

Self-Advocacy Toolkit

Executive Summary

1. Understanding and Supporting Self Advocacy

Self-advocacy has helped many people to find their own voice and to have a real say in their own life. People with an intellectual disability have not had the same opportunity as others to advocate for themselves. Every one can become a self-advocate. The text is an introduction to self-advocacy for self advocates and the people that support them.

2. Poster- ‘Respect’

A visual aid for self-advocates; a poster that enforces the idea of respect through self advocacy.

3. Myths

Plain language explanations of 4 common myths about people with intellectual disabilities

4. A life Worth Living, by Robert Martin (Self Advocate)

A speech given by Robert Martin to the World Congress - Mexico November 2006. He explains the pain he and his friends had to suffer and endure in the institutions and the support they need when they leave.

5. Poverty, A Personal View by Robert Martin (Self Advocate), Power Point Presentation

Robert explains what poverty (financial and spiritual) means to people with intellectual disabilities and describes its effect on their lives.



Understanding and Supporting Self Advocacy

Taskforce on Self Advocacy

Inclusion International

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Toolkit for Self Advocacy

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Or go to the website at : www.inclusion-international.org

Or post to : ***Inclusion International,
The Rix Centre,
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Introduction

The self advocacy movement for people with an intellectual disability started in the United States in the early 1970's.

People with an intellectual disability said they no longer wanted others to advocate for them – they wanted to advocate for themselves and the term self advocate was born.

Groups of people with an intellectual disability had also begun to form their own groups and these became known as People First. I am a person first; my disability is just part of my life.

These ideas quickly spread to other countries and the international self advocacy movement was started.

Inclusion International brought a group of self advocates from several countries together in 1993 and they wrote the “Beliefs, Values and Principles of Self Advocacy which was published in 1994.

People First also organised several international conferences for self advocates and this helped to promote the forming of self advocacy groups in many countries

The growth of the self advocacy movement has been amazing. With little resources other than a belief in their own ability, self advocates have changed the way the world thinks of them as people. Groups are active in many countries and regions and the self advocacy movement is growing in strength and commitment.

The United Nations Convention on the Rights of People with Disabilities was a good example of the strength of self advocates. Though the self advocates who attended were few in number, their influence was very strong.

The Self Advocacy movement will always face the challenge of fear and prejudice but it is committed to a better world for all people.

1. Understanding Self Advocacy

Self advocacy has helped many people to find their own voice and to have a real say in their own life. It is not something special for people with an intellectual disability. However people with an intellectual disability have not had the same opportunity as others to advocate for themselves. Others have taken this right from them.

Every one can become a self advocate. However some may need support to achieve this. They may also need the support of family and friends.

People become empowered when they are able to advocate for themselves. They gain the confidence to make their own choices. By learning first to make small decisions, they learn to make the larger decisions that affect their life.

Parents and other family members have a very important role to play. It is while growing up in your family that you should learn to make choices and decisions. Sadly many children with an intellectual disability do not get this opportunity. Often out of fear for their safety other family members make their choices and decisions for them. This needs to change.

Most people with an intellectual disability do not get the opportunity to attend a school of their choice. In fact most do not get an education at all. Many who attend school go to a special school away from their friends and neighbourhood children. Every one knows how important education is – unless of course you have an intellectual disability.

Many self advocates also talk about the control that those who provide services have over their choices and decisions. The staff decide what is best and the person has little or no choice in what happens. This destroys their ability to make their own choices and decisions.

Finally community attitudes need to change. As self advocates say it is not our disability that makes life hard – it is the thoughts and actions of other people.

2. The Principles of Self Advocacy

Some of the key principles of self advocacy are:

- **I am a person first**

A disability is just part of a person's life. However your intellectual disability can become your identity. Others fail to see the person you are. You lose your name and become a label.

- **I have the right to make my own choices and decisions**

We are unaware of our right to make our own choices and decisions until it is taken away from us. Most people with an intellectual disability lose this right at some stage in their life. Others make their decisions for them. They take control of the person's life.

- **My choices and decisions must be respected**

Like with others people the decisions people with an intellectual disability make may have good or bad outcomes for them. This is how we all learn. Protecting people from making decisions that may have a bad outcome controls their life. What is needed is support so the possible outcomes are understood.

