
**LISTENING AND LEARNING FROM CAREGIVERS OF
YOUTH AND YOUNG ADULTS WITH SUBSTANCE USE PROBLEMS**



April 2016

ACKNOWLEDGEMENTS

Funding from the Maryland Department of Health and Mental Hygiene, Behavioral Health Administration

The Maryland Coalition of Families (MCF) is grateful to the following family leaders and advocates that assisted with the focus groups:

Valerie Albee, Mariah's Mission Fund of the Mid-Shore Community Foundation
Ramie Bruguera, Yes My Kid
Jacque Burrier, Project Hope
Lisa Lowe, Heroin Action Coalition
Carin Miller, Save Our Children
Ginger Rosela, Advocates for a Drug Free Calvert County
Toni Torsch, Daniel Carl Torsch Foundation/MD G.R,A,S,P.
Linda Williams, Addictions Connections Resources
Amy Young, Parents Affected by Addiction (PABA)

A special thanks to Nancy Rosen-Cohen and NCADD for assistance with this project.

AUTHORS

Ann Mahling Geddes, PhD, Director of Public Policy
Jane Plapinger, MPH, Executive Director
Maryland Coalition of Families

DEDICATION

This report is dedicated to the families who have faced the challenges of caring for a child with a substance use problem.

REPRODUCTION

The Coalition intends for this information to be disseminated widely.

When copying or quoting, please credit: Maryland Coalition of Families (MCF), April, 2016

This document was developed under a grant from the Maryland Department of Health and Mental Hygiene, Behavioral Health Administration. However, these contents do not necessarily represent the policy of the Maryland Department of Health and Mental Hygiene, and you should not assume endorsement by the State Government.

© 2016 Maryland Coalition of Families (MCF). All rights reserved.

TABLE OF CONTENTS

| | |
|--|----|
| Acknowledgements..... | 2 |
| The Maryland Coalition of Families (MCF) – Who We Are | 4 |
| Executive Summary | 5 |
| Methodology | 8 |
| Data..... | 10 |
| Feedback from the Focus Groups..... | 12 |
| Did a child’s age impact the family’s experience of obtaining needed help? | 12 |
| What were the greatest obstacles encountered by families in seeking help? | 12 |
| What did families find most helpful? | 16 |
| Recommendations of families..... | 18 |
| Conclusion | 21 |
| Appendix A | 22 |
| Appendix B | 25 |
| Appendix C | 26 |



The Maryland Coalition of Families (MCF) is the statewide family voice for families of children and adolescents with mental health, substance use and/or other behavioral health needs. We advocate for improving services in all systems of care for children, youth and families. We provide:

- Information and resources
- One-to-one family support
- Trainings
- Support groups
- Policy advocacy

Incorporated in 1999 as a private, nonprofit organization, MCF is Maryland’s Statewide Family Network Organization, a designation from the federal Substance Use and Mental Health Services Administration (SAMHSA). MCF is governed by a volunteer Board of Directors comprised of at least 51% adult caregivers of a child or adolescent with a diagnosable emotional or behavioral disability. All of our family support staff are parents who have cared for a child with behavioral health needs and have been trained to help other families.

WE BELIEVE

- Children and youth with behavioral health needs are valued and require individualized services to achieve their full potential.
- Families are a constant in a child’s life and should be equal partners in planning, implementation, monitoring and evaluation of services.
- Services for children, youth and their families are provided from a strength-based approach and are responsive to the needs of the whole child and entire family.
- Local and state systems of care should be family-driven and culturally and linguistically competent.

OUR VALUES

- Respect for the dignity and individual differences of each family and the rights of families to make decisions for their children
- Partnership with providers, policymakers, administrators and other advocacy organizations to improve systems of care for children and youth
- Responsibility to assist families with understandable, complete and accurate information
- Commitment to empower families through support, training and education
- Accountable to families, the community, and to funders for the performance of quality of services and supports provided by the Coalition

FOR INFORMATION CONTACT:

Maryland Coalition of Families (MCF)

10632 Little Patuxent Parkway, Suite 234, Columbia, Maryland 21044

410-730-8267, 1-888-607-3637 Toll Free, info@mdcoalition.org, www.mdcoalition.org

EXECUTIVE SUMMARY

In 2015, the Maryland Department of Health and Mental Hygiene awarded a grant to MCF to hold focus groups with caregivers of youth and young adults with a substance use problem to hear their experiences and elicit recommendations.

In the summer and autumn of 2015, MCF held ten focus groups with caregivers in different regions of the state. The locations were Bel Air, Towson, Columbia, Gaithersburg, Frederick, Westminster, Denton, Hughesville and Baltimore City. Two focus groups were held in Baltimore City, one for English speakers and one for Spanish speakers. Focus group participants were parents/caregivers who “are caring for or have cared for a child under age 26 with a substance use problem.” One hundred and eight caregivers attended the focus groups. Three questions were asked to facilitate discussion:

1. What were the greatest obstacles you encountered in seeking help for your child? Were they different when your child was under 18?
2. What did you find most helpful? Was there a difference when your child was under 18?
3. What recommendations would you make?

