21 Conference of the Asian Federation on Intellectual Disability (7 – 11 October 2013, New Delhi, India):

Towards Dignity and Quality of Life – Evolving individual capacity with Family and Community Participation

The Challenges of the UN Convention on the Rights of Persons with Disability (CRPD) with regard to persons with intellectual disabilities and their families – Some reflections and information based on international experience and development.

Speech by Klaus Lachwitz, President, Inclusion International, London

Dear Mrs. Balasundaram,
President of the Asian Federation on Intellectual Disability

Distinguished Guests,

Dear Participants and Friends,

It is a great honour for me and I feel very pleased to get the chance to take the floor here on the occasion of the plenary session of this impressive Conference. I am speaking to you in my capacity as president of Inclusion International, a global organisation for persons with intellectual disabilities and their families, which comprises today more than 200 member organisations in 115 countries.

I am a lawyer by profession and I have worked in Germany for more than 30 years as legal advisor and human rights activist for parents and persons with intellectual disabilities.
I was elected President three years ago during Inclusion International’s 15th World Congress held in Berlin with 3000 participants from 80 countries including 800 self – advocates.

What is Inclusion International today? What are our main goals? How do we build up partnerships, coalitions and networks? How do we cooperate with you, the Asian Federation for the Intellectually Disabled (AFID) and other influential regional and global associations?

I will try to give some answers and to describe our main activities.

Basically Inclusion International is a family based umbrella organisation. Parents with intellectually disabled daughters and sons came together 53 years ago to exchange views and to help each other as in many parts of the world the support received by governments, public welfare offices or civil society was poor or did not exist.

“Let`s take things in our own hands!” was the message, sometimes the outcry! “Let`s try to find friends, peers, experts and politicians who are willing to accept us as an important part of society and who help us to develop strategies which enable us to move into society as equal partners together with our intellectually disabled children.”

In early history there was little support or understanding about inclusion. At that time we didn`t know what could be reached through inclusive health care, inclusive school education, training, supported work, reasonable and challenging leisure activities etc. As a result many families thought that first of all their sons and daughters with intellectual disabilities should be protected and that
special treatments and measures were necessary to educate and to include them.

Children with intellectual disabilities should go to school, but they should receive special education in a protected environment designed for them. Therefore special schools were built up. Adults with intellectual disabilities should have the chance to work or to deal with something reasonable during the day which keeps them busy and even productive. Therefore sheltered workshops were developed.

We still find these facilities and approaches in many parts of the world.

But a new generation of parents and persons with intellectual disabilities grew up which joined the international movement of physically disabled, blind and deaf persons who fought for changes, who did not want to be hidden, disadvantaged, neglected and segregated any longer. They have learned that participation and inclusion are the way forward!

In recent years we have experienced a huge paradigm shift caused, among other things, by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which up to now has been ratified by 134 countries, mostly without any reservations!!

Why do we have this Convention? Why was it needed?

The United Nations due to many international activities initiated by Disabled Persons Organisations (DPOs), NGOs, experts and scientists realized that the world is divided:
In particular *Human Rights Watch*, a highly respected international association, has proven that we still have to face unbearable situations in many countries: families with intellectually disabled relatives belonging to the poorest of the poor and living without any support, children who don’t receive any kind of education. Adults who are placed in huge and often closed institutions without any privacy and sometimes even without regular food, fluids and medical care.

But fortunately there are many positive changes and developments brought to the attention of the United Nations: Persons with disabilities have reached a lot with the support of families, friends and experts. They are part of civil society, they show and prove day by day that they can contribute to the needs of society, that they enrich all of us with their talents, engagement, optimism and their will to fight for inclusion and diversity.

The UN Disability Convention is one of the results of these activities and it is an outstanding result as it was passed by the UN General Assembly in December 2006 unanimously! There is a broad agreement worldwide that the Convention shows the way how societies should develop to accept and include persons with disabilities as *full citizens* of their countries with equal rights.

How comes that the Convention could reach such a high quality, such a progressive standard? The answer is: it was influenced, drafted and in many parts written by persons with different of disabilities! Their lived experience was the expertise used to write the Convention.

“Nothing about us without us!”
“We are the experts!

