

A Real Life - A Real Community

**The empowerment and full participation of people
with an intellectual disability in their community**

Speech Notes

Robert Martin

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Why has my life been so different compared to yours? What makes us with the label intellectually handicapped or mentally retarded so different? Why are we often regarded as people of little worth? Why do so many of us have to live with others, even share our bedroom with a stranger who is not even our friend?

Why do we not go to the same school as our brothers and sisters? Why do we have to go to a separate school if we are lucky enough to go to school at all? Why are we the last to get a real job doing real work when we are capable of working? Why are we amongst the poorest of the poor?

Why are so few of us married or live with a partner? Why are our families often treated so poorly because we are their children? Why is it so different for us even when we live in the same street?

Why are we seen as lesser human beings and our very existence as a person is challenged by some people?

Why do Governments and the United Nations not include us when they are discussing laws or declarations that affect us? Many still don't appear to fully understand why this is so important to us.

I have had to face these questions as I have grown into a real person. I have seen the damage done to people like myself by living in the institutions. It has not only been the institutions, it has been the community as well.

I see so many of my friends still struggling to be themselves, to be accepted for who they are. I will talk to you about what empowerment and full participation means for me. What it means for those of us who have an intellectual disability.

There are an estimated 60 million people like me in the world with an intellectual disability.

I accept my disability and all what it means to me. I get angry when people say to me "you do not have a disability" They know nothing of my life and the struggle that has been there for me and my friends.

First I will tell you something of my childhood. My story is not special. I was not treated so differently from many of my friends. As I have been able to travel around the world I have found our stories are so similar.

I was put into an institution when I was very young; I was just really a baby. There were several hundred of us in the institution. They locked us away from the rest of the community. I only saw my family for a few days each year. I would be allowed to go home for a short time but I was always taken back to the institution.

I cried for my family but no one came. I cried for my sister but she was also in an institution. I learnt to stop crying because nothing was going to change. I can remember that when I was about seven years old I was forced to stay with a family. I was treated like a slave.

I was expected to feed the pigs. I could hardly lift the bucket. I was after all only seven years old. I had to work like a man and was punished when I did not get all my work done. When I tried to run away I was taken back by the Welfare Officer. He said they were trying to protect me. Protect me from what?

I moved from institution to institution. When I was around 14 years old I was placed in a mental hospital. It was full of adults. I was so small they could not find clothes to fit me. I was a small boy in a man's clothes. I remember thinking of doing away with myself about this time. I could see no reason to go on.

I went to another institution which was a school for problem children. It was here that I learnt about sport. For the first time in my life I found something I was good at. Finally I was more than an intellectual disability. Others saw I had something to offer.

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It was at this time I was sexually abused by a staff member but nothing was done about it.

I wish I could say my childhood was unfair, that I was unfortunate, that I was unlucky. The truth is that it was much the same for so many of my friends.

I have had the opportunity to meet many people with an intellectual disability from all around the world. They have not all lived in institutions. They have not all experienced the hell of a mental hospital. But their stories are similar to my own. I wondered for a long time why that was so.

I had a friend from Sweden called Ake Johansson who sadly died about two years ago. Some of you will know of Ake. And that he spent so much of his life living in institutions. Ake said "Living in an institution was not a proper way of life".

Our right to grow up in a family with our brothers and sisters is denied. Our rights as citizens are denied. Our rights as human beings are denied. Our right to a proper education are denied. Our rights as a human being are denied.

Sadly if you have an intellectual disability, you are often treated like this.

Many of us who have lived in residential care have had a similar experience. Even if we lived with our family we may have been badly treated or abused. So many of us have not been able to enjoy a normal life in the community.

We have not live in a normal world. We were often grouped together because of our disability. We lost all rights as citizens. Others gained the right to make our personal decisions. We were often sterilised and were told we had had our appendix taken out. We then found later in life that our right to have children had been taken away. If we were lucky we attended a segregated special school. If we were unlucky we did not attend school at all.

Our families were not much better off. They often found their friends withdrew. Even their wider family stopped visiting. They became disability families. When I was able to look back on what happened to my family I started to understand how my disability had affected everyone in my family. It was not just my Mum and Dad and my Sister; it affected our wider family as well.

As a result we never learnt to make our own decisions. We were seen as incapable of making responsible decisions. We had no personal power and were totally controlled by others. We were disempowered; we did not participate in family life or in the community.