At the end of the focus groups families were asked to complete an 18 question survey (Appendix C).

With the exception of Baltimore City, recruitment for the focus groups was done largely through collaboration with groups dedicated to supporting youth with an opioid addiction and their families. The feedback from these focus groups was remarkably similar.

Recruitment for the two Baltimore City focus groups was done by MCF Family Navigators from the families with which they worked. Only two of the 20 families that participated in the Baltimore City focus groups had a child with an opioid problem, the others had children who used alcohol and/or marijuana. Because of the different composition of the groups, different themes emerged in the Baltimore City focus groups than in the other groups.

SUMMARY OF RECOMMENDATIONS

The families that attended the focus groups had very clear ideas about what needed to be done to improve the care of youth and young adults with substance use disorders, particularly those with opioid addictions. They also had strong ideas about substance use education, and about youth and family peer support.

One recommendation emerged in all ten focus groups, including those held in Baltimore City: the schools should provide more education about substance use to students as a means of prevention. This theme was universal.

The remaining recommendations listed below arose in the eight focus groups with primarily caregivers of a child with an opioid problem.

Education: Not only should schools provide more education to students, it would be particularly helpful if schools brought in young adults in recovery to present. Parents too need more education about the prevalence of substance use in their communities and the signs and symptoms to look for in the event their child is developing a substance use problem.

Coverage for Residential Treatment: Private insurance and/or the state should adequately cover the cost of residential treatment, particularly long-term residential treatment, so that families are not bankrupted, and so that there is not a great chasm between those who can afford to spend tens of thousands of dollars to cover the cost of residential treatment and those who cannot. Addiction is a disease, and should be treated as such. If insurers are violating the Mental Health Parity and Addiction Equity Act by refusing to cover more than a few days of residential treatment, they should be held accountable. Failing this, the state should provide residential treatment. Families should not be forced to have their child arrested in order to have the state cover the cost of intensive residential treatment services.

Availability of Treatment and Other Services: There should be more residential treatment beds available in Maryland, so that families can access treatment on demand. The moment when a youth with a substance use disorder agrees to seek help is critical and must be immediately capitalized on. Also, Maryland needs more long-term residential treatment programs. Families should not be forced to send their child out-of-state in order to access long-term residential treatment. The state should examine how to attract treatment centers that provide long-term residential treatment. Finally, there is a shortage of sober living houses.

Information: Families need an identified central place to go to get information on a broad range of questions, such as what treatment services are available on both a local and state-wide basis, how to access treatment, how to have treatment costs covered, how they might be included in their child's treatment after the age of 18, how to research out-of-state options, and what supports are available for themselves. Some health departments provide some of this information, but there is no one place that can address the full spectrum of issues faced by families.

Stigma: The stigma surrounding having a child with a substance use problem keeps some families from acknowledging that their child has a problem and from seeking treatment. The sense of blame and shame that accompanies having a child with a substance use problem isolates families and prevents them from seeking help. Education, including public service campaigns, need to be undertaken to convey the message that addiction is a disease that does not discriminate.

Health Insurance Portability Accountability Act (HIPAA): HIPAA can prevent families from advocating for their child or being involved in their child's treatment. Providers should be directed to encourage youth and young adults with a substance use problem to sign a release allowing communication with their families. They should not hold up HIPAA as an excuse to exclude families from involvement in their child's care.

Peer-to-Peer Support: AA/NA and Alanon/Naranon are not sufficient to meet the needs of youth and families. For youth, more intense peer support in their communities from youth of comparable age, and peer support in emergency rooms, would fill a critical gap. For families, more family peer-to-peer support group options as well as family peer-to-peer navigation services would allow them to better help their children and better support their own needs.

METHODOLOGY

In the summer and autumn of 2015, MCF held ten focus groups with caregivers in different regions of the state. The locations were Bel Air, Towson, Columbia, Gaithersburg, Frederick, Westminster, Denton, Hughesville and Baltimore City. Two focus groups were held in Baltimore City, one for English speakers and one for Spanish speakers. All focus group participants were parents/caregivers “who are caring for or have cared for a child under age 26 with a substance use problem. A total of 108 caregivers attended the focus groups, representing 103 youth and young adults. A \$40 stipend was provided to one caregiver per family. Three questions were asked to facilitate discussion in the focus groups:

1. What were the greatest obstacles you encountered in seeking help for your child? Were they different when your child was under 18?
2. What did you find most helpful? Was there a difference when your child was under 18?
3. What recommendations would you make?

A facilitator moderated the groups while a note taker recorded what was said. The sessions were also taped. At the conclusion of each focus group, families were asked to complete an 18-question survey (Appendix C).

