

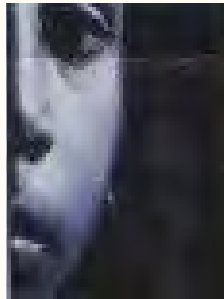
# MaD (MAKE a DIFFERENCE) SUMMIT 2013



A report by  
Anjali Mental Health Rights Organisation

# MaD (MAKE a DIFFERENCE) SUMMIT 2013

March 5, 2013 • Seva Kendra, Kolkata



A report by  
Anjali Mental Health Rights Organisation  
Kolkata, India

MaD (MAKE a DIFFERENCE) SUMMIT 2013

Editors: Sudeshna Basu and Ratnaboli Ray  
Design: The Second Floor • M: 98301 64770

**Acknowledgement**

Ms Anchita Ghatak

Dr Jhuma Basak

Ms Dolon Dutta Chowdhury

Mr Adhiraaj Ray

# Happiness

Happiness and joy  
Everyone is happy today.  
We will enjoy ourselves  
And revel in this happiness.

Come let us be happy  
And fill ourselves with joy,  
There is happiness the world over  
So let us sing along.

I am thankful for this life  
And hope this happiness will be there  
For all, for everyone.  
I don't wish for un-happiness.





Anjali, a mental health rights organization, was set up in 2000 with a vision of a world where the right to positive mental health can be secured for all. Anjali works in one of the most neglected areas of health. Mental illness is not a priority as a health issue in any part of the world and more so, in developing nations, like India. As one of the women from our constituency said, “The feeling of being valuable - ‘I am valuable’ - is essential to mental health.” This can be described as the tenet of Anjali.

## Anjali's objectives

- ◆ To establish mental illness within the mainstream health paradigm of India
- ◆ To 'speak for' a large population of marginalized people with mental illness vis-à-vis their right to a professional and inclusive system of care and treatment
- ◆ Building community ecosystem for mental healthcare and well-being
- ◆ Alliance building and networking for policy change

Anjali, in partnership with the Department of Health and Family Welfare, Government of West Bengal, implements Rehabilitation Programme in three government mental hospitals - Lumbini Park Mental Hospital and Pavlov Mental Hospital in Kolkata and Baharampur Mental Hospital in Baharampur. The rehabilitation programmes have been successful in reintegrating people with psycho-social disabilities back into the society and their families. It has been a long journey with many hurdles and roadblocks but Anjali's persistent efforts have ensured that reintegration was possible for the long-standing users.



A photograph of three women in traditional Indian attire (sarees) smiling and talking. The woman in the center is wearing a blue and white patterned sari and has a red bindi on her forehead. The woman on the left is wearing a yellow and orange patterned sari. The woman on the right is wearing a white and purple sari. They are in a well-lit indoor setting, possibly a community center or a social gathering.

## Rationale behind MaD Summit: Why was the programme conceived?

Mental health does not feature as a priority when it comes to social development discourse or resource allocation/policy making at the government level. Also, because of the various myths and misconceptions associated with mental illness and the neglect towards mental healthcare in general, the sector continues to languish on the fringes.

As a result, the perspective of ex-users are usually left out of the history books, the psychiatric literature and mainstream discourses, leaving explanations of the human psyche and evaluations of treatment regimens to the 'experts.'

Anjali conceived MaD (Make a Difference) Summit 2013 as a day-long meeting with persons with mental illness/psycho-social disability, who languished in government mental hospitals in West Bengal and later were reintegrated into their families or the community by Anjali.



The event attempted to approach the following questions:

- What does recovery mean?
- What are they recovering from?
- What determines whether someone has recovered or not? Is it possible to identify commonalities in the recovery process of different individuals, or is recovery strictly an idiosyncratic phenomenon?
- What have been their successes or hurdles on their road to recovery
- What are the policy implications of all of these?
- How policies can be made more gendered, with better

access of treatment and care to women? Also, how to reduce the patriarchal structure of policies, and schemes for livelihood?

- What is the learning that we can gather from these participants and their experiences upon returning to the community and how to bring relevant changes to the policy-making process in general, with the help of their inputs?

