



REPORT

'Transforming Communities for Inclusion of People with Psychosocial Disabilities: A Trans-Asia initiative'

*April 30th – 4th May 2013
Hotel Holiday Inn, Pune.*

Report on
‘Transforming Communities for Inclusion of People with Psychosocial Disabilities:
A Trans-Asia initiative¹
(April 30th – 4th May 2013), Hotel Holiday Inn, Pune.

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Note: This workshop was definitive for TCI, being the very first international plenary meeting of the Bapu Trust, to bring the key message of Inclusion to the Asian world. Some key discussions on identity, paradigm shift, etc. helped to shape the advocacy of TCI on Inclusion.

A growing vision and strategy for ‘transforming Communities for Inclusion of people with psychosocial disabilities’ emerged as a program idea of the Bapu Trust, after Bapu Trust leaders were trained through the CRPD TOTAL trainings (New Delhi, 2012) of the International Disability Alliance, followed by field visits to a few Asian countries on different occasions (Nepal, HongKong, Philippines). The Bapu Trust, following these visits, learnt that the Asian region provided uncharted opportunities for new legal, policy advocacial measures and new opportunities for the implementation of the UNCRPD, with respect to persons with psychosocial disabilities.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has brought new opportunities for qualitative change in lives of all persons with disabilities in the Asian region, with many countries ratifying it. With varying degrees of engagement, and depending on country context, users and survivors and persons with psychosocial disabilities have been involved in advocacy around in-country developments on the harmonisation of policies and programs with the CRPD, using strategic alliance with national cross-disability coalitions as the entry point for their advocacy. These attempts at inclusion within the cross-disability coalitions have had varying degrees of successes. There is also the feature of new emerging groups and DPOs of persons with psycho-social disabilities, users and survivors, or persons with ‘mad’ identities, usually unorganized, in some countries of the region, often doing, without any financial support, both the tasks of advocacy as well as developing support services. DPOs of persons with psychosocial disabilities are not recognized, least funded and have little power in influencing policy.

The vision of the Bapu Trust program on ‘Transforming communities’ is broad, including-

- 1) To provide a regional platform for people with psychosocial disabilities to create a common vision for advocacy

¹ Held in May 2013, this peer learning workshop on advocacy was organized by the Bapu Trust for Research on Mind & Discourse; supported by the Foundation of the Open Society Institute and co-hosted by Holiday Inn, Hinjewadi, Pune.

- 2) Through workshops and studies, to develop strategy papers for advocacy actions with respect to laws, policies and institutional relationships in the region for inclusion of people with psychosocial disabilities.
- 3) To develop a common vision for pedagogy and practice related to Article 19 (among other related CRPD articles) as a way of transforming communities to include people with psychosocial disabilities in the region.

Bapu Trust has envisioned that through 4-5 meetings over the next 2 years, a group of people and DPOs with psycho-social disabilities (and the users and survivors, and ‘mad’ persons in the region), will come together to share our experiences, develop a regional vision and platform for action, develop strategies for both advocacy and grassroots services, and eventually, dialogue with key global agencies such as the UNESCAP, WHO, and other regional forums such as APDF, DPI, etc. to bring our concerns to them. We also hope to be included and to participate more vigilantly in international advocacy processes at the UN level directly and where not possible, through dialogue with intermediary agencies.

These are some key issues that have come up, and Bapu Trust planned that some of these issues be addressed in a first peer learning meeting in Pune-

- a. Creating a vision for transforming communities in the region for inclusion: Beginnings.
- b. Naming/ identity / representation issue: whether every person with a mental health problem is a person with a psychosocial disability?
- c. Whether law or policy: The concern that no new barriers should be created in the region through a mental health act, or through creation of asylums based on involuntary commitment, or for that matter, through community based institutions (where the program may be community based, but work as if it is a prescriptive, closed door institution).
- d. Linkage with cross cutting Development issues relevant for the region (e.g. social protection)
- e. Dialoguing and building bridges with a cross disability perspective: advocacy within disability platforms.
- f. Article 19: how to amplify it at grassroots level – field visit to the Bapu Trust mental health and inclusion project; trainings; sharing of other grassroots experiences in the region for a peer review.

Participants arrived from Nepal, Bangladesh, China, India and the Philippines. In all there were 27 participants. All persons being people with disabilities, the majority were people with psychosocial disabilities. Moosa Salie (Chair, WNUSP) was present throughout the sessions. Mr. Javed Abidi (Chair, DPI) and Mr. Sudarshon Subedi (NFDN, Nepal) were also present.

30th April 2013

Introduction After a game of introductions, expectations were put on the table.

Expectations included local to global questions on **whether, what** and **how to...**

Whether	What	How to
Psychosocial disability is a disability / health issue	Motivates people to speak for themselves	Transform communities for inclusion
Psychosocial disability is an invisible disability	Will make the movement grow	Be skilled in independent peer led support
Honest, open discussions on psychosocial disabilities are possible	Will bring people with psychosocial disabilities together	Lead communities into supported decision making

We can create safe spaces for holding such conversations	Is community mental health, what is Bapu Trust saying about this	Archive stories of survivors and give visibility to their voice
There is confusion regarding what is a human right, and what is a service. Is giving a service fulfilling a human right, and will it suffice?	Is psychosocial disability	To help solve life problems, remove barriers and offer needed support
Is 'Mental illness' about social control / disability?	Is the economic cost of BT's community mental health work	To move forward in a very difficult policy environment
What should be the relationship between the self advocate and the parents associations?	To advocate for, law or policy?	Deal with institutions
We want to change the paradigm, or make a bad system less bad?	Will facilitate young people to come into the movement?	Influence multiple stakeholders

The facilitator summarised whether and how the peer learning workshop may address the expectations expressed by participants. Expectations were broad ranging from theory on what is psychosocial disability, to more local practical questions, how to create peer led support and help solve life problems ('social, economic'). Related to these were institutional questions, on moving forward to a politically different environment ('paradigm shift'). We see concerns from

Local grassroots questions → Systemic questions → Advocacy

Relating expectations to agenda: On Day 1, we addressed questions of identity, country situations and our key concerns and relate them with CRPD. On Day 2 and Day 3, we learnt by peer presentations on local peer, user or survivor led programs. Day 4 was devoted to systemic issues. On Day 5 only persons with psychosocial disabilities met to set the vision and advocacy plans for the region.

Safe spaces In response to a question, 'what is safe space?' the group responded that safe space is a space to be, without being judged. There will be no stigmatisation. A person will be able to follow their thoughts and feelings without interruption, and without being tagged. Personal things shared will remain confidential, and there will be respect and trust. Anyone can ask questions. We will be patient, open and honest with each other. No one will take pictures, videos and nothing will be posted on FB, Twitter, or other virtual media. List of participants will not be circulated, and report will say only what everyone agrees to.

Brief country presentations: Nepal, India, China, Philippines and Bangladesh

Groups from each country were asked to consult each other, and make brief interventions on 'Where do persons with psychosocial disabilities stand in my country?'

All the countries had ratified the CRPD a while ago, during 2007-2008. But only Nepal had signed the optional protocol. Harmonisation efforts were on in all these countries, at different measures of development. Struggles on identity and inclusion were the same in all the countries. There was a lack of visibility about this disability, and high level of stigma and discrimination. 'You look okay, so why do you want disability recognition', was a common experience. All of them had cross disability coalitions but there were grey areas on the inclusion of people with psychosocial disabilities, or positions regarding the proposed or extant mental health legislation. Questions were there on whether we were subjects of health department, or disability department, or both. In most parts of the region,

there is no mental health legislation, while draft legislations are poised for consideration, review or adoption. Some cross disability leaders considered mental health legislation as undesirable, while others didn't. NDN of India led by Mr. Abidi has firmly been against the mental health care bill, demanding the inclusion of people with psychosocial disabilities within the new disability legislation. There are not many medico-legal institutions in most countries represented in the workshop, excepting India and China, and no services at the community level. Integration into primary care has been talked about, but continues to be a big challenge, because such integration, where tried, have been dominated by bio-medicine and forced treatment. Rehabilitation model prevails in the region but not inclusive of persons with psychosocial disabilities. Most mental health services were provided by NGOs. We do not know of many culturally / regionally relevant models on supported decision making: decision making is complex in these regions with involvement of family, extended family and community. Violence exists in the community at large, including chaining, being put inside small bamboo cages,² abuse, etc. Dialoguing with and capacity building of all stakeholders was another theme which emerged in every country presentation. Details specific to countries are described below. Persons with psychosocial disabilities are not organized in these regions, their concerns largely being taken up by parents' associations. Access to justice is minimal because of lack of lawyers willing to represent the concerns of people with psychosocial disabilities. The accent of social / disability justice has been more on physical disabilities.

Nepal:

Nepal, being a post conflict region and prone to disasters, witnesses high rates of trauma and suicides, especially among women. A few NGOs have formed a 'Mental Health Network', but there are only 2 DPOs, Koshis and Mental Health Foundation. Access to government is possible and prominent members of the government have advocated for changes in mental health policy environment. Incapacity laws are not found within law to the extent as in India, and provisions are rendered obsolete in practice, but guardianship continues to create controversy³ and rights violations. There is 1 centralised mental hospital in Kathmandu, otherwise, no institutional context. It is heard that people are brought to India and left in asylums there. A mental health law does not exist. A draft mental health bill has come under controversy. Mental Health Foundation has demanded that any law applying on persons with psychosocial disabilities must be fully CRPD compliant. A comprehensive policy document prepared years ago was lost. Within the national coalition (NFDN), only 2 DPOs are working from the constituency of persons with psychosocial disabilities. A draft disability legislation is in the making, but at present, there is no government.