- **I have the right to choose the support I need**

People often assume they have the right to support a person with an intellectual disability to make their choices and decisions. This leads to power and control over the person's life. We all have the right to decide who we will ask for support or advice.

- **I am a full person, I have the same rights and responsibilities as others in my community**

This includes the right to decide where and with whom I will live and work. We are all full citizens and therefore our rights must be protected both before and under the law. Along with this comes our responsibility as a member of the community.

3. What people with an intellectual disability can do

There are many opportunities for you to become involved in self advocacy. These include:

- **Become a self advocate**

Learning how to speak for your self is the first step in self advocacy. People who can do this are listened to and treated with respect. You can also help others to speak for themselves.

- **Join a self advocacy group**

Belonging to a self advocacy group helps you to learn to speak for your self. They also offer friendship and a sense of belonging. Groups are a very important part of the self advocacy movement as it is where we feel safe to talk about issues.

- **Help others**

By helping others we help ourselves. People may need a friend they can trust. By helping others we learn together. We feel we belong.

- **Become a leader**

Leadership is learning how to take responsibility and to help others. The self advocacy movement must develop its own leaders by encouraging self advocates to take leadership roles. Leadership can be both rewarding and hard work.

- **Become a helper**

Groups need helpers or support people. When you become experienced you can start being a helper. At first you may help

others to meet and talk about issues. As your experience grows you may support meetings or run workshops.

4. What families and friends can do

Having the encouragement and support of family and friends gives people the confidence to speak for them selves.

- **Give encouragement**

This gives your family member or friend the confidence to try new experiences. Having the support of family and friends can be a great help.

- **Give support**

Support to know when meetings are being held and to get there is very important. You may also be able to give support during the meeting but remember it is their meeting..

- **Help with communication**

You know how your family member or friend communicates. You also know what they find difficult. Having a supportive family member or friend can make all the difference.

- **Support the making choices and decisions**

Learning to make choices and decisions is part of becoming an adult and a self advocate. As family or a friend you can help the person to understand their choices. You can help them to learn to make decisions by respecting the choices they make.

- **Learn about the community we live in**

Family and friends can help the person to learn about their community. This helps them to become part of the community they live in.

- **Making new friends**

Living a happy life in the community is about having friends. Many people with a disability struggle to make friends in the community.

Family and friends can help the person to both be part of the community and to meet new people who may become friends.

5. What volunteers can do

Volunteers are an essential part of the self advocacy movement. They bring skills and expertise that are essential for the self advocacy movement to grow.

They can develop a relationship with the person based on friendship rather than being paid to do a job. The range of activities volunteers can do is only limited by our imagination. Here are a few suggestions.

- **Become a buddy**

Buddy programmes are popular throughout the world. They are about a one on one friendship that encourages both people to share a part of their life. This may be going to the movies, to the park or just hanging out together.

- **Become a friend**

Similar to the buddy programme but not part of an organised programme. Friendships grow from many different situations. This may include belonging to the same community group or working on a programme together. Friends often introduce each other to their other friends and the number of friends grows.

- **Become a confidant**

People need others to talk to who they can trust. A confidant will listen and help the person to understand the choices and options available. However they are careful not to make decisions for the person.

- **Become a trusted friend**

This is a friend who usually helps a person with their money budgeting or some other task that needs a lot of knowledge and skill. A trusted friend has the experience to help. They may only assist in one important area of the person's life.

6. What support people can do

A support person supports an individual or a group. A support person is a guide or mentor. They help a person or a group to achieve their goals. A support person must not speak for those they are supporting nor influence the decisions that are made.

- **Support an individual**

Many people beginning their journey in self advocacy require the help of a support person. This must be a person they can choose and relate to.

Supporting a person requires patience and understanding. You must encourage the person to do it for themselves but give help when needed. You must also remember that you will not be their support person for life and that in time they will also ask for support from other people.

- **Support a group**

Many groups require support when first starting out. They may need help to organise a meeting, write the agenda or record what they have talked about. Other groups may need help to work out their goals or plans for the future.

A support person must not try to influence the decisions made by the group but should give some guidance as to the possible outcome of any decision made. A support person can also help the group to communicate with its members and to make sure people know when the group will be meeting.