The thrust of the Summit was, hence, on:

- Stories of Struggles
- Stories of Recovery
- Stories of Achievements





The objective of the MaD Summit 2013 was to raise consciousness towards the problems and stigma endured by women with psycho-social disabilities not only while they are institutionalized but also after they are reintegrated into the society and their families; and try to improve the support that society offers to these women. This Summit also aimed to contribute to our understanding of the many forms and faces of violence experienced by women with disabilities. Indeed, violence against women with disabilities should be a concern of the authorities and different civil society organizations.




## Sorrow

You have borne sorrow, pain and suffering  
Will you now accept sorrow?  
Do you think that is all you can hope for?  
Will that be your life?

There is no calm, no quiet  
Life is full of sorrow.  
Everyone is sorrowful, but you  
Want to create a life without sadness.

A smiling face, a happy face  
That's the face you want.  
And let the sorrows of life's battles  
Live in my heart.



## What was the expected outcome

Anjali, through the programme, aimed to delve in to the various challenges faced by women with psycho-social disabilities on a day-to-day basis and their impact on them, even after they are reintegrated into their families and society.

The programme also intended to come to a common understanding of the importance of empowering women with psycho-social disabilities, so that they acquire a more positive self-image, self-respect, assertiveness and effective inter-personal skills, and are able to live their lives as full citizens. There is a need to contribute to the possibility that women with psycho-social disabilities will be able to live without needing to worry about or fight for their access to treatment, care, rehabilitation, education, employment, housing, livelihood, vocational training, the right to have a family and, most importantly, free from the need to combat or tolerate violence at home or in the mental health institutions.

# Planning and preparation for the Summit





MaD Summit 2013 was planned with reference to International Women's Day, to celebrate the achievements and successes of the journeys of the women with psycho-social disabilities. It also aimed at contributing to the future of the women with psycho-social disabilities/mental health conditions by including them in the measures taken for the development, advancement and empowerment of women in general. Anjali's efforts in involving women with mental health conditions/psycho-social disabilities in various activities, educating and inspiring them, contributes to the enhancement of their capacity to speak up for their own rights, while at the same time, empowering them to bring about positive changes in a society where disabilities, gender and human rights will be acknowledged.

The programme was organised on March 5, 2013 at Seva Kendra Calcutta (52 B, Radhanath Chowdhury Road, Kolkata 700 015).



On the day of the MaD Summit, the auditorium at Seva Kendra looked vibrant and colourful with banners celebrating womanhood, empowerment and freedom. As participants started trickling in, there were mixed expressions on the faces. While some looked excited to meet friends after a long time, others looked around with uncertainty, some others were seen setting up the banners right; but everybody enthused over the initiative and the atmosphere was one of happy anticipation. The messages around the room were about power, rights, well-being, safety, freedom, liberty, respect, honour and equality.

“A right is not what someone gives you;  
It’s what no one can take from you”

“No one shall be subjected to torture  
Or, to cruel inhuman or degrading treatment or  
punishment”

“Let’s make her feel valuable  
Because she is”

“Pledge on Women’s Day  
Pledge for mental health rights”

“Recovery is wellness  
Recovery is empowerment”

This day will be different from all other days - the whole ambience promised that.

This was a get-together with a difference. This was perhaps the first time that such a collective had come together to set up a dialogue between the two movements - the feminist movement and the movement to ensure rights of women with psycho-social disabilities, so as to ensure that the future discourses are inclusive of mental health issues.

Leading human rights activists, woman's rights activists, development professionals and government policy makers were present on the occasion.

Two round-table discussions were held, one with the participants and the other with the family members of the participants to get a wholesome perspective.



# Session 1

## Round table with the participants

### Objective

This session was initiated to understand the perspective of the reintegrated participants; how they were doing right now, whether their lives have changed a lot after returning home, their day-to-day challenges and experiences. There was an attempt to understand what is meant by recovery, free choice or happiness, by the participants. Also, the session tried to comprehend if staying in a mental health institution once, changed their lives forever - irrespective of where one was staying at this moment.

### Observations

#### Recovery means:

- ◆ I am a full participant in the community and am responsible for my own life
- ◆ To no longer think of myself as “mentally ill,” and instead think of fulfilling roles such as a worker, mother, neighbour, friend, artist, lover, or citizen
- ◆ To rely mostly on personal, family, community, and social supports rather than getting support solely from the mental health system
- ◆ I am prepared to deal with the stresses in my life and view them as opportunities for growth







- ◆ To become so skilled and prepared regarding an “issue” that I no longer have to cope with it because it is no longer an issue

Seema said, “I spent 10 years in a hospital. My elder brother then asked me to stay with his family, but the younger brother refused. So, I now stay in a residential home in Kalyani. I am doing all my work, but sometimes I suffer from extreme anxiety - “Bhoy Kore” (I am afraid), as if I am “trapped’.”