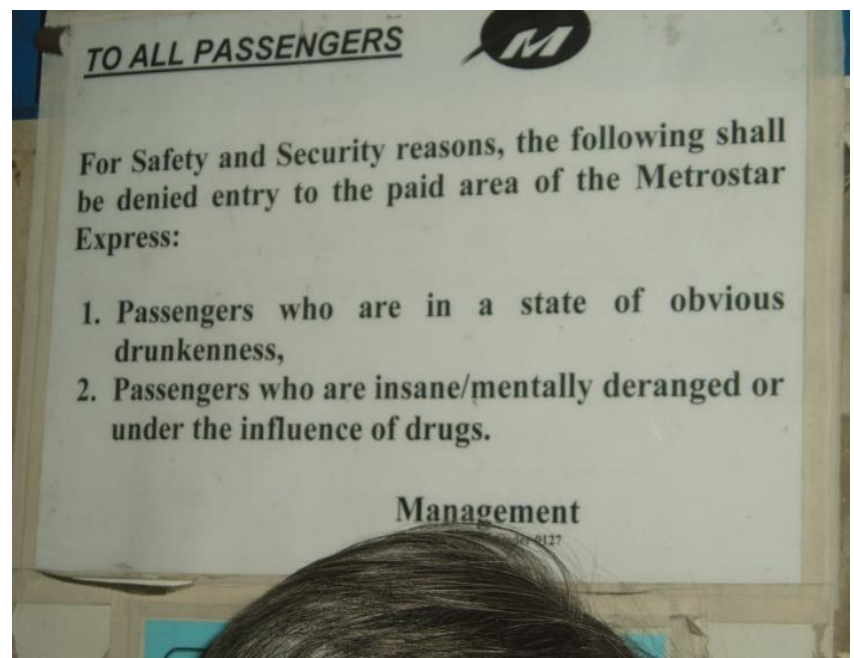
² <http://www.youtube.com/watch?v=zSJ27IshLKY> Abuses of persons labelled 'mentally ill' in Indonesia in the community. Prayer sites also have come into controversy because of the way people are sheltered there, with gross violations amounting to threat of life and survival. The situation in Pakistan is not very different as found at http://jpma.org.pk/full_article_text.php?article_id=1505

³ <http://www.gokathmandu.com/becoming-mentally-incompetent-kathmandu-nepal/index.php>

Philippines: Geographically, Philippines has really difficult terrains, with many islands, often not very accessible. 1 centralised mental health institution serves around 3000 to 4000 people, who are brought here from all over the country. In this institution, there is a big population of deaf and blind women, also children with mental disabilities. There is no mental health legislation, and a draft proposal for a law exists, which is in the congress. This law, while having sections on involuntary commitment, focuses a lot on community development, life styles, well being and health behaviours. In the provinces and regions, there are no services. People with psychosocial disabilities were not included in the census effort, so no demographics on the disability are available. Legal incapacity exists in the civil code in the context of marriage⁴. They may not get a job, but that is true for all persons with disabilities, who are seen as incapable. The deaf in the Philippines are most excluded too, by incapacity provision. Philippine law does not recognize personhood of these persons with disabilities. Recently, Metro Manila station has discriminatory notices which will ban people who are 'deranged' from entering the public areas of the station. Persons seen in this way cannot buy a ticket, cannot travel, and cannot travel with another person. They have to pretend to be 'normal' / cheat so that they can travel and have access to this transport system.

India:

India is a post-colonial country with British legacy in law. Due to existence of over a hundred incapacity laws, persons with psychosocial disabilities are not able to organize into DPOs. 'Civil death' is a reality for many persons with psychosocial disabilities, and in many legal situations, we are referred to as 'non-applicants'. Persons with psychosocial disabilities are not included within the disability policies or laws, due to centuries long historically entrenched medico-legal lineage of asylum culture. Revolving door system exists, of moving between detention within different kinds of closed door institutions and custody within shelters and homes. Many kinds of institutions with no quality standard or judicial cover custodialize persons with psychosocial disabilities, such as 'beggars' homes. A process of 'trans-institutionalisation' exists where a person may be shunted from one institution to another without any judicial review. 'Arrest without warrant' exists in the admission process, making it violent as persons are physically apprehended for incarceration. A big concern in India is the mushrooming of private institutions, where the same forced treatment laws are applied, making it a profitable business. Very few efforts are on to skill build in the sector for different kinds of people, families, and communities, including people with psychosocial disabilities. Constitutional right to liberty faces serious violations in these sets of institutions and procedures.



⁴ <http://domingo-law.com/annulment-and-psychological-incapacity-in-the-philippines/>
<http://www.abs-cbnnews.com/lifestyle/01/19/11/simplifying-path-annulment>, a new law which promises 'easier' annulment by using incapacity in a broader sense.

Bangladesh

Persons with psychosocial disabilities were not included in the Bangla disability welfare act. There is a 'Society for the welfare of schizophrenics', a family care giver organisation. They were responsible for the inclusion of people with psychosocial disabilities in the Persons with Disabilities Act of 2005. This organisation SWS also became member of apex body of the state disability department. They advocate for better medical services, more psychiatrists, better medications. There is 1 mental institution in Bangladesh and no institutional context so far. A draft mental health legislation exists, not yet passed. Not much information is available, and there are no OPDs of persons with psychosocial disabilities.

China

The government is inaccessible and provides no support for diversity and lifestyle. Psychiatry is used for political control. There is no opportunity for conflict resolution within family, society and local government. There are 4000+ closed door institutions in the country and that is the mainstay of the mental health system. Administration puts out statistics suggesting alarming figures of people with mental illness: 170 mn people with MI and 18 mn people with SMD. Even if some people may live in society, the society itself does not allow freedoms. Health care information is recorded in the personal ID card. There is a dynamic control of people living in communities because of the surveillance system. Psychiatry, with its primary role of social control, defines what is 'community' here. A mental health legislation was passed and came into force on 1st of May, and advocates feel that it raises the bar on involuntary hospitalisation while not doing away with it altogether. A few users and survivors have come together to form a network in recent times, however human rights work here is very challenging.

Parallel brainstorming session: Identity questions and how we are for others

In this session, a request was made by the facilitators that whoever self identified as a person with psychosocial disability should be in one group; other persons with disabilities will be in another group. Parallel sessions were held on (1) identity issues, how to bring clarity to concepts of mental illness / mental health / disability / social control and (2) What questions each group wanted to ask the other group. Each group deliberated and came back to plenary for presentations.

Persons with psychosocial disabilities shared that the group talked about their personal experiences, and what those meant in terms of identities. It was considered to be a 'flowery terminology' in order 'to fit in'. A 'user' simply means user of a method. 'Ex-user' was understood as someone who didn't feel the need to see a psychiatrist; or having personal techniques for self care. Or, maybe someone who is using a small measure of medication, but on a journey of self defined recovery. 'Mentally ill patient' is a term linked to a diagnosis; and when there is no support and self coping fails; a person who lives as defined by the medical system. 'Lunatic', 'insane', still found in some law, are outcome of the historical baggage with origin, linked to 'mentally ill', someone who is incapacitated by society and law. A 'survivor' brings to mind someone who has survived torture or ill-treatment, those who survived institutions of different kinds, and speaks to us. The term 'disability' emphasizes societal discrimination. In their identities, a person may shift from 'user', 'survivor' to 'person with disability', and vice versa. Following enduring trauma, a person may experience impairment (e.g. reduced capacity, deskilling or interest to do things): For that person, one pathway may lead to hospital, psychiatric labelling, incapacity and patienthood- the pathway of 'mental health'; or another pathway based on disability identity, disability pride and making choice about one's own recovery- the pathway of 'inclusion'.

There was agreement that the group were in a situation of 'identity crisis'. As human beings, persons with psychosocial disabilities are not recognized as people by others. So, who we are, becomes a question. Existing policies were not helpful to define our identity as it made us into 'patients'. Laws and norms do not allow personal identities to flourish, rather, they cancelled our personhood. Identity

is a local issue, about how people belong in communities. It is a significant question for inclusion. There may be a life span of different identities. 'I am a human being', that is the primary identity which should be respected. Why should persons with psychosocial disabilities have a special identity as a 'user' or 'survivor'? Everybody needs support, and inclusion: that some people need a different kind of support does not mean a special identity. Identity, knowledge and concepts about these also change with time and location. How we present ourselves or hide or 'pass' in a society depends upon the power situation. Social barriers and discrimination may determine how a person with a disability may settle identity questions. In cross disability networks, identity questions for persons with psychosocial disabilities become more complex and challenging. In recent times, we have elicited identity as 'most marginalized', 'people with high support need', etc. within the cross disability movement. Parents groups have also contributed to rewriting our self-identities with their own perspectives.

