

# BLAMED AND ASHAMED

The Treatment Experiences Of Youth With Co-occurring Substance Abuse And Mental Health Disorders And Their Families

## EXECUTIVE SUMMARY

Federation of Families for Children's Mental Health  
and  
Keys for Networking  
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# EXECUTIVE SUMMARY

## BACKGROUND

This report presents the findings of a two-year project intended to document and summarize the experiences of youth with co-occurring mental health and substance abuse problems and their families. The purposes of this study were to offer youth and their families the opportunity to reflect on and give voice to their experiences, to identify their successes and concerns, and to formulate recommendations so that a national audience might learn from their experience and improve services. The work was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) in the U.S. Department of Health and Human Services and conducted by two family-run organizations – the Federation of Families for Children’s Mental Health, Alexandria, Virginia and Keys for Networking, Inc., Topeka, Kansas.

A unique and key feature of the study was the high ownership of youth throughout the process. Their control over the study led to a strong sense of power which was key to establishing the trust and comfort necessary for participants to think deeply about and honestly share details and feelings about experiences that were very personal – even painful.

Between 1997 and 1999, over 150 people from California, Georgia, Illinois, Kansas, Maine, New Mexico, Virginia, West Virginia, and the Washington, DC area were interviewed or participated in focus groups. They represent a cross-section of youth with co-occurring mental health and substance abuse problems and their families. Youth participating were from every ethnic group and socio-economic status and ranged in age from 13 to 28. They all shared the experience of having resided in both mental health and substance abuse treatment facilities. Focus groups for youth and parents were held separately. Once the focus groups were completed, audiotapes were transcribed and a meeting was held in Kansas City to review and analyze the raw data. The Federation of Families for Children’s Mental Health and Keys for Networking wrote the final report.

## FINDINGS

The findings of this study are powerful. Tragically, youth with co-occurring mental health and substance abuse disorders and their families rarely get the kind

of help they need at the time they need it. Services and supports are fragmented, isolated, and rigid. These negative experiences, however, lead direct us to the changes that are necessary to get better outcomes. Peer-to-peer support for both youth and families, really accurate and useful information for both youth and families, and combined treatment that includes families are called for. And mostly, youth and their families want to be heard and respected. They want a say in deciding what services and supports they will receive as well as where and how they will be provided.

### RECOMMENDATIONS

The report's recommendations are framed in the spirit of promoting positive change. They focus on how treatment, services, and supports for youth with co-occurring substance abuse and mental health disorders and their families are:

- thought about;
- designed;
- provided; and
- evaluated.

The report's recommendations are intended to stimulate everyone who has an interest in this subject to reflect deeply about what can be done to improve practice and outcomes. Any change process occurs when individuals take responsibility and start to do things differently. Therefore, the recommendations are directed at providers, families, and youth. But they could be applied to a wide variety of individuals as well as programs and systems. In addition, the report offers SAMHSA suggestions for activities to fund that would begin to address the key information and service needs identified by this study.

#### *Recommendations for Providers*

Listen carefully and attentively and treat youth and families with respect and dignity.

- Rely on youth and families to guide you in understanding who they are, what they can do, and what problems they are facing.
- Use what you hear to reach your decisions and make your recommendations.

Involve youth.

- Actively engage youth in designing and evaluating programs.
- Offer youth access to information, and a voice in the decisions, which get made about their treatment.
- Create opportunities for youth to help others in treatment and afterwards.
- Create options for youth to use their experience and turn it into positive growth. Help them reclaim self-esteem.

Make sure families are included. Invite them into the treatment process.

- Provide whole family treatment throughout the length of time the youth is in residential treatment to strengthen the bonds that get broken when children are not living at home.
- Provide or link the family to services after the youth returns home from treatment.
- Help parents understand the treatment process and help them learn how to notice their child's progress as well as signs of relapse.
- Extend treatment to parents as well as youth.
- Work with families to help them set realistic boundaries and enforce the rules they can live with.

Offer services and programs that deal with youth in an individualized way and treat each youth as a total person and include the whole family in the healing process.

- Offer choices and include information about the benefits and risks associated with each one.
- Promote family-child interaction as core to treatment.
- Focus on the length of time the youth needs treatment instead of the length of time a family is able to pay for services or their insurance is willing to cover it.
- Combine substance abuse and mental health treatment-- only focus on one before the other if the drug use is so serious that youth cannot function.

Deliver usable and helpful information on illness, treatment, after care, and funding to youth as well as to parents.

- Have friendly staff available to answer questions at convenient times so families can ask their questions.
- Provide easy access to information.
- Develop information specific to “what to do if/when my child relapses” so parents, paraprofessionals, and clergy, listen and help them without treating them as a failure.
- Educate youth and parents on the effects and appropriate recommended dosage for prescription and non-prescription drugs.
- Include fathers especially; develop programs to inform and support fathers.
- Educate parents about the symptoms of abuse and the effects of drugs so they can provide information to their children and so they will recognize regression when it occurs.

Develop public awareness of mental health issues and positive models of treatment to disseminate in schools, to families, and through youth groups.

- Develop and disseminate press releases showing good-looking role models taking prescription medication for mental health needs.

### ***Recommendations for Family members***

Get involved and stay involved.

- Listen to what your child is saying. See it from their point of view, walk a moment in their shoes.
- Address substance abuse and mental health issues with your child at the same time. Insist that treatment programs address both. Know the treatment program, visit the program, and visit your child. Be there and be there often.
- Support your child in treatment and “hear” what they have to say about all their problems.
- Praise your son or daughter for making progress and watch for signs of regression – but remember regression is part of recovery.

- Participate in evaluating the program as well as your child's treatment.

Educate, educate, educate.

- Tell other parents about mental health/substance abuse issues and treatment.
- Offer what you know to other families who need your support and can benefit from your experience.
- Offer your child access to information, and assure that he/she has a voice in the decisions, that get made about treatment issues.
- Respect your child's and your own openness and readiness for disclosure.
- Read everything and ask for more.
- Ask other parents who have been through this. They know.

### ***Recommendations for Youth***

Speak up and be heard.

- Speak out about getting better – what is helping you and what you need to make progress.
- Ask your parents to be part of your treatment. Ask them to learn about the "treatment."

Get reliable information and share what you know.

- Educate your self on what prompts regression; know your own weaknesses.
- Know whom you can ask for help.
- Ask to mentor or help other young people with problems. They can benefit from what you have learned and what you have accomplished.
- Offer your expertise to treatment programs and share your observations with staff.

### ***Recommendations for SAMHSA***

Provide peer support

- Fund peer-to-peer youth outreach and network development.
- Fund family-to-family outreach and peer support activities.

Facilitate information dissemination

- ✧ Fund a multi-stakeholder process to identify information that is critically needed by youth and families.
- Fund family-run organizations to disseminate information in usable formats and using strategies that will get it to the people who need it most.

Support collaboration and integrated treatment

- Fund a multi-stakeholder process to promote collaboration between the substance abuse and mental health systems, agencies, and providers.
- Fund a multi-stakeholder process to develop and disseminate guidelines for providers to insure services for youth with co-occurring mental health and substance abuse disorders are fully integrated and effective.