USAID
FROM THE AMERICAN PEOPLE

GLOBAL MENTAL HEALTH CONSULTATIONS

Insights for Policy and Programming from People with Lived Experience

PHOTO CREDIT: LAURA ELIZABETH POHL

The Research Technical Assistance Center (RTAC) is made possible by the generous support of the American people through the United States Agency for International Development (USAID) under the terms of contract no. 7200AA18C00057. This document was produced by NORC at the University of Chicago with inputs from Hannah Stewart and Jaclyn Schess. Its contents are the sole responsibility of RTAC and NORC at the University of Chicago, and do not necessarily reflect the views of USAID or the United States Government.

November 2023

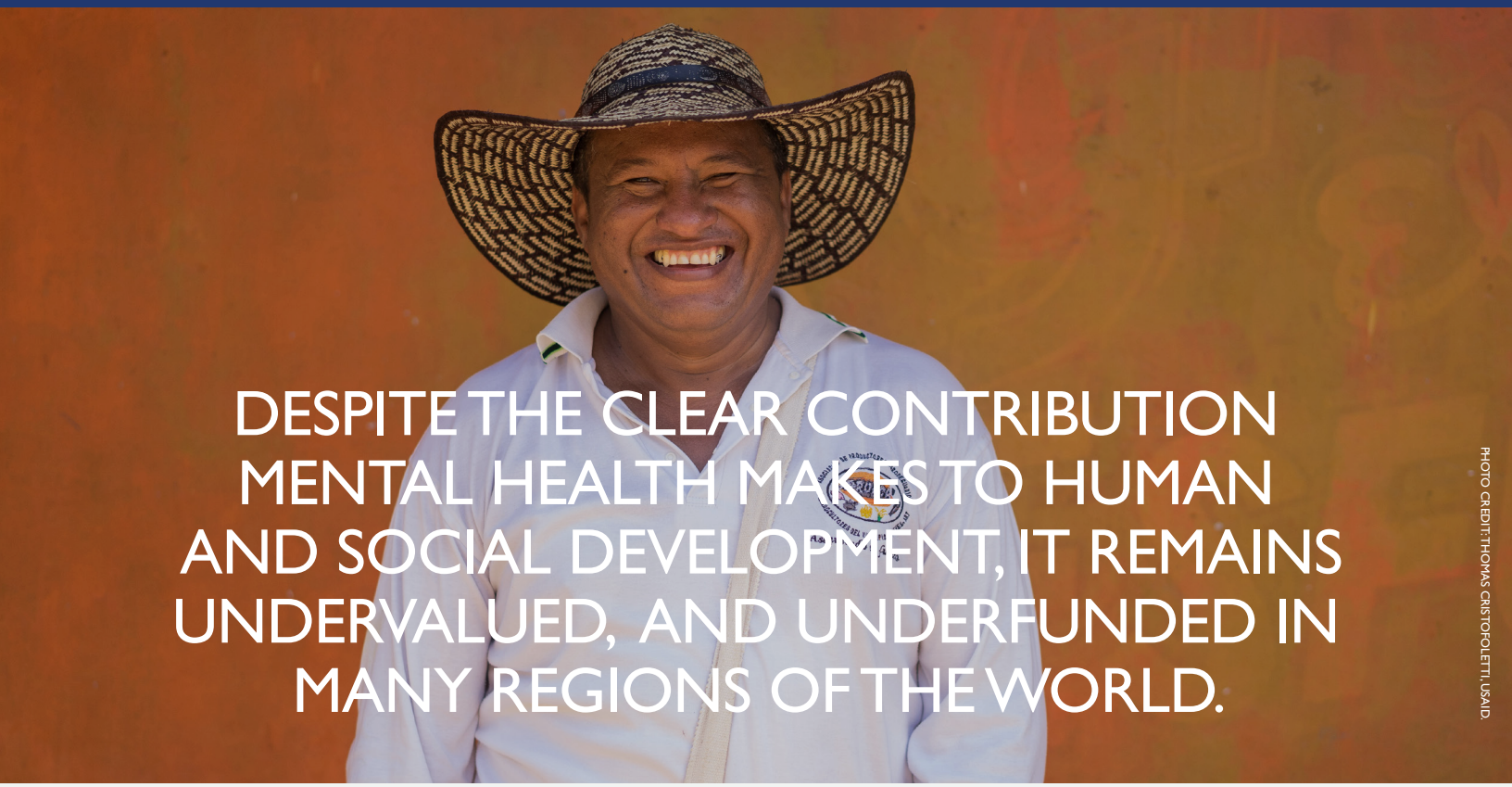

PHOTO CREDIT: THOMAS CRISTOFOLETTI, USAID.

Background and Introduction

The importance of mental health to individual well-being, as well as social and economic progress, is becoming more widely recognized. Mental health challenges result in untold human suffering, lost productivity, social isolation, and decreased quality of life. They hinders people's ability to fully participate in society and contribute to ongoing cycles of poverty and exclusion. Moreover, people in vulnerable situations, such as those affected by war, displacement, and natural disasters, are disproportionately affected by mental health problems.

Despite the clear contribution mental health makes to human and social development, it remains stigmatized, undervalued, and underfunded in many regions of the world. To close this gap and effectively address the complex and different mental health needs of communities around the world, the United States Agency for International Development (USAID) commissioned RTAC to carry out a consultation process to elicit feedback on the difficulties and opportunities encountered by different stakeholder groups. This process took place between late 2022 and early 2023.