Recruitment for the focus groups was done in three ways:

1. A notice of the upcoming focus groups was sent out in an email and in MCF’s Newsletter to our Constant Contact distribution list of 2,500 names. It was also posted on our web site
2. MCF staff recruited caregivers from families that they worked with
3. MCF partnered with various family groups for caregivers of youth with a substance use disorder to disseminate information about the focus groups

By far the most successful method of recruitment was the partnerships that MCF formed with groups for caregivers of youth with a substance use disorder. The following is a list of the organizations that MCF partnered with:

- Addictions Connections Resources (Harford and Cecil Counties)
- Advocates for a Drug Free Calvert County (Calvert County)
- Daniel Carl Torsch Foundation/MD G.R.A.S.P. (Grief Recovery After Substance Use Passing) (Baltimore County)
- Heroin Action Coalition (Montgomery County)
- Mariah’s Mission Fund of the Mid-Shore Community Foundation (Anne Arundel, Caroline, Dorchester, Kent, Queen Anne’s and Talbot Counties)
- Project Hope (Frederick and Washington Counties)
- Parents Affected by Addiction (PABA) (St. Mary’s, Calvert and Charles Counties)
- Save Our Children (Frederick County)
- Yes My Kid (Carroll and Howard Counties)

All of these groups are composed largely of families of youth with an opioid problem. Seventy-four percent of focus group participants reported that their child used opioids (primarily heroin); most youth were described by their caregivers as addicted. Sixteen percent of participants had

lost a child to substance use. Given the current opioid epidemic and startling opioid overdose statistics in Maryland, the feedback given by families of youth who used opioids is critical to understanding what might be done to improve this tragic situation.

While most of the focus group participants across the state came from the family groups referenced above, recruitment for the two Baltimore City focus groups was done largely by Baltimore City MCF family navigation staff from the families with which they worked. Because the recruitment method was different, the make-up of the participants differed from those in the other focus groups. Of the 20 families that participated in the Baltimore City focus groups, only two had a child with an opioid problem; the other families (including the six Spanish-speaking families) reported that their child used marijuana and alcohol.ⁱ

Since the make-up of the Baltimore City focus groups differed from the other groups, most of the themes that emerged were different.ⁱⁱ One shared theme, however, was the importance of education in the schools for prevention.

DATA

Geographical Distribution

Participants of the focus groups came from 17 Maryland jurisdictions:

| | |
|----------------------------------|-----|
| Baltimore City | 19% |
| Southern Maryland ⁱⁱⁱ | 13% |
| Eastern Shore ^{iv} | 11% |
| Baltimore County | 11% |
| Carroll County | 11% |
| Harford County | 11% |
| Montgomery County | 9% |
| Frederick County | 8% |
| Howard County | 7% |

Gender

Two-thirds of the children of focus group participants were male; one-third were female. This is fairly consistent with national studies. The 2013 National Survey on Drug Use and Health indicated that 12% of American males age 12 and older were currently using illegal drugs, compared with just over 7.3% of females in the same age group.

Age

The average age of onset (“At what age did your child first exhibit symptoms of using substances?”) was 15.7 years. There was a significant delay between age of onset and the age at which caregivers sought help for their child, which was 17.5 years. Some families explained that they initially felt that their child was engaging in typical youth experimentation with substances before realizing that there was a serious problem that needed to be addressed. Other families spoke of spending time in denial because they did not want to believe that their child had a substance use problem.

Mental Health

81% of the youth had a mental health diagnosis. Moreover, most youth had multiple mental health diagnoses. The following diagnoses were the most prevalent:

| | |
|-------------------------------------|----|
| Depression | 54 |
| Anxiety Disorder (D/O) | 43 |
| Attention Deficit/Hyperactivity D/O | 37 |
| Bipolar D/O | 19 |
| Post-Traumatic Stress D/O | 15 |
| Mood D/O | 14 |
| Obsessive/Compulsive D/O | 13 |
| Self-injurious behavior | 13 |
| Oppositional Defiant D/O | 11 |

Involvement with other youth-serving systems

Twenty-nine percent (29%) of the youth had either an IEP or a 504 plan when they were in school. The high rate of youth in special education probably results in part from the fact that so many had a mental health diagnosis.

Thirty-six percent (36%) of the youth had been involved with the Department of Juvenile Services. Fifty-one percent (51%) had been involved with adult corrections.

Substances of Use

As was stated previously, youth who used opioids were heavily represented in the focus groups. While the statistics from the focus groups do not reflect the general statistics of substances of use by youth and young adults in Maryland, the results give some indication of the popularity of various substances:

| | |
|---------------------|----|
| Marijuana | 73 |
| Heroin | 66 |
| Alcohol | 61 |
| Oxycontin/codone | 55 |
| Percocet | 46 |
| Cocaine | 37 |
| Xanax | 30 |
| Vicodin | 29 |
| Synthetic Marijuana | 19 |
| Hallucinogens | 18 |
| Inhalants | 14 |

Extent of Use

Families were asked on the focus group questionnaire the extent to which their child was using substances. There were three options: experimenting, using regularly and dependent. Because of the high number of opioid users, the number for “dependent” was quite high - 68%. Eight percent (8%) said that their child was using regularly and 11% said that their child was experimenting with substances. The percentages do not total 100% since some family members did not answer this question.