The mental health system does not give us personhood but forces us to take up some identities, and when we say 'user or survivor', we create our identity within the available and restricted medical frame. 'MI' causes stigma and people are exposed to the question, 'Are you okay?' A 'patient' identity is reductionistic being limited only to medical experience. 'User and survivor' came with baggage of western history and knowledge, and is not inclusive of experiences in the global south. This cultural heritage limited aspects of disability and life experience. Experiences may vary from a state of distress, when you need support, to prolonged mental torture and experience of reduced function, to a state of accepting and empowerment. This spectrum must be allowed to play out in people's lives. 'Mental illness' may be associated more with helplessness, vulnerability and mistreatment created by the care system; whereas disability may have more to do with feeling empowered, validated and being able to share your experience and asking for support without fear. All people in the room identified with 'person with psychosocial disability' than with 'user and survivor'. Some also identified with being a 'survivor'. It was okay for them to self identify as 'survivor and person with psychosocial disability'. Some with strong negative and damaging experiences within the care system identified as a 'survivor' and not as a person with a disability. It was felt that general identities and multiple identities (as a person, a professional, etc.) are the universals and we must access those elements too. The question remained how to reconcile these differences and whether there is a need to reconcile them.

Cross disability allies' presentation

There are not many DPOs for persons with psychosocial disabilities, or self-advocates within different countries in the Asian region. As NGOs (which are many more in number), do we put our energies into self-advocacy and catalyse a DPO movement, rather than on capacity building and awareness activities? The over protectionism around persons with psychosocial disabilities, and speaking on our behalf by well-meaning stakeholders needs to be contained by a self-advocacy movement. Due to stereotypes, the environment for them is hostile. We have realised that experiences and viewpoints of persons with psychosocial disabilities is different from parents and their families. Families are still talking about 'family burden'. And for a person with a psychosocial disability, what does it mean to self identify? Is it safe to do so? Do families facilitate this self identification and self advocacy? The transition is slow.

Is psychosocial disability a health issue, or a disability issue, or both; if so, in what ways? This question is daunting, and there is little clarity. As we have got closer to persons with psychosocial disabilities, we can understand the identity issue and associated disability experiences, but it is grey area.

When NGOs come across a person with a psychosocial disability whose rights are violated, they indulge in 'rescue' efforts. Then not knowing any other option, they hand them over to any custodial system. The person is shifted from one kind of cage to another kind of cage, from one closed system to another closed system.

The legislations are expected to make the systems *less* violative: That is the best outcome that society is seeing, in the name of 'making things better' and as a contribution from legislations: Less violation within confinement. Confinement itself is not questioned. There is talk about 'de-institutionalisation' in pockets. But there is no steady and firm experience for sharing with the world at large.

Acceptance of persons with psychosocial disabilities within cross disability movements in the region: The experience is chequered, being different in different country contexts. How much of the value of inclusion is tempered by anxiety about having to share meagre resources?

Finally, there are prejudices and stereotypes. For other people with disabilities, we know, 'If I am blind, I can get a Ph. D.; If I am in wheelchair, I can be an accountant or a computer specialist'; etc. But there is prejudice that, 'if I have a psychosocial disability, I have no brain function of any kind, and am incapable'. This is the biggest barrier to break.

Recap on UNCRPD

The group recapped on the CRPD, linking it with the discussions relating to the question of self identity. The learning that disability is an evolving concept, including impairment as well as all kinds of barriers, resulting in the restriction of participation or exclusion of persons with disabilities, was reinforced. A person with a condition in interacting with obstacles of a cultural, social, economic, attitudinal or other nature, may self identify as a person with a disability. Out of this definition emerges the idea that not every person diagnosed with 'mental illness' is a person with a psychosocial disability. This is true of other disabilities as well. A person may have a car accident, be a wheelchair user for a bit, and then move on from that condition to a life without experienced disability. A person may be labelled 'mentally ill' without any self-experience of distress or disability ('attribution' of an impairment). A mental health problem, experienced by a person along with barriers of different kinds, leads to restriction of participation and exclusion of a person, leading to a lived experience of psychosocial disability. As the care system steps in, with escalated disqualifications and containment of the person, restrictions to participation become higher and higher, leading to exclusion.

When the environment has facilitatory elements, that may mitigate the circumstances and a person may not feel disabled, and contrariwise. For example, in the experience of anxiety or mood swings, the level of barrier may be high to low. In one case, the person may recover and move on; in other, may self identify as disabled. Trauma experiences may be experienced as 'long term', counting as an experienced disability.

In definition of 'mental illness' as a medical condition, unlike other impairments, there are circles of discourses, including: mental illness as political / social control; mental illness as legal incapacity; disability; and notions like PTSD, and conflicted zones, mental health / illness being linked more and more with peace, normalization of daily life and overall community development.

Who is asking for a mental health law? What do we want from a law, and does reality match our expectations. It is as if there is 'THE BOOK' or an algorithm which self perpetuates resulting in mental institutions: First create mental health law, then set up authorities, then train the doctors, then start the whole process of forced treatment ... The cycle goes on, self-perpetuating itself in collective social understanding and in policy. The World Health Organization, in the late 70s, set this cycle rolling. There are also questions about political economy: In India, the mental asylums have grown from 40 to 400 or more, and most of those today are private institutions. Here, cash / profit is the mover. Families drop members off at high cost, for 'lifelong'. This is called 'long term care'.

CRPD must change this mindset. Slowly it will happen. We now start to ask, 'Who makes the decision?' and talk about choice versus control. Do I have my options? I don't want to make a choice between (bad and bad) OR (bad and worse). We start framing the debate in a different way and making up those solutions on Article 19 as we go along.

Parents' demand for institutions is based on their claim, that 'We know....' Can a cross disability leader who does not know persons with psychosocial disabilities, stand up to that firm intuition and challenge that. You can't tell them, 'You are wrong'. Within the movement also, the professionals and the peer group (of people with psychosocial disabilities) clash. When a group of persons with psychosocial disabilities is not there in a country, what should the cross disability movement and its leadership do?

There are steps to the process of inclusion, which we must cultivate. Advocacy is a technical issue, involving the question of representation. We need to build knowledge and skills. When we, as a coalition do budgets, and gather data, we have some response to the human rights of persons with psychosocial disabilities. We can develop some innovations, e.g. working with care givers for skill building them on independence. These will help address the barriers within the cross disability movement. It will counter the attitude that, 'I did not say anything about the rights of persons with psychosocial disabilities, because I didn't want to say something wrong'.

Inclusion involves many steps: (1) Reaching out to the constituency, mobilizing them (2) Being an advocate for the inclusion and for rights of persons with psychosocial disabilities (3) Gathering necessary knowledge and skills (4) Bringing in some people into the cross-disability groups (5) Facilitating DPOs and self advocates.

The WNUSP, other than the regional organisations, should also provide guidance on these areas, what to do, what not to do, for the Asian region.

The session ended with a recall of Principles, what participation and Inclusion means, non discrimination, and reasonable accommodation. 'Community' is for everybody. The Governments cannot force a particular type of exclusionary paradigm, for a specific constituency, it has to be full inclusion. The struggle of movements to demand and implement will be easier, and there would be better alliance, if we focussed on *all* articles of the CRPD.

Evening reflections and feedback

There is similarity between countries on the situation of persons with psychosocial disabilities. However, there is little space for sharing of experiences and strategies. A platform like this for focussing on a single and marginalized constituency is useful to help build hope and solidarity. Experience with cross disability movements is nearly the same. There needs to be a lot more interaction of persons with psychosocial disabilities with other disability groups. However, whether blind or disabled, identity issues are the same. This advocacy is at its nascent stage in the region. We need to understand the politics of policies, and politics of stakeholders. Organisationally, groups must deal with their own complex / multiple identities to be effective. This opportunity is available for persons with psychosocial disabilities who think a lot on identity issue and adaptation. The struggles about disclosure of identity, stigma related to disclosure, institutionalization and incapacity remain, so that persons with psychosocial disabilities never reach upto the point of Development entitlements. How to influence the government(s), the development sector, how to transform from an institution based society to inclusion in the community, and how to take this message to the DPOs and the federations... We need strong arguments and need to prepare the roadmap for this transition. There is also a difference between countries, for example, the homeless of Nepal; the private institutions of India; the political and legal system of China; etc. We have to discern how many common problems we can discuss and which of these we can solve. The younger generation of persons with psychosocial disabilities need leadership skills to take on these tasks. Persons with psychosocial disabilities may benefit more from joining grassroots DPOs and disability federations. However we do need a group for the region, thinking, sharing, researching, experimenting and advocating. We can learn from the west, but have a strategy, 'how to frame their topic into our topic', relevant for our region. For example, Open Dialogue method of Finland involves the system and doctors. In many countries of this region, there is no mental health system. In the end, advocacy will go only so far, it will not build

services. We need to see how we can invite investors in the development of humane community based services leading to inclusion in the region.

