This newsletter is a way for Self Advocates to keep connected and share news. Please share this with your networks.

If you have any ideas or feedback on the Newsletter, or if you would like to submit a story for the next edition, please email me at: david.corner@ihc.org.nz

Thank you
David Corner
Self Advocate representative for the Asia Pacific Inclusion International


Here are stories from two self advocates who went to the forum.

Global Forum: Achieving Inclusion Across the Globe

My diary of the Inclusion International Conference in Washington DC!

By Ciara Evans (England)

I represent Europe on the Council of Inclusion International. Inclusion International is a worldwide organisation that advocates for the human rights of people who have an intellectual disability.

On the council, there are self advocates and supporters. A self advocate is a person with an intellectual (learning) disability who speaks up for themselves and for others.

We were at the conference from Tuesday 23 October to Sunday 28 October.
Tuesday – arriving in Washington!

On Tuesday morning, my colleague Marsh and I met in Terminal 5 at Heathrow Airport, ready to fly to Washington DC! Our plane took off on time and we arrived in the afternoon.

Later in the afternoon, Marsh and I went for a walk around the city. We walked around the outside of the White House and the National Mall area. We then walked towards the Washington Memorial, the reflecting pool and the Lincoln Memorial.

On our way back to the hotel, we saw three helicopters fly overhead in the sky and one of them landed on the White House lawn.

We asked a policeman if Barack Obama was in the helicopter and he said yes. It was really exciting as we were about 500 yards away!

Wednesday – the first council meeting

On Wednesday, Marsh and I attended the Inclusion International Council meeting. We talked about the membership report and the officers’ reports.

We talked about the Self Advocacy Committee Report. This report talked about the work that our council members with an intellectual disability have been doing over the last year to promote self advocacy.

We also talked about the 2014 Inclusion International World Congress Conference that will take place in Kenya.

A lady from Inclusion Africa told us about some of the things that will happen there. The other item we talked about was nominations for new council members.
Thursday – the main conference

On Thursday morning, Marsh and I registered for the main conference. We attended the Self Advocates pre-Conference Day meeting. The meeting was hosted by Inclusion International and The Arc's National Council of Self Advocates.

The ARC is the largest organisation advocating for and serving people with intellectual and developmental disabilities and their families in the United States of America.

The meeting was co-presented by David Corner, who is a self advocate from New Zealand. He is on the council of Inclusion International and represents the Asia Pacific Region. Our Self Advocacy Committee Group presented a presentation on the Convention on the Rights of People with Disabilities (CRPD) and what it is about.

At the pre-conference day, there were presentations from self advocates from all over the world.

I met some self advocates from the USA, Australia, New Zealand, Japan, China, Africa and Nepal. I also met a very inspiring self advocate called Marisa who lives in Virginia, USA.

She works for The ARC. Marisa has been helping to shut down institutions in her area that are still open. Four of out five of the institutions are now shut, which is very good news! During the meeting, I also heard talks from other really inspiring self advocates.

Later in the afternoon, we went to the opening session of the conference. At the start of the session, three American soldiers marched in with the American flag and we all stood while the national anthem of the USA was played. One of the speakers was the Mayor of Washington DC, Vincent Gray, who welcomed us all to the city.
The Right to Live and Be Included In The Community

During the session, the report on Article 19 was launched. This is about The Right to Live and Be Included In The Community. I thought this was the most important part of the conference.

Even when people with an intellectual (learning) disability live in the community, they are often isolated. At our council meeting in Nepal last year, we did interviews with other self advocates and we filmed them on a video camera.

These were then used as part of the research for the report.

In my experience, I think these findings are true. In England, we still need to improve things for people with a learning disability. Mencap agrees with me and this is what they are going to do:

Mencap are going to publish a report on housing in England. Mencap understands that we have come a long way in supporting people to live independently, but we still have a long way to go.

The report is expected to show that still too many people with a learning disability are not getting a chance to live independently.

I am looking forward to seeing the report to see what it says and whether things I heard about at the conference are the same.

Letting our hair down at a red carpet event!

After the opening session on Thursday evening, we had a fun social event called Red Carpet and Film Festival.

We all walked down a red carpet while our photos were being taken. We were given either a coloured feather boa, sunglasses or a glittery tie to wear while we were walking down the carpet.

