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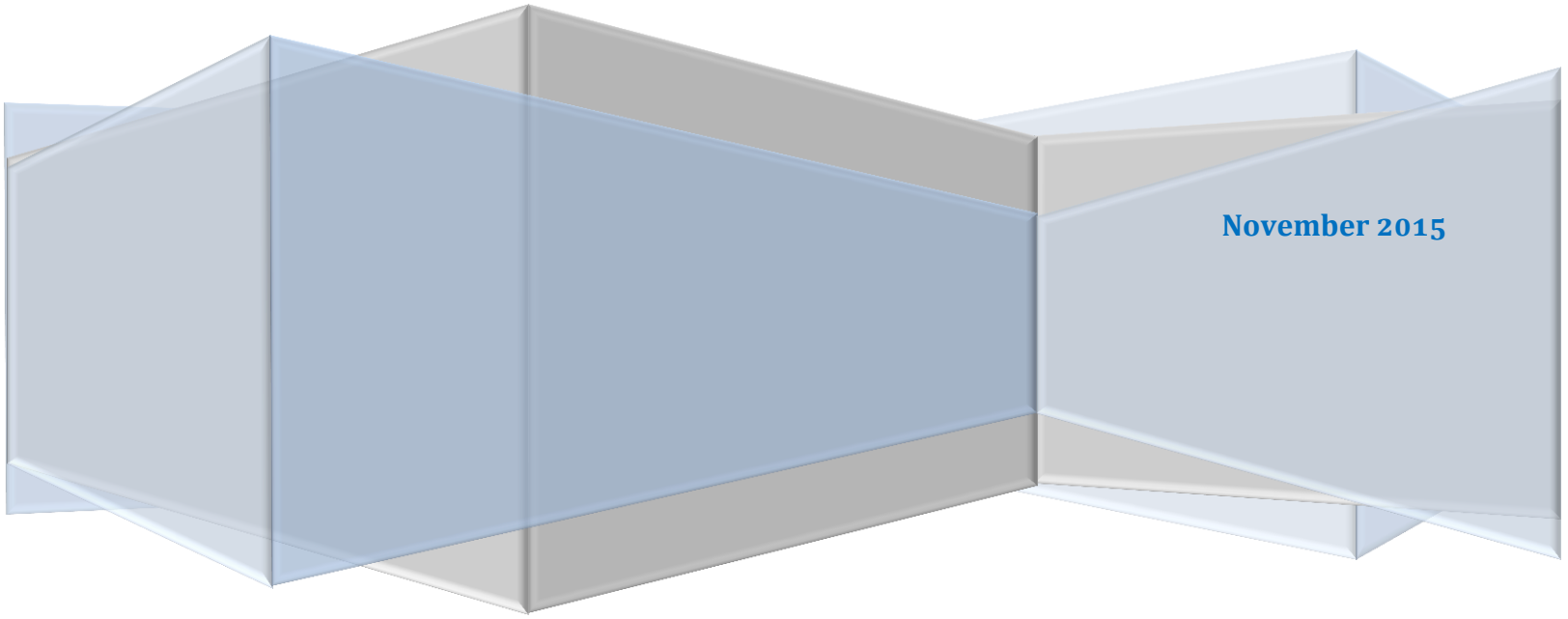
BEHAVIORAL HEALTH INTEGRATION AND FAMILY-RUN ORGANIZATIONS

A Survey Conducted by FREDLA

Family-Run Executive Director Leadership Association



November 2015

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INTRODUCTION

Data

According to 2012 National Survey on Drug Use and Health (NSDUH) H-47: Mental Health Findings,[i] an estimated 1.3 million U.S. adolescents ages 12 to 17 had a substance use disorder in 2014 (5% of all adolescents). The 2014 rate of past-month illicit drug use was:

- 3.4% among those ages 12 to 13
- 7.9% among youth ages 14 to 15
- 16.5% among youth ages 16 to 17.

The highest rate of current illicit drug use was among youth ages 18 to 20 (22.7%), with the next highest rate occurring among people ages 21 to 25 (21.5%).