1st May 2013: Transforming communities for Inclusion since 2008, visiting Bapu Trust program

The Bapu Trust, the oldest human rights DPO in mental health, led by a survivor, has been advocating for Development linked community mental health services which will provide psychosocial services for all people on customized need basis. The advocacy has been for community development for living a fulfilling and creative life; and not for just filling the 'treatment gap' of providing mental illness treatment in the community. As part of its larger advocacy, the BT has been demanding the repeal of the Mental Health Act, 1987; restrictions on licensing of institutions; reduction in number of institutional admissions; closure of institutions; and redesigning others. The BT has been involved in providing urban mental health services since 2004, in urban slums (2) of Pune city serving a population of 50,000 people. Our involvement through WNUSP in the making of the CRPD, and receiving the CRPD through the national 'harmonisation' process persuaded us to reconsider our program design. Through participation in a number of learning opportunities, BT leadership built their internal capacity on the CRPD and worked on compliance of UNCRPD with new program floor designs. BT painfully closed several non-compliant interventions which worked on principles of institutionalisation (even at the community level, calling it 'attitudinal institutionalization' or 'custodial mentality'). Since 2008, BT has been involved in engaging communities on the topic of inclusion of people with psychosocial disabilities, while delivering a range of services for people with mental health issues, other than liaison and leveraging work with community at large, taking their people towards inclusion in the community.

Field visit to the 'bastis':

One of the objectives of the Pune workshop was to table the Urban community mental health and inclusion program of the Bapu Trust. All participants visited the areas ('*bastis*') where BT works, and participated in a community interaction. *Basti* is loosely translated as '*slum*', but better translated as '*habitat*' or a '*settlement*', a place where people collect together. BT staff and volunteers had organised a street play on providing support to people with psychosocial disabilities. The script showed two stories, of 2 men in extreme state, one being provided support by his family; and the other excluding and abusing him. The participants got a brief sense of the urban context where BT worked.

BT videos on their program were shown, followed by discussion with the field staff. There were PPTs on Group support and other non-medical formal care (Arts Based Therapy).

Track 1 Introduction to Seher, Urban mental health program

Track 2 Non formal Care

Track 3 Support counselling and peer support: Some case studies

(Track 1) For the last ten years, Bapu Trust has been working for urban community mental health, in a few inner city slums of Pune. Pune district is one of the 35 districts of Maharashtra. Pune has a population of 10mn people. 42% of the city population live in the slums. There are over 550 slums in Pune city alone. The slums are the foundation of city life, providing all basic human services. Each slum has a unique character, depending on cultural, historical, social and economic factors such as civic facilities, migrant status, kind of housing, density of population, social support systems, or social capital, and everyday living problems of people determine their quality of life and psychosocial experiences.

Indian mental health system is focussed more on mental institutions, using traditional methods of institutionalisation, segregation and treatment without choice. We wanted to develop a program that will respect the personhood, dignity and choice of person with psychosocial disabilities. The entrance

of UNCRPD in India in 2007 was significant in reviewing and redesigning our program. Article 19 of CRPD compelled us to think about transforming communities for the inclusion of people with psychosocial disabilities, and to see the right to mental health care as a part of community development.

We are guided by Article 19 which provides the right to live with dignity and choice in the community. We have a vision to create **sustainable** mental health in low income communities, through integrating psychosocial health into community development. A core objective of this program is the **inclusion** of people with psychosocial disabilities. We do not assume that families and communities can naturally give care and support. We enable communities to do so by providing information, knowledge and skill sets. It is possible to multiply and increase emotional resources in the community through inviting **all actors and agencies in the community to participate**. This is our main practice. In this way, we enable people with psychosocial disabilities, especially those with high support needs, to be fully included. The program is based on the view that day to day effort to reduce conflict, experience of positive emotion, and building capacity to care, will have the outcome of fully inclusive communities. We address more specific needs of people with mental health problems and psychosocial disabilities through a variety of ways. Now, we have a two tier system of community development and inclusion.

- 1) Non formal care giving, meaning, capacity building the community to identify, support and care for each other, and for people with disabilities. This is the foundation of the program, where we teach community members and groups to give care and support, especially for those with high support needs.
- 2) Formal care giving, including psychosocial interventions using skilful techniques, both at individual level and at group level; and including a medical and social care component in liaison with the local government.

Track 2 on Non-formal care giving: When we began in 2004, we had only formal care giving. An expert psychologist would visit the communities once every week. She would provide counselling and psychotherapy. However, there were many challenges: high drop out rate, few clients and not knowing how to deal with those experiencing extreme states. There was no engagement with communities, and it was a top down approach.

Who is a non-formal care giver? A non formal care giver is someone from the community who is enabled to give support and care for people with disabilities and people with psychosocial disabilities. She could be a friend, a relative, a neighbour, a group of neighbours, a peer, field or social worker. They help to increase the social capital available to person with psychosocial disability.

What do we do in non-formal care giving? The success of urban mental health program depends on how enabled the communities are in providing support and care. The program adopts strategies of:

- Engaging community directly in providing skills on care giving and inclusion
- System of proxy relationship within community systems
- Neighbourhood care (circle of care) where a support network takes responsibility for giving care

Field workers not only share information, but also transfer skills of emotional support and care giving on daily basis. They use various activities including home visits, corner meetings, group gatherings, exhibitions, awareness programs, mobilising neighbours, CBOs, NGOs, etc.

Myths that we are trying to break with this system of care-

- That people with psychosocial disabilities are violent and dangerous, and need a 'special' place for internment.
- That community based voluntary care is not for people with high support needs.

The program addresses a full spectrum of people with mental health issues and psychosocial disabilities, including people in crisis, in the community.

Videos also included 2 case studies of people helped with support counselling / peer counselling. The support work is done by field workers. Work done by BT on support groups, and the formal care system (intersection with medical care; intensive psychotherapeutic work, arts based therapies for people with high support needs; other eastern healing based alternatives used in the program was also shared.

There was a discussion on the relationship of BT with the public health system. What is the quality and nature of that relationship. How does BT address the question of medication? This was clarified as follows: BT is not against medication, it is against medication in the context of institutionalisation, because in those cases force is the norm. BT makes a variety of choices available in the community, and if someone makes the choice for medicines, then we go with that. One woman who was in a very sad mood and weeping relentlessly got frustrated with our attempts to provide talk therapy. She insisted on getting the medicines immediately, and we organised for that: Those medicines helped her too. We usually check for belief systems with those who are in serious mental health situation. Reality is, medicines are not available within the public health system, and we even advocate for 'good medicines' to be made available. Medical care is not just psychiatric care, but comprehensive health care. Many clients BT serves are health compromised, and need treatment for malnutrition and other health problems first. A health check is mandatory for clients in extreme states.

Drums circle: We finished the BT presentations with a drums circle in the evening. Drumming and rhythm are often used in BT work especially with people in extreme states or those seen as 'severely disturbed' by families.

Evening reflections brought up following issues. The street theatre presented by Bapu Trust and the core elements of the program were dissected. Concerns that no photographs were allowed led to discussion: The fragile relationship with the community, based on trust, and there is always anxiety about violation of privacy. The play gave a positive message. The protagonist in the streetplay was a man, what if it was a woman, a married woman? The characters could be played by two different people, instead of the same actor. The streetplay can be used in other places in the region, e.g. Nepal, where the cultural context is very similar. There was huge participation from the basti people, including children. The inclusion message passed through to the masses. The message about pesticides is not clear (Pesticides, commonly available, are often used in India for attempting suicide.) The afternoon with BT was liberating. The amateur videos were a good attempt to present a complex program design. Psychosocial element is there, but the disability element is not there in the videos. More information must be packed into the videos, including an introduction, to bring better structure and message. The non formal and formal are key elements to the structure of the program: That should come in the introduction and properly introduced. The films are generalising all mental health issues as psychosocial disability; or else, they are giving a more general 'social work' picture about disability. The rights aspect of working with persons with psychosocial disabilities must be more fully presented. 1 case presentation of dealing with a person with psychosocial disability can be presented in the videos. What is mental health? This question must come in the introduction. Is Bapu Trust gatekeeping on who comes into their program? Or, anyone who comes in is a potential client? In China, there is a narrow concept of human rights. The afternoon made it clear that 'mental health' issue and psychosocial disability are not one and the same. The films can describe more, what kinds of interactions are maintained with other people in the communities... families, neighbours, etc. What is the ethical basis of 'proxy relationships' used by the field workers? Is it not wrong to pretend to be a relative / family member? What are the boundaries of this community support relationship? Neighbours play an important role in transforming communities, that aspect is brought out by the program. Make the videos slightly longer to capture more details, what is said, how the transaction happens. The work is within the rules of the community, where gender norms are discriminatory. In the case studies presented, there are definite gender rights issues. 'BT does not interfere in community process': Yet the process of how the field workers arrived at those resolutions shown in

the videos need to be developed. BT is already involved strongly in community process, so the team needs to accept that and develop a morality on gender, caste, etc. Psychosocial intervention does not mean reaching the ultimate personal realization: The films make this clear. Keeping the balance between what a person needs and what can be offered for the client to recover. The balance may have to be developed in each person's case; and more so, in the case of persons with high support needs. The films show that mental health is a local issue that can be owned by communities. The presentation on group work / Arts based therapies (ABT) was bit too technical. Why did BT choose ABT? The drums circles was good, energetic. We see medication is part of choice within the whole system of care.