- **Facilitate a discussion**

A group may require someone to help them facilitate a discussion or to work through an issue. Some groups will ask for regular support to do this. A facilitator usually only helps with this task rather than providing more general support.

7. A final word

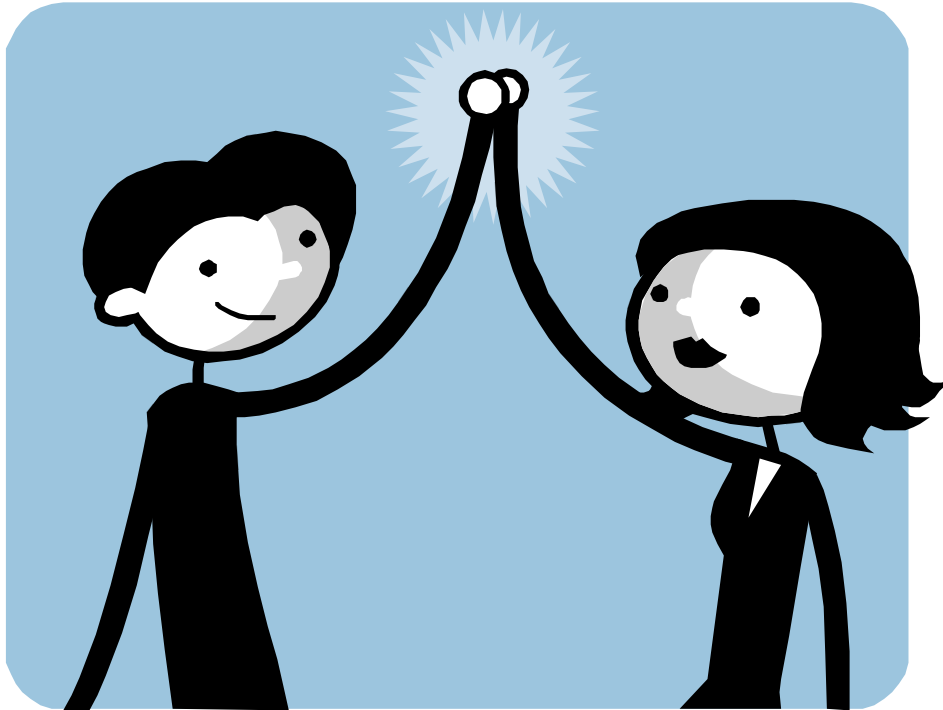
The self advocacy movement has been a pathway into the community for many people. It has given them the courage, skill, confidence and determination they need to live their life in the way that is right for them.

We believe that, given the right support, all people can both live and participate in the life of their community. It is the quality of the support they receive that will determine their success.

Acknowledgment

This paper has been developed from some of the work of the IHC New Zealand National Self Advocacy Team. It has been written to encourage discussion and debate. Please use it to support the further development of the self advocacy movement.

Respect



Makes life so much
Better
For Everyone

The Myths

A myth is something people believe is true because they don't know the truth or as a friend once said, they want to bury their head in the sand and not see the truth.

Myth 1

People with an intellectual disability are best looked after by other people who understand their needs.

If that is true then we would not have families as all people would be looked after by experts. It denies the person's need for the love and security of their own family.

Myth 2

A child with an intellectual disability will ruin your family life and they and you will be better off if others care them for.

This was and still can be used by "Professionals" to justify putting children with a disability in care. It destroys family life for the person as well as other family members by isolating the person from their family. This leads to feelings of guilt that may never be resolved in a lifetime.

Myth 3

People with high needs are best placed in care as their families cannot cope with the extra load.

This myth more than any other has destroyed the lives of people with an intellectual disability. People with high needs have an even greater need for a secure family life in a world that is very insecure for them. What is needed is support for their family within the community.

Myth 4

People with a disability don't have the same feelings as others and it is best if they are not told about their rights or sex, or having children and all that stuff as it may make them want things they don't understand.

The only thing different in the life of a person with a disability to that of other people is their experience in life and how they are perceived and treated by others. It is not our disability that makes life difficult for us, it is the thoughts and actions of others.

Like you-we want to be free to fly.



A Life Worth Living

By Robert Martin

Taskforce on Self Advocacy

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A Life Worth Living

A speech given by Robert Martin to the World Congress - Mexico November 2006.