Adolescents and young adults also face challenges with mental health issues. In 2014, about 1 in 10 youth ages 12 to 17 (11.4%) had a major depressive episode (MDE) in the past year. Among adolescents with MDE, 41.2% received treatment or counseling for depression in the past year. Combined 2010–2012 data from SAMHSA's National Survey on Drug Use and Health (NSDUH) indicate that 1 in 5 young adults ages 18 to 25 (18.7%) reported a mental illness in the past year and 3.9% were diagnosed with a serious mental illness. In 2014, 1.4% of adolescents had a co-occurring MDE and a substance use disorder.

Integration of Mental Health and Substance Abuse

Across the country, mental health and substance use administrations, funding and services are being integrated into one behavioral health system. Traditionally these systems have been siloed and had separate funding streams, workforces with very different training and qualifications, and separate sets of providers.

Systems Integration involves the development of infrastructure within mental health and substance abuse systems to support integrated service delivery. Mergers between state-level mental health and substance abuse administrations, as well as mergers between treatment providers and trade groups are changing the landscape of the field.

The federal Substance Abuse and Mental Health Services Administration (SAMHSA) supports integrated treatment for co-occurring disorders. Through SAMHSA grants, publications, technical assistance and support, SAMHSA has promoted integration at the state, community and agency levels. An article in Behavioral Healthcare[ii] states that, "In 2011, SAMHSA began to focus on 'behavioral health.' And, although a statutory change would be required by Congress before it could happen, the idea of 'blending' the federal block grants for substance abuse and mental health continued to swirl, both in the offices of state directors of those funds and at SAMHSA."

Family-Run Organizations

Starting in the 1980's family-run organizations grew out of children's mental health systems of care for children with mental health needs. Presently, there are about 120 local and state family-run organizations. These organizations are characterized by three features: a board of directors that is more than 50% family members with lived experience as the primary caregiver for a child with mental health needs; an executive director and direct service staff that are family members with lived experience; and, an organizational mission focused on supporting families caring for a child with mental health needs.

The changing landscape with the integration or merger of mental health and substance abuse is bringing into focus the need for family organizations to consider how to position their organizations in light of these changes. To better inform the field, FREDLA conducted a survey of family organizations on whether they currently serve or plan to serve the population of families caring for an adolescent or young adult with substance use disorders.

Acknowledgements

FREDLA is grateful to the family leaders who completed the survey. This survey was conducted without the use of any federal or state funds and does not reflect the views, opinions or polices of HHS, SAMHSA or CMHS.

Federation of Families for Children's Mental Health ~ Colorado Chapter, Colorado
Keys for Networking, Kansas
Parent Support Network of Rhode Island, Rhode Island
Wisconsin Family Ties, Wisconsin
Families as Allies, Mississippi
Texas Family Voice Network/TX System of Care, Texas
Families ASAP, New Mexico
Federation of Families of SC, South Carolina
Federation of Families Miami-Dade Chapter, Florida
Youth & Family Peer Support Alliance, Illinois
G.E.A.R. Parent Network, Maine
Association for Children's Mental Health, Michigan
UPLIFT, Wyoming
Tennessee Voices for Children, Tennessee
Oregon Family Support Network, Oregon
Parent/Professional Advocacy League, Massachusetts
National Family Dialogue, Minnesota
Georgia Parent Support Network, Georgia
Family Involvement Center, Arizona
Family Support Organization of Burlington County, New Jersey
Total Family Care Coalition, District of Columbia
Family Based Services Association of NJ, New Jersey
The Maryland Coalition of Families for Children's Mental Health, Maryland
MIKID, Arizona
Kentucky Partnership for Families and Children, Inc., Kentucky
The Family Cafe, Inc., Florida
Alaska Youth and Family Network, Alaska
North Carolina Families United, North Carolina
Allegheny Family Network, Pennsylvania
F.A.C.T., Missouri
Families United Network at Parsons, New York

Survey

In October 2015, FREDLA conducted a ten-question online survey sent to a list serve of 120 family-run organizations. A total of 31 family-run organizations responded to the survey (25.8% response rate). Of the organizations responding to the survey, 20 were state organizations and 11 were local family-run organizations. The following report provides a summary of the survey responses for questions 2-10. The first question of the survey pertained to the name and location of the organization.