May 2nd, peer learning on survivor led programs

In the morning recap, further discussion happened. Particularly confusing was the relationship between mental health and psychosocial disability. Who is that person with a psychosocial disability? BT is working to *prevent* people from entering into the mental health system, by strengthening community support systems already, and by preparing them for support and belonging. It gives a taste of well being to all people in the community (as many as possible.) These efforts help in building a foundation for Inclusion, by making whole communities responsible for Article 19. Where social disadvantage leads to 'stress', 'burnout', 'anxiety', 'tension', or 'trauma', BT intervenes with psychosocial support (support counseling, lifestyles, social capital, etc.) to address the distress. People here too are prevented from entering into the mental health medical system. People with mental health issues (depression, etc.) likewise are brought into the more formal system of mental health care using non medical alternatives (arts based therapies, counselling, support in grief, group support, and enhancing social capital). For those with psychosocial disabilities, other than these, the component of comprehensive medical care (general health care, addressing anaemia and malnutrition, indigenous care) are some key elements of choice provided (See Attachment I).

BT has an eye on its budgets and it leverages a lot from community social services (space for programs, fellowships and scholarships, pensions and allowances, food for starving persons, jobs, inclusion in schools, community participation and support, etc.) It pays for consultancy time from a variety of psychosocial service providers so that choice is created for its clients (arts based therapist; clinical psychologist). Core staff is mainly the grassroots staff. The research component of the program is costly, but in the service part, for every 10 rupees invested by BT, other social service providers pay 10 rupees in terms of contributions. BT will link up with disability department for entitling its beneficiaries.

BT has established a culture of *excellence* in constantly self reflecting on its own practice. Not that they know all the answers, but they keep asking questions, finding some potential answers and testing them out.

Other user / survivor led programs in mental health

It is traditional for mental health programs for the homeless to be of institutional nature, and 'rescue' operations are often violative of liberty, dignity, choice and other human rights. In such programs, sending people to their own homes, whatever the quality of life enjoyed there. *Iswar Sankalpa*, Kolkatta, India, presented on their 'psychiatry on the streets' support program for homeless people in Kolkatta. The program works on a process of recovery and social inclusion, by using community / neighbourhood resources, creating 'families', not necessarily one's own. In this program, there is no institutionalization. This program is sited on police campus and has established support systems on the streets. It has given a care giving role for the police, who have to go beyond 'round up'. Successful case studies of women worked with on the streets, assessed by a psychiatrist and the 'Emergency Response Unit' were presented. Program measures included- befriending the women, trust building, skills in engaging the women in a therapeutic relationship, voluntary methods of working, consent to

being counseled about mental illness and being treated, providing more intensive medical care at the night shelters provided by the Kolkatta Municipal Corporation, and follow up. An important support system established by Iswar Sankalp is the support and care provided by people in the neighbourhood (a person from the tea stall, laundry, etc.) The government is providing temporary disability certificates for people with psychosocial disabilities, rather than a permanent certificate. This results in a vicious cycle of relapse, whereas, with permanent social security, the relapse issue seems more contained. Further if social disadvantage is not addressed, people end up in 'revolving door' psychiatry. A great learning is that, when you involve community members in care giving, people actually feel good about giving care. We can talk about 'recovery'. The speaker expressed her concerns about the Mental health care Bill, which, if implemented, will pose serious impediments to their program. The MHC Bill has made consent into a legal issue completely, and such consent is made possible only within institutional context. Moral issue of consent, based on community process, on which Iswar Sankalp is based, will become impossible.

The Red Door, Pune project is a gateway into a space that explores the idea that every human being is normal, or conversely, each is mad in their own unique way. TRD believes that the middle class youth need to be accessed for support through media and methods that they favour: the internet. The *Red Door* provides an easily accessible safe space (real or virtual) for sharing of experiences using creative methods in a non-therapeutic setting. TRD is not just about 'mental illness' but about all the shades of grey of human experiences. TRD has focussed on children's groups, persons with disabilities, and women / girls, in both community contexts and institutional contexts. TRD has in this time offered peer support, and had outreach / training programs with the lay public, as a way of preparing communities to give support and care.

KOSHIS (meaning Striving) is a National mental health self help organisation of Nepal. It works in advocacy, as well as services. It works with many stakeholders, and is actively involved in national legal reform and policy making. In services, Koshis offers peer support and in collaboration with the Kathmandu mental hospital, in the transit house ('House of Hope'). The approach is holistic including psychological, psychiatric and social / livelihood interventions. The program is guided by CBR principles. Koshis works in 2 districts, and also provide trainings for income generation, through mushroom growing.

Survivors from Philippines shared about their work with the women interned in Manila mental hospital, and the discrimination of the deaf. There was open discussion in the group about peer support. Giving peer support to people in extreme states was a challenge, as there were little skills in this area. The need for training in peer support was once again heard.

Great web resources on Alternatives

- 1) One of the sustained Alternatives for people experiencing 'extreme states': Soteria, started by Dr. Loren Mosher. Find him at <http://www.youtube.com/watch?v=qnrYFXxl7yU>
Soteria is a world wide alternative network, and find another Soteria example at <http://www.youtube.com/watch?v=9IWHNI9DK6E>
- 2) Peter Lehmann, 'Recovery by Taking Psychiatric Drugs versus Recovery by Coming off Psychiatric Drugs' Lecture to 'GROWing towards recovery: A re-enchantment with life'. School of Nursing and Midwifery, Trinity College Dublin. January 11, 2013
<http://www.youtube.com/watch?v=L89m0SN9tPQ>
- 2a) Link to The Book on 'Coming off Psychiatric Drugs', find at <http://www.peter-lehmann-publishing.com/books/withdraw-ebook.htm>
- 3) Peter Lehmann, 'Alternatives beyond psychiatry: Presentation at INTAR conference', Toronto, 2008

<http://www.peter-lehmann-publishing.com/articles/lehmann/ppt/alternatives-toronto2008-ppt.pdf>

3a) Link to *The Book* on Alternatives:

<http://www.peter-lehmann-publishing.com/books/without.htm>

4) Useful resources from 'InterVoice', an international organisation working for several years worldwide, providing insight and support for voice hearing people:

<http://www.intervoiceonline.org/support-recovery/a-practical-guide>

5) Watch this breezy and racy presentation on 'Mental health and psychosocial support'

<http://www.youtube.com/watch?v=j-zWJbQ3baw>

6) Dr. Roger Walsh, a well known medical expert on the role of diet on mental health Watch him at <http://www.youtube.com/watch?v=KQjbQObx69M>

7) Finland's famous Open Dialogue method with psychosis, watch Robert Whitaker at

<http://www.youtube.com/watch?v=aBjlvnRFja4>

8) We have found that drumming is very useful in our work, especially with those in extreme states. For examples for use of rhythm in therapy, look up

a. <http://everybodydrum.com/rhythm/index.html>

b. Interview with the drum facilitation veteran, Arthur Hull, please find at

http://www.cruzy.com/index.php?option=com_content&view=article&id=66&Itemid=118

9) Intensive Course in Asia for Arts based therapies based on Buddhist principles and practices, please find at

a. <http://wcclf.org/signature.htm>

10) Intentional Peer support and training, by Sherry Mead and Chris Hansen, please find at

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

11) On Recovery by Sherry Mead, find at

<http://www.intentionalpeersupport.org/apps/videos/videos/show/17038001-shery-mead-on-recovery>

12) A classic form of Mindfulness Based Cognitive Therapy created by Jon Kabat-Zinn found at

www.mbct.com

13) A website giving great resources on Mindfulness: <http://www.mindful.org/>

14) A survivor group from UK has put up resources here:

<http://www.asylumonline.net/resources/alternative-sources-of-support/>

Evening reflections

The morning feedback and summing up by the facilitators was useful in bringing clarity to the issues of psychosocial disability / mental health issue. The practice at two levels of non-formal / formal care was useful. It suggested a way to create diversity of options. The context of homeless may differ from place to place. In Kolkatta, the homeless seem to be anchored to a community. Kathmandu situation may be different. In case of homeless, we only ask, 'Who will decide for them?' not 'Why not ask them?' Medical system wants us in, but they provide 'easy fix'; disability system does not want us in, though we agree to having a disability experience. So, there is a serious identity crisis. People will go where a door is open: For example, people will create programs in institutions. In China, and in India, people have chosen PROJECT UNLOCK: Unlock from home, lock in hospital; Unlock from hospital, lock in home. It is good to know about innovations, as we need to build our evidence. Open Dialogue method is probably very costly, too costly for our region, and people accept that evidence because medical professionals are creating it. Peer support is a very useful concept, but how to go about this? Can we have some trainings / sharings? How to give support to people who are experiencing 'first episode psychosis'? Role model and writing about self experiences with psychosis and peer support is another way of reaching the message across. Trainings on this could be developed.

May 3rd

Legal frameworks, human rights and litigation

Strategic Litigation: Tirza Leibowitz

Tirza Leibowitz (from the OSF) initiated the session with a presentation on Strategic Litigation. Strategic litigation is never used alone, and is usually contextualised. What is the goal expected, needs to be well thought out. For example, in her experience of 2 kinds of strategic litigations, litigation for supported decision making; litigation on elderly to improve the guardianship system, etc. One of these asked for removing the system altogether, whereas another asked for improvement of the existing system.

Individual cases may or may not be strategic. A single case can bring about desired changes at systemic level. It can have impact on a large number of people. Are courts now ready for strategic litigation on the use of forced institutionalisation and treatment? Outcomes on cases relating to forced confinement have not been too great. In Mexico, a person with autism challenged his guardianship. His lawyers had the opportunity of turning that into a strategic litigation. In Croatia, the right to vote was linked to being under plenary guardianship. With help of the disability movement, this link was severed using strategic litigation.

