TCI GLOBAL Fellowship Report

By: Chinthia Janaki Munasinghe
Background

Briefly explain why did you apply for the fellowship grant? What is the situation of persons with psychosocial disabilities in your country?

I am the first professional in Sri Lanka, who revealed my mental health status in 2002, which made people with mental health conditions to come out and share their experiences. More than a direct activist, I practice silent diplomacy as my strategy that suits Sri Lanka well. After I left Basic Needs my work with persons with psychosocial disabilities has become a passion, leading to serving as a volunteer and a facilitator than a leader or an advocate. When TCI announces the Fellowship, I thought that would further strengthen my service to Sri Lankans living with mental illnesses, while bringing together the provincial leaders of cross-disability movement and consumers in Mental Health, starting from our petite organisation: Nidahas Chinthana Sansadaya– Consumer Action Forum (NCS-CAF).

During my 25 years of working in the disability and mental health sector, I witnessed scarcity of leaders with psychosocial disabilities compared to the cross-disability movement in Sri Lanka. In the case of persons with psychosocial disability/mental health conditions, the advocacy actions are manipulated by the professionals in the health sector. After getting diagnosed with a mental illness, a person is labelled as a “patient” rather than a “human.” And they must survive in a highly stigmatized environment. In such a context it is not easy for a person to openly share their mental health status. My intention was to develop persons with psychosocial disabilities/mental health conditions to be inclusive in the advocacy actions of cross disability movement at inter-provincial, national, regional, and global level. Being associated with TCI as a core member, I knew TCI is the best channel to realise our dream.

Country Situation: Sri Lanka’s current economic crisis that worsened the day-to-day life of people – lost jobs, increased cost of living due to high inflation as well as country’s indebtedness and lack of reserves – created high level of stress leading to increase in persons with mental health conditions by 30%. (Records of Out Patients’ Department of Teaching Hospital, Galle). Lack of medication, therapeutic services and social support mechanisms further worsened the life of persons with psychosocial disabilities/mental health conditions.

In this context, the situation of persons with psychosocial disabilities is pathetic, as majority of them are not included even in the welfare scheme of the government (monthly allowance of LKR5,000/-) open for persons with disabilities. When the family is struggling for their day-to-

---

Lancet reports: “Threats to health from an economic crisis are multifold. Stress and lack of health care can increase cardiovascular morbidities. Malnutrition can affect generations of children. Communicable diseases can increase due to rising costs of amenities and the weakening of preventive and control measures. The accompanying political uncertainties, widespread protests, and social disruptions adversely affect mental health and worsen quality of life. These multiple crises have the potential to cripple health systems”. [Mathais, A.T; Jayasinghe, S. Lancet, Vol 10: July 2022]

1 Nidhas Chinthana Sansadaya (Consumer Action Forum) | Mental Health Innovation Network (mhinnovation.net)
day living and with high level of stress, there is a tendency for neglecting their family members with psychosocial disabilities, who would be considered a burden to the family.

There were many other observations we made:

- the community of persons with psychosocial disabilities/mental health conditions are a forgotten/invisible stratum of the society being excluded from community activities, when benefits and entitlements are concerned. Their voice is not prominent compared to early 2000
- the majority of the OPDs have not included persons with psychosocial disability as members, no one considered a person with psychosocial disability as a productive citizen but a “patient” and a “burden”. Added to that is the stigma that discourages persons with psychosocial disabilities/mental health conditions to reveal their status, and families intend to hide such family members, which also contribute to the exclusion.
- there is a 30% increase in mental health conditions, and also more number of suicides/suicide attempts reported due to country’s current economic crisis
- there are no support structures in the community to provide emotional support, attend to their psychosocial needs and help them manage their condition

After the fellowship program how confident do you feel? To what extent the fellowship program has built your and your organizations capacity?

My organisation – Nidahas Chinthana Sansadaya - Consumer Action Forum (NCS-CAF) was experiencing difficult times since 2020 as it was a self-funded organisation, with everyone volunteering and contributing financially to the activities at their level. The COVID-19 pandemic followed by the economic recession in the country, have affected their movements, gathering and also their mental health due to stress, reductions in labour work or lack of markets for their products. Many members experienced relapses including the President of the organisation and myself. Five active members died.