He tells of the pain he and his friends had to suffer and endure in the institutions and the support they need when they leave.

We are no longer talking about should institutions be closed; we are talking about when they will close. Why do I say this? Let me quote from Article 19 from the Convention on the Rights of Persons with Disabilities which is about living independently and being included in the community.

States Parties to this Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

This means we must be able to choose where and with whom we live. We must be able to get the support we need to live and participate in the community. We must have the same right to use the services in our community as others. People with an intellectual disability have been fighting for these rights for years. It is now our time to have them.

Article 12 of the Convention is about our recognition as persons before the law. This means we will enjoy the same right as others to our legal capacity. Our legal capacity is about our right to make our own decisions and to act on them. There will be safeguards to prevent abuse for those who need this protection.

However any support must respect our rights, our will and our preference and must be free of conflict of interest or undue influence. There will also be support in the form of supported decision making for those who need support.

We must never forget that the institutionalisation of those of us with an intellectual disability has been one of the most destructive pieces of social engineering in the history of mankind. It led to our segregation from society because we were marked as different. I know this because I was one of these people.

Our institutionalisation, led to our dehumanisation as children, as teenagers and as adults. The staff who worked in the institutions also became institutionalised in their thinking and the way they acted. How else

can we explain the abuse and degradation that was and still is so much a part of the lives of those of us who have been forced to live in an institution?

When we became institutionalised, we joined the poorest of the poor, not only in terms of money and social status but also in regards to feelings of self worth, our own value and how others saw us. As we move people from the institutions others need to understand how the institution takes over the very core of who you are.

The economic argument is still used by many to justify the institutions. Those who still argue that Institutions prove high quality care at an affordable price need to think again. They have not done their sums and worked out the true cost of keeping someone in an institution for say 50-60 years. If they did they would want to open the gates and hope that the person would never come back.

Whole towns still rely on their local institution for employment and their economic success. However they are forgetting about peoples lives.

It was never our decision to live in an institution. We never signed the papers or knocked on the door of the institutions. Others made these decisions for us because they had the right or power to do so. We never did anything wrong, we broke no laws but because of our disability we were removed from society.

I have many friends who have managed to leave the institutions and I do not know any one who would willingly go back.

Some will also say that the institution they work in or know is very good. That the staff, are very caring and there are lots of good things happening for our people. The key words in their statement are “our people”. They do not realise they are trying to own the life of another person.

We must never forget that institutionalisation is about the control of a person’s life. It is about the making of major decisions for them and expecting them to fit a lifestyle that someone else believes is good for them. If living in an institution is so good for us why do most other people grow up in a family? Why are families so valued in all societies?

The time for institutions is over. We must not forget the lessons of the past but it is time to move forward.

The title of my speech today is a life worth living, why our lives are as valuable as others. I want to speak from my own experience and what I have learnt along the way.

First we must make sure no more children are placed in institutions. We must stop our teenagers and adults being placed there. You can do this when you go home today – say “**no to institutions**”.

We must start building the support that both families and those of us with a disability need to live and participate in our community. I have seen too many of my friends struggle so hard when they left the institution because the right support was not in place. I still remember how hard it was for me.

I was so frightened and afraid. It was also like that for my family because there was no one there to support them. This same support must be made available to families who still have their child with a disability living with them.

Our families need support to understand our needs as we are growing up. They often need help when we are teenagers. They begin to realise that our opportunities to live and work in the community may be very limited. In the past it is often at this stage that we have been placed in institutions or residential care.

However there is another situation that often traps us into care. That is when we stay with our parents until they become too old to support us. One of three things will then probably happen. We may be placed in an institution or in residential care. This may mean we lose contact with our own parents and family.

We may be placed on aged care with our parents even though we are only 40-50 years of age. I know several people this has happened to. We may become the caregiver of our own parents. We move from being supported to giving support which may or may not work for us.

Last, but least likely, we may move to a home of our own or live with the people we wish to live with.

As we move people from the institutions we must remember that they may have no idea what living in the community really means. My friends who have come from the institutions in Japan visit the people still in the institutions. They talk to the people about their own life in the community. What is hard, what you have to look out for? They offer friendship and a helping hand.

This peer support is vital as it is only those of us who have made this transition who really understand it. However the funders and the officials do not recognise this need. They know best when sadly they do not really know at all.

