Mental health summit

Voices of people with lived experience

in the WHO South-East Asia Region

Kathmandu, Nepal, 19–20 June 2024

World Health Organization
REGIONAL OFFICE FOR South-East Asia

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Contents

Abbreviations

LGBTQI+	lesbian, gay, bisexual, transgender, intersex or queer
WHO	World Health Organization
SEARO	Regional Office for South-East Asia
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Overview

On 19 and 20 June 2024 the World Health Organization (WHO) Regional Office for South-East Asia organized a meeting in Kathmandu, Nepal entitled “Mental health summit: voices of people with lived experience in the WHO South-East Asia Region”. The 10 Member States of the WHO South-East Asia Region that participated in the summit were Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste. The meeting engaged people with lived experience of mental health conditions and caregivers.

Meeting objectives

- Share perspectives on the rights of people with lived experience, including access to health care, employment opportunities, housing and education.
- Promote policy reforms that protect the rights of people with mental health conditions by identifying existing gaps in health care, employment, housing, and education, and identify opportunities for reform.
- Provide a platform for people with mental health conditions to share their experiences, challenges and solutions through panel discussions and testimonials at a side event.
- Establish a regional dialogue on the engagement and empowerment of people with lived experience as per the commitments made by Member States in the Paro Declaration *(1)*.
- Draft a charter to protect the rights of people with lived experience, which can be modified and adopted at the country level.

Inauguration

Overview of the summit

Dr Andrea Bruni, Regional Advisor, Mental Health and Substance Abuse

The objective of the Paro Declaration, adopted in September 2022 by all Member States in the WHO South-East Asian Region, to incorporate ideas and inputs from civil society, including people with lived experience and caregivers, was highlighted. The purpose of the summit, the first in the Region, was to listen to and learn from people with diverse perspectives and experiences, from various contexts and backgrounds.

Welcome address by a person with lived experience

Ms Fahmida Akter, Lived Experience Advocate from Bangladesh

The critical role of lived experience in driving policy and legal reform, and the importance of including these voices in decision-making processes, was emphasized. The value of international gatherings such as the summit for cross-cultural learning and for fostering a sense of solidarity and shared purpose by learning from each other's successes and setbacks was underscored. Despite cultural differences, universal aspirations of justice, dignity and equality that unite everyone were highlighted. All attendees were urged to participate actively and engage in meaningful dialogue. The address concluded by emphasizing the motto "nothing about us, without us", stressing the need to involve individuals with lived experiences in all aspects of mental health advocacy and policymaking.

Welcome address by a caregiver on the importance of families and carers in policymaking

Mr Milesh Hamlai, Caregiver Representative, India

The address began by elaborating on the experiences of having a family member with a mental health condition at a time when information about mental health and treatment was scarce and not easily available. The stigma, discrimination and difficulties faced by families in seeking treatment were highlighted. The role of homes, communities and other interactions within society is crucial to mental health care, and particular attention was paid to the role of caregivers. Voices of people with lived experience and caregivers are key to amplifying the need for reform and to directing the process of change by swaying public opinion and influencing policymakers.

Opening remarks from a Ministry representative in Nepal

Dr Roshan Pokhrel, Secretary, Ministry of Health and Population of Nepal

The value of a platform for people with lived experience was lauded as important for sharing experiences about mental health to overcome stigma, and the challenges faced by people with lived experience. All participants were welcomed to Nepal, and the motto "nothing about us without us" was underscored as vital to mental health law and policy reform.

Video address on the commitment of WHO to engaging with people with live experience and caregivers

Ms Devora Kestel, Director, Department of Mental Health and Substance Abuse, WHO Geneva

Stigma and its impact on preventing people with lived experience and those close to them, such as their families and friends, from playing an active role in the mental health field was raised. This initiative was significant, as WHO has been actively engaging people with lived experience in various regions, producing guidance and tools designed to empower them and strengthen their capacity. The summit participants were assured of WHO's continued support, and invited them to reach out if there were additional ways the organization could enhance its efforts.

Video address on the Region's dedication to people-centred mental health care

Mrs Saima Wazed, Regional Director for the WHO South-East Asia Region

Reflecting on previous work in public policy for mental health and neurodevelopmental disorders, the importance of including people with lived experience in mental health policy design, which in Bangladesh led to a broader engagement of government and stakeholders at all levels, was emphasized. The pervasive issues in the South-East Asia mental health landscape, such as stigma, discrimination and limited mental health services were highlighted. People with lived experience often face exclusion, abuse and marginalization, which contributes to their silence and hesitation to seek help. Active engagement of people with lived experience is crucial for creating inclusive, recovery-oriented mental health systems. Such systems should empower individuals, support their independence, and promote meaningful lives through education, work and community engagement. The need for safe spaces, in which people with lived experience can share their stories, breaking down stigma and encouraging others to seek help, was stressed. The address concluded by calling for a multifaceted approach to mental health that includes involvement of people with lived experience, comprehensive awareness-building and user-oriented, accessible and culturally sensitive services.