We were excluded from the community. However it is often the community, the people who we can call friend, who help us to make decisions.

I now want to talk about another important factor that has made life difficult for us with an intellectual disability. That is segregation, keeping us hidden away.

I grew up in a community that segregated people who were considered different. I was segregated because I had a disability. The neighbour's children were not allowed to play with me. Perhaps they thought I would give them a disability. I did not go to school with friends. Pretty soon I had no friends. I did not play sport at school or at the weekend. I did not go to birthday parties, visit the zoo, feed the ducks at the park or go to the football with dad.

I did not go to family gatherings such as birthdays or wedding. I did not visit my relations. I did not know who my relations were.

I learnt later that it was much the same for my parents. They did not have the support of family and friends. No one was there to help them understand my disability. Their family and friends withdrew. They became a disability family because of me. It has taken me a long time to understand that.

I have learnt that discrimination and segregation becomes an accepted part of the community. Our parents begin to accept that it is right. Even those of us with the disability begin to accept that

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it is right. Everyone is in their rightful place and the community begins to congratulate itself on how it cares for the less fortunate. "Don't they have a wonderful place to live, don't they have wonderful staff and don't we spend a lot of our money caring for the unfortunates" they say.

I would ask one simple question. If it is so wonderful why doesn't everyone want to grow up like I did ?

Being segregated in your own community prevents you from participating in sport. It stops us from doing things that others take for granted. But most of all it stops us from growing into the person we have the right to be.

Our national sport in New Zealand is rugby and our national team is the All Blacks. When I lived in the institution I never knew who the All Blacks were. I never saw them on television or heard them on radio. I was given a rugby ball at the institution which I learnt to kick on to the roof. This meant someone had to get the ball down. Someone had to take notice of me. At least I got something right. I learnt to kick a ball.

If we are to have full participation this must first start in the community we are born into. It is about where we choose to live. Keeping people hidden away from their community can never be justified. Segregating people because they have a disability must stop.

I have often thought about who took my power. Why was I not like others? What was so different in my life?

How did I become disempowered. What happened?

I believe that it was the people who claimed they cared about me the most who took much of my power. They were professionals, the teachers, and the staff that chose to control my life. The doctors completely controlled my life in the institution. They were more powerful than god. My parents had no real say. Doctor knows best.

While some were kind others were mean and made our lives hard. They talked about us as if we were not people, if we were somehow invisible or absent. Some of the staff cared but for many it was just a job.

I remember getting sick in the institution and no one noticed for days. I just lay in a heap on the floor. I was also given the wrong medication and almost died.

I am now involved in training staff and recently I heard staff talking about taking the "wheelchairs" to lunch. They had totally forgotten that there were people in the wheelchairs. Perhaps they really only took the wheelchairs to lunch. How bizarre.

When others take over your life they strip your power from you. You don't get to make any decisions that are important to you. You lose your confidence. You get used to others deciding everything for you.

This is true even for the simple things in your life. Like what clothes will I wear? What do I want for tea? This can start when you are so young and you never get the opportunity to learn to make decisions.

This is wrong. Part of growing up is learning how to make decisions for yourself.

When I started in self advocacy I had to learn so many words. I had to learn what the words empowerment and full participation mean. It was not easy as they were so many words I had not heard before.

Let me talk about what empowerment mean for those of us who have chosen to call ourselves self advocates.

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We define empowerment as having a real say in decisions. Ake Johansson told me how he and his friends in Sweden started to empower themselves.

He said it was a big step forward for him personally and enabled him to serve on boards and travel to meetings in many countries, including Japan.

Empowerment for me is about making my own decisions. It starts with the small things. What clothes will I wear today? What do I want to eat? What television programme do I want to watch?

Most of you were able to start making these decisions as young children. I was much older and had to fight very hard for the right to make these small decisions. As we learn to make decisions we grow as people. We learn to make the bigger decisions in life.

Where do I want to live. Who do I want to live with. What work do I want to do. Do I want to get married?

I soon learnt that when you make decisions you also have responsibilities. There are consequences and some of these are good while others are bad. It is this area that causes us the most trouble. Other people, including our family, often think that we can never be responsible. They think we have to be protected.

I had to learn to be responsible for myself and it was not an easy thing to do. I made mistakes and often got myself into trouble. However I did learn even if few people believed I could do it.

