

# Self Advocate Activity in Japan

-Self Advocate Activity changes me, changes everyone, and changes society-

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## Introduction

Ten years ago, the National Conference of the “Inclusion Japan” was held in Okayama where I live. One of the concurrent sessions of the conference was “Self Advocate Workshop”. Triggered by the workshop, we have started “Okayama Peach Group” a self advocate group in Okayama. Thereafter, I have participated in the activity of the group, exchange with others group across the country and been involved in the activity of Inclusion Japan’s Self Advocate Programs. Thought the activity, I find myself changed and people around me changed.

## 1. Self-Introduction

Let me introduce myself. I live alone in an apartment. A home helper comes to my apartment to make supper once a week. For other days of the week, I buy supper in a supermarket nearby. I work for the company to make wine corks and the bearing that is a part of a car.

I was educated in special classes in an elementary school and a junior high school. I have started to work soon after graduated from the junior high school. I worked as a tile craftsman, a plasterer and others. For tiling, I was trained for 6 month to get certified and worked further 10 years as a professional tile craftsman. During the 10 years I lived in the house of my supervisor and worked together with him. When he retired, however, I also quit the job. In my 20’s, I was in a residential institution for three years. I will discuss on it later.

My hobby is surfing the net. I can find a lot of information through internet surfing. Access ing website of city office, I learn welfare services provided. In the website of Inclusion Japan, I find information that I need. Japanese chess and Go game are also my hobbies. I enjoy playing the games through the Internet. Many people I have never met access the site and play the game with me. I win often.

I am active in the Okayama Peach Group, in Okayama. I am the Vice President of the group. In addition to that, I am involved with self advocate activity in Inclusion Japan as a member of “The Committee to Promote Self Activity”. Prior to it, I was a member of “The Committee on Status of Self Advocate Organization” for three years. Now, I would like to talk about the Okayama Peach Group.

## 2. Okayama Peach Group

The group was found ten years ago when the National Conference of Inclusion Japan was held in Okayama Prefecture. Original entity was the youth class. In the youth class, decision making was in the hands of parents and teachers while we, people with Intellectual Disabilities, decide everything by ourselves in the Okayama Peach Group.



Members of Okayama Peach Group

At present, we have about 60 members. We have a board of directors to organize it. The Board is composed by a president, a vice president, an accountant, an audit and a secretary. The term of the board is two years. One who volunteers can be a board member. The directors select the president among themselves. Membership fee for a year is 2,000 Japanese Yen. We have the bylaw as well.

General assembly is held at a sheltered workshop in May. Once a month, some of the members clean the street in front of the station. We carry out many events such as one-day trip to Kobe or Kochi, air volleyball in a gymnasium, study meeting to learn about the welfare service and law once or twice a year, and gathering for a chatting. For the study meeting, we invite speakers from outside.



Cleaning the street in front of the Okayama Station.

We have exchange meeting with people with intellectual disabilities in other prefectures. We discuss about the activities of each group and also news in general. Though my home ground is Okayama Peach Group in Okayama Pref., I wish to be engaged in the National Movement of Self Advocate Activity, too.

### **3. Self Advocate Activity in Japan**

(1) There are many Self Advocate Groups in Japan.

We have about 250 groups across the country.