After a break, the participants reconvened to continue the morning session with presentations and panel discussions.

Presentations and panel discussions

Pathways for improving awareness of mental health conditions

Mr Amornthep "Sanju" Sachamuneewongse (Thailand)

The presentation focused on Amornthep's mental health journey, and the several challenges encountered that informed his understanding of the gaps within the mental health system in Thailand. Based on these challenges, the Sati mental health application was created as a digital platform designed to connect people in distress with trained volunteers who provide peer support.

The Sati app was developed to address gaps in mental health services, particularly around accessibility and affordability of care. Utilizing the WHO Pyramid Framework, the Sati app offers peer support through trained volunteers, with over 34 280 users to date. Sati works with government, private and public sectors to ensure that the service is provided at no cost, to reach as many people as possible.

The importance of collaboration between policymakers, mental health care providers, researchers and individuals with lived experience to improve mental health policies was strongly emphasized. While it was acknowledged that bridging the treatment gap is a complex, non-linear process, small steps that lead to significant changes were key.

Ensuring a right-based approach to mental health: perspectives of those with lived experience

Panel discussion

The presentation was followed by a 45-minute panel discussion on rights-based approaches that drew in the perspectives of people with lived experience. The panel's objective was to deliberate on why rights-based approaches are important in mental health, their essential principles, and how key decision-makers can adopt and practice a rights-based approach.

Tanmoy Goswami, a mental health lived experience expert from India, and the creator of Sanity, an independent mental health storytelling platform, moderated the panel. The discussion began by highlighting the importance of funding for people with lived experience for research on mental health and development of suitable interventions. A shift in discourse from improving awareness to improving access to mental health care, taking into consideration the high out-of-pocket expenditure for mental health and the dearth of trained mental health professionals, was key. While recognizing stigma, the necessity of addressing discrimination and also changing the medical discourse on mental health conditions was noted.

Tshewang Tenzin, Executive Director at Chithuen Phendhey Association (CPA) in Bhutan, an organization working with individuals living with substance use, was invited to share his perspective on the rights-based approaches. Reflecting on their lived experience with addiction and advocacy through the lens of rights, the conversation highlighted the neglect and stigma faced by health, law enforcement, family and education systems. Working in an organization delivering peer counselling and facilitating support groups highlighted the gap between awareness of rights and policy change. The necessity for change in the perspectives and attitudes of various stakeholders to recognize and uphold these rights of people with lived experience was stressed. This should begin by empowering people with lived experience with knowledge of their rights, followed by incorporating it into policy and practice.

Shantanu Sharma, a lived-experience motivational speaker, shared their experience of accessing mental health care in the two different health systems in Nepal and the United States of America (USA). The variances in seeking care in both contexts were discussed through their own experience. Key differences and gaps were highlighted in the health care services and approaches to protecting and promoting the rights of people with lived experience. In the Western model, while consent was taken and information was provided, the only way to receive care was through forced institutionalization. In Nepal, information on mental health conditions was usually not given to the person affected or to their family, but access to and availability of psychiatric care was better. The contributor concluded by advocating for a holistic approach to mental health services and dignity for all.

Nur Yanayirah, founder of Mother Hope Indonesia spoke about their lived experience with perinatal mental health and the importance of gender justice. The complexities of perinatal mental health through their personal experience were highlighted, including its impacts on the parents, child and wider family. To address perinatal mental health, a social determinants approach is required and not just medical intervention. Further, vulnerable groups such as pregnant teenagers who are stigmatized by their families, experience violence from partners and are often without a support system, as well as young girls forced into marriage, were highlighted as at high risk for perinatal health conditions. Vulnerabilities experienced by women in their households include an imbalance of power and gendered expectations, lack of reproductive autonomy, with no access to contraception and the inability to make a decision over the spacing of pregnancies, was associated with perinatal mental health conditions. In cultures where there is a preference for a male child, women have multiple births. This concluded by highlighting the indignities faced in health care facilities by women and called for care and support to be enhanced in these settings.

Shane Bhatla (he/they), a non-binary disabled activist from Thailand was invited to speak on intersectionality and its importance in the discourse on mental health. Multi-marginalizations on account of diverse gender, sexual orientation, disability, and migration status were highlighted as increasing risk of distress, suicide and mental health conditions. Other factors such as adverse childhood experiences and loss of partners or loved ones further exacerbate risk and poor mental health. The impact of social policies on vulnerable groups was stressed, such as policies on immigration, housing insecurity, policing and lack of protections for people from the LGBTQI+ community *(2).*

Vulnerabilities and risk are aggravated in situations of conflict and displacement or during health care crises such as the COVID-19 pandemic, when people with multi-marginalizations are further neglected and excluded. The talk ended by advocating for workplace protections for activists working at the intersection of social justice and mental health, and for an awareness of those who are invisible and not part of such spaces.

