



# INCLUSION AROUND THE WORLD

Inclusion International (II) is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. II represents over 200 member federations in 115 countries throughout five regions Middle East, Europe, Africa, the Americas, and Asia Pacific.

## CONTENT

- Messages from the President
- 15<sup>TH</sup> World Congress of II
- General Assembly of II
- Inclusion International Launches Convention Action Teams
- Campaign on Article 19- *Living in the Community*
- The IDA and Inclusion International
- Senada Halilcevic Calls on the UN to Make the Right to Live in the Community a Reality
- II sends submission to the Committee of Experts for the General Day of Discussion on Accessibility
- II Regional Forum
- Events



**W**elcome to the September issue of Inclusion International's newsletter. As you will see from the various articles in this edition, the work of Inclusion International (II) since the Berlin Congress has been expanding and building on the strategic plan which was approved by the II General Assembly last June. The Strategic Plan [http://www.inclusion-international.org/wp-content/uploads/II-Strategic-Plan-2010-2015\\_June-20101.pdf](http://www.inclusion-international.org/wp-content/uploads/II-Strategic-Plan-2010-2015_June-20101.pdf) lays out II's priorities for implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) in the areas of Inclusive Education, Legal Capacity, Living in the Community and the role of Families. II's implementation strategy over the next two years leading up to the General Assembly and International Conference on Living in the Community (Washington, DC, November, 2012) includes five major activities:

- ❖ II will host with its regional associations in each of the 5 regions a regional forum for families and self-advocates to learn from each other about initiatives in different countries that promote and implement aspects of the Convention; The first Regional Forum will take place in Bogotá, Colombia on November, 2010
- ❖ II will draw on the knowledge and expertise of its volunteers and member organizations to support country level initiatives to implement the CRPD (see article on II's launch of the CATs);
- ❖ II will in partnership with the International Disability Alliance (see President's Report and Report from the IDA Chair) monitor and contribute to the work of the Committee of Experts of the CRPD
- ❖ II will work with UN agencies and development agencies to identify opportunities to include and promote the rights of people with intellectual disabilities in their work.
- ❖ II will launch a Global Campaign to promote Article 19 *The Right to Live in the Community*. (Watch the Inclusion International Website [www.inclusion-international.org](http://www.inclusion-international.org) and newsletters for more details).

The newsletter is one of the ways that we communicate with our member organizations and other partners. If you have questions about any of these initiatives or if you would like to become involved in any of these activities of II listed please contact us at: [info@inclusion-international.org](mailto:info@inclusion-international.org)

## Message from the President



This is my first report to inform our members about Inclusion International's activities since I was elected President on June 20th 2010. This took place on the occasion of II's General Assembly, held the day after the closing ceremony of our World Congress in Berlin.

Firstly, we all needed a rest. The Congress was a huge success for our movement, in part due to the enormous number of participants from over 70 countries and nearly 800 self advocates very actively involved in the plenary sessions, forums and workshops. They showed how successfully they can communicate with each other if language barriers are removed or at least balanced with emotions, signs of joy (or reluctance), applause, singing etc.

The Congress was a big and ambitious undertaking for Lebenshilfe Germany, Inclusion Europe and Inclusion International. But it paid off. We hosted over 100 excellent speeches and statements from experts in the field, who taught us that the inclusion in society of persons with intellectual disabilities and their families under the auspices of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is one of the biggest ever challenges.

At the time of writing, over 90 States Parties have ratified the UN Convention. This means that they acknowledge that people with disabilities are full citizens of their countries with equal human rights, irrespective of the nature and profoundness of their disabilities. The message is very clear, but lived realities are often far removed from the contents of treaties. The Convention states, for instance, that inclusive education should be the norm everywhere, but we know that in many industrialized countries pupils with disabilities are still sent to special schools and that in developing countries many of these children do not receive any education at all.

The main question for all of us, therefore, is: how can we work together to raise awareness about the Convention across the globe? How can we help implement the Convention in our own countries? And how can we enhance solidarity between the various Disabled People Organisations (DPOs) that, in many parts of the world, have achieved some success in lobbying members of parliament, administrators, lawyers and other stakeholders whose decisions influence the lives of persons with disabilities.

