

Reflections

Presentation by Diane Richler to Closing Plenary Session of

Inclusion International 15th World Congress

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I had been asked to speak today about the policy conclusions from this 15th World Congress of Inclusion International. It has been an amazing coming together of almost 300 people from 70 countries – with over 800 self-advocates. But before I talk about the Congress, allow me to use this opportunity to reflect on my 8 years as President of Inclusion International which ends tomorrow.

Our analysis of any situation is shaped by our experiences. I was born a few years after the end of the Second World War. I grew up hearing stories of the atrocities of war and the result of hatred, but also believing in the possibility of peace and harmony based on human rights.

I studied psychology at university and began working with our Canadian member, the Canadian Association for Community Living (CACL) in 1971. I became outraged at the oppression and exclusion of people with disabilities. Those were days when talk of living in the community for people with intellectual disabilities was new. In Canada, the government had just commissioned Craig Mooney to write a major national report on services to persons with intellectual disabilities. In the text, he provided a definition for “group homes” – a new concept at the time. He praised the institution in one province for building a swimming pool so that the residents could invite the community for a swim – which he identified as the most progressive step forward he could find in the province. These were the days when our member organizations were trying to understand the concept of normalization, first introduced by the Scandinavians, and then elaborated by Wolf Wolfensberger with whom I was privileged to work for two years. Concepts such as living an ordinary life, and following a rhythm of the day and of the year similar to one’s non-disabled peers was considered radical.

Working with CACL I quickly decided that a community that included people with intellectual disabilities could include anyone. I couldn’t have known that many years later my own godson would benefit from my work. I have now spent almost 40 years fighting for inclusion – first supporting families, and then being part of a family. What have I learned?

1. *Inclusion International is more than an organization. We are part of a movement for change.*

At the core, Inclusion International is a movement of families. Our member organizations were started by families and it is a legitimate role for us to be there not just for people with disabilities – but for families. We need to include self-advocates and foster the development of self-advocacy. We need to include professionals and other community leaders and benefit from their contributions. But we also need to have a lens through which we analyse issues according to their impact on families and work to strengthen and empower families. For example,

sometimes it may be more important to provide support to a family – such as respite so parents can get a good night's sleep – than to provide a therapy to the child with a disability.

2. *We need to understand our challenges in the context of global issues.*

Globalization means that Starbucks has replaced little cafés on many Berlin street corners. It also means that the policies of the countries which make up the G8 touch the lives of people with disabilities in Africa and elsewhere. When wealthy countries spend less on international cooperation, there are fewer resources for education and health care for people with disabilities in much of the world. Likewise, the United Nations Millennium Development Summit in September will affect the poverty of persons with disabilities and their families.

3. *Being advocates means more than being watchdogs who criticize.*

We need to help find solutions that meet our objectives but also respect the rights and needs of others. If the Convention on the Rights of Persons with Disabilities is to be meaningful for persons with an intellectual disability, not only does our voice need to be strong, but we also need to help find the creative solutions that will change people's lives. For example, when we help improve education for all children, we make it possible for children with disabilities to be included in regular schools.

4. *We can contribute to democratisation and world peace.*

An important lesson I learned from working with friends in the Americas is that parents from opposing political backgrounds are willing to cooperate in the interests of their sons and daughters. It was cooperation between former members of military governments together with former revolutionaries who founded Inclusion Inter-Americana and made it strong. Our member in Finland, the Finnish Parents Association for the Intellectually Handicapped, FDUV has supported our Kenyan member, the Kenya Association for the Intellectually Handicapped to deal with the trauma and tragedy of post-election violence in 2008, and to bridge the gap between tribes. I saw similar positive examples when a group in Qatar invited Israelis to share their experiences and in the work of AKIM, our Israeli member in Arab communities. We can exploit our willingness to work across political differences to model new ways for working together.