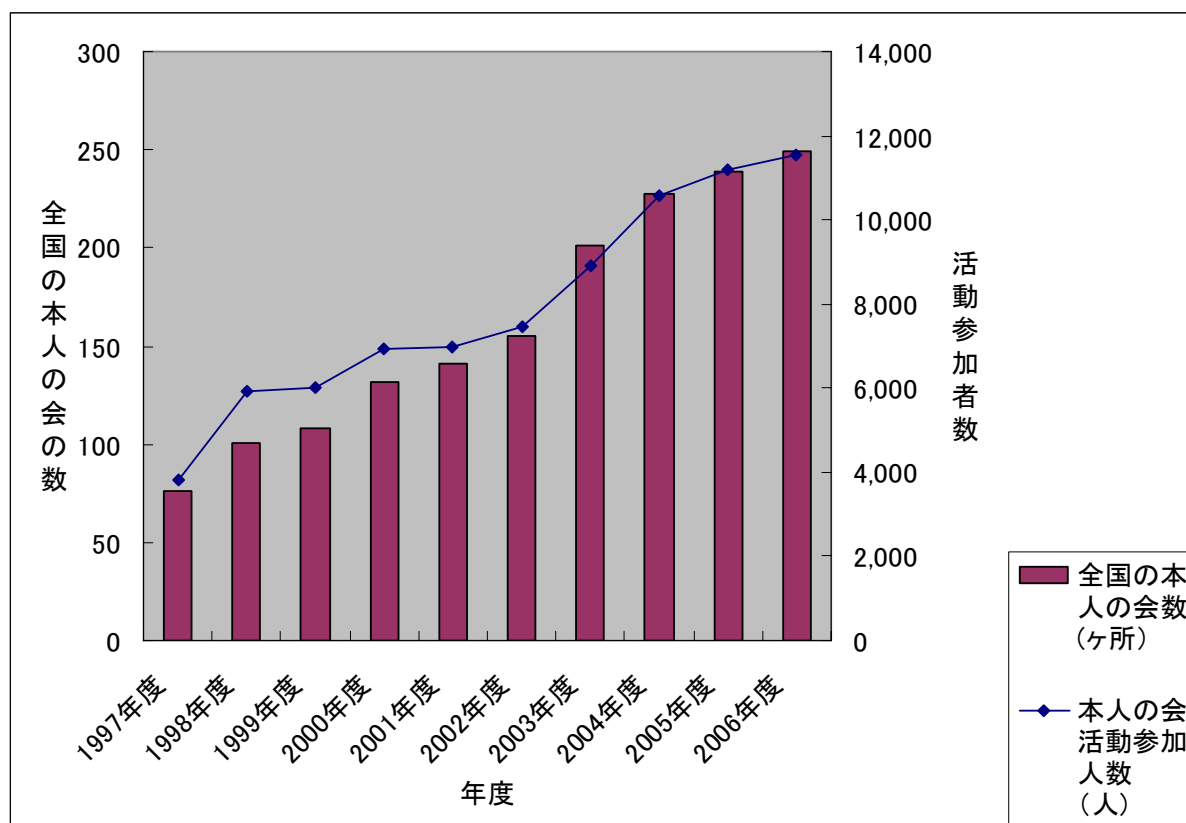
The establishment of the “Tokyo Cherry Blossom Group” and “Sapporo Friends Group” in 1992 was the opening of Japanese Self Advocate Movement.

As you can find in table 1, number of groups and number of members are increased in this 10 years. (See the table 1). Also Okayama Peach group was found 10 years ago based in the youth club.

Table 1. Change in Number of Self Advocate Groups and Number of Members

Year	Number of Self Advocate Groups	Number of Members
1997	76	3,833
1998	101	5,917
1999	108	6,000
2000	132	6,945
2001	141	6,964
2002	155	7,446
2003	201	8,912
2004	228	10,597
2005	239	11,191
2006	249	11,541

Source: Inclusion Japan



There are various kinds of Self Advocates Groups such as a group organized by graduates of residential institutions and/or day care centers, a group made up by the parents' association and so on. I happen to know a group organized by users' council of a residential institution. In their case, staff of the institution decides their activity. For instance, let's say, the group discuss about activity and decide they would go for a trip that can be rejected by the staff. It is not good. There might be a problem of the budget. If so, it can not be said unconditionally. I can not say on it.

In order to promote the Self Advocate Movement, it is important to find a good supporter. Good supporter is a person who understands us, a person who listens to us and a person who does not disclose our personal information to others. We wish them not to speak our privacy outside.

