

EDITION 1 - February 2007

Dear WNUSP Friends,

Welcome to the first edition of our official newsletter, WNUSP-News. In this edition we will be focusing on the recently adopted United Nations human rights treaty called, the Convention on the Rights of Persons with Disabilities or CRPD, for short.

Our main article is an interview with Tina Minkowitz, where she answers questions about the impact of the Convention on the lives of persons with psychosocial disabilities. Tina had participated as our chief delegate at the various meetings of the Ad Hoc committee, which was formed by the United Nations, and tasked with the responsibility of drafting the text of the Convention. She also spoke for the IDC [International Disability Caucus - (served as the coordinating body for the participation of people with disabilities in the drafting and negotiation process) - Ed.] at the general assembly adoption, which was the first time a user or survivor of psychiatry, representing a user/survivor organization and identified as such, addressed the UN general assembly.

The Convention is open for signatures on the 30th March 2007 at the UN and there will be activities there and at UN agencies in countries that are participating in the signing ceremony. The second section of the newsletter consists quotes from various user and survivor activists from all over the world, who had participated in the Convention process, or had actively lobbied their governments regarding the positions of the user/survivor movement, on the convention.

Link to the text of the Convention -<http://www.un.org/esa/socdev/enable/rights/convtexte.htm>

Please see the second accompanying edition of WNUSP-News for an overview and user/survivor focus on the Convention.

Tina Minkowitz , WNUSP co-chair, international human rights lawyer & psychiatric survivor, is interviewed by Bhargavi Davar from India on the CRPD

1.What are the implications of having a Convention on the Rights of Persons with Disabilities(CRPD) for persons with psychosocial disabilities around the world? Will this change the ground level realities for them?

For those of us who have been harmed by human rights violations, the Convention is the beginning of reparations. For those of us who are seeking the right to live in dignity with support of our own choosing, the Convention is a promise that needs to be fulfilled.

The Convention is a human rights treaty that will become binding on governments and set standards for the interpretation of our human rights by other parts of the UN system. This will

have far-reaching implications as governments come to terms with their new obligations.

Most importantly, the Convention obligates governments to recognize the legal capacity of people with disabilities on an equal basis with others. This is a 180-degree shift in the way that law has dealt with people with psychosocial disabilities. Because the law considered us incapable of making our own decisions, it has been an instrument of our oppression more often than it has protected us. Now we can look forward to equal protection of the law in all respects, and will be able to seek help without having to fear that our rights will be taken away as soon as we acknowledge having a psychosocial disability.

2. What actions will it take from governments around the world to realize the CRPD? Are you optimistic about what will follow?

Since the concept of legal capacity affects many areas of the law, changing the body of law to comply with Convention may be a complex undertaking. At the same time, governments will have to develop programs to ensure that people who want support in making decisions will have access to good quality support that meets their individual needs and respects their choices.

Governments are required to consult closely with organizations of people with disabilities in developing legislation and policies to implement the convention, and in other policymaking affecting people with disabilities. This gives us a good opening to advocate and assist with the implementation process.

In some governments, legislation needs to be changed before the Convention can be ratified. People who live in these countries will need to become involved in advocacy in the ratification stage if they want to have the maximum influence.

If implementation proceeds in a careful way, by governments cooperating with user/survivor organizations, I am optimistic that there will be some countries moving into new territory and establishing systems of supported decision-making without legal incapacity. We should aim to have at least one model of good practice in every region.

3. Can you give your impressions about the response of various governments around the world to the process of developing the CRPD? Has it been easy or difficult to build alliances with governments?

On the whole, it has not been easy to build alliances with governments, although there were some notable exceptions. There have been governments that supported us in various ways throughout the process, although not necessarily on every single issue. The campaign to get rid of the Article 12 footnote was notable for the success we had in building alliances across the board, not only with many governments but with the global disability community throughout several regions.

The footnote, which had been inserted at the end of the 8th Ad Hoc Committee meeting, stated that in Arabic, Chinese and Russian the term "legal capacity" meant "legal capacity for rights" rather than "legal capacity to act". This would have endorsed discrimination against people with disabilities in certain parts of the world. Capacity to act is the most important part of legal capacity, since it gives us the right to make our own decisions. We were able to build an alliance that ultimately reached consensus to take the footnote out of the text, reflecting agreement on this fundamental principle. Earlier in the negotiations, we had somewhat taken for granted the provision on equal legal capacity, and were fighting to strengthen the supported decision-making model in the text and ensure that no provisions endorsed guardianship, which would have made the provision on equal legal capacity meaningless. In the end we were successful in both aspects, and it was an interesting lesson in making sure to address all aspects of an issue including those that seem very basic.