The Fellowship activities has helped the organisation to revive and strengthen the capacity of office bearers and past leaders who joined my work in their localities. In November 2022, CAF leading members at the #WhatWENeed campaign planning workshop, along with other OPD leaders were able to develop an action plan that promote Community Inclusion. Now they are in the process of resource mobilisation for the implementation of the plan. CAF has also been selected as one of the 30 partners in an action research project on disability inclusion in eastern, uva and southern provinces of Sri Lanka. Centre for Accessibility Monitoring and Information on Disability (CAMID) - the organisation that facilitates the project selected CAF for its experience in participatory research and innovative advocacy practices. Under this project, they started working with 29 OPDs of persons with all types of disabilities.

They are happy to see the involvement of young disability advocates and former leaders of CAF, taking the leadership to support and strengthen persons with psychosocial disabilities, as most CAF members finding them growing old. They felt energised and inspired by members of cross-disability movement, who have taken the lead in WhatWENeed campaign designing in Sri Lanka.
Briefly explain how this fellowship opportunity has supported your work over the year and also list down major achievements you have achieved under the fellowship cycle?

The fellowship program has helped me to broaden the geographical presence of CAF operations, which was earlier restricted to three Divisional Secretariat divisions, i.e., Angunukolapelessa, Embilipitiya and Katuwana. Towards the end of the fellowship programme, we at Consumer Action Forum were able to initiate the National Association of Persons with Disabilities (OPDs) focusing on SOCIAL & ECONOMIC INCLUSION of persons with psychosocial disabilities – laymen's den for inclusion. Its present membership includes OPDs and Organisations working with persons with disabilities in 14 districts, namely, Batticaloa, Trincomalee, Ampara, Badulla, Monaragala, Rathnapura, Hambantota, Matara, Galle, Kandy, Colombo, Mullaitivu, Mannar, and Puttalam covering seven provinces of Sri Lanka with the geographical coverage. TCI Fellowship, supported my time and travel to visit to other areas, for initial consultations with OPD leaders and Civil Society Organisations (CSOs), practitioners in mental health and development.

Major achievements under TCI Fellowship:

- Social inclusion component of NCS-CAF was redesigned as collaborative actions with disability advocates in the cross-disability movement in Sri Lanka. NCS-CAF team was involved in sensitizing undergraduates, Human Resource teams of private sector and OPDs on the importance of including persons with mental health conditions in their activities in the community.
- Introduction to managing their own mental well-being and helping others struggling to come out from such conditions.
- Formation of a National Network for Inclusion with commitment from the OPDs in seven provinces of Sri Lanka to support persons with psychosocial disabilities to exercise their rights and address their needs.
- #WhatWENeed workshop – Developing material - posters, video adverts for social media which has been used by OPDs and other participating organisations in their disability day celebrations, and other workshops., persons with psychosocial disabilities were represented.
- represent persons with mental health thus conditions in the Executive Committee of Disability Organisations Joint Front, the National Network
- facilitating Southern Province 2023 planning session with disability advocates – to make their plan disability inclusive and in the process of inclusive intervention in government services.
- Start the consultations for community inclusive interventions in Southern and Eastern provinces for independent living integrated into the society as one of them.
- Join the Medical Faculty of University of Kelaniya as a Visiting Lecturer – to conduct participatory Sessions with the undergraduates/students.
Briefly explain the way forward and sustainability plan or plan of action of the organization after completion of the fellowship grant?

My commitments:

- Registration of the National Network and raise funds for institutional development;
- Organise TCI-Global Sri Lanka Country Mission
- Development of Strategic Plan of the National Network
- Continue with designing inclusive interventions in the development sector, with special emphasis on community inclusion of persons with psychosocial disabilities
- Training national network members on effective methods to advocate & persuade such as human library, forum theatre, silent diplomacy,
- participate in the national and provincial advocacy and inclusive planning sessions of the national and provincial governments.

