

Presentation for People First Japan

From Institution to Life in the Community

by

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About Robert Martin

Robert was born in Wanganui, a small city in the North Island of New Zealand over 40 years ago.

Due to some complications during his birth he acquired an intellectual disability. His family found it very difficult to cope with his needs and Robert was placed in an institution at a very early age.

Over the next ten to twelve years Robert moved from institution to institutions and had brief times at home with his family. He was finally placed into an institution that was a school and it was here that he found he was good at sport.

At the age of 15 he returned to his family and started to attend IHC. He moved into the Hostel and began his journey to living in the community.

Robert found these early years very difficult but also discovered that a few people believed in him as a person. His friends who used IHC services started to see him as a leader and he started to speak out on their issues.

Robert left IHC to work in the community. He met his wife Lynda and they purchased their own home in Wanganui where they still live today.

Robert maintained his contact with People First and was invited to become a member of the IHC Branch Committee. This is where he first met Desmond Corrigan who was to become his support person then colleague over the past 14 years.

Robert became a staff person for IHC and promoted self advocacy within IHC services. At the same time he started his international work with Inclusion International and has now served 10 years on their Council and is the Chair of the Taskforce on Self Advocacy. He now works full time as a member of the IHC Training Team.

Robert is very passionate about the right of people with an intellectual disability to live in the community. This is largely due to his experienced of life in the institutions. He believes all children should grow up in a family and families should receive the support they need to make this possible. Robert also believes people can leave the institutions and lead successful lives in the community. The essential key is the support the person and their family receive to make this possible.

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From Institution to Life in the Community

I want to start with a message our good friend Ake Johansson from Sweden. Many of you will know of Ake as he has visited Japan. Sadly Ake has died but his words will live on as long as people are shut away in institutions

Let us listen to some of Ake's words that can be found in the Beliefs Values and Principles of Self advocacy

“First we have to realise once and for all that spending time in an institution is not living. It is a waste of time being kept there for years. For some, it has been a lifetime. When we have made this clear, we can understand how wrong it is for anyone to be in an institution.

I myself have spent 32 years of my life in institutions and I can really speak up and certify that staying in an institution is not good for any human being in the world.

I have heard many times people call the institution 'nursing home' and say that people get such good care in a nursing home. I ask, "What kind of care did we get? And what has been good in these nursing homes?" Most likely I will never get an answer!

What I know is nobody develops in a proper way, staying in an institution. What comes out of it is a passive person who doesn't care about other people or things around them. It makes the person stay inside himself. This is the most serious reason why we have to close all institutions.”

Ake has taught us that living in an institution is not good for people as we do not grow into the person we can become. I know from my own experience that what he has said is true.

I now want to talk about some of the myths that surround our lives as people with an intellectual disability. A myth is something people believe is true because they don't know the truth. A friend once said, they want to bury their head in the sand and not see the truth.

The first myth is that if we have an intellectual disability then we are best looked after by other people who understand our needs. If that was true then people would not have families. All people would be looked after by experts. This denies our need for the love and security of our own family.

The second myth is that keeping a child with an intellectual disability in your family will ruin your family life and everyone will be better off if others care for the child. This destroys our family life by isolating us from our family.

The third myth is that when we have an intellectual disability we don't have the same feelings as other people. That it is best if we are not told about our rights or having children as it may make us want things we don't understand.

Have you ever wondered why so few of us have long term relationships or get married like the rest of the community? It is this last myth that prevents us from learning about these things. We are often prevented from forming relationships with other people.

Without exception our families are the most important people in our lives. Regardless as to the quality of family life we may enjoy we are born into a family and they are with us for the rest of our lives.

It is our family that gives us our identity, our place in the community and our value as a citizen. It is our families that give us the emotional support we need to grow from childhood to adulthood.

Family life is not always easy and it has its ups and downs. However when we are part of a family we learn to share the good times with the bad. When we are part of a family we have grandparents, uncles and aunties, and cousins.

I next want to talk about our rights and how we can turn our rights into reality.

We must have the same rights and be equal to others. Our laws may say we have the same rights as others but often we are still not treated as being equal. Somehow we are always seen as lesser people.

We must be respected and be accepted by society. This is about society's attitudes and values. We are criticised if we do not show respect for others but these same people believe they have the right to label us, treat us unfairly, and to call us derogatory names.

Where is the fairness in this? We want to be treated the same as others, nothing more – nothing less.

We must be seen as the full person we are. We are a whole person, there is nothing missing. We share the same dreams, have the same aspirations and the same fears that our friends without a disability share. Our disability is only a burden when others make it a burden. It is a part of our every day life and we learn to accept it.

We must have the opportunity to achieve our possibilities. For many of us in the past, the professionals and sometimes even our families decided what was good for us. Sometimes our families in their wish to protect us from harm and through their love and concern stop us from experiencing real life.

We need to be encouraged to learn new things and try new experiences as that is the way we all learn. Like others, we need support and help along the way.

We must participate in decision making. For me this means we participate in all the decision making that affects our lives. This includes our everyday living, where we live and work and what we do in our free time.

We must have the right to have a relationship. We have the same feelings as others. We need to be loved and to give love. We need someone special in our lives to share our good times and our sad times.

