did parents come to understand that there were differences between their perspective and that of their children?

To begin with, from the 1980s onwards, while continuing the symposium and photography exhibit activities they had developed up to that time, they started to reexamine the assertions that were being made within the context of these activities. This occurred not only because the parents’ efforts to appeal for investigations into the causes of disabilities had been brought to a halt, but also because along with an effort to more actively interact with their children they were attempting to find a new understanding. In particular, within the photography exhibition activities carried out in various local areas across Japan the first signs of a conflict among the parents and a shift in assertions could be found at some local branches even as early as the first half of the 1980s.

The “Parents’ Association” had been staging (since the late 1970s) photography exhibitions of monkeys with missing legs and arms (deformed monkeys), animals which had become emblems of environmental pollution and had received a lot of attention from the mass media, and a female elementary school student requested that they “stop putting up my photograph beside pictures of monkeys”. This may have been a child’s objection more to the paradox lurking within the feelings of parents unable to accept their children with congenital limb defects as they are than to the investigation of causes itself. (Nobe 2000:114)

In the “Parents’ Association” photography exhibits held in the 1970s, photographs of children were displayed alongside those of deformed monkeys in order to make the case that these children’s disabilities were being caused by environmental pollution (these were the “deformed monkey exhibitions” discussed in section 3.2). But the parents gradually began to have doubts about this method of drawing attention to this issue. One parent, for example, expressing a feeling of resentment distinct from a sense of achievement at having staged the exhibition, wrote in the organization’s journal: “many people did indeed come to see [the exhibitions]. Whole classes of high school students visited one after another. But they just looked without any sense of responsibility and left after satisfying their selfish curiosity” (Association of Parents of Children with Congenital Limb Defects 1995:177). Also, as is indicated by the way in

which the “paradox lurking within the feelings of parents unable to accept their children with congenital limb defects as they are” mentioned in the passage cited above was addressed as problematic, voices of doubt began to be raised among other parents who felt that “if we acknowledge that the word “deformed [kikei]” is used in a discriminatory way in our society, shouldn’t congenital limb defects and the word “deformed” be seen as incompatible?” (Association of Parents of Children with Congenital Limb Defects 1995:177-8).

In actuality, however, as an impetus behind the kind of circumspection among parents noted above (an impetus behind their coming to feel uneasy about “deformed monkey exhibitions”), there was also, slightly before this period (the early 1980s), the fact that the opinions of adult members[14] had been discussed repeatedly within the organization. Opinions from the perspective of children had indeed been addressed in the association’s journal even before this time, but because in most cases they had been the opinions of small children who tried to guess what their parents would think opinions from the perspective of people with disabilities had not been directly discussed. Then in 1979 adult members began to take the stage at symposia, and this led to opinions from the perspective of people with disabilities being discussed extensively within the organization. At one symposium, for example, adult member Mayuri Honda said the following about uneasiness toward the appeals for the investigation of causes being made by the “Parents’ Association.”

We must pursue and eliminate the causes behind the increase in the number of people with disabilities: this has become an effort to raise the issue of “medication X” being bad. The people in question, however, are already doing their best to live with their physical deficiencies in the midst of a society that cannot be described as ideal for people with disabilities. ...and going forward - while I cannot say we are able to live comfortably because to do so would be mere bravado - we should be able to go on living. To be completely healthy and able-bodied may be ideal, but to not be so does not mean we are defective people or that we find life difficult. (Association of Parents of Children with Congenital Limb Defects 1982b: 91-2)

Ms Honda’s point about “not finding life difficult” is connected to the fact that the disabilities dealt with by the “Parents’ Association” are congenital, and here it can be confirmed that unease about the organization’s activities related to the investigation of causes was at least being discussed. Similarly, at the same symposium adult member Sayoko Shizawa also talked about her current circumstances as someone living with a disability, saying, “people say that life must be quite difficult, but I almost never feel that way” (Association of Parents of Children with Congenital Limb Defects 1982a: 227-8).

Adult members of the “Parents’ Association” then began to “participate in the association’s activities in various ways and support the initiatives of the Parents’ Association” (Association of Parents of Children with Congenital Limb Defects 1995:281). For example, beginning with *Sacchan no mahou no te* [Sa-chan’s Magic Hands] (created by adult members Ms. Shizawa and Seiichi Tabata/the “Parents’ Association”/Ms. Nobe), adult members took part in the editing of many of the materials published by the “Parents’ Association,” and from this point forward adult members can be seen to have exerted a powerful influence on the organization’s activities.