Many persons with disabilities took part in the negotiation of the CRPD between 2004 and 2006. Thanks to their commitment, experience, knowledge and strong ties to human rights experts, the Convention was able *to reach the progressive standard*, which we are all very proud of. I would like to once again mention Robert Martin, a self advocate from New Zealand who on several occasions explained to the many delegates and diplomats representing the UN States Parties what it means to be forced to live in institutions and lose your civic rights, by being placed under full guardianship or

officially branded incapacitated. It was largely due to his impressive and moving biographical accounts that a large majority of the UN States Parties agreed to sign the CRPD in December 2006.

Initially the gathering of disabled persons in New York was merely coincidental. There was no overarching organisational structure, but many disabled activists began organizing side events and parallel meetings to deal with subjects under dispute, and to discuss the contents and wording of single CRPD Articles. All these activities became progressively structured between 2004 and 2006, and were united under the name 'International Disability Caucus'.

This Caucus marked the advent of a bigger international umbrella organisation. It was II's former President Don Wills who took the initiative and asked all world federations representing persons with disabilities that held official relations to the United Nations and its agencies (such as the World Blind Union, World Deaf Federation, Inclusion International, Disabled People International (DPI) etc.) to found an office at the UN charged with monitoring the implementation of the CRPD.

Today this umbrella organisation holds the name 'International Disability Alliance' (IDA). It is based in New York, as the United Nations headquarters there is where the CRPD States Parties tend to hold conferences to consider matters related to the implementation of the Convention. There is, however, a second IDA office in Geneva, Switzerland, as this is the official seat of the UN High Commissioner for Human Rights.

IDA is not a legal entity. It is run by the leading international DPOs, and decisions can only be taken unanimously. It is chaired alternately and for one-year periods by its member organisations. Presently, and until June 2011, former Inclusion International president *Diane Richler* is at its helm.

<http://www.internationaldisabilityalliance.org/>

Within a few years it is hoped that IDA will have fostered good relations to all UN offices, branches and agencies that deal with disability-related matters. This is a mammoth task, given that the UN is a complex bureaucracy with multiple activities, and publishes documents nearly every day. The task is made harder still by the difficulties involved in prioritising what is more or less pressing or important for persons with disabilities.

Thanks to IDA Director *Stefan Tromel* and his staff consisting of four highly qualified experts, IDA is currently a widely accepted partner of nearly all UN bodies. What is more, IDA works in close cooperation with the members of the International Committee on the Rights of Persons with Disabilities (Art. 34 CRPD), whose tasks include assessing the State Party Reports to be submitted two years after CRPD ratification, and to write *General Comments* about the conflicts arising from different interpretations of single CRPD Articles, and discrepancies between States Parties' approaches to implementing the Convention.

I am describing the background of IDA's development and structure in some detail to illustrate why my first official journey on behalf of Inclusion International led me to New York in August, to take part in various IDA conferences organized in connection with the third Conference of States Parties. This conference was of utmost importance for the future implementation of the CRPD, as the Committee on the Rights of Persons with Disabilities was enlarged from 12 to 18 experts. Due to a rather complicated voting procedure, 12 experts had to be newly elected.

The results of these elections have been published on the official United Nations CRPD website.

<http://www.un.org/disabilities/>

IDA organized an internal meeting with a fairly lengthy agenda dealing with organisational and financial matters. In addition IDA held an open meeting with UN officials and other well-reputed Nongovernmental Organisations (NGOs) such as Human Rights Watch, Amnesty International etc. to discuss how DPOs and NGOs might best cooperate in the future for the benefit of persons with disabilities.

I would lastly like to mention a meeting on Art. 12 CRPD (Equal recognition before the law) held by IDA just before the beginning of the Conference of States Parties. Statements were delivered by Inclusion International's director *Connie Laurin-Bowie* and by Tina Minkowitz, representing the World Federation of Survivors of Psychiatry.

Both organisations are the main protagonists when it comes to implementing Art. 12, which guarantees that not only person with physical disabilities, but also persons with intellectual disabilities or psychosocial problems, "enjoy legal capacity on an equal basis with others." The CRPD does not differentiate between disabled persons with primary human rights who can claim all human rights enlisted in the CRPD themselves, and disabled persons with secondary human rights who need a guardian or a legal representative to speak on their behalf. The working group and the ad hoc committee drafting the CRPD decided that the Convention should not create a rift between different groups of persons with disabilities, but should instead contribute to the treaty's common aim of furthering the inclusion of *all* people with disabilities in society, hereby acknowledging them as full citizens of their countries.