This peer support is vital if people are to have a real choice as to where they live and with whom they live with as promised in the Convention. Living in the community means different things to different people. For me it is about having the right to live the way I want to live.

It is not about living in residential care with 5 star standards. It is about living in my own home with those I wish to live with me. At the moment that is with my wife Lynda and our cat Pippa. Sure we need support to live in a way that is healthy.

We should not have to live in dirt and squalor. However we should also not have to live in homes where we cannot be ourselves because of the staff. Where we are frightened to put our cup down, because, it might mark the table. I have seen some homes like this and it is really sad.

When you live in the institution your only friends are those around you who share your disability. There is seldom any opportunity to get to know any one else.

When moving people from the institutions we must protect their friendships. I have seen many people lose their friends when they leave the institution. They are sent to different towns and cities. They move to different homes and other places to live. We must remember that these people do not drive a motor car; they do not know how to catch a bus or a train. They usually cannot write and email is a word other people use.

We must also remember that some of these friendships have been made over the many years we were locked away. They are very important to us. What we need is an awareness and good support to ensure these friendships continue. Unfortunately this is seldom a priority for others when we leave the institution.

We do not have to live in the same house, in the same street or even in the same city to keep our friendships. What we need is the right support.

When I first left the institution I was totally reliant on others if I wanted to go anywhere. They decided if I could go and how I would get there. Now I am able to make these decisions for myself and I can travel the world. It is not like that for most of my friends.

I now want to talk about our families. I always knew I had a family, mum, dad and my sister. However as I was growing up as a child in the institution I really did not know them. I have other friends who never saw their parents. They often had brothers and sisters who they did not know existed. Their brothers and sisters also did not know they existed.

I personally know of people who because of being placed in an institution they have lost their whole family. They have a name but no one is sure if it is their correct name because their file has been lost.

Many of the important parts of our lives were never documented. As we passed from institution to institution our history was lost. Our friendships and relationships were not known. Sometimes when we leave the institution others want us to leave our previous life behind. They want us to only live a new life. They forget that living in the institution is part of our history, part of our life.

My family became a disability family. Because I had a disability they were shunned by the rest of our family and their friends. Many parents here today will know exactly what I am talking about. Both we and our families need support and help when we leave the institutions. Our parents will often be carrying a lot of guilt.

Our own brothers and sisters may not know who we are. Our wider family may have never met us and may still not want to do so. Our neighbours will often think we are dangerous and should not be living anywhere near them. It is usually a very hard time for us as we try to learn to fit in. However in my experience there is little help available for either us or our families. We are just expected to get on with life.

I now want to turn to something that you will not find in the text books on life. It is what happens to you as a person when you are institutionalised. This is probably the most important part of my speech today as it is an area that is simply not understood.

I have spoken many times about my own life and the lives of my friends. I have shared how it felt to lose my family, my right to be a child and the pain so many of us suffered in the institutions. What I have never shared is some of our inner feelings and I think it is the right time to do this now.

Many wonder why I am so passionate about not only closing the last institution but also bulldozing them into the ground. Why I stood up time and time again at the United Nations to say the institutions must go.

When you are forced to live in an institution something dies inside of you. You feel worthless and just a burden to your family. You struggle to go on each day. You cry for your family but the tears dry up when you realise that they will not come.

You see the abuse around you, the cruel things done to your friends and if you are unlucky they are done to you. You see the unfairness but are powerless to stop it.

You will probably learn to bully others as this is how you survive. You learn to trust no one, that the doctors, the nurses and the officials are not your friends.

I lived in a hell hole, an institution called Lake Alice for 6 months. It was the most desperate 6 months of my life. Now the people who were running it at that time are facing criminal investigations and the government is being forced to pay millions of dollars in compensation.

I well remember at the age of fourteen that I did not want to go on. I wanted it all to stop. I saw no reason to live. I wanted to end my own life. I did not have a life worth living. It is like that for many of my friends but little or nothing is done for them when they finally leave the institution.

It was thirty five years after leaving the institutions that I finally was given some counselling for the abuse I suffered in them. So many of us were over medicated or given the wrong pills. I almost died when this was done to me. Years later many of those of us who have left the institutions are still on old drugs or high levels of medication because our needs are not seen as an important to others.