The panel concluded with a request to the plenary to reflect on the global perceptions of mental health that frame mental health in terms of "productivity", which minimizes the human condition and experience of living with a mental health condition. Such an approach is cause enough to act.

Application of WHO QualityRights Initiative to protect and promote the rights of people with lived experience

Jasmine Kalha, Programme Director and Senior Research Fellow, Centre for Mental Health Law & Policy, Pune

The QualityRights initiative by the WHO aims to improve mental health services and protect the rights of persons with psychosocial, intellectual and cognitive disabilities by assessing and improving the social environment, building capacity among health workers, users and families, and reforming policies based on best practices and human rights. QualityRights provides practical tools for comprehensive assessments, reporting findings, and for using recommendations to enhance care and uphold human rights. Assessments are based on themes from the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and involve qualitative interviews, observations and documentation reviews, conducted by independent teams, including mental health professionals, persons with lived experience, caregivers and human rights advocates

Key processes to implement QualityRights were discussed, which include setting priority areas through meetings and focus group discussions, forming core teams at each facility to develop strategic plans, and executing and evaluating these plans. Pathways to capacity building and the tools that exist for it were also discussed.

The development of family and peer support systems was underscored as necessary to establish a strong community foundation for mental health care along with training people with lived experience and caregivers to lead these initiatives, whether through structured support groups or individualized peer support during recovery. Peer support is essential for fostering a recovery-oriented, rights-based approach to care, with tools such as the recovery plan on the QualityRights website guiding these efforts. QualityRights in Gujarat, India, whereby hospital-based volunteers were engaged in developing individualized recovery plans and leading support group meetings that prioritized recovery, was highlighted.

Empowering communities to build their capacities and improve the social environment was highlighted as a positive outcome of QualityRights. The framework has been successful in changing health care professionals’ perceptions of people with lived experience, building momentum for social change, and creating substantial improvements. It enables communities to craft strategic plans tailored to their resources, fostering a democratic and inclusive approach to decision-making.

Policy and legal reforms: perspectives of people with lived experience and caregivers

Panel discussion

The final panel of the Summit was a 45-minute discussion focused on policy and legal reforms, incorporating the perspectives of four individuals with lived experiences. The objective was to explore how policies and laws support people with lived experience and their carers, to identify challenges in enacting policy reforms within specific contexts, and to recommend strategies to advocate for reforms that improve access to quality mental health care and protect the rights of people with lived experience.

The moderator of the session, Ananda Galappatti, a medical anthropologist and Mental Health & Psychosocial Support Network (MHPSS) practitioner emphasized the importance of acknowledging personal experiences in shaping professional goals and practices in the field of mental health. Self-awareness among professionals to recognize how their backgrounds, particularly experiences of mental health conditions within their families, influence their work was highlighted. This is key to fostering stronger solidarity with people with lived experience and enhancing the role of professionals as allies in centring diverse lived experiences.

Matrika Devkota, founder of Koshish in Nepal, a nongovernmental organization (NGO) led by individuals with lived experience, discussed the importance of involving people with lived experience in policy- and decision-making processes. The gap between the intention to include people with lived experience and their meaningful engagement was reflected in diverse approaches to formulating mental health and disability legislation in Nepal, which ranged from tokenistic to consulting with people with diverse lived experiences.

Vijay Nallawala, founder of BipolarIndia, and Managing Trustee of Mental Health Support Foundation – peer-support networks for persons with mental health conditions in India – discussed the role of peer-support organizations in translating policies into reality. While India has progressive policies, such as the Mental Health Care Act (2017) and the Rights of Persons with Disabilities Act (2016), there are significant delays in their implementation. Advocacy required sustained effort, involving more intersectional approaches.

Aminath Ula Ahmed, Co-Founder and Chairperson of the Mental Health Support Group in the Maldives, highlighted the challenges in aligning mental health policies with local contexts. The reliance on Western models, which often do not align with local needs, was criticized, and the importance of creating context-specific laws was stressed. There is a need to move beyond paternalistic views and language that diminish the lived experiences of those with mental health conditions.

Agus Hasan Hidayat, founder of REMISI, a psychosocial disability organization focused on community-based support programmes and advocacy for the rights of people with psychosocial disabilities in Indonesia, highlighted the barriers faced by young people with psychosocial disabilities, in particular the dominance of the biomedical model and the culture of paternalism. There is a need for community-based psychosocial support and legislation aligned with the UNCRPD.

Group work

Regional charter for mental health and meaningful engagement of people with lived experience –policy processes and service design: way forward and priority recommendations

In the afternoon, participants gathered for a 90-minute group work session. Participants were divided into groups with seven groups of people with lived experience and caregivers and three groups of government officials. The seven groups consisted of between and seven participants from different countries. The session was divided into two parts to deliberate upon *(1)* the potential contents of the charter and *(2)* the importance of people with lived experience and caregivers being involved in policy processes and strategies to achieve that objective.