#### **4.3 Development of activities based on daily life**

Following these developments, in the early 1980s the “Parents’ Association”’s photography exhibitions transitioned towards “exhibitions of photographs of children

with limb defects and the bodies with which they were born (exhibitions of photos of children only)” and in the late 1980s the titles and contents of these exhibitions reflected a further shift towards “friends full of life photography exhibitions (exhibitions of photographs emphasizing images of children who are smiling and full of energy).” Instead of the “photographs of sick children portrayed as the victims of environmental pollution and society’s development” designed to “make viewers feel pity,” exhibitions of photographs of lively looking children began to be held that focused on their everyday lives and gave viewers the impression of “looking at pictures of their friends” (Association of Parents of Children with Congenital Limb Defects 1995:179).

In addition, the symposia that had been held on an ongoing basis up until that time began to be held as “children’s symposia” at which children played a prominent role rather than as venues to appeal for the investigation of the causes of disabilities. At “children’s symposia” children took the stage to read compositions they had written and give performances using modified musical instruments. For example, at a “children’s symposium” held at the organization’s Saitama branch in 1983, over 250 participants watched “children [talk] about their own thoughts and experiences” at an event entitled “Children beginning to speak about life” (Association of Parents of Children with Congenital Limb Defects 1995:188). These “children’s symposia” became an opportunity for parents to pay attention to the frank and honest voices of their children that were not normally heard at home (Association of Parents of Children with Congenital Limb Defects 1995:189).

On another front, from the late 1980s onwards various publications such as *Boku no te, o chawan taipu ya* [My hands are chawan (bowl) type] (1984) and *Inochi hazumu nakamatachi* [Friends full of life] (1989), began to be released by the “Parents’ Association.” These publications were texts that “presented an image of the everyday lives of parents and children through their memoirs and essays and through the documenting of various things children said as they were growing up” (Association of Parents of Children with Congenital Limb Defects 1984:134), and portrayed “[children] living with their families in the midst of ordinary local society as a completely normal way of life” (Association of Parents of Children with Congenital Limb Defects 1989b: 106). Beginning with accounts of personal experiences from the collected writings published regularly by local branches, many children became involved in volunteer activities, and records of activities such as a ski camp opened as “a place for children to grow” (Association of Parents of Children with Congenital Limb Defects 1995:146) were assembled.

In parallel to these activities based on the everyday lives of parents and children, activities aimed at raising issues concerning genes and eugenics were also undertaken. Specifically, these activities involved speaking out against the view that “children with disabilities should not be born” and “families with disabled children are unhappy.” For example, one parent of a child with a hereditary disability questioned the movement attempting to stop the birth of children with disabilities through the promotion of secondary preventative measures, saying, “why am I strange for intentionally giving birth to a child with a disability? ...[our family] is a very normal, happy family. Who gets to decide whether this kind of happy family is right or wrong?” (Association of Parents of Children with Congenital Limb Defects 1995: 265-6). And from the 1980s onwards various symposia addressing issues of heredity and eugenics have also been held in addition to the “children’s symposia” mentioned above. “To raise [these children] is to experience their charm and the enjoyment of living together with them, and this state of affairs is not at all “unhappy” (Association of Parents of Children with Congenital Limb Defects 1989a: 90). Based on their own experiences of daily life, these parents are demonstrating that “life with a disabled child is not unhappy.”

## 5 Conclusion

In this paper I have examined the development of the activism engaged in by the “Parents’ Association” and clarified the ways in which the assertions made by this organization have been transformed.

Looked at from the perspective of the activism developed in the 1980s, the push for the investigation of causes in the 1970s can be seen as a movement based on a conflation of the points of view of parents and children. For example, in the 1970s, as is indicated by statements such as “we must investigate causes for the sake of the children” and “it is clearly the duty of parents to view congenital limb defects as ‘damage’....and to bring their causes to light” (Association of Parents of Children with Congenital Limb Defects 1989a: 90), parents positioned themselves as victims’ family members and were not sufficiently aware of the differences in perspective between parents and children within families.

The fact that from the 1980s onwards the “Parents’ Association”’s activism has developed as a movement recognizing the differences in perspective between parents and children can also be confirmed by looking at the transformation of the view of disabilities held by these parents. Up until that time they had pursued the investigation of causes based on the assumption that “disabilities are something children would be better off without, something that should not exist,” but from the 1980s onwards, in contrast to this view, by adopting the perspective of the children themselves they have come to accept the bodies of children living with disabilities as they are. By showing society the daily lives of these children just as they are, these parents are asserting that “life with a child who has a disability is not unhappy.”