At the end of the carpet, there was a man acting like a reporter giving us the star treatment. When it got to my turn, I gave him a surprise and I sang a little bit of Somewhere Over The Rainbow!

During the film festival, we watched some fantastic short films featuring people with an intellectual disability. They really helped to showcase the talents of people with an intellectual (learning) disability.

I stayed up late and went for a few drinks with some of the other people from the conference. It was nice to get to know them. We let our hair down after a busy day!
Friday – challenging attitudes

During Friday morning, I went to ‘the Market Place’. There were lots of stands promoting different services for people with an intellectual (learning) disability. Marsh and I walked around the stands and talked to people. I helped out at our Inclusion International stand. I told people about the work that Inclusion International do.

Later in the morning, I went to some of the presentation sessions, which were really good. I went to a session that was just for self advocates. It was hosted by Tom Shakespeare, who works for the World Health Organisation. He talked about the World Report on Disability and about forced sterilisation.

The next session I went to was about supporting parents who have an intellectual (learning) disability. There were speakers talking about issues that parents with an intellectual (learning) disability had faced. At the session, there was a couple called Donna and Ricardo Thornton, who both have an intellectual (learning) disability. They told their story to the audience. It was really inspiring to hear.

Personally to me, their story was really inspiring to listen to as I am getting married soon.

Donna and Ricardo met when they were both living in an institution (large care home) in the United States of America. They became good friends. After a while, their friendship then turned into a relationship. A few years later, they decided to get engaged and get married as they wanted to be together.

They then faced a lot of discrimination from professionals about their decision. Ricardo and Donna fought the discrimination they faced and proved to everyone that they were in love and that they were happy.

A couple of years later, they finally got married. Since then they have also had a child of their own.
Saturday – my presentation

During Saturday afternoon, I was on the speakers’ panel for a presentation session called Life after School – Transitioning from School to Work.

My presentation was about how people with an intellectual (learning) disability should get good support at work from their colleagues, and about my experiences of having a job and working for Mencap.

I was really pleased with how it had gone and I felt confident. A couple of people came up to me afterwards and said that they liked my presentation.

After my presentation session, Marsh and I went to the closing plenary session. Towards the end of the session, I went up on to the stage with a self advocate called Kevin Smith, who is from a self advocacy group called People First of West Virginia.

We both talked about some of the highlights from the conference, and introduced a video that was made up of highlights from the conference.

At the end of the session, Klaus Lachwitz who is the President of Inclusion International, closed the conference and invited everyone to take part in the closing event.

Rock The Night Away! It was hosted by a professional dance group. We all got dressed up and danced until the early hours of the morning!

Sunday – coming back to the UK

During Sunday, I attended the General Assembly meeting and the second council meeting.

On Sunday evening, we left the hotel and travelled back to the airport. We were all a bit nervous because Hurricane Sandy was going to hit the East Coast of America and we weren’t sure whether our flight was going to go! But we were very lucky and our flight took off without a hitch.

Looking back, the conference was fantastic.

It was great to meet so many passionate people and hear about the lives of people with learning disability all over the world.
In October last year, I travelled to the Inclusion International Congress in Washington DC. with People First National Manager, Cindy Johns. I had never been to America before and it was a long flight. When we arrived in Washington and got settled into the hotel we went for a walk to the White House which was near our hotel.

On the first day, I went to a self-advocacy leadership day while Cindy went to another leadership forum. We talked about self-advocacy groups and what makes a good assistant.

That night Cindy and I went to a film festival showing films about people with learning disability. As we went into the festival there was a red carpet and everyone got interviewed. I got a miniature Oscar trophy.

We met lots of new people from all around the world. There were people from over 40 countries.

At Inclusion International’s Annual General Meeting, People First New Zealand’s membership got accepted and I introduced myself and thanked everyone for accepting it. We are proud to be part of Inclusion International.

We got stuck in Washington for a few days as our flights home were cancelled because of Hurricane Sandy. We ended up having to stay for one night and one day in Los Angeles as well so we took a bus trip around the city.

It was a great trip and I really enjoyed meeting other people from around the world. Thank you to IHC New Zealand for sponsoring Cindy and I to attend.

It was great to hear about how people with learning disability live in different countries.

