

5<sup>th</sup> Anniversary of Kazenoko Sodachien

In Commemoration of the Establishment of Kazenoko Sodachien Guardians Association

**Commemorative Lecture**

## **Considering “Mutual Living”**

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### **Introduction**

To start with, I would like to clarify one thing so there's no confusion. I have studied social welfare for a long time, but my specialty is not actually disability-related. And yet, I was asked to talk about something here today. I ended up not being able to refuse and took up the offer. The reason for this is because Suisen Fukushima posted an article, “Social Independence of People with Intellectual Disabilities and the Role of the Daycare Center for People with Intellectual Disabilities” in the magazine my training center publishes. I think this pamphlet should be among the prints handed out today. We publish this magazine every year, and though it may sound impolite to choose only the best of those submitted. And how should I say, we appreciate and commend them. This is the kind of thing we are involved in, and one of the papers submitted was from Suisen Fukushima.

I read their paper and learned of their great efforts, so we decided to present them with a certificate of commendation. I took this opportunity to visit their centers. I was impressed by their work and felt I had to support them. They were trying to establish a support group at the time, so it was a great honor for me to accept their offer to be the president, though it is usually not within my nature.

This is how I came here to talk to you today, so my story today might come across amateurish. When you get old like me, you can see things objectively and fairly by gaining distance from the world. I think this is the privilege of the elderly. There are no stakes, and there is no money to be received. We fear nothing, so complain to anyone, even the mayor or the prefectural governor. When you are in this position, you become unfussy and can see things with quite a broad mindset. From this position, I view the issues of people with disabilities.

### **Welfare of people with disabilities in Japan**

When I think about it now, the Act for the Welfare of Disabled Persons in Japan has a long history. The Physically Disabled Persons Welfare Act was created in 1949, and the Intellectually Disabled Persons Welfare Act was created in 1960. They have implemented many measures, but they have been not able to function well in my view. I admit they have made some achievements for the welfare of physically disabled persons, but it seems to me that the welfare of intellectually disabled persons has not effective. For example, they instituted a compulsory schooling system for disabled children. However, when we look at what happens when they graduate from the school, there are many people who have a hard time finding a place to go. I've heard of many situations like that. I wonder whether the welfare of

intellectual disabled persons might be a bit different from the welfare of physically disabled persons. From my point of view, the welfare of intellectually disabled persons doesn't seem to progress or make achievements. To be blunt and I'm sure it pains the people in the city office to hear this, but when I consider why this has happened, I think that the specialists for the welfare of disabled persons in the Ministry of Health and Welfare were misguided or misunderstood things.

## **Social disability is the real disability**

Eight social welfare acts were revised. The Act for the Welfare of Disabled Persons was also revised and when we look at this, for example, it says that home care services will be provided or daycare centers established for people with physical and intellectual disabilities. By welfare of disabled persons, they are referring to disability as the disability that an individual has. I'm sure for doctors, a disability is whether a patient is able to see or not, is able to hear or not, or there is something wrong with a patient's leg. For a school teacher or a teacher at a school for disabled children, the question is the degree of the student's intellect. With relation to social welfare, I do not believe these are the disabilities. I believe that physical and intellectual disabilities are not the disability. The obstacles to life are social disabilities.

It is the individual's societal disabilities that make their life very difficult. I've had such opinions for a long time. Incidentally, an action plan was defined ten years ago, in the International Year of Disabled Persons. The action plan was enormous, but there was a part which was written like this,

“The disability is neither physical nor intellectual. It is a disability of the relationship between the individual and their environment.” That is the social disability I am talking about. What I'm saying is that ignoring the individual's relationship with the environment, and saying that they are physical or intellectual disabilities is off the mark. However, specialists think that the root of disabilities lies in the individual's physical or intellectual disability, so they end up saying that people with disabilities need rehabilitation. But really, the welfare problem begins with how we can eliminate the disabilities in social relationships. The measures for the Act for the Welfare of Disabled Persons in Japan in relation to this problem are extremely poor. Phrases like “To enlighten” are used, but it is very partial and looks like an added sentence. I think that how we address socially related disabilities is essential for the welfare of persons with disabilities, but this point isn't emphasized by the law or government offices. I believe that's where the Ministry of Health and Welfare are off the mark.

