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INCLUSION INTERNATIONAL

AND

THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

**Learning from how the UN Convention was achieved.
Shaping global action to deliver the benefits for people
with intellectual disabilities and their families.**

**Notes from the Inclusion International Council's discussions
London, 30 November & 1 December, 2007**

I. Introduction

The new United Nations *Convention on the Rights of Persons with Disabilities* (the Convention) is an historic achievement of the world-wide disability community. Over the past six years, Inclusion International (II) and its allies across the globe played a major part in shaping this Convention to ensure it properly reflects the interests of people with intellectual disabilities and their families.

The Convention and its key articles now provide a powerful framework for improving the lives of people and families in the years to come. But these improvements require widespread national ratification* of the Convention and its successful implementation.

On the 30 November and 1 December 2007, Inclusion International's Council, meeting in London, decided to focus part of our time together on discussing the Convention. Twenty people participated, including almost all the Council, four supporters of self-advocate members and three staff.

We had two main objectives:

First, to share with each other the story of how the Convention was achieved – drawing lessons for how II and its members can best be effective in influencing important policies at the global level.

Second, to use these lessons in starting to plan the future action - globally, regionally and nationally - required to ensure that the Convention does indeed deliver better lives for people with intellectual disabilities and their families.

This work was carried out in a six hour workshop, with presentations, small and large group discussions, facilitated by David Towell, a volunteer who knows II well. These discussions aimed to be both *effective*, focussing on the issues most important to us, and *inclusive*, ensuring we were able to use everyone's ideas and experience.

* These Workshop Notes try to use plain English, except where the Convention itself uses technical words, like 'Articles' 'ratification' and 'implementation', which it is important to understand. The Convention Articles Briefing Paper, which will follow these Notes, includes explanations of these Convention terms.

There are four main products from this work:

The Workshop Notes

The main points from these discussions were written on flip charts as the Workshop progressed. With help from participants who led the

small group work, David has written this summary of our conclusions.

The Convention Timeline

In an important part of our meeting, we traced how II and its members influenced the Convention, sharing stories of our contributions at different stages along the long road to reaching agreement at the UN. To help here, we used a Timeline showing key steps on this path and where II made its main inputs. Connie Laurin-Bowie will produce a picture of this Timeline to be sent to Council.

The Convention Articles Briefing Paper

Focusing on the Articles in the Convention most important to people with intellectual disabilities and their families, we tried to ensure we have a common understanding of what these Articles mean and started to identify issues likely to arise in their national implementation. There is more work to do here as the ratification process proceeds but Diane Richler and Connie are writing a Briefing Paper that builds on II's position papers (focusing on the articles concerned with Legal Capacity, Education and Living in the Community).

The Convention Story DVD

For the first time, the work we did together was videoed by Raquel Gonzalez, II's Coordinator. This video will provide a record of the story of II's role in the development of the Convention.

In addition, the experience of the workshop suggested the importance of Council finding good ways of continuing to share stories of what is happening across the globe as each of us in our different countries and roles tries to promote national ratification of the Convention and its successful implementation in the years to come.

II. Our part in making the Convention

We began the Workshop by standing alongside a large wall-chart of the Convention Timeline and marking our own names against the stages where we had each been directly involved.

Over the six years in which support for the Convention was being built, almost all Council members – supported by II staff - made important contributions, in some cases many times.

From Robert Martin's early contribution to an international disability conference in Beijing, Raquel Jelinek's efforts to ensure that the Mexican government's advocacy for the new Convention fully included the interests of people with intellectual disabilities, through many other places, especially focused at the UN itself in New York, and now reaching out across the world as very many countries decide how best to take the Convention forward.....

Inclusion International and its allies have worked continuously to build an effective strategy for global influence.

There were many challenges along the way – and more to come!

It was important that we built our position in the negotiations in consultation with our member associations so as to maximise the strength of our message.

