Texans for Recovery and Resiliency

Uniting youth, young adults and family mental health and addiction recovery

A SAMSHA funded collaboration between the statewide family mental health network and the statewide peer addiction recovery network.

TXFFCMH + RecoveryPeople

Texas Talks Back

A Grounded Theory of the Lived Experience of Texans and Their Loved Ones in Recovery from Co-Occurring Disorders

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The survey instrument was created in collaboration among project leadership. It became apparent, early on, that a simple quantitative data collection approach would not be sufficient in capturing the experiences of individuals and their loved ones that have received mental health and substance use services in the state of Texas. We decided that a more intensive qualitative approach would give us the grounding needed to speak more fully to the treatment experience, both good and bad. All team members discussed information that would be important to collect, and this information was curated and developed into survey questions by the project evaluator. These questions were submitted back to the team for further feedback and tweaking before the survey became accessible to the public. All told, the survey was streamlined over three rounds of writing, discussion, and feedback with the team.

We also felt it useful to participants to include information that operationalized the questions we are asking. As individuals who have been involved in many past research projects, we were aware that it can be a frustrating experience for participants to not understand what is being asked of and/or about them. Therefore the survey also included definitions of the terms and concepts we were researching.

The survey was also presented in a conversational style that is unusual within traditional research models. We felt that doing so honored the true experts within this process (the survey participants) by creating a more relaxed, supportive survey experience, rather than the more formal, didactic experience most individuals are used to. Feedback was overwhelmingly positive regarding the survey within social media. Participants said that while the survey was lengthier than others they have completed in the past, they found the questions thought-provoking and the survey style both engaging and affirming of their experiences.

We invite others to utilize this survey tool within their own communities, and invite feedback about your experiences with it. The text of the survey, which was subsequently built into SurveyMonkey Pro, is replicated in its entirety within this report.

Texas Talks Back: The Survey

Survey Introduction

Thank you for agreeing to complete this survey! We understand that talking about your personal experiences can be stressful (as well as take a lot of time). But we also know that the people who have lived through the challenges of these experiences are the real experts regarding what works, what doesn't work, and what could be improved when it comes to treatment and support.

And we really need your help to make services better. You may have had other experiences where you felt that people didn't listen to what you needed or wanted.

And here is our chance to change that.

So please answer all the questions to the very best of your ability. And please feel comfortable being completely honest. It's the best way for us to help make sure that other youth and families get the most support and help possible.

Definitions

We are going to start with a few definitions. The thing that is most difficult about surveys, sometimes, is figuring out what the survey is really asking. And we don't want to be confusing. So these are some words that you will see a lot in this survey.

History of Substance Use – All this means is that you, or the person you are taking the survey about, was identified as using substances to change their emotional state. You (or they) may have never been diagnosed as having a substance use disorder but part of their treatment was based on someone thinking that you (or they) were using substances in a way that was causing you (them) harm.

Substances could include:

- Alcohol
- Illegal street drugs (like marijuana, heroin, cocaine, or amphetamines)
- Prescription drugs that either weren't prescribed to the person taking them (like someone else was prescribed Xanex but you took one of theirs) or taken

in a way that was different from how they were prescribed (like you were prescribed one Trazodone a day but took 5 at a time so you could sleep)

A list of the more commonly abused drugs (along with their street names) can be found here. And there is a separate list for the most commonly abused prescription drugs, which can be found here.

History of Mental/Emotional/Behavioral Health Issues – All this means is that you or the person you are taking the survey about was identified as having some mental or emotional health issues that were causing issues for the family.

For example, everyone gets angry sometimes, but if that anger causes problems in school, at work, or in relationships with other people then it can be considered a mental, emotional, or behavioral health issue.

Some of the more common mental/emotional health issues in youth include ADHD, depression, anxiety, bipolar disorder, oppositional defiant disorder, and conduct disorder.

History of an IDD Diagnosis – This one is a little bit more confusing because these words have changed a lot in recent years. IDD stands for intellectual and/or developmental disability. An intellectual disability means that you or the person you are taking the survey about had an IQ test at some point that showed their IQ at 70 or below. We used to call that mental retardation. A developmental disability means that you or the person you are taking the survey about had a diagnosis on the Autism spectrum, a diagnosis of Asperger's Syndrome, or a diagnosis of Social Communication Disorder.

Co-Occurring Disorder – All this means is that you or the person you are taking the survey about had more than one of the issues described above. It is very common that individuals with a mental/emotional/behavioral health issues also have a history of substance use or an IDD diagnosis. In fact, most people have at least two diagnoses at some point in their treatment.

Trauma History – When we think about trauma, we usually think about abuse or neglect. And those are forms of trauma. But trauma can include many other things including losing someone important to you, witnessing violence growing up even if it didn't happen directly to you, going to the hospital, or going to jail. The biggest question is whether or not you consider an event in your life to be traumatic. If you consider an event traumatic, so do we.

The Questions

First, a few questions about you:

How old are you right now?

What is your gender?

__Male __Female __Other

What is your family's annual income (best guess)?

Please describe your race/ethnicity using the current US Census categories (choose as many as apply):

- White (Please list origins if known. For example, German, Irish, Lebanese, Egyptian, etc.)
- Black, African American, or Negro (Please list origins if known. For example, African American, Haitian, Nigerian, etc.)
- Hispanic, Latino, or Spanish origin (Please list origins, if known. For example, Mexican, Mexican American, Puerto Rican, Cuban, Argentinian, Columbian, Dominican, Nicaraguan, Salvadorian, Spaniard, etc.)
- American Indian or Alaska Native (Please list name(s) of enrolled or principle tribe(s). For example, Navajo, Mayan, Tlingit, etc.)
- Asian (Please list origins, if known. For example, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.)

- Native Hawaiian or other Pacific Islander (Please list origins, if known. For example, Native Hawaiian, Guamanian or Chamorro, Samoan, Fijian, Tongon, etc.)
- Some other race or origin (Please list)

What county in Texas do you currently live in?

Are you a:

__ A youth ages 14-17

__A young adult ages 18-24

__A parent or caregiver to a youth who has a history of substance use or a co-occurring disorder

__A sibling of a youth with a history of substance use or a co-occurring disorder

__A family member of a youth who has a history of substance use or a co-occurring disorder

__Another supportive person (friend, teacher, coach, pastor, etc.) of a youth who has a history of substance use or a co-occurring disorder

Sorry that all took so long, we are finally getting to the really important stuff! Thank you for hanging in there!

These first questions are about how you (or the youth you are taking the survey about ended up receiving services in Texas.

Please mark all that apply about you (or the person you are taking the survey about):

__History of substance use

__History of mental/emotional/behavioral health issue

__History of IDD diagnosis

__History of trauma

__History of involvement and/or placement in the child welfare system (CPS, foster care, emergency shelter)

__History of homelessness

__History of involvement with the legal system (jail time, probation, etc.)

__History of negative experiences with the school system

__History of family loss, person, home, pet

__History of multiple hospitalizations due the behavioral health or SUD concerns

__History of accessing the revolving door of intervention with poor plans and little follow through

If you are taking this survey on behalf of someone else, did you experience any of these issues in your own life?

__History of substance use

__History of mental/emotional/behavioral health issue

__History of IDD diagnosis

__History of trauma

__History of placement in the child welfare system (CPS, foster care, emergency shelter)

__History of homelessness

__History of involvement with the legal system (jail time, probation, etc.)

How old were you (or the person you are taking the survey about) when you first started using substances?

If you (or the person you are taking the survey about) also had mental/emotional/behavioral health issues, how old were you when those started?