## (2) National Conference

Once a year, we have the National Conference of Self Advocate Groups at the same time when the National Conference of Inclusion Japan is held. The National Conference of Self Advocate Groups is prepared by the organizing committee consisted of people with intellectual disabilities in a prefecture where the conference is held. The committee discusses how to carry out the conference including themes of sessions such as

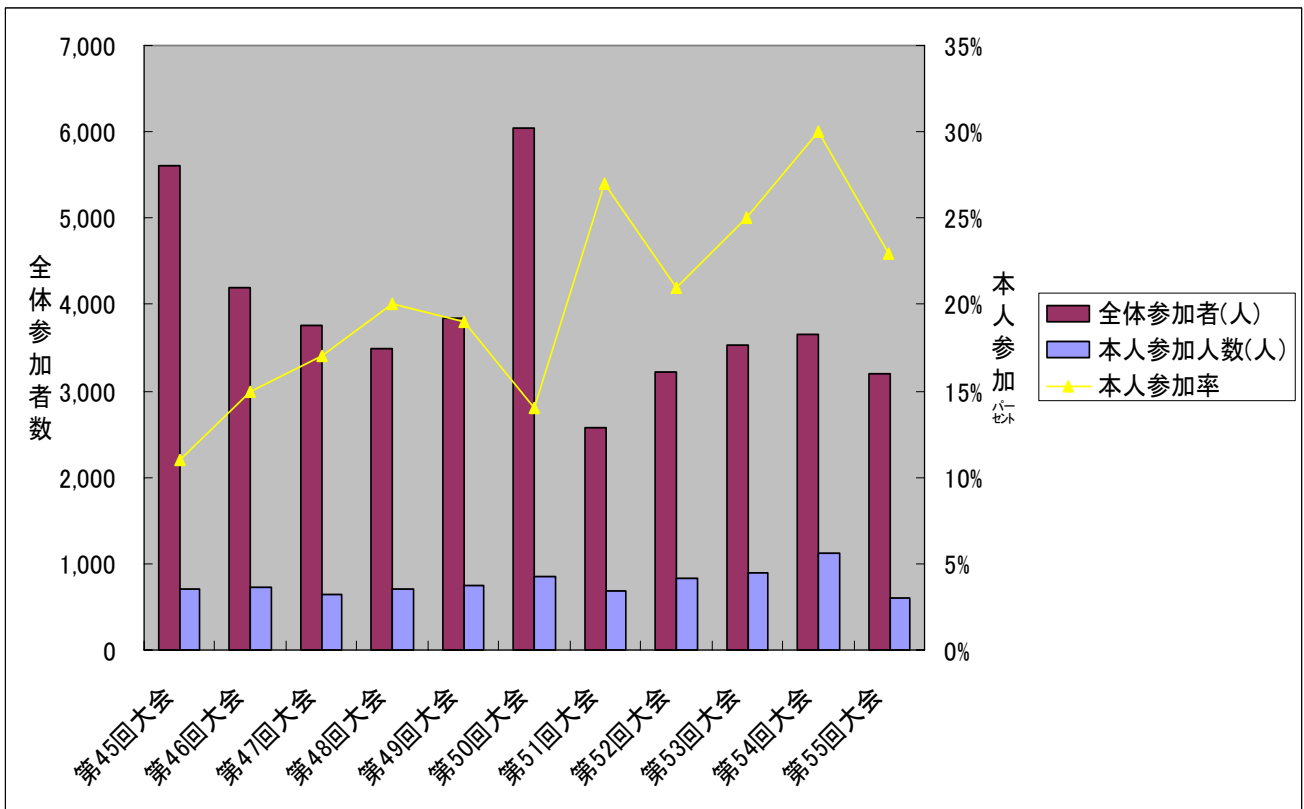


Concurrent Session, the National Conference

“Self Advocate Movement”, “Human Right” or a session “Theme decided upon discussion” and so on. You can find a lively discussion in the conference. As you see in the table 2, number of participants for the conference is increasing.

**Table 2. Change in Number of all Participants, Participants with intellectual disabilities, Participants of Participants with Intellectual Disabilities for the National Conference of Inclusion Japan**

Year	Prefecture To be held	Number of Participant (A)	Number of Participants with Intellectual Disabilities (B)	Percentage (A)/(B)
1996	Saitama	5,600	700	11%
1997	Okayama	4,200	720	15%
1998	Gifu	3,750	648	17%
1999	Hokkaido	3,500	700	20%
2000	Nara	3,840	740	19%
2001	Tokyo	6,040	853	14%
2002	Aomori	2,576	685	27%
2003	Kagawa	3,211	834	21%
2004	Okinawa	3,532	896	25%
2005	Hiroshima	3,655	1,118	30%
2006	Chiba	3,200	600	23%
	Total	43,104	8,494	20% (Average)



The committee summarizes the discussion made during the conference and present “The Resolution” in the last of the conference. In the resolution, we kept saying “Nothing about us without us” for years.

