

**Assessments of Forums of Service Users in Mental Health in  
Sri Lanka**

**Study on Organizations of Mental Health  
Service Users and Carers**

**A Mapping in Sri Lanka**

Conducted by



For



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BasicNeeds Sri Lanka expect this study will be a useful resource for mental health service users, carers, community members, local and international volunteers, mental health professionals and other professionals in this sector and activists who fight to protect and promote rights of people with mental illness and to obtain better life for them and their family members.

### Abbreviations and acronyms

BAMHDO	- Batticaloa Mental Health Development Organization
BNSL -	- BasicNeeds Sri Lanka
CBTD	- Community Business and Technology Developers Ltd
CSO	- Community Service Officer
CAF	- Consumer Action Forum
CMHD	- Community Mental Health and Development
FGDs	- Focus Group Discussions
GA	- Government Agent (District Secretary)
MH clinics	- Mental Health Clinics
MH Service Users	- Mental Health Service Users
MH Rehabilitations	- Mental Health Rehabilitations
MOH	- Medical Officer of Health
MOMH	- Medical Officers of Mental Health
NIMH	- National Institute of Mental Health
WHO -	- World Health Organization
PSW	- Psychiatry Social Worker
RDHS	- Regional Director of Health Services
SEED	- Sarvodaya Economic Enterprise Development Services (Gurantee) Ltd
NAITA	- National Apprentice and Industrial Training Authority
Vidatha	- Vidya Ha Thaksana (Government Science and Technology programme for villages)
VSO	- Volunteer Service Organization

# Study on Organizations of Mental Health Service Users and Carers A Mapping in Sri Lanka

## Executive summary

Mental health service user groups and advocacy movements are widely believed to significantly influence changes in services and factors which affect the lives of persons with mental illnesses. World Health Organization (WHO) has clearly emphasized the advantage of active involvement of service users and families of people with mental illness in advocacy movements<sup>1</sup>. In Sri Lanka too, groups of Mental Health (MH) service users and their carers have begun to grow in some provinces of the country within the last ten years. However, a systematic information and knowledge base on capacities, issues and potential of these groups is not available at national level. This mapping is therefore the first step taken to fill this gap by studying the MH service user and carer's organizations in Sri Lanka. Key objectives of this study are to review strengths and weaknesses of these organizations and the impacts created by these organizations in mobilizing participation of MH service users and carers in changing conditions that affect them.

This study was conducted with 13 organizations which were selected through a telephone survey of 32 organizations in 19 districts. The key criteria of selections were the period which the organization was in operation. The study applied participatory methodology which included brainstorming sessions and focus group discussions with MH service users and carers and interview with service providers.

Study shows that prevalent feature in the formation of many MH service users and carers' forums is that main linkage to the forum initially has been through the MH service provision centre (at hospital or rehabilitation centre). In this context, initial formation of these organizations was effort of MH professionals or mental health related workers (such as the psychiatry social workers) who provide service at particular local centre. In relevance to MH national policy and it's emphasizes on community mental health; this should be viewed as a significant progress in translating the policy into practice. As a result of this linkage with MH service provision centre and as initial leading involvement of MH professionals, highest prevalence objectives of formation of these organizations are to build capacity of MH service users and carers for improved rehabilitation care and continuous treatment. However, there is a notable disparity between the nature of purposes that motivated the service users and carers to join the forums and the expressed/stated objectives of the forums. Highest prevalence purpose of MH service users and carers to join the organizations was to fight the stigma related and to improve theirs and their families' social integration. Study, therefore, reveal both positive outcomes as well as constraints created through this prevalent and continuous linkage with MH service centres and MH service providers.

Although these forums have strong and close links with the MH service providers, except one organization, most organizations had leadership positions open to MH service users or their carers,. This is an essential step to build their self confidence and provide them with opportunities to build leadership and negotiation skills. However the actual benefit of this is realized only in occasions when they are practically received opportunities and space to

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<sup>1</sup> Advocacy for Mental Health, Mental Health Policy and Service Guidance Package (2003), World Health Organization, Geneva, Switzerland.

function as leaders in these positions. Where real opportunities are given to service users in organizational responsibilities, it has played a significant role in active participation in the decision making processes of their organization. A sense of equality and more openness in communications was observed when MH service users work amongst themselves or have their own forums. It also helps them to move at their own pace and they gradually mobilized to build their own capacity. Contrary to this, in some locations, the dominant role played by medical professionals has curtailed space for active participation by service users and carers. Moreover, when more capable carers take the lead role in the decision making, the service users will not gain full benefit from their own organization.

More common activities implemented by MH service users' and carers' organizations are capacity building programs in livelihood, cultural and religious rituals and ceremonies, and events to raise public awareness on mental illness. Most prevalence activities of many organizations are cultural and religious rituals and ceremonies, comparison to other interventions. Reasons for high prevalence of these activities are based on traditional values that are an integral part of the living of the community and relatively low cost of implementation. One hand these activities bring mental relief and therapeutic experience to MH service users as well as their carers. On the other hand opportunities MH service users receive through these activities to express their talents and to integrate with society is very significant and relevant, since most highlighted issue by them and carers is stigma and social exclusion. According to WHO definition, if advocacy in mental health begin when MH service users and cares make their voice heard, many organizations have provide that opportunity through these activities. However, a few organizations have been able to work with a far reaching vision for the improvement of living conditions of MH service users and carers and have worked beyond the scope set by health care system and initiated systematic advocacy initiative targeted policies and practices. Although only few organizations have implemented such initiatives, it is worth to mention that activities such as forum theaters and world mental health day celebration with public participation have immense space to make influence to higher level stakeholders as well as general public. These are also activities which expressed leadership of MH service users in advocacy and capacity they have to mobilize other service users. Moreover, two organizations have also carried out activities related to organizing and coordinating mental health service provision. In relevance to recent global trend to consider MH service users as expertise of mental illness and of their knowledge to cope with it; this can be viewed as significant start in user led mental health service.

Networks built by these organizations with service providers is other main aspect reviewed under the study. Discussion conducted with MH service users and cares showed that health sector institutes are closest organizations for them. This could, again, be linked to most of the MH service user /carer organizations being initiated by MH professionals and meetings held at MH service centre premises. Livelihood support given by local government institutions were also highly appreciated by many organizations. This was considered as a useful contribution that helped improve their quality of life.

Although these organizations have produced positive outcome on lives of MH service users and carers as well as mental health service in Sri Lanka, factors supporting and challenging the sustainability of these organizations are really important to widely discuss. As many of the MH service user and carer organizations are located in the premises of MH service centres, this provided them environment where these forums could continue to function at low cost. However, the threat to the sustainability of such forums would arise when the key medical professional who supports the organization and who link with MH service centre is

transferred/moves out of the hospital/district. Furthermore, lack of economic capacity of MH service users and carers is a key challenge in ensuring their continuous participation in organizational functions. The members themselves are mostly at a low income level and would be unable to personally bear the cost of meeting places/travel etc. The MH service users and carers high reliance on the professionals for key decision making is also another key barrier in building active leadership for organizations which are sustained by community themselves. Lack of capacity building for community mobilizations which go beyond medical parameters is also another limitation link with this challenge. In relevance to these challenges as well as weakness mentioned relate to active participation of MH service users and to promote more organized advocacy movement, following recommendations are derived from the study.

1. Capacity building process in user led advocacy.
2. Strengthen the livelihood status of members (MH service users and carers) of organizations.
3. Capacity building in leadership development and community mobilization Providing leadership to experienced users' organizations in supporting development of other groups-
4. Provide inputs to improve organizational and management capacities.
5. Capacity building for health and other stakeholders supported users' organizations
6. Facilitate participatory monitoring and evaluation mechanism

# Study on Organizations of Mental Health Service Users and Carers

## A Mapping in Sri Lanka

### **(1) Introduction**

The mapping of Organizations of Mental Health Service Users and Carers was conducted in two phases. The first stage, conducted in November 2010, was through a telephone survey of 32 organizations in 19 districts. This was with the purpose of identifying organizations for further study in Stage 2. The criteria of selections were the period which the organization was in operation, scale of activities implemented and the location being in an area in which the VSO is active. As VSO's Strategic Plan 2010 emphasis on Advocacy, there are programmes support VSO volunteers to become advocates, capacity buildings on participatory research, analysis and collection of evidence in order to support work of VSO partner organizations. This will support notational campaigns as well as feed VSO global advocacy work with connection of service users. This study therefore gave attention to this strategy and plan of VSO in selection of organizations in areas where VSO is active.

Finally thirteen organizations were selected based on above criteria for a more detailed study. Stage 2 of the study was conducted from December 2010 to March 2011.

#### **(1.1) The context**

Mental health service user groups and advocacy movements are widely believed to significantly influence changes in services and factors which affect the lives of persons with mental illnesses. World Health Organization has clearly emphasized the advantage of active involvement of service users and families of people with mental illness in advocacy movements.

*“Over the past 30 years, families of people with mental disorders, and, subsequently, people with mental disorders themselves, have become increasingly involved in the advocacy movement, acting on their own behalf through their organizations. This has led to the emergence of the concept of self-advocacy, i.e. people’s ability to act and advocate on behalf of themselves and their families. This concept is significant because it implies that people affected by mental disorders can act with a high level of motivation and an intimate knowledge of mental disorders. Such involvement can have a positive effect on the mental health of volunteers, through improved confidence, self-esteem, motivation and a sense of belonging.”* Advocacy for Mental Health, 2008, WHO

In Sri Lanka too, groups of service users of Mental Health (MH) and their carers have begun to grow in some provinces of the country within the last ten years. These initiatives have proved that mental health service users and their cares in Sri Lanka are able to come together to form their own groups with aim of collectively changing the situations in which they live. However, a systematic information and knowledge base on capacities, issues and potential of these groups is not available at national level. Moreover, linkages among these groups in different parts of the country and their networks at national level with decision makers and higher stakeholders

are not visible and clear. This gap in knowledge, therefore, is a barrier to integrate these groups for collective effort on mental health advocacy as well as to devise effective mechanism to better support such collectives.

State and non-state service providers who work with MH service users and their carers have long felt the need for accurate databases on such collectives and improved understandings of the role and contributions of these groups. The mapping of the MH service user and carer groups/associations is a first step taken to fill this void. BasicNeeds Sri Lanka (BNSL) conducted this sample study for VSO Sri Lanka. The findings of the study would subsequently be disseminated widely, leading to interventions that support forums/groups of mental health services users and carers.

### **(1.2) Objectives of the study**

- Review strengths and challenges of selected mental health forums identified in the first stage of the study
- Review activities and outcomes of these forums in relation to self support, improvement of mental health services, fighting against stigma, and advocacy.
- Explore the nature of operation, scale and scope of the forums of MH service users and carers.
- Understand factors that support sustainability of the forums/groups of MH service users and carers and their future potentials and challenges.

## **(2) Literature Review**

### **Organizations of Service Users and Carers and mental health advocacy**

This section reviews the existing literature on groups of mental health service users and their family members, their involvement in mental health services and in advocacy. Objective of this chapter is to explore the key dialogue around these topics and define the concepts around this subject. However, in Sri Lanka, there is no existing literature or researches on groups and forums of service users and carers and their involvement in mental health advocacy.