If you (or the person you are taking the survey about) also have an IDD diagnosis, how old were you when you received that diagnosis?

If you (or the person you are taking the survey about) also has a trauma history, how old were you when you experienced your first trauma?

If you (or the person you are taking the survey about) has a history of placement in the child welfare system (CPS, foster care, emergency shelter), how old were you the first time you became involved with the child welfare system

If you (or the person you are taking the survey about) has a history of homelessness, how old were you the first time you or your family were homeless?

If you (or the person you are taking the survey about) has a history of involvement with the legal system (jail time, probation, etc.), how old were you the first time you became involved in the legal system?

How old were you (or the person you are taking the survey about) when you got caught using substances or people first accused you of using substances?

How were you (or the person you are taking the survey about) caught or why were you (or the person you are taking the survey about) suspected of use?

Ok, this is the part where you tell us all about your treatment experiences. The good, bad, and ugly.

What formal treatment options and recovery supports did you (or the person you are taking the survey about) use at any point after your use was suspected or discovered? This may include educational resources, counseling, case management, medications, inpatient treatment, 12 step meetings, other support groups, etc?

What other supports did you (or the person you are taking the survey about) use to help support your wellness? This may include things like church attendance, prayer, exercise, writing, art, music, a different educational environment, etc.

Who was supportive of you (or the person you are taking the survey about) getting treatment? Family, friends, other people in the community?

Who first helped you access services?

Where you mandated to treatment by the court system, schools, or job?

How long were you in services?

Are you still in services now?

If you stopped services, is it because you graduated the program you were attending? If not, what was the reason for discontinuing services?

When you left services, did you feel that you were ready to leave (no longer needed those supports)?

When you left services (if you are not still in services) who helped you plan for your aftercare/maintain your recovery? (e.g., where you could go for other supports, what to do if you needed help again)?

If you were provided aftercare resources did you use any of them?

Did any of the post treatment planning include a new peer group?

Did any of these services involve your family or caregivers or were they just for you (or the person you are taking the survey about)?

Did you experience any difficulties accessing treatment? What kinds of barriers did you experience?

Were there other services out there that you wanted to access but weren't able to at all? If so, what were the barriers to accessing those services? (Note: This question refers to services that were available in your area that you did not qualify for, for any reason).

Are there any services that don't exist that you wish existed? How would those services have helped you (or the person you are taking the survey about)? Note: This question refers to services that were not available in your community at all that you wish had been.

Which services were the most helpful to you? Why?

Which services were the least helpful? Why?

What person (or people) was the most helpful to you in your recovery? What was special about what they did?

What person or people was least helpful to you in your recovery? What did they specifically do that you that you found frustrating or unhelpful?

Was there anything about your family or culture that people didn't understand that made your treatment difficult at times?

If the governor met with you and asked "What could be done to improve services for you?" What would you tell him?

Is there anything else we should know about your experience that we didn't already ask?

Participant Recruitment

Individuals invited to participate in the survey were individuals who identified as transition aged youth (ages 14-17), young adults (ages 18-24), and other adults of any age who had either experienced treatment in the state of Texas as an individual with a substance use disorder and a mental health diagnosis or the family member/loved one of an individual with the aforementioned diagnoses

Additionally, many individuals elected to disclose additional diagnosis related to their experience, including trauma history, intellectual disability, and/or developmental disability.

We utilized snowball (also known as chain) sampling procedures to identify individuals with lived experience of navigating the mental health and substance abuse treatment systems in Texas. Noy (2008) noted that within a qualitative research framework, sampling procedures are often minimized or even dismissed as the least interesting part of our quest for increased knowledge and understanding. However, how researchers and participants first interact has a considerable hermeneutic significance to the overall research design and therefore should be addressed accordingly. Noy (2008) validates this assertion, stating, "When sampling methods are employed in qualitative research, they lead to dynamic moments where unique social knowledge of an interactional quality can be fruitfully generated" (p. 328).

We include this information within our report in the interest of research transparency, both successes and potential flaws. We invite commentary on our methodology and the resulting data as well as encourage replication by other researchers in their own communities.

Goodman (1961) defines snowball sampling as a sampling methodology in which a random sample of individuals (s) is drawn, and these individuals are asked to identify a specific number (k) of different individuals who are then nominated for study participation as well. This is snowball sampling in its most pure form.

Within qualitative research paradigms, this methodology has evolved as a way of expediting access to specific populations needed within studies that require purposive sampling techniques. It has become the most widely utilized sampling procedure in social science qualitative research (Noy, 2008). Snowball sampling, it can be argued, is a targeted form of social media networking.

Snowball sampling is defined as a means in which the researcher utilizes initial contacts as informants, requesting referrals for study participants, and then asking these study participants to refer colleagues who may also be appropriate for and interested in participating in the study. Thus, the term snowball or chain refers to the accumulative, linkage nature of how potential participants are contacted.

Just as in most areas of life, when we need information or referrals we ask our friends and colleagues. Snowball sampling, then, is a means of making connections, or accessing the "dynamics of natural and organic social networks" (Noy, 2008, p. 329). Because we were purposive in our sampling, in that we were focusing on individuals and family members that had accessed mental health and substance use treatment within the state of Texas, using a sampling methodology that relied on social networks is both intuitive and rational.

Using Survey Monkey Pro, individuals with lived experience of navigating the mental health and substance use recovery systems in Texas were invited to complete a questionnaire consisting of open and closed ended questions (see above). Questions included demographic information about the participants as well as open ended questions about their treatment experiences. Statistical analysis tools (both those available within Survey Monkey Pro and others used by the grant evaluator) were used to generate descriptive data based on the responses of the survey participants.

Individuals that were associated with this project shared the link to the survey, built within Survey Monkey, through their professional and personal social networks, encouraging individuals who saw the link to pass it along to friends and colleagues who might also express interest in participating. Many people did so, sharing on social media that they had completed the survey and had encouraged others to do the same. Participation was robust for research of this nature, with 83 individuals participating to some degree within the study.

Participation was completely voluntary and anonymous; no identifying information was requested within the survey itself. No questions were forced response, and individuals were encouraged to share only to their level of personal comfort and to the appropriateness of their experience.

The only means of tracking timelines of trauma history with substance use and mental health diagnostics was the date/time stamp on the survey responses themselves. Additionally, the feature in Survey Monkey that allows you to track computer usage was also disabled, allowing for more anonymity and the ability to let individuals who share a computer to complete the survey all on the same system.

Questions within the survey (see the complete survey were designed to collect not just descriptive statistics, but additional information allowing us to develop a *grounded theory* of both the strengths and needs of individuals receiving services within the state of Texas.

A Grounded Theory Research Design

Grounded theory was originally developed by sociologists Barney Glaser and Anselm Strauss as a means of discovering and understanding data grounded in the context of social systems (Strauss & Corbin, 1998). This emphasis on theory

generation and structured procedures has opened the door to qualitative examination becoming more accepted in academia and social sciences (Patton, 2002). Within this methodology, the researcher does not begin with a preconceived theory, but uses the data collection and analysis procedures to inductively sculpt a theory regarding the studied experience. By its very nature, the process is both highly systematic and substantially creative (Patton, 2002; Strauss & Corbin, 1998).

This model of *structured flexibility* allows researchers to be open to possibilities not yet explored and to gain fresh perspective while maintaining a level of organization and rigor that allows the researcher to develop substantive theory. Instead of embarking on a data collection strategy that presumes certain outcomes, we focused on being open to the experiences of survey participants without any preconceived notions.