We all know that exercising our legal capacity is not easy. Life can be very complicated, and the majority of us need help deciphering contracts when we rent a flat, invest money etc. People with intellectual disabilities tend to need a huge amount of support. Even when legal matters are explained in *plain language*, not all disabled people can communicate with words or gesticulation. It is therefore one of our main goals to establish *models of support* enabling persons with intellectual disabilities to exercise their legal capacity. This is proving a huge task. There is hardly a country in the

world that can claim that it has already done away with *substitute decision-making* and replaced it with *legal support/legal assistance*.

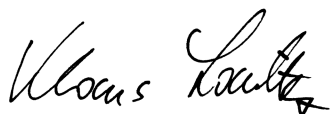
The application of Art. 12 is of major interest to many of Inclusion International's members. I recently received two invitations from Slovakia and Hungary, illustrating that many unanswered questions still remain:

- On September 23rd 2010 our member organisation in Slovakia *ZPMP v SR: Association for Help to the Mentally Handicapped Persons in Slovakia* organized a seminar entitled: *Against the discrimination of persons with mental handicaps!* Some lawyers representing DPOs and an official delegate from the Slovakian Ministry of Justice explained that there have been impressive attempts in Slovakia to abolish the old-fashioned guardianship law and to replace it, step by step, with a new law that strengthens the independence of persons with intellectual disabilities. There are different proposals under discussion, and partial guardianship may be realised in future, but the debate is ongoing. There is thus a great willingness to learn from Inclusion International's activities.
- I was asked to describe the international ratification process and the binding force of the CRPD.

My Presentation is available on [www.inclusion-international.org](http://www.inclusion-international.org)

— On Sept 29<sup>th</sup> 2010 the *Mental Disability Advocacy Center (MDAC)* held a seminar in Budapest called "*Legal provisions on guardianship and voting rights in Hungary*". The reason for this meeting was a May 20<sup>th</sup> 2010 ruling by the European Court on Human Rights: *Alojos Kiss versus Hungary*. The Court decided that it is unjust to prevent a person under partial guardianship from voting in elections, as enshrined in the Hungarian Constitution. The right to vote is one of the basic human rights outlined in the 1966 UN Covenant on Political and Civil Rights, and in the CRPD. The Hungarian government has therefore been called upon to change the constitution. But such an amendment first requires a 2/3 majority vote in parliament, and so far nothing has happened. Mr. Kiss is still unable to take part in elections, just as around 60 000 people under full guardianship in Hungary are not allowed to vote, get married or go to work.

I was asked to deliver a presentation entitled "*Guardianship Laws, the Right to vote and Art. 12 CRPD (Equal recognition before the law). Some reflections from an international perspective.*" My Presentation is available on [www.inclusion-international.org](http://www.inclusion-international.org)



Klaus Lachwitz  
President

## **Inclusion International celebrated its 15th World Congress *Transforming Rights into Action* on 16–19 June 2010 in Berlin**



The Congress welcomed nearly 3000 participants from 80 countries including 850 self-advocates, as well as family members, policy makers, professionals and friends. They came together to learn about the experiences of people with intellectual disabilities and their families, throughout their lives. The Congress opened with a letter of support from the Secretary General of United Nations, Ban Ki-Moon as well as a video message from the Chancellor of Germany, Angela Merkel.

Congress sessions focused on the UN Conventions on the Rights of Person with Disabilities addressing a wide range of important topic such as:

- The right of disabled people to make decisions for themselves.
- The right to be included in the community.
- The right to inclusive education.
- The right of families to get the support they need.
- The right to live without poverty and discrimination.

Some of the sessions and events have been documented through the following online sources:

Session reports: [www.e-include.eu/articles](http://www.e-include.eu/articles)

Sessions presentations: <http://www.inclusion-international.org/about-us/world-congress/>

Photos: [www.flickr.com/inclusion2010](http://www.flickr.com/inclusion2010)

Videos: [www.youtube.com/inclusion2010](http://www.youtube.com/inclusion2010)

### **Inclusion International General Assembly- 20 June, 2010.**

The biennial General Assembly of Inclusion International (II) took place in Berlin, Germany on 20 June, 2010 following Inclusion International's 15th World Congress- *Transforming Rights into Action*.