Empowerment is not something you suddenly have one day. It takes time to learn to make decisions. You start with the small things first and as your confidence grows you learn to make bigger decisions. You start to learn about responsibility and consequences.

When these things have been denied to you can be in a big hurry to make decisions. You want to make decisions for everything. You have to learn to take it slowly.

One of the big mistakes staff make is when they believe that you should be responsible for the decisions they have made for you. That was what made me very angry. They would decide how my life was to be and then punish me when they thought I was not being responsible. They were not my decisions so why was I responsible for them?

When we are segregated from our fellow human beings we lose our ability to make decisions. We think we are useless and we are being punished for being bad people. When we are discriminated against we also believe it is our fault, we are the ones who are wrong.

I soon learnt that if I stood up for what I thought were my rights I was the one who got into trouble, I was the trouble maker. People who had taken my power were not prepared to allow me to be a full person. They did not want me to make my own decisions.

However I had some staff who encouraged me to make my own decisions. My family taught me to stand up for myself but did not support me to play sport or be part of the community. But generally people did not see why it was necessary for me to make my own decisions.

Most people were not listening to me. I realised that I was going to have to fight to be heard. I then started to make my own decisions with my fists. I am not very proud of that today but at the time I felt I had no other choice. That was when I got into big trouble and was regarded as a trouble maker and a bad person.

Why am I telling you this story? It is because I see so many of my friends with an intellectual disability still hitting out because they are frustrated and no-one is really listening.

I learnt there was a smarter way. I learnt to listen to my friends and we learnt how to support each other. Over many years I was able to learn to make decisions. I started to understand responsibility. People started to see that I was more than a troublemaker.

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I got together with some of my friends who were living like me. We decided things had to change. Making the changes was not easy. Many staff and even our own family members did not want us to have a real say. We sometimes got it wrong as we had so much to learn. However we learnt from our mistakes. I guess we became empowered and started to participate in some of the decision making that affected our lives.

What does empowerment means for me?

I believe "Everyone is a person and should be respected for who they are and the things they bring as that person". It is about having a real input into my daily life-what ever that may be. It is having the confidence to believe in myself and the decision I make.

It is having enough self esteem to believe that I am of value and bring value to others. It is knowing that others will listen and respect my opinions and wishes. It is being respected as an equal and not talked down to as if I am inferior or cannot understand.

It is having the right to make decisions and to seek help from people I choose to ask for help. It is knowing that I have a say in where I will live and what work I will do. It is living with my own family, with my wife and our cat in our own home. Most of all empowerment is having a voice to say what I wish and knowing I have choices in my life.

What does full participation mean for me?

It is knowing that I have a life and what I want to achieve. It is the community accepting me for who I am and not expecting me to be the same as everyone else as everyone in the community is different and must be accepted.

It is living in the community where my family and I chose to live. Where we learn to get on with our neighbours and they with us. As adults we must be able to decide where we live and with whom we live.

It is having real friends, friends we choose, friends who will support us, not friends chosen for us. It is being able to go to a community school that meets our needs. It is having support that will strengthen the skills I have learnt.

It is having my everyday choices and decisions listened to. It is being able to have my say on matters that are important to me. It is having access to aids such as wheelchairs, communication boards, hearing aids to allow us to participate in the community.

It is about having the opportunity to play sport in the community alongside your neighbours and friends. Sport helps us make friends and for others to value us as real people. I have played sport all my adult life. I have been involved with sport for people with a disability such as Special Olympics. I have also played sport such as cricket and soccer in ordinary club teams in the community. We need the opportunity to do this.

Full participation is having the same opportunity as others to work in the community in a real job for real pay. Full participation is about being part of your community and enjoying the same rights, responsibilities and status as everyone else.

I am often told that empowerment and full participation is fine for people like me but what about those, who because of their disability, cannot walk or talk. I love that question.

For me empowerment and participation is just as essential for those of my friends that do not walk and talk. Just because you cannot talk it does not mean that you do not have a voice.

I often tell the story of Mark. He is a real person. He cannot talk in the normal way. He cannot walk either. What I learnt from Mark is that we all smile when we are happy and frown when we are sad. Mark talks by using his face. When things are going his way he smiles his agreement. When things are not going his way he frowns and looks very sad.

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When you really get to know him you realise what the raised eyebrow means. Mark wanted to live closer to home. We all finally got the message loud and clear. He now lives in the community. His family is around him.

