## A Community-Academic Approach to Preventing Substance Use Disorders

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#### ABSTRACT

<u>Background</u>: The COVID-19 pandemic and activism against structural racism heightened awareness of racial-ethnic disparities and disproportionate burden among the underserved. The opioid crisis further compounds these phenomena, increasing vulnerability for substance use disorders (SUD). Community based participatory research can facilitate multi-disciplinary collaboration, yet literature on these approaches to prevent and reduce SUD and associated stigma remains limited.

<u>Objective</u>: Discrimination, stigma, and multiple crises with healthcare and systemic barriers increasingly marginalize the underserved, specifically around SUD. The Detroit Area Mental Health Leadership Team (DAMHLT, since 2015), aims to optimize SUD prevention, enhance resiliency and advocacy to advance knowledge on SUD research and influence community-level research and practice.

<u>Lessons Learned</u>: DAMHLT's approach on bi-directionality, community level access to realtime epidemiological data, advocacy (i.e., institutional responsiveness) and dissemination may be translational to other partnerships.

<u>Conclusion</u>: As we move through an ever-changing pandemic, DAMHLT's lessons learned can inform partnership dynamics and public health strategies such as hesitancy on public health response.

**KEYWORDS:** Community-Based Participatory Research, stigma, substance use disorders, opioid use disorders, community-identified needs and recommendations, COVID-19, community-academic partnership, community engaged research, community health partnership, Mental Health

#### Background

The coronavirus pandemic impacted the community and systems of care, adjusting the way people interact and how society functions. Although awareness of systemic racism gained steam from social activism led by stakeholders and organized movements for equity, structural deficiencies communities of color and the underserved bear are so deep vulnerable communities and individuals continue to experience disproportionate burden and discrimination. This burden overwhelms the opioid crisis, increasing risk for overdose and death from substance abuse and marginalization among the underserved from discrimination, stigma, and multiple crises with healthcare and social structures (1).

Undeniably, a relationship exists between racism, disparities, and substance use disorders (SUD), especially among at-risk people of color (2). Vulnerability for SUD has in fact increased during the pandemic contributing to co-occurring disorders, namely opioid use disorders (OUD), evidenced by increased rates of overdose deaths and naloxone administration by Emergency Medical Services, with SUDs cited as a leading cause of morbidity in the United States (3,4). A surge of addictive behaviors (new and relapsing) including behavioral health disorders is a consequence of COVID-19 (5).

Partnership, collaboration, and community engagement are critical in context of an everchanging pandemic environment that coincides with the opioid crisis and public health issues such as disparities in systems which breed discrimination and stigma. Equally compelling, increased recognition of community voice and engagement creates an exciting opportunity for systemic change (6).

Engaging the community in clinical health research grounds the science for both the community and intended research. Community based participatory research (CBPR), widely

recognized as a collaborative approach involving all partners in the research process, recognizes the unique strengths each member brings (7). CBPR is facilitated through a community health partnership where partners share interest in improving community health (8,9).

This paper, predominantly led and written by community stakeholders in all aspects of manuscript preparation and submission, shares lessons learned about the Detroit Area Mental Health Leadership Team's (DAMHLT) approach to identify community-informed recommendations to prevent and reduce SUD, and how the group adapted during the pandemic.

DAMHLT, a community-academic partnership utilizing CBPR in its work from conception through implementation, originally focused on the Metropolitan Detroit region, later expanding statewide during the pandemic. The partnership believes community-engaged approaches underscore ways to amplify community voice and leverage community strength for SUD prevention. DAMHLT addresses critical gaps in community access to real-time data and scientific discovery on SUD, especially among community-based organizations. Equally important, DAMHLT acknowledges academic investigators often lack grounding in the community and community voice as a sounding board to inform research from lived experience. Thus, the partnership aims to optimize SUD prevention, enhance resiliency and advocacy through bi-directional community-academic approaches that involve sharing, learning, and informing research focus to increase utility in producing and advancing scientific knowledge on SUD (10). Community-level access to data is essential for this bi-directional relationship and DAMHLT's approach.