Below is the NCS-CAF Action Plans developed at the #WhatWENeed workshop:

<table>
<thead>
<tr>
<th>Theme</th>
<th>Actions</th>
<th>Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community inclusion</td>
<td>• Awareness on CAF mission among persons with mental health conditions and their families</td>
<td>March/April 2023</td>
</tr>
<tr>
<td></td>
<td>• Community consultation workshops/programmes on inclusion of persons with mental health conditions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Mobilizing and capacititating community leaders of OPDs, CBOs on consulting persons with mental health conditions on their needs and wants – Self-Help Group formation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Media campaigns to promote mental well-being and abilities of persons with mental health conditions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Human library and Forum Theatre workshops as invited by the government and civil society organisations.</td>
<td></td>
</tr>
</tbody>
</table>

Access to Health and support Services

- Support and monitor access to health and mental health services at base and rural hospital clinics, while promoting membership and programmes implemented by Cross-disability movement for inclusion.
- Educate higher officials of the health sector, on the observations and challenges, while establishing links with other stakeholders who could collaborate to address the challenges
Follow-up visits linked to mental health clinics in the localities where OPDs are in operation
Provide emotional support and referrals/host destitute persons with psychosocial disabilities for community living

March 2023 onwards  Theme

Actions

Period

Livelihood development

- Research – KIIs, FGDs, about Psychosocial disability
- Orientation programme for field staff of the government and non-government programmes on livelihood development in collaboration with Psychiatry units of District/Base hospitals.
- Introduction to inclusive livelihood opportunities for those who are not engaged in productive activities as therapeutic interventions

May 2023

Mental well-being promotion

- Support Primary Health Care staff to organize and conduct awareness programmes as human libraries with inputs from persons managing mental health conditions
  a. During special religious days in agreement with the temples, churches, mosques etc.,
  b. Organize commuter awareness programmes in the intercity buses and railways
  c. Social media campaigns
  d. Mass media programmes
- Training community leaders in collaboration with mental health professionals, wounded healers and persons with lived experiences
- Undergraduate sensitization programmes using Human Library as a platform in collaboration with Disability Studies Department of University of Kelaniya

On going

Advocacy and partnership building

- Review of social and economic status of persons with mental health conditions and their families and their inclusion status in the community-based development interventions
- Sharing the review findings with Provincial Authorities to i) sensitize them on the abilities of persons with mental health conditions and the importance of inclusion; ii) Develop inclusive livelihood development programmes to ensure persons with mental health conditions and other disabilities are included.
- Contribute knowledge & information, and participate in advocacy actions of TCI-Global and international organisations, as well as Disability Organisations Joint Front (DOJF),
Consumer Action Network – Mental Health (CANMH), and other national organisations advocating for the human rights and inclusion.

April onwards

Briefly describe if there were any learnings for you during this fellowship period which you would like to share with us.

- The voice of persons with mental health conditions was not prominent compared to early 2000, as the consumer movement was over-powered by the mental health professionals. Partnering with the cross-disability movement has given NCS-CAF the opportunity to share their lived experience, alternative approaches to advocacy (human library and forum theatre) and learn from the OPD leaders their advocacy actions as front-line leaders.
- Combined approaches to advocate for their rights, persons with disabilities and those with psychosocial disabilities/mental health conditions would benefit mutually. Southern provincial authorities, being impressed by the pre-preparation efforts of the OPD leaders representing all types of disabilities, assigned them as review team for monitoring Southern Province Action Plan 2023 for ensuring inclusion. This kind of outcome has not been reported in other provinces.
- The OPDs from seven provinces that have not included persons with psychosocial disability as members, became interested in including them. Yet, NCS-CAF has a role to educate the stakeholders from social services, economic development, and communities to encourage persons with psychosocial disabilities and their families to come out and join in with OPDs.
- Addressing the lack/scarcity of therapeutic services such as counselling services, occupational therapists, etc., OPD leaders and volunteers could developed alternative support structures for mental health first aid/emotional support and referrals for specialized services. Consultative approach to life planning that has been practiced by NCS-CAF, creative actions to develop messages and designing productions/interventions observed to create enthusiasm, build self-confidence and bring about relaxation. This was observed at the #WhatWENeed workshop.