#### **(2.1) Mental health service users and carers**

Mental health service users are most frequently portrayed as patients – as objects of the clinical gaze of mental health professionals (Pilgrim & Rogers, 1999) – and therefore in terms of their illness. This clinical gaze place service user in more passive place rather than as active consumers who can take decision about service they receive and who able to influence factors affect their lives. Other hand, MH service user is defined somebody who is currently or has recently used primary or secondary mental health services.<sup>2</sup> This illustrate service user as consumer of particular service and as citizen. In this study, ‘mental health service user’ has been used in this last definition.

Carer has been defined in study as somebody providing practical or emotional support to a person experiencing emotional or psychological distress<sup>3</sup>.

#### **(2.2) Importance of participation of service users**

Over last 30 years there is growing attention and emphasize on users and carers participation in mental health service provision, management of services, advocacy and research (as new paradigm of user led researches). Literature and researches on this subject explain importance of their involvement, especially service users, in these areas.

*Users are experts about their own illness and need for care* - There is widespread recognition that service users are experts, with an in-depth knowledge of mental health services and of living with a mental health problem (e.g. Chief Medical Officer, 2001). This is supported by clinical evidence as well.

‘Very often people who have experienced several episodes of psychosis learn to recognize early warning signs that they are becoming unwell. Changes in mood, behaviour and thoughts usually begin to appear 2-6 weeks prior to a relapse, and this period is known as the *relapse prodrome* (Birchwood M J Smith F Macmillan B Hogg 1989 Predicting relapse in schizophrenia *Psychological Medicine* 19 649-656)

‘Some typical prodromal symptoms are increased tension, depression, concentration problems, irritability, mild paranoia, anxiety, eating problems, sleeping difficulties, becoming suspicious, social withdrawal. It is not surprising that people who have not learned to recognize their prodromal syndromes very often wish to do so, they want to learn about the early warning signs of their difficulties in the hope that this will help them to prevent relapses from happening.

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<sup>2</sup> Liz Fletcher (2008), Where are we up to with user involvement in mental health services, A qualitative evaluation study in greater Manchester area. blueSCI and Greater Manchester West NHS Foundation Trust.

<sup>3</sup> Ibid

Research has shown that people who have experienced episodes of psychosis tend to monitor their own symptoms, and modify their behaviour or lifestyle if they notice any changes (Herz M C Melville 1980 Relapse in Schizophrenia *American Journal of Psychiatry* 127 801-812). They may engage in diversionary tactics, seek professional help and resume or increase their medication'. Taken from '**Think You're Crazy? Think Again** A Resource Book for Cognitive Therapy for Psychosis 2008 Routledge Morrison A, Renton J, French P, Bentall R

Users may have different but equally important perspectives about their illness and care - Involving users can provide insights that prompt practitioners to re-evaluate their work, challenge traditional assumptions and highlight key priorities that users would like to see addressed

User involvement may increase the existing limited understanding of mental distress - May (2001) suggests that the inclusion of users' experiences and knowledge through service user involvement will supplement the existing limited understanding of mental distress.

User involvement may be therapeutic in itself - User involvement can be therapeutic. Helping to shape services, particularly when users work together collectively, can help to increase confidence, raise self-esteem and develop new skills (Mental Health Foundation, 2003).

User involvement may encourage greater social inclusion - People with mental health problems are among the most socially excluded within any society, subject to the interlocking and mutually compounding problems of impairment, discrimination, diminished social roles, unemployment and lack of social networks (Office of the Deputy Prime Minister, 2004)

### **(2.3) Advocacy and mental health**

#### Mental health advocacy as a concept

Like many concepts, advocacy is contested and has many different definitions. In context of mental health also, 'advocacy' have taken different shapes and interpretation as follow in relevance to scope of different organizations and scholars who involve in mental health and advocacy.

*'The concept of mental health advocacy has been developed to promote the human rights of persons with mental disorders and to reduce stigma and discrimination. It consists of various actions aimed at changing the major structural and attitudinal barriers to achieving positive mental health outcomes in populations. Advocacy in this field began when the families of people with mental disorders first made their voices heard.'*<sup>4</sup>. WHO

*'Advocacy is an ongoing process, or a series of organized actions, applied in order to change, modify, implement, or reinforce attitudes, practices, policies, laws, programs,*

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<sup>4</sup> Advocacy for Mental Health , Mental Health Policy and Service Guidance Package (2003), World Health Organization, Geneva, Switzerland.

*services, social norms and values by influencing or pressuring people with power, systems, the structure and the community at different levels for the betterment of those affected by the issue'. - BasicNeeds<sup>5</sup>*

*'At its simplest advocacy enables individuals to have a say in their life and the dimensions that affect their livelihood, whether that be their care, their family, their housing or their work...However, mental health advocacy can take place on a wider scale than that of individual action... Strategic or systemic advocacy in mental health looks at the systems and organizations that provide care and intervention as well as the barriers to individuals having a voice in their lives'. - P Cutler, R Hayward and G Tanasan<sup>6</sup>*

*'Advocacy means supporting service users to speak and persuading service providers to shut up and listen' (IAS, 2000)<sup>7</sup>*

*'Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice. (Advocacy Across London 2002 p2)<sup>8</sup>*

Although definitions are different, the following key elements can be extracted in relating to advocacy in mental health.

- Actions to promote human rights of persons with mental illness and to change structures, policies, conditions affect lives of them.
- As a baseline, it is an action enables people with mental illness and cares first made their voice heard and to express their need.
- It takes place on wider scale and strategic, systematic and a series of organized actions.

In this study, these common elements of concepts have been used to review activities implemented by 13 organizations. Study will use advocacy as its simplest form (action enable voice to hear) as well as it systematic and organized form to understand these activities.

#### Importance of advocacy in mental health and participation of service users

Advocacy is considered to be one of the eleven areas for action in any mental health policy because of the benefits that it produces for people with mental disorders and their families. (See Mental Health Policy, Plans and Programmes). In most parts of the world, unfortunately mental health and mental disorders are not regarded with anything like the same importance as physical health<sup>9</sup>. In this context, WHO raised importance of advocacy

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<sup>5</sup> Christina Angela Ntulo - The Self Advocacy Toolkit - For users of mental health care services, BasicNeeds UK in Uganda, Kampala.

<sup>6</sup> Paul Cutler, Robert Hayward and Gabriela Tanasa (July 2006) , Supporting User Led Advocacy in Mental Health, Features > Advocacy, eumap.org

<sup>7</sup> Rick Henderson, Empowerment through advocacy – mental health advocacy in focus

<sup>8</sup> Ibid.

<sup>9</sup> Advocacy for Mental Health, Mental Health Policy and Service Guidance Package (2003), World Health Organization, Geneva, Switzerland.

in relevance to problems and challenges in mental health services and its quality, violations of human rights of persons with mental disorders, issues of poverty, stigma and exclusion and insufficient implementation of mental health policy, plans, and legislation. As some scholars show that absence of strong advocacy movements in much of the world contributes to the persistence of appalling conditions for people with mental disorders as well as their political disempowerment.<sup>10</sup>

BasicNeeds placed necessitate for advocacy initiative in context of marginalization of service users at every level local, district and national and in actions to lobby for improvement in the mental health service delivery. <sup>11</sup> BasicNeeds present following guiding principles for the advocacy<sup>12</sup>.

- To be able to affect and realize concrete improvements in the lives of the mentally ill, their carers and families.
- To give consumers as sense of their power.
- To alter power relations.

Involvement of users and carers in advocacy actions and in movement were highlighted by leading organizations work for mental health (WHO, BasicNeeds and World Federation for mental health and World Psychiatrist Association) and scholars work on this subject. Over the past 30 years, families of people with mental disorders, and, subsequently, people with mental disorders themselves, have become increasingly involved in the advocacy movement, acting on their own behalf through their organizations. This has led to the emergence of the concept of self-advocacy, i.e. people's ability to act and advocate on behalf of themselves and their families. This concept is significant because it implies that people affected by mental disorders can act with a high level of motivation and an intimate knowledge of mental disorders. Such involvement can have a positive effect on the mental health of volunteers, through improved confidence, self-esteem, motivation and a sense of belonging.<sup>13</sup>

Self advocacy is built on the principles of Self Determination<sup>14</sup> as follow.

- Freedom to plan a real life.
- Authority over their (service users') resources.
- Support for building a life in community which service users live.
- Responsibility to give back to their community.

In participation of service users and carers in advocacy, some scholars (Rick Henderson, ) emphasize importance of making distinctions between 'what is advocacy' and what is 'advocacy isn't' as follow.

Distinctions between advocacies and other informal support (Rick Henderson ) <sup>15</sup>

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<sup>10</sup> Michelle Funk, Alber Tominoletti, Natalie Drew, Jacob Taylor And Benedet Tosaraceno – Advocacy for mental health: roles for consumer and family organizations and governments

<sup>11</sup> Christina Angela Ntulo - The Self Advocacy Toolkit - For users of mental health care services, BasicNeeds UK in Uganda, Kampala.

<sup>12</sup> Ibid.

<sup>13</sup> Advocacy for Mental Health, Mental Health Policy and Service Guidance Package (2003), World Health Organization, Geneva, Switzerland.

<sup>14</sup> Christina Angela Ntulo - The Self Advocacy Toolkit - For users of mental health care services, BasicNeeds UK in Uganda, Kampala

<sup>15</sup> Rick Henderson, Empowerment through advocacy – mental health advocacy in focus

<b>Advocacy is</b>	<b>Advocacy isn't</b>
Choice	Advice
Equality	Befriending
Justice	Mediation
Support	Counseling
Empowerment	Social work
Protection	
Information	

WHO mentioned awareness, awareness-raising, information, education, training, mutual help, counseling and mediating as *advocacy actions*. However, in reference to above table (presented by Rick Henderson), activities such as counseling and mediating are not advocacy actions. This shows that there are some disparities among definitions about advocacy actions. WHO much focus on mental health service perspective while Rick Henderson's distinction table and BasicNeeds explanation of principles self advocacy emphasize empowering service users to take control over their lives and conditions affect them.

This study will, however, consider both these aspects in relating to analysis of activities implemented by these organizations.

#### **(2.4) Factors promote user participation and effective advocacy**

There are key factors which promote participation of service users and promote effective advocacy as mentioned by Paul Cutler, Robert Hayward and Gabriela Tanasa as follow.

Service users want other service users - The research findings of Inter-Action consistently demonstrate that service users want other users or ex-users as their advocates. At the same time the professional is inevitably in a position of power due to his status and role. Also professionals are likely to have divided accountabilities to both the user and their own organization. Therefore it is essential that mental health advocacy organizations and activists focus on the training and support of service users as self-advocates.<sup>16</sup>

Diversity and local needs - Diversity is a key factor in providing effective advocacy, and grassroots groups are often well placed to recognize the diverse local needs and access local resources to meet them.<sup>17</sup> Advocacy projects therefore need to reach out to potential users in ways that promote positive images of mental health and that demonstrate the benefits of using local advocacy services.

Using experiences of service users - Case studies, life stories and vignettes can be particularly powerful in illustrating positive local experiences. This also links to the wider need to improve awareness and education about the topic of mental health in the community amongst employers, local officials, health professionals and the general population.

