

BRIDGING THE DIVIDE:

Accessing Care for Youth and Young Adults with Co-Occurring Mental Health and Addiction Disorders

Parent/Professional Advocacy League
Massachusetts Organization for
Addiction Recovery

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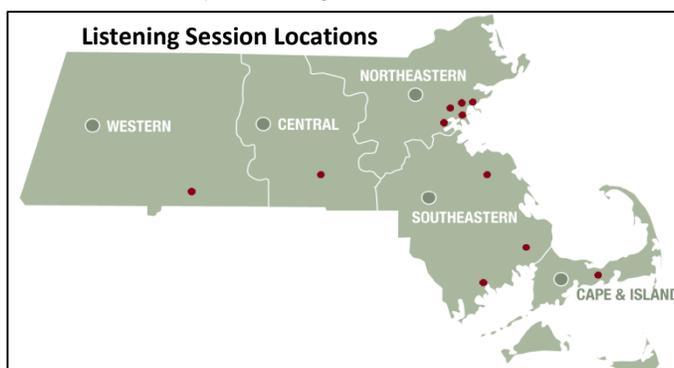
Bridging the Divide: The Struggle for Youth and Young Adults with Co-Occurring Disorders in Massachusetts

Background

In the winter and spring of 2014-15, Parent/Professional Advocacy League (PPAL) and Massachusetts Organization for Addiction Recovery (MOAR) held 11 listening sessions across the state. Hosted by various communities, the listening sessions were designed to capture information about access to services and gaps in care for youth with co-occurring substance use and mental health challenges.

Although 3 listening sessions were initially proposed, the demand proved far higher. Communities requested the opportunity to provide input and the number of listening sessions held grew to 11, with 115 participants. At first, the listening sessions only surveyed family members of youth and young adults with co-occurring disorders; but the focus expanded to include both the youth and provider voice in order to achieve a more complete snapshot. It was also important that the project also included diversity, not only geographically and culturally, but also linguistically and economically. The final array of listening sessions included 2 youth-only listening sessions, 3 provider-only listening sessions, 5 family-only listening sessions and 1 that was a mix of families and providers. The listening sessions identified discrepancies in access to services and availability of information for youth and young adults with co-occurring disorders based on disorder identified and geographic region.

The community listening sessions were well attended. Families, youth, providers, people in



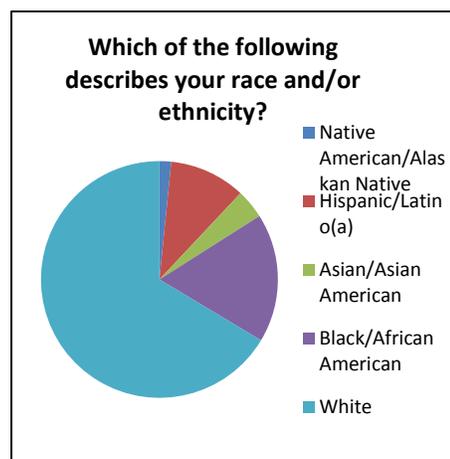
recovery and others interested in closing the gaps in existing services and supports for young people with co-occurring disorders brought their ideas, information and concerns. National studies report that 71% of youth and young adults with substance use disorders also experience a co-occurring mental health disorder, yet the discussion surrounding co-occurring disorders in youth and young adults is quite sparse.

PPAL and MOAR staff enlisted the aid of an advisory committee to help draft and edit questions for the survey which was handed out at the beginning of each listening session. Each participant filled out a data sheet including demographic data, questions about insurance, needs and experiences, which was then entered into a database and analyzed. At each listening session a staff member scribed so that there would be a qualitative data set to analyze at the culmination

of the listening sessions. The listening sessions focused on gaining a better understanding of the gaps in behavioral health policy, planning and services with emphasis on geographical, cultural, linguistic and racial diversity.

Demographic data

The 11 listening sessions captured both quantitative data (through data sheets) and qualitative data from 115 participants across the state. The participants included youth, parents, providers, people in recovery and community members. Participants described themselves as black (19.47%), Hispanic (11.5%) or Asian (4.42%), as well as white (73.45%). One question asked on the data sheet concerned the type of insurance provider that was used by the families, youth or providers. A substantial amount, 56.6%, of family members and youth received coverage through MassHealth, where only 32.1% had private insurance. Providers reported an even larger difference where 16% said that a majority of their clients have MassHealth and less than 1% had only private insurance. That being said, 9.43% of the providers stated that many of their clients were insured by a combination of of MassHealth and private insurance.



Two listening sessions were attended only by youth and young adults and were youth-led. Youth participants reported that they worried substantially about out-of-pocket expenses affecting the willingness of both youth and adults to access mental health or substance use services. The majority, 68.4% of the youth, stated that they worried about the out-of-pocket expenses, with only 5.26% saying that disagreed and 26.3% were neutral or had no opinion.