It was also sad to hear that many people still live in institutions around the world and don’t get choices about where they live.
In each newsletter, we like to share stories from self advocates and their family members from around the world. This is a way to learn about how things are for people with intellectual disability and their family members in different regions of the world.

Ismail Kaji – Self advocate (England)

Ismail grew up in London with his Mum and sister. Ismail says that whilst he was growing up, life seemed hard. He and his sister had lots of health problems and he felt like he spent all his time at doctors’ appointments.

As a child Ismail attended a special school he feels like he learnt enough to help him get a good start in life. When he was 13 Ismail moved to Malawi a country in Africa, to live with his dad. Ismail went to a mainstream school there.

After his time in Malawi, Ismail moved back to London where he has lived ever since. After college Ismail started working at UK learning disability charity, Mencap. He works full time as a campaigns assistant.

Ismail got married when he was 23. Soon after this, he moved into his own home and started a family. He now has three children. His daughter is 11 and his two sons are 7 and 2.

Ismail is grateful for lots of things in his life. His work, kids and home make him very happy, but Ismail does find some things tough. He says “It’s only me working so life can be challenging. I have a mortgage and all the bills to pay and budgeting can be hard. I want to make sure I’m not in debt so that I can help other people in the future.”

Ismail’s job as a campaigner means that he is able to go to lots of important meetings including some with the UK government. Ismail is able to speak up for other people with learning disabilities in these meetings and try to make important differences.
Joanne McDonald – Self advocate (North Ireland)

My name is Joanne McDonald and I live in rural North Ireland. I was born with a learning disability, but it has not stopped me from having a very good life. I still live at home with my family and my parents have always supported me to speak for myself and I have become more independent through the support I have been given.

When I was very young I went to a mainstream playgroup with support from my mum. Following this I moved on to a school for children with special needs and I really enjoyed my time there where I made many friends and gained a good education, growing as a person as well. I then went on to study business administration through a government training scheme and from this I accessed the Prince’s Trust, where I first became involved in Mencap through an administration placement.

Within this placement I also became involved in a self-advocacy group which inspired my passion about Mencap and helping people with a learning disability.

In my job I work part time, delivering Learning Disability Awareness Training to a wide range of employers. I am still an active member of my local self-advocacy group, where I continue to work towards equality for people with a learning disability.

Outside of work I lead a very independent lifestyle, often using public transport to get where I want to go. I enjoy doing the same things as most people my age such as going out, shopping and going to the cinema or theatre.

Through my involvement in Mencap I feel very lucky to have the opportunities that I have and I hope that other people with a learning disability can have the same choices as me in future.
Gary Bourlet – Self advocate (England)

In 1984, he created the self advocacy group People First London. People First London is a group run by and led by people with a learning disability. It fights for the rights of people who have a learning disability, they make easy read information, they have meetings and they give training to professionals about disability. People First London also supports self advocacy groups across the UK.

Gary Bourlet is now campaigning to start a new People First of England self advocacy group. He has started to ask people how they can help to create it.

It could be made by lots of self advocates coming together from across England to campaign for the rights of people with a learning disability. We can all come together at a national level to campaign together.

There is a People First group in Wales and Scotland, but there is not a People First of England Group.

There are problems with money and funding cuts. Money for services that support people with a learning disability have been made smaller. When this happens, it has an effect on people with a learning disability. This means they cannot take part in everyday activities like everyone else.

It would be a good thing to have a People First of England group for self advocates because it means that we could make better changes for people with a learning disability. We could work together and support self advocacy groups across England better. We could also have a stronger voice to campaign for people with a learning disability.

If you want to talk to Gary about his plans, here is his twitter address: @garybourlet
Stories from Self Advocates and family members

Senada Halilcevic – Self advocate (Bosnia and Herzegovina)

As a child, I went to rehabilitation and finished special school there. I graduated from secondary school at the Centre for Education Dubrava, to be a knitter. After graduation I went home to Hvar. I could not find a job in my profession or find any kind of job. I did not have support to live in the community.

While I was living with my parents, I had no support and neither did my parents. I lived with my parents for three years. Family problems arose and I ended up in an institution again. After a few years I could not see my life in an institution anymore. I wanted to live like all other people. I succeeded in fighting to leave the institution. Life in the institution was not good. I could not go out to town when I wanted to. I could not socialize with other people. I could not work and earn my salary.