During the meeting Inclusion International presented its new Strategic Plan 2010-2015. The Strategic Plan has retained Inclusion International's Vision and Mission Statement but it has revised the Strategic Priorities. A new updated version of II's Position Paper on Legal capacity was also

introduced. The revised version complies with Inclusion International's philosophy and it's consistent with the UN Convention. Both documents are available on II's website [www.inclusion-international.org](http://www.inclusion-international.org)

Inclusion International's Executive Director, Connie Laurin-Bowie, presented the "Principles to Guide the Implementation of Article 12 (Legal Capacity)" and said that in addition to supporting a number of country level initiatives related to law reform and the development of supported decision making models, Inclusion International had developed a set of guidelines for implementing Article 12 and it is currently consulting with other groups to ensure that no group of people are made more vulnerable in the application of Article 12.

The agenda also dealt with the election and re-election of Officers and Councillors.

#### *Officers*

- Klaus Latchwitz- Elected as President
- Diane Richler- remains as Past President for two years.
- Ralph Jones- Re-elected as Secretary General
- Tim Gadd- Elected as Treasurer

#### *Councillors*

- Quincy Mwiya, re-elected as Regional Self Advocate – Inclusion Africa
- Roland Tamraz, re- elected as Regional Representative – Inclusion MENA
- Mia Farah, re-elected Regional Self Advocate – Inclusion MENA
- Ivo Vykydal, elected Regional Representative – Inclusion Europe
- Ciara Evans, elected Regional Self Advocate – Inclusion Europe

Diane Richler announced that *Honorary Life Memberships* had been conferred to the following people in a previous ceremony and acknowledged the Life Members for their many years of work with ILSMH and Inclusion International: Donald Beasley, Maria Amelia Vamprés, Paule Renoir, Peter Mittler, Tom Mutters, Ingrid Körner, and Yvonne Posternak.

Following the request for membership from several organisations the following admissions were approved:

#### *Full Membership:*

- Inclusion Ghana
- Caritas Egypt – Seti Center
- Al Zawrak – Lebanon (shared membership)
- Lebanese Association for Self-advocacy-Lebanon (shared membership)

#### *Affiliate Membership:*

- Asociacion azul – Argentina
- Help Center – Saudi Arabia
- Rehabilitation Institute for Autism and Related Communication Disorder- Bahrain
- Inclusion Mauritius (formally APEIM).

As the meeting was coming to an end it was announced that Inclusion International had agreed to formally accept the invitation from The Arc of the United States to hold the next General Assembly in Washington DC in 2012.



## **Inclusion International Launches Convention Action Teams**

As a part of Inclusion International's strategy to promote implementation of the Convention on the Rights of Persons with Disabilities, II has developed a process through which it can support its national member organizations to participate in the implementation of the Convention. Support to the member organizations will be provided by Inclusion International's newly established Convention Action Teams (CATs):

- 1) Convention Action Team on Inclusive Education;
- 2) Convention Action Team on Legal Capacity and Supported Decision Making;
- 3) Convention Action Team on Family Support and Family Policy;
- 4) Convention Action Team on Living in the Community.

### **The mandate of II's CATs is to:**

- ❖ Respond to opportunities and challenges which arise at a country level by supporting national associations to contribute to national initiatives related to implementation
- ❖ Act as a technical support to member organizations working at a country level with governments on implementation;
- ❖ Develop a resource base of tools for family based organizations to use at the country level in promoting the implementation of the Convention (in each of these areas);
- ❖ Collect information and stories about the challenges and success of implementation;
- ❖ Provide analysis of the experiences related to implementation that may be used by family organizations; governments or multilateral institutions.