Simultaneously, groups consisting of government officials deliberated on strategies to involve people with lived experience and caregivers in policymaking, programme planning and evaluation.

Forum discussion

Forum discussion by government officials on ways to engage people with lived experience and caregivers in mental health laws and policymaking

Following the 90-minute session, the government official groups presented on the importance of engaging people with lived experience and pathways and processes for engagement, summarized below.

- The involvement of people with lived experience in policymaking processes is essential as it improves the quality and equity of services and policies, reduces stigma and empowers people with lived experience and caregivers.
- Insights from people with lived experience can promote a person-centred rights-based approach and reduce stigma and discrimination, especially in aspects of policymaking relevant to education, employment and health care.
- Strategies for involvement would require a focus on tackling power imbalances in formal systems through grassroots empowerment, culturally appropriate means of engagement and accessibility.
- Such involvement can be achieved through building networks of people with lived experience, setting up structured pathways for involvement and leveraging technology to improve accessibility.
- Aspects of policy processes that would benefit from lived experience include understanding the challenges faced by people with lived experience and caregivers, mental health planning, implementation and monitoring, and funding and mobilization of resources.

Forum discussion

Forum discussion: perspectives of people with lived experience and caregivers

The day began with a presentation of the deliberations of the group work from the previous day to the plenary. The presentations of the group work are summarized below:

Priority rights identified for the charter

The following rights were identified and discussed:

- right to education, freedom from discrimination and bullying, affordable and prompt health care, ethical portrayal of mental illness by the media, social protection, equal opportunities and fair pay without discrimination;
- rights addressing deinstitutionalization, equal work and employment opportunities without discrimination (fit-to-work medical certificates being difficult to obtain for people with mental health conditions), affordable and accessible health care, informed consent and equal access to justice and social protection;
- right to employment with reasonable accommodation without discrimination, equal recognition before the law, personal autonomy, social protection, accessible and affordable health care including psychosocial care, and the right to home and family, to vote and to be voted to public office;
- right to participate in decision-making and policy processes, education and employment on an equal basis with others, health care that respects human rights, affordable treatment, safety and support for caregivers;

Rights were categorized as personal rights, health care rights, social rights and legal rights, and included the right to supported decision-making, participation in policy processes and budget decisions, legal capacity, privacy, accessible and affordable health care and dignity and freedom.

Principles that should be respected across all sectors include:

- dignity, autonomy and protection from discrimination;
- respect for home and family, including autonomy in making decisions about marriage and starting a family, equal education opportunities and tailored programmes for people with lived experience, protection at the workplace, and affordable health care including psychosocial care; and
- right to parity with physical health care, universal health care, access to health care records, social integration including marriage and family-related rights.

Prevention of discrimination and accommodative and inclusive workplaces were emphasized.

Challenges and strategies to enable meaningful engagement of PLEs and caregivers

- Lack of awareness and trust, and the presence of stigma among the general public and policymakers about mental health conditions, and the importance of their engagement in policy and decision-making were noted as challenges, as were tokenistic approaches to involving people with lived experience and the lack of mechanisms to hold decision-makers accountable.

- Engagement platforms for people with lived experience and caregivers that were not designed for full and equal participation to capture the diversity of lived experience were identified as a barrier.
- Another challenge was the differing and competing interests of various actors, combined with insufficient effort from the government to involve people with lived experience in policy processes.
- Capacity-building for people with lived experience and advocacy were suggested as the tools to overcome the challenges and promote involvement in policy processes.
- Protection from reprisal was also raised as important in promoting the engagement of people with lived experience with policy processes, service design and implementation.
- Spreading awareness, improving accessibility of platforms for involvement, and promoting inter-ministry collaboration were also proposed as strategies to improve engagement.

Plenary discussions

Plenary discussion: finalizing regional charter framework

Before finalizing the charter framework, Dr Andrea Bruni and Dr Soumitra Pathare, Director at the Centre for Mental Health Law and Policy, Pune, India opened a discussion at the plenary on the salience and use of regional tools and frameworks to guide priority areas and action for mental health in countries. Some important points emerged on the involvement of people with lived experience during emergency and disaster-management situations, the importance of carers in such participatory processes and engagement of self-care groups.

The presence of other charters, and the challenges of translating them to implementation within countries, were acknowledged. There was agreement on the importance of formulating a charter that captures the contextual nuances of the region and does not solely draw from Western contexts. Since countries such as Maldives were drafting new legislation for mental health, it was highlighted that this would be an opportune time to develop and disseminate the charter. The plenary also stressed that a hybrid process should be adopted to develop such frameworks to capture insights and perspectives of individuals who might not be able to attend such conferences. The discussion concluded by emphasizing the diversity of PLEs and caregivers present at the Summit. Given the size and cultural diversity, such an event cannot be fully representative. However, this is the start of a larger process and not a one-time event.