While there is more than one type of grounded theory analysis, the one chosen for this project is known as *constructivist grounded theory.* This form of theory generation is somewhat different from the classic structure because the emphasis is on what people are doing and then finding meaning within those actions (Charmaz, 2008a). We do not navigate our world in a vacuum, but rather negotiate around other individuals, rules that govern the organizations and societies in which we live, and the barriers that come between us and our goals. In this vein, it makes sense that this version of grounded theory has also been called a more structured form of phenomenology, which focuses on *the essence of meaning* (Creswell, 2002). For example, if many people leave treatment before treatment is complete, why did it make sense for them to do so?

Researchers utilizing this form of grounded theory are, by definition, less interested in defining one single core category. Instead, the focus of the researcher is on finding multiple realities based on differences in locals and other contextual complexities (Creswell, 2007). Reasons change based on precipitating events and are unique to the experiences that led us to that point of action.

This methodology was chosen because it is designed to explore multiple theoretical possibilities, is reflexive in design, culturally competent, advocacy and social justice oriented. The social justice orientation of this methodology is an integral part of this research design, as the constructivist approach is inherently more advocacy oriented (Charmaz, 2008c) than other research paradigms. This framework examines not just actions and interactions, but also is used to consider the equity and power inherent in their underlying processes, thus allowing the researcher "to seek new information to examine questions concerning equality, fairness, rights, and legitimacy" (Charmaz, 2008c, p. 209). The purpose of our research is to affect change, not study a phenomenon for its own sake.

Charmaz (2008c) additionally states that part of the purposive sampling within this is to choose participants already engaging in reflexivity regarding the problem

being studied. The individuals who took part in this survey chose to do so because they have a vested interest in systemic change in how we navigate wellness and recovery. They have lived this experience either through their own recovery journey or that of a loved one.

The collective voice of our survey participants is what led to a new model of advocating for change-producing strategies. While the researchers themselves also had lived experience within the mental health and substance abuse system, this model is not *our* story. The strategies that emerged from our data analysis was developed "by making explicit connections between the theorized antecedents, current conditions, and consequences of major processes" (p. 210). Eighty-three individuals within the state of Texas shared their experiences with an honesty and clarity that was humbling to those of us navigating this project. The model of change that emerged is a direct reflection of *their* story.

This methodology is in keeping with the purpose of this research, which is that individuals with lived experience are the true experts within the mental health and substance abuse treatment systems. They should have equal partnership in how programs are developed, funded, and implemented. The import of this research is not knowledge for its own sake, but the changes that knowledge can bring about (Wilson, 2008). This research is not intended as an intellectual exercise, but as an opportunity to invite in the individuals who should have the primary voice in affecting systemic change.

Data Analysis

While a few questions within the survey had specific choice responses, allowing for the use of the data analysis tools available within Survey Monkey Pro, most questions allowed for an open ended response that required coding before descriptive statistics could be formulated or grounded theory categories assigned.

We utilized open coding to process the collected qualitative data with the goal of understanding how "the core category explains the behaviour in the substantive area, i.e. it explains how the main concern is resolved or processed" (Grounded Theory Institute, 2010a). Data was labeled and, as themes within these data incidents became saturated, the core categories making up the basis of the different treatment theories were identified (Grounded Theory Institute, 2010b).

Initial coding. What Charmaz (2008a, 2008b) terms initial coding is similar in structure to Strauss & Corbin's (1998) definition of open coding. Open coding focuses fundamentally on the discovery of concepts, actions, and theoretical potential instead of topics (Charmaz, 2008b; Strauss & Corbin, 1998). The emergence of concepts within the data and our subsequent naming of these concepts create the building blocks of theory development.

As concepts emerged within the data, they were coded, using in-vivo naming procedures whenever possible. Similar themes were placed within the same code categories. Categorizing of concepts allowed us to reduce the data units they work with and, more importantly, "categories have analytic power because they have the potential to explain and predict" (Strauss, & Corbin, 1998, p. 113). After the initial coding process, a more focused coding strategy took place.

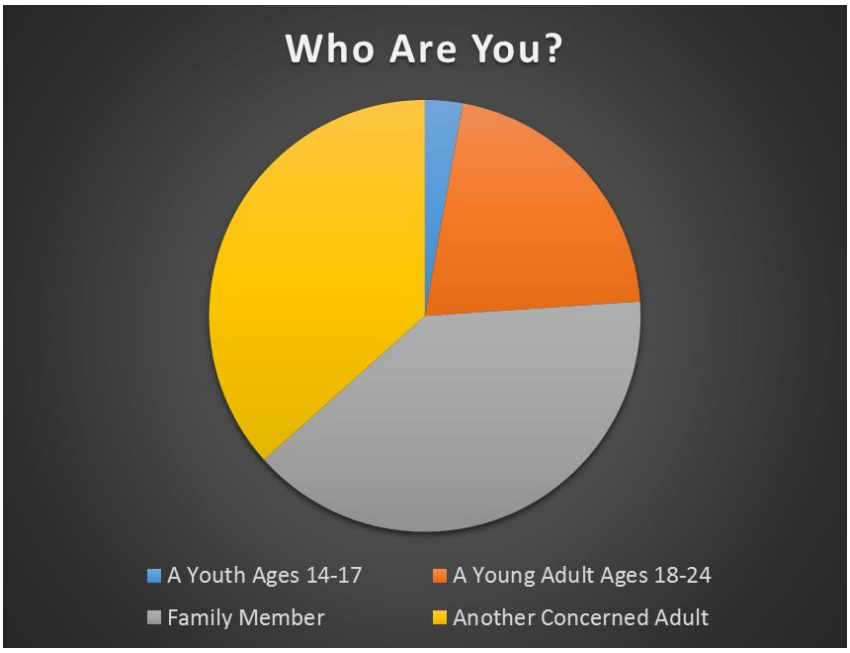
Focused coding. The difference in coding process between classic grounded theory and constructivist grounded theory becomes evident at this point. Whereas axial coding is described as a process of seeing the linkages and interplay between categories (and subcategories) of data (Strauss & Corbin, 1998); focused coding is a way of synthesizing larger amounts of qualitative data by determining which initial codes occur most often and appear most significant (Charmaz, 2008a, 2008b). Focused coding assisted the grant monitor in determining what codes were best at construing meaning within the phenomenon studied (Charmaz, 2008b). Within the focused coding process, the grant monitor began to identify possible theoretical categories.

The selective coding process is where theory begins to evolve from the data collected (Charmaz, 2008a, 2008b). Theoretical categories are the ones that can "carry the weight of analysis" (Charmaz, 2008b, p. 164). The emergence of theoretical categories is a necessary step in achieving theoretical saturation (Charmaz, 2008b). Unlike classic grounded theory, which looks for one central code that all other codes relate to (Strauss & Corbin, 1998), these theoretical categories are essentially hypotheses formed about the phenomenon allowing for further investigation within upcoming town hall meetings and future studies.

The grant monitor, Faith G. Harper, PhD, LPC-S is available if you have any specific questions about the development and dissemination of this survey instrument and the research paradigm utilized as our data coding methodology. The rest of the Texans for Resilience and Recovery team is equally available to provide any other needed technical assistance regarding replicating a similar undertaking in your community. Emails have been provided on the cover page of this document because we would love to hear from you!

Descriptive Data

Who participated in our survey? We asked more demographics than typical for this type of survey in hopes of capturing a glimpse of the systemic issues within families and communities that we have noticed ourselves as professionals and individuals with lived experience.



While a few youth in recovery participated in the survey, the majoirty of individuals with personal lived experience were already young adults speaking to experiences in their recent past. We also had many family member participants (either parents, siblings, or another self-identified family member). Additionally we had many people who had loved and cared for someone in their community through this type of treatment experience without having any blood relation to that person. This information is important for treatment professionals to consider when identifying supports and treatment options. Family is often of our own choosing and definition and the potential for healing in those relationships should not be discounted.