For more information visit [www.inclusion-international.org](http://www.inclusion-international.org)

## **Inclusion International Campaign on Article 19**

Inclusion International, along with its member organizations in over 115 countries, is launching a campaign to promote Article 19 of the CRPD, Living in the Community. Article 19 ensures that people with disabilities have the right to live in the community with the supports they require, with equal access to community services such as education, health care, transportation, etc. This commitment has significant implications for governments, communities and service providers. It requires that we collectively address the current reality of the lives of people with disabilities who live in situations of isolation, segregation, confinement and dependence, whether in an institution or in "institutionalized" living conditions. ...*Read more about the Campaign on*

<http://www.inclusion-international.org/home/inclusion-international-campaign-on-article-19/>

## The International Disability Alliance and Inclusion International

By Diane Richler- Past-President, Inclusion International and Chair, International Disability Alliance

On September 1-3, 2010 the Conference of States Parties of the Convention on the Rights of Persons with Disabilities (CRPD) met in New York to elect members of the Committee that monitors the Convention. The International Disability Alliance (IDA) was an active participant in the Conference and also held a series of related meetings which I chaired.

In 1999, Inclusion International was one of the founding members of the IDA, a coalition of the major global organizations of persons with disabilities. We joined with Disabled People's International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf, the World Federation of the Deafblind and the World Network of Users and Survivors of Psychiatry because we recognized the benefits of combining our advocacy efforts with the United Nations and its agencies.

During the negotiation of the CRPD, the IDA was invaluable in creating a forum – the International Disability Caucus—so that the various disability groups could present a unified voice to governments. After the CRPD was ratified, membership in the IDA was expanded to include regional coalitions of disability organizations and other global organizations such as Down Syndrome International in order to continue the broad collaboration among disability organizations. The principles of maintaining leadership by persons with disabilities and of operating by consensus are paramount. For people with intellectual disabilities it is especially important that they also have families represented at the table and in the decision making leadership. The IDA principle of consensus helps to ensure that in fighting for their rights, no one disability group will either deliberately or inadvertently infringe on the rights of another group.

The chair rotates among the members on an annual basis. This year is Inclusion International's turn to chair and since Klaus Lachwitz wanted to devote all his available time to his new role as President of Inclusion International, I became the chair of the IDA in July.

This is a time of great change in the IDA. Ratification of the CRPD requires the monitoring of its implementation at the national level and within all the human rights machinery of the United Nations. It also means ensuring that the development aspects of the Convention are fully implemented. To support this, the IDA has opened 2 offices, in New York and Geneva, with a staff of 7 people.

Inclusion International is working closely with IDA to ensure that there is a synergy between our activities. For example, the IDA developed a tool to help disability organizations monitor the Convention and we both contributed to the tool and are using it. We are also collaborating on IDA's projects to increase the capacity of national disability organizations to monitor the Convention, and in developing implementation guidelines. The IDA can support all its members to be more effective globally and also at the national level. We need to ensure that capitalize on the support the IDA can give us, while keeping our own objectives clear, and our own voice strong.

## Senada Halilcevic Calls on the UN and Governments to Make the Right to Live in the Community a Reality



Ms. Senada Halilcevic, a self-advocate and representative of Inclusion Europe and Inclusion International addressed the Third Conference of State Parties to the Convention on the Rights of Persons with Disabilities at the United Nations headquarters in New York on 2<sup>nd</sup> September, 2010. She spoke about her experience of living in a institution in Croatia. Her presentation drew praise from the gathering of over 300 representatives of governments, multi-lateral institutions and civil society.

For persons who have an intellectual disability and their families, one of the most important rights enshrined in the Convention on the Rights of Persons with Disabilities (CRPD) is the right to live independently and be supported in the community (Article 19). All too often, persons who have an intellectual disability have been deprived of their liberty and prevented from making any choices in their lives because of being confined to institutions. Enormous pressure has often been placed on families of people with intellectual disabilities who have faced huge challenges to meet the needs of their disabled family member. In many cases, institutions have been the only option provided.

In order for people with an intellectual disability to be able to exercise all the other rights protected in the CRPD, they and their families require a range of supports and services. In some countries there is a need to close institutions and provide supports for the people who live in the community.

In other countries, where institutions are not prevalent, there is a need to develop a full range of supports and services that respect the CRPD.

Ms. Halilcevic talked about her life in an institution and the process that she went through to move out of the institution.

Ms. Halilcevic left the institution and moved to the community at the age of 30. She conveyed very powerfully how her life changed the day she left the institution. She said, ***“My life started the day I left the institution”***.