<sup>16</sup> Paul Cutler, Robert Hayward and Gabriela Tanasa (July 2006) , Supporting User Led Advocacy in Mental Health, Features > Advocacy, eumap.org

<sup>17</sup> Ibid

There is evidence to show that 'social contact – direct personal contact between members of the general public and members of a stigmatised group is one of the most promising strategies for reducing stigma and discrimination' Jillian London, Sara Evans-Lacko 'Challenging mental health related stigma through social contact' *European Journal of Public Health* vol 20 2 130-131 available [eurpub.oxfordjournals.org/content/20/2/130.full](http://eurpub.oxfordjournals.org/content/20/2/130.full)

Link to local practices and customs - The most effective measures have linked advocacy activities to local practices and customs. Advocacy consultations and workshops, for example, have been timed to coincide with local market days when the rural populations naturally travel to market towns.

Small scale and localized - The most successful and effective advocacy projects in Europe are often those that are small-scale and localized. This is where local people have designed a project to meet their specific needs and where service users are central to the planning, delivery and evaluation of advocacy services. This is best achieved through localized funding that is small scale and focused.

Creating positive outcome for the individual - Effective advocacy is about creating positive outcomes for the individual and the local community. It is about achieving real changes to a person's life, such as improved housing, work, better social relationships and higher income. It is not simply about the protection of human rights in the abstract.

## **(2.5) Barriers to active user involvement**

Understanding barriers to user involvement is important in studying forums of service users and carers in Sri Lanka. This section will focus on such barriers mentioned by studies and articles of other countries, since such literature is not available in Sri Lanka.

Lack of information - Accessible information is an essential prerequisite for meaningful involvement, yet there is evidence of a widespread lack of information for service users on the nature of mental health problems, the side-effects of medication, alternative forms of treatment and mental health law (Webb et al, 2000; Hogman & Sandamas, 2001).

Financial and time costs - User involvement, if properly implemented, can be financially expensive and time-consuming for the organization and service users themselves.

Concerns over representativeness - Professionals wishing to promote user involvement have frequently expressed concerns about the 'representativeness' of individual service users, sometimes suggesting that particular users may be 'too well', 'too articulate' or 'too vocal' to represent the views of users generally. However, Lindow (1999) suggests that the concept of 'representativeness' may be used as a subconscious method of resisting user involvement.

Power differentials - At one level, such a finding seems quite simple to interpret, since it is obviously the case that most professionals have more power and status than do users and carers. However, issues of power operate on a number of different levels. Structural inequalities in society are magnified in the power differentials that exist in a mental health context. Those groups disadvantaged in society as a whole – poor

people, those from ethnic minorities and women – are over-represented in psychiatric facilities. Those who make the final decisions about their treatment – psychiatrists and psychologists – tend to reflect the opposite pole of the social strata. Tokenistic involvement has been experienced by some of the sample and is felt to hold back the potential benefits of involvement working. When it is clear decisions have already been made or people are only treated well when they are needed to “rubber stamp” a new policy or decision.

## **(2.6) Stigma , mental health and advocacy**

### Definitions of stigma

According to WHO stigma ‘is something about a person that causes her or him to have a deeply compromised social standing, a mark of shame or discredit. Many persons with serious mental disorders appear to be different because of their symptoms or the side-effects of their medication. Other people may notice the differences, fail to understand them, feel uncomfortable about the persons affected and act in a negative way towards them. This exacerbates both symptoms and disability in persons with mental disorders’<sup>18</sup>. We can see similar definitions in other organizations and government departments as follow.

“Stigma is defined as shame and disgrace. It's like a stereotype, and because it's based on myths and misunderstandings, it's always negative.<sup>19</sup>” (*Schizophrenia Society of Ontario, Canada*)

‘Stigma is a mark of disgrace that sets a person apart from others. When a person is labeled by their illness they are no longer seen as an individual but as part of a stereotyped group. Negative attitudes and beliefs toward this group create prejudice which leads to negative actions and discrimination<sup>20</sup>’ (*Government of Western Australia, Department of Health, Mental Health*).

### Impact of stigma

Stigma has been discussed in WHO document<sup>21</sup> s as a factor which affect on many parts of life of person with mental illness. This include unwillingness in MH service users to seek help, isolation from social life, denial of adequate housing, loans, health insurance, and jobs because of mental disorders, isolation of their families from society and fewer resources provided for mental health other than other areas of health

### Advocacy to change stigma

Mental health literature pointed out that one of key target of mental health advocacy should be fight against stigma and discrimination. Actions under this cover community education, anti stigma training for teachers and health workers, empowerment of consumers and family organizations, legislations on rights of consumers, educating media , social integration of consumers and improvement of mental health services<sup>22</sup>.

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<sup>18</sup> Advocacy for Mental Health, Mental Health Policy and Service Guidance Package (2003), World Health Organization, Geneva, Switzerland.

<sup>19</sup> <http://www.schizophrenia.on.ca/about-schizophrenia/5-stigma/8-what-is-stigma.html>.

<sup>20</sup> [http://www.health.wa.gov.au/docreg/Education/Population/Health\\_Problems/Mental\\_Illness/Mentalhealth\\_stigma\\_fact.pdf](http://www.health.wa.gov.au/docreg/Education/Population/Health_Problems/Mental_Illness/Mentalhealth_stigma_fact.pdf)

<sup>21</sup> Advocacy for Mental Health, Mental Health Policy and Service Guidance Package (2003), World Health Organization, Geneva, Switzerland.

<sup>22</sup> Ibid

### **(3) Methodology**

#### **(3.1) Sample**

Organizations - 13 Organizations for this study was selected through the telephone survey of 32 organizations in 19 districts, which were conducted in November 2010. The criteria of selections of 10 organizations were the period which the organization was in operation, scale of activities implemented and the location being in an area in which the VSO is active. Thirteen organizations were selected for a more detailed study. Rests of 3 organizations selected for the study are new forums started last year. These were selected on criteria of scale of activities implemented so far or representative areas in relating to high prevalence issue of mental health.

Participants – All organizations were informed to invite equal representation of service users and carers who are members of the organization. Totally 20 were invited by from each organization through relevant health professional, health worker attach to organizations or service user/carer/volunteer hold a key position in the particular forum. Main criteria for the selection of members are

- Participants were selected from each organizations based on criteria of members who involved in organizational works at least more than 6 months period and who have close relationship with the particular organization.
- For the selection of service users, their stability status at present and their ability for communication was also considered.

Mental health professionals and other health workers support the organizations were invited for a separate discussion.

Summary of number of participants in the 13 workshops

<b>Gender</b>	<b>MH Service Users</b>	<b>Carers</b>	<b>Community</b>	<b>Doctors</b>	<b>Other Staff</b>	<b>Total</b>
Male	39	25	10	7	20	101
Female	78	76	25	3	9	191
<b>Total</b>	<b>117</b>	<b>101</b>	<b>35</b>	<b>10</b>	<b>29</b>	<b>292</b>

#### **(3.2) Data Collection**

Following methods were followed for the data collection of the study in relating its objectives.

(3.2.1) Participatory workshop - Study has used tools such as brainstorming, obtaining individual responses on soap cards and focus group discussions under following sessions in half day workshop to collect data.

- 1.) Explaining objectives of the meeting and obtain consent for the reporting.
- 2.) Self introductions of participants and their individual purposes of joining to the organizations – Soap cards feedback session.
- 3.) Identify common problems Review on activities and results – Focus group discussions.
- 4.) Relationships with external organizations and stakeholders – Brainstorming session.

- 5.) Barriers and challenges - Brainstorming session
- 6.) Future plans and strategies - Brainstorming session

Purpose of following such an approach is to facilitate every participant give opportunity to express their views individually (in soap cards) as well as collectively (in focus group discussion and brainstorming). This kind of mix approach was followed with intention of avoiding influence of possible power imbalances on the discussion and to facilitate equal participation of service users as well as carers.

Each workshop was facilitated by a main facilitator (researcher) and group facilitators for focus group discussions. Whole workshop was documented by a process writer.

(3.2.2) Observation – Facilitators recorded their observations in relating to discussions and interactions among groups. Aim of this was to identify relationship between information (such as activities) and lives of service users.

(3.2.3) Interviews with stakeholders who support organizations – Interviews were conducted with mental health professionals and health workers who support the organizations. Following topics were followed flexibly according to context and status of particular organization.

1. Mental health status in the area in general
2. Importance of having group/organization of consumers/carer
3. Their support to this group
4. Their views on participation of consumers and carers in leading such an organization – in relating to their capacities and support they need from professionals
5. Factors motivate their active participation and factors support for sustainability of this kind of group?
6. Challenges and barriers for participation and for sustainability
7. Supports they receive from other organizations
8. Future plans to strengthen the group

(3.2.4) Addition these methods, information in first stage was also used in relating to formation of organizations.

### **(3.3) Data analysis**

Study followed qualitative analysis method with using some basic statistics through following methods.

- Individual responses of participants on their purposes to join the organizations of MH service users were categorized under main themes identified by reading the document and generated statistics by using the MS Excel to see frequency each theme. Chart 1 and Table 3 was generated by this method.
- Same method was used to analyze common issues presented by MH service users and carers. Chart 2 was generated from this analysis. However, this is not pure statistical analysis base on quantitative research principles and this is rather simple statistical analysis to understand frequency of response. This is a relevant method, since responses were received for same set of questions presented to the groups.

All process documents and observation notes of each workshop were analyzed by interpreting the similarities and differences of each organization in relevance to themes used for the analysis.

### **(3.4) Limitation**

As mentioned above, data for this study was mainly collected through ½ day workshop with MH service user, carers and community members and interviews with health professionals in particular locations. Data and observations used for the study is therefore limited to this scope which is not sufficient in some cases to understand factors beyond the ideas presented at discussions at each locations. As example, to understand level of participation of MH service users and carers in planning and implementation of activities of particular organizations, research should have extensive observation cover on several aspects of activities. However, due to time constrains and cost, such in-depth observations were not possible in this study, except participations of activities of two organizations addition to discussion had with them.

Moreover, in some organizations facilitators faced difficulty in get involve some service users and other participants in the some data collection activities. E.g in brainstorming of ideas motivated participants to be member of particular organization, 91 MH service users out of total 117 did response properly. Rest of service users did not response or did not response clearly as some of them are not in stable status or some of them did not like to response. Similarly there are few carers and community members did not response clearly as some of them did want to protect their privacy. In ethical sense, research team therefore realized their difficulties and respected to these participants' need not to reveal their private information.

## **(4) Data and Analysis**

This study was conducted with 13 organizations in seven districts and had discussions with 117 MH service users and 101 carers, 35 community members, 39 medical professionals and other health workers attached to medical service centres to which these groups are linked and with 7 non-medical service providers who support/work with these groups. Focus group discussions (FGDs) were conducted with the service users and carers and some of the service providers while key person interviews were held with people who were instrumental in motivating and mobilizing the formation of the groups and who liaise closely with the MH service users and carers to support their collectives.

A salient feature of the MH service user and carer groups is their close, and in some cases inextricably welded, link with the MH clinic/ local hospital: Almost all of the service user and carer groups either function with the support of such a link or had strong support from medical professionals in the inception of the group. Responses given to the question on Objectives that influenced the formation of the organization in Table 1 on MH user and carer organizations clearly illustrates in this situation. This is discussed in detail in section 4.2.