Answer Choices	Responses	
Male	19.28%	16
Female	80.72%	67
Other	0.00%	0
Total		83

While an "*other*"option was included within the gender identifier category for individuals who do not identify on the gender binary, no participants did so. Just over 80% of respondents were female, just under 20% were male.

The majority of individuals who took this survey identified as White, using the US Census categories and definitions associated with race and ethnicity. Of the individuals who identified, as White, all listed Eurpopean ancestry (primarily Irish or German), except for two people who identified as American Indian. All individuals who identified as Black, listed either Black or African American by origin. All individuals who identified as Hispanic, listed either Mexican American or Hispanic by origin. Of the individuals who identified as American Indian, responses were more tribal specific, noting Kiowa, Keetowah Band Cherokee, and Navajo. The individual who identified as "Other" had listed "Jewish" as their identifier.

White (Please list origins if known. For example, German, Irish, Lebanese, Egyptian, etc.)	83.33% 65
Black, African American, or Negro (Please list origins if known. For example, African American, Haitian, Nigerian, etc.)	6.41% 5
Hispanic, Latino, or Spanish origin (Please list origins, if known. For example, Mexican, Mexican American, Puerto Rican, Cuban, Argentinian, Columbian, Dominican, Nicaraguan, Salvadorian, Spaniard, etc.)	16.67% 13
American Indian or Alaska Native (Please list name(s) of enrolled or principle tribe(s). For example, Navajo, Mayan, Tlingit, etc.)	3.85% 3
Asian (Please list origins, if known. For example, Asian Indian, Chinese, Filipino, Japenese, Korean, Vietnamese, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.)	0.00% 0
Native Hawaiian or other Pacific Islander (Please list origins, if known. For example, Native Hawaiian, Guamanian or Chamorro, Samoan, Fijian, Tongon, etc.)	0.00% 0
Some other race or origin (Please list)	1.28% 1

Additionally, 16% of the respondents identified with a sexual orientation other than heterosexual. The specific needs of LGBTQQIAAP individuals within the treatment system cannot be understated. Researchers working in this field (as well

as service providers within treatment programs) rarely ask about sexual orientation, although studies demonstrate that substance use and abuse rates are higher among LGBTQQIAAP individuals than among the general population. (SAMHSA, 2012). Almost all study participants did respond to this question when asked, and the number of individuals who identified in a non-heteronormative category was in keeping with general statistics regarding same-gender sexual attraction and behaviors within the U.S.

Answer Choices	Responses	
Straight	**83.75%**	67
Lesbian	**3.75%**	3
Gay	**1.25%**	1
Bisexual	**10.00%**	8
Pansexual	**1.25%**	1
Asexual	**1.25%**	1
Queer	**2.50%**	2
Questioning	**0.00%**	0
Transgendered	**0.00%**	0
Other (please specify)	**0.00%**	0
Total Respondents: 80		

Socioeconomic Status

In 2013 dollars, the median household income in the United States from 2009-to 2013 was 53,046 and the average household size was 2.63 (census.gov, 2015). The per capita income average was $28, 155 and 15.4% of individuals lived below the national poverty level (census.gov).

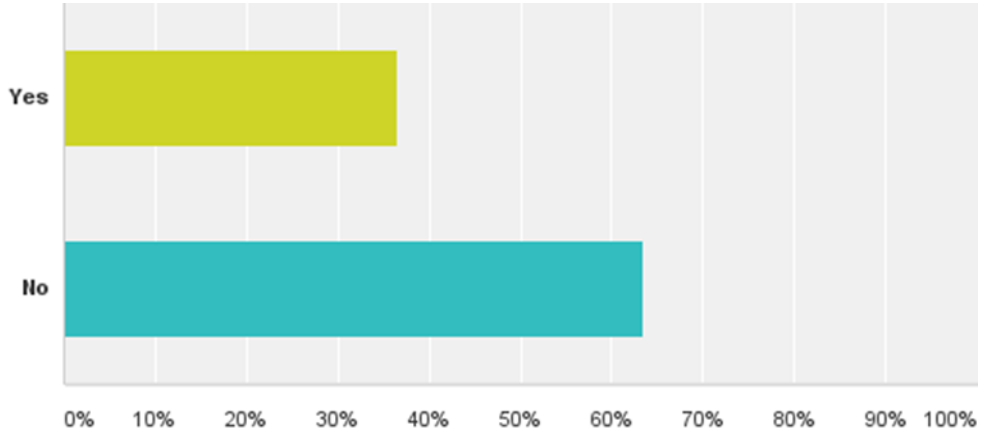
The federal poverty level, set by the federal government is influenced by the number of individuals residing in the household. The federal poverty level, higher in Alaska and Hawaii, is as follows for Texas and other mainland states (healthcare.gov, 2015)

Household Members	Federal Poverty Level
1	11,770
2	15, 930
3	20,090
4	24,250
5	28,410
6	32,570
7	36,730
8	40,890

While the number of individuals living in the household was not a question asked on the survey, you can see by the numbers below that most of the survey participants fell squarely in what the federal government terms middle or upper class. The individuals who noted themselves as being upper class had far fewer issues accessing services, as did the individuals who did fall below the poverty level. The individuals with the most financial struggles were the individuals whose income levels would be considered middle class.

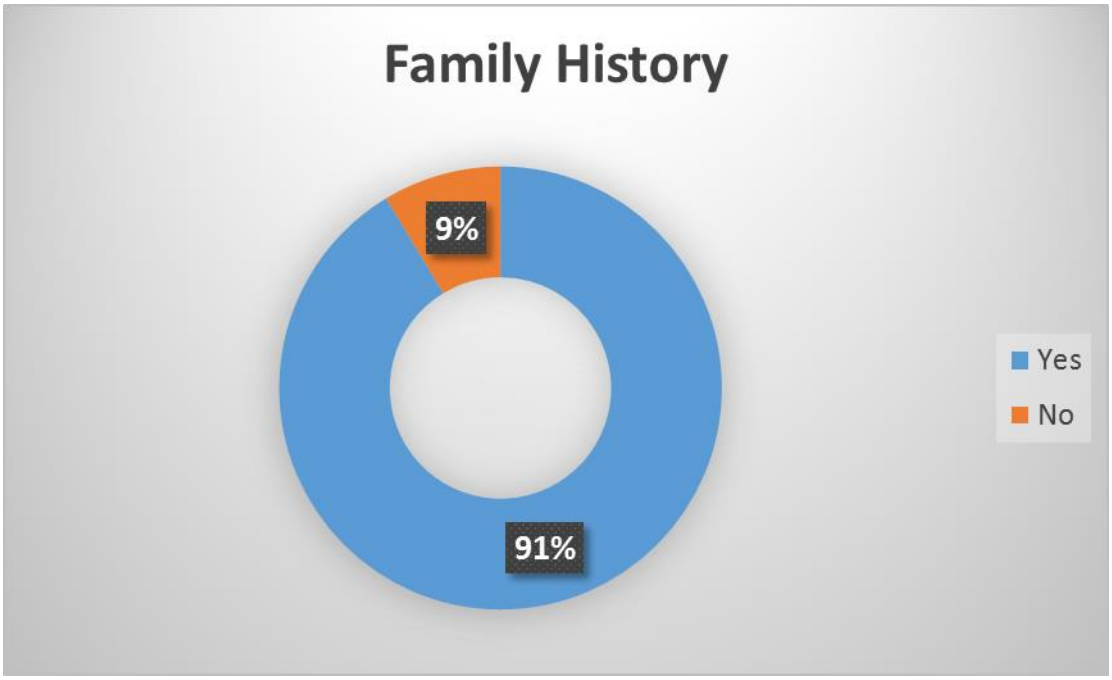
IRS Household Income Bracket (IRS.gov, 2015)	Percentage of Survey Participants Within This Bracket
0-9225	4%
9226-37,450	23%
37,451-90,750	44%
90,751-189,300	15%
189,301-411,500	8%
411,501-413,200	0%
413,201+	1%

37% of the individuals who participated also had a military connection within their families. This is important data to be aware of in conjunction with the understanding of substance use and abuse within the military. While the use of illicit drugs is less within military families than within the general population, the use of alcohol and abuse of prescription drugs is higher and continuing to rise (National Institute on Drug Abuse, 2013).