My life now is very dynamic and very exciting. I live alone in a rented flat in Zagreb. I work and I socialize with my friends. I can manage my salary the way I want to and spend my money the way I want to. I travel. I decide what my flat will look like.

I can say that I am living my dream right now. I am very happy.

Ha Thi Thu Nguyen – Mother (Vietnam)

This is a story of the First Group of Young Adults with Intellectual Disability in Ho Chi Minh city, Vietnam

Being a Vietnamese mother who has a daughter born with Down syndrome, I have joined the network of the Disability Resource and Development (DRD) project in Ho Chi Minh city, and participated in the group of parents who have children with intellectual disabilities in Ho Chi Minh city.

A great opportunity came to me when I was invited to participate the workshop organized in Bangkok, Thailand by the Asia-Pacific Development Center on Disability (APCD) in December 2008. This workshop was organized for special school teachers, heads of organisations and parent group leaders who are working for people with intellectual disabilities in Asia-Pacific region.

Participating in the workshop, I met the specialists and parents who have children with intellectual disabilities from different countries. I listened to different ideas and learnt about different practices in supporting people with intellectual disabilities to live and be included in the community. With a happy smile, a young female teacher from Bangladesh showed us crafts made by her students. A father from...
Myanmar and a mother from Laos proudly talked about the Gold Medals achieved by their children in a Special Olympics Competition. Other mothers who have children with autism told us about the progress of their children through the activities organized by themselves.

The thing which impressed me most was that many parents who have children with intellectual disabilities organized a small group for their child and other children. Although their group finances were limited, they worked effectively.

After completion of the one-week workshop, I returned home in Ho Chi Minh city, Vietnam. I spent a lot of time thinking about what to do for my daughter. In the city where I live, people with intellectual disabilities must leave their special schools at the age of 16-18. After leaving, they do not have many opportunities to join social activities. As a result, their emotional life became poorer. Gradually, the skills learnt from the special schools will be lost.

After leaving school, my daughter spent most of her time watching with a blank face as what she could understand was very limited. Without a supportive environment, no friends, my daughter became more and more silent. Sometimes, she mumbled to herself.

I was worried about her status and decided to do something for my daughter. By different ways, I found and contacted to more than 10 families who have children with intellectual disabilities at same age as my daughter. I met them, talked and persuaded them to send their child to join our group. Finally, 4 families agreed to send their child to my house to join the group activities together with my daughter. I named our group My Future. This name is about not only our anxiety of our childrens’ future, but also a big question for parents’ future.

After My Future was established in January 2009, I was very happy and spent all my time working for the group. I have designed learning activities, set timetable for every group member, and have done some on-the-job training for teachers. I received effective support from Professors of Social Work department from universities. They sent to us student volunteers who came to talk and work with our group members. Every day, my house was overflown with joyful smiles. All parents have been closed to each others like family members. Actually, I felt younger in my heart!

At present, after 4 years of establishment, My Future has 11 members. They are close friends. All parents also are close and share similar interests of life. Beside learning and playing, My Future members are also working and have a monthly salary. Although their salary is still very little, the earning helps them to understand an important thing that only working can bring money, and if they have money, they can buy what they want. With their monthly salary, many members have been able to buy gifts for their family members. I was so happy when hearing from my daughter that she wants to buy a tie for her younger brother.

Now, thinking about this journey I have been on, I felt very lucky when I was invited to participate in the workshop organised by APCD 5 years ago. The workshop made me think and find a solution to help my daughter and her friends, to help myself and other parents. I am very happy and feel useful.

If you would like to contact me, my email address is: nguyenthuha62@yahoo.com

At the moment, our My Future group is the first and only group for adults with intellectual disabilities in Ho Chi Minh city.

We are working hard to develop and share our practices with other parents, aiming to help other people with intellectual disabilities to have a supportive environment to learn, play, work, and develop after leaving their special schools.
Leona Gitmans Te Aranga Self Advocacy Award

Rosemary Scully wins the People First New Zealand Leona Gitmans Te Aranga Self Advocacy Award

Every year, People First New Zealand gives out the Leona Gitmans Te Aranga Self-Advocacy award. Having this award is very important to People First. It gives us a way to thank people for the self-advocacy work that has been done in New Zealand.

