



**Bapu Trust for
Research on Mind
& Discourse**

Human Rights of persons with psychosocial disabilities in the post 2015 Inclusive Development Agenda: Towards HLMDD, September 2013

WNUSP is an international organization of persons with psychosocial disabilities and users and survivors of psychiatry. The WNUSP calls for all development action in relation to disability to be based on, and fully compliant with, the objectives, principles and provisions of the CRPD. The WNUSP advocates that the legal barriers to full enjoyment of all human rights be removed, as a first step towards effective participation and full inclusion within the Development process. Specifically,

- (1) repeal of any legal provisions that authorize detention or compulsory treatment in mental health settings;
- (2) repeal of any legal provisions that authorize guardianship or substituted decision-making, a position that is congruent with provisions 12 and 14 of the CRPD. And finally,
- (3) In compliance with Article 19 of the CRPD, ensure the right of choice to live in the community and being able to access a variety of support and recovery services necessary for full inclusion within the Development process and living a life of autonomy and dignity.

Where are we in 'Inclusive Development'?

Widespread discrimination towards people with psycho-social disabilities / users and survivors of psychiatry is an obstacle to our meaningful inclusion in civil, political, social, cultural and economic life. Entrenched discriminatory attitudes, reflected in traditional legislative frameworks and customary normative practices, drive our exclusion and also increase our risk of exposure to violence and the continued deprivation of our liberty and all other human rights, despite a long history of Development thinking and practice.

The WNUSP advocates for a CRPD compliant human rights based approach to Inclusive Development, a position congruent with several disabilities inclusive recommendations from global organisations, towards setting the post 2015 development agenda and HLMDD. The HLMDD consensus document of July directs states to 'Strengthen and apply the international normative framework on disability and development by encouraging the ratification and implementation of the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol as both a development and a human rights instrument'.

The 'Asia Pacific input into HLMDD' also reiterates that 'The HLMDD outcome document should reinforce the spirit and content of the Convention on the Rights of Persons with Disabilities. It should not in any way weaken interpretation of the Convention'¹. A resolution by the World Health Assembly² directs the Director-General to prepare a comprehensive WHO action plan based on the evidence in the *World report on disability*, and in line with the CRPD.

The Secretary General's report to the forthcoming General Assembly on progress in meeting the Millennium Development Goals and recommendations for what should replace them in 2015, issues a strong statement on human rights, a justice based approach to Development and facilitating inclusion for persons with disabilities. The Secretary General has called for integration between MDGs and global human rights treaties. The report recognizes that a welfaristic approach to Development, merely in terms of an expansion of services, will lead to exclusion of those groups whose human rights and civil liberties are presently violated. For example, people who are denied recognition of their legal capacity and personhood are excluded from development and opportunities of any but the most limited kind; likewise, people who are segregated from society in institutions. They cannot contribute to development of society and they cannot do much for themselves or their families. These resolves from various global bodies should have the outcome of changing the lives of persons with psychosocial disabilities, empowering them on equal basis with others.

Development practice and the CRPD

There is no direct reference to 'Development' in the Convention on the Rights of Persons with Disabilities, except in the Preamble³: Reasonably so, as the CRPD takes the Development paradigm beyond 'sustainable development', emphasizing full inclusion and effective participation of persons with disabilities in the Principles and found *passim*. The CRPD places a mandate on states parties to think beyond 'growth', an economic concept central to 'sustainable development'; and to think and practice *inclusion*, a social concept. Inclusive Development connotes the experience and expansion of human freedoms (economic, social and political), embracing all segments of society and not just a privileged few⁴. Several articles of the CRPD have the accent on inclusive development in this sense, and more specifically Article 19, which assures the right to living independently and being included in the community.

¹ 'Asia-Pacific Input to the High-level Meeting of the General Assembly on the Realization of the Millennium Development Goals and Other Internationally Agreed Development Goals for Persons with Disabilities', New York, 23 September 2013

² In May 2013 the Sixty-sixth World Health Assembly adopted resolution WHA66.9.

³ The UNCRPD acknowledges 'the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development'.

⁴ Sen, A. K. (2009). *The idea of justice*. Cambridge, Massachusetts: The Belknap Press of Harvard University Press.

