**English**

**Questionnaire on “disability-inclusive policies”**

1. Please provide information on how your country is considering the rights of persons with disabilities in their **policies aimed at** **implementing and monitoring the Sustainable Development Goals**, including:

* Existing national strategies and action plans,

Why we need a global Mental Health Target in the SDGs

***HIGH PREVALENCE: 1 in 4 people experience mental illness, 1 billion people worldwide experience a disabling condition. The WHO estimates that 1 in 4 people will experience an episode of mental illness in their lifetime, ca. 600 million people worldwide are disabled as a consequence. Most (85%) of these people live in Low and Middle Income Countries (LMICs)* [including my country] *India. Psychosocial disability is one of the most pressing development issues of our time.*** This is as per Vikram Patel’s estimate. While these figures indicate that there is an urgent need to bring in the western psychiatry paradigm into India by scaling up western psychiatric treatments for mental illness for instance there is increasing evidence on the other hand to show that people suffering from mental illnesses in low and middle income countries actually show higher recovery rates because of the therapeutic aspects of community living which can feed into recovery at a much, much, better and higher pace. While we do need SDGs in many places in India we must also consider views from the user-survivor standpoint as to why we need SDGs. There are a number of non-psychiatric alternatives that people with mental disabilities have access to in India and yes even in the rural areas- such as a number of community based and local non-psychiatric alternatives such as gardening, the use of various *rishtaas* and *choornaas* meaning local herbal concoctions and herbal jams. There are sites of traditional healing which if tapped can yield better outcomes for mental health treatments when combined with medication because these are things that many people have belief in – in fact whenever there is a mental illness people first seek recourse to faith healers and so if the faith healers themselves have psychiatrists with them in traditional healing sites to dispense medication many, many, people would avail both of these as is the case with Milesh Hamlai’s Dava Dua project and again for people who can’t cope without medication there would be the added benefit of a religious support system which could simply transform lives if taken along with medication for these people. And for those who can manage without medication the spiritual support system of the Dhargas or other religious healing sites would be an added benefit if combined with proper non-victim-blaming family support and healing modalities like yoga, pranayama, art therapy adapted to the Indian context and so on. The problem arises when what we see in the west as part of experiments are factored into Indian contexts without even considering local realities and are expected to produce the same results which they certainly wouldn’t. Also the west needs to learn from our country the same way that it is thought that India should learn from the west as far as psychiatry goes. Are all of these debates being factored into the millennium development goals in India? I should think not!!!

GLOBAL EMERGENCY: Human rights violations, stigma and discrimination

***Worldwide people with psychosocial disabilities experience most severe human rights violations, including being tied to beds, kept in isolation, being chained and caged in small cells, and being physically abused by ‘traditional’ healing practices. This failure of humanity is a global emergency and requires immediate and sustained action.*** This is as per Vikram Patel’s analysis. The failure of humanity would be even greater if psychiatric treatments that are cruel and torturous were to be forced upon people against their will as per the user survivor standpoint. Reasons why approaches like the Soteria Models that are so good in themselves are not being promoted in India could only be attributed to the greed of pharmaceutical companies and doctors that are trying to manufacture illnesses in order to be able to make dough. Family systems that make people dysfunctional are to be completely changed and revised. The intricacies of interaction of family members with the affected person would have been terribly dysfunctional thus inducing mental illnesses in the victims with sensitive minds in the first place. If we don’t target the problem at its root it can lead to disastrous consequences such as over-medicalization of illnesses. Also says Patel, ***THERE IS A GROWING BURDEN OF DISEASE: Reduced lifespan by up to 20 years Mental and behavioural problems account for 7.4% of the global burden of disease measured in DALYs, and command nearly ¼ of the global total. This is the biggest single cause, more than cardiovascular diseases and cancer combined. In high income countries men with mental health problems die 20 years and women 15 years earlier than other people. In low income countries this mortality gap is likely to be much wider.*** THE GROWING BURDEN OF DISEASE? Aren’t the families and psychiatrists that lack holistic perspectives and engage in horrible patterns of behaviour as much a burden to the psychosocially challenged as the psychosocially challenged are a ***burden*** to these families? Who first induced/started the problem?