## **Various Measures for Disabled Persons**

Recently we have organized a study group for young people gather in our training center. There, we heard a report from a person who studied disability related problems in a foreign country. After all, there are many unwarranted assumptions in the U.S. too. The measures for disabled persons thought up by specialists or governments are totally different from those thought up by the Association for Physically Disabled Persons. And their principles are different from those of the Association for Intellectually Disabled Persons. All three are different in their thinking.

<The Specialists' Way of Thinking>

The difference is that specialists and governments regard the central issue of disabled persons as providing rehabilitation or training for functional recovery in order to improve movements in daily life.

<The Association for Physically Disabled Persons' Way of Thinking>

However, the Association for Physically Disabled Persons are saying that this does not matter at all. The ideal to them is for disabled persons to be able to have individual residence and live freely by themselves. There are now many independent life support centers. Their goal is for each person with disabilities to rent a house and live an independent life in their own right.

<The Association for Intellectually Disabled Persons' Way of Thinking>

The thinking of the Association for Intellectually Disabled Persons' Way is again different. Their theory regarding welfare is to make a new plan for everything from existing society, schools, and medical organization systems to residences, roads, and workplaces. They use the word "redesign" in reference to rebuilding schools, residences and workplaces in order for everyone to live in equality. They say that the ideal is to be able to create an inclusive society where everyone can live together. In other words, the Association for Intellectually Disabled Persons requests changing every institution and all equipment so that everyone, including them, can live as equal. That is to say, the difficulties in the lives of people with intellectual disabilities are that they are discriminated in society, they are different from us, and inferior. There is this kind of discrimination. We cannot live without abolishing discrimination. They are saying that they want a society in which everyone can live with confidence. That is, their purpose for creating a new plan is for a diverse society.

## ***A* and *B* who graduated from a school for disabled children**

As a simple example, I know two young men who I will refer to as *A* and *B*, who graduated a few years ago from a school for disabled children. They are both noted as having moderate intellectual disabilities in their identification booklets. They have the same level of intelligence, but the daily lifestyle of *A* and *B* are totally different.

<In the case of *A*>

When I visit *A* on a weekday, his mother says, "He is not here today." When I ask her, "Should I come tomorrow?", she says, "He won't be here tomorrow either." Then when I ask her, "When should I come?", she says, "Please come by on Sunday." This is because he started to work at a factory where his father works the day after he graduated from the school for children with disabilities. His father works at a small factory. He asked the president of the company, "My son graduated from school this year. I would like him to work somewhere. Could you hire him?" The president said, "This is such a small factory, and I have never had experience hiring people with disabilities. But if you can take responsibility for him, let's ask everyone's opinion." All the employees agreed.

*A* can't make the commute to work by himself, so his father takes him and bring him back every day. Anyway he has done odd jobs at the factory for two, three years now. When *A*'s father is sick or has other plans, a coworker comes to pick him up and bring him home. So he can go to work every day without

absence, even when his father cannot accompany him. His mother packs a lunch for him, which he takes to work every day apart from Sunday. On occasional Sundays, a neighbor takes him out fishing.

When I ask his mother how she raised him, she says that she let him try anything, even the smallest things. When he couldn't do it, she helped him, but basically, if it's something he seemed able to do, she taught him again and again.

<In the case of *B* >

On the other hand, *B*'s family runs a grocery business. Whenever I visit *B*, he is always lying down in the room next to the entrance. I suggested to his parents to let him work in their store. His parents said that if he works there, all the customers will leave. So I said, "How about cleaning the store?" They said they would end up having to do it again themselves if he did it. *B* has nothing to do and doesn't know what to do with his time.

<The difference in social relations affects their lives. >

When we consider these two situations, they both have an average IQ, but their lifestyles such as family relationships, working relations, friendships, and community relations are totally different. The difference in the relationship between the individual and their environment makes a difference to their lifestyle. As I said before, it might be an exaggeration to say that it doesn't matter their IQ is or how severe their intellectual disabilities are, but the important thing is the social relations that surround the individual. So I understand through my experience that the attitudes and ideas of the people around the person with intellectual disabilities affects the welfare of that person, and the words spoken at the International Year of Disabled Persons, "Disability of the relationship between the individual and their environment.

## **Changing social relations**

If, like this you think the difficulties of living are caused by intellectual disabilities, it is ok to guide the person with intellectual disabilities so that they can do what they can by themselves to resolve these problems and live their daily lives. However, it is an error to only take into account one aspect of social relationships.