Q 2. Has your Board of Directors discussed behavioral health integration? (n=28)

Non-profit boards of family-run organizations are responsible for determining and carrying out the organization's mission, planning and setting policy. Decisions about expanding services begin with the board of directors based on needs reported by the families served by the organization.

The majority of the organizations (73%) reported that their boards had discussed behavioral health integration. Thirty-six percent (36%) reported that their board had not discussed the issue.

Answer Options	% Responses	# Responses
Yes, Board discussed and decided to continue to focus on children with mental health disorders.	14%	4
Yes, Board decided to expand services to families caring for a child with substance use disorders.	28%	8
Yes, Board discussed and determined that the organization already serves families caring for a child with substance use disorders - no changes.	28%	8
Yes, Board discussed - Another organization in the state/community serves families caring for a child with substance use disorders.	3%	1
No, Board has not discussed behavioral health integration.	36%	10
Total Respondents (n=28)	109%*	28

*Two organizations checked more than one response to the question.

Q 3. Does your family-run organization currently provide specialized services for families caring for a child with substance use disorders? (n=30)

Survey responses indicate that less than half of the organizations currently provide specialized services for families caring for a child with substance use disorders.

Answer	%	#
Yes	46.67%	14
No	53.33%	16
Total	100%	30

Q 4. Please describe the specialized services you provide to families caring for a child/young adult with substance use disorders. (n=22)

Parent Support Network of Rhode Island runs a weekly support group of parents, family members and friends of youth and adults in recovery with substance use and mental health needs. PSN has a peer support recovery specialist who provides individualized direct services to parents, youth, and young adults in recovery (substance use or mental health).

Wisconsin Family Ties does not have any specialized services for these families, but provides their standard peer support services and systems navigation. About 8 years ago, WFT received funding to help create a directory of adolescent treatment providers and developed a comprehensive resource for families. Almost all of the families directly served had children with co-occurring substance use / mental health disorders. The board decided that given the strong correlation between MH and substance use, WFT were already serving this population.

Federation of Families Miami-Dade Chapter in Florida provides peer support by parents with lived experience of a child with substance abuse and/or mental health.

Tennessee Voices for Children Strengthening Families Course is provided to parents and youth with Substance use issues or at risk of substance use.

Parent/Professional Advocacy League in Massachusetts is very involved in advocacy and policy and design for co-occurring substance abuse and mental health services but does not provide direct services. PPAL works closely with 2 substance use advocacy/family organizations and collaborates on how to help families, just as they do for co-occurring medical and mental health. PPAL supports and advocates. Advocacy can include helping to get into a recover high school, insurance advocacy or services. Support includes providing information and referral.

National Family Dialogue is based on families with child/ young adult with substance use disorders.

Georgia Parent Support Network uses several best practices and referrals to providers who specialize in substance use disorders.

Family Involvement Center in Arizona reports that in Arizona's public health system, families of children with mental health and substance use challenges are served by the same provider networks with the practice model addressing both mental health and substance use challenges through Child and Family Team process and same system of care. FIC also provides youth services through transition age and thus are working with both the parents and the youth or young adults.

Total Family Care Coalition in the District of Columbia has a recovery support program which includes serving child/young adult with substance use disorders

Maryland Coalition of Families has hired a part-time family navigator to provide information and support to families caring for a child/young adult with a substance use disorder.

Kentucky Partnership for Families and Children partners with two grant programs: Kentucky's Reclaiming Future grantees, a grant program that helps young people involved with drugs, alcohol, and crime, and the Kentucky Adolescent Treatment Enhancement and Dissemination (KAT-ED) grant. KPCF works to not provide separate services, but inclusive services.

Alaska Youth and Family Network provides outpatient support and treatment to the children and families while they are being served if an appropriate and more specialized treatment provider isn't available in our community. All of these services are provided by parent/youth navigators who are certified chemical dependency counselors.