#### The Partnership: Detroit Area Mental Health Leadership Team

Concepts of cultural congruence and sensitivity are central to this partnership as health disparities typically impact underserved populations, including racial and ethnic minorities, immigrants, and refugees who have been historically marginalized and disadvantaged from injustice and discrimination (7,11). Established in 2015, DAMHLT is supported by the Community Engagement Program with the Michigan Institute for Clinical and Health Research (MICHR) at the University of Michigan (UM), a National Institutes of Health Clinical and Translational Science Awardee from 2007-2022.

The partnership's leadership team of 21 partners (n=9 community, n=1 for-profit, n=6 academic, n=5 staff) utilized a community advisory board (CAB) structure (12) and process to advocate research is relevant, driven by community-identified priorities, and conducted by transdisciplinary teams who shape research processes and outcomes with a focus on respect and acceptability to the community (13,14). DAMHLT's framework (see Appendix 1) empowers collaboration and consensus on community-identified needs and recommendations to inform research, community-level practice, and advocacy for institutional responsiveness.

With MICHR pilot funding, DAMHLT convened 1) a series of educational and policy conversations aimed at building a community-based learning community to advance institutional responsiveness to the Metropolitan Detroit opioid crisis, and 2) dissemination of findings. These efforts led to an advocacy brief of community recommendations to address SUD stigma that explored COVID-19's impact; and staging a community-academic network for SUD. DAMHLT broadened to a statewide approach since partners felt the brief was appropriate across communities and the partnership's reach was growing. The network includes communityacademic partners with varying levels of engagement and support defined as supporters, advisors, collaborators, and leaders, with collaborators and leaders providing stronger levels of

commitment (see Appendix 2). DAMHLT typically engaged all four levels of engagement and support consistently throughout its work. A UM institutional review board application was submitted, however, withdrawn since "the activity falls outside the Common Rule and FDA definitions of human subjects research" (15).

#### DAMHLT's SUD Related Work

Following CBPR principles (7,16, 17), DAMHLT's CAB were involved in all aspects of the work including problem identification, planning, analysis, advocacy, and dissemination. The partnership developed and facilitated its research agenda through monthly meetings and approaches such as email, google box, video conferencing, and literature reviews with staff support. The SUD efforts were informed by three domains 1) learning health sciences, which analyzes differently sourced data-information to create knowledge, information, and inform practice and evaluation (18,19), 2) deliberative democracy, that facilitates interaction between stakeholders resulting in informed opinions (20), and 3) how representativeness can inform

*Pilot Opioid Learning Community Series*: Held in 2018-2019, community-academic experts presented the following topics in five sessions: opioid prescription abuse and prevention; youth trends on SUD and behaviors; rescue and recovery addiction research on data, process, and interventions; and recreational and medicinal cannabis use and policy. Personal testimony and public deliberation followed each presentation. The series was designed during a 11/2-day retreat with DAMHLT's CAB to develop a pilot proposal funded by MICHR. The proposal outlined the research questions, learning community model, series topics, and outreach and dissemination. Findings from a survey designed by and administered to CAB members to prioritize community issues when the partnership began informed the retreat process. During the

planning, new legislation was being introduced to increase recreational-medicinal cannabis access in Michigan. Since marginalized communities are often inundated with commercial access to alcohol, tobacco and other drugs, the CAB was concerned a similar situation would occur. Thus, a session explored views on cannabis as a gateway drug, especially impacting youth, and community education on the new legislation.

In partnership with the UM Region V Public Health Training Center, a National Public Health Learning Network consortium member, participants received thirty-six Continuing Education Units at no cost. Evaluation surveys were administered to collect information on improved knowledge of session topics, any action identified to apply information learned, effectiveness of training delivery/materials, topics for new sessions, and effectiveness of the sessions and series (n=116, see Appendix 4). The series was recorded, transcribed, and well attended by representatives from healthcare, SUD/OUD treatment, academia, and faith-community based organizations (n=230, see Appendix 2). DAMHLT employed widespread marketing, leveraging relationships and knowledge of key leaders and organizations. Registration occurred via an emailed flyer and online platform.

*Analysis:* The transcripts were qualitatively analyzed by DAMHLT's CAB to present key themes in a column matrix listing themes as headers to quotes and subthemes. Distinct comments not linked to the themes were captured under the other category.