We must not only be aware of our rights but we must also know how to make them real both for ourselves and our friends.

I have recently been in New York at the United Nations discussing the proposed Convention on Disability. This has made me very aware of the need for international laws to protect the rights of all people, but especially those of us with a disability.

I am convinced there needs to be more protection for those of us who cannot speak on our own behalf. The Convention will help provided Governments not only sign the Convention but also put it into practice.

We need to learn about Declarations and International Laws that our Governments has agreed to and signed. We need to meet with the authorities and officials who are responsible for this work so we start to understand why this is so important.

We must learn about disability policies and issues in our own countries. It is often these policies that keep our people in institutions even when they want to leave.

If we are to learn about these declarations and charters we must start attending meetings where they are discussed. We must get invited to conferences and seminars that are held to talk about these things. We can do this with the help of other organisations that are involved and who are our friends.

I will now talk about institutions and how we have managed to get people to leave them and live in the community. Hopefully there will be no people with an intellectual disability living in an institution in New Zealand within the next two years

Moving people from the institutions to the community has taken over 30 years. It has been a very slow process and many people have opposed the closing of the institutions.

IHC New Zealand which is similar to Inclusion Japan has been a very strong advocate for the moving of people into the community. They

argued very strongly to stop children from being placed in the institutions and have helped adults to move into the community by providing housing and support.

Now in New Zealand there are many Service Providers who support people with an intellectual disability to live in the community. It was not always like that.

Institutions were introduced in New Zealand to provide care for people who were seen as not been able to cope with living in the community. They were set up with good intentions at the time but have outlived their usefulness.

The institutions were seen as a safe place where people would be cared for by staff who understood their needs. In my experience they are not safe. I have seen what has happened in institutions; I almost died in one due to neglect.

They do not meet the social and emotional needs of people. Not all staff in institutions are caring or are interested in us as people.

Many countries that have institutions are encouraging people to leave the institutions to live in the community. The key to this process is the planning and providing the support that is needed.

Those of us who belong to groups such as People First have a key role to play in the planning process. We must get involved when people want to leave the institution to live in the community.

We need to invite people from the institutions to visit our homes so they can see for themselves how we live. We need to be a friend who they can trust so they can share their fears and worries.

We need to understand why there are institutions and who supports them. When we understand this we can start helping those who want to leave. We need to find other groups who want to help and work with them to help people find a place in the community.

In New Zealand most institutions are now closed but it has been difficult to get the Government to close the last three.

The relationship between IHC and groups such as People First has been very important in the closure of the last of the institutions. We have provided the human face to the policy to get them closed. By working together we have made a lot of progress.

When we did our first campaign to close an institution I met with the Director of Advocacy for IHC and we worked out how we could influence public opinion. We designed a brochure about institutions and delivered it to many houses in the area. I also spoke to the local newspapers and radio stations.

The brochure caused quite a stir and got everyone talking about the problem. The decision was finally made to close the institution and move everyone into the community.

The second campaign was very different. The government said for a long time that they were thinking about closing this particular institution but we could never get a clear commitment.

The IHC Advocacy Team and People First got together and planned a campaign to try and encourage the Government to make a decision. We arranged a march on Parliament which in New Zealand is a very strong way of protesting. We got as much publicity as possible about the march in the newspapers, radio and on television.

The Government said they were about to make a decision hoping that we would not march. We said we would march either in protest or celebration of their decision.

The Government announced that they would close the institution so we marched in celebration and got a lot of positive publicity for doing so.

I will now give you some of the reasons why it can be difficult for people to leave the institutions.

The Government may have a policy to have institutions and there is legislation and funding to support them. This takes all the money and there is no money available to support community services.

Sometimes there are outdated guardianship laws that are used to prevent people from leaving or there are legal processes that take years.

Parents may be worried that if their son or daughter is placed in the community they will not get the care and support they need. This fear is often the result of the staff in the institutions talking to families.

The institution may provide a lot of jobs for the local community or they may spend a lot of money in the local community.

There may be many other reasons and it is important to find out what these are in our area. Once we understand the reasons we can prepare a campaign to promote change.

Finally I want to talk about some of the pressures of living in the community.

We are not being fair to people if we promise them that by leaving the institutions their life will always be wonderful and everything will be easy.

As we learn to take more control of our lives, we must also learn to make more decisions. We must be given time to learn how to make decisions that are right for us.

When we start making our own decisions we have to learn about responsibility. We need support to learn about being responsible for our own decisions.

When we have spent a long time in an institution we find it hard to make real friend. Many of our friends in the institutions are the staff as we do not have the opportunity to make friendships with other people.

We have to learn that we cannot always have everything we want even when we live in the community.

However I know from my own experience of leaving the institution that you will never want to return to the institution. Regardless of the

pressures you face living in the community our life is just so much better.

In closing I want to thank People First Japan for inviting me to speak at their conference. It is only by sharing our thoughts that we learn new ways.

As a person who has spent his childhood in an institution I am very committed to people being given the opportunity to live in the community. Just remember that support is the key and that we must also be there to help our friends.

We must all remember that we are never on our own and that there is always some one out there willing to extend a helping hand.

Robert Martin