These are the slogans which best describe the atmosphere when a working group was established by the United Nations in 2004 in New York consisting of diplomats, experts and disabled persons to negotiate and draft the text of the Convention watched by some hundred observers with all kinds of disabilities from all over the world.

Inclusion International took part in the negotiating process in New York. We brought self – advocates and families to New York to participate in the process and to bring their perspectives to the negotiations.

At the first UN Working Group meeting we were officially represented by Robert Martin, a self – advocate with intellectual disability from New Zealand who had lived in a closed institution for 15 years. He was one of the first self – advocates who spoke up in a plenary session of the United Nations! He described the living conditions of his friends and comrades in plain language. He was able to deliver examples of good practices like inclusive education for all and supported employment and he got angry and even cried when he spoke about bad examples proving how often persons with intellectual disabilities are still discriminated against by excluding them from society, school education and work in the open labour market; by placing them under full guardianship, by legally incapacitating them, by denying their right to vote, their access to justice and by placing them in big institutions often far away from the next community.

I assisted him by trying to explain the legal terms involved, if an UN – Convention dealing with human rights is drafted, but he was the
one who together with some persons with psychosocial disabilities, for instance, convinced the diplomats and States delegates in the working group that ALL persons with disabilities including those with severe and multiple disabilities are fully covered by the Convention on the Rights of Persons with Disabilities.

In all of our efforts Inclusion International wants to give persons with intellectual disabilities, their families, their mothers and fathers a VOICE in society. We are shouting for the human rights of persons with disabilities, we are fighting for equality, inclusion and better services which do not exclude and segregate any longer. We are lobbying and we are trying to find out and to respect the interests, requests and needs of persons with intellectual disabilities and their families.

What are our main challenges and aims today?

Inclusion International has developed a strategy to help our members to implement the Convention. Our capacities are limited. We, therefore, focus on four core issues: It’s Family Support (Art. 23 CRPD), it’s Inclusive Education (Art. 24 CRPD), it’s Living independently and being included in the community (Art. 19 CRPD) and it’s the Right to decide and to exercise legal capacity (Art. 12 CRPD).

We try to show practical ways how to interpret and implement the contents of these human rights articles at regional and national level. We describe facts, we collect good and bad examples, we ask our members to send us stories describing the living conditions of persons with intellectual disabilities and their families, the positive and negative reactions of administrative bodies, politicians, municipalities, professionals etc.
We have already published three comprehensive Global Reports: One on Poverty (Art. 28 CRPD), one on Inclusive Education (Art. 24 CRPD), one on Independent Living and being included in the Community (Art. 19 CRPD) and we are working pretty hard now on a campaign and a global report on the Right to Decide (Art. 12 CRPD).

All these documents are very comprehensive. It’s an amazing collection of data and direct experience about the living conditions of persons with intellectual disabilities and their families. Through regional forums, focus groups, consultations and meetings we have connected with thousands of people all over the world and we have received detailed country profiles and stories.

You can find all that on Inclusion International`s website:

www.inclusion-international.org

I must confess that there are some voices which claim that the Convention on the Rights of Persons with Disabilities is a product of western countries bearing the handwriting of the industrialized nations. But this is not true as the hundreds of “experts with disabilities” and official States delegates who took part in the UN – CRPD - negotiation process between 2004 and 2006 represented all kinds of countries and it is not only the wealthy and emerging nations, who have ratified the CRPD, but many developing countries too. In Asia, for instance, with the exception of Japan, Vietnam and a few smaller countries nearly all big countries have ratified the Convention on the Rights of Persons with Disabilities without any reservation. This is a remarkable result as nearly 50 percent of all persons with disabilities live in Asia and nearly 40 percent in China and India.
Let me finish up by reaching out to you: The Asian Federation on intellectual Disability (AFID). We extend ourselves as a partner to AFID and its members and invite you to work with us to ensure that the voices of self – advocates and families are guiding us and that their experience is the expertise we use to move forward. We need your support, we need your knowledge, and we need your friendship!

Again it is the UN Convention on the Rights of Persons with Disabilities which can serve as an excellent example for that: One of the best messages sent out by the Convention was texted by the Chair of the UN Working Group and Ad – hoc Committee which drafted and finalized the Convention. It was Don McKay, the UN Ambassador for New Zealand, who stated in the UN General Assembly in December 2006:

“Disability is no deficit any longer! Disability is no matter of charity, it is a matter of human rights!”