We tried to spread it across the country.

For your information, attached are resolution of this year in Chiba Prefecture (Appendix-1) and a resolution ten years ago in Okayama Prefecture (Appendix-2).



Presentation of Resolution (Okinawa conference)

This year, the National Conference will be held in Toyama prefecture. Persons with Intellectual Disabilities and their supporters in the prefecture are not so confident to organize conference because it is the first time for them. But I believe that they would do their best. They might face a lot of problems and difficulty in preparing and organizing it. It is a good lesson for them. After the conference, they will find themselves developed a lot.

These days, we have opportunities to make speech in the conference of parents' organizations. Listen to our voice and parents can understand us. Last year, in the Notional Conference of parents' association held in Chiba prefecture, I made a speech on the Guardianship system designed to manage assets and advocate right of persons with intellectual disabilities. About the system, a lawyer and a professor of a university also spoke at the conference. But I did not understand what they spoke because there were a lot of difficult technical terms in their presentation. Asked about my comments on their presentation, I said "Their presentation is too difficult to understand for me. Hope they speak in easy words that people with intellectual disabilities can understand". Then, I showed them a guidebook, made by our selves, which helps us understand the system. Audience said that my speech was better than the lawyer and professor and gave me a big hand.

### (3) Exchange Meetings between Self Advocate Groups

A Self Advocate Group has their programs such as study meetings on pension and service system, trips, year-end and new-year parties, recreational program and so on. In addition to that, they hold meetings with other groups to exchange information, opinion and to make friends.

Through discussion with other groups, we understood that other people from other prefecture had problems in work, life and others that resembled us.

We can solve the problems through counseling each other.

We, Okayama Peach Group, also have an exchange meeting with other groups whom we came to know each other in the national conference. What we do in the meeting? At first, exchange name cards, and then talk to each other. At present, we have a good relationship with a group from Totori prefecture. The group, newly established, has many problems in managing it and we, as a group of experience, give them advices. You may wonder how can people with intellectual disability advice others? Shouldn't it be role of parents?

Parents' advice doesn't work because they teach in their own way that is too difficult to understand for the people with intellectual disability. When parents advice people with Intellectual disability, they have to select sentence and words they can understand. Parents accept questions from them anytime they want.

Three years ago, Exchange program between Japanese Self Advocate Groups and South Korean groups have been started. By the matter, I visited South Korea last year.



Mr. Kubota to make presentation in South Kore

4 years ago when the 16<sup>th</sup> Asian Conference on Mental Retardation was held in Tsukuba, Japan, I participated in a lecture of Mr. Robert Martin from New Zealand.

Since 1990 when the World conference of Inclusion International was held in Paris, Japanese Self Advocates have participated in the World Conference of Inclusion International and learn a lot from other countries.

#### (4) Our Voice in Policy Making

These days, we have opportunities to participate in policy making of the Government.

Some of my friends in Tokyo participate in a government meeting to make measures on Japanese welfare system for the people with disabilities.

In the meeting, he/she asked the policy makers to modify the sentences and to change words used in “The Government Fundamental Plan for the People with Disabilities”, because it is hard to understand for people with intellectual disabilities. If he/she does not understand it, how can he/she make opinion on it.

He/She also said that there was a Policy Paper written in plain sentences and words that people with intellectual disability can understand in the other country.

The government accepted his/her opinion and decided to modify the expression.

We, together with cabinet office, started to study on it, and made up “The Government Fundamental Plan for people with disabilities” that a people with intellectual disability can understand one year later.

For this work, members of self advocate group all over the countries cooperated

Not only the Central Government, but prefecture government such as Tokyo and Hokkaido invite our friends to their meetings in making measures on disability.

When the National Conference of Self Advocate Groups was held in Chiba Prefecture, the Organizing Committee of the conference had a chance to discuss on a measure for people with disabilities with the chief of the welfare section for the people with disabilities, Ministry of Health, Welfare and Labor. In consequence of the discussion, the committee, in cooperation with the Ministry, made a brochure on “Law to support independent living of people with disabilities” that people with intellectual disabilities can understand.