When we take up issues such as guardianship or institutionalisation, do we go and litigate around due process issues (how to have a better guardianship arrangement or a better institutional process?); or challenge these more fundamentally? If we go for improvement of due process, all that the government will do is to issue guidelines and step up monitoring for a bit. The paradigm will not change very much.

Tirza gave the scope of strategic litigation and the variety of cases that can be taken up:

- Mapping, identifying, litigating and eliminating discriminatory laws (e.g. on legal capacity)
- Eliminating abusive systems (e.g. close door institutions)
- Challenging systems level abuses (e.g. restraint, seclusion, shackling)
- Get the government's obligation to provide support (e.g. article 19 litigation)

There are a host of litigable issues in the inter-phase between criminal law and mental health law. There are some offences that have special impact on people with disabilities, for example the vagrancy laws. So making those linkages with other groups may be more effective. It may also be needed to litigate on reasonable accommodation for people who go through the system. For example, when a person is shifted between parallel systems, the sentence could be endless.

Users and survivors, and persons with psychosocial disabilities have an important role in strategic litigation. Lawyers are messengers. DPOs must have in-house lawyering capacity. It may be needed to build the capacity of the lawyers on disability rights. The users and survivors and the lawyers have to work with some common understanding, and CRPD being the frame.

Don't litigate for the sake of litigating. If the risk for negative outcomes is high, immediate need to intervene may lead to regressive judgments. The answer is not clear sometimes. But everywhere CRPD must be the frame. Start chipping away at existing law bit by bit.

It is useful to try not to use the terms 'Mental Health Law' without awareness of what it means around the world. We don't have to talk about the mental health legislation to ask for resources for community based services. If we want more services, we don't need a mental health law.

A strategic step that can be taken, is to showcase good community based programs. In the litigation, be clear, don't talk in SLOGANS, for example, don't say, 'Integrating mental health into primary health care'. Explain community based support systems and services, give concrete details.

It is not only about mental health legislation, but also about civil rights law, disability law, community development law, health care law, etc. Your scope of intervention in law has to be broad. You also have to see who is making that mental health legislation? (The India group shared that the Indian Private Psychiatrists Association made the Mental health care bill.) In most countries of the world, having a mental health legislation didn't do any good.

Having a mental health law will result in 'bundling'. If you want your pension, become 'incapable'. If you want that allowance, become 'incapable'. Etc.

Mental Disability Rights Advocacy China

Mental disability rights advocacy in China was presented by participants from Equity and Justice Initiative (EJI).

In China, we find a highly institutionalized context, with over 4000 state run mental institutions. There are two extremes, of ignorance as well as institutional abuse, and threats of personal safety. Under very difficult, unsafe and politically threatening circumstances EJI has taken the challenging mission of 'promoting the transformation from substituted decision making to supported decision making'. The strategies used by EJI are



- Research and Advocacy for Legal Reform
 - Strategic Litigation and Non-litigation Case Service
 - Peer-support and Self-advocacy by Survivors/Users
 - Awareness Raising



If a legal framework is already in place, it is hard to change. Mapping of legislations becomes priority, including civil codes / constitution; civil laws, how civil commitment is made, procedural safeguards issue, and finally, criminal detention. Within legal framework, we also need to see

how to use existing common law (e.g. power of attorney), without going for special legislations.

In 2010, EJI released a report, 'The Involuntary commitment system of China: A critical Analysis'. This was a comprehensive legal analysis of the institutional laws and how they are used. Another lawyers' handbook was publishing on 'Lawyering Strategies in the Representation of Mental Health Care Users / Survivors'. Capacity building of lawyers were done. Slowly a Chinese network of users and survivors is coming together. A protest was held against involuntary commitment. EJI does media advocacy also every now and then. One of the achievements of EJI in legal advocacy is that now legal aid can be accessed by users and survivors. The Mental Health Law now includes the Right to refuse hospitalization; substantive improvement in standards of involuntary commitment; and the standard of capacity to informed consent.

The system of plenary guardianship for adults is also very much there. China has many incapacity laws. EJI has been working on right to access a lawyer / access to justice; right to refuse treatment. They are

concerned how, in what ways, lawyers can come into supported decision making process. The dilemma exists, whether we should bring correctional methods into incapacity legislation, or we should bring full legal capacity into law and litigation. EJI debated whether capacity to consent is a medical standard or a legal standard. Law is such, that if MI is determined, automatically, capacity to consent is lost. Using general laws on capacity is an option. Other option is to bring legal capacity into law.

The strength of EJI is that it is good at legal research, legal reform, lawyers' network and legal service (both formal and non formal), but it is not good at community services. There is in fact trust in lawyers for help, and EJI gets numerous calls for help. There is less concern of being labeled or stigmatized. There is a need to capacity build civil society at large on the CRPD and the rights of persons with psychosocial disabilities.

EJI also advocated inclusion within 'disabled persons protection law', enacted by government.

Budgets monitoring as a tool for advocacy

Enabling CRPD compliant budget advocacy is a crucial tool for DPOs to advocate for the mobilisation and effective use of public resources in the implementation of the UNCRPD. With support of NDN, and led by IDA, resources mapping was done in India and the Philippines. Often we ask for 'stepping up' expenditure for mental health. Public budget does not give information on quality of spending and outcomes. It does not mean, where money is spent, we are happy how it is spent. There is no way of knowing what impact. XII Plan documents in India suggest that disability is considered largely as a medical issue. Rehabilitation centers do not have any general guidelines for their work. Institutions provide employment opportunities for a variety of people. But there is a need to develop true alternatives, put the debate on the table. The money is there, the demand / supply process is in place. But how do we frame the supply? Who is giving the frame for the supply? Who is making the accreditation, on what standards? WHO, Psychiatric Associations, World Bank.... The voices of communities are not heard. Our community is considered 'incapable'. We have to study the systems that spend the money, which ministries, under which boxes?

Philippino coalition for persons with disabilities includes over twenty DPOs / NGOs / national federations / parent organizations. It has cross disability representation, including psycho-social, intellectual sensory (hearing / visual / speech), mobility, and chronic illness. The coalition represents over 100,000 Filipinos with disabilities. As part of its monitoring work on the UNCRPD, the coalition has been engaged with studying government spending for persons with disabilities from December 2011. As with India, all national government agencies budget at least 1% for persons with disabilities. In such studies we have to follow budget allocation, release as well as utilisation. Having comprehensive flavour, the project activities includes in the first phase, budget tagging, budget tracking, analysis of a program for persons with disabilities, procurement policies, tax incentives and spending in local governments. In general, the Philippine government has not spent what it should have for persons with disabilities (since 2008). There is no disaggregated data; there is lack of clear policy, and poor monitoring mechanisms. In the Philippines, the coalition is concerned about mandatory earmarked budget for spending for persons with disabilities in general. They are also concerned about spending on regulatory mechanisms for provision of community services; social protection; poverty reduction; access to justice and spending on justice; economic empowerment; and procurement policy. At this point, the coalition is involved in advocacy at legislative level, in partnership with Social Watch Philippines (which has started an Alternative Budget Initiative).

Panel discussion on 'Inclusion of persons with psychosocial disabilities within the cross disability movements'

Discussants: Liza Martinez, Philippines; Mr. Javed Abidi, National Disability Network, India; Mr. Sudarshon Subedi, NFDN, Nepal

Facilitator: Alexandre Cote

Three questions were posed before the panellists

1. How did the cross disability move come into contact with persons with psychosocial disabilities?
2. What are the contributions by persons with psychosocial disabilities to the cross disability movement?
3. What are the challenges posed by inclusion?

First contact

Nepal: In the beginning, the professionals led the disability movement. After 1991, there was an opportunity to establish a self advocacy movement. Nepal did not think cross disability until after exposure to the CRPD, and association with DPI. This topic of inclusion also came up when changing national law. Self advocacy organisations like Mental Health Foundation and Koshis, who were earlier independent, started pushing NFDN on inclusion. Some DPOs are internalizing the issues of persons with psychosocial disabilities.

Philippines: Until now, there is no DPO of persons with psychosocial disabilities in the Philippine coalition. There is 1 DPO in the country, but they have not yet signified that they will join the coalition. Some independent self advocates have joined, through personal contacts here and there. There are some organisations working, such as Depression Fighters of Philippines. The deaf community of Philippines have strong affiliation with the group of persons with psychosocial disabilities. We had close experience of the deaf in the Manila mental hospital. This all got us interested and we try to keep up with building our own awareness.

India: In 2001, there was a fire accident in south India ('Erwadi' incident). NCPEDP wrote to Maneka Gandhi at that time, but they had no contact with any person with psychosocial disability. At the humanitarian level, inclusion was understood and accepted. In 1995, the Persons with Disabilities Act was enacted. 'Disability caused by mental illness' was a part of the law but did not result in a paradigm shift. This group was there on the list, but was a forgotten group. With CRPD coming in, Disability Rights Group / National Disability Network advocated inclusion and cross disability perspective. The laws were getting modified and the government was putting together a group. We heard about some activists / survivors and started inviting them. At first there was suspicion, doubts, anger. We were not so well aware about the disability. Interactions started, but trust building takes time.