North Carolina Families United reports that all youth up to age 26 that have a substance use disorder can take advantage of NCFU's youth leadership series, YouthMove NC, and have care coordination using the RENEW high fidelity wraparound process for youth ages 14-26. All families that meet the requirements and fall in a funded service area are eligible to receive a Family Partner and /or high fidelity wraparound services.

Allegheny Family Network in Pennsylvania they help to connect teens 12-16 with the appropriate services in Allegheny County and then support the parents through this time. If the parents also have addictions that need to be addressed, AFN connects them with the appropriate services as well. AFN also has a dual diagnosis support group for parents who have their own issues and are parents of children with behavioral or D&A concerns. If youth are 16 -21 AFN will connect them with appropriate "Transition Age Youth" services available in Allegheny County for youth this age dealing with behavioral and/or D&A concerns.

Q 5. How are these specialized services funded? (n=22)

Funding for specialized services to families caring for a child with substance use disorders came from several sources:

- State block grant funding
- Medicaid billing
- System of Care Expansion grant funding
- Contracts with the state's substance abuse agency
- Contracts with the state's behavioral health agency
- Contract with state's disability agency under a prevention grant

Five organizations responded that they did not receive separate funding to serve families caring for a child with a substance use disorder, but it was a service they provided under their ongoing behavioral health contracts.

Q 6. If you currently do not have specialized services, do you have plans to begin providing specialized services to families caring for a child with substance use disorders? (n=18)

The majority of family organizations responded that they are not planning to begin providing services to families caring for a child with substance use disorders.

Answer	%	#
No	77.78%	14
Yes	22.22%	4
Total	**100%**	**18**

Comments from the field on providing specialized services

We are not to the point of formalizing this process. We have had many more discussions about serving children with co-occurring mental health and physical disabilities.

We are not at this time as our current funding is only for behavioral health disorders and not substance abuse disorders - in a few years perhaps.

We are looking into getting our staff in a better place regarding substance abuse concerns with youth since currently we deal more with this regarding the parents' addictions. Our staff knows how to refer youth to appropriate programs but since our focus has been on the parents since our county has a Youth Support Unit we will refer the youth to them. We would like to get the staff more training in supporting the parents with addiction concerns since they affect the entire family.

Q 7. Do you require that employees providing services to families caring for a child with substance use disorders have "lived experience" with their own child having a substance use disorder? (n=26)

More than half of the organization responding indicated they did not require parent peer support providers to have "lived experience" caring for a child with a substance use disorder.

Answer	%	#
No	57.69%	15
Yes	42.31%	11
Total	**100%**	**26**

Comments from the field on staff with lived experience

We do look for this and some also have lived experience as an adult in recovery (substance use or mental health).

We plan to stay focused primarily on child and adolescent mental health. We have enough training and experience to assist families whose children also have substance use issues.

We feel it is important that they have lived experience but to date we have not been able to identify the parent of a child with substance use disorders.

It is our policy to hire employees working directly with youth and families to have lived experience with either substance abuse and/or mental health, personally or in their immediate family. Employees attend ongoing training through SFBHN relating to mental health and substance abuse and are trained on the referral process for outpatient and residential treatment services. It is preferred but not required.

When we provide this service we will require the lived experience of employees.

We look for a range of lived experience including experience with juvenile justice, child welfare, substance use and so on.

This is critical. The systems are so different.

In our state families are dually certified. Our providers are CPS-P providers which covers both.

Most all of our Parent Support Partners have some lived experience with their own child having a substance use disorder. Parents we serve often have two or more peer parent support staff they interact with --- receiving parent support in their homes and community, and also receiving parent support and education from our training/family education department. In almost every situation at least one of the staff positions working with the family would have substance use disorder. In addition, we have a Parent Assistance Center for telephonic support or "walk-ins" to the center. With the variety of staff role, we would almost always have parent staff with "lived" experience.

We do not require specific "lived experience", but to work at our organization everyone has "lived experience as a primary care taker or consumer of a child serving system."

If possible we try to make this match. Since we do not have specific funds dedicated to this if it is not available we will assign to a Family Support Partner that may not have lived experience. If we had dedicated funding we would hire staff that had lived experience.