## **II sends submission to the Committee of Experts for the General Day of Discussion on Accessibility**

The Day of General Discussion will take place on 7 October during the CRPD Committee session. The discussion, to be held in 3 separate sessions will focus on the following issues:

Session 1: **The right to access on an equal basis with others to the physical environment and transportation;**

Session 2: **The right to access on an equal basis with others to virtual and material information and communications;**

Session 3: **Discussion of the best practices on the implementation and promotion of the Right to Accessibility.**

The paper submitted by Inclusion International illustrates some of the accessibility issues which face people with intellectual disabilities all over the world by providing examples of some of the ways in which Article 9 on Accessibility intersects with other rights articulated in the CRPD. Inclusion International' submission recommends that in order for people with intellectual disabilities to access mainstream services and supports such as Education; Health Care and Justice on an equal basis with others:

- ❖ stakeholders in these systems from teachers, nurses, doctors, policy makers, judges, police and lawyers need to be provided with training;
- ❖ services must be organized from the outset to consider and include all people with disabilities (including people with intellectual disabilities)
- ❖ communications must be delivered in easy to read and understand formats
- ❖ supports to the individual must be made available to ensure that the person is able to access the service or environment

To read Inclusion International's full submission visit [www.inclusion-international.org](http://www.inclusion-international.org)

## **II Regional Forum for Families: "The Road to Inclusion: Together we can make the change!" 10-13 November, 2010**

This is the first of five regional forums to be held by Inclusion International in the next two years to promote the implementation of the Convention on the Rights of People with Disabilities supporting the work of its member organizations and other organizations of persons with intellectual disabilities and their families in implementing the changes required. All information, documents and tools generated in these forums, will contribute to II's global strategy to promote the Convention.

Inclusion International in collaboration with Asdown Colombia, Inclusion Interamericana, and Fundación Saldarriaga Concha are organizing the following events to take place in Bogota, Colombia on November 10 to 13, 2010.

**1. International Meeting of Families- November 11 and 12, 2010.**

The Road to Inclusion: Together we can make the change!

"Human Rights, a reflection for the needed changes in peoples everyday life"

**2. Conference for self-advocacy training- Wednesday November 10 8:30 a.m. to 5:00 pm**

Youth and adults with intellectual disabilities work together to strengthen as self-advocates. The importance of their voice in the changes that are required will be set from a human rights framework proposed by the Convention on the Rights of People with Disability.

**3. Meeting of Inclusion Interamericana- Saturday November 13 9:00 am-1: 00 pm**

**4. Workshop (Working as a social network)- Saturday November 13 2:00 pm-5: 00 pm**

For more information about these events visit [www.inclusion-international.org](http://www.inclusion-international.org)

or contact Ines Escallon [escallon@rogers.com](mailto:escallon@rogers.com)

## INCLUSION INTERNATIONAL EVENTS CALENDAR 2010

- IDA meeting. August 28<sup>th</sup>-31<sup>st</sup>, 2010.-New York, USA
- Third Congress of State Parties. September 1<sup>st</sup>-3<sup>rd</sup>, 2010-New York, USA
- Iberoamerican Congress on Education- Buenos Aires, Argentina. September 13-15<sup>th</sup>, 2010  
<http://www.metas2021.org/congreso/presentacion.htm>
- Against Discrimination of People with Mental Handicap- Bratislava, Slovakia. September 23-25<sup>th</sup>, 2010
- MDAC Workshop on Litigation Strategies- Budapest, Hungary. September 23-25<sup>th</sup>, 2010
- Meeting on Article 12 of the CRPD.-Budapest, Hungary. September 23-25<sup>th</sup>, 2010
- Committee of Experts Meeting- Geneva, Switzerland. October 4-8<sup>th</sup>, 2010
- Asia Pacific Disability Forum- Bangkok, Thailand. October 16-17<sup>th</sup>, 2010
- Inclusion Interamericana Regional meeting. 13 November, Bogotá, Colombia.

September 2010



The Spanish and French Newsletters will soon be available on our website  
[www.inclusion-international.org](http://www.inclusion-international.org)

Inclusion International, KD.2.03,  
Docklands Campus, 4-6 University Way,  
London  
E16 2RD- UK  
Email: [info@inclusion-international.org](mailto:info@inclusion-international.org)  
[www.inclusion-international.org](http://www.inclusion-international.org)