*Advocacy*: The matrix was refined and prioritized in two community advocacy meetings attended by approximately 80 stakeholders utilizing "live charting," which facilitated "real time" editing and consensus via deliberation in small and full groups. The following themes emerged: culture, community education, stigma, access to data, family cohesion, and access to care.

Stigma arose as the most alarming priority. Original quotes and statements were itemized under the themes resulting in a revised matrix. Additional input on the draft occurred during a presentation and policy planning session at the UM Learning Health Sciences Department symposium in 2019.

Advocacy Brief Against SUD Stigma: DAMHLT's CAB organized the matrix in narrative form as an advocacy brief when the COVID-19 shutdown began. They were fearful SUD would increase and access to prevention and recovery would reduce from structural changes in delivery systems due to the pandemic. Since the CAB represents providers addressing mental health, SUD and OUD, they felt compelled to include the community's voice and what the community was experiencing in the brief.

Thus, the CAB held a series of meeting to discuss what providers were seeing, additional burdens clients were experiencing, and how providers were adjusting to the pandemic. Topics included escalating community need, stigma, disparities, barriers, the impact of distancing on isolation, inadequate information, organizational protocol development, changes in service delivery, and telehealth.

This new discussion was synthesized into the advocacy brief (see Appendix 3). Specifically, the introduction's OUD section was revised to forecast the community's concern that OUD and SUD may increase from factors associated with COVID-19 such as increased isolation, anxiety, loneliness and economic hardship which could also impact behavioral health outcomes. Additionally, data describing increased rates of overdose deaths and Naloxone administration by Emergency Medical Services during the March-July 2020 period was included. The stigma brief outlines barriers, often systemic, that influence and shape SUD stigma, along with community-identified recommendations for needed research to reduce stigma. The

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recommendations focus on treatment, collaboration, media, access to information and education. The team intentionally chose an advocacy versus policy position since advocacy can lead to new policy and/or change existing policy and practice (22,23).

*Outreach and Dissemination*: A final draft of the brief was disseminated to the network for input and consensus via email. The final advocacy brief was disseminated via web-based communications including mail chimp, targeted email, newsletters and DAMHLT partner outreach. The original plan to present the brief in an in-person town hall meeting was modified according to safety protocols to a virtual event after the shutdown was lifted.

#### **Lessons Learned**

DAMHLT was successful building a community-academic partner network. The learning community series and advocacy brief bridges community level access to data, shares community-identified needs; and recommends institutional responsiveness to address SUD, associated stigma, and continued research on SUD related stigma. Indeed, advocacy is a basic tenet of DAMHLT.

Underserved communities possess resiliency that, when leveraged through partnerships with researchers, may be effective in developing a greater understanding of communityidentified need that influences SUD, as well as sustainable strategies promoting resilience and solutions to SUD (24). However, research on these types of community-academic partnerships is limited (25) especially concerning SUD stigma (26,27).

Lessons learned from DAMHLT's approach on partnership dynamics and community engagement to enhance community voice, inform advocacy and prevent SUD may be appropriate for similar partnerships. They include 1) *community-academic bi-directionality* in developing and advancing scientific knowledge on SUD, 2) *community-level access to real-time epidemiological data*, 3) ongoing *community education* focused on cutting edge state-of-thescience and practice on SUD, 4) *disseminating scientific findings* via a multi-pronged community approach including outreach and place-based community organizing, and 5) *advocating for institutional responsiveness* to community-identified need and recommendations.

Scientific knowledge development is defined as teaching, learning, and sharing of ideas (28). Historically, the production, dissemination, and advancement of knowledge have taken a top-down approach limited to academic institutions (29). Nevertheless, it is well documented that research-based interventions are effective only to the extent communities are willing and able to implement and participate in these programs (10). Thus, to optimize SUD prevention and enhance resiliency, bi-directional community-academic approaches that involve sharing, learning, and informing research focus may have significant utility in producing and advancing scientific knowledge on SUD (10). Community-level access to data is essential for this bi-directional relationship.

Enhancing community-level access to scientific knowledge and readily available data remain important federal priorities to improve overall public health, especially among underserved communities (30). Researchers have identified barriers to enhancing community access to scientific knowledge, including cultural differences, meaningfulness of results, and disagreements on disseminating findings (31). It is essential, therefore, that researchers develop strategies to overcome these barriers to increase community-level access to data.