We don't provide that type of service. We will refer families to substance abuse programs.

Q 8. Do you require that employees have specialized training to serve families caring for a child with substance use disorders? (n=29)

Training on substance abuse disorders was split with about 51% of the organizations stating that they did provide training on substance use disorders while 48% do not provide training on substance use disorders.

Answer	%	#
No	48.28%	14
Yes	51.72	15
Total	**100%**	**29**

Comments from the field on training

We have training modules that mirror the Federation's Parent Support Competencies--confidentiality, ethics, behavior management, etc. The modules though are taught by persons with lived experience.

Peer Recovery Specialists are required to do 46 hour peer recovery specialist state certification which requires 46 hours core curriculum, 500 hours direct work experience, with supervision sign off. There is also an exam that needs to be passed.

Our standard training does contain information of substance use disorders and treatment options. Everyone gets this training; nothing specialized for this specific population. State certification of peer support workers is requiring competency in both mental health and substance abuse. We will do what is required for certification.

This year we will be altering our Parent Peer Support provider training to be more inclusive of this population.

We have supported staff to attend Certified Alcohol Drug Counselor Training, but do not require it.

We provide monthly training to the family peer support folks in our state. We train more than 200 each year. At least two trainings are about substance abuse. However, we have found they are of limited use unless they address co-occurring disorders as the national data shows that 74% of all young people with substance abuse disorders also have mental health disorders.

We encourage and support Community Reinforcement and Family Training (CRAFT) parent coach's model.

Family Peer Support Specialist Training for behavioral health. Three staff with lived experiences also attended coaches training with Partnership for Drug Free Kids.

The employees that provide these services are certified as chemical dependency counselors and are supervised by a Marriage and Family Therapist that also carries the specialization.

The general requirements, plus 2 electives on substance use disorders.

Q 9. What impact do you think behavioral health integration will have on your organization? (n=31)

The data suggests that behavioral health integration will result family-run organizations providing additional training on substance use disorders to better serve their families.

Answer Options	%	#
Will not have any impact on our organization	29.0%	9
Will cause us to rethink our mission	22.6%	7
Will change how we define "lived experience"	32.3%	10
Will change who we hire	29.0%	9
Will change our training for staff	58.1%	18
Will offer new funding opportunities	54.8%	17
Other (please explain)		10
	TOTAL	**31**

Comments from the field on impact of behavioral health integration

We have already changed our mission to include substance abuse.

Both providers and parents interested solely in adolescent substance use disorders have been cool, if not hostile, to the mental health community. While we have attempted to bridge this gap, there is still a wide chasm between the two camps.

I think it might mean all of these things eventually.

Because of our experience in working with a SOC grant, we have always provided services with a behavioral health philosophy.

Through the SAMHSA R&R grant we are already creating new collaborations and state partnerships. This is also an area of concern for our state Medicaid.

If done properly, behavioral health integration will have a major impact on our organization. In our state, there is no family organization that provides navigation services to families caring for a child with a substance use disorder. Instead of the state funding two organizations, it makes sense for us to expand our mission to include substance use disorders. To stay true to our vision of providing family navigators with lived experience, however, we will need to hire new staff.

We see Integration as a holistic approach to a person's physical and mental health. We see that a lot of special training will be needed as we believe the physical health community will find greater need for "Community Workers" with lived experience. We do not see substance abuse as the major "new area." We have always served families whose children received substance abuse and a myriad of other services through the Medicaid BH system. We see integration as involving the Physical Health side and a better coordination between those systems, and a great potential for growing our organization.

We changed their mission and vision over six years ago from "mental health" to "behavioral health." We recognized and discussed as a board, staff and with community partners if we should have an inclusive family and youth system or if we should have parallel systems. At that time, and still today, KPFC provides the same skill building opportunities, navigational assistance, and networking support for all parents raising

children with behavioral health challenges.

Our behavioral health system has been integrated for quite some time, but our organization has been largely unable to benefit directly from integration because Medicaid regulation didn't afford us access to them. We are working very closely with the State and stakeholders that have a stake in Medicaid reformation to maximize our opportunities under reformation and expansion.

