

The Voice of Self Advocates

Day : Tuesday Pre-Congress Session

Time : 9.15 to 10.00 am (this time may change)

Session : Plenary

Panel : Haydee Beckles, Marie Farah, Robert Martin (chair),
Self Advocates from Europe, Quincy Mwiya,

Format : Robert will introduce the panel and give a short introduction for the session. Each Panel member will then speak on their topic as shown below. There will be 5 minutes for questions and comments from the audience. Finally one or two people who are Keynote Speakers from these sessions will be invited to give their reaction to what the Self Advocates have said.

1. The Role of Siblings in the future of the Family Movement

Experiences of listening to Brothers and Sisters.
How can they be more instrumental in the movement?

Sharing our stories and experiences as brothers and sisters of people with intellectual disabilities helps to build solidarity and a community of advocates for inclusion. Being a brother or sister of a person with an intellectual disability has both personal implications in the role you play as a part of a family and potentially in the role that one can play in advancing inclusion.

Some of the most important advocates for inclusion have been politicians, lawyers, doctors and philanthropists who have a brother or sister with an intellectual disability. Driven by the relationship they have with their family and their family member with a disability, these individuals have taken on both personal commitments and political struggles.

This session will bring together some of the leaders in our movement who have made a difference for their siblings with a disability as well as in the systems that impact on their lives.

Panellist – Quincy Mwiya and support – James Mungomba

As Self Advocates we will share:

- A family is more than having a mother and a father. Brothers and sisters who are part of our family share our family heritage. They are part of who we are.
- How brothers and sisters can be our best supporters and role models. They can educate others about our disability
- We learn about life from our brothers and sisters. They can introduce us to others who are their friends and they may become our friends.
- We all need people who really understand us, people who know who we are. Apart from our parents it is our brothers and sisters who know us best.
- When we live in poverty it is our family who support us. If we lose our parents through famine, through AIDS or for any other reason it is our brothers or sisters who will look out for us.
- Because brothers and sisters know us best they can be our best advocates. Their voice as a family member is strong. They can get others to listen to our needs.

2. The Role of Religious Institutions in Promoting Inclusion

For many people with intellectual disabilities and their families the religious institution that they belong to has either been the link to inclusion in the community or one of the barriers to participation.

Drawing from these experiences and stories, representatives from a range of different faiths and religious organizations will reflect on the policies and practices of organized religion and their impact on people with intellectual disabilities and other marginalized groups in society.

Panellist – Haydee Beckles and support – Eneida Ferrer

- Being able to find our inner self and being able to understand our own spirituality is no different when you have an intellectual disability.
- Being able to attend religious instruction and observe the practices of our religion or faith is just as important to us as it is to others.
- Our participation in the practice of our religion or faith can help us to understand others and for them to understand us. This is how we can become known and how we can make friends.
- However in the past our experience as people with an intellectual disability has not always been positive.
 - Some of the worst abuse we have suffered has been in institutions run by Religious Organisations. It was not the Organisation that abused us but those who worked for them. Unfortunately they were able to hide behind the name of the organisation and we were not believed.
 - Some Religious Organisations still believe that we are best segregated from society as we need to be protected. This does not help us.
 - Some Religious Organisations will not fully include us in the practices of our religion or faith. We are not allowed to participate in the same way as others as they think we do not understand.
 - Some faiths still believe our disability is the result of mistakes by us or our parents in a previous life. This does not help us to be valued for who we are.
- Our religion and faith is just as important to us as others. We want that to be respected and valued in the same way as those who do not share our disability.

3. Vulnerability and Violence: Breaking the Silence

This session will explore the issue of violence against people with disabilities (in the family; in the community and systemically). Drawing from personal experiences; research and practice in different contexts participants will discuss strategies for reducing vulnerability of the individual, family, and community.

The session will include panel presentations of experiences and perspectives on violence as well as research findings from UNICEF and other agencies on the issues of violence. Participants will have an opportunity to explore policy and community strategies to respond to violence.