He goes to his work each day in his wheelchair. People know who he is. He has family. He has friends. He has a real life now but it was not always like that for Mark.

There are many Marks in this world. They will never be doctors or teachers or do the work I do. However this does not mean they cannot have a say in the decisions that matter to them. It does not mean that they cannot be part of the community. All that is needed is for us to take the time to listen. We must learn to provide support that leaves the power with the person.

We must stop taking peoples power from them.

I now want to talk about the language that is used in the world of intellectual disability. We all use language or words everyday. We use language to describe our thoughts and feelings.

We use language to describe the things that are important to us as a person. We use language to tell people we love them and sadly some times that we hate them. We use language in our tender moments when we are at peace with the world.

We use very different language, which I will not use today, when we are angry or very upset. We use written language to write our charters and our laws. Our language becomes part of our culture. We use it to express thoughts, feelings and law.

Sadly language is also used to discriminate against those of us who have a disability. Children learn the language of discrimination and segregation at a very early age from their mother and fathers. It was children of my own age that called me stupid and moron when I was three or four. It was this rejection from other children that did the real damage to me as a child.

Civil Authorities use language to write laws that discriminated against us by saying where we can live, who we can live with and what community services we can use. The language used to label us has been very effective in stripping way our power as an individual. It has stripped away our ability to make our own decisions or to have our own say.

I really struggle with some of the language used by some to describe us. Many still use the term mentally retarded. This Conference is organised by the Asian Federation for the Mentally Retarded. Maybe it is time to think about this name as we can change the words we use without losing our identity.

We should use words and terms that respect the dignity of the person.

Others have made these changes including Inclusion International. It was a struggle for some but once the change is made no one wants to go back to the old words.

I have a friend Barbe who is very clever. If people call her mentally retarded she called them normates. People get the message.

I am aware that words have different meanings for different people. I also know that what is acceptable for some people is offensive to others. The use of words change. What was acceptable 20 years ago may not be OK now. Be aware that the person can become the label. I say labels are for jam jars. The best label for me is my own name.

I am Robert Matin and a New Zealander. I am a person first and my disability is only part of my life. My disability does not own me. My plea to you is be aware of the power of language. Be aware of the negative labels.

I now want to talk about some of the ways our need for support has been seen by others. First, particularly in Western Countries, there was the medical model.

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We were seen as having an illness and needed to be cared for in a hospital. In the medical model Doctor new best. Professionals controlled our lives. Decisions were made without us being present.

We were often the subject of experiments and trials that we new nothing about. We were seen as been sick and due to our disability we would not live a normal life span. Medical support was often withdrawn in our forties because in the eyes of the doctors we had reached the end of our natural life. We then fulfilled their expectation and died. I have been in hospitals that provided care and I assure you that you do not want to see what I have seen done to people in such places.

We reject the medical model but governments throughout the world still put us in the same category as people with an illness.

In some countries a legal model has been developed around people with a disability. This is based on the principal that one can seek compensation when you have been subjected to cruel or inhuman treatment. This can change the way services are delivered as professionals and service providers soon learn that if they continue bad practice they will be sued and may be put out of business.

It is only works when there are strong laws in a country that hold professionals accountable and people with a disability have the support to seek compensation for pass wrongs.

The human rights movement has been very effective in improving the living condition of many people throughout the world, including some of us with an intellectual disability.

It is based on the rights of the individual and the development and protection of these rights. So many people with an intellectual disability are still locked away in institutions. They often have their heads shaven, may be locked in a cage and fed very poorly. Some even today are dying of malnutrition or through lack of care.

We still have bins; some call them institutions, where over a thousand people are forced to live together. Many live in communities that at best tolerate us as people, at worse give us labels such as Mongol, stupid, imbecile and swear words that destroys our belief in ourselves as people.

I have recently spoken at the United Nations on the importance of the rights of all people with a disability. We currently have the Standard Rules that sets out some protections for people with a disability. However these need to be updated and this work is being done at present. Many of us are supporting a United Nations International Convention on Disability which will hopefully help protect the rights of all people with a disability.

This is provided governments sign it and implement the necessary changes. Unfortunately some governments believe that things are so good in their own country that they do not need to sign the Convention. The Human Rights movement is beginning to include people with disability in those countries that support human rights law.

However it has made no difference where such rights are seen as totally unimportant

In my work with self advocacy I have found that human rights can be effective when we can understand our rights. If we don't we are still at the mercy of the professionals who understand these things.

