

Report

NEEDS ASSESSMENT FOR FAMILY MEMBERS OF INDIVIDUALS WITH OPIOID USE DISORDERS



Introduction

BACKGROUND

Beyond the impact on individual health, opioid use disorders have significant implications for the well-being of the family members of people who experience opioid addiction. Partners, parents, children, and siblings of individuals with opioid use disorders may experience a variety of psychological and social consequences, such as trauma, chronic stress, economic instability, and disruption of familial relationships.^{1,2} Additionally, children and adolescents who grow up in households with a substance use disorder are at an increased risk of developing substance use disorders, themselves.³ An understanding of the experiences and needs of these family members is essential to initiating a needs-based continuum of support that can mitigate the multigenerational impact of opioid use in our community. In addition, family members are broadly understood to play an integral role in supporting individuals in recovery from opioid and other substance use disorders. In order to best leverage familial supports for sustained recovery, it is essential to first address the needs of family members.4

PURPOSE

The Needs Assessment for Family Members of Individuals with Opioid Use Disorders was conducted to enhance local understanding of the treatment and support needs of family members of individuals with opioid use disorders in Denver. The results of this needs assessment are intended to inform the work of Denver-area treatment providers and other organizations who work with families and individuals who are experiencing the impacts of substance use on their lives. Specifically, these findings can guide efforts to:

- Mitigate the multigenerational impact of opioid use disorders
- Leverage familial relationships to support sustained recovery among individuals with opioid use disorders
- Prevent future substance use and other behavioral health challenges among the children of individuals with opioid use disorders

¹United Hospital Fund. (2019). The Ripple Effect: The Impact of the Opioid Epidemic on Children and Families.

² Lander, L., Howsare, J., & Byrne, M. (2013). The impact of substance use disorders on families and children: from theory to practice. Social Work in Public Health, 28(0), 194-205.

³ Winstanley, E.L., & Stover, A.N. (2019). The impact of the opioid epidemic on children and adolescents. Clinical Therapeutics.

⁴Daley, D.C. (2013). Family and social aspects of substance use disorders and treatment. <u>Journal of Food and Drug Analysis</u>, 21(4), S73-S76.

Methodology

KEY INFORMANT INTERVIEWS

As part of the formative research for this project Denver Public Health conducted 12 Key Informant Interviews with multi-sectoral stakeholders from organizations that work with families and individuals who are experiencing the impact of substance use on their lives (see Appendix for a list of Key Informants).

The purpose of these conversations was to gain understanding of stakeholders' perspectives regarding key issues and how they might envision using the results of this needs assessment to support their work. The results from these interviews helped shape focus group protocols.

FOCUS GROUPS

Two English-speaking focus groups were conducted utilizing an online platform.⁵ Participants were considered to be eligible for participation if they were a Denver metro area resident, 18 years or older, had not used opioids in the last year, and were within 1-2 generations of the relative that they were going to be speaking about in the focus group session. No more than two family members representing the same relative could participate.

Participants were asked to complete a pre-focus group questionnaire prior to attending a session, which collected basic demographic and context-specific information. Each session lasted approximately two hours during which participants answered a total of 11 questions. Participants who completed the survey and attended the focus group were sent a \$75 King Soopers gift card in appreciation for their time and input. All participants were aware they were participating voluntarily in the focus groups and could choose to stop their participation at any time.

All focus group data was recorded digitally and transcribed for later analysis using Atlas.ti. The lead researcher utilized deductive coding to identify themes that assisted us in identifying the needs of family members of individuals who use opioids.

HIGHLIGHTS

from the Key Informant Interviews

Stakeholders saw substance use affecting the individuals and families that they serve in a number of ways:

- Inability to participate in work or school
- Difficulty maintaining personal and familial relationships
- Increased risk for experiencing homelessness
- Increased interaction with the criminal justice system
- Negative impact on personal finances
- Decreased access to healthcare

Stakeholders also endorsed a number of resources and supports that are needed to help mitigate these impacts:

- Increased access to day treatment, particularly for youth
- Removal of financial barriers, through increased insurance coverage and/or affordable fee structures
- Diversion programs that support connections to therapy or treatment
- Easily accessible information (in multiple languages) regarding how and where to access treatment, including a description of the requirements for services
- Increased availability of recovery housing
- Trainings for family members focusing on the effects of trauma, mental health and substance use

⁵ Originally intended to be in person, with two English-speaking focus groups and one Spanish-speaking focus group, the final focus group sessions were switched to an online format with 6-7 participants each. Only two English-speaking sessions were held. This was due in large part to the COVID-19 pandemic, which led to restrictions on group meetings and limited the marketing and communication resources that were available to support participant recruitment, particularly within Spanish-speaking communities.