Ms Monira Rahman and Ms Tanya Fernandes then co-facilitated a session to finalize the rights charter. Keys aspects of the charter were reiterated as a high-level and general declaration of values intended to be interpreted and operationalized to country-level contexts. The charter is framed in accessible and inclusive language, without the use of qualifiers or terms that are exclusionary. The learnings from the rights presented at the group presentations were summarized, beginning with general principles that were frequently mentioned by all groups, such as dignity, respect, privacy and confidentiality, safety and security, transparency, autonomy (making decisions themselves), equality, diversity and inclusion, and meaningful participation.

This was followed by synthesizing the rights heard from the various groups into categories, as below.

Table.1. Summary of rights discussed by groups

Rights domain	Specific rights
Overarching rights	▪ freedom from discrimination, torture, and cruel, inhuman, degrading treatment ▪ freedom from abuse, all forms of violence and exploitation ▪ right to support and infrastructure that must be adapted to each person in each context (reasonable accommodation) ▪ freedom of expression ▪ right to social protection ▪ right to meaningfully participate in design and planning of policies, programmes and budgets
Health care	▪ right to access affordable, quality, geographically accessible, timely health care on the basis of free and informed consent. ▪ right to make decisions on health care treatment and to give free and informed consent ▪ right to dignity and respect in all aspects of health care treatment ▪ right to preventative, promotive and protective social care services and support
Employment	▪ right to fair wages ▪ right to non-discrimination ▪ right to equal work opportunities
Education	▪ at all levels and all forms to nurture different talents, skills and abilities/potentials
Political and civil participation	▪ right to vote ▪ participation in public processes ▪ right to be voted into public offices
Respect for home and family	▪ right to choose whom to marry ▪ right to choose to have or to adopt children, or not to have children ▪ right to raise children
Community-based rights	▪ right to live independently and in the community ▪ right to participate in community processes ▪ right to leisure and recreation ▪ right to access services in the community

The facilitators then opened the floor to receive feedback from the plenary on rights that were missing or needed to be modified. Some suggestions that emerged were to include the right to ethical portrayal of mental health conditions in the media, and the right to be free from forced institutionalization. The participants also had thoughts on including "intersectionality" within the charter framework, specifically recognizing the increased risk of multi-marginalization and the right to be free from increased vulnerability due to social, structural and systemic factors that may affect mental health.

After considerable deliberation, the participants agreed that it might be fruitful to consolidate all learnings from the summit, draft the charter and circulate it with participants for their written feedback.

Plenary discussion: modalities of establishing a regional platform

The charter framework discussion was followed by a plenary moderated by Dr Soumitra Pathare to discuss modalities for establishing a regional platform. Participants were asked to share their ideas and input on how the charter can be adapted to specific country contexts, and recommendations for establishing and building a regional platform.

Several suggestions emerged from the plenary to sustain and expand the regional network of people with lived experience and carers and to leverage the network to promote cross-learning throughout the Region. The suggestions included:

- organizing an annual conference using technology to grow the network of regional members;
- creating more diverse and representative country-level networks, leveraging accessible tech platforms such as WhatsApp;
- conducting more virtual consultations and keeping an open channel for ideas;
- building informal networks, and creating small safe spaces for human connection;
- capacity development for people with lived experience to share and participate in policy processes to be effective advocates;
- liaising with government departments to implement the charter through a national-level task force that includes representatives from civil society organizations (CSOs) and people with lived experience;
- working with CSOs in countries to advocate for the implementation of the charter; and
- developing a platform for knowledge sharing, capacity building and fostering a support network of people with lived experience and carers in the region.

Countries such as Maldives are committed to creating and implementing a platform for people with lived experience. In Nepal, the National Human Rights Commission representative indicated they would put forward the charter to the government. Representatives from Bangladesh vouchsafed to use the charter as an advocacy tool within their organizations.

The Summit concluded with closing remarks from Dr Andrea Bruni, who expressed his thanks to all participants and reiterated their commitment to grow and sustain the momentum built over the past two days.

References

1. Paro declaration by the health ministers of Member States at the seventy-fifth session of the WHO Regional Committee for South-East Asia on universal access to people-centred mental health care and services. World Health Organization. Regional Office for South-East Asia; 2022 (https://iris.who.int/handle/10665/363095).
2. Improving LGBTIQ+ health and well-being with consideration for SOGIESC [website]. World Health Organization; n.d. (https://www.who.int/activities/improving-lgbtqi-health-and-well--being-with-consideration-for-sogiesc).

Annex 1. Regional Director's opening remarks

Dignitaries, Partners, Colleagues and Friends – a very good morning to you all. Thank you for inviting me to address you today. I am sorry I am not able to be there in person, but I appreciate being able to share my thoughts with you.