5. *We need to find new ways to work in solidarity with others.*

At a gathering such as this congress, we realize how similar our struggles are to those of others and how much we can learn by sharing experiences and lessons learned. We need to find better ways to develop knowledge by sharing experiences between people in countries with a lot of resources, in countries with few resources, and between those in resource-rich and resource-poor countries. We also need to find others who share similar goals of inclusion, equality and respect for human rights and learn from them. Michael Fullan, a world-renowned educator observed that "Information remains only as information unless it socially processed." He

observed that it is social interaction that translates information into knowledge. That means that by interacting with others and sharing the information we each have, we can generate new knowledge that can help us all.

Now let me turn to some of the messages that have come through from this Congress.

Although we had sessions covering a wide breadth of topics, there were several themes that came through over and over, in slightly different words, in different languages, but with the same meaning. Thanks to our new communication strategies, these messages were not only delivered in conference sessions, but were expressed through art, and tweeted and re-tweeted around the world.

“Enough talk. It’s time for action.”

“We need to listen to people with disabilities.”

“CLOSE INSTITUTIONS. We want to live in our own homes with our friends.”

“Going to school together is the beginning of inclusion.”

“End discrimination.”

“Laws are important but they don’t unlock hearts and minds.”

“It’s important to have friends.”

“We need national and regional platforms for self-advocacy.”

“Remember people who can’t speak for themselves.”

“Working together is ‘good for the soul’.”

Two personal stories stand out. One is from a woman who lives in a place with 400 residents and who when asked what she had learned at this congress replied, “I can be myself.”

The second is about a young man who participated in a session in which I was one of the panellists and where the topic was international cooperation. It was quite a technical session, and I spoke about the partnership Inclusion International had with the government of Panama to reduce barriers to inclusion for people with disabilities and their families. After I spoke, a young man in a wheelchair came up to the front of the room and waited to talk to me at the end of the session. He speaks with difficulty and since he is German we needed a translator. He reached into his pocket, produced a 5 euro note and asked me if I could send it to people with disabilities in Panama. He is a man with few resources, but was moved to want to do what he could to improve the lives of others. Imagine what we could accomplish if every person at this congress took personal action to deal with the challenges raised at this congress in the same way that this young man did?



At the beginning of the congress I read a message that we had received from Ban Ki-Moon, Secretary-General of the United Nations. We will now take the messages from the congress and communicate them to Ban Ki-Moon suggesting how we can build on the partnership he committed to with us.

As President of Inclusion International it has been my great honour to represent families and people with intellectual disabilities from all over the globe and I was privileged to visit over half of the 115 countries where we have members. Please forgive me if I close using a Canadian example.

Canadian geese are a well-known symbol of my country. They are large, graceful birds with long necks that fly in a "v" formation. When they first take off, they are very noisy and the flock looks disorganized and chaotic. But within seconds they form a line side by side, and then the line bends in the centre with the geese at each end falling back a little to form a "v" shape. Apparently, flying in a "v" helps them fly faster and longer – similar to how team members help the leaders in the Tour de France bicycle race – and adds as much as 71% to the flying range of the birds than if they flew alone. Any goose that gets out of formation quickly feels the "drag" of going it alone, and gets back into formation. When the lead goose gets tired, it falls back and another takes its place. All the while, the geese in back honk loudly as if to encourage those in front to keep working hard. When one goose gets sick or is wounded, two others fly out of formation and follow it down to protect it. They wait until the bird is either able to fly again, or dies, and then take off and catch up to their flock.

Similarly, when we have a shared vision and a sense of community we can achieve our goals. We need a common vision, to support each other, let different people take the lead, and be sure to help those in crisis.

As I leave the Presidency of Inclusion International I want to thank all those who have helped me to travel much farther than I ever could have done on my own – the Council members of Inclusion International, our small but dedicated and exceptional staff, the Canadian Association for Community Living and Inclusion Inter-Americana who gave me this opportunity, the members of Inclusion International around the world who have inspired me, and the countless individuals who have supported our work. A special thanks goes to my husband Ron and all my family.

Meeting members from around the globe at this congress and listening to speakers, I have been constantly impressed by our common vision, by our breadth and by our knowledge. Thank-you for allowing me to serve and represent this wonderful organization.