### **(4.1) Composition of the MH service user and carer forums**

#### **(4.1.1) Formation of organizations – people/service providers' involvement**

Eight (8) out of the 13 organizations studied were formed by the medical professional in charge of MH (consultant psychiatrist, MOMH). Three (3) forums were formed through the mobilization on the psychiatrist social worker (PSW) who worked through the hospital of their area. Only two (2) organizations were formed outside the direct intervention of medical service institutions but these too were supported by MH professionals. These two forums are:

- Sisilsa Mental Health Promotion Association formed through the collective initiative of the Community Service Officer (CSO) of the area and with support of a group of elderly community members of Panadura.
- Community Action Forum (CAF) formed through the collective effort of the MH service users and carers, BasicNeeds Sri Lanka and the consultant psychiatrist to the Community Mental Health and Development (CMHD) project of BasicNeeds Sri Lanka.

In addition to this, some forums had been revived by the medical professional in charge after these groups were dysfunctional for long periods: For example, Manasika Sahana of Kuliapitiya and Vasantham of Kalmunai.

Four (4) organizations have been registered formally while another 3 organizations are in process of development of constitutions and of planning to registration.

As highlighted earlier, prevalent feature in the formation of MH user and carer forums is that the main linkage to the forum initially has been through the MH service provision centre i.e. MH clinics. However, some initiatives have been motivated by active user groups: Some examples are:

- Psychiatrist Social Worker (PSW) was influenced through a performance of the forum theatre of the CAF in Colombo resulting in forming the HithaMithuru Society for MH users and carers in Kandy.

- The Mental Health Family Association in Siyambalanduwa was motivated to be more active after the MOMH shared the positive experiences of Sithpahan Pravardana Association and Sahana Rekawarana MH forums of Horana.

Resulting from the close link with the MH service centres, almost all the forums, in the early stages of their formation held the forum at the MH service centres: E.g. MH clinics, medical camps, at the MOMH office. In many cases the meetings were also coordinated and facilitated by the MH service providers. Some forums continue to have their meetings at the MH service centre and generally meet when the service users and carers periodically visit the MH clinic or the MH rehabilitation. However, some organizations that are more developed now have their own premises and have independent mechanisms to coordinate meeting among its membership.

**Table 1 – MH user and carer organizations**

	<b>Name of the organization</b>	<b>District</b>	<b>Date Started</b>	<b>Objectives that influenced the formation of the organization</b> (As expressed by participants and key stakeholders)
1	Parents association of Arunalu Rehabilitation Center, Uhumiya	Kurunegala	April 2002	<ul style="list-style-type: none"> <li>▪ To raise awareness of carers to look after service users after discharged from the rehabilitation center.</li> </ul>
2	Community Mental Health Committee	Colombo	December 2005	<ul style="list-style-type: none"> <li>▪ To influence government to obtain mental health clinic for the area-Kaduwela</li> </ul>
3	Batticaloa Mental Health Development Organization (BAMDO)	Batticaloa	June 2005	<ul style="list-style-type: none"> <li>▪ To promote mental health and reduction of stigma through economical development.</li> <li>▪ To help and improve consumers welfare.</li> </ul>
4	Consumer Action Forum (CAF)	Hambantota	January 2006	<ul style="list-style-type: none"> <li>▪ To create quality mental health services for people experience mental illness and their families</li> <li>▪ Improve quality of lives of people experience mental illness and their families</li> <li>▪ To influence policies and practices by using experience and information of people with mental illness and their families</li> </ul>
5	Sisila Cares and Consumers Society At Deltota Rehabilitation Centre	Kandy	April 2006	<ul style="list-style-type: none"> <li>▪ To create mechanism to strengthen the relationship between carers and the service users after they discharged from the Rehabilitation centre.</li> </ul>

6	Sith Pahan Prawrdana Association and Sahana Rekawarana Associations – at Horana base Hospital	Kalutara	2008	<ul style="list-style-type: none"> <li>▪ Develop mechanism for community based rehabilitation of service users.</li> <li>▪ Empower carers to work together for service users.</li> </ul>
7	“Vasantham” Kalmunai Consumer Organization	Ampara	October 2008	<ul style="list-style-type: none"> <li>▪ To improve the Kalmunai mental health services is on prevention of mental illnesses; promotion of mental well being and rehabilitations people and maximizes their normal life, where illness does occur.</li> </ul>
8	“Manasika Sahana” Organization	Kurunegala	October 2009	<ul style="list-style-type: none"> <li>▪ To raise awareness of carers to support service users for their rehabilitation and proper recovery</li> </ul>
9	Sisilasa Mental Health Promotion Association in Panadura Base Hospital	Kalutara	September 2009	<ul style="list-style-type: none"> <li>▪ To raise awareness for community on mental illness.</li> <li>▪ To direct mentally ill people for the treatments.</li> <li>▪ To link elderly societies functions in Pandura MOH area to the work for people with mental illness</li> </ul>
10	HithaMithuru Society	Kandy	May 2010	<ul style="list-style-type: none"> <li>▪ To build up closer relationship with service users and carers attend the clinics at general hospital in Kandy.</li> <li>▪ To raise awareness.</li> <li>▪ To find out a collective mechanism with participation of service users and cares common problems such as lack of livelihood.</li> <li>▪ To enable service users and cares to independently find solutions to their own problems against feelings they had that are not capable of finding solutions for their problems.</li> </ul>
11	Mental Health family association at base hospital , Siyambalanduwa	Monaragala	June 10	<ul style="list-style-type: none"> <li>▪ To make awareness of every aspect of mental illness.</li> <li>▪ To involve carers for rehabilitation of their family members with mental illness.</li> </ul>
12	‘Prageethi’ at base hospital	Kurunegala	September 2010	<ul style="list-style-type: none"> <li>▪ To build capacity of carers and service users to find out solutions collectively for their problems due to illness and poverty.</li> </ul>
13	Villas Rekawarana Sapayanno at NIMH	Colombo	2005	<ul style="list-style-type: none"> <li>▪ Support rehabilitation of service users</li> </ul>

(4.1.2) Initial objectives of formation in relevance to identified needs

Views were expressed on objectives by the MH service users, carers and service providers during the FGDs and interviews held for the study at first stage was used for this analysis. The highest prevalence of objectives/aims was to develop and strengthen carer and MH service user links for improved rehabilitation care and continued treatment at MH clinics. Promote mental wellbeing and quality of life was featured in four objectives while enabling MH service user and carer collective initiatives to resolve their issues were mentioned as their objectives by three organizations. Amongst the other priority expectations from the forums were influencing policy and practice (2 mentions with one specifically to have a MH clinic started in a selected location), economic support (2 mentions with one linked to reduction of stigma through improved economic situation), two mentions each on general awareness raising on MH and improved access to MH treatment.

(4.1.3) Organizational representation of service users, care givers and other community members in key positions of the organizations

Table 2 – Key positions holders in MH user and carer organizations

<b>Organizations</b>	<b>President</b>	<b>Secretary</b>	<b>Treasure</b>
Parents association of Arunalu Rehabilitation Center, Uhumiya	Carer	Carer	Staff
Community Mental Health Committee	Volunteer	MH Service User	Carer
Batticaloa Mental Health Development Organization	MH Service User	MH Service User	Carer
Consumer Action Forum	MH Service User	MH Service User	MH Service User
Sisila Cares and Consumers Society	MH Service User	MH Service User	Staff
Sith Pahan Prawrdana Association and Sahana Rekawarana Associations –	Carers	Carers	Carers
Consumer Organization “Vasantham”	Health Staff	Health Staff	MH Service User
“Manasika Sahana” Organization	Carer	MH Service User	Staff
Sisilasa Mental Health Promotion Association in Panadura Base Hospital	Carer	MH Service User	Volunteer
“HithaMithuru Society”	Service User	MH Service User	Carer
Mental Health family association	Carer	Carer	Carer
‘Prageethi’	Carer	Carer	Carer
Villas Rekawarana Sapayanno at NIMH	Carer	Carer	Carer

The pattern of MH service user, carer or MH service provider staff functioning in office bearer positions were studied to ascertain the degree of trust and confidence placed in the MH service users to function in leadership positions of their forums. A Table 2 highlights, a positive feature was that despite the forums’ strong and close links with the MH service providers especially medical professionals, most organizations had leadership positions open to MH service users or their carers. Except one organization (in Kalmunai), in all the others service users/ carers hold the key positions of president, secretary or treasurer.

In BAMDO all of the main positions except that of the treasurer and related sub positions are held by service users. In CAF the service users hold all the key leadership positions and are responsible for five main sectors of operationalizing the forum: These are management and finance, mental health development, and livelihood development, participatory research and consultancy, and community partnership. Gradual trust building on the capacity of MH service users to function effectively in leadership positions is seen in one organization (Sisila Carers and Consumer Society) which originally limited its key office bearer positions to carers but have since of late, opened these for MH service users.

In five organizations (in Horana, Uhumiya, Kurunegala and Moneragala and NIMH<sup>23</sup> Colombo) only carers hold the main leadership positions. The reason cited for this is that the service users are not in a stabilized status to take responsibility of office bearer positions. In one organization (in Horana) the constitution of the forum itself restricts appointment of service users to office bearer positions.

Analysis of the patterns of leadership positions in the MH service user and carer forums indicate that greater sensitivity and effort is needed to facilitate space for MH service users to discover their potential to function in leadership positions and take responsibility in operationalizing the forums that are established to promote their well being. This is all the more significant when considering the following two factors:

- a) Holding leadership positions in their forums would provide the MH service users with the space and experience to develop leadership skills which in turn could pave way for them to be more active in other community based organizations in their communities/ occupation related associations/school development societies etc.

Evidence in other research shows that holding leadership positions in their forums would help service users develop a positive sense of identity, have a life which is more meaningful and for which they have more of sense of responsibility, these have all been identified by service users as being important in their recovery from mental illness (Andresen R Oades L Caputi P 2003 The experience of recovery from schizophrenia: towards an empirically validated stage model *Australian and New Zealand Journal of Psychiatry* 37 5 586-594)

- b) The highest number of issues expressed by the MH service users in the FGDs conducted for this study was related discrimination and stigma. (Refer Table 2) Non availability of leadership positions for MH service users in their own forums would reinforce the stigma and negative attitudes towards the service users while developing leadership capacities and opening up leadership opportunities for them would go a long way in negating the stigma attached to people with mental illnesses

#### (4.1.4) Role of the service providers/health professionals/health workers who work with MH service user and carer organizations

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<sup>23</sup> NIMH – National Institute of Mental Health

The forums link with a range of service providers as illustrated in Table 1. However, the main support, advice and guidance come from and also sought from the medical professionals who are directly linked with the forums. This is the case with all the forums except CAF which has now established a more independent stand for itself. The high level of reliance on the medical service providers is understandable since the initiative to form the forums, in most cases, was taken by a mental health professional in charge or a medical staff who had direct contact with the service users.

These mental health professionals or their subordinates provide guidance in the key operationalizing the forums and play an active role in raising awareness on MH related issues and options as well as link them with other relevant service providers. According to WHO's guidelines on Advocacy on MH, service users and carers should be supported by MH professionals to initiate such organizations to work for rights of service users and advocacy. The mental health professionals have direct and easy access to the forums and are able to take a key role in the facilitation of the forums since many of these organizations are centrally functioned in premises of hospitals /other health centres.

The high reliance on the mental health professionals has both advantages and disadvantages. The main advantages are:

1. It sustains the forums due to its direct link with the established state health care system. The forum is assigned the position of an extended treatment facility. This is clear when considering that one of the highest expectations from the forums were support for better rehabilitation and recovery.
2. It ensures that service users' treatment seeking behavior is maintained. The regular visits to the MH clinics/hospital are linked with periodic meetings of the forums. The medical professionals who support the forums initially have the opportunity to motivate service users and carers for a collective initiative.
3. It is easier to coordinate the forums through the service users' link with the MH service provision centre. Members of these organizations represent different geographical areas and therefore it is convenient to coordinate with them through the MH clinics/hospitals which they regularly access.