4. What was it like to work accross disabilities? Was there support from other disability groups? Do you see the potential for support for the wnusp from the other groups?

I think it enriched both our work and the advocacy of the disability community as a whole, to work in a coalition with other disability groups. We were able to use concepts such as access, inclusion and the social model of disability, which had been developed by the mainstream disability community. In our work on legal capacity, we found that our ideas coincided closely with the model of supported decision-making developed by people with intellectual disabilities and their supporters. We contributed to further developing the model both from a theoretical standpoint and a practical standpoint, and promoting legal capacity and the support model as a central issue for the entire disability community. In a recent meeting of the International Disability Alliance (eight international organizations of people with disabilities, in which WNUSP participates) several organizations mentioned legal capacity as an issue of importance to the disability community as a whole.

The international disability community is much further along in cooperation than are many national disability communities. WNUSP is a member of the International Disability Alliance (IDA), 8 international representative organizations of people with disabilities. IDA created the International Disability Caucus (IDC) which served as the coordinating body of the participation of people with disabilities in the drafting and negotiation process. The IDC was based on the principle "Nothing about us without us", that people with disabilities as a whole need to have an influential role in the treaty and that each constituency's advocacy had to be respected.

5. What was it like for you when the CRPD draft was accepted at the last AHC?[Ad Hoc Committee - (a temporary committee of the UN General Assembly charged with considering and then negotiating the CRPD) - Ed.] What were your immediate thoughts and feelings?

When the footnote was removed and we had a text we could support without reservations, I felt a mix of emotions, relief, joy and even bitterness and disbelief. The roller-coaster of the past several years was finally over. Could I relax? The process was hard on all of us, and it is taking me some time to adjust to the world in which there exists a good Convention. To really assess the implications, as you have asked me to do for this interview, requires a shift in perspective: from the theoretical to the practical, from the goal of a legal agreement to the goal of changing everyday realities, a goal that is now more attainable. I used to think that it could not happen in my lifetime, now I can imagine that it will.

6. What are the next steps / actions for you with respect to the CRPD?

As a US citizen, I know that my country is unlikely to ratify and I will have to find ways to work for our goals without participating directly in a national implementation process.

I have the idea of doing some work exploring non-violence as a framework to deal with many human rights issues in the USA including forced psychiatry. Forced psychiatry, as an act against a person's will, is an expression of conflict, and usually the conflict is about competing interests and needs in a family or community. How do we engage in non-violent resolution of such conflicts? What is the role of support systems in providing a safety net or preventing the escalation of conflict? This is something that interests me and that I hope will contribute to raising awareness. It may be non-violence rather than non-discrimination that can bring us within a framework where we can be heard, in a country that has seen an escalation of the "war

against the poor" as well as foreign invasions as a collective punishment for terrorism, that are troubling to a growing number of citizens who have so far been unable to change the course of the government.

On the international level, I remain committed to building WNUSP as the representative organization of users and survivors of psychiatry at the world level, and the leading organization with human rights expertise on the issues of people with psychosocial disabilities. WNUSP has a role to play in helping our members to work on national implementation, and in continuing our advocacy at the international level, with UN agencies, the international disability movement and the human rights community. We need to look at implementation from a holistic perspective, including awareness-raising and development of model programs and legislation. Some of these activities can be coordinated to share our knowledge and build up a common base of resources for other advocates and for governments.

7. Which articles in the draft do you think are the biggest gains (or the biggest losses) for persons with psychosocial disabilities?

Article 12 guarantees the legal capacity of people with disabilities on an equal basis with others in all aspects of life. This is the most important gain for people with psychosocial disabilities, because it confronts discrimination at its source. The premise of Article 12 is that people with disabilities have the same rights as others to make mistakes and to live and grow based on our own personalities, our own wishes, our own limitations. The support model of equal legal capacity recognizes that there can be times when we need help, but help is not going against a person's will. As our movement has always said, "If it's force, it's not treatment".