#### Partnership Dynamics: Substance Use Disorders

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From the pilot learning community series evaluation, participants overwhelmingly report increased knowledge on the changing face of addiction, series topics, and how this approach can inform policymakers, practitioners, and consumers (see Appendix 4).

"Loved the combination of data, personal stories and testimonies." "Excellent format to tee off w/presentations and allow for questions and discussion after. Loved the SOS (32) data and info!" "We rarely hear how addiction effects the ENTIRE household."

Participant recommendations on future topics provide insight on how data and information could be beneficial to their work, which could also inform academic research.

"Now to apply what we learned about the opioid epidemic to prevent future drug related crises."

"More information on dispelling stigma and programs of support."

"What other drugs are coming to be dangerous."

Importantly, there is a need for community-level education focused on the dynamic nature of SUD (33). A multi-pronged approach is required for effective dissemination of scientific knowledge to enhance resilience among underserved communities (34). Mirroring previous research, word-of-mouth and county-level government dissemination were considered valuable dissemination mechanisms (35) in the learning community series evaluation.

Beyond advancing scientific knowledge, advocating to implement community-driven recommendations to attenuate SUD is essential to build trust and work toward SUD solutions that resonate with underserved communities (36). Undeniably, access to community-level SUD education has significantly decreased over the last decade (33). To address this downward trend, the learning community series trained multiple staff within community-based organizations.

Finally, the importance of trusted relationships, effective community organizing and outreach to ensure widespread dissemination, especially among respected community leaders and organizations with significant reach, relationships and influence is vital. DAMHLT's network began with nearly 100 community-academic partners. Partnership representativeness now includes roughly 600 stakeholders in which partners support varying levels of engagement defined as leaders, collaborators (approximately 33%), advisors and supporters; were actively engaged with DAMHLT supporting its work through outreach and advocacy (see Appendices 1-2).

#### Limitations

DAMHLT's CAB and network represents organizations who address SUD/OUD. Stakeholders reported being in recovery and having family members either challenged with, or whose death was attributed to SUD. A limitation of the partnership's representativeness is lack of stakeholders with active SUD engaged with its work.

#### Conclusion

Community engagement increases the relevance, responsivity, and resiliency of responses to the unique issues facing communities. DAMHLT has been successful in building a

network of community-academic partners engaged in its work. More recently, the CAB served as advisor to four investigators who submitted applications on pain research, opioid prevention and SUD stigma, of which two, housed in the UM Department of Anesthesiology, received multi-year funding (approximately \$4.6M) from the Patient Centered Outcomes Research Institute and National Institutes of Health in 2021. DAMHLT is supporting implementation of these efforts. This new collaboration is promising for sustainability and bridging community engagement among academic investigators within the community.

DAMHLT encourages bi-directional learning, community education, and access to realtime data and scientific discovery recognizing the value of lived experience to influence community-level research and practice. As we live during an ever-changing pandemic environment, DAMHLT's lessons learned can play a key role in partnership dynamics and the design and delivery of public health strategies.

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### **Appendix 1: Collaboration Framework**

The Detroit Area Mental Health Leadership Team (DAMHLT) aims to build relationships between community-academic partners and advance scientific knowledge on community priorities to inform research and practice. Partners serve as leaders, collaborators, advisors and supporters.



Figure 1: Collaboration Model

### Core Tenets

- Utilize community engagement, bi-directional learning, community education and advocacy to address community-identified need and strategies that encourage institutional responsiveness to research development, behavioral health and Substance Use Disorders (SUD).
- Build authentic relationships between stakeholders, clinical and community-based practitioners and researchers. Ensure appropriate representativeness reflecting lived experience and innovation during discovery and decision-making processes.
- Encourage community-driven strategies based on philosophies of care such as culturally congruent and trauma-informed practice that focus on respect and community accountability.
- DAMHLT's community-driven strategies supporting SUD resiliency align with federal policies such as Healthy People 2030, the Affordable Care Act, and the Substance Abuse and Mental Health Services Administration.

The collaboration model was adapted from the <u>D</u>eliberative <u>E</u>ngagement of <u>C</u>ommunities in <u>De</u>cisions about <u>R</u>esearch <u>S</u>pending - DECIDERS (37).