Since the main text of the CRPD does not explicitly refer to Development, the Monitoring Committee too, has not in general commented on Development, but have commented at every step on both, the removal of barriers and Inclusion. The CRPD committee, in several of its Concluding Observations, has reiterated key provisions of Article 19 and has explained certain obligations arising from this article, such as the phasing out and elimination of institutional systems of care and their replacement by community-based services that meet needs expressed by persons with disabilities. The Monitoring Committee has in every country situation, provided direction to states parties on the removal of barriers to the enjoyment of full inclusion in communities, criticising states parties that maintain mental institutions and practice forced treatments through a mental health legislation and calling for repeal of such legislation; and calling for derogation of guardianship laws providing for substituted decision making, which must be replaced by support in decision-making that respects the person's autonomy, will and preferences. The International Disability Alliance⁵, a consortium of international and regional DPOs, including WNUSP, advocates the prevention of development money from going to efforts that will build or consolidate barriers to full participation.

The CRPD committee, in May 2013⁶, recommended that international communities should 'Take measures to ensure that persons with disabilities enjoy their right to development on equal basis with others'. They have called for the adoption of a social and human rights model of disability, and urged that the Principles of the CRPD be reflected in the HLMDD outcome document. One of their key recommendations is: 'Remove barriers which hinder the full enjoyment of persons with disabilities of their human rights and fundamental freedoms, inter alia by appropriating adequate funds for the implementation of CRPD and other relevant legal acts and policies, as well as recognize that persons with disabilities enjoy full legal capacity on an equal basis with others in all aspects of life, pursuant to article 12 of the Convention, which is also essential for achieving an inclusive and sustainable development for the society as a whole'. The Committee could not have been more explicit on legal barriers to participation of people with disabilities in development.

Systemic discrimination and inequality

Equality and non discrimination are key elements of the CRPD, and these values also drive the Development agendas. In the abled vulnerable groups, after decades of Development policies and practices, it has been found that horizontal equity (equality within groups) is better served than vertical equity (equality between groups), particularly in south countries

⁵ IDA, "Overcoming invisibility: Making the MDGs inclusive of and accessible For persons with disabilities", In 'IDA Contribution to "Informal Interactive Hearings of the General Assembly with Non-governmental organizations, civil society organizations and the private sector, 14-15 June 2010"'

⁶ 'Statement of the Committee on the Rights of Persons with Disabilities on including the rights of persons with disabilities in the post 2015 agenda on disability and development', May 2013, United Nations Human rights, Office of the High Commissioner, Geneva.

⁷. However, people with psychosocial disabilities are deprived of, not only de facto equality and face inequities; but also de jure equality, due to discriminatory provisions of incapacity in a variety of laws, and face exclusion. There are other problematic legal provisions concerning ‘incapacity’ governed by national laws: such as exclusion from political participation, depriving us of the right to vote; family laws that deprive us of the right to family (marriage, adoption, custody of children); discriminatory inheritance, contracts and finance laws on a ‘finding of unsoundness of mind’; etc. In countries where the justice systems are weak, such legal barriers to full and effective participation multiply due to denial of access to justice. The barriers for access to Development of persons with psychosocial disabilities are not just about everyone not having equal access to social and economic rights; but of the rule of law denying all fundamental civil political rights and sometimes, citizenship rights to some groups of persons with disabilities. The HLMDD report by the high level panel⁸ recommends inclusion within the given frame of the MDGs in the post 2015 development scenario: However, no goal of the MDGs addresses the lived reality of millions of persons with psychosocial disabilities / users and survivors of psychiatry who have no way of exercising the right to development. WNUSP advocates that any effort to include us would begin with dismantling those legal barriers on enjoyment of full legal capacity⁹, so that the rule of law can be implemented inclusively and not function as a barrier to full and equal human rights.

Right to health care: Providing care or securing the gates?

In the post CRPD era, the World Health Organisation (WHO-DSA) has released the report on *Mental health and development: targeting people with mental health conditions as a vulnerable group*¹⁰. They also released the Draft Comprehensive mental health action plan, 2013-2020¹¹. WNUSP has been in dialogue with the WHO (DSA) in the last decade, tabling our serious concerns about involuntary commitment, the over medicalisation of our lives, and the medico-legal denial of all our human rights. Mental health care professionals, guided by the WHO frame of reference, have been gatekeepers of persons with psychosocial disabilities, and have set irreconcilable inequality between us and other health care patients; worse, continuing methods of ‘treatment’ which the UN Special Rapporteur

⁷ Osmani, S.R. (2008) ‘The Demands of Inclusive Growth: Lessons from South Asia’. The Mahbub Ul Haq Memorial Lecture. In *The Pakistan Development Review*, 47 : 4 Part I (Winter 2008) pp. 381–402

⁸ ‘A new global partnership: Eradicate poverty and transform economies through sustainable development: The report of the high level panel of eminent persons on the post 2015 development agenda’. UN Publications, Geneva, 2013.