In speaking about the voices of people with lived experiences, I would like to start by telling you a personal anecdote. Before I had the privilege of being Regional Director of WHO's South-East Asia Region, I worked in public policy relating to mental health and neurodevelopmental disorders through a foundation I had started some years earlier. In 2011, I launched the Global Autism Public Health initiative in Bangladesh, in partnership with Autism Speaks and WHO, and also facilitated the formation of the Parents Forum for the Differently-Abled. Both of these platforms were launched with the vision of encouraging social participation and promoting the inclusion of self-advocates and their caregivers within policy design and programme development.

When we worked on Bangladesh's National Strategic Plan for Neurodevelopmental Disorders, and the National Mental Health Strategic Plan, we first made sure that we heard from people with lived experience. This was absolutely invaluable because after their input we realized that we had to engage a broader group of government representatives and official stakeholders than we initially thought. For example, after input from parents, we understood that many of the problems they were facing could not be solved by national government – and would instead need changes at a local government level.

We therefore brought to the table representatives from cities, municipalities and other local government entities to enable changes at the level of last-mile infrastructure and service delivery. Had we not done so, we would have crafted a policy that, while impressing on paper, in its implementation would not have led to the results needed and deserved by the targeted beneficiaries. This experience showed me how vital it is to include the voices of people with lived experience in every planning process.

People with lived experience can be powerful advocates for people-centred, recovery-oriented, human rights-based mental health care and for policy and legislation that protects their rights. As for any other segment of the population, those with mental health conditions have a right to life, a right to non-discrimination, a right to health, a right to privacy, a right to legal capacity and a right to inclusion. They also have a right to participate fully in society.

The significance of mental health, and its impact on individuals' overall well-being and quality of life, is undisputed. One in seven people living in our South-East Asia Region suffers from a mental health issue. Worldwide, those with mental disorders remain stigmatized and misunderstood. Stigma and discrimination, combined with the lack of adequate services for individuals with mental disorders, significantly impact individual, family and community well-being. It impedes access to services and gives rise to isolation and shame, only deepening the existing burden of the mental disorders.

There are many common challenges faced by those with mental health conditions that we need to address immediately. These include:

- exclusion
- marginalization and discrimination
- involuntary admissions
- denial of employment opportunities
- physical abuse and violence
- limited access to effective mental health and general health services
- sexual abuse and violence
- arbitrary detention
- the denial of rights to marry and have children and financial exploitation.

These factors contribute to a cycle of silence, whereby individuals are hesitant to openly discuss their experiences or seek help. Misconceptions surrounding mental health also perpetuate the notion that individuals with mental disorders are weak, dangerous or unable to contribute meaningfully to society. This hinders early intervention and treatment, allowing mental health conditions to deteriorate, leading to worsened symptoms, diminished quality of life, and an increased risk of self-harm or suicide.

Further compounding the issue is the lack of accessible and quality services in many parts of the world, including in this Region. In addition to health, these services include education, provision of employment opportunities, access to finances and social protection. Limited resources, inadequate funding, and a dearth of trained professionals pose substantial barriers to individuals seeking help.

To create a mental health system that truly serves the needs of its diverse population, the active engagement of those with lived experience is crucial. Their lived experiences provide invaluable insights, promote inclusivity, reduce stigma, enhance accountability, and align with recovery-oriented care principles. Importantly, recovery-oriented care is not only about treatment of symptoms but also about empowering people to have control of their own lives. It involves supporting people to find hope, develop self-esteem and resilience, build healthy relationships, regain independence and to live a life that has meaning for them, whether that be through school, vocational training, work, friendships and community engagement.

It is also important to create safe spaces for open dialogue. Stories of recovery and resilience shared by individuals who have successfully managed their mental health conditions can help break down stigma and inspire others to seek help. Peer support networks and community organizations can play a pivotal role in fostering understanding and acceptance.

Addressing issues facing those with mental health conditions requires a multi-faceted approach that includes active involvement of those with lived experience. It requires comprehensive awareness building to challenge stereotypes and misconceptions about mental health, and also the development and expansion of mental health services, that are user oriented, accessible, affordable and culturally sensitive.

I thank you for inviting me to speak today, but more than that I thank you for your consideration of the voices of those with lived experience.