### **Appendix 2: Community Advocacy Network**



Figure	2:	Process	Мар
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Partnership Representativeness				
	Detroit Area Mental Health Leadership Team	6 UM faculty, 2 county government, 1 for profit, 7 CBOs, 2 UM staff; 3 MICHR staff		
Community Advocacy Network	Opioid Learning Community Series (5 sessions)	230 stakeholders from 68 unique institutions (3 faith, 15 academia, 36 CBOs, 10 healthcare, 7 local/county/ state government)		
	Advocacy Planning Against Stigma (2 meetings)	N=80, representativeness similar to the learning community series		
	Outreach and Advocacy	Listserv of approximately 600 stakeholders (CBOs, healthcare, law enforcement, academia, education, faith- based, etc.)		

Note: DAMHLT's network partners address Opioid and Substance Use Disorders. Partnership representativeness lacks (or acknowledgement of) members with active SUD. The network includes varying levels of engagement as defined in Appendix 1, and typically engaged all levels (leaders, collaborators, advisors and supporters) in its work consistently.

#### **Appendix 3**

### **Advocacy Brief:**

Combating Stigma Associated with Opioid Use Disorders in Metropolitan Detroit

### **Opioid Use Disorders (OUD)**

This multidimensional public health emergency hit Metropolitan Detroit hard. While work toward statewide prescribing policy and practice successfully gains traction, combatting bias is at a standstill. Stigma reduces help-seeking behaviors and effectiveness of approaches to address OUD. Opioid and Substance Use Disorders (SUD) will increase due to COVID-19. Increased isolation, anxiety, loneliness, and economic hardship are impacting behavioral health outcomes in the United States, and these effects will likely remain for years to come. Social distancing, business and school closures, job loss, and shelter-in-place orders will complicate existing barriers to behavioral healthcare in Michigan, including workforce shortages, lack of affordability and insurance, and stigma. 1,2







### Detroit Area Mental Health Leadership Team

The Detroit Area Mental Health Leadership Team, a communityacademic partnership with the Michigan Institute for Clinical & Health Research, prioritized the opioid epidemic as an emergent public health epidemic. The team aimed to increase knowledge on the issue and advocacy for community recommendations to address OUD among academia, government, funders, and community and health care institutions. At-risk determinants such as access to care have widened since the coronavirus pandemic. Providers are challenged with shifting how service and practice occurs.

### Scope of Stigma

There is little consensus on how and when mental illness stigma impacts the decision to seek care. Stigma can shame, humiliate, and devalue individuals socially, widening cultural incompetency in the field. In urban communities like Metropolitan Detroit, where trauma, poverty, isolation, and health/mental health inequities are prevalent, stigma increases vulnerability in individuals suffering from OUD, their families, and supporters. Long standing structural inequities, such as racism and social/economic disparities, contribute to underlying reasons why at-risk individuals engage in inappropriate behaviors.



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The use of dehumanizing language inappropriately characterizes those who suffer with substance and opioid use disorders.

Opioid use disorder Substance use disorder						
🛞 INAPPROPRIATE TERMS						
addict	addiction	bashed	blasted	blown	bombed	
burnout	<del>crack head</del>	drug abuse	drug addict	druggie	doper	
hash head	junkie	pothead	smoked	stoner	user	

📀 APPROPRIATE TERMS

Rates of overdose deaths and Naloxone administration by EMS have <u>increased</u> since the pandemic began in Detroit: <sup>3</sup>

+17.2%

218 suspected overdose deaths were recorded between March 1-July 12, 2020. 186 were recorded between October 19, 2019-Februrary 29, 2020. +20.7%

EMS administered Naloxone 939 times between March 1-July 4, 2020. 778 were recorded between October 27, 2019-February 29, 2020.

# 638,000

Michiganders experience substance use disorders, and 80% are not receiving care. 4

**69%** 

of Medicaid enrollees are not receiving care for their substance use disorders despite behavioral health being covered. 4

### **Community Recommendations**



Public Health Approach: Recognize OUD as a public health crisis. Work to reduce stigma, decriminalize and increase understanding of OUD through research, conversation and practice.