Residential Substance Use Treatment

Again, probably because of the high number of youth who abused opioids, many had been in residential treatment. Fifty-two (50%) of the youth had been in short-term residential treatment, and 32 (31%) had been in long-term residential treatment. Many had been in both. The terms “long-term” and “short-term” were not prescribed, but left for the families to define. Many families stated that their child had been in residential treatment multiple times.

Many families - 38% - sent their child out of state for residential treatment. Almost all of the families who reported that their child had been in long-term residential treatment received treatment outside of the state. Florida was most frequently cited, by 14 families. Pennsylvania was next with a total of 10. Multiple other states across the country were named, including: California, New Jersey, Texas, Virginia, Illinois, Nevada, Arizona, Utah, Washington, New York, Kentucky, South Carolina and North Carolina.

FEEDBACK FROM THE FOCUS GROUPS

DID A CHILD'S AGE IMPACT THE FAMILY'S EXPERIENCE OF OBTAINING NEEDED HELP?

In the focus groups families were asked to what extent their experiences differed before versus after their child turned 18. This question did not elicit many responses. Since the average age at which families sought treatment for their child was 17.5 years, the question did not apply to a number of families. Those who did answer the question spoke primarily about the Health Insurance Portability and Accountability Act (HIPAA), and the fact that they were not allowed to participate in their child's treatment to the same extent that they had before their child turned 18.

A few families, however, spoke of a scarcity of services for adolescents:

"There was nothing in Maryland for him. He was 16 at the time."

"There are not enough resources for adolescents – not inpatient or outpatient."

"Need expanded services for juveniles."

Yet families of youth over the age of 18 also pointed to a shortage of services. Except for the problems with HIPAA, the focus groups did not yield a significant number of detailed responses to enable a discussion of the differences in treatment for those under or over the age of 18.

WHAT WERE THE GREATEST OBSTACLES ENCOUNTERED BY FAMILIES IN SEEKING HELP?

Families were asked what obstacles they encountered when seeking help for their child. The barriers discussed broadly fell into five categories. In rank order from most to least frequently encountered obstacles:

1. Insurance and out-of-pocket costs
2. Availability of treatment services in Maryland
3. Lack of information
4. Stigma
5. HIPAA

Obstacle #1: Insurance and Out-of-Pocket Costs

The majority of families that participated in the focus groups had private insurance. When asked what were the greatest obstacles they encountered when trying to access help for their child, by far the most frequent response was limited insurance coverage, and being overwhelmed by out-of-pocket costs. Families reported that while it was relatively easy to get approval and coverage for outpatient programs, getting approval for residential treatment was extremely onerous, and the approval was rarely for more than a few days. This varied somewhat from insurance plan to insurance plan, yet even those with the best insurance coverage could only access residential treatment for 28 days – which families felt was insufficient for opioid addiction. Most insurance companies offered just 7 to 14 days of residential treatment, and then only if a youth had failed at an outpatient treatment program first.

“Insurance has been the biggest problem. They wanted him to do day treatment before residential treatment.”

“The most insurance would approve was 7 or 10 days.”

Owing to the limited insurance coverage for residential treatment, many families incurred tremendous out-of-pocket costs in order to access inpatient treatment.

“Private insurance denied almost all treatment at all levels. I spent \$65,000 using private facilities.”

“We spent all the money we would have used to send him to college. We could have sent him to Harvard with the money we spent.”

When discussing the problems of getting insurance to pay for their child’s treatment, families frequently made the comparison that they would not have the same problem if their child had a somatic health care problem. They argued that substance use disorders are a disease and should be treated on par with other diseases by insurance companies.

“If you have cancer, they’re not going to cut off your treatment after seven days.”

“It’s a disease. It should be treated as a disease.”

“With cancer and other medical illness, they treat you until the end of your disease – they don’t do that with addiction, because they don’t realize it’s a disease.”

Families that had Medicaid did not identify access issues as a problem. In part this may have been due to the fact that most families who had Medicaid did not have children with opioid addictions, and were not seeking residential treatment. Yet even families that did want to access residential treatment reported that it was easier to do so if their child had Medicaid.

“Private insurance paid some. Then he became a ward of the state to get Medicaid for short- and long-term residential.”

“They wouldn’t take my son because he had private insurance, but they would’ve accepted him if he had Medicaid.”

The failure of insurance companies to pay for long-term residential treatment was especially burdensome to families of youth with opioid problems, who repeatedly spoke of the need for long-term treatment.

“These 30 day programs, they are just not enough.”

“Treatment for heroin addiction needs to be a minimum of one year.”

Hence many families spent tens of thousands of dollars out-of-pocket to pay for long-term residential care.