Annex 2. Programme

Agenda

Day 1: 19 June 2024

Welcome from Nepal	Dr Kedar Marahatta
Overview of the summit and objectives	Dr Andrea Bruni
Address by person with lived experience	Ms Fahmida Akter (Bangladesh)
Address by caregiver	Mr Milesh Hamlai (India)
Opening remarks from a Ministry Representative in Nepal	Dr Roshan Pokhrel, Secretary, Ministry of Health and Population of Nepal
Video Address by WHO Director for Mental Health	Ms Devora Kestel
Video address by Regional Director SEARO	Ms Saima Wazed
Presentation: Pathways for improving awareness of mental health conditions	Mr Amornthep Sachamuneewongse (Thailand)
Panel discussion: Ensuring a right-based approach to mental health: perspectives of those with lived experience	Moderator: Mr Tanmoy Goswami (India) Panelists: Shantanu Sharma (Nepal), Nur Yanayirah (Indonesia), Shane Bhatla (Thailand), and Tshewang Tenzin (Bhutan)
Tea break and photo	
Presentation: Application of WHO QualityRights Initiative to protect and promote the rights of people with lived experience	Ms Jasmine Kalha
Panel discussion: Policy and legal reforms: perspectives of people with lived experience and caregivers	Moderator: Mr Ananda Galappatti (Sri Lanka) Panelists: Matrika Devkota (Nepal), Vijay Nallawala (India), Agus Hasan Hidayat (Indonesia) and Aminath Ula Ahmed (Maldives)
Lunch	
Part 1: Drafting contents of the regional charter for mental health	In groups
Part 2: Meaningful engagement of people with lived experience in policy processes and service design: way forward and priority recommendations	In groups

Tea break	
Forum discussion: Ways to engage people with lived experience and caregivers in mental health laws and policy making	Moderator: Dr Soumitra Pathare and Dr Andrea Bruni Presentations by government officials

Day 2: 20 June 2024

Morning session: 09:30 to 12:30

Forum discussion: Perspectives of people with lived experience and caregivers	Group moderator
Tea break and photo	
Plenary discussion: Finalizing regional charter framework	Introduction by Dr Soumitra Pathare and Dr Andrea Bruni Co-moderated by Ms Tanya Fernandes and Ms Monira Rahman
Lunch	

Afternoon session: 14:00 to 16:30

Plenary discussion: Modalities of establishing a regional platform	Moderated by Dr Soumitra Pathare
Wrap up by Dr Andrea Bruni	

Annex 3. Participants

WHO representative

Dr Rajesh Sambhajirao Pandav
WHO Representative to Nepal

Country representatives

Bangladesh

Dr Helal Uddin Ahmed
Program Manager for WHO Biennial and Associate Professor
Child Adolescent and Family Psychiatry
National Institute of Mental Health and Hospital
Agargaon, Dhaka, Bangladesh

Mr MD Kamal Hussain
Assistant Secretary
Health Services Division
Ministry of Health Services Welfare
Dhaka, Bangladesh

Dr SM Mustafizar Rahman
Program Manager – 2
Non-Communicable Disease Control
Director General of Health Services
Dhaka, Bangladesh

Bhutan

Mr Sonam Jamtsho
Deputy Chief Planning Officer
The Pema Centre
Thimphu, Bhutan

Mr Ugyen Dorji
Senior OT Technician
Department of Psychiatry
Jigme Dorji Wangchuck National Referral Hospital
Thimphu, Bhutan

Indonesia

Dr Iwan Syahril
Director General
Early Childhood Education, Primary Education, and Secondary Education
Ministry of Education, Culture Research and Technology, Indonesia

Dr Medira Ferayanti
Head of Sustainable Capacity Building Development
Directorate of Teachers and Education Personnel

Dr Hanifah Cahyani Utami
Assistant to the Director General
Early Childhood Education, Primary Education, and Secondary Education

Dr Richard Andreas Hariandja
Senior OSH Examiner
Directorate General of Labour Inspection
OSH Development
Ministry of Manpower of the Republic of Indonesia

Dr Yutika Adnindya
Policy Analyst, Directorate of Mental Health

Mr Rachmat Koesnadi
Director of Social Rehabilitation for Disaster and Emergency Victims
Ministry of Social Affairs, Republic of Indonesia

Mrs Tina Camelia Zonneveld
Junior Social Worker
Directorate of Social Rehabilitation for Persons with Disabilities
Ministry of Social Affairs, Republic of Indonesia

Maldives

Ms Aminath Shahuza
Public Health Coordinator
National Mental Health Department
Ministry of Health, Maldives

Mr Mohamed Fizny
Deputy Minister
Ministry of Health, Maldives

Ms Aminath Fazeela
Clinical Nurse
National Center for Mental Health
Indhira Gandhi Memorial Hospital, Maldives

Sri Lanka

Dr Rohan Rathnayake
Director – Mental Health
Ministry of Health
Colombo, Sri Lanka

Ms WGD Karunaratne
Director
Department of Social Service
Ministry of Health
Colombo, Sri Lanka

Thailand

Dr Benjamas Prukkanone
Medical Officer, Advisory Level
Director, Office of the Secretariat to the
National Mental Health Commission
Department of Mental Health
Ministry of Public Health
Nonthaburi, Thailand

Dr Nuth Graipaspong
Medical Officer, Senior Professional Level
Galya Rajanagarindra Institute
Department of Mental Health
Ministry of Public Health
Nonthaburi, Thailand

Miss Pratthana Rattanatirawan
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Ministry of Public Health
Nonthaburi, Thailand

Miss Surapar Surapongtawee
Social Worker, Senior Professional Level
Srithanya Hospital
Department of Mental Health
Ministry of Public Health Nonthaburi,
Thailand