Added value to the movement

Liza Martinez shared that, the cross disability movement has had the value of 'inclusion' for a long time. Yet, it was in abstract. Having that face / a live person who is telling his or her story is important.

In Nepal, Shudharson Subedi shared that having the two DPOs in the coalition has sent message to the cadres and they have started working on inclusion.

Javed Abidi from India talked about elements which makes the whole movement truly 'cross disability', holding together like a rainbow. When new groups got added, such as people with leprosy, the movement learns to introspect, learn new things. When the message goes out from the leadership, members start adding value to the introspection. Only recently we have had some people admitting that they are people with psychosocial disability. For others this is a new experience.

Challenges

Liza Martinez shared that it is a challenge to change the attitude of society and of the policy makers. Its also difficult to break the chain of a medically / professionally dominated society. Implementing policy and legislation for the group which is UNCRPD compliant is a huge challenge.

Shudharshon Subedi shared that the number of members from this constituency is very low. In the cadres, only about a quarter of us actually believe that persons with psychosocial disabilities should be part of the disability sector. This fact was disturbing. There are anxieties about competition over meagre resources. The highly discriminatory laws do not allow for inclusion. These are colonial and archaic, and we are concerned, how they can even exist. They do not understand what is the disability. Stigma, privacy and disclosure issues are all there.

Javed Abidi shared that at national level, message goes out, but how does it percolate at the state level. Are we so selfish, that we want to address only our own disability? With persons with psychosocial disabilities, there are not enough numbers. And of course, the legal barriers! However, we have to put out this message that, 'Its ALL or NOTHING'. The biggest challenge was how to bring the blind and persons with psychosocial disabilities group together. We split when the intellectual disabilities group left the coalition. Political realities are rough. The present RPDA draft is 8 on a scale of 10, an improvement over the past, but not perfect. It has moved from cold storage to the oven. Is it possible for the movement as a whole to wait another 10 years? Soon in India, there will be elections. There is no solidarity on the Mental health care Bill. There is no readymade formula for it to become something else. We can say some cross disability sentiments are there, the movement has responded on inclusion, and not left it just to persons with psychosocial disabilities. In the Delhi dharna against the MHC Bill, cross disability activists were there in full measure, only few persons with psychosocial disabilities were there. Our involvement surprised the country, the media, the mental health sector. At that time we were able to stop the Bill from reaching the Cabinet.

SWOT analysis

Strengths

- Ratification of CRPD by many countries in the region
- Clarity about the coalition in the region and consensus already reached
- Other disability constituencies and their added strengths to our movement
- Successful grassroots advocacy and experiences of providing peer support / mental health care
- Regional collaborations and ongoing conversations
- Global, regional support from cross disability coalitions
- Availability of online communication in the region
- Growing knowledge on policy and legal advocacy interventions
- Growing knowledge on alternatives
- Increasing number of self advocates
- Public awareness of psychosocial disabilities
- Evolving laws for people with disabilities
- Solidarity
- Safe spaces

Weakness

- Lack of self advocates at the national level
- Lack of awareness and knowledge of psychosocial disability issues
- Limited acceptance by cross disability movements
- Language barriers at the regional level
- Stigma

Lack of a regional dialogue
Culturally we do not challenge bio medicine
'Invisible' disability- not a priority or different priorities
Slice of the pie becoming smaller: fears
Lack of resources
Lack of vision and unity, intragroup conflicts
Identity crisis
Lack of understanding of sexuality, right to have family
Lack of alternatives / natural therapies
Collectivism, sacrificing individual rights for collective purposes
Lack of voice of persons with psychosocial disabilities

Opportunities

External funding and international co operations for innovations
New emerging area, innovation potential
More voices (CSOs)
Regional collaborations through internet
Existing practices to leverage from
Private sector / CSR motivation
Research, data, publications and emerging resources worldwide
UNCRPD committee COs, and possibility of influencing UN agencies
Media (digital media included)
More interest in strategic litigation
Socio economic and cultural changes
Our 'global movement in mental health advocacy'
Critical psychiatry
Few young supportive psychiatrists
Integrative psychiatry
Alternatives networks (INTAR, InterVoice, etc.)
Available medical ethics and informed consent process
Alliance with cross disability movement
Alliance with LGBT, women's groups, other human rights groups
Human rights law networks
Technological and information opportunities
Economic strengths of the region
CRPD and other HR monitoring treaty bodies

Threats

Prevalence of medical model
Lack of financial support especially rural areas
Geographical barriers
Patriarchy
Lack of culturally relevant theory and practice
Long history of stigma
Negative Attitudes
Legal capacity laws
Professionals' mind sets
Changing political environment is difficult
Mental health is low priority
Knowledge limitations (no new knowledge)
Political climate within the health system

Pharma lobby
Power of experts
Lack of policies ensuring choices and self esteem
Mushrooming of institutions
Lack of policies during situations of risk and humanitarian emergencies
Easy availability of mental institutions
Discriminatory laws and practices
Unavailability of the system as per choice
Inappropriate use of resources

May 4th: Strategy and vision for the region for people with psychosocial disabilities

This day was devoted only to vision building and strategizing for people with psychosocial disabilities. Several questions of identity, mobilization and organization came up. It was aimed from the morning that we will name ourselves, and come up with a 'statement of purpose'.

How much should we get involved in global political circles, and in what way? We were aware of the dialogue between Global Mental health movement and Transcultural Psychiatrists. This was more of a professional turf struggle among academicians and clinicians. While linkage with the academia is all important, our question was more about how to mobilize persons with psychosocial disabilities / users and survivors in the Asian region. Should we go for a regional organization? How would we call ourselves?

Where do we stand at regional, global level? The identity issue is still troubling. There is a need to acquire and transfer knowledge and skills within the Asian region. Fund raising for regional work is also very necessary. We must recognize the difference as well as universal picture for countries in the region. In this workshop we have seen the spectrum from China to Nepal. We should identify indepth work that we can sustain for sometime; rather than superficial work.

A legal strategy paper will be very useful. We must study the regional differences between countries; and also advocate for repeal of all discriminatory, incapacity laws and laws legitimizing forced treatment, if any. We must ensure that Article 12, 14, 17, 19 of CRPD are complied with in all countries. In Nepal, the community has challenged the law makers to come up with a fully CRPD compliant mental health legislation. Article 25 of ensuring consent based, good quality health care is also an important point of advocacy for us in the region.

Since traditional family is still very much largely the support system, and also, people with psychosocial disabilities do not exercise right to marry, have a partner, have a child, etc., the right to family should be considered as an advocacy agenda too.

Developing political literacy (identifying political agendas, allies and actions) would be useful, perhaps through a capacity building workshop.

Capacity building was needed on developing good practices and modeling 'alternatives'. Where there are no psychiatric services, use of term 'alternatives' is perhaps not appropriate. A wide variety of systems and practices are being used in the region, such as eastern healing techniques, indigenous healing, yoga, meditation, running, martial arts, cognitive behavioural and counseling techniques, diet therapies, naturopathy, homeopathy, Chinese medicine and other local systems of healthcare, etc. Because the laws are not there, or they recognize only psychiatry, even counseling and psychotherapies are considered as 'alternatives', whereas in the west, they are part of mainstream systems. We need capacity building on how best we can reclaim and use these and other fitness resources. We needed new terminology to 'alternatives' and 'transforming communities for inclusion'

is more development & community orientated, than medical orientated. *An Asian Hub on transforming communities for inclusion, recovery and rights based approach to care could be created to upload and share resources on this subject.* We need to consider local operational solutions and many can be so found, instead of adopting western models.

These services must be linked with access to development. While MDGs, and inclusive development is being talked about in highest policy circles, persons with psychosocial disabilities are nowhere in the picture. Before racing / squirreling for the Development acorns, the gates must be open to let us out into the play arena of inclusive development. Opportunities for entering the education system and completing it must be created. Focus on inclusive education must have this age and life span outlook on disabilities. Some people with disabilities need to be included right from the early age; others need an opening when at a later age, they experience disability, and drop out of the education system, typically in high school or early years of college.

Our movement must conceive of the meaning of 'reasonable accommodation', 'support system', 'user run services' and 'peer support'. Global organizations like WNUSP must help us in this process of meaning creation. If each individual is left to define reasonable accommodation for themselves, our chance of inclusion in the cross disability movement is forever lost. Trainings must also be offered sometimes to build regional capacity on these notions and their operations at grassroots level.

Life cycle approach will determine the range of support services required. Children and adolescents facing a crisis require really sensitive, and holistic interventions. 'Early intervention' in the mental health field can be experienced as highly traumatic. Young adults who have experienced psychosocial disabilities will greatly benefit from support groups right from the stage of 'early intervention', to hold people through to recovery, including preventing relapse. Such efforts will lead to the increase of 'social capital' available to persons with psychosocial disabilities, to enable living independently and to be included in the community. Such approaches would also be gender sensitive and empowerment oriented. The traditional mental health systems are useful, but need to be changed systemically to incorporate these values and ideas. The care systems should be open to alternatives and choice. Policy should compulsorily allow for choice and alternatives and remove the gate keeping barriers set up by the medical system.