Article 25d requires health care to be provided on the basis of free and informed consent, to people with disabilities equally with others. This strengthens our right to have our decisions to accept or refuse treatment respected. Governments have an obligation to prevent nonconsensual treatment, which cannot discriminate based on disability.

Article 19 establishes a right to live in the community with choices equal to others, and to not be compelled to live in any particular living arrangement. This mandates de-institutionalization of the many thousands of people with psychosocial disabilities who have been put into institutions by force or because they have nowhere else to go. Governments must make support available in communities and otherwise take effective measures to realize the right of people with disabilities to live in the community.

Article 14 guarantees the right to liberty on an equal basis with others and ensures non-discrimination and reasonable accommodation with respect to the deprivation of liberty. This gives us the basis to end all forms of psychiatric detention and to address the concerns of people with psychosocial disabilities in the criminal justice system from a non-discrimination perspective.

Article 17 establishes that people with disabilities have the right to respect for our physical and mental integrity on an equal basis with others. Integrity strikes a powerful emotional chord for users and survivors of psychiatry and other people with disabilities, and we can use this article, along with Article 15 on freedom from torture, to challenge forced psychiatry and harmful experimental treatments.

8. Everyone is talking about the forward looking nature of the CRPD. Do you agree with this?

The Convention is forward-looking because it requires governments to go beyond the current realities and strive for something better, even in areas like legal capacity where there is as yet no model of good practice by any government. We do have models for supported decision-making that come from civil society (from users and survivors of psychiatry and from people with intellectual disabilities) and a commitment to make the necessary changes in legislation, policy and programs. WNUSP strongly advocated this approach and we are very happy that it succeeded.

9. How would you describe the role played by WNUSP in the process of the Convention?

WNUSP was involved in all aspects of the development of the treaty, since we learned about the initial meeting of experts convened by Mexico in 2002 to prepare for the first Ad Hoc Committee session. We won respect both as generalists and specialists, contributing to many articles and an overview of the whole as well as our ground-breaking work on legal capacity. Much of our language was adopted in the successive drafts of the Convention, not only in the articles identified with users and survivors of psychiatry but throughout the text.

WNUSP was involved in the creation of the International Disability Caucus (IDC), and in the evolution of the IDC from a more procedural coordinating body to an effective spokesperson for

the disability community on the treaty, with diverse leaders coordinating different aspects of the work according to their expertise.

WNUSP was able to take advantage of a process that allowed people with disabilities to come forward and define our human rights. When we started, we were not sure how it would end, but believed that it was a matter of principle to raise the issues we were most deeply concerned with and take them as far as we could. In the end, we succeeded beyond our expectations.

WNUSP brought people to the Ad Hoc Committee meetings from every region of the world, who are now in a position to be focal points for advocacy in the implementation stage. We brought together many kinds of experience, from human rights advocacy and legal expertise to creation of support programs and alternatives to the mental health system. We worked hard, at the Ad Hoc Committee meetings and between them, together with our IDC colleagues. We learned how to lobby governments and sometimes learned by trial and error what not to do. We had one member on a government delegation who played an invaluable role keeping us informed and participating in negotiations from the inside.

On the whole, we had amazing results for a group of people with little experience in inter-governmental processes, raising issues that were considered controversial by a majority of those present. We developed solidarity and educated governments and people with disabilities about the rights of users and survivors of psychiatry, and brought greater focus to our own advocacy. The process as well as the resulting treaty has been an enormous advance for our movement.

10. Are there any calls for action you propose to the world of persons with psychosocial disabilities?

The Convention presents us with a challenge. Will we let others define how the treaty will be interpreted and applied, or will we fight as hard in the ratification and implementation phase as we did in the drafting and negotiations?

Everyone has something to contribute. Tell your own story to raise awareness. Work with the media or on cultural programs. Find allies in your government. Run for office. Create support programs that work and share your knowledge with others. Help to write new laws and change

or abolish old ones.

We will have to learn a lot in the process, but we can do it, we are survivors and resisters and people who are proud to be mad.

Quotes

"The Convention in recognising the full legal capacity of all persons with disability makes a major effort at breaking the stereotype of incompetence and incapacity which attaches to persons with psychosocial disability. And change of the imagination and in the world of ideas has to happen before change can occur in the real world. The Convention shall greatly assist in reconstituting the world of the imagination."