The main disadvantages on relying heavily on the MH professionals are:

1. It creates dependency on medical professionals and thereby diminishes the voice of the MH service users and carers.
2. It could reduce active participation and initiative taking by service users and carers due to power and identity issues. This could result in reinforcing/ increasing power imbalances and service users' role could be reduced to token participation which negates the concept of mobilization of MH service users and their empowerment.

Although the degree of involvement of the MH service providers varies with different forums, its significant role in the formation of the forums is undeniable. The need for MH service user and carer collectives is recognized and supported by the MH service providers because of its ability to ensure MH service users' regular interaction with the MH service centre (MH clinic or local hospital). Although the progress of BAMHDO and CAF and innovative approaches CAF has taken have motivated some service providers to organize forums for MH service users in their locations, these groups are yet to try out mechanisms that promotes their greater potential to be more active outside the treatment seeking, recovery and rehabilitation focus and make greater contribution to enhance the social integration of the MH service users..

## **(4.2 ) Participation and Voice**

### **(4.2.1) Factors motivate service users and care givers/Purposes of joining an organization**

The level of participation of service users and carers is closely linked with their purpose of joining the forums. Analysis of individual responses by participants in the participatory discussions conducted for this study highlight that the main purpose of joining a MH service user and carer organization was to fight the stigma related to being a person with mental illness and to improve theirs and their families' social integration (24%) . This is evident in Chart 1 and Table 3. Closely following the expectation of improved social acceptance and reduced stigma are hopes of improving their mental health (21%) and self help (16%). These responses were mostly given by service users and carers (See table 3). These three responses taken together underline not only an ardent wish by the service users and carers that their mental health is improved but that it would result in greater social acceptance and equality on par with other members of the community.

Livelihood support and access to knowledge on MH have motivated 7% and 9% of those who participated in the study to join a service user/carer forum while another 6% was motivated by expectations of gaining relief aid/assistance. Eight percent (8%) were motivated by a desire to work collectively, be involved in team work and to strengthen the user/carer groups. Specific interests were expressed by some user groups to be actively involved in team work to address their issues as well as in general community work: E.g. the elders in the forum in Panadura.

Volunteers/CSO and SSOs high interest in supporting other service users and thereby helping the service users and carers to deal with the stigma and discrimination was highlighted in the FGDs. The varied expectations from the forums is illustrated by the interest expressed by volunteers to improve mental health services through the forums (3 out of 20 volunteer responses) but only 1 out of 91 responses by service users stated this as an expectation from the forum. Carers did not identify this as a purpose that motivated them to join the organization. Similarly 1 volunteer response (out of 20) stated that the hope of studying new approaches for service provision motivated their interest in the service user/carer forum. This too was not reflected in the service users or carers' expectations.

There is a notable disparity between the nature of purposes that motivated the service users and carers to join the forums and the expressed/stated objectives of the forums. The highest prevalence of objectives was related to improved rehabilitation and recovery while it features lowest in the users' and carers' expectations from the forum. This underlies a tendency by the MH service providers to the forums as a mechanism to ensure service users' adherence to recommended medical care while the users and carers have expectations of dealing with social discriminations through their link with the forum. It needs to be reiterated that the forums make a significant impact on the service users and carers by having a collective that promotes their sense of belonging and which motivates them to access regular medical care. However, the disparity in the service providers and users expectations raises the question as to whether the forums need more support to deal with the stigma, social pressure and the resultant discriminations that the service users and their carers have to deal with on a daily basis.

Chart – 1 Reasons for joining the organization – Based on total of individual responses of MH service user, carer and volunteer/CSOs

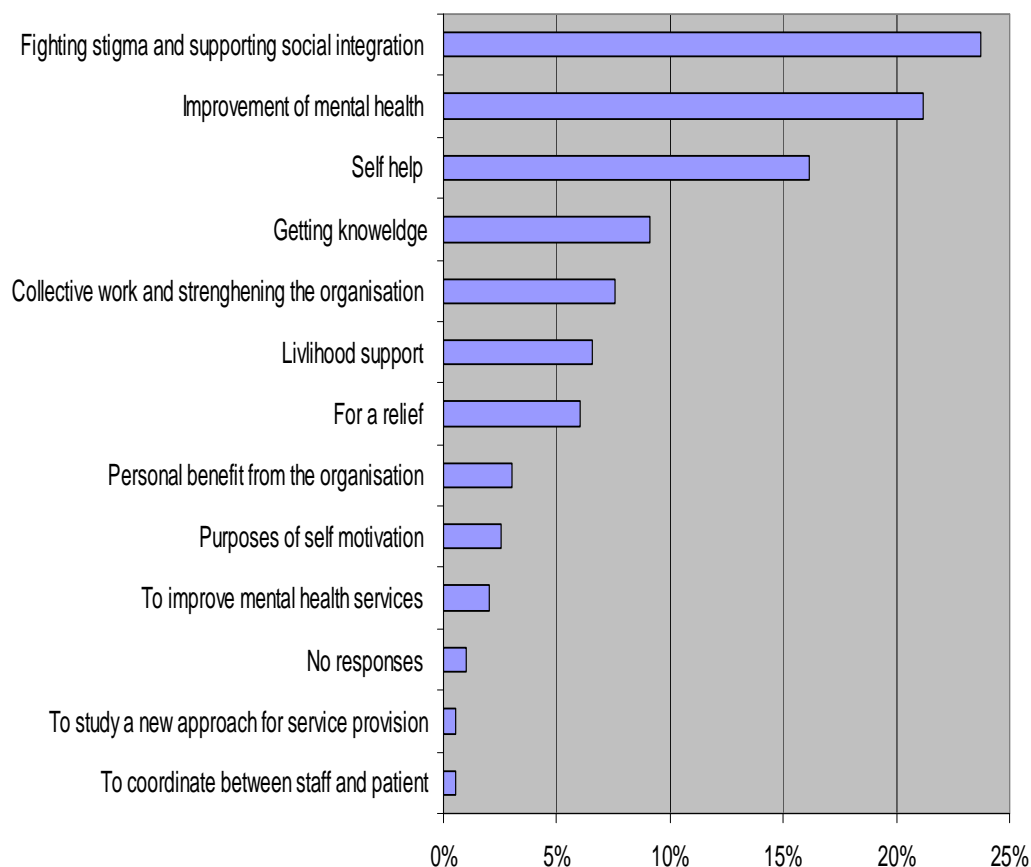


Table 3 – Purpose of joining the MH service user and carer organization

Purposes	Service Users	Carers	Volunteers	Total	%
Supporting other service users, fighting stigma and supporting social integration	20	16	11	47	24%
Improvement of mental health	20	21	1	42	21%
Self help	16	14	2	32	16%
Getting knowledge	6	11	1	18	9%
Collective work and strengthening the organization	7	8	0	15	8%
Livelihood support	8	5	0	13	7%
For a relief	7	5	0	12	6%
To improve mental health services	1	0	3	4	2%
Personal benefit from the organization	2	4	0	6	3%
Purposes of self motivation	2	2	1	5	3%
No responses	2	0	0	2	1%
To coordinate between staff and patient	0	1	0	1	1%
To study a new approach for service provision	0	0	1	1	1%
	91	87	20	198	

#### (4.2.2) Opportunities for active participation by service users and carers in planning and implementation of activities

The level of participation by service users and care givers in the decision making and implementation of action plans of the organizations varies significantly among the organizations studied for the mapping.

Table 4 – Nature of participation in the forums

<b>Nature of participation</b>	<b>No. of organizations</b>
Service users take leading and active role in planning and implementation.	02
Cares takes active role, but with few service users who hold key positions – in planning and implementation	04
Only cares take active role in planning – But service users are involved in implementation through providing their skills, labor and resources.	05
Only health staff take role in planning	01
Paid staff and a service user in main position takes active role in planning and implementation	01

In most organizations decision making and planning process was done through monthly meetings/special meetings organized to plan special activities. This is also the space where service users and carers express their issues as well as their views on the functioning of the organizations. The level to which members make use of this opportunity and whether the focus of issues go beyond that of medical and health aspects too varies with the focus of the organizations and the degree of independent agency that is enjoyed by each forum.

As depicted in Table 5, out of the 13 organizations studied only two organizations, CAF and BAMDO, held meetings with the facilitation of service users. In all other organizations the meetings were facilitated by the relevant medical/health care professional or the PSWs although in 4 of these organizations carers take an active role in the discussions. Where opportunities are given to service users to facilitate meetings it has played a significant role in enabling /motivating them to confidently voice their views and actively participate in the decision making processes of their organization.

Although the degree of participation by service users varied among organizations, a common and a significant aspect that was highlighted by service users and carers of all organizations was the positive impact the regularity of meetings brought to their lives. The opportunity to meet together and discuss their issues, achievements and express their views was considered as an important opportunity by all the service providers and carers who participated in the FGDs. The ability of the forums to build on this positive note and integrate these views in planning and action in the forums and promote active participation in the decision making processes was observed to be largely dependent on the structures and the culture of the organizations.

#### (4.2.3) Factors challenge and obstacles the participation

Several factors challenge active participation of the service users. Primary among these are the economic problems faced by the service users, the power imbalances between the medical professionals and members of the forums and the lack of trust in the capacities of the service users.

*Economic problems –*

Service users and carers in a forum are drawn from different geographical locations in a district. Travelling for meetings, discussions and collective activities that happen through the forum requires the service users to find bus fare, which is a challenge for most service users who are dependent on others for their upkeep/who have meager financial resources.

Two options to address this issue are identified from the current practices of forums

- Organizing divisional level meeting or micro meetings of the forum within a cluster of villages is practiced by CAF. This minimizes/eliminates the travel expense and encourages greater participation.
- Holding the meetings on a MH clinic day would eliminate extra time and cost of travel. However, this may, again, pose challenges when mobilizing members beyond a medical/health care environment.

*Power imbalances between MH/health care professionals and service users/carers. -*

The power relationship between the service user and the medical professional is imbalanced due to the higher educational/social and economic status that is generally associated with the medical professionals. In addition the low economic capacity of the service user families and lack of self confidence stemming from the social discrimination as well as having the meeting in a medical/health care environment weakens the service users/carers ability to negotiate for more equal space for participation.

An option that is practiced by some health care professionals has been to play a facilitative role with understanding that the service user/carer community should take leadership in process. This has given space for the relevant community members to gradually develop into leadership roles: With active participation in the decision making of the organization they have become able to take ownership of the organization, while being open to advice from relevant health care professionals.

CAF functions without the direct guidance of medical professionals and therefore provides greater space for service users to gradually build their capacities through mobilization, by observing the other more active members and through association with different stakeholders. However, since most forums operate under the direct guidance/involvement of medical/health care professionals and the opportunity to work at a pace that the service users are comfortable to move forward is not available in such scenarios.

Contrary to this, in some locations, the dominant role played by medical professionals has curtailed space for active participation by service users and carers. Their inhibition and lack of interest in the happenings of the organization was observed in these locations and thereby has posed obstacles to their participation in the decision making in their forums.

