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Mental Health Service Users Association Stakeholders' Consultative Meeting

March 24, 2022



Compiled Report



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The genesis

The rationale behind organizing a stakeholders' meeting is to make the Mental Health Service Users Association (MHSUA) known to potential partners. The establishment of the MHSUA was not recognized by stakeholders apart from few partners such as the Mental Health Case Team of the Ministry of Health, the Addis Ababa University, Psychiatry Department, few individuals close to members of the Association.

Preparations

After the Executive Committee of the MHSUA agreed on the date of this meeting, a brainstorming session was conducted with colleagues of SHM Foundation, Ember Mental Health to develop a strategy for the event. The session outlined the purpose of the event, the attendants' list by category, the event lineup and the materials that are needed to have in place.

WHAT you need and WHO is in charge	Purpose of the event <i>WHY are you having the event</i>	Attendants list <i>WHO do you want to connect with</i>	Event lineup <i>HOW are you engaging with your audience</i>	Assets <i>WHAT materials do you need to have in place</i>
	<p>What do you want your guests to KNOW, think or understand about MHSUA during / after the event?</p> <ul style="list-style-type: none"> That we exist, we are established and running. We don't want the event to be theoretical, we are talking about people, and we want them to connect with us when we talk about MH. That mental health illness doesn't mean you are not productive. 	<p>Guests categories:</p> <ul style="list-style-type: none"> Gov. hospitals with mh sections (mh units heads) Private clinics / health centres (3 representatives) Psychiatrists that helped us being established Professional associations (psychiatrists, psychologists, social workers...) Media (youtubers that do mh awareness; radio stations; TV specialised in health sector) Ministry of Health / Woman and Youth representatives Federation of associations of persons of disabilities University psychiatric dept. MHSUA Members 	<p>Do you already have a lineup in place?</p> <p>8.30am – 9.00 registration 9 – 9.10 Opening Speech by a representative of the Gov. 9.10 – 9.15 Welcoming speech by Eleni 9.15 – 10am Panel discussion (TBD)</p> <p>10 – 10.20am Tea break</p> <p>10.20 – 11.35 am (TBD) Research pieces by 3 graduated students: 1) Service users training health professionals 2) Service users involved in designing an intervention 3) Service users' contribution to the health system</p>	<p>Promotional materials to invite guests</p> <ul style="list-style-type: none"> Invitation letter by Eleni Programme of the event Social media cards/announcement ? Website announcement? Press release for the media? <p>• Opening Speech for the representative of the Gov.</p>
	<p>How do you want your guests to FEEL or respond during / after the event?</p> <ul style="list-style-type: none"> Empathetic We want them to understand the pain and celebrate our success 	<p>How are you going to invite your guests and promote the event</p> <ul style="list-style-type: none"> Letter written and signed by Eleni, delivered by other members Some phone invitations Person in charge of guest list, RSVPs and queries: Yewoinshet with support from Lela 	<p>11.35am – 12pm Q&A</p> <p>12 – 1pm Presentation by Eleni</p> <p>1pm – 2pm Lunch</p> <p>2pm – 2.15pm Personal experiences (Eleni)</p> <p>2.15pm – 3.15pm Religious people panel (TBD)</p> <p>3.15pm Tea break afternoon (networking)</p>	<p>Promotional materials at the event</p> <ul style="list-style-type: none"> Programme of the event MHSUA presentation doc with different options of support Slide/s to project on a screen? Banner? Business cards?
	<p>What do you want your guests to DO during / after the event?</p> <ul style="list-style-type: none"> Offer their support. We will provide a presentation so they can know what kind of support they can provide us (provide options). They can also provide a new area of support. 	<p>Things to consider in the invitation: How many are invited in each invitation letter? How to confirm and by when? Put a person to contact for any question</p>		<p>Tech equipment for the event</p>
		<p>Storing system We need to create it. Eleni will create the list, then Yewoinshet will be in charge of managing the guest list and RSVPs (with support from Lela at first)</p> <p>Things to prepare: A guest list that includes: their role, contact information, their RSVP, if they received the invitation. Use this database to track what activities are done, how many people are joining per invite according to their RSVP and to make check-in calls to check if they received the invite, and if they are joining (in case they didn't reply)</p>		<p>Refreshments</p>
				<p>Updated information on your website Is there something missing in your website that is important for the stakeholders to see?</p>

After the above strategy is drafted, it was much easier to follow up on the items identified.

The stakeholders' consultative meeting

Pre-event

Before the event started, members of the MHSUA arrived an hour before the start of the meeting to place banners - one at the main gate of the meeting hall and another at the stage of the meeting hall.