Overall, listening sessions attracted participants from some of the most diverse cities in Massachusetts including communities that varied greatly in income per capita. Survey questions also included questions about access and stigma. While 36% reported that substance use services were difficult to access, 42% identified difficulty in access mental health treatment. 77% agreed or strongly agreed that they worry that stigma affects people's willingness to access services; 66% said they thought privacy concerns impacted access and 80% thought that out-of-pocket expenses affected people's willingness to access services. Gaps in information, barriers caused by stigma, the need for education, lack community resources and how there is one door for mental health services and another for addiction services were all identified as significant challenges during the listening sessions.

Findings

After an analysis of the data, five clear findings emerged.

Finding #1: The qualitative data revealed a dire need for services that provide treatment for both mental health and addiction issues.

- Communities consistently reported that services were provided either for mental health or for addiction, but only rarely were services designed to address the two needs simultaneously in one program or in one treatment center.
- Families reported that the lack of services to address both addiction and mental health issues created stress on families and increased their burden of care. Families struggle to get youth and young adults into just one treatment center for mental health or addiction services, much less being able to get them to go to two different services

Finding #2: The majority of participants stated that access and availability of services and resources limited to youth and young adults with co-occurring disorders is minimal.

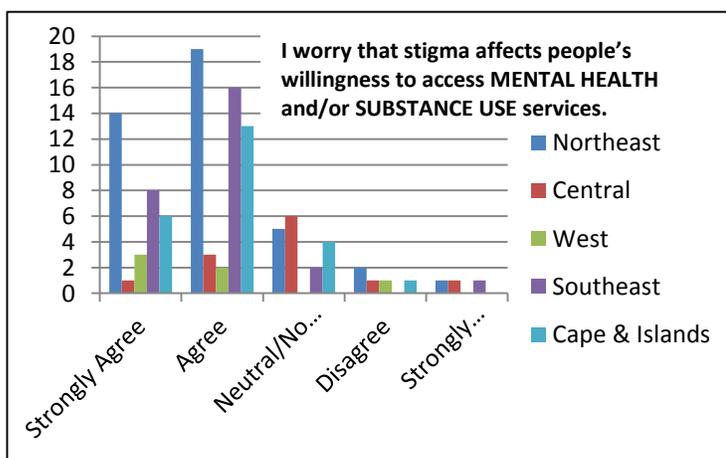
- There is a significant need for more youth-centered programs, limited to youth and young adults, including groups like NA and AA. Many youth and young adults do not feel comfortable in settings where they are the only young person.
- Participants felt very strongly that programs or treatment centers for mental health and addiction should have programming specifically for youth and young adults.
- Youth also felt that there should be programs that they can access without parental consent; a place that they feel is safe for them to go for help or resources.

Finding #3: Education, information and language describing co-occurring mental health and substance use needs is not available or very difficult to find.

- There are very few educational materials and resources available about co-occurring disorders. Participants clearly stated that there is an urgent need for educational resources about co-occurring disorders.
- Using traditional media, social media and creating a public health campaign on the prevalence of co-occurring disorders is important in Massachusetts.
- Participants believed that everyone from youth to families, providers and teachers need information and education on topics such as drug education, signs of crisis, what to do in a crisis, resources available, etc.

Finding #4: Schools should play a role in educating and providing resources and support for youth and young adults with co-occurring disorders.

- Participants reported that is very little education about substance use, and none about mental health issues in most public schools. Many communities felt that schools should provide information and education to their students and that this education is best taught by peers, or those with lived experience.
- School guidance counselors can make resources available and be able to make referrals to community service providers. They can be made aware of community based services already in their towns and cities. Schools need counselors who are educated about mental health and addiction.



Finding #5: Few trainings for families, community members and youth exist to build knowledge and skills on co-occurring disorders.

- Families reported that there is a need for trainings on topics such as “signs of substance use,” “what is a co-occurring disorder?” and “how to talk to your kid about their drug use”
- There is a need for common language and vocabulary to talk about mental health and substance use. Families and community members reported having to learn new jargon or finding out that terms they were familiar with had different meanings. Many felt that it would be helpful to create a training that helps families understand the different terminology used.

Recommendations

After a thorough qualitative analysis, PPAL and MOAR have the following recommendations:

1. Develop treatments and services that are designed for and available only to youth and young adults.
2. Design a class on co-occurring disorders for schools to implement into their curriculum.
3. Create a packet filled with information and resources on co-occurring disorders to distribute to communities and schools statewide.
4. Create and update informational materials regarding co-occurring disorders in youth and young adults, translate into Spanish and distribute to communities across the state.
5. Strengthen the youth and young adult voice as well as voices in diverse communities through trainings, materials, social media campaigns and marketing efforts.
6. Develop a training highlighting the different vocabulary of children's mental health, adult mental health and addiction as well as the value of linking to a statewide family, consumer and recovery networks. Focus on the differing language of mental health and addiction recovery, as well as the value of youth, family and consumer voice.
7. Convene a Stakeholder's Meeting for a diverse group of individuals across the state who have an investment in the increasing incidence of co-occurring disorders in youth and young adults.