## Notes

[1] The “Parents’ Association” is known to many people today through *Sacchan no mahou no te* [Sa-chan’s Magic Hands], a picture book that has sold over 700,000 copies. Approximately 1,400 families, mainly of children with congenital limb defects, belong to this organization. Beginning with Ms Nobe, for this paper I conducted interviews between August and November of 2004 with individuals who have been active in the organization since its founding in the 1970s (the Nara branch’s Keiya Nishimura, the Nagano branch’s Ichiro Nebashi, and the Ibaraki branch’s Kazue Sato). I also received assistance in obtaining documents from the organization’s administrative staff. I would like to express my gratitude to all of these individuals.

[2] I have already discussed the movement to expand institutions during the period of rapid economic growth and the activities of the “National Association for Children (Persons) with Severe Physical and Intellectual Disabilities” in a separate paper (Hori 2006). The movement of parents of children with severe disabilities, as can be seen from ideas proposed by the “National Association for Children (Persons) with Severe Physical and Intellectual Disabilities” such as “the National Association’s three principles” and “parents’ charter,” was developed while consistently impressing upon its members the need to “ready oneself as a parent.” This movement has had a direct influence on various implemented policies, including, for example, the 1967 revision of the Child Welfare Act.

[3] Concerning petitions for clemency pursued by those on the parents’ side before that time, see, for example, the journal of the “National Association for Children (Persons) with Severe Physical and Intellectual Disabilities” *Ryoshin no tsudo* [Parents’

gathering] Tokushu -- atotatanu kono higeki [Special feature -- This tragedy without end] (September, 1967 Issue).

[4] Information from an interview with Akiko Nobe conducted on September 17th, 2004.

[5] Information from an interview with Keiya Nishimura conducted on November 5th, 2004.

[6] Dr Kida is an advisor to the "Parents' Association" and specialist in clinical teratology. He was involved in Thalidomide trials as a member of the Thalidomide recognition committee, and later continued to be active as a medical advisor to the "Ishizue" Thalidomide welfare center.

[7] For example, in data gathered in March of 1978 as part of a "Parents' Association" study, 53 out of 181 mothers surveyed were found to be using hormone drugs. This fact was later reported in major newspapers (see, for example, Naze sentenijoji ni? Haha no 3 wari horumon-zai fukuyou -- oya no kai jittaichosa [Why [did they become] children with congenital defects? 30% of mothers take hormone drugs -- a study by the "Parents' Association"] (Sankei Shinbun May 5th, 1976 morning edition).

[8] November 1st, 2004. From Kazue Sato based on data she had gathered/produced herself. This "request document" preceded the inception of the "monitoring group" in 1979 (discussed later in this paper) and therefore comes close to fully encompassing the demands being made of the state/ministry of health in the 1970s before the ensuing changes in the assertions of the "Parents' Association."

[9] Information from an interview with Ichiro Nebashi conducted on November 19th, 2004. After consulting with the person in question, and in consideration of the unique nature of hereditary issues, in this case only I have used a pseudonym to avoid disclosing the respondent's identity.

[10] Looking at the development of the "Parents' Association" movement in its entirety, it may indeed be possible to point to this movement as one possessing the typical characteristics of a new social movement described by "new social movement theory." But the essential interest of new social movement theory, as represented by leaders in this field such as Alain Touraine and Jurgen Habermas, has been to place new social movements in a historical structural context (late capitalism) and understand the meaning of their formation, and as such this approach can be seen as having a macroscopic understanding of the era as its focus.

[11] January 14th 2006. Oral statement by Ms. Nobe based on the minutes of discussions with the "National Green Grass Association."

[12] Watabe's statement was published as an essay entitled Shinseina gimu [Sacred duty] in the "Kogo Zokkai [Lay interpretations of classical language]" column in Shukan bunshun [Weekly Bunshun] (October 2nd, 1980 Issue). In this essay he referred to the high medical costs incurred by Akahito Oonishi as a result of his hemophilia and asserted that there is a "sacred duty" to avoid giving birth to people with hereditary disabilities.

[13] As is indicated by the "Parents' Association"'s founding document, which states that "old customs and prejudices concerning 'congenital defects, i.e. heredity,' remain strongly rooted, particularly in rural areas, and as a result of this children and their families undergo considerable emotional suffering" (Association of Parents of Children with Congenital Limb Defects 1995: 341), up until this time the "Parents' Association" movement had developed without addressing or disapproving of prejudice and discrimination concerning heredity.