Obstacle #2: Availability of Treatment Services in Maryland

Not only would insurers not pay for long-term residential treatment, families said that there were next to no long-term residential treatment programs in Maryland, so they had to send their child out-of-state to access these services. It was cited above that 38% of families had sent their child out-of-state for treatment, to a total of 15 different states.

“So many parents’ kids are out-of-state, because that’s where the resources are – not here. All the resources are out-of-state.”

“There is one place in Maryland that does long-term treatment. They have 18 beds.”

Families also repeatedly noted a shortage of sober living residences in Maryland.

“There are not enough sober living houses for when they come out of rehab.”

“We need state-funded sober living houses.”

There were shortages of other treatment resources as well that resulted in a delay in being able to access treatment.

“I called the Health Department and the wait time was six days before he could just get an intake.”

“If you find a rehab they will tell you that you have to wait for a bed.”

Families felt that the moment when their child agreed to treatment was critical and needed to be capitalized on immediately.

“When an addict asks for help, you have to move quickly.”

“The day you convince them to go is so critical – they need to go that day.”

A lack of long-term residential treatment programs, a shortage of sober living facilities, and the inability to access treatment on demand all posed significant barriers to getting necessary help.

Obstacle #3: Lack of Information

Families described their challenges trying to learn about available resources, the array of services, insurance, and how to advocate for their child. This theme was repeated again and again in the focus groups.

“From the parents I talk to, the biggest frustration is that when they find out their child is struggling with substance abuse, they have no idea where to go to get help.”

“The greatest obstacle in seeking help was trying to determine what options were available in terms of treatment.”

A solution to this problem was proposed many times:

“There needs to be a central place where parents can get information.”

“There should be one or two places where a parent can call to get help for their addict child.”

Families wanted a broader array of information than what was available from their local health department. In the absence of such a resource, they relied on the knowledge of other family members who had the lived experience of caring for a child with a substance use problem. Finding such a person was a matter of happenstance.

Obstacle #4: Stigma

A number of families stated that because of the stigma associated with substance use, they were reluctant to admit that their child had a problem, especially publicly.

“I think substance abuse is an issue that is much, much more common than most people think, but is often hidden because as parents we feel like failures. It’s hard to admit.”

“There’s too much stigma attached to this stuff – ‘it’s not my kid.’”

Not only were families impacted by stigma – it had a broader reach.

“The principals are hiding it. Another kid dies, but you hear nothing about it from anyone but your children.”

“We are a society in denial. The public schools are in total denial. Public officials want our counties to look beautiful.”

Families attributed stigma to the lack of education about substance use. Educating the public, officials, educators and parents about addiction as a disease that does not discriminate would do much to reduce stigma.

“We need education on shame, and advertisements to change the way people think about drugs.”

“Addiction is a disease, not a drug problem.”

There also emerged a broader theme about education not only to reduce stigma, but as a preventative measure. This will be discussed in greater detail in the section on recommendations.

Obstacle #5: The Health Insurance Portability and Accountability Act (HIPAA)

Some families thought that HIPAA was the greatest barrier that prevented them from helping their adult child. Insurance companies and providers refused to talk with them or provide them with any information. They felt that providers hid behind HIPAA to exclude them from participating in their child's treatment, and that providers did not encourage the youth to sign a release allowing communication. When asked if she was included in her child's treatment one mother answered:

"No, since he was over 18 (though he was unemployed, living in my home and was on my insurance with me paying the co-pays.)"

Yet many families of youth over the age of 18 spoke of being included:

"The recovery center had once a week family meetings, were available to talk with us if we called, and the half-way house was very open with communication."

"It depended on the treatment facility. Most were receptive as long as my son agreed to have me involved."

Families were fairly evenly divided when asked whether or not they were included in their child's treatment after the age of 18. While HIPAA presents an obstacle, it clearly is not insurmountable if providers promote family involvement.

WHAT DID FAMILIES FIND MOST HELPFUL?

While families had a wealth of things to say about the obstacles they encountered, there were fewer responses when asked about what they had found helpful. Very few said AA/NA or Alanon/Naranon. Some families specifically mentioned that drugs were sold at certain NA meetings, and that young women frequently were preyed upon. They also spoke of the significant age difference between their child and most AA/NA members as creating an obstacle. It should be noted, however, that a few families had positive things to say.

"Naranon saved me."

"AA and NA can work."

Families also spoke about specific programs as being particularly helpful.

"He is in a good half-way house in long-term care. It provides structure and camaraderie."

"A recovery club in Baltimore. They have picnics and functions. He loves it. He will not leave Baltimore City because he will not leave his recovery club."

A number of families had positive things to say about their child's involvement with the justice system:

“DJS was awesome. When we got him into the juvenile system, they got him into the drug court program.”

“I had him emergency petitioned. DJS took off with it. His caregiver was very helpful. She had him set up to go to a half-way house. She made all the calls. They were a great help for me.”

“Having my kid in jail was helpful...after he got out of jail they sent him to a long-term treatment facility.”