As DPOs, we must demand services, not supply them. We must lobby to create pathways for full and effective participation and inclusion of people with high support needs, and inclusion, even within cross disability coalitions. We need to play a key role in monitoring the CRPD; among other conventions, treaties, and regional commitments made by governments. State must be proactive in identifying, mentoring, reorganizing services within the frame of the CRPD. NGOs and DPOs can create models for showing the possibility. Particularly, models are needed which will reduce or stop people going into mental institutions. We are expecting to be fully included within disability rights bills, in countries where these exist or are being formulated.

Study of COST in the mental health sector is a mandatory activity for this group in each country situation: Institutionalisation, how much that costs; de-institutionalisation of 1 person; community care; cost of choice in non medical approaches; etc. If we don't have concrete figures at our beck and call, we will not have sound arguments.

We drew a political map of all the players in the mental health field, and our likelihood of joining hands with any or all of them. Considering that there were global disability networks, regional disability networks, academic institutions specializing in disabilities, medical and trans-cultural psychiatry forums, many counseling, psychotherapy and alternatives forums, human rights networks, user survivor networks (national, regional and global), various national cross disability coalitions, legal aid networks and collaborations, community based rehabilitation networks: It is impossible to be a part of or collaborate with each and every one of these networks and alliances. Also in any and all countries

of the region, there is no national user / survivor network; or network of persons with psychosocial disabilities. Therefore, to maximize contributions, we can consider being a resource group or a think tank for Asia.

Eventually, the group settled on the name of '*Strategy group for transforming communities for inclusion of persons with psychosocial disabilities*'. Based on these reflections, a 'statement of purpose' was made, shared below.

Schedule 1

Statement of Purpose

From the

**'Trans Asian Strategy Group
for persons with psychosocial disabilities'**

Prepared at

'Transforming communities for Inclusion of Persons with Psychosocial Disabilities: A Trans-Asia initiative',

Held at Hotel Holiday Inn, 30th April – 4th of May 2013

People with psychosocial disabilities, along with a few cross disability leaders, from 5 countries of Asia (Nepal, Philippines, Bangladesh, China, India) met in Pune this summer, organized by the Bapu Trust and supported by the Foundation of the Open Society Institute¹.

The objectives of this meeting were to provide a regional space for people with psychosocial disabilities to share, learn from each other, and create strategies for inclusion; and to find a common vision for future advocacy on the implementation of CRPD for people with psychosocial disabilities, supported by the national cross-disability movements.

On 4th of May, persons with psycho-social disabilities from the region met, and we came up with a Statement of Purpose, for future action in the region. Our Statement of Purpose is as follows:

- 1) We name ourselves as the **‘Trans Asian Strategy Group of Persons with psychosocial disabilities’**.
- 2) Our scope of work is Asia.
- 3) Among the many identities available to us, we choose a common identity as ‘Persons with Psychosocial Disabilities’.
- 4) Human experiences of ‘identity’ are broad and all encompassing, including gender, ethnic, professional, creative, recreational, sport, spiritual and other possibilities of belonging in groups. Our identity (as ‘user’ / ‘survivor’) should not be determined only in respect of our individual relationship with mental health system.
- 5) Our **purpose** is to advocate for the inclusion of persons with psychosocial disabilities in the Asian region by using comprehensive strategies of (a) creation of knowledge base (b) development and sharing of social innovation and skills and (c) public policy advocacy in the region.
- 6) We stand firm on the principles of CRPD and its broad and inclusive definition of disability.
- 7) Congruent with the CRPD frame, we are not singularly focussed on medical treatment issues (either **for** or **against**). We highlight a range of issues beyond the notion of medical treatment: social inclusion, safety, self-dignity and the fulfilment of human rights, liberty and freedoms, education, independent living, employment, etc. We will address the indivisibility of human rights as framed by the CRPD. In further discourse of our human rights, our priorities will be all civil and political rights, as we, as a constituency, are at more risk of losing these rights through incapacity norms.
- 8) Health care services are already available as part of our choice in most countries of the region. We have certain expectations from health care services, viz., care and treatment should be available based on our choices and freedoms. Governments should recognize diversity of needs across the spectrum of mental health and psychosocial disability; and enable a diversity of services across the spectrum.
 - a. Where non-medical alternatives do exist in Asia, health service providers often end up gate keeping, in the name of ‘best interest’. We expect existing health care service providers go beyond gate keeping on alternatives.
 - b. Government should ensure and promote a wide range of non-medical support systems and alternatives, so that we can truly exercise choice.
 - c. We have inherited many social, cultural and spiritual traditions and practices, which can be developed as stand-alone alternatives and / or to complement medical treatment, based on personal choice and genuine free and informed consent.
- 9) We favour de-institutionalisation in the Asian countries where institutions do exist.
 - a. We favour the preparation and transformation of communities for the inclusion, and full and effective participation of persons with psychosocial disabilities, by developing holistic community level support systems.

- b. The issue is not about being 'least restrictive' in medical practice, but how to enable a support system. Governments must engage in learning more about harm reduction strategies in situations of health care or other psychosocial crises.
 - c. In the age of the CRPD, restriction of human rights is not option, and we are focussed on exploring ways of facilitating the support of persons who have psychosocial disability, in ways which are respectful of everyone's human rights as human beings.
 - d. There may be people in our community who experience extreme states and will appear to need involuntary treatment. But we can be respectful of their consent through the creation of different kinds of formal and informal support systems.
 - e. We believe, based on new scientific knowledge, that early interventions must be skilled in holistic and alternative approaches, so that a chance at recovery can be provided right at the start of the psychosocial distress experience. If addressed early, many people who experience extreme states need never enter the medical system.
 - f. We envision healthy mind and body for the region, not dependent on medicine but free of medicine as possible.
- 10) We are concerned about the overall medical negligence of people with psychosocial disabilities, who are diagnosed as 'mentally ill', homeless or who are living in institutions. If suspected to be 'psychotic', they are not given proper medical diagnostics and treatment, and their general health issues are considered to be additional symptoms of their mental illness.
 - 11) There are a number of countries in our region, where new laws or amendments of old laws are being proposed. We want laws, old and new, existing and proposed, relating to disabilities or general laws, applying on us to be fully compliant with the CRPD.
 - 12) Living independently is a larger social and gendered construct in the Asian region. We need to address that through larger debate on its impact of people with psychosocial disabilities.
 - 13) Violence against people with psychosocial disabilities and issues of safety, especially for vulnerable populations like women and children, will be a priority for the strategy group.
 - 14) Within larger Development agendas and goals for the region, the strategy group will highlight the demand for equal and equitable distribution of resources to promote and protect of PPSD in the Asian region from the government and international community, donors and multilateral development agencies and business communities (MDGs, post-2015 Development agenda, World Bank, etc.).
 - 15) We understand the full political map of players who are within our action map and our individual engagements with various groups: They include the various medical and medical-cultural groups active in the region; the World Health Organisation and its different departments; cross-national human rights institutions active in the region; worldwide organizations on social innovations, psychosocial interventions and alternatives; the world and regional networks of users and survivors of psychiatry; bi-lateral aid agencies; and finally, cross disability alliances representing people with disabilities regionally and worldwide. In terms of who we will dialogue with among these players, the door is open. We engage and dialogue with everybody.
 - 16) We need better internal organisation and communication to prepare for any political intervention as a group. We will work at an appropriate time in future, towards the creation of a movement for persons with psychosocial disabilities in the Asian region. That is not our present priority.
 - 17) As a strategy group, we need to educate and skill ourselves in learning about global alternatives to give support and care to people in extreme states.
 - 18) We need to brainstorm on one or more legal strategies which will start a support system in place when in extreme state.

Schedule 1

DAY 1 Unbundling	Day 2 and 3: Developing services and addressing dilemmas		Day 4 Institutional environment	Day 5 Peer learning
Parallel brainstorming session: Persons with psychosocial disabilities/allies to specify expectations towards the workshop and questions for the other group Definition issues: mental health problem / psycho-social disability, identity question,	Bapu Trust field visit and inputs: Visit communities, exchanges with professionals involved Watching videos about Bapu work and exchange feedback	Presentations from other user led service providers	Legal framework, rights and litigation: Tools to advance rights of persons with psychosocial disabilities or to consolidate barriers?	Learning from the week, Exchange, open discussion, sharing experiences
		Presentation/Discussion of example of alternatives/issues from other countries representing	Introduction to the economy of mental health sector: What does it mean for people, families and public budget?	Which movement of persons with psychosocial disabilities in Asia?
			Panel with cross disability leaders on Inclusion within cross disability movement: Javed Abidi, DPI chair and IDA vice Chair Shudarson Subedi: president Nepal federation of disabled people Liza Martinez: Phil Deaf Resources	Way forward planning next steps
Plenary discussion				
CRPD refreshment: Principles and states obligations, review of CRPD committee CO&R				
Visioning: Implementation of the CRPD for persons with psycho-social disabilities- country experiences				

ⁱ The program was organized by the Bapu Trust for Research on Mind & Discourse; supported by the Foundation of the Open Society Institute and co-hosted by Holiday Inn, Hinjewadi, Pune. The 'Vision and strategy for Transforming Communities for Inclusion' idea was conceived of through the period of the TOTAL trainings, in many conversations and the Pune peer learning workshop was eventually facilitated by Bhargavi Davar and Alexandre Cote.