Several registration sheets were displayed at the reception of the meeting hall so that participants note their name, the organization they represent, their email, phone number and signature. We displayed several copies so that participants can fill them out without waiting for each other to finish. After registering, participants were handed over the booklet with schedule of the event, papers to write on, a pen and bottled water.

The IT support person set up the microphones and tried to arrange for a live streaming of the event via Google Meet. After creating the link, he tested it from his phone and it was working so the link was emailed to Dr Mathero who was expecting the link to join us on line.

The event

Yodit Tesfaye, member of the MHSUA executive committee, was the mistress of ceremony for the event. She warmly welcomes the participants and led them through the lineup of events till the end (Annex 1).



Yodit Tesfaye, Executive Committee Member of MHSUA, Mistress of Ceremony

Per the schedule, the keynote address was delivered by Dr Dereje Assefa, Team Leader of the Mental Health Case Team at the Ministry of Health. He noted the following key points.

The burden of mental illness is affecting the country; mental illness is the leading cause for reduced productivity in life and early death in the world. This heavy burden of disease has similar patterns in Africa and Ethiopia. 600,000 to 1.2 million Ethiopians are said to be affected by schizophrenia, 680,000 by bipolar disorder, 7 million by depression.

However, the most alarming issue is that among persons with mental health conditions, around 90% do not get the medical help they deserve. Taking this treatment gap into account, the 1993 Health policy has indicated that mental health prevention and treatment requires a lot of

work. The Health Sector Development Plan also indicated the gap in mental health service delivery. Based on this, the first National Mental Health Strategic Plan was designed. Although it has not delivered its promises to the fullest, it has contributed to the mental health service expansion by increased human power. Around 10 University hospitals started a BSC program in Psychiatry Nursing and in Master's program in Integrated Community Mental Health. Three universities also started psychiatry residence program.

Although there is an increase in the number of mental health professionals, the treatment gap is still enormous. Therefore, the National Mental Health Strategic Plan 2020 - 2025 has been revised last year to serve as a roadmap.

The Ministry of Health (MOH) will work with all stakeholders and play its leading role in

- strengthening mental health leadership and governance;
- accelerating the development of competent and adequate mix of human resources for mental health;
- ensuring a sustainable supply of pharmaceutical and technological supplies;
- securing adequate financial resource;
- making treatment, care, support and rehabilitation services accessible, affordable and equitable and
- strengthening the research, information, monitoring and evaluation systems for mental health.

As the determinants of mental health are diverse and mostly lie outside the health sector and act at different stage of life; multisectoral and lifelong approaches will be the ways forward.

Although the Strategic Plan has been coordinated by the Ministry of Health, its successful implementation relies on each one of us gathered here as stakeholders of mental health.



Dr Dereje Assefa, Team Leader - Mental Health Case Team, Ministry of Health

As WHO recommends, the role of civil societies in the mental health sector is immense. One of such entities is the Mental Health Service Users Association which plays a vital role. Stakeholders gathered here; we have the responsibility to support the MHSUA so that it can play its fundamental role in the mental health system. We need to involve service users and their organization in

- contributing to create more effective and accountable policies, laws and services for mental health
- identifying community needs and appropriate interventions
- fighting against stigma and discrimination

So far, the Ministry of Health is involving the MHSUA in the Mental Health Technical Working Group, in national workshops, in annual review

meetings, in the national commemoration of the World Mental Health Day. I thank the MHSUA for their devoted participation so far. I call upon each one of you to work with the MHSUA in the effort to improve the mental health service delivery of the country. Thank you!

Following Dr Dereje's speech, Eleni Misganaw, President of the Mental Health Service Users Association (MHSUA) provided a general overview of the MHSUA starting by presenting the genesis of the Association. The MHSUA was founded by 5 service users. Sadly, one of the founding members, Dagmawi Tilahun, passed away last August 2021. The service users were gathered by a local non-profit - Ethiopian Mental Health Society, chaired by Prof. Atalay Alem. The registration process took nine months. The founding members were requested to provide a certificate from their respective psychiatrists certifying they are in remission, that they can run such a formal association. This demonstrates the stigma against mental illness, which is also institutional.

She also flagged that people have hard time understanding the Association is user-led. Even after mentioning its name, many people consider the Association as an NGO helping service users. This shows the stigma that is embedded in beliefs that service users are not able enough to run their own Association.



Eleni Misganaw, President MHSUA

She noted members of the Executive Committee of MHSUA have held around 24 regular meetings and 1 urgent one. Before getting the office, these meetings were held in cafes, which was far from being convenient. Luckily, the office was a new one so it gave the chance to do partitions as wanted: smaller room for office purpose and a larger one for meetings and trainings. Used furniture and other office equipment were obtained from the Ministry of Health and the Ethiopian Mental Health Society. An easy-to-memorize number was purchased from Ethio telecom (+251 945 565656) and a wireless office telephone. A website is also developed (www.mhsua.org). Most of the tasks of the Executive Committee in the past three years have been preparatory works for the Association to kick off.