In Okayama, my home town, though the barouche has not been made yet, we have the Mayor and Government officers participate in our meetings sometimes and listen to us. According to it, they changed the notebook that certifies us as people with intellectual disability into a card.

In Inclusion Japan, we carry out study projects on “Guardian system”, “Welfare services”, “Employment” and “Recreations”.

Now let me discuss on activities of Self Advocate Committee set within Inclusion Japan.

#### **4. Self Advocate Activities in Inclusion Japan.**



## (1) Committee to Promote Self Advocate Activity

I was a member of the committee for two years. Aim of the committee is to promote the self advocate activity. The committee consists of 6 people with intellectual disabilities and 6 supporters, 12 in total. The 12 members were divided into consultation team and information team.

The consultation team traveled all over Japan and learned about difficulty people with intellectual disabilities faced. As for what we, the consultation team and information team, have noticed through the talk with people with intellectual disability, is everybody does not know about the guardian system. They said “The system is too difficult to understand”, “I don’t know how to use the system” and “I don’t know who I can consult with.”

Therefore, the information team decided to make a booklet that explain about “the guardian system” and “way for better life” and “contract”.

At first, we gathered various brochures on the guardian systems and checked whether or not they are understandable. Next, we extracted words that we were hard to understand Third, supporters added explanation to each word. Finally, we examined whether or not it was available. With the brochure made, specialist on the system such as lawyer, a social worker and a judicial scrivener tried to explain the system to us. We had questions and answers, too. This is what we did to make the brochure “Going our own way”. We had a study meeting using the brochure.

It is hard to imagine ourselves ten years later. Say an extreme way, it is hard to think about ourselves even tomorrow. However, we can remember something happened in the past. I went to a school or worked for a sheltered workshop five years ago.

Therefore I take schedule of last week into account and think about next week. In this way, we can plan our future.

We should understand a support system and use it.

## (2) The Committee on Status of Self Advocate Organization

I was a member of the committee for 3 years. The committee was divided into three groups. We traveled a lot and talked with people with intellectual disabilities in many places visited. I went to Nagano prefecture to visit a residential institution, Nishikomago. I have visited them as they said that they would close the residential institution. But what I found out there was very little progress. Because there were not enough group homes in the community to accommodate people who would leave the institution, they could not close the institution.

Many people wished to get out the residential institution.





Mr. Kubota discusses with residents of the Nishinagago in the institution.

Even now, I visit to a residential institutions and join a meeting of a self advocate group to discuss with people with intellectual disabilities.

I believe that people in the society should listen to people with intellectual disabilities, but parents and supporters. Society has to realize that there are people who can not express what they wish, and people who have no person listen to them.

## 5. Community Living

### (1) Residential Institution

As I said, I lived in a residential institution for 3 years. When I was there, I could not trust the staff because they hit and kicked us, residents. Staff seemed to tease us and release his/her own stress. I wondered if it happened in other institutions and asked my friends who I met at the national conference. They said yes.

We can not keep our privacy in the institution where 4 persons share a room. Key was worn by the staff and the staff has the key. It was a residential institution where I lived.

Situation is getting better. Nowadays, we find some residential institutions promote community living. One day, visiting to a residential institution, I found a room made like a group home, and therefore it is possible for a person with intellectual disability the simulation experience of the community living. He/she cooks by him/herself without support by the staff. In the day time, they were out for work.

### (2) Community living

If he/she wishes to get out from the residential institution and live in a group home or in an apartment, he/she has to tell it to a staff of the institution. Also, he/she needs to study about the community living. As he/she lived in a segregated setting for a long time, he/she lost way of living in a general community. Living in the community, he/she has to pay for electricity, water and telephone. He/she has to take out fire insurance. In making contract with the insurance company, he/she needs a consultant otherwise he/she may be deceived. Another difficulty he/she might face is misunderstanding by the people in the society. They have a fixed idea towards a people with disability.

To break their idea, he/she needs the people to know about him/her personally, not as a group of persons with intellectual disability. Therefore, I recommend him/her to invite the people to the residential institution and let the staff explain about him/her. For this, effort of the staff is necessary.