CROSS-CUTTING ISSUE: Impact across the whole range of SDGs

Mental health is related to many other aspects of health and development, like being critical to success in addressing poverty and economic development. The mental health status has strong links and impact across many thematic areas of the SDGs. The WHO has considered this in the Global Mental Health Action Plan. For once we hear something sensible.

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***‘STRONG EVIDENCE: Treatment gap of up to 98%. Globally, there is chronic under-investment in psychosocial disabilities, and a huge mismatch between investment by governments and the relative burden, resulting in a huge treatment gap and a lack of access to treatment. In low income countries, less than 20% of people are able to access services, in some countries, and for more severe illnesses, the treatment gap is as wide as 98%. This lack of access to treatment breaches the fundamental right to accessing health care’*** as per **Patel.** While it may be a fundamental right to access medication it is also as much a fundamental right to access non-psychiatric alternatives and resist forced treatment by psychiatry. It needs to be done and decided on a case to case basis. It is a sliding scale and not a total all or none phenomenon. Also there may not be any treatment gap at all!!! There could be gross and disparate social inequalities involving finance, gender etc. thus triggering off mental illnesses when help is nowhere in sight. Why isn’t Patel considering that at all? Are all of these things coming from various quarters being considered when sustainable development goals are being formulated?

***GLOBAL POLICY: Growing international recognition***

***Recently, global development budgets saw growing recognition of the need to address psychosocial disabilities in development. The WHO, the EU, and several high-income governments focus on scaling up services for mental health in low- and middle-income countries. Yet, more commitment is needed by governments and organisations to provide sufficient budgets for psychosocial disability treatment and services*** as per**Patel.**We require budgets to re-start and replicate several initiatives like Soteria Model to solve the problems of people during or just before a first episode of psychosis gets triggered off. Otherwise we will only end up overmedicating people when what might have really been needed would be love, care, non-psychiatric alternatives and work to keep them busy.

* Budget allocation for their implementation,

There is absolutely no talk of government funding and allocating a budget for the kind of things that I talk of and which would greatly benefit the client. The open dialogue approach, Soteria approach, healing via theatre and art etc. etc. are not even been heard of by the governments and general public most often because these are supposedly not ‘evidence based’ whatever this means. Conventional victim blaming and medical approaches are seen as THE WAY to treat people with psychosocial disabilities due to the predominance of the medical model and outdated modes of counselling. The Swedish non-psychiatric ombudsman approach would also be a great model if scaled up in the Indian context- the government however doesn’t even care for all of these!!! Such discourses are not entertained due to a supposed ‘lack of funds since India has never been a rich country like Sweden’ as far as the common arguments of both doctors and beauracrats go. The experiences of the experiential experts are never considered to be valid in themselves.

* Existing mechanisms or frameworks to monitor their implementation,

When there are no such frameworks as I have mentioned above [and which The Bapu Trust in Pune is trying very hard to bring in] how can there even be monitoring or implementation of these- how can something that is not even being encouraged to exist really be monitored?

* How do these strategies/plans take into consideration the situation of women and girls with disabilities, and of children and older persons with disabilities?

The strategies and plans don’t take into consideration the situation of women and girls with disabilities especially psychosocial disability and I talk in the context of mental health/psychosocial disability. In many of the Indian PHCs outdated victim blaming models are being used to counsel the women who come there. Not even a trained psychologist is present in most government village level PHCs. So can there really be any talk of sensitive models of counselling for distress? For example if a psychosocially challenged woman is raped or sexually abused and comes to the PHCs for counselling and help the doctor there may more often than not ask her what she really did to provoke the man in the first place. Such women would be doubly devastated – first because of their disability and secondly because of their gender. The children’s needs are yet to be considered sensitively in many of the settings and so are the needs of the elderly although the situation is slightly better for the elderly who may have better leverage on account of the concept of duty towards the elderly being over rated in Indian society. Gender sensitivity and sensitivity towards children are discourses that are simply absent.

How is the participation of persons with disabilities and their representative organizations ensured in the development and implementation of such strategies/plans?