I want to go back to some of the questions I asked at the start. Why has our life been so different. Why are we often regarded as people of little worth? Why do so many of us have to share our bedroom with a stranger?

Why do we have to go to a separate school? Why are we the last to get a real job? I believe there is a way forward, things can change.

In a word our future is tied to one word, to one concept and that is inclusion.

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I have a vision for the future. It is a vision shared by many of my friends. I want you to also share this vision, not because you feel sorry for us, but because you believe we are right.

Our vision is for an inclusive community, a community with a place for all.

First we need to agree what we mean by community.

A community is part of the society we live in. It is the people who are our neighbours, who live in the same streets. It gives us a place, an identity. I live in the Eastown community in the City of Wanganui in New Zealand.

A community can be a group of people who have a similar belief. I am part of my church's community.

A community can be a group of people with a similar interest. I am part of the Wanganui sporting community.

Most people belong to more than one community. However when you have a disability you often belong to only one community, the disabled community. When I was a child I only belonged to the disabled community. My friends belonged to this exclusive club as well.

When we belong to a community we form relationships with other. We get to know others and they get to know us. We find people who will help us and make friends.

I will call these linkages, they are the relationships that make communities work. A healthy community needs lots of these linkages. We need to link with our neighbours, people who live in our street. We need to link with people who we share a common interest with. We need to link with people who we share a common belief with.

Through these linkages we learn to look out for each other, our children play together, they share birthdays, they go to school together. We have family and friend who will help us when we are looking for a job. How many of you here today got your first job through a friend or a friend of a friend.

We often meet our future partner through the friends we make in the community. We have people we can go to for advice or to get help. We have people we can look up to; they are our role models and our heroes.

Those of us who have a disability have the most to gain from living in a healthy community but in the past we were the ones who were usually excluded.

We want change.

We want to live in a community that does not try to change us, that does not try to make us the same as others. That cannot be done. Each of us is a unique individual; it is no different when you have a disability.

We want to live in a community that does not exclude us because of our disability. Rather it sees the abilities we have and values these as other abilities are valued.

We want to live in a community that will not accept special laws or the placing of restrictions on where and how we can live.

We want to live in a community that does not segregate us or try to shut us away from others.

We want to live in a community that consults us when our needs are being discussed. A community that no longer makes decisions on our behalf. A slogan you will increasingly hear from people with a disability is;

"Nothing about us-without us".

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We want to live in a community that will open its doors to us and welcome us as equals.

We want to live in a community that gives us the opportunity to grow up in our family and to take a full part in family life.

We want to live in a community that helps our family to understand our disability and how our needs can be met.

We want to live in a community that supports our right to go to school with all the other children who live in the same neighbourhood.

We want to live in a community that ensures our rights are respected and protected in the same way as these rights are protected for others.

We want to live in a community where special laws made to protect us are not then used to discriminate against us.

We want to live in a community where Guardianship laws are not used to take away our right to decide where and with whom we want to live with as adults.

We want to live in a community that encourages us to learn about decision making and being responsible for our own decisions. Until this happens true empowerment and self determination can only be a dream.

We want to live in a community where there are no negative labels. Governments and those who provide support can no longer keep using such labels because they are convenient for them.

We want to live in a community where the organisations that support us ensure that we can fully participate in decisions on matters that affect our welfare or the way services are provided.
We want to live in a community where we are given the opportunity to work in a real job in the workforce alongside our non disabled peers.

We want to live in a community where we are able to participate in sport and recreation of our choice. It is through sport that so many of our friendships grow.

We want to live in a community where discrimination in housing for people with a disability is not tolerated.

We want to live in a community that comes together and accepts that all people regardless of race, religion, skin colour, or ability are entitled to the same dignity and respect. I would call this the Inclusive Community and believe it is the key to our future if we are to join you as equals.

Some of us with an intellectual disability have made great progress in self determination and full participation. We have learnt to speak out.

We are starting to be accepted in our communities. We are supporting each other and we are building friends and allies. However we need your support and commitment if we are to build communities that are truly inclusive.

We need you to believe in the justice of our cause. We need you to help us make things change so we all can have a richer and fuller life. We need your support to live in communities that will empower us to become the person we have the right to be.

We need your support so we can fully participate in the community we chose to live in

But most of all we need the opportunity to become real people with a real life and live in a real community.

Thank You