It was important – many times – to bring our experience to the table with other disabled peoples' associations to establish wider alliances. In turn this required some difficult negotiations to get acceptance for our ideas on issues, like inclusive schooling and the significance of families, where some other groups took a different view.

It was important that we found allies within our national and, in Europe's case, regional governments so that there was support all round the table in New York for key proposals. It was also important that we made the personal contacts, for example, within the UN and with Ambassador MacKay who chaired the Ad Hoc Committee meetings, so as to inform key officials and ease the path to success.

For a global Convention, it was important that we were represented in these negotiations by a broad team which itself reflected the world's diversity –

North and South, men and women, disabled people and families, members with expertise in law, education and community living. The five Council members who are self-advocates and their supporters, coming as they do from five different Continents, were especially effective in showing how we seek to represent the whole of humanity. In turn, these contributions often showed considerable courage as our representatives addressed hundreds of others in the formal setting of the UN or took the argument to other groups who were not used to people with intellectual disabilities speaking up.

And exciting though this long story is, it is important to keep in mind the energy and concentration required by people taking the main leadership roles as we sought to make sure that our representatives were in the right places at the right time with the right arguments to make a real difference.

III. Lessons from the Convention story

With all of us having contributed to creating this shared story of how II and its allies shaped the Convention, we broke into smaller groups to draw lessons for how we can best be effective in achieving positive change in the years to come – not just globally but also regionally and nationally.

Together we identified eight key elements in our strategy for the Convention which seem to be relevant for future action.

We (II and its members) are successful when:

1.We start from the experiences of people with intellectual disabilities and their families.

Collecting and telling real stories about the daily lives of our grass roots members is the most powerful thing we bring to the tables where big issues are discussed. We showed how to do this in the major report on poverty and exclusion *Hear Our Voices* launched at the 2006 global Congress. There were many other examples in the Convention story.

2.Self-advocates and family members speak for themselves about their experiences, including the experiences of disabled people who need a lot of support.

This experience is best presented first hand.

Robert and Zdenka Petrovic's stories about their own lives and why they are concerned about the lives of other people;
Mia Farah's willingness to tell others that she can decide for herself;
Haydee Beckles and Quincy Miya's ability to share the importance of family in their lives:
all are very persuasive when they are listened to carefully.
And we also liked the example of Sue Swenson and her son – who doesn't much use words - directly engaging with other disabled people in New York to show the importance of having someone who knows you well to help you communicate.

3.We bring our diversity to the table.

A global movement for inclusion has to include as far as possible the diversity of our movement. So when we speak up with different voices but similar messages from across the world, we add to our reputation as Inclusion *International*.

4.We work hard to share our knowledge with each other and develop these common messages.

We are more influential if we are 'singing from the same hymn sheet' in different places with different groups and at different levels, from the local to the global. For example, our ability to make the same arguments about the right to inclusive education in Mexico, in the European Union and at the UN adds greatly to our influence. But this also means we have to invest in sharing what we know about applying the same principles in very different countries and shaping our arguments to take account of these differences. We also have to ensure we have a deep understanding of new opportunities like those offered by Articles in the Convention

5.We build strong alliances with other interests.

We are seeking big changes in the world to build an 'inclusive future'. We need all the friends we can get to advance this vision. In shaping the Convention, this meant making connections not only with other civil society groups but also with governments and where possible with allies in the global institutions. And of course, our main interest is in ensuring disability issues are addressed in the mainstream policies

which affect all our lives.

6.We are good strategists.

In an alliance which is strong on values, wide in membership but small in its global resources, we have always to be thinking carefully about how best to mobilise and link the other elements in our strategy to maximise our impact. We have to be smart at spotting opportunities. We need to share our dreams but also be good at transforming these into policy proposals. And we always need to be learning from our experience so as to do better.

7.We use the widest possible variety of resources, human and financial.