Renu, bright, beautiful and flamboyant, came all the way from Benaras, Uttar Pradesh, to attend this summit. She

said, “My life is tragic as I do not have my parents, and my husband has been missing for the past 15 years. I live with my brother-in-law and consider him to be my partner now. I often travel to my sister’s house in Faridabad near Delhi, by myself. My daughters are married and I am now a ‘free bird’. But, I get bored.” She also added that, “I worked at different places and saved a lot of money. At present, I am working as a cook at a men’s hostel and earning INR 1500 per month.” She articulated her want of love and also mentioned that, “I want to die in a place that is my ‘own’.”

INTERNATIONAL WOMEN'S DAY

# 'Mad' SUMMIT 2013

A Get-together of recovered persons  
from Mental Health Conditions

March 2013 at Anjali



**ANJALI**

A Mental Health Rights Organization

2nd floor, P-23 D

Tel: +91 33 2290 3711 ■ E-mail: an

health.org





Meera, made the following comment about her marriage: “Oh, it was a rotten marriage. It really was.”

Laxmi, who was living with her brothers, reported that she moved out because, “I felt unsafe with one of my brothers.” She also spoke of the exploitation in the hands of her sisters-in-law. She had to work 24x7 in the house and was given no money. She felt powerless and controlled by her brothers.

Lata, who spent most of her time at home, explained that she “didn’t see anybody for days. . . I was just eating and sleeping.”

Ronita shared that she interacted only with her living companions, who had also experienced mental health problems.

Participants indicated that they often felt lonely and withdrawn. Despite the dependence on professionals and others noted above, isolation was common.

#### **The issues that emerged during the session:**

- Powerlessness
- Isolation
- Lack of safety and mobility
- Stigma, that remained with them forever, even after they fully recovered
- Discrimination faced by women - as they were away from family and home for a long time - they were marked as “loose women” (‘Baje Meye’)
- Apprehension of the common people that they can become violent at any point of time
- Lack of self-esteem, as lot of the times one feels s/he cannot finish small tasks