Not all families, however, felt that the justice system had been helpful:

“I would suggest that the DJS agency be completely updated and redone. It is broken and only does more harm than good.”

“The courts were not helpful.”

On balance, more families had positive things to say about the justice system than negative. In fact, it was seen as a vehicle to access treatment services.

“Two different people at two different agencies recommended that I place drugs on her and have her arrested.”

“You have to get the law involved if you want services.”

It is unfortunate that legal involvement was viewed as a means of accessing otherwise unavailable treatment.

Finally, families described grassroots family peer support organizations as providing the most help to them.

“Other parents dealing with addicted children. They have been more valuable a resource than anything. I’ve educated myself more through my peers than through people who ought to know.”

Currently, there are a number of grassroots substance use family organizations. As stated earlier, members of these groups are primarily families of a child with a heroin addiction. The groups engage in various functions – fundraising for treatment scholarships, education/awareness activities, support groups, and legislative advocacy. A number of the members of these groups also provide family navigation services. They are caregivers with lived experience caring for a child with an addiction who volunteer their time to assist other families. They have learned through experience how to navigate the maze of insurance, access treatment and other available resources, and share their knowledge. These groups were mentioned again and again as having been the most helpful support for families.

RECOMMENDATIONS OF FAMILIES

Some of the recommendations that came up over the course of the focus groups have already been addressed – better insurance coverage for residential treatment, especially long-term treatment; greater accessibility in-state to long-term residential treatment; more treatment beds in order to provide treatment on demand; more sober living houses; a single point of contact for families that would respond to all types of questions about accessing help; and greater public education to address stigma.

Two other important recommendations emerged over the course of the focus groups. The first was better education regarding substance use – of youth, of families, of communities. The second was expanded peer support, both for youth and for their families.

Education: In all of the focus groups, the topic arose that schools should provide better education about substance use. Families felt that there was a significant gap in what was needed and what was being provided. Better education in the schools would be the most effective means of prevention.

“We need more money for educational assemblies at schools.”

“There needs to be more education in the public schools for prevention.”

A number of families suggested that education be provided to students by youth in recovery from substance use.

“Need meaningful education. Not the same old stuff. Need real youth that have lived it and come out the other side.”

“Bring recovering addicts in to speak – people that are in recovery and in their age group.”

Not only did families speak about the education of youth, they talked about the need for parent education.

“Please if we could get more education for parents.”

“Should somehow make it mandatory that the parents and the kids know what’s going on. Do some kind of assembly.”

Families spoke about their initial ignorance of the extent of the drug problem in their communities. Many regretted that they didn’t know more about the possible signs of substance use, particularly of opioid use. They said that they probably would not have sought out the information, assuming that substance use, particularly opioid use, would not be an issue for their child, so the information must be provided to parents in a broad way, such as at back-to-school nights, in mandatory assemblies, or in public information broadcasts.

Finally, families spoke of the resistance of schools to addressing the topic of substance use. Families in two different communities related that the schools had rejected their attempts to bring in education to both youth and families. They perceived that the schools were either in a state of denial, or did not want to endorse the fact that illicit substances were a problem in their communities owing to stigma.

Peer Support: Peer support is a cornerstone of both Alcoholics Anonymous and Narcotics Anonymous, as well as Alanon and Naranon, but families were looking for more. For both the youth with a substance use problem and their parents/caregivers, further peer supports were recommended.

Families expressed a need for youth peer recovery specialists in their communities.

“Need youth in successful recovery to talk to people struggling with addiction.”

“Train young people to become peer recovery coaches - not counselors; not sponsors. Follow someone for a year, sort of like a case manager.”

Families suggested that there needed to be peer recovery coaches who would connect with youth when they were in the hospital.

“A peer recovery person working in the ER would help...they should be addicts.”

“Need increased funding for peer support specialists to work in the hospitals.”

Families mentioned that such programs already exist in certain hospitals, but only a few. Instead, in many instances when a youth was brought to a hospital (often after overdosing), families felt that the ERs acted judgmentally, provided no support, and strove to get the young person discharged as quickly as possible. Families recommended a wide-scale expansion of peer support programs in ERs, along with on-going peer support in the community.

Not only do youth struggling with substance use problems need peer support, family members need it as well.

“It is also important for the addict’s parents and siblings to get help through support groups.”

But many families expressed that they had needed more than support groups; they needed help navigating all of the complex issues they encountered in trying to access help for their child. They reported having received this help from family peer-to-peer support.

“Find the persons who’s a few years ahead of you. They help.”

“Getting out of this is best done by people who have been there.”

“Parents are calling us all the time. ‘Where can I go?’ ‘What can I do?’”

As previously mentioned, there are a number of grassroots substance use family organizations. Some of these groups have members who provide family navigation services. These people are caregivers with lived experience caring for a child with a substance use disorder who assist other families. They have learned through experience how to navigate the multitude of complex issues that families face, and they provide assistance, along with emotional support. Families expressed a need for more of this service.