In other words, the goal is how to solve disability-related concerns; how to change social relations.

There are three points I'd like to raise about this.

### **1 . Changing the Way People Without Disabilities Think**

Primarily, people without disabilities should change the way they think. If we put it in extreme terms, the target of the Welfare for the disabled is the public. The people without disabilities who discriminates against people with disabilities is in the wrong. These people without disabilities are the wrong-doers. We have to realize that the people without disabilities are the wrong-doers. We are creating disability-related issues. It is quite difficult to make people realize this. However, I know of an actual case.

Incidentally, it was the International Year of Disabled Persons, so events appropriate for the year

were organized in each city, town and village. The case I know is in a town in Nagano prefecture with a population of 15,000 where members of the women's association are very active. Therefore the members gathered to discuss what they should do for the occasion. They came up with a lot of ideas such as holding a symposium, a thank-you party and so on. We thought about various things but felt we should ask the mothers of the children with disabilities. We asked a dozen mothers of children with disabilities what they really want us to do. They said they felt discriminated by the public in the bus every morning when they went to the school for children with disabilities. People avoid them and don't choose to sit nearby as if they were dirty, and if their child touches someone, they act as though they have been touched by something dirty. To add to that, some people say terrible things to their child like, "If you don't listen to me, you will be like that child." We suffer from this kind of discrimination in the bus every day. That is the hardest thing. Our wish is to eliminate that kind of discrimination.

< We were the wrong-doers. >

Listening to this story, the members of the women's association were surprised. They realized they were the wrong-doers and the people who caused deep suffering to the people with disabilities. They immediately suggested hosting a town rally in affirmation of the fact that they were the wrong-doers. And so, the people of the town realized that the error of their thinking. They recognized that it was not right to discuss disability-related concerns and let this matter slide. With this kind of model to look at, it is possible to recognize the discrimination we citizens are responsible for every day. I think we have to seize such problems that are occurring for people with disabilities now.

## 2. Understanding we are all equal as human beings

Secondly, other people must understand that people with either physical or intellectual disabilities are the same human beings as them. If I put it in more extreme terms, children with disabilities might have what we call the purity of human beings.

< Make these children the light of the world >

Mr. Itoga wrote a book called "Make These Children the Light of the World". There are many more examples in this book. For instance, there are many children in *Daini Biwako Gakuen* with severe intellectual disabilities cannot sit or have to eat lying down are. When a member of the staff who was taking care of one of these children tried to change their diaper, the child lifted their bottom to help make her job easier. The child didn't just lie there like a log and cooperated with the staff as a human being to make their job easier. Which means the child understood what the staff was trying to do. The members of staff were enlightened by these experiences and the fact that they could relate to each other as human beings and reported this to the president.

< These Children are To Be the Light of the World >

Mr. Ryuji Ito who teaches at Yokohama City University, wrote a book called "These Children are To Be the Light of the World." In this book, Mr. Itoga says that these children persevere in their own way, so the public should recognize this and learn from this kind of behavior. Therefore he titled the book as

“These children are the Light of the World”. In the modern world, people are forgetting humanity, and placing values on things like money, power and intelligence. It is the kind of world where people who have abilities and money are valued. Japan is a model of this. Money, ability, and good school results are more important than human nature. Mr. Itoga emphasizes in his book that in a world where people have lost their human nature, purity remains in children with intellectual disabilities.

#### <What Children with Intellectual Disabilities Teach Us>

Mr. Ito made a suggestion to stop using the word “*Shogai-ji*” (children with disabilities) and use “*Keihatsu-ji*” (children with enlightenment) instead. The word “*Shogai-ji*” sounds bad. The word “*Keihatsu-ji*” can express the real thing humans have. For example, when you watch a sports festival at a school for children with intellectual disabilities and a child falls during a footrace, the child who was running next to this child stops running, help them, and they both end up running together at the back. They were smiling. Generally, when a child next to you falls down, you will get a competitive edge and run. However people who watched the sports festival saw the child helping his friend rather than coming first in the race and were impressed by the sincerity in the child’s actions. If this happened at a regular school, people would probably say, “Oh, that’s stupid. He should leave the child and run.” But I think the sports festival at a school for children with intellectual disabilities is different. We have to learn humanity from them. In this way, Mr. Itoga was saying “These children are the light of the world”.

