

## Inclusion International XIV World Congress

### 1. Introduction

Today, I'd like to say a little about ourselves and our organization.

It all started 43 years ago in 1963 when a group of siblings got together and decided to form an organization. They called out for support and participation through an article in the Asahi Newspaper. The gist of that article is as follows.

Do not suffer alone or mutter your frustrations.

Why? Because these are everyone's sufferings,

so let's build a society where siblings along with persons with disabilities can say

"It's great to be alive!"

In response to this appeal, siblings and other supporters assembled to formally establish this Society.

Now I'd like to go on to some of our activities. Every April, we have a general meeting. We publish an in-house publication quarterly and with each printing we update our home page. We also put out other printed materials. For example, in order to stress the need to understand the siblings' situation and the importance of family support, last year we compiled a pamphlet titled "In order for Families to Continue Being Families". Approximately 25,000 copies were sent out to some 800 places, such as parents' groups, welfare organizations and special schools. With this same aim in mind, this year we published a book titled "The Siblings Need Love, too"

In addition, we have get-togethers from time to time where siblings can freely express their thoughts and feelings. And, of course, we do individual consultations by telephone or email, the latter becoming more and more popular.

Recently, we have been holding more and more study meetings to discuss new laws dealing with welfare systems and helping persons with disabilities become more independent. And, at a meeting to discuss relevant new legislation passed in Tokyo, we pushed for better income security and improved services for persons with disabilities in order to help them become more independent. Also, from the point of view of the siblings, we appealed for increased support for the families.

Our Society also makes direct appeals to the government and the public. Recently we visited the Health, Labour and Welfare Ministry to explain the situation of the siblings.

As a final note on our activities, I'd like to talk about very young siblings, mainly elementary school age. We have started conducting camps and offering other recreational

events to show support for these young people. The main impetus for this has come from the younger members of the Society who find it worthwhile to help others who find themselves in the same situation.

## 2. The Siblings of Persons with Disabilities

Next, I'd like to talk a little about the siblings of persons with disabilities.

I think you would readily agree that when thinking about the life of a person with disabilities, the role of the siblings is absolutely important. The parents will, in time, pass away. The doctors will probably change. It is the siblings who will likely live their entire lives together with the persons with disabilities. The ideal situation is that everyone gets along well and can live independently of each other. Of course, in order to live independently, some level of support will probably be necessary. But, the main point is that hopefully everyone can make basic decisions for himself or herself. In other words, no one is completely dependent on the other. All the siblings live independently while understanding each other's situation. Of course, this is easier said than done.

Persons with disabilities face different problems at different stages in life. At each stage, the siblings are also greatly affected.

Let me give you a concrete example.

Most parents would be greatly shocked when they first learn that their child has a disability. Without the proper support, they might waste a lot of time not knowing how to raise the child. Many parents focus only on that child and, intentionally or not, do not give enough attention to the siblings.

Because of this lack of attention, the siblings of persons with disabilities feel unhappy from a very young age and can find no one to turn to.

When the siblings start school, they painfully realize that their family is different from others. They might be teased or discriminated against by insensitive fellow students. But they have no one to talk to.

These feelings of helplessness continue into adolescence. During this stage, in addition to worrying about their relationship to their brothers and sisters, the siblings begin to think seriously about their own futures. It goes without saying that as persons with disabilities grow up, so do the siblings. Their relationship with each other can face further challenges.

When reaching young adulthood, siblings encounter real-life turning points, such as higher education, employment, and marriage. The siblings may feel they should study something connected to welfare. When thinking about getting a job, they might feel they should find employment not far from the family. As for marriage, things can get especially delicate. Some may even feel reluctant to marry knowing they will eventually become the

main caregiver. They might worry that their partners and/or their families might reject them. They often hesitate to reveal right away that they have a sibling with a disability.

As the siblings age, the parents at some point pass away and they are left with the problem of how they should relate to their brothers and sisters. As a rule, when the parents die, the siblings are considered the "guardians," whether the brothers and sisters live with them or in some facility. When living together, it is likely that some burden will be placed on the sibling's spouse. Because of the presence of a person with disabilities, many things, both good and bad, can happen to the parents, spouses and children.

The present situation is that many of these siblings do not realize that many others share the same problems. They go through life thinking it's their problem and no one else's. Many do not know about our Society and how it can help them.

But, when these people first come to one of our meetings, they suddenly give vent to their pent-up feelings. Many shed tears as they reveal their most personal thoughts. Many others feel relaxed at last and are all smiles.

The Society is a place where anyone can say whatever he or she wants to. It is a place where you can find mutual understanding. You are not alone. You have friends in the same situation. There is always someone who will understand how you feel. Just as parents need their groups, we need The Society of Siblings of Persons with Disabilities.

### 3. Directions for the Society

The Society works toward finding solutions to the problems faced by both siblings with and without disabilities. As I mentioned before, in order for able-bodied siblings to live secure lives, it is necessary for siblings with disabilities to live as independently as possible. In such an environment, the siblings can maintain a good relationship with each other. And, we cannot be happy if our brothers and sisters with disabilities are unhappy. A proper welfare system would also be of great help. Therefore, all siblings, those with and without disabilities, share the same goal, which is independence and happiness.

However, because our activities are not directly based on the point of view of persons with disabilities themselves, the Society's mission encompasses a wider perspective. We would especially like to see more support for the entire family. In other words, the siblings must be raised in a love-filled environment. If the siblings are not happy, we cannot expect the siblings with disabilities to be truly happy. As a result, we have arrived at a point where we must consider the question of how a family should be. The ideal family situation would be for both able-bodied siblings and those with disabilities to live as independently as possible while warmly supporting each other.

To this end, support for everyone is vital. In that sense, it includes all families, including

those with no persons with disabilities. In other words, we can say that our Society aims for the happiness of all. However, in order for a family to be a real family, a family with persons with disabilities needs support. It is this support we are appealing for.

It is absolutely necessary for support of the family to begin from the moment they learn that there is a child with a disability. If family support starts from the very beginning, the parents' confusion can be kept to a minimum. Parents would be able to give equal attention and love to all the children with no one feeling left out. The family can function as a family should.

In closing, I hope that more and more people know about the Society for Siblings of Persons with Disabilities and its activities. This includes those involved with welfare, educators, and especially those siblings who do not even know of its existence.