"I would like to say that I guess my initial response was (...), kind of, like this is just a phase (...) that this won't continue. And so yeah, my initial (...) reaction was to try, just try and take care of it ourselves (...) but of course once it continued, we did seek out treatment through rehab centers and professionals and that kind of thing but the initial part of it was (...) definitely the surprise and the not understanding but also that 'we can deal with this.'"

Results

PARTICIPANT DEMOGRAPHICS

There were thirteen total participants in the focus groups: eight females and five males. All participants have lived in the Denver Metro region for a range of 15-77 years, with an average length of time of 45 years. Seven of the total 13 participants voluntarily shared during the focus group sessions that they also used to use opioids. The participants' relationships to an individual with an opioid use disorder were primarily "parent" (n = 5) or "sibling" (n = 5). There was also a single representation of a "child," uncle," and "grandmother" in the combined focus groups. The age range of the participants in the combined focus groups was 17 to 64 years, with an average of age 42.2 years old. Their relatives have or had used opioids for anywhere from 9 months to 15 years, with an average of 8.6 years of opioid use. Based on the results of the pre-focus group questionnaire, the majority of participants reported being confident in their understanding of opioid use, addiction, and treatment.

FINDINGS: Experiences as Family Members of Individuals Who Use Opioids

To better understand what it is like to be a family member of a person who uses opioids, participants were asked about their initial reaction to finding out about the opioid use and the effect of their relative's opioid use on their personal home and work life.

Family members most commonly expressed "shock", "surprise", and "disbelief" at finding out that their relative was using opioids. Everyone in the focus group indicated that their first instinct was to keep it in the family and try to reason with the individual. However, after that passed most participants began to seek resources outside

of the home-either resources that they knew of from their own experience using opioids or treatment and recovery resources that were identified through Internet searches or recommended by professional sources.

Several participants discussed feeling stressed or worried about their relative. They were concerned about the safety of their relatives as well as the long-term financial aspect of helping to support their relatives in seeking treatment. Participants also expressed feeling embarrassed or concerned about stigma when trying to seek resources for their relatives. Furthermore, the majority of participants experienced sleeplessness and an inability to concentrate at work.

FINDINGS: Unique Needs of Family Members of Individuals Who Use Opioids

Participants were asked to speak about their unique needs and experiences accessing resources as family members of an individual who uses opioids. When speaking about their needs, they noted:

- Help me help my loved one family members want to make the situation better for their relatives and ideally stop the opioid using behavior
- **Compassion and understanding** some participants expressed the need for compassion; from co-workers, counselors, and from the family member who is using opioids themselves
- Receptive and experienced counselors they want to be heard by the counselor about their desire to help their relatives, and they want to speak with someone who has experience with addiction and recovery
- Explain the available treatment options it can be confusing and difficult to understand what treatment options are available, especially for minors vs. adults
- Financial resources to pay for treatment for their relatives
- **24-hour hotline** a number to call that immediately gives them information on resources
- Support group for family members of individuals with opioid use disorders – a counseling group where family members can get together and share their experiences with people who are encountering similar situations

While family members were able to describe their unique needs, it is worth noting that the participants found it difficult to separate their needs as a family member from those of their relatives. Many participants expressed a desire for resources to help their loved one, but not many sought resources for themselves. The few resources that they did connect with included: counseling, family counseling as part of their relative's rehab program, talking with other family members, and attending Nar Anon meetings.

"I would agree with (PARTICIPANT) (...) a lot of sleeplessness and wondering (...) what's going on. And when you, when of course they either aren't home or even when they are home. (...), what are they doing and you know and so a lot a lot of stress around that, definitely. (...) I don't want to say that I missed work because of it but it definitely affected me in the way that I would work because(...) it was just always on my mind. So-it was tough to concentrate, I would say."

"Right, I just didn't know that there was even anything out there for loved ones that were with people that were using, if that makes sense. I feel like when you see things. They're always about the person using I didn't know there were resources for loved ones of people that use. So I felt like even more advertising of that would be beneficial because I never even thought of anything like that which would make sense, but it's news to me that that even exists."

FINDINGS: Barriers/Challenges to Finding Useful Resources

Participants were asked if there was anything that prevented them from being able to find resources to help themselves as a family member of an individual with an opioid use disorder. In general there was a lack of knowledge about what resources, if any, were available to help family members specifically.