What a change! And what a challenge for researchers and scientists! We do have, for instance, an entirely new text in the preamble of the Convention describing the term “disability”: Persons are impaired, but they are disabled because they are confronted with barriers. Barriers caused by attitudes, by inaccessible environments and technical designs. Scientists and researchers can help to dismantle these barriers by developing, for instance, new communication tools and systems accessible and usable by persons with intellectual disabilities; by convincing architects, engineers and planning authorities to build and produce on the basis of standards which are “universal
designs”, i.e. devices open and adaptable for all citizens irrespective of their disabilities;
by drafting new concepts for inclusive education and by developing a social infrastructure respecting the needs of disabled persons, children and the elderly who very often face the same or similar barriers.

As I am a lawyer by profession I can`t leave this speaker`s podium without referring to a difficult and complex subject in the Convention: According to Art. 12 CRPD which is headlined: “Equal Recognition before the Law” persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and all States Parties of the Convention are obliged to provide access to the support persons with disabilities may require in exercising their legal capacity. *Substitute Decision Making* which still forms the basis of many guardianship laws is not in line with Art. 12 of the Convention, but there is hardly any country in the world which has succeeded in developing models of legal support so far which do not incapacitate persons with disability any longer, but just help them to make their own decisions and to execute their legal capacity.

We need models of legal support respectively legal assistance which replace the traditional guardianship concepts. We need the help of practitioners, professionals, scientists and progressive guardians to develop such models. It is an inter-professional and interdisciplinary task which urgently needs to be tackled!

Inclusion International, therefore, came to the conclusion on the occasion of its General Assembly which took place last year in Washington, USA, to start a *Global Campaign on “The Right to Decide”*. It`s not a scientific study we are aiming at. It`s an attempt
to find out how and by whom decisions are taken, if persons with intellectual disabilities are involved and it starts with personal life decisions.

Self advocates who belong to Inclusion International’s council have described that in a Flyer which you will find on your seats as follows:

I quote: “People with intellectual disabilities have told us that they want to control their own lives. They want to be able to make decisions and to be listened to. People with intellectual disabilities have the right to make decisions about:

- Getting married,
- Where we live,
--Who we live with,
--Voting,
--Our money,
--Contracts – like a rent agreement,
--Health

We know that all of that depends from culture, religion, social conditions, political attitudes and circumstances etc. But members from all over the world respond that many persons with intellectual disabilities are not supported to develop decision making abilities as they grow. And many families lack the skills and tools to understand how to support their sons and daughters to express themselves. Therefore, guardianship applications and court orders which incapacitate a person with intellectual disabilities very often seem to be the only way to “protect” them.
It`s a huge conflict which arises from these facts and responses as - I repeat - *guardianships* and other forms of *substitute decision-making* are not in line with Art.12 CRPD.

Our campaign, therefore, tries to

- advance the rights articulated in Art. 12 CRPD,
- raise awareness about the impact of the denial of the right to make decisions,
- identify *models of support for families and individuals* that enable people to control their own lives,
- explore *models of supported decision making*.

As the big majority of persons with disabilities live at home with their family and as many of these families don`t receive the support they need and are very often isolated, our campaign can succeed only, if families with intellectually disabled relatives are strengthened in the communities and the rural areas they live.

Family support and the counselling of families are some of the most important key elements to implement the human *Right to decide* as described in the Convention on the Rights of Persons with Disabilities (CRPD)!!

We, therefore, welcome it very much that this Congress is held under the headline: *“Towards Evolving individual capacity with Family and Community Participation”*. It’s a very promising title setting the course for the implementation of the human rights for persons with disabilities as described in the CRPD.

You see: we expect a lot and we press for changes, but we are confident that step by step the UN Convention on the Rights of
Persons with Disabilities will be implemented in many parts of the world. This AFID - Congress proves that the “Potentials” are there and that we together with you are on the right path!

Thank you and on behalf of the Council of Inclusion International I wish all of you fruitful lectures, statements and discussions!

New Delhi, Oct. 8, 2013