The work on the Convention over all the years it took was a huge effort. We could only sustain this with the modest resources available to II's Council where we were able to draw on the expertise of many of our members and allies. We also needed both public agencies (including the UN itself) and our members to provide the financial support required to make good use of these human resources.

8.We always keep our focus on real change in the everyday lives of people with intellectual disabilities and their families.

And returning to our starting point, we work through our national and local associations to ensure we are equipping local people to fight for the implementation of progressive public policies where they live and to monitor the impact in people's lives.

IV. The Convention: What's happening now?

Drawing on their experience from around the world, Council members then briefly shared a picture of what is happening now to take the Convention forward and what challenges are starting to appear in national implementation.

We were **encouraged** that:

Seven countries (at the time of the workshop) have already ratified the Convention, eight others are currently close to doing so, and so there is a good prospect of soon achieving the twenty required for the Convention to come into effect.

The Conference of State Parties (The governments who have ratified the Convention) will convene six months after 20 countries have ratified. The Conference of state Parties will appoint the Committee on the Rights of Persons with Disabilities at the time of their first meeting. The Committee will have the job of monitoring national progress, further interpreting the Convention Articles and dealing with complaints from within countries which have signed and ratified the 'optional protocol'.

Countries ratifying the Convention are now obliged to establish national arrangements for coordinating Convention implementation (for example, a national Office of Disability Issues) and an independent agency with the task of promoting and reviewing progress.

Countries are taking different approaches to changing their own laws to meet the Convention requirements. Some (e.g. Japan) are reviewing their legislation before ratification. Others (e.g. Hungary) are using ratification as the starting point for change.

There are also differences in the way civil society organisations (like our national associations) are getting involved in this change process. For example, the Arabic countries, Mexico and Norway are each taking different routes to promoting understanding of the Convention and

participation in its implementation.

There are some emerging examples of international cooperation to promote ratification, for example a partnership among the ‘First Ladies’ in the Americas.

But we also identified a number of important **challenges**:

Some developing countries are among the first to ratify the Convention. In these and other poor countries (for example, where many children of all kinds are excluded from education), there is a difficult question of how best to define the objectives in gradually moving towards Convention implementation. There are also questions about the international assistance available to help these countries.

More generally, there seem real risks that the Convention goals will be diluted, for example, as governments discover more about what they have signed up to, the Convention is translated into languages where some concepts in English are not easy to express, and indeed where governments adopt interpretations of some Articles which don’t fit with the original intention of the Convention.

In countries and regions (i.e. the whole of the European Union) where there are federal structures (i.e. different government powers are held at different levels) there may also be problems about where government responsibility for ratification and implementation actually lies.

V. Using the opportunities; addressing the challenges

*In the time we had available, the workshop addressed these challenges in two ways. First, the President made a presentation about the way in which II understands three of the most important Articles in the Convention – on Legal Capacity, Education and Living in the Community – and what we might expect some of the implementation problems to be in the light of the debates which surrounded agreement of these Articles. Diane and Connie are producing the **Convention Articles Briefing Paper** to summarise this presentation.*

Second, choosing three different parts of the world – Mexico, Lebanon and

Eastern Europe – and taking issues arising in relation to these three Articles as our focus, we met in problem-solving groups to explore how Council could assist its national or regional member to make progress. A summary of each group discussion follows.

Mexico: The definition of legal capacity

Based on notes supplied by Raquel Jelinek.

Mexico had taken the lead in proposing the new UN Convention so its approach to ratification is especially important. Raquel Jelinek told us that Mexico has already ratified the Convention but that it's government has introduced a reservation to the Article on legal capacity and added an 'interpretative declaration' which had the effect of undermining the Convention proposals by continuing to allow disabled people to lose their legal status.

CONFEE, our Mexican member is already campaigning against this weakening of the Convention and Raquel asked us to consider how II could assist this campaign.

II will:

Send a guide to the Convention published by the UN itself and developed in collaboration with the Union of Parliaments. The President is sending this directly to the Mexican government.