*Lack of trust in the capacities of service users-*

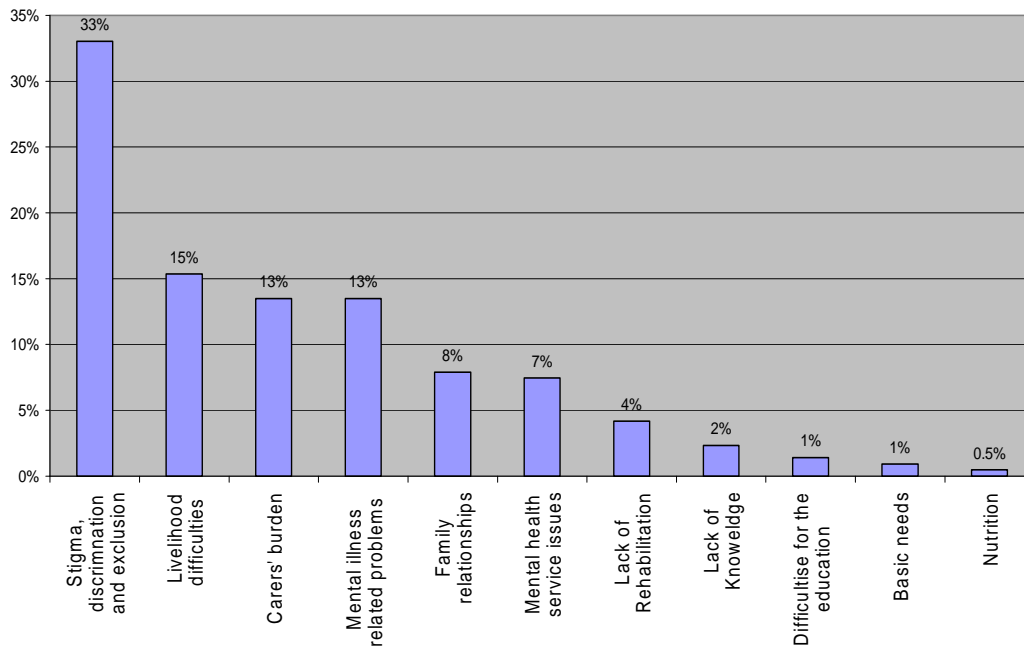
The level of active participation by the service users was also influenced by the opportunities they had to function in leadership positions and participate in the significant negotiations and discussions related to the functions of the forum. This is directly related to whether key office bearer positions are open to them, whether service providers have confidence and are willing to support them to function effectively in leadership positions.

Observations during the field work for the study indicated that the service users are at times treated as mere recipients rather than active agents of the forums and those main decisions are often taken by the health care staff/key supporters of the forums. In some instances the people who registered with the MH clinics are considered by local MH professionals as automatically gaining membership of the organizations but the service users were largely unaware as to the purpose or the potential of the organization to positively impact on their lives if they participated in it with a sense of ownership.

**(4.3) Activities and outcomes with relevance to problems of service users and advocacy**

**(4.3.1) Problems as identified by service users and cares**

**Chart 2 - Common Problems - Analysis derived from group presentations of service users and carers**



**Table 5– Common problems expressed by service users and carers – Summary according to main categories**

<b>Main categories belong to problems mentioned under group discussion</b>	<b>Frequency mentioned</b>	<b>%</b>
Stigma, discrimination and exclusion	71	33%
Livelihood hardships/ Economic burdens	33	15%
Carers' burden	29	13%
Mental illness related problems	29	13%
Family relationships	17	8%
Mental health service issues	16	7%
Lack of Rehabilitation	9	4%
Lack of Knowledge	5	2%
Difficulties for the education	3	1%
Basic needs	2	1%
Nutrition	1	0.5%
<b>Grand Total</b>	<b>215</b>	

Table 5 and Chart 2 illustrates that the most frequently mentioned problems of MH service users and carers were those related to stigma, discrimination and social exclusion (33%). This was also reflected in the purpose of joining the forum, where the highest number of mention (24%) was related to fighting stigma and discrimination related to mental illnesses. It is evident that this is the most crucial issue that negatively impacts on the MH service users and their carers.

Amongst the other significant issues are those related to livelihood and economic issues (15%) carers' burden (13%) and issues related to family relationships (13%). Issues related to mental health services (7%) and lack of rehabilitation facilities (4%) emerged as the 5<sup>th</sup> and 6<sup>th</sup> priorities according to the frequency of mention.

#### (4.3.2) Activities and outcomes

A summary of the key activities carried out by the organizations studied and the relevance to the issues raised are presented in Table 7.

Table 6 – Activities and relevance to issues

Activities	Number of organizations implemented	Relevance and Impacts
<b>Livelihood</b>		
1. Capacity building programmes including rehabilitation programmes for skill development, improving existing skills and developing new skills for self employment, find and start self employment.	07 HithaMithuru Society , CAF Community Mental Health Committee, BAMDO, <b>Vasantham”</b> Sith Pahan Prawrdana Association and Sahana Rekawarana Associations	As analyzed in table and chart above, economic burden is the second most significant issue mentioned by service users, carers and community workers (volunteers, CSOs, SSOs) who participated in the study. Therefore, any interventions to develop livelihood status have significant relevance to the issues faced by MH users/carers. Many of the livelihood support activities are on building capacities for livelihood development.
2. Expenditure analysis programmes (Only CAF)		
3. Consultation workshops on starting businesses	01 CAF	
4. Business planning and resources survey		
5. Develop linkages between stabilized service users and working places to find out employments for them.	01 Sisilasa Mental Health Promotion Association	
6. Encouragement for self-employment through cooperation, advising, encouraging and community help.	BAMDO	
7. Micro – credit programmes		

Activities	Number of organizations implemented	Relevance and Impacts
8. Trade fair and selling products of service users at exhibitions of other organizations.	02 CAF Deltota	
<b>Social and cultural activities – as way to social integration</b>		
<ol style="list-style-type: none"> <li>1. Festivals to celebrate Sinhala and Tamil New Year</li> <li>2. Religious activities</li> <li>3. Festivals related to religious events - celebration of Wesak, Poson and Christmas and Dansals.</li> <li>4. Pilgrimages.</li> </ol>	All the organizations	<p>Stigma and Exclusions is foremost issue that was expressed by the service users and carers during the study. Therefore, it could be expected that the cultural and social activities have relevance to this issue as they provided opportunity service users to build up social relationships with other community members and to express their talents. This enhances their self esteem and self confidence as mentioned by participants during the FGDs.</p> <p>For some services users and care givers these activities were also therapeutic as they provided relief from their daily stresses. Although these interventions have provided some degree of space for social interaction at particular events, it is difficult assess how far these interventions changed the stigma and exclusion to a significant level especially in promoting service users and carers' sense of social acceptance and during significant life events such as marriages and accessing satisfactory employment.</p>
<b>Public awareness on mental illness and mental health</b>		
<ol style="list-style-type: none"> <li>1. Celebration of World Mental Health day <ol style="list-style-type: none"> <li>1. Walk and musical programme – Sith Pahan Prawrdana Association and Sahana Rekawarana Associations.</li> <li>2. Drama performance – Sisila Mental Health Promotion Association.</li> <li>3. Trade exhibition and celebration of World</li> </ol> </li> </ol>	7 organizations	These events targeted general public, mental health professionals, health administrators, government administrative stakeholders, security forces and in some occasion media personnel too (at Kandy and at Horana). Therefore these have relevance to educating public about mental illness and mental health and sensitization other higher level stakeholders about issues faced by people with mental illness as well as the

Activities	Number of organizations implemented	Relevance and Impacts
<p>Mental Health day – by Sisilasa Parents' Association.</p> <p>4. Mental Health Day (selling of things and running the exhibition) – BAMDO</p>		<p>general public. This again has the relevance for the stigma reduction. Moreover, these have contributed also to improvement of life skills, self esteem and confidence of service users. At organizational level, members improved their capacity to organize events and as mentioned by some service users (Kandy) they have built their confidence as team to organize event of a significant scale.</p>
<b>Mobilizing service users for and building their capacity</b>		
<ol style="list-style-type: none"> <li>1. Community consultation workshops</li> <li>2. Awareness on human rights of service users – provide by service users to service users (outside the organization)</li> <li>3. Experience sharing and awareness for other service user organizations by CAF for organizations in Kandy, Uhumiya and Vakarai</li> <li>4. Formation and facilitation of self help groups.</li> </ol>	CAF	<p>This has contributed towards initiating mental health programmes in villages where the forums are not currently active. This was done through mobilizing the community to use its own resources (without external funding) for such workshops.</p> <p>Service users participated in awareness raising programme on mental health</p> <p>This has contributed towards motivating service users and carers in other organizations to share experience and to be involved to collectively work to influence public attitude.</p>
<b>Advocacy</b>		
<p>Influencing public and stakeholders in the sectors of health, development and media</p> <ol style="list-style-type: none"> <li>1. National workshop on mental health by Hitha Mithuru Sangamaya in Kandy with support of CAF to perform forum theatre.</li> <li>2. Forum Theater - CAF conducted 36 workshops at village level, 4 at district level and 2 at national level. While village level targeted</li> </ol>	<p>2 Organizations</p> <p>Hitha Mithuru Sangamaya</p>	<p>The workshop was attended by influential decision makers in the district. E.g. –Governor, Divisional Secretary, MH professionals, and media as well as representatives of the public</p> <p>This event sensitized higher level stakeholders and public with sessions of interactive discussion on issues of mental illness and services available for them.</p>

Activities	Number of organizations implemented	Relevance and Impacts
<p>public , district and national level targeted following stakeholders</p> <ol style="list-style-type: none"> <li>1. Mental health professionals.</li> <li>2. Health administrators.</li> <li>3. Media.</li> <li>4. NGOs and other development agencies.</li> <li>5. General public</li> </ol> <p>3. Presentation research paper on 'Service User and Livelihood development' at International workshop conducted by SEED (Sarvodaya Economic Enterprise Development Services (Gurantee) Ltd).</p>	<p>CAF</p>	<p>In the locations where the forum theatre performances were held, it has contributed to influencing the attitudes of the general community, religious and community leaders and service users who were hitherto not linked to the user/carer groups. Some of them have subsequently joined with these groups.</p> <p>At national and district level, workshops and performances by the forum theatre drew active participation by MH professionals other stakeholders in the discussions held at the end of the performances. These indicated that the messages on greater sensitivity towards MH service users have been effectively communicated through the theatre performances.</p> <p>As participants and stakeholders from different countries, CAF received opportunity to shared perceptions of service users on livelihood development.</p>
<p>Influencing policies and practices</p> <ol style="list-style-type: none"> <li>4. Participating in district coordination meetings conducted by GA (Government Agent) in Hambantota.</li> <li>5. Influence the government to increase the local mental health service.</li> <li>6. Participation in the</li> </ol>	<p>2 organizations</p> <p>CAF</p> <p>Community Mental Health Committee, Kaduwela</p> <p>CAF</p>	<p>Through raising awareness of GA about scarcity of psychotropic drugs in the Base Hospital in Tangalle, hospital received some supply of drugs.</p> <p>Obtained support of the GA to obtain support of the Social Service officers to access self employment assistance to service users.</p> <p>The organization with the support of the PSW was able to influence the establishment and improvement of local MH services in the area – such as starting of 4 MH clinics at 3 rural hospitals with appointment of 10 MOMH and appointment of mental health coordinator for RDHS office.</p> <p>The participation of the MH service users in the programme and portrayal of their talents through the forum</p>

Activities	Number of organizations implemented	Relevance and Impacts
sensitization programmes for media people as part of media strategy development implemented by BNSL. This was done in collaboration with the consultant psychiatrist who guided the BNSL programme.		theatre contributed highly to sensitize the journalists on the capacity of people with mental illnesses. This enabled the journalists to better understand the need for sensitive reporting on MH service users and the importance of respecting their dignity. This aspect was featured in some newspaper articles published subsequently.
<b>Service users involvement in mental health service coordination and provision</b>		
1. Organized a mental health camp with mental health professionals. 2. Rehabilitation care for other service users (outside from the organization)	01 CAF	32 service users were accessed medical treatment and other services such as counselling and raising awareness on MH at this camp.
3. Follow-up of other service users	02 CAF BAMDO	In CAF this is mainly done by service users and contributes to developing their capacity as well as encouraging other service users for improvement of their capacities through collective work  In BAMBO this is done with the volunteers taking the lead but with the participation of service users.