She then highlighted the major objectives of the Association and the main challenges faced by service users in the country. She highlighted who the stakeholders of mental health are in the mental health landscape of Ethiopia and their major roles. She finally called upon the participants to take their respective responsibility as stakeholders to bring solutions to the highlighted challenges.

Then a poem was presented by members of Psych In Action, which is an initiative of psychology students from Addis Ababa University.

Sigma and discrimination: Panel discussion

Panelists' profile

Dr Dawit Assefa is a consultant psychiatrist currently working in Eka Kotebe hospital. He also used to serve as Medical Director of the country's only specialized mental hospital, Amanuel Specialized Mental Hospital.

Mrs. Meaza Menker is a clinical psychologist and mental health consultant. She wrote a book to serve caregivers of autistic children. She also founded a school where children with special needs are integrated.

Gash Nigussie Bulcha is a pastor of a local protestant church. He is well known for his teachings and mentorship to the youth.

Haji Nuredin Jemal is the director of Plan Policy directorate under the Ethiopian Islamic Affairs Council. He also takes part in awareness raising activities focusing on Islam and social life.












Abba Gedion Birhane is an instructor in the Saint Trinity University under the Orthodox Tewahido church. He is knowledgeable in the teachings and practices of Orthodox Tewahido Church.

Moderator: Dr Yonas Bahiretibeb from Addis Ababa University, Psychiatry Department

Some of the key issues raised in the panel discussion are noted below:



stigma and discrimination prevent persons with mental health conditions from accessing mental health services




-  stigma occurs at various levels: self-stigma, community level stigma, institutional or structural stigma have an added adverse effect on the help seeking behaviors of persons with mental health conditions
-  the self-stigma can result in denying the status of ill health. Accepting the status of ill health for an individual comes with the loaded stigmatized perceptions that the community has put around mental illness
-  Ethiopia is a country with a generally religious society. How come religion has not reduced the stigmatized attitude attached to mental illness? Do the religions prescribe such attitude?
-  The religious leaders agreed that lack of awareness is the major reason behind stigma against mental illness
-  There should be an understanding that we all are on the large spectrum of mental illness. Understanding this prevents stigmatizing a certain part of the population as mentally ill.
-  Mental health is affected by social, economic, political, spiritual factors and genetic dispositions. Therefore, its treatment should also be all comprehensive. The social aspect should be treated by interventions at social level, the spiritual factors at spiritual level, the physical at physical level etc.
-  Human beings have holistic identities, both physical and spiritual.
-  The Bible and the Kuran encourage physical health as well as spiritual health. They encourage a holistic approach to health. The spiritual solutions and the medical treatment are not mutually exclusive. We should not view them as separate entities. They both are important for the flourishing of the individual and for healthy status.
-  Jesus Christ spent his time on earth with people that the society has stigmatized. So a follower of Him should not discriminate people based on their health condition.
-  Jesus has made it clear that the man who was born blind was not because of a curse by God or a reprimand for his parents' sin. There is no reason to have a negative attitude towards ill people in general. The Kuran also teaches that discriminating against people with mental health condition is a sin.
-  It is important to work on the mental health of children and youth because most issues are linked with childhood traumatic events. In addition, most issues identified at early age have the potential to continue to adulthood.

- ✿ The way we think about mental illness exposes service users to stigma. So appropriate knowledge and shift in attitude is a must.
- ✿ The media plays a vital role in influencing attitude.
- ✿ When a person is mentally ill, we generally think that all activities and all attributes that make them a human being stops all together. This needs to change through awareness raising.
- ✿ We should not deny the human dignity of persons with mental conditions. Their human rights should be respected.
- ✿ The person should also be separated from the illness. The person is not the illness but it is a person with mental illness. We need to recognize the full dignity of the person first.



Panelists taking part in the panel discussion

- ✿ Spiritual places have a legitimate authority over their followers. We need to build on this.
- ✿ Sometimes, the person with mental health condition is exposed to abusive treatments at these places. Religious service providers should be educated and be aware of mental health conditions and the best way to treat the person. Some religious leaders discourage taking of medicines and some psychiatrists may discourage spiritual treatment. This needs to change.
- ✿ A referral pathway between spiritual places and medical treatments should be well developed.

-  Family should be supported well because they also face the social stigma. They bear the economic burden of mental illness as well.
-  Such workshops should also be given within the religious circle. An open discussion should be encouraged.
-  We need high-level interventions to bring a shift in attitude.