Panellist - Robert Martin and support - Desmond Corrigan

- Living with violence is all too common away of life for those of us with a disability and in particular when we have an intellectual disability.
- Much of the violence happens when we are away from or family, when there is no-one to protect us.
- This violence often comes from prejudice, the prejudice caused by those who do not understand us. It comes from those who bully us because they think we are weak and cannot fight back.
- It comes from those who think they have the right to abuse us or know that they will never appear in court because we will not be able to say what they did.
- It comes from those who think they should or can control our lives. We are often abused by those who reject us as a possible partner in life but then sexually abuse us for their own sexual gratification. This is their ultimate control over us.
- However sometime the violence is within our own family as they struggle to both meet and understand our lives and our needs. Some families feel helpless and alone, they are isolated from their natural support.
- When violence occurs we are the ones who are put on the behaviour programmes while others get help and counselling. Few people are trained to help us. There are very few community programmes on reducing violence that include us. Others often do not take the violence against us seriously. This is particularly true when the violence comes from those we live with.

4. The Role of Post-Secondary Education in the Promotion of Inclusion in Society

Facilitator: Melanie Panitch (Ryerson University)

Colleges and Universities play an important role in building the professional and human resource base for the economies and cultures of wealthy and developing countries alike. Post-secondary institutions can promote inclusion in communities by:

- *Developing professional curriculum (engineers, doctors, lawyers, etc.) that promotes understanding and practical strategies for inclusion across faculties.*
- *Investing more in research and knowledge development about inclusion.*
- *Collaborating with disability organizations to assist in mobilizing knowledge development for inclusion.*

Panellists– Self Advocate from Europe and support – Gengoux Gomez

- Before we can have true inclusion in our community we must first win the right to attend school and have a place at school. It is through our schooling that inclusion in your community starts.
- Most children with an intellectual disability live in countries with developing economies. Most of them do not get the chance to attend school and they finish up being excluded from their community for life.
- Even in the so called developed countries our education is always seen as less important than. This can also lead to a lifetime of exclusion. As self advocates we are fighting to be included, to be part of the community in the same way as everyone else. However we face many barriers and sometimes open hostility in our fight to achieve this.
- We want the same opportunity as others to live in the community. We want the same opportunity to participate in community life. We want the same opportunity to seek work and to be valued like others.
- We want the community to accept us and value us for whom we are. We do not need to be rehabilitated to live in the community, the community has to change so we are accepted and valued as we are.
- We want to join with others to make this happen. We can work with others. We have a lot of knowledge and experience. We are the experts in our own lives.

5. Teachers Federations

Facilitator: Michael Bach (Canadian Association for Community Living)

This session is about building partnerships between teachers' federations and family associations. Teachers face a range of issues in the classroom that impact on their ability to effectively include all children.

Teachers Federations can be allies in making progress towards inclusive education if we can help to address some of the broad challenges facing education today.

This session will bring Teachers Federations from different parts of the world to explore potential partnerships between advocates for inclusive education and teachers.

Panellist – Marie Farah and support – Fadia Farah

- When we are excluded from knowledge we are excluded from a valued life. We must all have the opportunity to attend school and to learn.
- Our lack of education as children with a disability has been our biggest handicap in life. It is the extra burden we are all forced to carry.
- There must be one inclusive education system for all but it must meet our individual needs. We must not be segregated into special school or special classes. When this happens we do not learn about others and they do not learn about us.
- Teachers must learn how to teach all children and this includes those of us who have a disability. They may need extra training and support when we appear in their classroom for the first time.
- We as self advocates should take part in the training of teachers. We know about our disability and what works for us and our friends. Teachers need extra training in communication skills so they can communicate with everyone.
- We want Teachers to be the champions for our right to education in the same way as they are for others. Teachers must start believing our education is just as important.
- Teachers must learn that we are just as talented as others; be it in learning, in art or crafts, in sport or whatever. Our achievements and the way we need to be helped to learn may be different but our need to learn is the same.