⁹ WNUSP, June 17th, 2011. ‘Legal Capacity as Right, Principle and Paradigm: Submission to the Committee on the Rights of Persons with Disabilities in response to its Call for Papers on theoretical and practical implementation of Article 12’.

¹⁰ Available at: http://www.who.int/mental_health/policy/mhtargeting/en/index.html

¹¹ ‘Draft comprehensive mental health action plan 2013–2020’, EXECUTIVE BOARD EB132/8, at the 132nd session 11 January 2013, Provisional agenda item 6.3

for Torture has affirmed, is torture¹². We also bring to the notice of the international communities, the links between psychiatric treatments and iatrogenic disablement (brain damage, tardive dyskinesia, Parkinsonian symptoms, akathisia, cognitive impairment, and various cardiac, insulin related and other metabolic disorders) and early death¹³. Worldwide, the first determination of 'mental illness' leads to civil, political, social, and other consequences detrimental to our moving freely in society as equal citizens, and the full enjoyment of all human rights. In countries that are in a post colonial situation, mental health professionals use the old laws of incapacity and lunacy acts, in new medical formulations, to keep us institutionalised¹⁴. WNUSP seriously challenges the practices of the psychiatric professionals, which do not seem to be framed within *any* theory of bio-medical ethics. The popular reference to 'evidence base' can never, under any standard of science or reason, be applied to 'cures' such as physical restraint and confinement, or to forcing someone to ingest mind-altering drugs or to undergo electroshock or psychosurgery. We continue to raise questions about the very basis of scientific inquiry upheld by psychiatry and allied sciences, as we are exposed, as a community, to the serious fall outs of a fledgling science, with grandiose vision to label all human behaviours as abnormal, witness, recent debates about the DSM 5¹⁵.

We further bring to the notice of the international communities that an 'institution' is not just a physical structure of confinement, but can mean severely restricted lives within families and communities as well. The long term, even intergenerational, traumas of this institutionalisation and social victimisation in the name of 'mental illness' is widely reported and recorded in our lived experiences. Recognizing that the WHO has a key role to play in removing barriers to our institutionalisation in the above sense, WNUSP has long since advocated a "change from a medical model of mental illness to a non-pathologizing one that recognizes mental and emotional differences and distress as part of everyday life, even when such experiences are disruptive to the person's ability to carry on life as usual".

¹² "The Special Rapporteur draws the attention of the General Assembly to the situation of persons with disabilities, who are frequently subjected to neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence. He is concerned that such practices, perpetrated in public institutions, as well as in the private sphere, remain invisible and are not recognized as torture or other cruel, inhuman or degrading treatment or punishment" and *passim*; 28th July 2008, Sixty third session Item 67(a) of the provisional agenda A/63/150 of the United Nations General Assembly. The Special Rapporteur also included among the practices of concern as torture and ill-treatment, that „persons with disabilities are exposed to medical experimentation and intrusive and irreversible medical treatments without their consent (e.g. sterilization, abortion and interventions aiming to correct or alleviate a disability, such as electroshock treatment and mind-altering drugs including neuroleptics).“ In 2013, the Special Rapporteur called for an absolute ban on forced and non-consensual medical interventions imposed on persons with disabilities, including nonconsensual administration of electroshock, psychosurgery and mind-altering drugs such as neuroleptics, restraint and solitary confinement for long- or short-term periods. A/HRC/22/53.

¹³ <http://www.madinamerica.com/2011/11/%EF%BB%BFearly-death-associated-with-antipsychotics/>

¹⁴ Davar, Bhargavi (2012) Legal Frameworks for and against persons with psychosocial disabilities. *Economic and Political Weekly*, Vol XLVI, No. 52, pp. 123-131

¹⁵ Frances, Allen (2013). "Diagnosing the DSM" Retrieved online from the New York Times from <http://www.nytimes.com/2012/05/12/opinion/break-up-the-psychiatric-monopoly.html>

Further, “Wellness should be defined as being able to live well, whatever that means for an individual.¹⁶” In remaining silent on many critical issues concerning us, including ethical standards of medicine, involuntary commitment, mental health legislations, the question of choice, and prohibitions on torture within the mental health system, the WHO (DSA) has been said to indulge in ‘medical colonisation’¹⁷. The efforts of the WHO (DSA) in lieu of the HLMDD and post 2015 Development agenda fails to conform to the basic tenet of the CRPD, viz., a social and community based model of mental health care based on full respect for each person’s expressed needs and choices.