He/she might be hard to find an apartment to live because an owner hesitates to rent. I could get it for me as the staff was very enthusiastic. The staff worked for me because I told him that I wished to live independent.

He/She needs to know how to cook and wash. Moreover, he/she has to have information for

independent living. It is not easy to find information he/she can understand that we make it for ourselves by ourselves.

### (3) Welfare Service

We need a support. We know there are support programs available for us. But we do not know where and how we can reach them. We hope the government to disseminate the information on the programs more that we can reach them. If there are many places to consult, everyone can reach the program. Please open the window for the programs in a holiday, even half a day. We need information on kinds of programs available, price of each programs. A brochure we can understand. We need not only the brochure understandable, but understandable explanation by the officer at the window.

## 6. Conclusion

**The experience in the Self Advocate Activity changed me.**

Through the Self Advocate Activity, I learned how to explain. Before the Self Advocate Activity, I was hard to speak in public. But now, I can do it.

I've gotten many friends. When I have gotten new friends, wider home range opened, and more chance to talk about each other such as, hobby and difficulty we face. Then, a mobile phone and a personal computer are necessary.

Getting to know what I want to do.

Before Self Advocate Activity, I followed everything what staff of the residential facility tolled me because I believed that the staff knew of me, rather than I did. After starting the activity, however, I gradually came to doubt if the staff knew what I wanted.

After I have gotten to know about Japanese situation, I am interested in it in other countries. The environment around us is changed. The residential institution is changed. Social Barrie free advanced.

My teacher at the junior high school told me “ If you wish other person to change, you yourself have to change.” Now, I realize the words.

# Resolution

## The National Conference of Self Advocate

The 55<sup>th</sup> National Conference of Inclusion Japan

1. Nothing about Us, Without Us  
Include us when the government, families and supporters discuss and decide something concerned with us.
2. Work Place  
Prepare more places where we can work in peace.
3. Places to live
  - 1) Prepare Public housing available for us
  - 2) Establish Rent Assistant system across the country
4. Consultation  
We need consultation services. Open the windows for consultation in weekend, too.
5. Certificate of Intellectual Disability  
A certificate notebook is inconvenient. It should be changed into a card.
6. Going out
  - 1) Discount transportation fee no matter his/her disability is severe or not.
  - 2) Make the sign of the station as well as announcement understandable for us. Modify the system of stations, trains and buses so that we won't have any difficulty to use them.
7. Financial Assistance  
Provide all of us certified with disability pension.
8. Advocate our right  
Some of us suffer from abuse and harassment. Please stop it and advocate our human right.
9. Law for supporting independent living of people with disability •
  - 1) It is hard to understand. Explain it in plain words in every occasion available.
  - 2) According to the law, we are required to pay fee in using every service. That means that more money we have to pay if we need more services. A person, who needs more services, has more difficulty to live. How they can pay? Revise the law to protect our life.
10. Spread Self Advocate Movement  
Increase number of young members and good supporters through exchange program with youth class.

Be it resolved as above.

November 11, 2006

All the Participants of National Conference of Self Advocate  
The 55<sup>th</sup> National Conference of Inclusion Japan held in Chiba Prefecture

# Resolution

## The National Conference of Self Advocate

The 46<sup>th</sup> National Conference of Inclusion Japan

1. Nothing about Us, Without Us  
Listen to each of us.  
Include us in a discussion and decision making about us.
2. Financial Assistance  
Provide all of us certified with disability pension.
3. Certificate of Intellectual Disability  
At present, the certificate is issued by each prefecture. It is inconvenient for us. You can reform the system by, for example, making it common throughout the country.
4. Transportation  
Improve the transportation system so that we can use it easily.
5. Marriage  
Support us in getting marriage and having children.
6. Work Place  
We wish to work. Promote our employment.
7. Living  
Prepare more living places for us.

There were other critical issues other than mentioned here.

We will continue to discuss on various issues.

We will spread Self Advocate Activity across the country and establish the All Japan Self Advocate Organization.

We will exchange information among groups and deepen relation.

We discuss on what we should do, what we should learn to develop ourselves. We do our best.

November 9, 1997

All the participants of Concurrent Session 8

The 46<sup>th</sup> National Conference of Inclusion Japan held in Okayama