WOMEN

International Women's

JALI

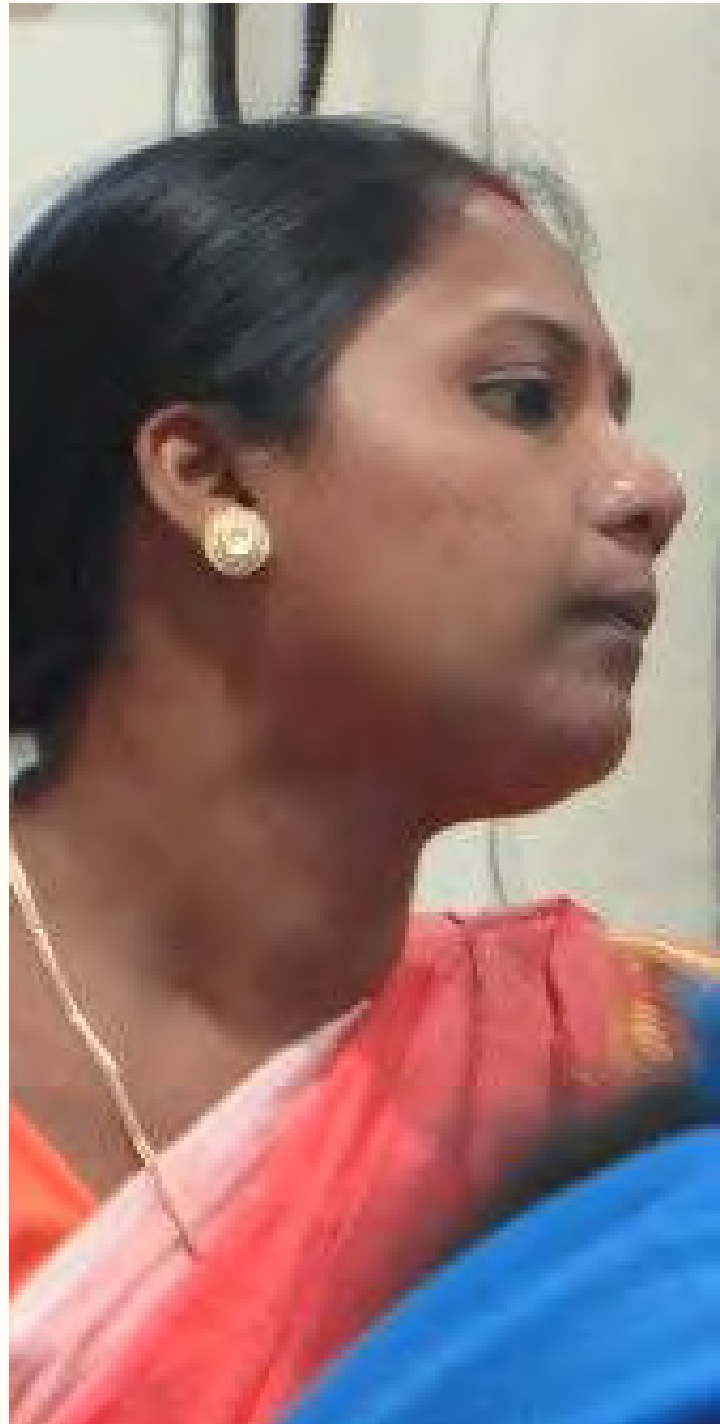
Women's Organization



- Small mistakes at work often treated as symptoms of mental illness
- The fear of being called “Pagol” (Mad) if one forgets a trivial thing. Others also forget things, but they are marked always
- Medicines are expensive and not easily available. To procure them becomes a problem, despite the fact that medicines are needed for maintaining well-being
- Eagerness to participate in the society, and not feel apart
- Rehabilitation is a major problem, since family is not friendly most of the time, and one cannot stay on the roads as police beat up and sexual abuse is common
- Participants live in perpetual fear that family members/police/anyone can forcefully commit them into an institution

### **Outcome of the session**

One of the major issues that evolved in this session, as the women narrated their stories, was the socialization factor. One could get a picture of the social processes of the lives of the women with psycho-social disability - their insights and societal reactions were intertwined in these narratives. There remained a gaping hiatus between full recovery as a patient and full reintegration into society as another human being.



## Session 2

# Round-table with the family members and caregivers

### Objective

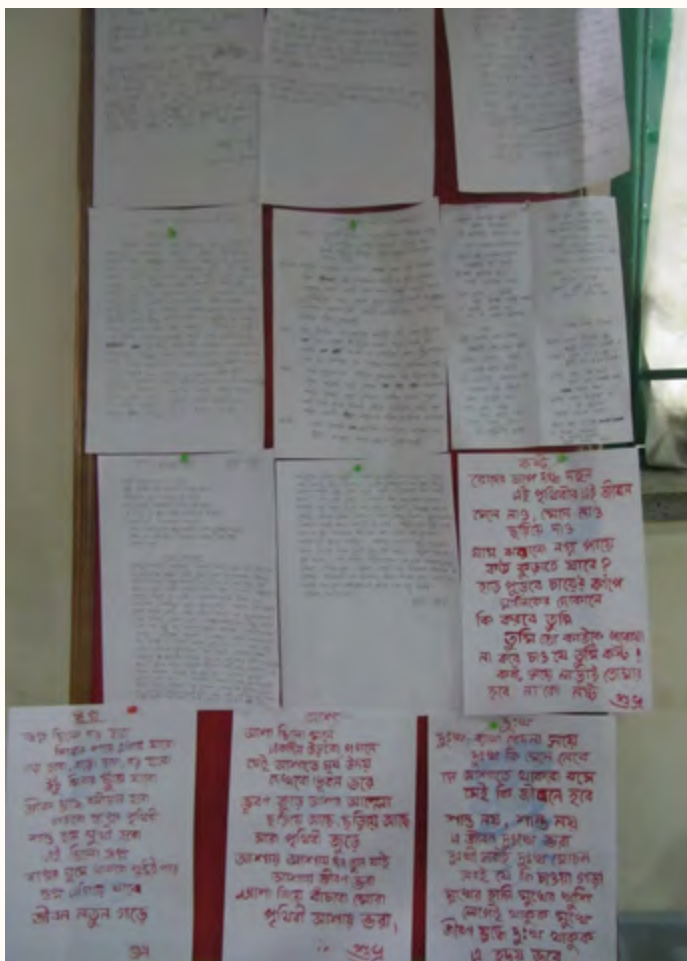
Round-table II comprised of the family members of users who participated in the Summit. The objective of this session was to understand how the family members reacted and managed the situation of having someone with mental health issue within family. One needs to understand the problems they face and the stigma they have to fight, for the well-being of the users.