Another issue rarely asked within these kinds of studies is questions regarding intergenerational substance use, mental health issues, and trauma. While epistemological research is inherently complex and results in correlative rather than causative data, enough research has been published to posit a new answer to the nature versus nurture debate. And that answer is the question is moot. Research is demonstrating that trauma, medical illness, mental health issues, and substance use changes the genetic structure of the epigenome among those who experience such issues. These genetic changes are handed down to the next generation, and often at least one more generation beyond the second (Hughes, 2014).

While this research is by no means comparing itself to a rigorous study of intergenerational trauma, we were interested in whether or not our data supported the possibility of epigenetic inheritability. The answer in this case was a resounding yes. Additionally, all respondents identified a familial history within two generations (i.e., parents or grandparents).



When asked about the history of the youth in question, the complexity of their experiences demonstrated the possibility of being substantially linked with the experiences of the biological family member. The first chart demonstrates the history of the youth in question, the second the experiences of the biological family member.

Youth in Services

Answer Choices	Responses	
History of substance abuse	**76.67%**	46
History of an mental/emotional/behavioral health issue	**78.33%**	47
History of IDD diagnosis	**11.67%**	7
History of trauma	**50.00%**	30
History of involvement with/placement in the child welfare system (CPS, Foster Care, Emergency Shelter)	**16.67%**	10
History of homelessness	**16.67%**	10
History of involvement with the legal system (arrest, jail time, deferred adjudication, probation, etc.)	**40.00%**	24
History of negative experiences with the school system	**50.00%**	30
History of a family loss (person, home, pet)	**46.67%**	28
History of hospitalization(s) due to substance use and/or behavioral health issues	**50.00%**	30
History of poor treatment or follow through from agencies providing your care	**36.67%**	22
Total Respondents: 60		

Biological Family Member

Answer Choices	Responses
History of substance use	58.82% 20
History of a mental/emotional/behavioral health issue	44.12% 15
History of IDD diagnosis	0.00% 0
History of trauma	50.00% 17
History of involvement/placement in the child welfare system (CPS, foster care, emergency shelter)	8.82% 3
History of homelessness	14.71% 5
History of involvement with the legal system (arrest, jail time, deferred adjudication, probation, etc.)	32.35% 11
History of negative experiences with the school system	32.35% 11
History of a family loss (person, home, pet)	50.00% 17
History of hospitalization(s) due to substance use and/or behavioral health issues	23.53% 8
History of poor treatment or poor treatment follow-through from agencies providing your care	20.59% 7
Other (please specify)	8.82% 3
Total Respondents: 34	

From Usage to Recovery

First Substance Usage

Among survey participants, the age of first usage ranged from 2-30, although the majority of individuals started using between ages 7-16. The average age of first use was 14.5. The number of individuals who began using at a very early age speaks to the necessity of concentrating prevention efforts in our schools and communities before adolescence.

First Issues With Mental/Emotional/Behavioral Health

Among survey participants, the age of first mental health issues varied widely. The average age was 20.5. While 46% of individuals surveyed indicated that the mental health issues predated the substance use, 54% noted that the mental health issues either occurred at the same time as the substance use or after substance use began.

Intellectual Disability/Developmental Disability Diagnosis

7% of participants noted a co-occurring IDD diagnosis. Interestingly, the average age of diagnosis and treatment was much younger for IDD issues than mental health and substance abuse treatment. All individuals who responded noted a diagnoses before age 12, and the average age of diagnosis was 4.5

Trauma History

While there was a wide range of ages at which individuals experienced their first trauma (as defined above), the most interesting data point in this question is that 100% of the individuals who noted a trauma history noted that the trauma either predated or preceded their substance use. This information was tracked by comparing age of first use to age of first trauma, using the date/time stamp of survey completion, rather than asking survey participants directly if their use began before or after their first trauma, in order to not "load" the nature of the question.

History of Involvement in the Child Welfare Serving System (CPS, Foster Care, Emergency Shelter)

15% of individuals surveyed noted involvement within the child serving system. One individual noted that they were they were told to relinquish custody when insurance benefits were maxed out for their 12 year old son in order to continue his treatment, but found alternative supports.

History of Homelessness

16% of the individuals surveyed noted that the individual in question was homeless at one point in their lives. While a few people noted that the entire family was homeless when they were young children, most individuals stated that their period of homelessness was in their early 20s, after they aged out of youth supportive services.

Involvement in the Legal System

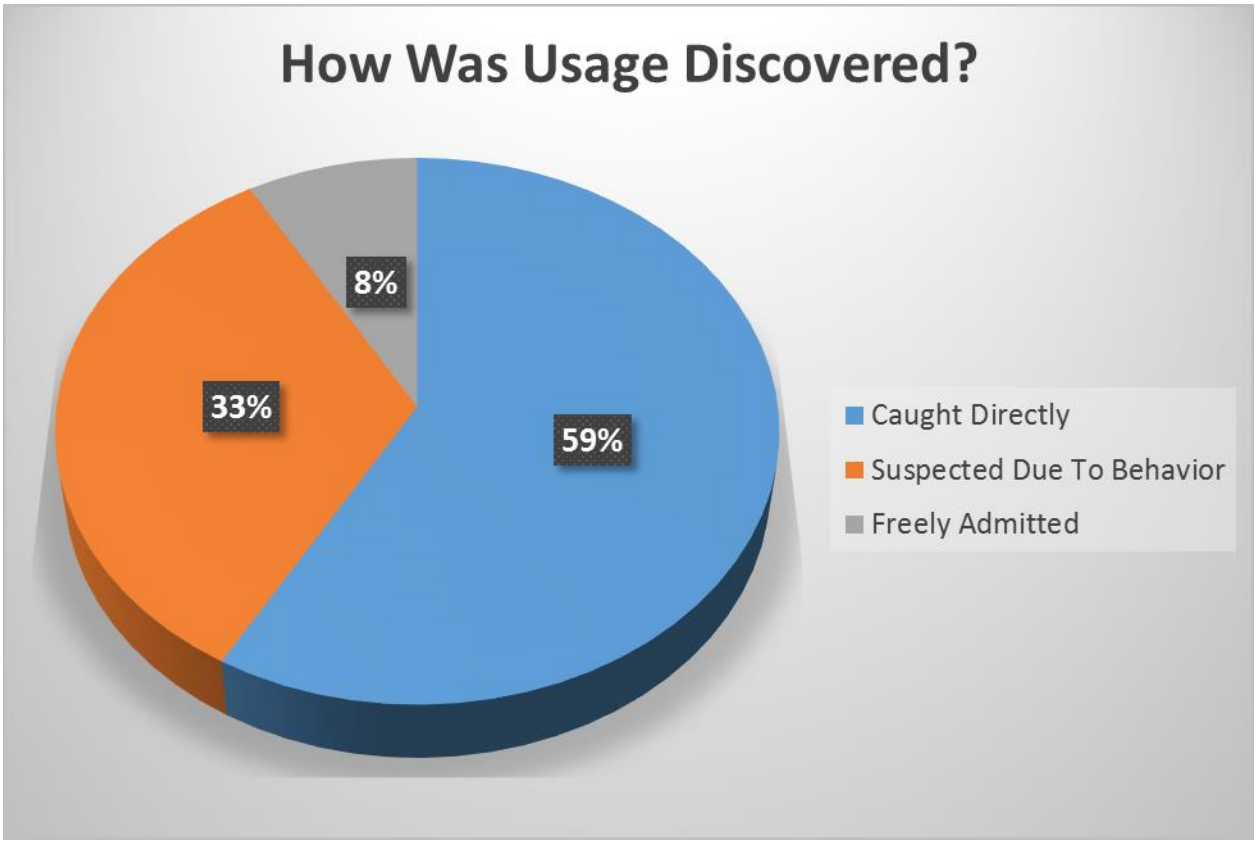
34% of the individuals surveyed noted involvement within the legal system. While the age range for that involvement went from 12 to 33, the average age of involvement was 16, which is shortly after average age of first use.