“We need to have family navigators and peer specialists throughout Maryland.”

“Ideally we’d have paid peer support.”

Maryland has a history of providing peer-to-peer support to adults with mental health disorders and family-to-family peer support to families caring for a child with mental health problems. Families of youth with substance use disorders need and want similar supports.

CONCLUSION

Family voice is critical to better addressing the problems that families encounter. Hence the value of focus groups. From this series of focus groups, it is clear that families of youth and young adults with substance use disorders have very specific ideas of what needs to be done to better support themselves and their child.

- better insurance coverage for residential treatment, especially long-term residential treatment
- greater accessibility of in-state long-term residential treatment
- more treatment beds in order to provide treatment on demand
- more sober living houses
- a single point of contact for families that would respond to all types of questions about accessing help
- better education, of students, parents and the public at large
- greater involvement of families in a youth's treatment by providers
- expanded youth peer support
- greater access to family peer support and navigation services

Families are eager to partner with policy-makers, government officials, providers and other stakeholders to better meet the needs of youth and young adults with substance use disorders and their families.

APPENDIX A

While select quotes were included in the report to illustrate the most common themes, here are additional quotes for a fuller understanding of the experiences and perspectives of families.

INSURANCE AND OUT-OF-POCKET COSTS:

“My insurance does not want to pay after 3-7 days.”

“My insurance only allows for 14 days in rehab and then they kick you out.”

“They said that she was not bad enough to go to rehab...The greatest obstacle was getting my daughter into treatment when I thought she needed to be – before things got really bad.”

“You have to fail at outpatient before you can try inpatient.”

“If you have cancer and need chemotherapy, they don’t approve you for just two treatments.”

“I’ve never gone through a bigger struggle than I went through with insurance companies when trying to get substance use services for my child. They choose what they want to cover and what they don’t want to cover, and I found out they can change their minds at any time and stop services.”

“The financial piece was a huge part of it. We invested over \$100,000 over the course of three or four years now in rehabilitation centers.”

AVAILABILITY OF TREATMENT SERVICES IN MARYLAND

“Rehabs are not long enough – they need to be longer.”

“Rehab – point blank – needs to be longer.”

“Need long-term treatment centers – 12 months or more.”

“By long-term I mean like a year.”

“We need more inpatient facilities that are at a minimum three to six months.”

“California, Florida and Arizona have numerous established treatment centers and recovery sober housing. Why can’t Maryland?”

“There is a sober living house in Charles County, but it is male only and there are only four beds.”

“We need more sober houses.”

“There are not enough licensed sober living houses. Anyone can open one. It is a huge business.”

“There is a lack of services for women – sober living houses, homeless shelters.”

“Need immediate treatment: within 36 hours.”

“So often their children are ready to go and they can’t find a place for them.”

“If they are ready, you need to strike when the iron is hot...they should have a place where they can stay that is like the ER.”

LACK OF INFORMATION

“I had no idea who to contact and how to advocate for my child.”

“I did everything in my power. I reached out everywhere. I was in the dark, and I had no idea where to go to get help.”

“The hardest part was finding the resources. There doesn’t seem to be a central place to even go.”

“There needs to be a main resource for people to go to in the tri-county area.”

STIGMA

“A major problem is the shame that is caused by addiction.”

“I kind of had my head in the sand.”

“When my son died, my husband was embarrassed because his son died of an overdose.”

“Address the shame with education.”

“It’s like the AIDS epidemic – nobody’s going to hear us until somebody big helps out.”

EDUCATION

“There should be drug education in the schools taught by a former drug user.”

“Parent education is needed.”

“The public school systems and the parents need to be better educated.”

“Whatever can be done to educate parents.”

PEER SUPPORT

“Need a peer recovery coach on-line 24/7.”

“Need youth support in each county.”

“Have peer support available in ERs.”

APPENDIX B

A NOTE ON MEDICATION ASSISTED TREATMENT (MAT)

Since MAT currently is a much-discussed topic, the following question was included on the survey that focus group participants were asked to fill out: Do you have an opinion about medication assisted treatment for opioid addiction?

As expected, opinions were divided. The majority were in opposition. Many focus group participants had very strong opinions about MAT – both negative and positive.

1. There was a group of family members that supported some forms of MAT, but not others. Methadone especially was singled out as a bad option. Suboxone too was often maligned, while most felt that Vivitrol was ok.
2. There was a group of family members that opposed MAT on the basis that it didn't work – their child had tried it and failed, sometimes having abused it.
3. The most frequent response in opposition was: "It's just giving up one addiction for another."
4. A number of families said that they supported MAT under certain conditions, such as in conjunction with other treatment, and/or in the short-term, and with reputable providers.
5. There was a significant contingent of families that spoke in favor of MAT because it had helped their child.
6. Some families spoke of their child being on MAT, either methadone or suboxone, for the long-term, and credited it not only with keeping their child off of heroin, but also with allowing them to live full and productive lives.