### Observation and Outcome of the session

The family members shared stories of their wives, daughters, mothers and sisters who had suffered from mental health problems, were institutionalised, recovered, came back and now living with the family; and the problems and concerns that they are facing at this moment. Most of the family members shared their discomfort and remorse when they had put their family members in the institutions and are happy upon reintegration. But, they also shared their apprehensions as there are circumstances where they 'feel' they are unable to provide 'proper' care to the participants.

While talking about her mother, Ranu shared that, "My mother is better after coming back from the hospital. She now does all the household work. She also cooks





for the family, and looks after me and my siblings. We are happy to have her back.”

While talking about his wife, Satish said that, “She is better now; she cooks in a doctor’s house and earns INR 1500 a month. Both our daughters are married. However, she sometimes wants to visit Kolkata to meet her old friends at the hospital and Anjali.”

While talking about his two daughters, Naren said, “Both of them remain quiet throughout the day. Sometimes they

help their mother in the household works and sometimes they do not. They rarely go out of the house and do not have friends. Also, my younger daughter sometimes does not want to take medicines and becomes more reclusive and stiff.”

While sharing about the case of his mother, Sudip said that, “My mother is not well. I work in a shop and my income is limited and there are times when I cannot buy the requisite medicines for my mother. She also works sometimes as a domestic help, but because of her condition, she cannot work consistently.”

While talking about his sister, Susanta said that, “She behaves differently when she is outside her house and when she is at home. She does not listen to anybody; she is very demanding and expects everything to be at her beck and call; does not take care of our parents. She is disrespectful of to my wife and me; and does not help in household work. But again, she is completely different when she interacts with friends, neighbours or our distant relatives.”

There was a great sense of anxiety among the care-givers and family members about the well-being of the participants. The care-givers were apprehensive about how their family members would find them jobs and help them to become financially “independent”, since they had lived in a mental hospital.

When asked about their expectations from the participants, they shared;

- They should be engaged/ employed in some form or other
- They should regularly take their medicines
- Stay at home and not ‘wander’ off
- Some of the family members complained that the participants are late risers

- Should be self-dependent
- Should follow norms and routine of the family
- Should not create problems for the family/ parents

Another issue for the women, was, 'where do they belong'. There were issues of abandonment, where the husband had left his wife and remarried; children had left their mothers and parents/siblings had deserted their daughter/sister. In some cases, the participants were forced to stay in private homes with minimum connection with their families. Very few care-givers shared that they wanted to see their daughters/ sisters married. Somehow love, romance, intimacy, marriage, children, family are not given any importance by the family members. When probed further, family members did express that these were part of symptoms, residual symptoms. The general attitude of the family members towards the participants ranged from a feeling of helplessness to a feeling of pride for what they had achieved and the fact that they had recovered.





## Session 3

# Interaction with the Officials from Department of Health and Family Welfare, Government of West Bengal

### Introduction

The objective of this session was direct interface with the users/survivors and their families with the officials of the health department. This session was important because the users rarely get a chance to interact with the highest officials of the State, who are the policy makers. The officials were briefed on the whole day's proceedings and the charter of demands that came out from the day's discussions was read out:

The charter of demand included (from the participants and their families);

- Availability of more doctors/professionals and care givers so that the demand and supply gap gets reduced
- Medicines should be affordable and accessible
- Improvement in the quality of both private and government mental health institutions
- Employment opportunities for women with psychosocial disabilities