The Treatment Experience

Who Noticed and When?

The average age that individuals were either caught using substances or first accused of using substances was 15.8, approximately a year after the average age of first use. Most individuals were directly "caught" using drugs, drugs were found in their possession, or they had a positive urinalysis related to other treatments. Most

others were caught based on behaviors and choice of friends, a few freely admitted their usage to their families.



What Treatments Were Received?

The majority of individuals surveyed noted more than one formal treatment option as part of their recovery journey and more than half of the respondents identified traditional outpatient therapy as part of their treatment. Over a third of participants noted treatments including 12 Step programs, inpatient treatment, and psychiatric care including medication management for the mental health aspect of their diagnosis. Most startling, 13 % of participants stated they received no formal treatment services for their substance use and mental health issues. It is important to note that individuals surveyed differentiated 12 step recovery programs from other peer groups they belonged to. All considered 12 Step a formal treatment option, and other groups (church groups, etc.) as part of their more informal wellness supports. This supports the NSDUH (2013) definition of treatment, where mutual aid (more aptly termed than self-help) is considered a formal part of treatment.

Formal Treatment Options	Percentage of Individuals Who Utilized This Option
Traditional Outpatient Treatment/Therapy/Counseling	54%
12 Step Program	39%
Inpatient Program	37%
Psychiatric Treatment/Medication Management	33%
Case Management/Service Coordination	11%
Psychoeducational Supports/Skills Training	7%
Intensive Outpatient Program (IOP)	4%
None	**13%**

In contrast, everyone listed at least one alternative treatment support. These informal options had a clear impact on the recovery journey of the individuals who participated in this survey. Church and prayer played a large role in the recovery of many people, and a wide variety of spiritual communities were noted, including Zen Buddhism and Judaism. Groups and social supports (other than 12 step treatment programs that were noted in the previous question) outside of friends and family was the second most cited support, and many of these groups were defined as being attached to their spiritual community.

Friends and family were also important, even when that meant leaving some individuals behind in pursuit of healthier support systems. One individual started afresh in a new community, in order to leave a family system that was encouraging continued use. They stated *"Moving 1000 miles away from here did it: I was in "fight or flight" mode and I knew I had been losing the fight and it was time to fly. There was no way I was NOT going to get clean – I am too good of a person and too strong of a person to let some drug run my life."*

Other noted supports included expressive endeavors such as writing and art, activities designed to promote physical wellness such as exercises, nutrition, and meditation. Interestingly, several individuals also noted that going back to school and focusing on continuing their education was an integral part of their recovery. As one individual shared: *"Continuing my education really helped keep me motivated to get well and be a better person."*

Other Wellness Supports	Percentage of Individuals Who Utilized This Option
Church/Prayer	71%
Social Groups/Supports	34%
Family/Friends	18%
Music	18%
Art	16%
Writing	13%
School	11%
Exercise/Nutrition	11%
Meditation/Mindfulness	8%

Voluntary vs. Involuntary Treatment

33% of the individuals surveyed stated that their treatment was mandated either through the court system, their school, or their employer. Another 7% noted that

treatment was strongly recommended by someone in their life, though not explicitly mandated. The individuals who followed through on these recommendations were grateful for them, one person stating *"That recommendation has been integral to my care for the last 10 years."*

Length of Treatment

While many people discussed treatment options that ranged from 1 to three months, many others have noted that treatment (in some form) has been an integral part of their recovery on an ongoing basis. 70% of the individuals surveyed mentioned that they were still receiving some form of treatment, often a 12 step group and medication management. One person surveyed stated they have not been receiving treatment but are about to return for needed support.

Family Involvement in Treatment

55% of the individuals surveyed stated that family was involved in their treatment efforts on a regular basis. One individual noted that they had a family member attend an Al-Anon once, two more noted that family treatment was offered but declined. The range of involvement was broad. Some individuals mentioned contracting with their spouse to take over their care if their symptomology worsened, but that the spouse did not attend sessions regularly with them. Another individual mentioned that all members of their family attended all training sessions with their child for the 18 years that child remained in their home.

Who Was Instrumental to the Recovery Journey?

When asked who first helped the surveyed individual access services in their community, professionals topped the list. This category included any member of the community paid for their services, whether it be a judge, probation officer, licensed mental health clinician, or peer support specialist. This category was followed closely behind by family, and a few individuals cited friends as being instrumental to them first accessing services. However, many people noted they had no supports and they had to seek treatment and navigate the system by themselves. As one participant stated, *"Not that many people cared at the time."*

Individuals Who Helped Access Services	Percentage of People Who Had This Support
Professionals Supports	46%
Family	17%
Friends	20%
None	**20%**

While it often took a professional in the community to identify a treatment need and help individuals access treatment, many people identified overwhelming support from their family and friends as well as the professionals that provided their services, once they started receiving treatment. This was sometimes a matter of individuals not knowing that the individual in question was in need of treatment.

One respondent stated that they were surrounded by support, *"My entire family, including mother, father, brother, sisters, cousin, friends, boyfriend, counselors, etc., but this was only once I told them the truth about what was happening."* Another individual echoed this: *"My parents, brothers and their wives, my grandparents, and a handful of friends were there for me through thick and thin. My counselor in rehab was one tough cookie who broke through my very hard shell and showed me what it was like to be a caring, non-selfish human being. Also, my psychiatrist has been with me for many years and he notes often how well I have done in the past 7 years."*

However, as with the previous question, many people had little to no support in their recovery. One individual stated their repeated offenses drove many people away. Another stated that the individuals in their life at the time were as sick or sicker than she was, and were not in a place where they could support her recovery journey, creating a situation where she had to go it alone. When speaking to this, she stated *"I am an extremely strong willed woman."*

Recovery Supports	Percentage of People Who Had This Support
Family	77%
Friends	40%
Community Supports	23%
None	**12%**

Service Termination

Why Did Services End?

Of the individuals no longer in treatment, 61% completed/graduated from their treatment program. Of those who chose to discontinue services before they were complete, 67% cited barriers to treatment completion. Cost was the largest culprit, but scheduling conflicts regarding work and other obligations were also cited, as was going to jail where treatment was not offered. The other 33% who did not complete treatment stated that the treatment was not effective. One respondent stated that they *"never felt like personal trauma was addressed accurately*" and another noted that many services were located *"in the most dangerous, drug infested parts of the city, and make recovery harder. Additionally, they have tended to be ineffective, for profit entities that feed off desperate people and perpetuate disease."*

Were You Ready For Services To End?