What happened to us as people has never been understood. I see their frustration and anger as to what happened. I see them being overwhelmed and see their feeling of helplessness. This is not just in New Zealand that this happened. I remember being in a Self Advocacy meeting in London with people from all around the world. I remember all of us bursting into tears when we started to talk about what had happened to each of us in the institutions.

It was my friend Ake from Sweden who taught us all that living in an institution is not a human way of life. I have never forgotten his message. My plea is for greater understanding and help in this area. It is not enough to live and participate in the community. We must also have the right to be a full person and have a life worth living.

This means that instead of placing us on a behaviour programme because of how we now act due to what done to us in the past, we get the help we need to heal some very strong wounds. Counsellors must stop putting us in the too hard basket; they must learn to work with us and to meet our needs. It also means that regardless of when we left the institutions the need for us to come to terms with our incarceration is recognised. Our need to understand what happened to us is dealt with.

Finally if the transformation from institution to living in the community is to be successful then we must start to change the perception in the community of who we as people with an intellectual disability are. It is not about

transforming us so we can live in the community. It is about transforming the community so there is a respected place for all, there must be no exceptions.

We must be included, included in our families, included in our schools, included in the workforce, included in community housing and included in our wider community. It is through this inclusion that we will become real people; we will take our place in society. We will finally have a life worth living.

It is all too often the prejudice, the misunderstanding and sadly sometimes the hatred that we face that makes our lives so difficult.

My dream is simply this.

As the Convention, for the Rights of Persons with Disabilities says we will all live in communities that respect the rights of all people. We will all be able to choose to live where and with whom we wish.

We will all be able to have the support we need to live a full life regardless of our needs. We will all be able to communicate with each other in a meaningful way regardless as to how this is done. We will all have the same opportunity to make friends, build relationships and belong to our family.

I believe all means everyone – there must be no exceptions. We will achieve this dream when the last institution closes and at last we are free. Segregation and separation will be no more. All people will be supported to live the life they choose for themselves, no matter what that choice may be.

We will truly have a life worth living.

Robert Martin

Poverty

A personal view
by
Robert Martin

Inclusion
international



What is poverty?

- For most it is an economic issue. It is seen as not having enough money to live like other people in the community.
- For others it is a spiritual issue, a poverty of spirit that gives us a feeling of hopelessness and exclusion.
- I believe these two things are connected.

The Effects of Poverty

- Poverty leads to others as not seeing us as having any value as a person
- We become an outcast and seen as a person of little worth.
- We can suffer utter despair and feel not wanted.

Poverty Affects All People

- Even the so called wealthy countries have poverty.
- I come from New Zealand which is a wealthy country but we have poverty.
- We have areas where 3 or 4 families live in a small house as they cannot afford to live in a house of their own.

The Poverty Trap



- When we have a disability we are often placed in a poverty trap.
- We are the last to get a job, we are the last to get an education, we are the last to get good health care.
- We are often forced to live in very poor areas where there are no job opportunities.
- This is true throughout the world

Poverty and Disability



- When we have a disability we seldom have an income like others.
- At best we are reliant on the government for support from welfare benefits.
- We may have to get help from charities and others who give out aid.
- Many of us are totally reliant on our family even when we are adults.

Being Controlled

- When we live in poverty others control our lives. They decide how we will live. They may well decide what food and clothes we can buy.
- This leads to segregation as we are no longer part of the mainstream of life.
- It affects all the people around us as they often have to share our poverty with us.

Asking Others for Help

- I grew up in an institution where others controlled me.
- I know what this did to my life and my belief in myself as a person of value.
- I know what it is like to all ways having to ask others for handouts, to buy the simple things in life that others take for granted.

Being Born into Poverty

- Children born with a disability are often born into poverty.
- They will always be reliant on others to meet the basic needs of life.
- Their family will be effected as they become a disability family.
- Mother may have to spend most of her time providing care.

Poverty Can Cause Disability



- Poverty is also a major cause of intellectual disability.
- Our parents poor diet and lack of health care can lead to us being born with a disability.
- The environment can also cause us to be born with a disability

We Can Make a Difference

- We need to work together to reduce both the effects of poverty and poverty itself.
- Poverty is an issue for all people who have an intellectual disability, their families and those who support us.
- We can make a difference, we just need the will to do so.