Service users' involvement in strengthening mental health services: a case study

Dr Sisay Abayneh presented his PhD dissertation on the role of service users and their care givers in strengthening the mental health system. This session is meant to amplify the active role of service users in the mental health sector.

The research was conducted in Sodo district in Southern Ethiopia to explore how to achieve involvement of persons with mental health conditions in mental health system strengthening.

In this research, persons with mental health conditions (MHCs) were meaningfully engaged at all stages of the research process.

A Theory of Change model was produced with a range of stakeholders, including persons with MHCs and caregivers.

Then a Participatory Action Research approach was applied and stakeholders - including persons with MHCs - identified top local priorities that need to be addressed to achieve involvement.

A smaller Research Participant Group comprising persons with MHCs, caregivers and health professionals was then established and worked together to explore in more depth the priorities identified by the stakeholders.

An action plan was then developed, which the Research Participant Group is implementing with assistance from academic researchers. Persons with MHCs were also actively involved in disseminating the major outcomes of the research as engaged-owners of the process.

Experience sharing from Mathewos Wondu Ethiopian Cancer Society

This session is included so that the Mental Health Service Users Association learn from the experience of Mathewos Wondu Ethiopian Cancer Society and the strength of patient-focused organization.

This society is founded by parents who lost their 4-year son, Mathewos Wondu, due to blood cancer 18 years ago.

Lemma Ayele, the Operations Director of the Society shared that the main focus areas are pediatric cancer, breast and cervical cancer (covering cost of transport from and to their regions, medicines and diagnostic laboratory services, psychosocial support service, including transport, accommodation, food in between treatments etc.)

The Society also focuses on policy revision, awareness creation and prevention of tobacco control as risk factor for lung cancer. Wondu Bekele, the CEO and founder of the Cancer Society has received many international awards for his war against cancer.

What helped most the Society is its networking and partnership with like-minded institutions and professional associations. This is a lesson to take.

It also works with celebrities to raise awareness and for fund raising activities. Lemma suggested that MHSUA should have ambassadors of mental health to raise its profile. He also highly recommended that it is important to work with the government, no matter how the bureaucracy is difficult, it is worth the effort.



Prof Atalay Alem, moderating the discussion


Major points from the discussion among participants





no one is immune from mental illness. This is a condition that can knock our doors at any time.





Our collective effort is mandatory to bring the desired change. If we have to fill a glass of water using a spoon, it will take time but it will be filled eventually. Therefore, we are all present here because we have a spoon of water to fill the glass. We are all stakeholders of mental health. Our coordinated effort is essential to bring a change in the mental health sector.


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Our community does not have the awareness that mental illness can be treated medically. Therefore, this association should collaborate with the media to raise awareness and fight against the stigma against mental illness.
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There should be a strong collaboration with religious/traditional healers as they are the first service outlet for the community.
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Mental health should be included as part of the curriculum especially health professionals
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The association should have a communication strategy to do consistent and persistent campaigns to normalize the discussion around mental health and raise community's awareness. It should also expand its networking and partnership outlets to reach service users in regional areas outside of Addis Ababa.
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There should also be a synergy among stakeholders to implement the national mental health strategic plan.
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the Association needs to target prisons to raise awareness
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let us all strive to read the National Mental Health Strategic Plan and extract our share of contribution



Annex 1

Stakeholders' Consultative Meeting March 24, 2022 Ethiopian Public Health Institute, Addis Ababa Schedule

Time	Description	Facilitator
8:30 – 9:00	Registration	MHSUA
9:00 – 9:05	Welcoming speech & overview of schedule	MHSUA Vice President Yewoinshet Berhanu
9:05 – 9:15	Keynote address	MoH, MH Case Team Leader Dr Dereje Assefa
9:15 – 9:30	Overview of MHSUA	Eleni Misganaw, MHSUA President
9:30 – 9:35	Poem	Psych In Action
9:35 – 9:45	Personal testimony	Eleni Misganaw, MHSUA President
9:45 – 9:50	Discussion	Getenesh Tilaye, MHSUA EXCO member
9:50 – 10:10	Tea Break	EPHI
10:10 – 11:30	Panel Discussion	Dr Yonas Baheretibeb
11:30 – 12:30	Discussion on way forward	"
12:30 – 1:30	Lunch	EPHI
1:30 – 1:40	Song	Psych In Action
1:40 – 2:10	Service user involvement in MH service strengthening: case study	Dr Sisay Abayneh, Madda Walabu University, Bale
2:10 – 2:25	Experience sharing from Mathewos Wondu Cancer Society	Ato Wondu
2:25 – 3:15	Discussion	Prof Atalay, AAU
3:15 – 3:20	Closure	Eleni Misganaw, MHSUA President
3:20 – 3:30	Tea break	EPHI
3:30	End	