UN Human Rights Council Intersessional seminar on the protection of the family: role of the family in supporting the protection and promotion of human rights of persons with disabilities

Thursday, 23 February 2017
Geneva, Palais des Nations
Room - XVII

Introduction
Inclusion International was an active participant at this one-day seminar on the role of families. The session was opened by the President of the Human Rights Council, H.E. Mr. Joaquín Alexander Maza Martelli. Speakers for the event were:

- Ms. Catherinne Ivonne Pedreros, Secretariat of the Committee on Rights of Persons with Disabilities
- Mr. Mark Mapemba, Self-advocate, Inclusion International
- Ms. Maha Kamaleldin Elsayed Helali, Board member of the National Council for Disability of Egypt and President of Inclusion International MENA Region
- Ms. Catalina Devandas Aguilar, Special Rapporteur on the rights of persons with disabilities (video).
- Ms. Sue Swenson, President elect of Inclusion International
- Her Excellency Ms. Sheikha Hessa Khalifa bin Ahmed al-Thani, former Special Rapporteur on Disability of the UN Commission for Social Development
- Mr. Sovann Phon, Self-advocate of Komar Pikar Foundation (KPF)
- Ms. Fauzia Haji, Secretary General of Inclusion International
- Mr. Edwin Romel Béjar Rojas, Family Judge of the Superior Court of Cusco, Peru

The seminar was sponsored by Qatar, Egypt and Russia. There were over 100 people in attendance. Participants included representatives of member states and from civil society.

Background
Inclusion International worked closely with OHCHR to develop this event. We helped to identify speakers that met their criteria and contributed a draft discussion paper on families. The discussion paper, along with an infographic, were circulated at the event. This event is one part of a discussion the Human Rights Council is having on “protecting families”. There are some tensions and sensitivities regarding this. There are member states seeking to use a family agenda to limit the scope of families to include only a mother/father and biological children. There are additional tensions that there are member states seeking to secure rights for the family unit as a whole – which could threaten the rights of individuals within the family unit.

Inclusion International’s Participation
Our participation helped members to understand the role of families and the supports they need to promote the rights of persons with disabilities. Building on the issues identified in our discussion paper, representatives called on member states to provide families with:

- Information – positive disability information, help navigating systems, planning for the future
- Help with disability associated costs – via cash transfers, tax relief and/or benefit programs
- Supports for parents – including breaks from caregiving responsibilities and employment protections
- Capacity building of parents and their organizations – critical for getting information and providing opportunities to connect with other families
Highlights from the discussion included: Sue Swenson, II’s President-elect speaking of her personal role in fight for her son to be seen as a person by others. She highlighted that families need information so they can support their sons and daughters in progressive ways. II’s Secretary General, Fauzia Haji, highlighted that the challenges families experience are not due to disability but a result of the barriers and lack of support in our communities. She called on member states to invest in inclusive communities. Mark Mapemba, II’s regional self-advocate representative for Africa, encouraged member states to invest in family-based organizations and building self-advocacy. Self-advocate from Cambodia, Sovann Phon reflected that his family sometimes finds it hard to understand him and they need help to support him.

Outcomes
Inclusion International was successful in influencing the global understanding of the role of families supporting a person with disability. Presentations by our representatives were well received by member states. Many member states expressed an interest in having more information on best practices and offered to share examples of country-level policies and programmes. Russia supported our recommendation to have the CRPD Committee develop a General Comment on the Role of Families.

Next Steps
- OHCHR to develop an outcomes paper.
  - track the development of this paper and circulate it when it is completed.
- Engage in a discussion with IDA regarding a General Comment.
  - initiate an informal discussion with IDA to gage the support of IDA members and the CRPD Committee for a General Comment and understand concerns they may have.
- Identify and engage potential allies on the CRPD Committee.
  - initiate an informal discussion with supportive committee members to gage support for a General Comment and understand concerns they may have.
- Conduct a risk assessment.
  - Determine the actual risks of pursuing a General Comment on the Role of Families and develop risk mitigation strategies.