As Table 7 illustrates the activities implemented by organizations covered under study and the outcomes /impacts are significantly varied. Overall these interventions can be discussed under following common themes in relevance to the advocacy.

- a) Space for service users and carers to raise their voice and special advocacy initiative.
- b) Engaging MH service users in mental health support services.
- c) Facilitating space for social integration and social skills development.
- d) Impact on the promotion of human rights of MH service users

#### (4.3.3) Relevance of activities to Advocacy on MH

- i) *Space for service users and carers to raise their voice and advocacy initiative.*

Like many concepts, advocacy is contested and has many different definitions. At its simplest advocacy has been identified as actions that enable individuals to have a say in their life and the dimensions that affect their livelihood, whether that be their care, their family, their housing and their work<sup>24</sup>. This definition is similar to WHO explanation that 'Advocacy in this field

<sup>24</sup> Supporting User Led Advocacy in Mental Health.

(mental health) began when the families of people with mental disorders first made their voices heard'<sup>25</sup>.

According to the WHO definition, if the baseline of advocacy is considered as enabling service users to have a say on their lives and issue that impact on their lives, then this baseline outcome is achieved by many organizations interviewed. A few organizations, however, have been able to work with a far reaching vision for the improvement of living conditions of MH service users and carers and have worked beyond the parameters set by medical /health care support systems. Table 7 indicates that two organizations with leadership mostly taken by the service users have played a significant role in some advocacy activities such while one other organization with the support of the PSW has achieved significant outcomes in influencing MH service availability in their areas. In other organizations different degrees of outcomes is seen in influencing communities and stakeholders.

*ii) Engaging MH service users in mental health support services*

The current global understanding on mental health services views the service user as an active agent in facilitating own healing as well as having capacity to contribute to the MH services in general. This growing world wide trend enhances the recognition and space given to service user movements. Simultaneously it contributes to strengthening such movements. Moreover, service users' experience in mental illness and their knowledge to cope with it is considered as expertise. Their involvement in service provision therefore is seen as beneficial to themselves as well as to other service users.

Table 7 indicates that although not on a large scale, two of the organizations studied have carried out activities related to organizing and coordinating mental health service provision. CAF organized a mental health camp in which mental health professionals provided their service to users. In addition, stabilized service users also carry out follow-up visits to help other service users to continue with their treatment and to link them to MH professionals in case of relapses. In BAMDO volunteers work together with service users to provide this service while in CAF follow up visits are carried out mainly by the service users.

*iii) Facilitating space for social integration and social skills development*

Several of the organizations studied have carried out cultural and religious activities aimed at improving social integration and skills development of MH service users and their carers. Table 7 indicates that this has the highest level of intervention, in comparison with the other three types of activities. The reason for higher preference for these activities was easy to identify in the discussions with the service users and their carers. On the one hand religious and cultural activities such as New Year festivals, religious celebrations build on traditional practices/beliefs that are familiar to people and are an integral part of their living: Therefore there is a greater acceptance of and keenness to be involved with such religious rituals and traditional cultural events/activities; The cost of such activities being relatively low, being implemented at village temples and in the community may be a contributory reason. On the other hand, the tendency to rely on religious or cosmic forces during MH illnesses or crises is a common practice. Participation in religious rituals/prayers brings mental relief and has a therapeutic value. Therefore, these activities contribute to individual and collective mental wellbeing of MH service users and carers.

Relevance to advocacy on MH is in the ability to provide increased space for MH service users and their carers to mingle with the community. The significance of this is best understood when

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<sup>25</sup> Advocacy for Mental Health – WHO

one considers the discrimination and isolation that most MH service users are often subjected to within their community. Interaction with volunteers/CSOs, MH professionals and other service providers and being involved in planning and implementing the activities provide skills development opportunities for the MH service users and their carers. When their improved skills and capacities are showcased through community based and other public events, it contributes to build positive images of the MH service users/their families leading to improved social integration.

Some examples of the skills and capacities showcased through the events are:

- Members of organizations adopted a range of activities to find funds for the activities carried out through the organizations. These included collecting contributions from members, selling tickets, selling products of service users and carers, and obtaining small funds from local business community
- Rallying the cooperation of the local community was also clearly visible in some of the activities. This support was given free of charge to organize common events such as the New Year or celebrations. This was made possible in situations where key members of the organization had contacts with influential community members. In Panadura and Horana, the CSO had played a notable role in helping the organizations establish useful linkages to organize common events effectively.
- Some of the skills that participants used /developed by engaging in the organization of such public events are planning, designing, communication skills, writing and documentation, financial recording and maintaining accounts etc.

Community based religious/celebration and common activities also prove the importance of combining medical treatment with social interventions, especially those related to changing societies' attitudes towards MH service users and their families. However, the extent to which such an impact was made by the activities listed in Table 7 in challenging the deep rooted stigma related to MH was difficult to ascertain through this brief study.

*iv) Impact on the promotion of human rights of MH service users*

WHO explains that the concept of mental health advocacy has been developed to promote the human rights of persons with mental disorders and to reduce stigma and discrimination. Some activities carried out by the organizations have contributed towards raising awareness of the rights of the MH service users E.g. forum theatre by CAF. However not all organizations have deliberately focused on this aspect. It could be said that the approach of most organizations has been more need based than directly and overtly rights based. Although reduction of stigma was specifically aimed at through some activities this seems to have used an approach of arousing the compassion and the realization of the capacities of MH service users and therefore the need to treat them with more dignity. The right to equality by MH service users who are unable to showcase such skills and capacities but who have a right to be treated with dignity does not seem to be emphatically communicated through most of the activities carried out by the organizations studies. However, at national level, some activities, especially workshops to influence journalists and some activities of BAMHDO have focused the human rights perspective. Understandably the level of outcome of these activities is varied and need to be matched against the problems expressed by the MH service users and their carers to better assess the impact of these on the participant members of the organizations.

#### **(4.4) Networking with other organizations**

##### **(4.4.1) Support and services**

The MH service user and carer forums/organizations have not worked in isolation: They have been able to liaise with other organizations and have obtained their support and services in several ways.

Table 8 illustrates the nature of support given by other organizations and that state and non governmental organizations as well as banks have extended their support to the MH service user and carer organizations. In the health sector their role emerges clearly as initiators of the service user/carers forums.

Table 7 – Support and services by other organizations

<i>Commonly mentioned organizations</i>	<i>Support and Services</i>
Health sector - RDHS, MOH, Hospital staff, MOMH, Psychiatrists, PSW etc	Formations and functioning of organizations addition to mental health service
GA	Supported the registration of some organization (CAF) and to influence other service providers to support MH service users
Divisional Secretariat offices and Community Support Officers	Supported the registration of the organizations. Support of Social Service officers under programmes of DS offices. Donations, provision of equipment and loans for people with mental illnesses.
Department of agriculture	Training for carers and service users and provision of extension services for group farms maintained by some organizations
National Apprentice and Industrial Training Authority NAITA	Vocational training opportunities
VIDATHA centers	Vocational and self employment training
Agrarian Services centres	Self employment trainings
Banks	Providing micro-credit facilities and financial assistance for public events held by some organizations.
Local business community	Financial assistance for public events
NGOs – SEED, VSO, BasicNeeds, Laymen’s’ Den, Nivahana and CBTD.	Some provided support to start MH service user/carers organizations and others provided training on livelihoods, community mobilizations and mental health.

Discussions on working with other organizations highlighted that the MH service users and carers consider the health sector institutions as those which are the closest to them and whose support is consistent. This could, again, be linked to most of the MH service user /carer organizations being initiated by MH professionals and meetings held at MH service centre premises. Livelihood support given by local government institutions were also highly appreciated by many organizations. This was considered as a useful contribution that helped improve their quality of life. Successful livelihood also helped MH service users and their carers to link with a wider range of service providers/organizations. Apart from these two sectors, the support of other organizations did not seem to be readily and consistently available to the MH service users and carers. Linkages with them were pursued only occasionally in relation to a few special activities.

#### (4.4.2) Involvement of MH service users and carers in establishing linkages and networking

In many organizations the lead to build external linkages and networking was mainly taken by the MH professional, psychiatric social worker or community service officer who interacts closely with the MH service user/carer forum. Compared to MH service users more carers were noted to be involved in networking in many organizations. However, in some organizations the active engagement of MH service users in networking and liaising with other organizations was visible. Some examples are CAF, Hithamithuru Sangamaya and Sisilasa Service Users and Carers Association. In these organizations MH service users were active in building strategic relationships with stakeholders of higher decision making levels.

MH service users were more active in networking when MH service user /carer organizations networked amongst their organizations. Networks among Sith Pahan Prawrdana Association and Sahana Rekawarana Associations in Kalutara districts and networks between CAF in Hambantota and Hithamithuru society are examples for this. Although this is still in the initial stages, the interest of maintaining this network was observed. Such collaboration amongst MH service user and carer organizations would contribute significantly to wider advocacy on MH/ Rights of MH service users etc.

Except the few NGOs mentioned in the table, there seems to be a lack of interest by other NGOs to invite MH service user and carer forums to their networks or liaise with them and contribute to their work. This restricts the opportunities the MH service user/carer organizations have to develop their capacities, access training and strengthen their organizations. CAF has, to some degree, contributed to skills development of other service user organizations but overall, consistent and reliable programmes that the MH service user/carer forums can link with and work collaboratively to reduce stigma/access opportunities for livelihood development etc. are minimal.

#### **(4.5) Sustainability factors and challenges**

- *Reliance on the MH service centre and medical professionals* – Many of the MH service user and carer organizations are located in the premises of MH service centres to which the members regularly come to access treatment. This provides an environment where these MH service user/carer forums could continue to function at low cost. The continuity of the interest and support of the MH professionals is also assured in such cases. However, this limits the scope of these service user and carer organizations to go beyond the medical boundary and play an active role in address their main issues for which social interventions are necessary: for example reduction of stigma and improving social integration, improving livelihood opportunities.

The threat to the sustainability of such forums would arise when the key medical professional who supports the organization is transferred/moves out of the hospital/district. This would weaken the service user/carer organization because some of these organizations currently tend to rely heavily on the support of the medical professionals even to facilitate the meetings/take key decisions of the organization.