Please write about any challenges and difficulties you faced during conducting various activities in the fellowship period. Also, describe if any solutions or suggestions were utilized to address these.

- The biggest challenge was the country’s economic crisis that led to fuel shortages, restricting travel which led to delays in inter-provincial work and interactive workshops planned during the fellowship. Work of my organisation was also on hold due to unpredicted recurrence of COVID-19 pandemic. Field activities planned under the Fellowship were either delayed for more than three months, with some managed with virtual forums/meetings. Despite those issues, I managed to conduct initial sensitization programmes for OPD leaders, members, and community leaders from the districts – Mannar, Batticaloa, Puttalam, Kilinochchi, Galle, Matara, Hambantota, Monaragala,
• Political environment is also not favourable for community-based consultations with the enforcement of Emergency Law, after the former President left the country. We were to wait patiently even to organise the #WhatWENeed workshop.

• Other challenge was managing my mental health condition balancing my work, commitments to the fellowship with high level of family commitments – responsible for looking after my parents and aunt who are in their late 80s. I ended up depressed, and still recovering. It was a struggle, and knowing that it is my responsibility to control depressive thought, I informed my close friends, Waqar and the TCI team, my clients, NCS-CAF and OPD leaders who helped me recover from that huge stress. Some lend their ears; some organise occasions for me to be relaxed, and all the clients have extended deadlines. I felt privileged compared to many who do not have such support mechanisms around them.

• NCS-CAF members do not possess SMART phones, and therefore virtual meetings were not possible. With the partnership of CAMID, a Tablet was donated for inter-district communication purpose, and a SMART phone was purchased for the NCS-CAF Secretary so that they could gather in small groups at one member’s home to participate in the virtual meetings, without leaving their localities. Besides, a WhatsApp group was formed so that important messages could be shared faster.
Preparing key messages at the #WhatWEneed workshop
Facilitation with sign language interpreter Nandani Gamage, CAMID

Sharing lived experience at a Human Library Workshop organised by University of Colombo
Wellassa Organisation of Persons with Disabilities (WOPD) during consultations on their opinion of including persons with psychosocial disabilities in their membership/programmes.
#WhatWENeed workshop – Posters and Video adverts were shared through social media

Consulting OPD leaders and women leaders affected by armed conflict with a Tamil Language Interpreter (Northern province)

#WhatWENeed Workshop, November 2022
Paste below any media clippings/national news which you would like to share with us

**LINKS:**

*Ten year National Mental Health Policy unveiled | Daily News*

*Some characteristics of suicide and mental health in Sri Lanka - Opinion | Daily Mirror*

*Discrimination: a common factor for mental health in Sri Lanka (newsfirst.lk)*

*Mental Health and Stigma in Sri Lanka – Groundviews*

*Development of mental health care in Sri Lanka: Lessons learned Kathriarachchi ST, Seneviratne VL, Amarakoon L - Taylor J Psychiatry (e-tjp.org)*

*(PDF) Mental Health System Development in Sri Lanka (researchgate.net)*

*Sri Lanka struggles with mental health burden - The Lancet*

**GOOD PRACTICES:**

*WAPR - CAF.ppt (live.com)*

*Consumer Movement of Sri Lanka (canmh Lanka.org.lk)*

*Effectiveness of Horticulture Therapy in Integrating People With Mental Illness Into The Society - Basic Needs Sri Lanka 2008 | PDF | Mental Disorder | Focus Group (scribd.com)*

*Sharing skills and experiences – Good practices in mental health (mhpss.net)*

*Disability Inclusion Global Best Practices Report - Disability:IN*

*(2) Promoting a Disability-Inclusive Workplace: Best Practices and Benefits | LinkedIn*

*Disability Replication Guide_English_29 October_Final (ilo.org)*


*Forum Theatre To Share Lived Experience of Persons With Mental Health Conditions | PDF | Mental Disorder | Social Stigma (scribd.com)*
Transforming Communities for Inclusion (TCI)

Secretariat:
C/O Bapu Trust, III Floor, Building B1, Kaul Building, 8 GuruNanak Nagar, Pune 411042, Maharashtra, India.
Contact Number: +91-20-26441989, +91-9823291989