Among the individuals who completed services, 55% stated they did not feel they were ready to leave. One person stated that they had been suspended from the school that was providing treatment, eliminating their access to care. Another stated that while they had completed treatment they were still struggling, noting, *"PO told mom when she asked for some services, that he is your child, he is finished the program so here he is, all yours!!"*

Aftercare Planning

When asked who helped with aftercare planning and recovery maintenance, 48% of the individuals no longer in services noted that they had no assistance in this

regard. One individual stated *"There was a large gap in follow-up accountability and mostly very poor discharge planning was done."* Another individual stated *"The resources I first found did not inform me there were other available resources."* 40% noted they were offered some kind of formal aftercare resources, whether it be a 12 step sponsor and home group, or outpatient follow up services. The final 12% only had only family to help find aftercare support as need.

Aftercare Social Networks

Oftentimes one of the biggest indicators of sobriety maintenance is a change in peer groups; however, only 40% of the individuals who received aftercare planning had a formal conversation about peer groups as part of that planning. Another 8% determined their own need for changing peer groups and selected out of relationships that did not support their new recovery. As one individual stated *"I've just recently (past 6-10 months) ditched negative friends who I felt were only bringing me down emotionally. I have recently begun socializing with my co-workers at my current and previous job and they are all positive influences. I've also learned to be comfortable being alone and being happy with what I have."* The other 52% of respondents stated that they had no discussion of peer supports as being part of their aftercare experience.

Accessing Aftercare

While many individuals did not have aftercare planning, of those who did, 80% utilized these services. One individual spoke to exceptional aftercare supports, stating *"The treatment center sent staff to our home for 24 hours a day for 6 weeks. They helped us restructure the home to better fit his needs. When we won the suits against the district they had to agree to all recommendations from the treatment center. Which included parent and in home training. This continued until he aged out of the program. I (parent) attended workshops, lectures, conferences, and worked with trainings to understand and be involved in the process of keeping my son at home."* Another individual mentioned that aftercare supports were *"seldom provided"* but always utilized when given.

Treatment Successes and Treatment Barriers

We asked questions designed to get an idea of the positives and negatives of treatment experiences, both the services themselves and the individuals that provided them. The questions were asked in an open format, allowing individuals to speak to their experiences in their own voice. These responses were coded into the categories you see in the graphics below.

Helpful Services

The services, both provided by licensed professionals and peer professionals, were the most often cited as helpful services. Formal therapy services assisted in *"always having someone to talk to"* and peer support meant individuals "*understood the problems we were facing and offered realistic suggestions, and listened without judging."* These services are often longer term in nature, and provided needed ongoing care, per survey respondents. One individual noted that Clarity Child Guidance Center (located in San Antonio, TX) provided both strategies for discharge as well as follow-up services after discharges, which was noted as being *"great continuity of care."* Another individual noted that her child's in home trainers *"have been wonderful and having the same individual working with my child for 20 years"* helped keep their child safe and living at home. Several individuals noted that these longer terms services helped provide them both stability and accountability for their actions.

Rehab and other impatient services were also cited as important by a number of individuals. One respondent noted how much it reframed her experience, stating *"Rehab taught me not to be a selfish bitch (excuse my language). I thought I was a super cool person who didn't have to follow the rules without consequences. My counselor in treatment told me just because I'm super middle class, doesn't mean I'm not still an addict and that makes me no different than the crack whore I shared a room with. She brought me back down to earth, teaching me boundaries and positive coping skills."*

Safe recovery based housing and medication management were also cited as being helpful to several participants. Sadly, many people noted that nothing was helpful in their recovery journey. One participant stated *"they overburdened me"* and another stated that the doctors *"made me feel unimportant."*

Service Supports	Percentage of Individuals Who Found This Service Helpful
Therapy/Skills Training/Case Management	44%
12 Step Recovery/Other Formal Peer Supports	30%
Inpatient Treatment	12%
Residential Support (Recovery Housing)	6%
Medication Management	6%
NONE	**18%**

Barriers and Difficulties With Services

While multiple people cited therapeutic treatment as helpful, many more stated that it was unhelpful. The information shared pointed to formal therapeutic supports, no individuals cited peer supports as unhelpful. Multiple people cited ineffective providers and treatment systems when asked this question. One individual noted that the "*recovery center [was] not only completely ineffective (not statistically better than random) but it actually caused emotional harm due to the lack of qualifications by everyone who worked there and the gross negligence due to denying existence of actual diagnosed psychiatric disorders. Aftercare was completely unhelpful too, just a way for them to force anyone who relapses back into their treatment center."* Another stated *"Skills training through MHMR was unrealistic for our family, and it was impossible for my son to accomplish the tasks required. Judgmental case managers implied his problems would go away if I was a better parent (false) and repeatedly blamed me for his behavior rather than offering any real help. It did not appear that they really understood his situation or my efforts to seek treatment for him."* A third stated *"Case management is a joke, so is nursing services. In all the years I have been in this field only 2 case managers knew something besides my son's name. Nursing services do not know how to help a family. They do not keep accurate records nor do they follow through. The*

assessments that are required annually are copied and pasted on new forms. The state accountability is also a waste of money. I have documented and brought complaints concerning theft, Medicaid fraud, and abuse and they do not follow up."

Other frustrations include punitive legal actions *("Court is not the place for an addict."*), inappropriate mediation management *("I feel like they would give me any mediation just to give it to me and not really understand me and give me the proper medication."*) and the school system *("ARDs helped to tell me how bad my child was.")* The clear message in all these statements was a frustration with ineffective providers and ineffective systems providing cookie-cutter care rather than respecting the individual experience and needs.

These statements lend themselves as a possible explanation as to why trained peer providers were not mentioned as an answer to this question. When working in conjunction with trained, licensed providers, they have a unique empathy to the lived experience of the individuals and families they serve and are able to offer suggestions and strategies that are concrete and pragmatic. As noted in the question about the most helpful supports, peers provided support that did not judge or shame the experience of the family in question, which is vital to the recovery process. Within the research community, this is often termed as the use of "practice based evidence" over "evidence based practice."

Services Supports	Percentage of Individuals Who Found This Service Unhelpful
Formal Treatment Programs/Therapy	25%
Punitive Legal Measures	13%
Financial Supports	8%
Medications	8%
School Supports	8%
All Were Helpful	**8%**

Individuals Most Helpful in Recovery

One of the most interesting aspects of the answers to this question came in the explanation about why that particular individual was so helpful. While individuals played different roles in the lives of the respondents, one link was clear. Almost all of these people had a shared lived experience that made them empathic. A *"counselor who was also in recovery,"* a Federation of Families director who "*didn't blame me, but understood what we were experiencing and offered practical solutions for addressing challenging behaviors,"* a *"mother who has been sober 30 years as well,"* a probation officer who *"recognized the struggle, and helped try to address the problem rather than impose punishment,"* and *"friends going through the same thing."*

This speaks to the importance of how we interact with those in need of recovery support, regardless of our role in their lives. The individuals who spoke at length about these people, noted that the support was unconditional but their behavior always had consequences. It wasn't a "letting off the hook" experience, but an experience one respondent termed *"tough love."* Respondents noted that they were not shamed for the complexity of their experience, but still held accountable for their actions. The phrase that repeated itself throughout was *"they understood."*

Relational Supports	Percentage of Individuals Who These Supports Helpful
Peer Supports/Mentors	31%
Professional Treatment Providers	28%
Family	28%
12 Step Sponsors	14%
Friends	6%
No One	**6%**

Individuals Least Helpful in Recovery

Almost all the individuals surveyed had a story about someone in their lives who acted as a barrier to their wellness. When describing different professionals in the community, they described individuals who were ineffective, unqualified, and

unknowledgeable about treatment needs. There were many stories describing experiences in which school officials were unaware of the IEP strategies in place, mental health professionals with no experience treating the presenting issues, or representatives of the legal system that did not understand the needs of individuals seeking treatment. The recurring responses focused on how these individuals did *not* understand their treatment needs. As one individual stated, *"My outpatient counselor was horrible in my opinion. She had never dealt with addiction personally (I called her a 'do-gooder') because she just wanted to talk about all the positive things and stuff literature down my throat. Our sessions consisted of her asking questions and me spitting out what she wanted to hear so I could leave."*

The most horrific events were at the hands of law enforcement. One parent noted that the police would beat her son when he ran away and was on the streets. Another parent mentioned that the police continuously accused her child of engaging in attention seeking behavior, and that they did not have a mental health issue, despite a diagnosis of bipolar disorder.

