Grassroots Initiative to Address Mental Health Needs Among People Living with HIV (PLH) in San Diego, CA, USA

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Your Voice Initiative

In September 2024, we launched *Your Voice* in collaboration with 12 NGOs to survey 100 people living with HIV (PLH). Focus groups provided a safe, supportive environment for participants to share their experiences with mental health (MH) care and research. The diverse cohort included women, transgender individuals, youth, seniors, long-term survivors, and members of Black, AANHPI, and Latinx communities, as well as veterans and artists living with HIV.

Background

The San Diego HIV Consortium (SDHIVC, sdhivc.org) convenes monthly to share updates on HIV research. Although participants expressed strong interest in mental health (MH) research tailored to people living with HIV (PLH), they were unable to identify any active studies. Instead, they voiced even greater concern about the lack of access to MH care. In response, the Consortium launched an educational series on MH and clinical research, equipping participants with the knowledge to share their experiences effectively and advocate for greater access to therapy.

Lessons Learned

Participants identified substantial barriers to accessing therapy and emphasized the need to integrate mental health (MH) services into HIV care. They stressed the importance of fostering social connections to combat loneliness and promote overall well-being, encouraging others to "seek social situations." Stigma—both within healthcare settings and the broader community—was prominently reported as a persistent barrier to care.

Conclusions

We presented these findings to the San Diego County HIV Planning Council, which welcomed the actionable recommendations. People living with HIV (PLH) emphasized the urgent need for culturally diverse mental health (MH) services and greater attention to the unique challenges faced by those aging with HIV. Participants reported long wait times for MH care—up to six months—particularly among people of color. Regarding research, PLH stressed the importance of direct communication with investigators during study design and advocated for researchers to report study results back to participants.

Key Insights

1.**Peer Advocacy:** Participants called for expanded access to peer advocates and navigators, noting that private insurers often lack HIV-specific support services.
2.**Innovative Solutions:** Younger participants proposed creative strategies to address mental health needs, such as culinary medicine and community-based wellness programs.
3.**Political Engagement:** The initiative fostered greater confidence in self-advocacy and political involvement, both viewed as essential for strengthening social support networks.
4.**Institutional Collaboration:** Focus group leaders identified significant gaps in healthcare navigation and recommended partnerships with local institutions to better educate PLH on research participation and healthcare access.

Next Steps

The Consortium will conduct a detailed survey to assess PLH experiences within the mental health (MH) care system, identify stigma-related barriers, and gather input on future MH research priorities — with a focus on non-pharmacologic interventions such as different types of psychotherapy, yoga, art, music, and sound therapy. We are also finalizing a referral list of therapists with available appointments and reviving the San Diego Buddy System, now tailored toward enhanced peer navigation support.

	Focus Group	
	Group	# attended
1	Women	12
2	Trans Women	10
4	Black	5
5	AANHPI	5
6	LatinX	15
7	Youth	3
8	Long Term Survivors	6
9	Artists LatinX	14
10	Vets	3
11	Aging Artists	10
12	Sobriety	7
13	UCSD CAB	8
14	Unsheltered	2
TOTAL		100