The RTAC team collaborated with USAID staff in the planning of the consultations. The activity design was informed by USAID's inputs to the process and the RTAC team's expertise in global mental health. The consultations were structured to cover causes, challenges, and barriers in global mental health; principles and approaches to mental health; and recommendations for mental health policy and programming. To protect the anonymity of participants and promote a candid engagement, USAID staff members did not join the conversations.

Within this effort, USAID sought to ensure that the voices and views of people with lived experience were taken into account. This summary provides high-level feedback and recommendations from consultations sessions with this stakeholder group.

Consultations

Eleven consultation sessions were held specifically with people with lived experiences. Thirty-one people from 14 different countries were represented in the sessions. There was robust representation from parts of East Africa, South Asia, and South-east Asia. However, there was little representation from Latin America and Europe. Additionally, there was a noticeable lack of representation from several areas where USAID engages in development work including the Middle East, North Africa, West Africa, Central Asia, and Eastern Asia. Though uneven, the representation included in this consultation is generally reflective of membership in key lived experience organizations focused on global advocacy.

The consultations were conducted online by two facilitators, Hannah Stewart and Jaclyn Schess to address content areas aligned with the broader consultation process as noted above. An online collaborative tool was utilized throughout the interviews to allow participants to contribute their feedback verbally or through adding inputs to the collaborative space themselves.

Definition of lived experience

What is lived experience? For the purpose of this activity, people with lived experience are defined as "people with life experiences involving systematic power dynamics of oppression, which include both first-person accounts and expert knowledge", as it relates to mental health. This definition was constructed by considering both phenomenological and standpoint theories as explained below.

Phenomenology suggests that lived experience represents knowledge that people gain from first-hand experience, living the phenomena of interest (Reid et al., 2005). This unique perspective positions these individuals to communicate parts of said phenomenon that would be invisible otherwise (Mapp, 2013). Standpoint theory contains a recognition of power and marginalization that complements this phenomenological outlook. An individual's social position shapes the knowledge they have access to and what knowledge they privilege (Wylie, 2003).

The result of this definition was the inclusion of people who have lived experience of mental health conditions, psychosocial disability, and as caregivers to said individuals. However, each individual brought a variety of unique and important identities into the consultation space, including those who were also clinicians, researchers, advocates, and community organizers.

Consultation results

Across these consultations, four key themes emerged: stigma and discrimination, challenging policy landscapes, availability of various services, and youth mental health. Sub themes for each of these are included in Table 1.

People with lived experience often identified mental health challenges as being intertwined with societal and structural issues related to discrimination, poverty, and lack of political priority. Additionally, people with lived experience emphasized that successful mental health policies would increase the number of people accessing community-based, culturally appropriate mental health supports, embed mental health across organizations' work, and lead to organization-wide frameworks for lived experience engagement.

Table 1. Mental Health Challenges

THEME	SUB-THEME
Stigma and Discrimination	Causes of Stigma
	Impact of Stigma
	Who is vulnerable?
Challenging Policy Contexts	Direct—Mental Health Policy
	Indirect—Other Policies
Available Services	Accessibility
	Appropriateness
Youth Mental Health	

PHOTO CREDIT: ANA KARINA DELGADO, HEARTLAND ALLIANCE

Recommendations

Participants had several recommendations to ensure that mental health programming and policy is effective for people with lived experience. These are outlined below. Additionally, people with lived experience highlighted that mental health programming and policy must prioritize principles including safeguarding human rights, inclusion and participation of people with lived experience and community members, emphasizing prevention and recovery, recognizing the need for evidence generation, and sustainability of program and outcomes.

Decreasing stigma and discrimination:

- Utilize culturally appropriate language to talk about mental health
- Include and increase the advocacy capacity of people with lived experience
- Increase anti-discrimination policy across sectors

Addressing accessibility:

- Integration of mental health across health systems and programs
- Task-shifting and digital intervention approaches
- Include people with lived experience across all programming, in all levels of programming

Addressing appropriateness:

- Adapt programs for context
- Engage local leaders
- Support evidence generation for locally-developed or adapted programming

Embedding human rights:

- Embed and reflect the language of the Convention on the Rights of Persons with Disabilities (CRPD) in mental health policy
- Incorporate WHO QualityRights into staff training and programming
- Ensure programs have processes that allow service users to report abuse and discrimination

Engaging people with lived experience:

- Develop an organizational framework for lived experience engagement
- Position people with lived experience as experts
- Pay people with lived experience for their expertise
- Build capacity of and partner with lived experience led organizations

Improving mental health services:

- Use primary and secondary prevention frameworks to strengthen mental health systems
- Address social determinants of health
- Monitor and evaluate diverse programming with mental health and psychosocial support indicators
- Integrate indicators of recovery into monitoring and evaluation efforts

Implementing community-based care:

- Ensure funding reaches community services, as opposed to institutional settings
- Ensure people with lived experience, caregivers, and the larger community buy-into community based services
- Diversify community supports, including mutual-aid and peer-support models

PHOTO CREDIT: BENOIT ALMARAS, HANDICAP INTERNATIONAL

References

Mapp, Taniya. "Understanding Phenomenology: The Lived Experience." *British Journal of Midwifery* 16, no. 5 (May 1, 2008): 308–11.

Reid, Katie, Paul Flowers and Michael Larkin. "Exploring lived experience." *Psychologist* 18 (2005): 20-23.

Wylie, Alison. "Why Standpoint Matters." in Figueroa, Robert, and Sandra G. Harding, eds. *Science and Other Cultures: Issues in Philosophies of Science and Technology.* New York: Routledge, 2003.