The award is given to someone who has been a leader in self-advocacy and has spoken up strongly for the rights of people with learning disability in New Zealand. Award winners receive a Pouamu (a greenstone necklace), money and a certificate.

People First’s National Committee decide each year who will get this award and in 2012 the award went to Rosemary Scully from Dunedin.

Rosemary has been very involved in research about people with learning disability and has been part of many research advisory groups over the past 20 years. She is currently on research advisory groups for both Donald Beasley Institute and the University of Otago.

She has also been a keynote speaker at some national conferences.

Rosemary feels very strongly and speaks up about women’s health issues. She was a co-researcher on a research project called “Identifying and Addressing General Life Concerns of Women with Intellectual Disabilities”.

Rosemary is truly a leader in self advocacy and People First New Zealand were honoured to give her the 2012 Leona Gitmans Te Aranga award.

Rosemary getting her award from the Hon. Tirana Turia, Minister for Disability issues and People First National Chairperson Michael Aldridge.

Past award winners have been:

Graeme Parish, Christchurch

Sylvia Tia, Whakatane

David Corner, Mana, Wellington
In October 2012, Inclusion International (II) released a Global Report on Article 19, Living and Being Included in the Community, Inclusive Communities = Stronger Communities. The report came out of a two-year global campaign. During the campaign, II heard from people with intellectual disabilities and their families about what living and being included in the community means to them. II received contributions from thousands of people in over 95 countries; country profiles from 41 countries; individual stories from 36 countries and input from focus groups in 23 countries and 5 regional forums.

People with intellectual disabilities and families told us that living and being included in the community is about: Choice; Support and Community Inclusion.

The report highlights that transforming communities to be inclusive and ensuring that people with disabilities are included in mainstream programmes are essential for securing the rights of people with intellectual disabilities.

To build inclusive communities we need to change how we support people with intellectual disabilities. This includes:

- Moving from segregated models (i.e. employment, housing, education) to community based models that enable individuals to access systems and supports in the community.
- Building and supporting self-advocacy groups.
- Developing family resource and training programmes and assist families to build and sustain natural supports in the community.
- Securing budget allocation for disability supports and inclusion in mainstream budgets.

The report demonstrates that inclusive communities are better communities for all. The report and a short video about the report can be found on our website, www.inclusion-international.org.
IDA Governing Body meeting in Geneva

By Quincy Mwiya (Zambia)

The International Disability Alliance (IDA) Governing Body Meeting was held in Geneva in January 27-29, 2013. Members from Inclusion International went, including the President, Klaus Lachwitz, Quincy Mwiya, Self-advocate; Anna MacQuarrie; and James Mung’omba. Quincy was the official representative of Inclusion International on the Governing Board of IDA and the entire team gave him the support he needed so he could fully participate in the meeting. During the meeting, many documents were tabled for discussion including:

• Update on youth issues
• Update on Training of Trainers and Leaders (ToTAL)

The challenges were:

• He was the only one with an Intellectual Disability
  Some discussions were very technical and difficult to understand
  Sessions too long and difficult to concentrate
• Some presenters were too fast for Quincy to grasp ideas

One interesting item on the agenda for Quincy was about youth issues. In September 2012, the IDA decided it would provide support to youth sections of IDA members to arrange a youth organizations’ led initiative. This included:

• Making sure that youth representatives were included in meetings
• Arranging time for youth representatives to prepare for these meetings
• Drafting an international ‘Youth with Disabilities Action and Advocacy Plan’ to be submitted to donors and to IDA.

Quincy intends to lobby for full participation of people with intellectual disability to be included in this youth led work.

Another agenda item discussed was an IDA Project called ToTAL. David Corner from Inclusion International was part of the ToTAL team in Fiji and you can read more in David’s report in this newsletter.

Overall, the meeting in Geneva was a success and empowering for Self Advocacy and for people with intellectual disabilities.

On behalf of Inclusion International, Quincy made an earnest appeal to the Governing Body of IDA that in future, documents should be written in plain language that is easy to read and understand.