FINDINGS: Resources Needed by Family Members of Individuals Who Use Opioids

Focus group participants were asked if there were any resources that they wished they could have right now.

The majority of participants indicated that they would like access to counseling for family members of individuals with opioid use disorders. Some considerations for counseling would be:

- Cost of counseling ideally, counseling services would be covered by workplace, free, insurance-friendly, and/or government-paid.
- Time away to go to counseling this time might be covered by paid time off or under medical leave policies.
- Place counseling should be offered in a comfortable, convenient setting and/or via telephone.
- Type participants were open to both group and individual counseling
- Provider expertise counselors should abide by confidentiality rules and reduce feelings of stigma; individuals with lived experience could be effective counselors



Other desired resources included:

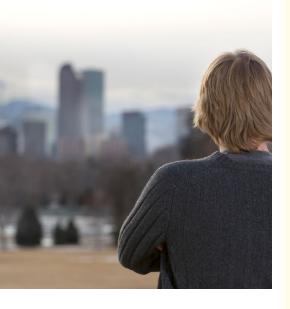
- 24-hour counseling hotline for family members Called a long and short-term need for family members, this telephone hotline would be available at all hours to address immediate needs and occasional less urgent questions from family members. The hotline could be used by family members for getting advice about their relatives as well as for their own emotional and educational support.
- A wellness check or follow-up program for family members Participants were interested in having someone who could come to their house or calls them to check in on any follow up needed for family members. The idea is that no one is left alone.
- Exercise programs for family members Participants discussed exercise as a way to relax, feel better about their situation, and be more open and ready to take care of the relative. This could be done with individuals or in a group setting and as part of a rehab program or offered by a treatment center

Participants acknowledged that different people may need different resources, and therefore, it is important that all available resources be offered as options to family members of individuals with opioid use disorders. This collection of resources might be offered at a "one stop shop" or established in different settings and organized centrally.

Discussion

Theme #1: The primary desire of all focus group participants — is to get help and healing for their relative who uses opioids. They recognize that they have specific needs as family members, but their main and primary interest is to see a positive change in their loved one.

Theme #2: If you have ever used opioids, it is difficult to separate your own experience as an individual who has used opioids from the "other" experience of being a family member of an individual with an opioid use disorder. Along with that is the personal knowledge of the addictive powers of opioid use; their own experience with becoming free of opioid use; and the experience that lays ahead for their loved one. In this set of focus groups more than half (seven) of the 13 participants voluntarily shared that they had previously used opioids. Many of their answers reflected their own experiences with opioid use.



Recommendations

- Continued research: This study only had a small and relatively homogeneous sample. It would be beneficial to repeat these focus group sessions with more people and in different languages to learn more about the needs of different groups in the Denver metro area.
- Develop and distribute comprehensive information related to

 how and where to access substance use treatment and 2) support services that are available to family members of individuals with substance use disorders. This effort should be undertaken in combination with continued community engagement, so as to identify and adopt best mechanisms for disseminating resource information to family members of individuals with opioid use disorders.
- Incorporate patient navigation services within substance use treatment programs that are accessible to both patients and families.
- Incorporate therapeutic supports for family members of individuals with substance use disorders within substance use treatment programs. This may include offering family support groups and/or connections to peer support for families.
- Undertake continued engagement with family members of individuals with opioid use disorders to ask specific questions about their experiences and perceptions of family therapy sessions – a resource that was noted by stakeholders, but not mentioned by focus group participants.
- Ensure adequate insurance coverage (across all payers) for evidence-based mental health and substance use treatment services, without unnecessary barriers.
- Promote adoption of workplace policies to support family members of individuals with substance use disorders, including paid time off and family medical leave policies that encompass substance use treatment.
- Work to reduce stigma through efforts to raise community awareness of substance use disorders.

Appendix

LIST OF KEY INFORMANTS

Name	Area/Organization
Amanda Duerst Ingram	Denver Health - School-Based Health Centers
Elissa Hardy	Denver Public Library
Erin Girardi	Denver Health - School-Based Health Centers
Helen Morgan	Denver District Attorney's Office
Jennifer Loth Hill	Denver Department of Public Health & Environment
John Eisen	Colorado Coalition for the Homeless
Ken Weil	Social Impact Solutions
Rick Thompson	Servicios De La Raza
Scott Prendergast	Denver Adult Probation
Terri Hurst	Colorado Criminal Justice Reform Coalition
Will Latimer	Mental Health Center of Denver
Kacy Behrend	Denver Health - Outpatient Behavioral Health Services
Kacy Behrend	Denver Health - Outpatient Behavioral Health Services