[14] While their number has been small, people who are not parents but individuals with disabilities themselves who take part in the organization's activities have existed within the "Parents' Association" since its founding. These individuals continue to be referred to as "adult members" and are treated as full-fledged members of the association.

## Bibliography

- Green Grass Association Kanagawa Alliance, 1970, "Short Special Feature: Concerning Discussions," *Ayumi* 11: 2-7.
- Habermas, Jurgen, 1973, *Legitimationsprobleme im Spatkapitalismus*, Suhakamp. (= 1979, translation by Hosoya, Sadao, *Legitimation crisis*, Iwanami Shoten.)
- Hori, Tomohisa, 2006, "Lobbying Movements by Parents of Children with Severe Motor and Intellectual Disabilities during High Economic Growth and their Background," *Japanese Journal of Social Welfare*, Japanese Society for the Study of Social Welfare, 47(2): 31-44 .
- Ishikawa, Jun, 1995, "Birth of a new sense of parenthood among parents of children with disabilities," Inoue, Mariko & Omura, Hideaki eds., *The Rediscovery of Familism*, Sekai Shisosha: 25-59.
- Kajita, Takamichi, 1991, "Post-war Japanese Social Movements: focusing on the "development state" and "Japanese qualities"," Society for the Study of Social Movement Theory eds., *Towards the Unification of Social Movement Theory – Theory and Analysis*, Seibundo: 179-201
- Kasuga, Kisuyo, 2001, *Sociology of Care Issues*, Iwanami Shoten: 77-114.
- Matsubara, Yoko, 2000, "Japan: The Sterilization Law Called Known as the "Post-war Eugenic Protection Act"," Yonemoto, Shohei ; Matsubara, Yoko ;Nudeshima, Jiro & Ichinokawa, Yasutaka, *Eugenics and Human Society*, Kodansha: 170-236.
- Nitagai, Kamon, 1976, "Development Policy = Planning and Residents' Movements: Issues Raised by Residents' Movements," Matsubara, Haruo & Nitagai, Kamon eds., *The Logic of Residents' Movements*, Gakuyo Shobo: 201-45.
- Nobe, Akiko, 2000, "The Lives with Disabilities Movement," Kurihara, Akira ;Komori, Yoichi ; Sato, Manabu & Yoshimi, Shunya eds., *Talking: Disseminating Knowledge Across Borders 2*, The University of Tokyo Press : 105-29.
- Okahara, Masayuki, 1990, "Love as a Social System: On Liberation from the Family," Asaka, Junko ; Onaka, Fumiya ; Okahara, Masayuki & Tateiwa, Shinya, *Ars Vivendi: Sociology of Disabled People Who Have Left Homes or Institutions*, Fujiwara Shoten : 75-100.
- Association of Parents of Children with Congenital Limb Defects, 1975, *Untitled*, Association Report 1.
- , 1978, *Congenital Anomaly Issues*, Association Report 3.
- , 1982a, *Symposium on Congenital Anomaly I: A Warning to Humanity*, Hihyosha.
- , 1982b, *Symposium on Congenital Anomaly II: Questioning Life*, Hihyosha.
- , 1984, *My hands are chawan (bowl) type: Children with Congenital Anomalies*, Sanseido.
- , 1989a, *Concerning the Investigation of the Causes of Congenital Anomalies: Life's Today/Tomorrow*, Association Report 5.
- , 1989b, *Friends full of life*, Shonensha.
- , 1993, *The Parents' Association and Recorders: What is a Recorder to a Child with Disabilities Affecting Their Hands?*, Association Report 6.
- , 1995, *Twenty Years of the Parents' Association*, Association Report 7.
- Touraine, Alain, 1978, *La voix et la regard*, Paris: Seuil. (=1983, translation by Kajita, Takamichi, *The Voice and the Eye: An Analysis of Social Movements*,

Shinsensha.

Tsuchiya, You, 2002, *Living as a Family Member of a Person with a Disability*, Keiso Shobo.

Yokozuka, Koichi, 1981, *Mother!, Don't Kill*, Suzusawa Shoten.

Youda, Hiroe, 1986, " "Confusion" and "Opposition": Parents in the Process of Becoming Accepting of Children with Disabilities," *THE LIBERATION of HUMANKIND – A Sociological Review*, The Japanese Association of Sociology for Human Liberation 1: 8-24.

———, 1994, Current "Family System and the Independent Living of People with Disabilities in Japan: Beyond the Japanese Type of "Modern Family System"," *Japanese Journal of Family Sociology*, Japan Society of Family Sociology: 65-79.

National Association for Children (Persons) with Severe Physical and Intellectual Disabilities, 1965, Parents' gathering 1.