Since our county has a Youth Support Unit that will work closely with these youth I do not see it effecting our organization any differently than it currently does.

Final comments from the field

Actually about half of our clients are the same families, we have just never discussed issues with substance abuse--now we have access to training opportunities and support from our state's department of aging and disability services and to do so.

In the past we have felt that this was just another population that had similar experiences. We have learned over the past few years that their experiences are very different and rather than integrating them as we had anticipated they will most likely require separate support networks.

I think you should look carefully at the state where the SFN is part of the R&R grant.

The National Family Dialogue was created to meet an unmet need in the family to family work. Many times the doors were closed in mental health family to family organization for this voice. We are hoping this is changing and are here ready to share our experience with substance use disorder prevention, treatment and recovery.

Many of the youth we serve are dual-(or triple) diagnosis youth.

In our state the integrated health approach is on physical and mental health integration....with substance use disorders considered to be part of our behavioral health services. Our focus and knowledge has for a many years been on physical and mental health .....and earlier integrated care where primary caregivers and pediatricians are more involved in helping to identify mental health challenges and understanding that our children with significant mental health challenges are likely to develop significant physical health problems at an earlier age due to the stressors of growing up with a diagnosed mental health problems. A large number of our Parent Support Partner staff hired years back before our state began to concentrate on the relationship between physical and mental health, are parents who were raising children with significant medical issues from an early age WITH mental health diagnoses also....or their children developed significant physical health problems due to the stressors or living with mental health from a young child.

Our state's mission is to keep youth in their home which is directly the opposite of current treatment for drug addiction. Current addiction treatment is to change the people, places and things that trigger your use. Our state has some growing to do.

We are now serving a population with far more than mental illness/behavioral difficulties, which impacts the hiring and training of staff. It's far more complicated and impacts our ability to carry out wrap around - we are still true to the model, but it's far more difficult and is sometimes not carried out to the standard we'd like to see.

I think that as a family organization even though I do not think this will have much impact on us, I will still train staff to be able to step up if the opportunity arises. I think that we need to always be training and improving the knowledge of our staff. Hoping to be prepared for whatever is next!

We work with families whose children have mental health issues. Some of those children/youth also have substance abuse issues as well. We will link those families with substance abuse services, will attend meetings with them and help them navigate that system as well as any other system in which a child/youth with mental health issues maybe involved.

Summary

Family-run organizations are at very different places with regard to behavioral health integration. Survey responses and comments from the field indicate that many family-run organizations are serving families of children and youth with both mental health and substance use disorders. However, most family-run organizations have not yet established specific funding or staff training to meet this need. The survey responses highlight a critical decision point for family-run organizations in determining whether to intentionally expand services to specifically address the needs of families caring for a child with substance use disorders or to only modify their services and training. In either case this is a capacity issue facing family-run organizations.

As states continue to move forward with the integration of mental health and substance use services, it becomes more important for family-run organizations to explore how integration will impact the services and supports they provide, whether there is a need for staff with different 'lived experience' and how to ensure parent peer support providers are appropriately trained to recognize and respond to the needs of a family supporting a youth or young adult with substance use disorders.

The integration of mental health and substance use services can create new possibilities for family-run organizations to build collaborations, identify new funding streams, and expand their capacity to support families. To ensure the integration of mental health and substance use services results in better access and more highly qualified support services for youth and families, family members, youth and leaders from the family-run organization(s) need to consider taking action on several fronts: 1) having conversations within their boards about behavioral health integration and the impact on their organization; 2) partnering with organizations focused on substance use within their states/communities; and 3) participating in behavioral health integration discussions in their state to ensure an integration plan that is inclusive and effective for all.

[i] Substance Abuse and Mental Health Services Administration, Results from the 2012 National Survey on Drug Use and Health: Mental Health Findings, NSDUH Series H-47, HHS Publication No. (SMA) 13-4805. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2013.

[ii] Alison Knopf, Behavioral Healthcare, *http://www.behavioral.net*, Mental health/substance abuse treatment mergers continue, with mixed feelings on substance abuse side, October 2, 2013