Timor-Leste

Ms Anabela Clementina da Costa Guterres
Official Senior Program Manger
Ministry of Health
Democratic Republic of Timor-Leste
Dili, Timor-Leste

Dr Fernanda Soarea de Jesus
Senior Occupational Therapist
Ministry of Health
Democratic Republic of Timor-Leste
Dili, Timor-Leste

Experts

Dr Soumitra Pathare
Director
Centre for Mental Health Law & Policy
Indian Law Society (ILS)
Pune - 411004

Ms Tanya Nicole Fernandes
Project Manager and Research Associate
Centre for Mental Health Law & Policy
Indian Law Society (ILS)
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Dr Ananda Galappatti
Medical Anthropologist and a Practitioner
Mental Health and Psychosocial support
Batticaloa, Sri Lanka

Dr Nur Yanayirah
Maternal Mental Health Advocate Nutritionist
Founder of Mother Hope Indonesia
Gang Lindung, Cibening, Bintara Jaya
Bekasi, Indonesia

Ms Jasmine Kalha
Project Manager and Research Fellow
Centre for Mental Health Law & Policy
Indian Law Society (ILS)
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Mr Bipul Kumar Paul
CEO, Abashon Design & Consultancy
Mymensingh
Bangladesh

People with lived experience and caregivers

Bangladesh

Ikram Masdud
Monira Rahman
Nazia Haque Oni
Nasrin Jahan
Nayeema Islam Antora
Fahmida Akter
MD Azizul Haque
MD Jianur Kabir

Bhutan

Tshewang Tenzin
Tharpa Dema
Tshering Yangden

India

Prabeer Kumar Basu
Milesh Hamlai
Tanmoy Goswami
Geeta Shakya
Vijay Nallawala
Ganesh Natarajan
Jasmine Mary John

Indonesia

Salwa Paramitha
Rachel Emmanuella Gratia Lengkey
Desty Endah Nurmalasari
Alfitra Yosi Putrijaya
Agus Hasan Hidayat
Muhamad Hibatul Idris
Rifky Azrif Irmanda
Gayo Allaam Alfani

Maldives

Irshad Qasim
Naseema Usman
Husnu Afrose
Aminath Ula Ahmed

Nepal

Manoj Gurung
Matrika Devkota
Shantanu Sharma
Shiksha Risal

Sri Lanka

Ponnahennedige Lakindu Vikmal Dias
Piyal Dissanayakalage Nishadini Shalini
Divyanjalee
Geeganage Piyantha Saman Kumara
Janine Manishka Gunasekara

Thailand

Soontorn Imwattana
Amornthep Sachamuneewongse
Parisara Ariyavechakul
Shane Bhatla
Somboon Chungto
Dhammikah Pornpattananikom
Kawintra Yenpensuk
Rachada Hansapipat

Other UN agency/others

Mr Numan Ozcan
Country Director
International Labour Organization
Dhobighat, Lalitpur
Nepal

Ms Pragya Pradhan
Country Manager
UN HABITAT
Sanepa, Lalitpur
Nepal

Ms Ayshanie Medagangoda Labe
Resident Representative
United Nations Development Programme
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Ms Carolin Spannuth Verma
UNHCR Representative
United Nations High Commissioner for
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Anil Kuti, Maharajgunj, Kathmandu
Nepal

WHO

Dr Andrea Bruni
Regional Advisor – Mental Health
SEARO

Dr Sajeeva Ranaweera
Consultant – Mental Health
SEARO
Shabana Khan
Executive Assistant – Mental Health
SEARO

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WCO Bangladesh

Dr Pema Lethro
NPO NCD
WCO India

Dr Atreyi Ganguli
NPO – Mental Health and Substance Abuse
WCO India
Dr Ashra Daswin
NPO (Mental Health and Substance Abuse)
WCO Indonesia

Dr Kedar Marahatta
NPO Mental Health, Disability and Injury Prevention
WCO Nepal

Dr Yasara Samarakoon
National Consultant Mental Health
WCO Sri Lanka

Dr Olivia Corazon Nieveras
Medical Officer – NCDs
WCO Thailand

Observers

Nepal

Kalpana Nepal Acharya
Human Rights Officer (disability focal person)
National Human Rights Commission

Dr Pomawati Thapa
Section Chief NCD and MH Section
Epidemiology and Disease Control Division
Department of Health Services

Nistha Shrestha
Disability Focal Person
Leprosy Control and Disability Management Section
Epidemiology and Disease Control Division

Dr Sunita Malekhu
Director
Autism Nepal Care Society

Ramji Adhikari,
Founder president
Manav Seva Ashram

Ram Lal Shrestha
Director
CMC Nepal

Deepak Raj Sapkota,
Director
Karuna Foundation

Sugam Bhattarai
General Secretary
National Federation of Disabled Nepal

World Health Organization

REGIONAL OFFICE FOR South-East Asia