### 3. Mutual Feelings, Mutual Living.

My third point is empathy. We have to feel together and live together as people, regardless of whether we are people with or without intellectual disabilities. Children with intellectual disabilities know they have intellectual disabilities. They know they can’t do arithmetics or read well compared to other children. Therefore, when a child gets close to and comes to trust a member of staff, they often ask them to help them understand. If a person treats these children like fools, they instantly feel that the person doesn’t understand them well. Before anything else, the third solution is to make children with intellectual disabilities feel that they are the same human being as them, that they are understood, and that they are allies.

#### <Sweat Together, and Struggle Together.>

How are we going to do this? It is very difficult, but Ichiji Tamura is a good example. He helped Mr. Itoga when he established Omi Gakuen (A residential care center for children with intellectual disabilities), and spent over 50 years with children with intellectual disabilities. He was a teacher and wrote a book called, “Dokan Kyoku”. ‘Dokan’ means to sweat together, and ‘Kyoku’ means to struggle together with the children. These actions deepen understanding of each other. It is not about teaching or learning. By doing messy things or by struggling together, children with intellectual disabilities know that the person is a real human being who can understand them. We believe that is one of the important principles in understanding human beings. It is applied not only to the staff but also to the parents, siblings, and friends.

## **A Society of Mutual Living**

I introduced three principles. The thing we find in common among them is “Mutual Living”, -today’s title. We should set an immediate goal for mutual living and address disability-related concerns. We need to create a space where people with and without disabilities can live together. To a child, this is called a home. “Home” is a place for mutual living. It is the first place for mutual living, but mutual living at home is not so easy.

### **<Living together with a person with disabilities >**

When I listen to or read about mothers with children who have disabilities, they were all shocked and confused when their babies were born with disabilities. They gradually get back on their feet from this state of disorder. Then they accept their child’s disabilities as they are instead of ignoring them. I use the word “acceptance”, but actually they treat the child as a member of the family. They come to think of it as living together with a person with disabilities. There are various struggles on the way to reaching the point of “acceptance”. When I read the records of families who have children with disabilities, I really understand how much they struggle. Unfortunately, there are some families that abandon their child or divorce because of failure to accept the circumstances. There are also families that abuse their child. That’s not okay, and eliminating the disability should be the second step. First, we should accept the child with disabilities as they are and as a member of the family. This needs to start at home. When the child becomes an adult, they shouldn’t be taken care of by their mothers and should live independently.

## **A Lifestyle that the person with disabilities decides for themselves**

For that matter, group homes are now being established. Group homes for people with intellectual disabilities are different from homes for independent life training and welfare home which are established by law. The characteristic of group homes is that the people with disabilities can decide who lives there, and it is not decided by the government. They make their own rules for group living, for example, what time they are going to wake up, what time they are going to eat, and so on. It can be called an independent life. They navigate their own life. That’s the feature of group homes. From now on, more and more group homes should be established to provide mutual living spaces for adolescents. There are trial places like that for people with physical disabilities in Osaka city. I think group homes for people with intellectual disabilities should be established too. Recently, a book called, “Group Homes for People with Intellectual Disabilities” was published by the Asahi Newspaper Public Welfare Organization. You might have already read this. This kind of movement is happening in Japan too. People controlling their own lives, making their own decisions and deciding by themselves how they are going to live, that’s called an Independent Life -making an equal society in which all of us can manage to live. I think this is very important when you see this from the position of people with disabilities.

## **The Progress in Welfare of the “Watchers-being watched” Relationship**

Until now, our policy for people with intellectual disabilities has been to view them in a unilateral

manner. Normal people have looked at people with disabilities objectively, examining how low their abilities or intelligence are and where the disabilities are. But, instead of looking at them objectively, in the “Watchers-being watched” relationship, you see them as your equal, and then you can start to see a real human being. When you look at them objectively, they only appear as figures: how tall they are, or how much they weigh, however it is necessary to recognize that they are the same human beings as us, in order to live together as family or friends. We observe people with disabilities, but the people with disabilities also observe us, which is to say that a mutual relationship is important. I believe that the welfare of the relationship with the watchers who are simultaneously being watched will progress.

The End

This commemorative lecture was given at the ceremony for the “5<sup>th</sup> Anniversary of Kazenoko Sodachien” and the commemoration of the “Establishment of Kazenoko Sodachien Guardians Association” on November 9<sup>th</sup>, 1991.