#1

Language can be used to express stigma, discrimination, and

stereotyping. Language is used in policy and practice to define health conditions and influence public opinion, promoting public health approaches to address them. This means we need to reframe substance abuse and addiction as substance use disorders, a health condition, or disease. Labeling persistent stigma as a public health concern is the first step toward establishing a widespread agenda to address the growing epidemic. #2

Lack of research on the consequence of OUD-related stigma has left gaps in our understanding of the problems related to mental health treatment access, acceptance, and outcomes. Further research is needed to address this gap, inform treatment access, scientific knowledge, acceptance, and help develop and test intervention strategies.



"It takes a village" to build communityacademic partnerships, collaboration, and reduce social, educational, and economic disparities that breed stigma and discrimination. Develop prevention and intervention strategies that involve families and community. Implement initiatives that encourage respect, dignity, and quality of life for all. #4

Community-based organizations in Metropolitan Detroit serve at the forefront in the battle against OUD; yet, their access to data, surveillance, and best practices is dated and limited. Utilizing models such as the Opioid Learning Community Series, which is modeled after a learning health sciences approach, can increase community-level access to information and strengthen the quality of community-based practice.



Barriers include lack of access to care, acceptance that care is needed, and care seeking due to stigma. Public awareness of educational resources not only increase access to network providers, but also the public's understanding of perceptions with having a mental illness or OUD, and when and where to receive services.

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Educate the community on the role of stigma in cultural norms, laws, and institutional practices to help them advocate for change. Educate local stakeholders on factors that impede community-level solutions, such as what makes certain individuals more prone to OUD

#7

Encourage recovery-oriented systems of care that promote empowerment and choice. A focus on specific evidencebased treatments and practices, such as increasing neighborhood access to Naloxone and harm reduction strategies, can increase willingness to seek care by reducing travel requirements and fear of stigma associated with receiving care at a behavioral health facility.



Implement robust provider education to improve identification and treatment of OUD, including checking the Prescription Drug Monitoring Program for current prescription status and urine screens. Create provider education on pain management that includes alternative therapies, virtual care, and increased access to treatment in underserved areas.



In the context of COVID-19, primary care providers will be the first line of defense for substance use, suicidal ideation, and other behavioral health conditions. Identify effective approaches supporting primary care practices in improving virtual care and assist them in addressing the adverse behavioral health effects of COVID-19.



Engage media as partners in the fight against stigma by eliminating sensationalizing and dehumanizing language when covering the opioid epidemic. Repackage this approach to embrace individuals afflicted, their families, and support systems, emphasizing factors that contribute to individuals becoming involved in OUD, such as social determinants, behaviors, and choice.

### References

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Appendix 4: Opioid Learning Community Series Evaluation				
Increased Knowledge Gained	Future Session Topic Recommendations			
"Loved the combination of data, personal stories and testimonies."	"Now to apply what we have learned about opioid epidemic to prevent future drug related crisis."			
"The training was extremely useful to me as a mom and a person who works with	"More info from those in recovery."			
community members. I will put the training to use."	"With an increase in the opioid epidemic, a Naloxone training seminar would be useful."			
"I wish there were more seminars. I have	"Anger and Narcan."			
learned so much these past 5 sessions."	"Stigma of use."			
"Excellent format to tee off w/presentations and allow for guestions/discussion after.	"More information on dispelling stigma and programs of support."			
Loved the SOS (38) data and info!"	"More information on community engagement, sustainability."			
"I have very limited knowledge of opioid use disorder, and substance use more broadly. As our work turns more to substance	"Link between addiction and brain chemistry."			
misuse, this, has greatly informed me."	"What other drugs are coming to be dangerous."			
"We rarely hear how addiction effects the ENTIRE household."	"Relationship between medical/therapeutic professionals and other social services'- What are you allowed to ask, what is the referral process?"			
"Well rounded training. Very informative/ helpful to not only have academic but also real life experience."	"Effect on children and other family members."			
"Money needs to be used for treatment more so than research."	"Stigma/corresponding approaches and interventions for various cultures/ethnicities."			
"It's important to understand the feelings Abusers have."	"Would like more resources/training info to take back to the workplace."			
	"Would have liked more information on police/community involvement."			

Note: Two surveys, utilizing identical domains were administered (n=116) to 1) participants and 2) only those obtaining continuing education units (CEUs).