Transforming communities for Inclusion of persons with psychosocial disabilities

The CRPD provides the right to enjoy reasonable accommodations and supports for independent living, according to Art 19 and also Arts 27 and 28. WNUSP has argued that individuals must have access to supports, *accommodations* and services needed to leave institutions and live in the community, or to avoid institutionalization, including *assistance in securing housing and livelihood*, and that services are available in the community to meet the needs of persons with psychosocial disabilities that meet the expressed needs of individuals and that respect the individual’s autonomy, choices, dignity and privacy, *with an emphasis on alternatives to the medical model of mental health*. We have also advocated that a person has every right, as enshrined in the Right to Life in some parts of the world as constitutional right, to define their own personhood, experience their sense of self holistically, and seek pathways to recovery, on their terms. WNUSP and our related networks have developed robust alternative models for a social response to persons experiencing madness, mental health problems and trauma. These models emphasize the primacy of first-person experience, honoring thoughts and feelings, meeting practical needs, taking enough time for resolution or healing, providing supportive spaces where a person may pursue their own recovery using methods that they enjoy and believing in every person’s ability to transform his/her life. World wide knowledges on non medical ways of healing and recovery, led by humane professionals as well as persons with psychosocial disabilities / users and survivors of psychiatry, coming from all parts of the world exist to research, document and draw from, in implementing Article 19, and related articles of the CRPD¹⁸.

¹⁶ <http://wnusp.net/index.php/letter-to-who-dar-partners-meeting.html>

¹⁷ WNUSP and IDA, ‘The elephant in the room – Involuntary psychiatric treatment and the WHO’, October 2010.

¹⁸ Peter Statsny and Peter Lehmann, (2013, New Edition) *Alternatives Beyond Psychiatry*, Peter Lehmann Publishing: Berlin; *Intentional Peer support and training* by Sherry Mead and Chris Hansen, find at <http://www.intentionalpeersupport.org>; *Mindfulness based cognitive therapy*, find at www.mbct.com; Finland’s *Open Dialogue* method for people in extreme states; The *Soteria Network* at www.soterianetwork.org.uk; Resources on *InterVoice* find at <http://www.intervoiceonline.org/support-recovery/a-practical-guide>; *Integrated Arts Based project* using Asian healing techniques find at <http://www.wcclf.org>; *Somatic healing* based trauma counselling, find at www.traumahealing.com; *Diet based cures* at www.alternativementalhealth.com; on *creating community based support systems* using a variety of

Post 2015 agenda for Inclusion of persons with psychosocial disabilities in Development

WNUSP is committed to a vision about the holistic nature of all human rights – civil and political together with economic/social/cultural, vide the Vienna Declaration and programme of action on human rights: Human rights are “universal, indivisible, interdependent and inter-related”¹⁹. Inspired by the CRPD, which is stellar reinforcement of the Vienna Declaration, and in light of the above considerations, the WNUSP recommends the following towards the post 2015 Development agenda:

- (1) Addressal by international communities, of the exclusionary practice of gate keeping by psychiatric professionals worldwide, of persons with psychosocial disabilities, and creating barriers for them from making choices with respect to their own well being, health care and accessing other human rights (e.g. right to family being the most commonly denied right particularly in developing countries)
- (2) The Door to Development is locked for us. We urge that in setting the post-2015 Development agendas, those doors be open through repeal of mental health legislation; and our inclusion in other legislations so that we can participate on equal basis with others in accessing all our human rights, social, economic, civil, and political, within communities.
- (3) The HLMDD outcome document must have a stand alone provision regarding de-institutionalisation, and universal access to development without exceptions.
- (4) International communities, and the HLMDD outcome document, must recognize the value and availability today of a wide range of non medical approaches to recovery and healing, for all persons with disabilities, giving primacy to the lived experiences and choices of persons with psychosocial disabilities.

non medical alternatives at <http://camhjournal.com/healing-services/comprehensive-urban-community-mental-health-interventions/>; etc.

¹⁹ UN General Assembly, *Vienna Declaration and Programme of Action*, 12 July 1993, A/CONF.157/23, available at: <http://www.refworld.org/docid/3ae6b39ec.html> [accessed 2 September 2013]