Amita Dhanda, India

"I expect that the Convention is a strong enough tool (at least much stronger than anything else before) to challenge coercive practices in psychiatry. If implemented correctly, the historical imbalances in the power of users/survivors and the "mental health establishment" will be broken and users/survivors will be empowered as equal individuals and also through our organisations. The vision of a much better world becomes a bit closer with an appropriate implementation. This will require us to develop our movement locally and globally, to share and learn, to participate in social change in a more conscious way than we have ever done."

Gabor Gombos, Hungary

"Of great importance is first that the Convention put such things as guardianship and involuntary treatment into a human rights context, and that it does this at the highest level of universal standards of human rights and dignity, by incorporating it into the body of UN declarations. This means that the Convention can be used by all of us as a tool and a reference in our fights in the various nations around the world. I think we still have a long way to go to change national laws on guardianship and involuntary treatment, but the Convention is a very important step in that direction."

Maths Jespersen, Sweden

"I think the Convention is a victory and has been a long struggle in the user/survivor community to promote and protect the human rights of people with psychosocial disabilities all over the world. The Convention on the Rights of Persons with Disabilities recognizes that every person with disabilities has the right to respect and protection of his or her physical and mental integrity on an equal basis with others.(Article 17). The importance of

self-determination and the freedom to make your own choices can no longer be denied. I think the next step is to support and work with people with psychosocial disabilities to interpret the Convention in order to support their own well-being and to live as equal members of society."

Celia Brown, USA

"The Convention provides activists with a new basis from which to work in our struggle to protect and promote the human rights of persons with psychosocial disabilities. We now have an international human rights instrument that prohibits all discrimination on the basis of disability. It affirms respect for our individual autonomy including the right to make our own choices. It recognizes our right to legal capacity on an equal basis with others and to the support we may need to exercise that legal capacity. It recognizes our right to liberty and to freedom from torture and cruel, inhuman and degrading treatment on an equal basis with others. It proclaims a respect for our physical and mental integrity on an equal basis with others, our right to choose our place of residence and not be obliged to live in a particular living arrangement and our right to health care on the basis of free and informed consent. We have built and continue to build strong alliances with other international disability rights activists and we are developing leaders in the user/survivor movement all over the world who are working together to turn these words on a piece of paper into reality."

Myra Kovary, USA

"El trabajo de la Convención ha devenido por el esfuerzo de u/s , en un marco legal que muestra al mundo la dignidad y derechos de las personas con discapacidad psicosocial , tenemos ahora la responsabilidad de hacerlo efectivo en cada uno de nuestros países , somos SURVIVORS."

"The Convention it's possible because of the effort of user/survivors(U/S), giving us a legal frame that shows to the world Dignity and Rights for Persons with Disabilities, we have now the responsibility to make it effective in our own countries, we're SURVIVORS."

Elena Chavez, Peru

""People first" is now realizing by the Convention. We all are human beings and have equal human rights as others. The Convention will realize the alternative world without force. By using the Convention and making the national legal system, we are fighting against discrimination and getting the equal participation to the society and community living with assistance we need. Nothing about us without us!"

Mari Yamamoto, Japan

"The UN Convention is an exciting opportunity for the world to start to re-examine it's ways of seeing and treating people labeled with psychosocial disabilities. It is time for us to begin an

ongoing creative dialogue about what works (and what doesn't), and to start to commit our energy, resources, research and practices to developing non-coercive alternatives that focus on capacity, inclusion and possibilities rather than on safety and risk, exclusion and minimization. Not only does this promise to reduce the net cost to governments, communities and individuals, but it holds possibilities of developing more inclusive and intentional communities for all of us"

Chris Hansen, New Zealand

"We in Ireland, through the passing of the UN Convention, are reviewing it's impact on our national laws as this is being written. Do we at last have a document that will remove the stigma, that allows us as users, to be treated differently by our fellow citizens, because we are just that, different? Let us hope so, when this is ratified, we can mount a robust challenge, to establish our constitutional rights as equal citizens. I look forward to the day."

John McCarthy, Ireland

Dear reader our website www.wnusp.org is currently down. If you want to contact the editor you can email me at moosa_salie@absamail.co.za .

Moosa Salie, Facilitator WNUSP newsletter Co-Chair WNUSP Secretary PANUSP