There are some DPOs that are making a little headway via trying to tap the 3% reservation funds allocated for the PWDs but this is just a starting phase that needs to catch up very soon. Some initiatives are being taken up by the rural DPOS and they do benefit the rural PWDs but a rights based approach in the real sense of the term is yet to be instituted. For instance a letter may be written to a government authority that there are no psychiatric medicines in such and such a Taluk hospital and that users are having relapses due to non-availability of psychotropic or other drugs o trained psychiatrists but there really is no talk of instituting non-psychiatric alternatives like what has been mentioned above as part of the answers to previous questions.

1. Please provide information on the **legislative and policy framework in place in your country concerning non-discrimination**, including:

* Whether “disability” is specifically mentioned as a prohibited ground of discrimination,

Although disability is being specifically mentioned as a prohibited ground of discrimination still people with a mental illness have absolutely no legal capacity in that their guardians have to take decisions for them by law. Also the ‘mentally ill’ or the ‘psychosocially challenged’ have no voting rights. They cannot contract without guardians entering the picture on their behalf and are non-persons before the law although many groups are working to change this.

* The existence of any budgetary mechanism to ensure the provision of reasonable accommodation by public entities,

As per the CRPD guidelines India is on paper at least, obligated to ensure provision of reasonable accommodation for its persons with disabilities. Accessible buildings , toilets , lifts etc etc are to be provided all of which are on paper but the situation of the PWDs is still absolutely dismal in the sense that in many places these things haven’t really been brought into vogue. Many NGOs are fighting for the Children with disabilities in Rural Indian schools to be having access to teachers who can understand sign language or braille for instance and getting a child with a disability admitted to a government school itself can be construed a herculean task.

* Whether the denial of provision of reasonable accommodation amounts to discrimination,

Yes denial of provision of reasonable accommodation amounts to discrimination on paper at least since India ratified the CRPD on October 1st 2007. But implementation is grossly lacking although NGOs are making huge efforts to make the population pick up in these matters.

* The existence of any affirmative action measures for persons with disabilities,

These are as mentioned in the CRPD which has been ratified by India on paper. Nothing new!!!

* The existence of any legal, administrative or other effective remedies available for persons who have been subject of discrimination on the basis of disability (including denial of reasonable accommodation),

The Jeeja Ghosh-case is a case in point. Jeeja Ghosh had been offloaded from a Spice Jet flight from Kolkata to Goa. The pilot was not comfortable with a handicapped passenger flying on her own, unaccompanied by an escort. Even a call to the executive director of the Indian Institute of Cerebral Palsy, who told the staff Ghosh is completely capable of travelling on her own, did not help matters. “I was seething. I have never felt so insulted. The sheer insensitivity made me cry,” said Ghosh. Spice jet has since tendered an apology. But the damage has been done. It's easy to pick on the pilot for being insensitive, for not having the courtesy to come up and talk to her on his own to decide whether she could fly or not. But this is not an isolated case. Nor is Spice Jet the only airline that does not know how to deal with a disabled passenger.

In September 2011, Go Air prevented a blind woman with two children from getting on a flight from Mumbai to Ahmedabad. In May 2011 Kingfisher asked a blind woman to disembark from a Mumbai to Goa flight.

This happens even though airline rulebooks clearly say airlines cannot discriminate against the disabled and must offer them assistance so that they can travel with dignity.

But that is the rulebook. In the world outside the rulebook, as a society we either avert our eyes from people like Jeeja Ghosh or look at them with pity. We don't want to deal with them on our watch. It makes us uncomfortable. We don't know how to even begin to deal with their otherness.

There's no reason to pretend she does not have cerebral palsy, that she is not different. All we need to do is ask if they need any extra help. "I am a regular flier. All I need is a little bit of assistance," she said.

It’s disturbing that an airline did not have the training to offer that modicum of assistance. Getting from one place to another is a fundamental piece of being able to operate independently in the modern world. Jeeja Ghosh is doing her part in fending for herself. As a society, we have to figure out a way to help her do exactly that, instead of offloading her from the airplane.

Ghosh said she was lucky. She knew where to protest. Many others in her situation would have just swallowed that humiliation and tried to go on with their lives. She protested. And won a court case against Spice Jet.