- *Continuity of active membership dependent on the MH service centre* - In organizations that function through the MH rehabilitation centres members are noted to be actively engaged in the service user and carer organizations when they frequently

visit the centre. However with the spacing out of the visits this is likely to reduce. In addition, the practice of enrolling all MH service users who attend the MH clinics as members of the service user organizations reduces the probability of their continued participation after recovery/stability.

- *Lack of economic capacity* –This could threaten the MH service user and carer organizations because currently they are supported by some NGOs or GOs to conduct their meetings. The members themselves are mostly at a low income level and would be unable to personally bear the cost of meeting places/travel etc.

However, this threat could be minimized with the mobilization of the members to be more self reliant and develop on their existing and potential support circles: for example the local business community etc. This is a long process and judging by the functioning of some forums such as CAF and BAMDO developing innovative mechanisms to rally the support of the community and for members themselves to be more reliant on their skills and capacities is possible, if appropriate approaches are adopted.

- *Continuity of support of CSOs dependent on their service availability* – The Sith Pahan Prawrdana Association and Sahana Rekawarana Associations in Horana and Sisilasa Mental Health Promotion Association in Panadura are supported keenly by the Community Service Officers. The continuity of their service is currently undecided by the government. The uncertainty of the CSOs position directly affects the MH service user and carer organizations sustainability in locations where s/he has been the key support person of the forum for network building with service providers.
- *Lack of opportunities for capacity building of health care and other professionals on service user empowerment* - While most of the health care professionals take a sincere interest and work with commitment to strengthen the MH service user and carer organizations that they have initiated not all them are sensitive to the need to be proactive in empowering the service users. Their lack of awareness on effective ways of community mobilizing, supporting empowerment processes and advocacy challenge the service user organizations to expand their scale and nature of activities and function independently. The service users high reliance on the professionals for key decision making is observed in many organizations. These need to be challenged sensitively and appropriately and with both the MH service users/carers and the health care professionals.

The need for capacity building of health care professionals to be more sensitive to the processes of service users' empowerment is all the more important because some of the crucial issues faced by them need to be addressed outside the medical/health care parameters: For example reduction of stigma and poverty. Another crucial need is to help the service user forums to develop their skills in organizational management. This is unlikely to foster in environments where a health care/other professional/s takes and maintains the key decision making positions to themselves intentionally or unintentionally. The members need space to grow into leadership and decision maker positions at a pace that a MH service user is able to and deal with the power imbalances within and outside their forum. The space for this needs to be proactively facilitated by the main health care professional/other service provider to ensure effective functioning and sustainability of the MH service user and carer forums.

## **(5) Lessons learned in Development of Service Users and Carers Groups**

- Mental health professionals and other staff related to MH have contributed immensely to form groups/organizations/forums of MH service users and their carers. The MH National Policy places priority on community mental health and the interest taken by MH professionals and other staff to form and support service user and carer groups to collectively address issues that affect their lives should be viewed as a significant progress in translating the policy into practice.
- Several MH service user organizations that were included in this study ensured that service users and carers were appointed to the main office bearer positions. A few organizations have taken a further step in the right direction and have opened up these positions to service users. Appointment of service users and carers, especially users, to key positions is essential to build their self confidence and provide them with opportunities to build leadership and negotiation skills. However the actual benefit of this is realized if the appointment to these positions also in reality gives them the space to function as leaders in these positions. If the more capable carers or the mental health service providers take the lead role in the decision making, the service users will not gain full benefit from their own organization. Furthermore their voice will be suppressed in reality while the already capable professionals/staff or carers views will be forwarded as those of the MH service users. Such scenarios could erode the self confidence of the service users who are already marginalized from the decision making processes in their community and often in their families. The capacity of the MH service users to collectively change the conditions of their lives by working together with their carers and with the support of the service providers assistance when necessary needs to be proactively encouraged: Organizations need to learn from one another and ensure this space for MH service users by actively engaging them in planning, implementation and monitoring of the activities of their organization and in the organizational management aspects.
- The main factor that motivated MH service users and carers to join the organization is their vital need to reduce the stigma to which they are subjected. However, the objectives of the organizations indicate that these lean more towards meeting MH service provision needs, especially that of rehabilitation. While recognizing that recovery, rehabilitation and stabilization is important to portray positive images of the MH service user and thereby reduce stigma, it is also undeniable that medical care alone cannot deal with the issue of stigma: social interventions are essential to effectively deal with the issue and well planned and consistent work towards this was not sufficiently visible in the activities carried out by the organizations.
- A lack of trust in the capacities of some service users in organizations while some others and carers are given more space and support to take leadership roles affects the capacity development of MH service users who have a leadership potential but who may not have had opportunities hitherto to develop these. Greater sensitivity seems to be needed to mobilize leadership skills of all MH users in the organizations so that they can contribute as agents changing conditions of their lives. Promoting a sense of equality within the organizations and encouragement to try out their skills can capacities within the organization emerged as a need in many organizations.

- A sense of equality and more openness in the communication was observed when service users work amongst themselves or have their own forums. This gives them the same to share their views, experience and problems more openly and with a feeling that all are in the same situation. It also helps them to move at their own pace and gradually be mobilized to build their own capacity. The feeling of 'being the same/others are like me' is a motivational factor to work together to deal with their problems/ to pursue their interests in creative work or livelihood activities etc.
- Networking among organizations provides valuable learning for the MH service user and carer organizations. Although there are practical issues such as transport difficulties and travel costs etc, the opportunity to share experiences broadens the understanding of the members and motivates them to look for options to deal with the challenges their organizations/members face.
- Service users and carers are more willing to organize cultural and social activities which give them therapeutic experiences and opportunities for social integration. However their involvement in the community need not be limited to that. Experiences of some organizations have proven that given the opportunity for capacity building the MH service users and carers could be mobilized towards a broader vision. This could also lead them to be more active in educating the public on MH and influencing strategically important stakeholders and policy and practices of service provision.

## **(6) Conclusion and Recommendations**

### **(6.1) Conclusion**

In relevance to mental health policy in Sri Lanka and WHO guidelines, support and contribution of mental health professionals and other mental health workers to form organizations of service users and carers are very important in context of community mental health and also in building capacity of them to work collectively to change issues affect on their lives. Having an organization is therefore first step for service users as well as for carers to raise their voice, issues and suggestions.

Overall common activities implemented by these organizations have positively impacted on their skills development, social integration, and changing social attitude at local level. Most of these programmes were at micro and divisional secretariat level while a few organizations expanded its activities to provincial and national levels. Involvement in these activities provided opportunity to service users and carers to voice their views and to integrate with society. Thus, this has formed the starting point of advocacy on MH service users and clearly reflects the WHO recognition of service user collective work as the beginning of a long process of advocacy on MH. The study, however, identified that only a few organizations operate from such a broader premise and have undertaken systematic advocacy initiatives which targeted multiple stakeholders ranging from general public to influential stakeholders (to mental health and development) such as key governance representatives, (mental health professionals, higher level health administrators, media) and development practitioners. Most organizations focused their work at micro level which is valued for its contribution to social integration and therapeutic value but fails to tap the potential for more effective impacts on the MH users, their care givers, families and the community.

The other main challenge revealed by the study is that although organizations have basic opportunity to express themselves, power imbalances functioned in some organizations as those are facilitated by health professionals and this obstructs active participation of service users and carers. While some carers in such situations have been able to find some space to express their views, the status of the MH service users becoming passive participants.

## **(6.2) Recommendations.**

1. **Capacity building in user led advocacy** – It is important to build capacity of service users and carers to be actively involved in a systematic and well focused advocacy initiatives. The aim of such initiatives should prioritize reduction of stigma, reflecting the priority need of the MH service users. Other important considerations should be lack of livelihood activities and access to quality mental health service. Building the capacity of MH users for self advocacy will strengthen them to actively design, implement and participate in provincial or national advocacy interventions. However, capacity building in advocacy should be designed carefully and appropriately to suit the cultural context of service users and care givers and be within the range of capacities and resources that are easily accessible to MH service users and their carers. Organizations such as CAF, who had already actively involved in such advocacy initiatives, can take leadership in appropriate capacity building initiative. Capacity building processes should be followed by advocacy initiatives that are designed in consultation of service user members, care givers and other members in relevant organizations.
2. **Strengthening livelihood status of members (service users and care givers) of organizations** – Since livelihood issues are mentioned as a barrier to active participation and as an issue that affects the quality of lives of service users and carers members of the organizations, it is important to develop mechanisms to strengthen their livelihood status. These mechanisms may include therapeutic livelihood activities, entrepreneurship development, vocational trainings, business planning trainings and developing linkages with service providers and organizations support for livelihoods. Strengthening livelihood status should be strategic and give priority to addressing needs related to income generation activities of the membership.
3. **Capacity building in leadership development and community mobilization** – Lack of active participation of service users in context where power of health professionals or carers dominance is key issue highlighted in the report. In this context, trainings on leadership development and social mobilization are useful to fill this gap and to mobilize more active participation. However training alone is not sufficient to build active leadership and participation of members. Relevant organizations should develop their plans to encourage and mobilize such a participation in their activities. More responsibilities should be shared equally among the member service users and carers of the organizations.
4. **Providing leadership to experienced users' organizations in supporting development of other groups-** Involvement of experienced service users for development of other organizations have contributed to build confidence and to motivate other service users to engage actively in their organizations. Contribution of Consumer Action Forum to development of HithaMithuru Society is the example for this. Moreover, service users and care givers are willing to learn from experience of other organizations

and their members. It is therefore vital to involve experienced organizations of service users to build capacity of other organizations and to facilitate experience sharing between among organizations. However, precaution should be taken to ensure that experienced organizations do not suppress the fledgling organizations or take over the leadership role inadvertently.

5. **Inputs to improve organizational and management capacities** - Although all the organizations have some management structure, a need to strengthen the planning, implementation and management of organizations is required. This would promote independent entity and sustainability of these organizations and thereby give them space to grow beyond the parameters set by their initial links with the MH health care staff. Training on management of community based organization, project management and participatory planning and monitoring may be useful to enhance such capacity of members of these organizations. However, this kind of capacity building process should be designed with proper understanding of capacities and resources of each organization individually and of their problems and needs locally. This is because it is vital to be sensitive towards the local contexts, needs and aspirations of the member community and their capacity. It is recommended that tailor made capacity building training programmes be avoided and each organization be engaged in a consultation process to identify the nature of capacity building support that is most effective for each organization.
6. **Capacity building for health and other stakeholders supported users' organizations** - The study has identified the limitations and constraints that the service provider's face when mobilizing the service users and care givers. They also face challenges when designing and mobilizing members for appropriate advocacy interventions and in dealing with power imbalances in the organizations. There is also a need to broaden the scope of the organizations and help them work with both medical and social service providers. This requires capacity building for the MH professionals and health care staff. Suggested themes for such capacity building are community mobilization, animation techniques and supporting service user advocacy.
7. **Facilitate participatory monitoring and evaluation mechanism** - One weakness of many organizations covered in mapping is that they do not have a strong mechanism to review/evaluate their progress, achievements and their challenges with participation of their members. Although some of those have meetings to discuss activities and its follow up visits, these are not effective reviews which enable its members to reflect what they have done and to collectively understand their challenges. The lack of such review and insight also hinders the participation of members who are more withdrawn/ reserved and who need greater encouragement to be involved in team work. Therefore, introducing community participatory approaches to review/evaluate would be useful to these organizations to motivate its members and to build their active ownership in process. It would also contribute towards the sustainability of these organizations.

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