At the start of the meeting, Quincy had difficulties in understanding all what was being discussed. However, he understood many other issues that were discussed and was very happy to be part of that process.
Inclusion International Launches New Campaign: The Right to Decide

In April 2013, Inclusion International started a new campaign on decision making, The Right to Decide. The goal of the campaign is to advance the rights articulated in CRPD Article 12 and to support families and others to understand the implications of legal capacity for people with intellectual disabilities and how to support people with intellectual disabilities to make their own decisions.

People with intellectual disabilities have said that being able to make their own decisions, with support as needed, is a top priority. Yet, around the world, adults with intellectual disabilities are not allowed to do this. Too often, people with intellectual disabilities don’t get to decide how they spend their time; are not allowed to control their finances, vote or get married; they are voiceless in their own lives.

II wants to hear your thoughts on what having the right to decide means and how people with intellectual disabilities can be supported to make their own decisions.

You can get involved by:

Sharing your stories and examples.
Tell us:

- how supported decision making is being used – what is working; what are the challenges
- about the importance of having control in your life
- about decisions you have made

Joining our on-line consultation and webinars (to be announced)

Organizing a national or regional discussion group with families and/or self-advocates

Please visit our campaign website, www.therighttodecide.org, to learn more about the campaign, to download the campaign toolkit, and to get engaged.
ToTAL Training Workshop in Fiji

By David Corner (New Zealand)

In February 2013, Anna MacQuarrie, Julia Hawkins and I were asked as representatives of Inclusion International, to go to Fiji to help Alexandre Cote from the International Disability Alliance (IDA) co-facilitate some training for people in the Pacific region.

The training was called Training of Trainers and Leaders (ToTAL) and it focused on the UN Convention on the Rights of Persons with Disability (CRPD). Leaders from disability organisations from all over the Pacific region came to Fiji to take part in the training.

The ToTAL Project was in its pilot stage and the first round of workshops on module 1 had already been completed during the winter of 2012. In Module 1, the workshops hadn’t had any participation by people with intellectual disability. Alexandre, who is the IDA’s Secretariat has had a lead role in developing and delivering the total workshops around the world. He asked if Inclusion International would help coordinate some training about intellectual disability for the upcoming Module 2.

Module 2 in Fiji was designed to provide more in depth and detailed knowledge about some of the aspects of the CRPD and to ensure that participants have a more clear understanding of the priorities and the and the interpretations of the CRPD.

We were asked to deliver a half-day workshop specific to intellectual disability and the priorities identified by people with intellectual disabilities and their families and organisations.

We talked about:
- what is intellectual disability
- what is self advocacy
- the circle of friend’s concept
- what is good support.

We also showed video clips of people with intellectual disability from around the world.

It was really great to see a parent and her son with an intellectual disability at the training as well.

This was a wonderful opportunity to work with the International Disability Alliance and to ensure that the perspectives and voices of the people with intellectual disability were included in this work. It was really good to be invited to do the training as it is part of the Asia Pacific region of Inclusion International which I represent.

I hope that I get another opportunity to do more work in the Pacific region soon.
Farewell Council Member Haydee Beckles

By Mia Farah (Lebanon)

I first met Haydee in New York. I was representing MENA during the negotiation of the CRPD. Haydee was there representing the Americas. I was immediately attracted by her confidence and kindness. She was speaking in Spanish and knew little English, but she managed to be my guide in New York, and she tried to explain to me how things work at the UN. While I was lost, she was there to help me and with a lot of patience she used to repeat things until I understood them.

Haydee is a very warm and pleasant person. She knows how to listen to people and how to communicate with everyone. I would like to add that when talking with people, Haydee is quite poetic. This strengthens what she says, yet gives it a gentle touch. As Diane Richler once said, Haydee is the poetess of the group of self-advocates.

As a council member of Inclusion International, Haydee used to talk about family, especially about her father. In one of her presentations she said that her father taught her to laugh and not to cry. He explained to her what and how she can do things. Yet the most important thing she learned from her father is: “I have value and I am equal to others.”

Haydee has come up with so many other ideas and has contributed so much in giving positive input about the role of the family in particular and the Convention in general, contributing to the success of the role of Self Advocates in many conferences.

Haydee just finished her term with Inclusion International and left us, but even if we used to see each other during the meetings and for a very short time, she was a true friend and a great person to talk with.

We will all miss you Haydee and we all hope that we will meet again one day anywhere in this world. Good luck and keep on the good faith.