Ask the Human Rights Commission and the UN Commissioner on Human Rights to provide direct advice to Mexico.

Seek more letters of support for the Mexican civil society initiative to remove the 'interpretative declaration' before Mexico sends its documents to the UN.

Lebanon: Advancing inclusive education in the developing world

Based on notes supplied by Moussa Charfeddine

This group addressed the challenges of progressing inclusive education in three parts:
mapping the current features of the educational system in the Lebanon and the challenges these present;
identifying the variety of international funding sources which could promote progress; and
identifying how II could best assist.

The situation.

Currently in Lebanon, people with intellectual disabilities are perceived in terms of their limitations and widely believed to need special education. Families have very limited educational options and family-based associations have a very limited role.

Moreover in government, educational programmes for disabled people are still the responsibility of the Ministry of Social Affairs (not Education) and the committee established by legislation to address this problem is not yet active.

In the educational system itself, 70% of schools are in the private sector. All the special educational facilities are run by NGOs and these serve no more than 3% of the children in need. The examples of inclusive education are in private schools charging three times the fees for other children.

Funding Agencies

The group was able to identify no less the 12 funding agencies with an interest in these challenges: some global (like UNESCO, UNICEF, UNDP and the World Bank), some regional or national (like the European Commission, USAID and the Japanese International Development Agency, JAIKA), some global charities, also sometimes government funded (like Sweden's Save the Children, Oxfam in Quebec and Norwegian People's Aid) and some Foundations in the region (like the Prince Alwaleed Ben Talal-Kingdom Foundation and UAE TARAHUM Project), between them sponsoring many projects.

How II can help

International funding is certainly required to support progress in the situation of Lebanon. There is a particular need to invest in:
building the capacity of civil society through strengthening the self-advocacy and parent movements;
building the technical capacity for inclusive education in both administrative and academic institutions.

There are four ways that II could bring its influence to bear:

Advising and facilitating the support programs of the International and Regional Funding Agencies.

Informing member organizations about the available funding opportunities.

Recommending member organization where to apply and how best to approach these agencies.

Creating a joint project proposal to funding agencies along with the II Regional organization.

Eastern Europe: Ending the scandals of institutionalisation

Based on notes supplied by Fred Heddell

The discussion arose because of recent television reports about institutions in Bulgaria and elsewhere, where the conditions are terrible and the children and adults rarely leave their beds. (The scale of this challenge across Europe has recently been documented in a study commissioned by the European Commission, involving Inclusion Europe.)

Robert made a powerful statement in support of II's policy that institutions are wholly inappropriate ways of housing people and asked assistance in identifying how II and its allies could ensure an end to these scandals, in line with the Convention Article on 'Living in the Community'.

The discussion identified three sets of proposals concerned with:
Campaigning for better alternatives;
Building public support;
The important role of self-advocates in these campaigns.

Better alternatives

II should campaign for:

Support for families so that children don't need to leave their family;
Development of community-based services and support;
An immediate ban on new admissions to institutions;
A large-scale programme to help people currently living in institutions return to life in the community.

Public attitudes

Real commitment to change requires public support and the recognition in Eastern European countries and more widely that institutions are unacceptable.

II should campaign to influence:

The general public in countries like these;
The public in other countries where concern about scandals could actually lead to old institutions being rebuilt;
The media in these countries;
Large aid agencies.

Involving self-advocates

Self advocates, particularly those who had lived in institutions, should be involved at every stage of planning the move away from institutions.

VI Closing comments

We ended the workshop with a review of what we had done together.

J.P. Gadkari, participating in his first Council meeting, emphasised the importance of Council building on the Convention success to promote global change consistent with its principles. Yves Giraud suggested we should find ways of continuing to exchange stories from national experience as more countries address the Convention requirements.

Raquel Jelinek appreciated this way of working together and saw the need for similar processes within our countries.

Haydee Beckles concluded the workshop with a poem about the importance for all of us of having the right to be the person each of us chooses to be!