* The establishment of governmental agencies or other similar institutions to guarantee to persons with disabilities equal and effective protection against discrimination.

Yes there is a Department for the Empowerment of Differently Abled and Senior Citizens:

1. Please provide information on the **legislative and policy framework in place in your country concerning** **accessibility for persons with disabilities** in relation to the physical environment, transportation, information and communications, and to other facilities and services; including:

* The existence of national standards, guidelines, and regulations on accessibility and universal design, including access

Now there is this new thing called access audit of buildings and other public structures that the PWDs will also have to use.

* to Information and Communication Technologies,
* The existence of time bound action plans to make public and private facilities and services accessible for persons with disabilities,

The public transport via train and government buses have special seats for the disabled but the disability -rights-vouching people are fighting for two seats in each compartment to be reserved for the disabled.

* The existence of accessibility requirements for public procurement,
* The existence of any enforcement mechanism of accessibility standards,
* The provision of training on accessibility issues for State officials and other actors.

It is only now that many NGOs are taking action to educate the state officials and other actors with respect to disability in the context of accessibility via various trainings for the government officials.

1. Please provide information on the **legislative and policy framework in place in your country concerning support services for persons with disabilities**, including:

* The diversity and coverage of services available (e.g., services for supported decision-making, communication, mobility, personal support, housing and living arrangements, access to general services such as education, employment, justice and health; and other community services),

Yes there are some government schemes to this effect. Each Panchayath has to allocate 3% reservation funds for the PWDs – persons with disabilities. There are numerous governmental schemes for the persons with disability e.g. Niramaya scheme but they are only there on paper. They need to be tapped by means of NGOs conducting various trainings for the DPOs to tap them by placing their demands before the government and Panchayath leaders. Central Government Schemes such as:

1. ADIP
2. Deen Dayal Rehabilitation Scheme
3. National Awards for People with Disabilities
4. An Integrated Programme for Older Persons
5. Vocational Rehabilitation Centre

* Incentives to Private Sector Employers for providing employment to persons with Disabilities.

None.

* The availability of certified sign language interpreters,

Yes.

* The types of service delivery arrangements (e.g. direct provision, public-private partnerships, partnerships with community-based or non-government organizations, contracting out, privatization),

In Karnataka we have Manasudhara scheme wherein the state government gets into a partnership with the NGOs to establish day care centres for the persons with psychosocial disabilities.

* The financial mechanisms to ensure affordability of support services for all, persons with disabilities,

These are in place in some areas pertaining to disability but still that is only on paper - most of the money is siphoned off by the government officials who are in charge.

* How services enable direct choice and control of users with disabilities?

That is yet to happen since this is going to be a very gradually evolving concept in India. In the context of mental health, some conferences and seminars are being conducted regarding the same but we have a very, very, long way to go.

1. Please provide any **other relevant information** (including information from surveys, censuses, and administrative data – statistics, reports, and studies),in relation to the **implementation of existing disability-inclusive policies and action plans in your country**.

PLEASE REFER THE FOLLOWING:

* THE MENTAL HEALTH CARE BILL 2012
* MENTAL HEALTH ACT 1987
* THE REHABILITATION COUNCIL OF INDIA ACT
* THE PERSONS WITH DISABILITIES ACT 1995
* LEGISLATING THE RIGHT TO CARE BY VIKRAM PATEL.
* LEGAL FRAMEWORKS FOR AND AGAINST PERSONS WITH PSYCHOSOCIAL DISABILITIES BY BHARGAVI DAVAR.
* NATIONAL POLICY FOR PERSONS WITH DISABILITIES – ACTS AND RULES.
* RIGHTS OF PERSONS WITH DISABILITIES BILL
* RIGHT TO HEALTH BILL
* DISTRICT MENTAL HEALTH PROGRAM- DMHP

ALL OF THESE DOCUMENTS [POLICIES, REPORTS AND ACTION PLANS] ARE MEANT TO DEAL EXTENSIVELY WITH ISSUES OF PERSONS HAVING PSYCHOSOCIAL DISABILITIES.