- Ensuring disability certificate and pension are easily available for people with psycho-social disabilities
  - Effective and proper protocols to combat incidence of sexual violence and rape, reported within institutions
  - Ratification of the existing laws against forced admission by the family members/ Police/ Judicial system
  - Regular awareness programmes in rural areas not just on treatment but more focused on societal barriers to recovery
  - Destigmatisation programme to ensure respect and dignity for persons with psycho-social disabilities
  - More accessible information about services available in the State
- Ensuring compassionate behavior of service providers
- On behalf of the health department, West Bengal, Dr. Debashis Bose, Joint Secretary, Dept. of Health and Family Welfare, Govt. of West Bengal addressed the gathering. He congratulated Anjali for organizing such a programme and responded to the charter of demands raised by the participants and their families. He said:
- The acceptance of physical disability among community is further than psycho-social disability, since mental health condition has huge stigma attached. It is important to share and make the community understand that mental illness is just another illness which is curable.
  - He mentioned that State Government has set up fair-price



medicine shops and doctors are supposed to prescribe generic drugs which is much cheaper than the drugs which are available at the market

- He also mentioned that the State has more human resource placed at the government facilities compared to other states, but there is a demand and the State is reassessing and allocating human resource as per requirement.
- On the income generation programme, he mentioned that the State has introduced Bangla Swanirvar Karma. Recovered persons from mental hospitals can be recommended to this programme, under “Special

Category” and his department will take action accordingly.

- Regarding disability certification, he shared that his department is negotiating/ liaisoning with the Social Welfare Department and measures will be taken to resolve the issue.
- He also added that the health department is also in favour of speedy discharge and would like to start half-way homes in the State soon
- Regarding sexual abuse within institutions, he said they will take action as soon as they receive a complaint. A circular on this issue has been issued.



- Regarding forced commitment, he said that his department is open to take any suggestions, both from State as well as civil society organizations, as to ways to manage this concern.

### **Outcome of the session**

Despite the strong positive assurance from the State representative, most of the demands in the charter still remain unfulfilled. Medicines are still exorbitant for most families to afford. The State is yet to create a “Special Category” for the employment of recovered persons from mental hospitals. The issue of forced commitment remains unresolved till date, and no action has been taken in this

regard. Government facilities are still inept at handling users, due to lack of human resource and attitudinal barriers.

### **Conclusion**

Keeping in mind the objective of the MaD Summit 2013 - to get a wider perspective of the users with mental illness, and their families; on their ordeals, their struggles, their joys and their successes, for a more inclusive empowerment discourse for them in future - it can be said that the Summit was immensely enriching and an eye-opening experience for all.

The interaction enabled us an insight into the plights of persons with psycho-social disability after recovery, who



despite their alleviation of 'symptoms' seem a long way from the recovery of their initial status in society and family. Stigmatised for life, they are not-so-welcome, and in some families women bear the added brunt of ignominy. Economic/ financial independence, for most, is a far cry and families

often ignore the prospect of marriage and settlement for women with mental conditions. Regular and proper medication also is a big hindrance in the path to their complete recovery; and the constant threat of sexual abuse looms large over them. The point of view of the families was equally important, their apprehensions, their fight against the society to protect the individual from being stigmatized, their limitations in providing medicines beyond their budget, and their ways to handle the idiosyncrasies of the users. While it was an important step ahead for Anjali towards its vision, it was an equally vital step for the participants and the families, to be able to express themselves unhindered, exchange ideas and experiences, which fostered a strong feeling of community and helped them make their own demands for empowerment. The State, above all, also got an overview of the various loopholes in its policies and activities, and ideas on how to rectify them and work towards the amelioration of the most neglected health issue. The programme was, in fact, almost like an evidence building exercise to assist the government to reorganize its service.

The various issues that came up during the two sessions also provided leads to the different civil society organizations for advocacy and women's rights organizations towards building a more inclusive language, by accepting and recognizing the problems of women with mental disabilities.

Anjali looks forward to more such summits in the future as it helps to generate data/evidence among all, by providing a platform to the community to voice its concerns, apprehensions, fears and experiences directly, which is perhaps more touching and appealing than getting an indirect view from those who are not direct participants, i.e. either users themselves or the family.

• MEDICINES

- © PROVISIONS for
- © DISABILITY CER
- © SPEEDY





## Landing on one's feet

I will need to stand on my own two feet  
But that doesn't mean I'll stay put  
Only when I move will I have arrived.  
Do you get it?

You need to understand that it means  
Suffering and sorrow, and the sweat of one's brow  
And that is how  
You land on your feet.