MAT clearly is a controversial topic. One family member referred to the history of over-prescription of opioid medications by physicians, which led to so many people becoming addicted to opioids, and said:

"Parents are somewhat reluctant to trust the medical community...it is the same pharmaceutical/medical community, spending millions on lobbying to protect profit margins, that now is promoting MAT."

Providers, agencies and advocates must respect that families have very diverse perspectives on MAT, ranging from positive experiences to wariness or outright opposition. While it is ultimately the decision of a young person about whether or not to pursue MAT, there should be sensitivity shown to the concerns of families.

APPENDIX C

SUBSTANCE USE SURVEY COMPLETED BY FOCUS GROUP PARTICIPANTS

1. Where do you live?

- Allegany County _____
- Anne Arundel County _____
- Baltimore County _____
- Baltimore City _____
- Calvert County _____
- Caroline County _____
- Carroll County _____
- Cecil County _____
- Charles County _____
- Dorchester County _____
- Frederick County _____
- Garrett County _____
- Harford County _____
- Howard County _____
- Kent County _____
- Montgomery County _____
- Prince George's County _____
- Queen Anne's County _____
- St. Mary's County _____
- Somerset County _____
- Talbot County _____
- Washington County _____
- Wicomico County _____
- Worcester County _____

2. Please indicate your child's gender:

Male _____ Female _____ Transgender _____

3. At what age did your child first exhibit symptoms of using substances? _____

4. At what age did you first seek help for your child's substance use? _____

5. Where did you first go to seek help for your child's substance use problem?

6. Does/did your child have a mental health diagnosis (diagnoses)? Check all that apply.

Anxiety disorder _____ Self-injurious behavior _____ Personality Disorder _____
PTSD _____ Mood disorder (other than _____ Schizophrenia _____
Attention-deficit bipolar or depression) _____ Other psychotic disorder _____

Disorder (ADHD) _____ Obsessive Compulsive (psychotic disorder NOS) _____
 Bipolar disorder _____ Disorder _____ Oppositional Defiant
 Depression _____ Conduct Disorder _____ Disorder _____
 Eating disorder _____ Other (please specify) _____

7. Has your child ever had an Individualized Education Program (IEP) or a 504 Plan?

Yes _____ No _____

8. Has your child ever been involved with juvenile services?

Yes _____ No _____

9. Has your child ever been involved with adult corrections?

Yes _____ No _____

10. What substances does/did your child abuse? Check all that apply.

| | | |
|--|---------------------|---------------------------|
| | | <u>Prescription Drugs</u> |
| Alcohol _____ | Marijuana _____ | Oxycontin/codone _____ |
| Synthetic Marijuana (eg. "Spice" "K-2") _____ | Salvia _____ | Xanax _____ |
| Inhalants _____ | Hallucinogens _____ | Vicodin _____ |
| Heroin _____ | Cocaine _____ | Suboxone _____ |
| | Other _____ | Adderall _____ |
| | | Valium _____ |
| | | Percocet _____ |
| | | Ambien _____ |
| | | Fentanyl _____ |
| | | Klonopin _____ |
| | | Other _____ |

11. How severe is/was your child's use of substances?

Experimenting with drugs/alcohol _____

Using regularly _____

Dependent upon drugs/alcohol _____

12. Did you lose your child to substance use? _____

13. Has your child ever received treatment for substance use ? Check all that apply.

| | | |
|-------------------------------|-----------------------------------|--|
| Individual counseling _____ | Detox _____ | Medication Assisted Treatment _____ |
| School counseling _____ | Residential (short term) _____ | AA or NA _____ |
| Outpatient _____ | Residential (Long term) _____ | Half-way/Sober Living House _____ |
| Intensive Outpatient _____ | | |
| Partial Hospitalization _____ | | |

(If your child has experienced one particular treatment service multiple times, please note how many times)

14. Did your child receive treatment out-of-state?

Yes _____ No _____
If yes, where? _____

15. Please explain who covered the cost of your child's treatments (Medicaid, private insurance, private pay) for various treatment services.

16. Did you feel that you were included as a partner in your child's treatment for substance use?

Yes _____ No _____
Please explain.

17. Do you have an opinion on Medication Assisted Treatment for opiate addiction? (eg. Suboxone, Methadone). If yes, please explain.

18. What else would you like to tell us?

Thank You

i Of the 103 youth represented in the focus groups, 66 had used heroin (often with other opioids) and 10 had used other opioids but not heroin. Most were described by their caregivers as addicted. The remaining 27 youth used substances other than opioids – 18 of them came from Baltimore City.

ii In the Baltimore City Spanish-speaking focus group, families primarily were concerned that there weren't enough resources for the Latino community. In the English-speaking group, the major concern of families was their inability to compel their child to engage in treatment after the youth turned 18.

iii Calvert, Charles, St. Mary's and Prince Georges Counties

iv Cecil, Queen Anne's, Caroline, Wicomico and Talbot Counties