Standing on my own two feet  
Is courage.  
And with this strength and identity  
I will move on.

# Participants

Name	Name of the Organization
<b>Government Officials who had attended the Summit</b>	
Debashis Bose	Joint Secretary, GoWB
Subha Mukherjee	TO & DS, GoWB
Dr. T. K. Nandi	DDHS (Mental), GoWB
Dr. Jayanta Moitra	Supreintendent, Lumbini Park Mental hospital
Dr. Raghaves Majumdar	Supreintendent, Pavlov hospital
Dr. Tapas Banerjee	Pavlov hospital
Sudip Chakraborty	SWO, Pavlov Hospital
<b>Participants representing other NGOs/CBOs</b>	
Gargi Singh	Antara
Natasha Ahmed	ASIA
Gautam Bose	CAMP
Minakshi Chaudhury	Centre for Care of Tortured victims
Kalpana Kaul	Consultant
Sarmistha Dutta Gupta	Ebong Alap
Gopa Routh	Gana Unnayan Parshad
Pinku Mitra	Gana Unnayan Parshad
Nandini Sarkar	Iswar Sankalpa
Dolon Ganguly	Jeevika Development Trust
Amit Bhattacharya	Jeevika Development Trust
Mousumi Sarkar	Jeevika Development Trust
S. Debnath	Kolkata Sanved
Sreeja Debnath	Kolkata Sanved



<b>Name</b>	<b>Name of the Organization</b>
Jhulan	Kolkata Sanved
Mohit Ranadip	Mon Foundation
Krishna Mira Roy	Parichiti
Ayeshaa Sinha	Parichiti
Anchita Ghatak	Parichiti
Rajarshi Das Gupta	Sachetana
Sr. Mariosa	Shantidan Missionaries of Charity
Sr. Anastasia	Shantidan Missionaries of Charity
Suparna	Shantidan Missionaries of Charity
Riddhi K. Shah	Shantidan Missionaries of Charity
Mafuja	Shantidan Missionaries of Charity
Rani	Shantidan Missionaries of Charity
Sushma	Shantidan Missionaries of Charity
Urmila	Shantidan Missionaries of Charity
Sanchita	Shantidan Missionaries of Charity
Tamal Majhi	SLARTC
Shampa Sengupta	Sruti Disability Rights Centre
Sukanya Gupta	Swayam
Dolon D. Choudhury	Individual
Nibedita Sanyal	Individual
Adhiraj Ray	Individual
Dr. Jhuma Basak	Individual
Urmi Basu	Individual
Amal Kazumi	Individual
Om Prakash	Individual
Uttama Roy	Individual

Name	Name of the Organization
<b>Representatives from media houses</b>	
Rupsa Sengupta	Ebala
Chandrima Bhattacharya	The Telegraph

### Reintegrated participants who had attended the Summit

Abhimanyu Ghosh	Dulal Chandra Layek	Priyanka Mondal
Aloke Chakraborty	Durgapada Layek	Ranjit Bhattacharya
Alpana Karati	Gita Ghosh	Renu Tiwary
Alpana Karati	Golaap Khatun	Ritam Ghosh
Anjana Mahato	Hasan Galib	Runu Bera
Ashima Mondal	Japanee Das	Sambhunath Das
Ashoke Gupta	Japanee Das	Sandhya Mondal
Bharati Dutta	Jayanti Karmakar	Seema Dey
Binod Tiwary	Jaydeb Karmakar	Seikh Akhtar
Biswanath Bera	Jhunu Bera	Shyamali Samanta
Biswanath Bera	Jolly Bhoumik	Somok Ganguly
Champa Naskar	Kalpna Bhattacharya	Subhro Banerjee
Chanchal Chakraborty	Kanak Kayal	Subrata Poddar
Chanchal Malakar	Kanak Kayal	Sujata Ganguly
Chandan Malakar	Kanchan Bera	Sujit Ghosh
Chaya Mahato	Kaushik Dutta	Supriyo Chowdhury
Chiranjit Das	Kushal SenGupta	Sutapa Mal
Debasis Panda	Lakshmi Bhakat	Tanmoy Karmakar
Debobrata Panda	Nithilesh Mahato	Tarun Bhaumik
Dipak Jaiswal	Niti Choudhury	Tasinara Bibi
Dolly Bhoumik	Pradip Saha	