Friends and family were also consistently listed as being unhelpful to the recovery process. As one individual *noted "Friends acknowledged the problem but still applied peer pressure to use drugs."* Others discussed the impact of unsupportive family, from individuals being judgmental to completing denying them treatment when they were youth.

Very few people stated that everyone they encountered was helpful. Again, it was interesting to note that professional peer providers and 12 step sponsors were again absent from the list of individuals thought to be unhelpful.

Relational Roadblocks	Percentage of People Who Found These Individuals Unhelpful
Treatment Providers	33%
Family	20%
Representatives of the Legal System	20%
Friends	17%
Representatives of the Educational System	10%
No One Was Unhelpful	**3%**

Safety Issues

While initially drafting this survey, we had several questions proposed that tied to the same theme, that of safety. Rather than leading individuals toward certain answers that we expected, we offered participants the opportunity to share in a general sense when they felt unsafe within the treatment process. The broader question gave us different responses than we may have garnered otherwise. Or, as one respondent noted, *"loaded question, as this is maybe the core to much!"*

The majority of respondents noted that the lack of safety came from their own illness or that of the loved one they were taking the survey about – i.e., that they didn't have the resources to keep themselves or the loved ones around them safe. One respondent likened it to being "surrounded by demons" and many others spoke about chronic suicidality as a part of their struggle. One family member discussed the multitude of ways they had to keep their child safe in their home with alarms, and cameras, and even sleeping in front of the doors of their homes.

Only a few respondents noted professionals in the community whose lack of competence caused safety concerns. Again, interactions with the police were noted. One respondent stated *"I still feel unsafe every time I see a police car. They have no idea how to effectively interact with people with mental illness and they put everyone at risk. Locally, they have hired some bullies. I feel fear when any of my*

children (all adults now) are out in _____ at night…not because of crime but because of our law enforcement staffing."

When individuals didn't feel safe because of the actions of others, it was often individuals in the system who were using substances and were violent and threatening to those around them. Several people mentioned an abusive male partner in their lives, and the threats made against them telling stories of how they were held hostage in their own homes and the actions they took to survive. Other women discussed how men in their recovery programs made sexual advances towards them that felt intensively threatening. While others discussed how relapse within their sober community often triggered the other residents, most of the individuals who answered this question in the affirmative were women who had been abused or felt threatened by men in their lives.

Cultural Differences

Forty-seven percent of the individuals surveyed stated that they did not experience any cultural barriers to their treatment. 6% noted that they struggled with a culture that accepted drinking as a norm, rather than as a problem behavior for that individual. The majority of individuals who noted a cultural problem, spoke at length about the stigma of mental illness, specifically. One individual stated that they were continuously fighting against the *"pull yourself up by your bootstraps"* mentality. Others were accused of intentional selfishness, one stated that they experienced *"biased assumptions that I was pretentious or arrogant"* while another stated their family thought they were *"being a selfish, angry brat."* Another stated that the people in their life *"were afraid and ashamed of someone like me instead of trying to help me."*

Many individuals spoke more specifically as to how they (or their loved one) were judged for the behaviors associated with their diagnosis. One individual stated:

> *People with "invisible mental health issues are often ignored until it's too late. Having mental illness and addiction issues is always difficult and getting the right treatment is even more difficult. Many people in the medical field and police thing everyone is only trying to get a narcotic or drug when in fact there are many who need those meds to help them. I suffer from depression but people think I'm fine because I cope better than most. Mental illness and addiction will always be a problem to treat especially if the police do not get proper training on how to deal with those who are suffering.*

Another stated:

> *When our son was diagnosed, people in the community and family members would tell us to get control of our child. The medical community will not allow him access to care because of his behavior. I have been told he was not a child, but a Tasmanian devil. We have been asked not to return to multiple*

churches due to his behavior. We could not go to the local swimming pool. There are so many misconceptions about his disability,

This question was initially desired to look at barriers to treatment due to the customs and habits of different ethnic groups. Interestingly, while many individuals identified as African American, Hispanic, or American Indian, no one mentioned any barriers to treatment related to their ethnic background. Instead, the universal cultural stigma associated with mental illness and addiction was mentioned over and over.

What Else Do We Need To Know?

Two final questions were attached to this survey. As with all qualitative research, it is easy to miss important information due to how questions are presented. Some of the richest responses come from asking "what did we miss that's important?"

So the following questions closed the survey. The first was literal, and is a common ending question within the constructivist grounded theory methodology.

Is there anything else we should know about your experience that we didn't already ask?

The second question was similar, but added a more specific face of power to what was being asked. While many people may be understandably skeptical of the power a researcher has, we all understand the power of politics. So the second question was:

If the governor met with you and asked "What could be done to improve services for you?" what would you tell him?

The answers to these questions were rich and many are replicated below as they eloquently speak to the frustrating experience of fighting for recovery in a flawed treatment system.

Expanded Services

- Adolescent substance abuse services are needed. There are no voluntary inpatient treatments for adolescents in_____. The substance abuse outpatient services can also be expanded on, aftercare services are a great need, family treatment and recovery support, recovery coaches for every adolescent that is in need. Many of our kids are losing their life to substance abuse and we need to be paying attention to the needs.

- Promote campaigns that promote the removal of stigma. Mandate healthcare to address substance abuse issues at the beginning of any and all doors to any kind of service.

- Invest in BH Health as a Public Health Care Issue.

- There is need of more safe housing after treatment. 30 days of treatment is not long enough. There needs to be more long term rehab services. Also there needs to be a way to enter someone in involuntarily when they are a harm to themselves or others

- Peer services and networks

- Make trauma therapy more accessible and inpatient treatment more affordable and a 90 day minimum

- Housing, jobs for felons

- More access to quality inpatient and outpatient services

- My experience was pretty good, but that others lack access to detox beds, have long wait lists for treatment, and the staff at many of these agencies are not very compassionate. Many are, but many are not.

- My child (children, I have 3 adopted from CPS) have arms and legs that work but their mental illness has been tremendously disabling. They all had the best psych services but that wasn't enough. Despite their birth moms were diagnosed as substance abusers and bipolar while incarcerated, foster families and adoptive families were told nothing about mental illness. The son who was never hospitalized is in prison now. Bipolar for one child morphed into schizophrenia. The prodromal years had him constantly being accused of bad behaviors at school that we know now are typical for prodromal schizophrenia.

- Have better mental health services in State. Not incarceration.

- Leave open medical help

- Get doctors and counselors that really want to help kids and care about their issues

- I would say that every person matters in this world no matter the disability we didn't ask to be this way, but we as citizens and children of God deserve to be given the chance to live life the best way we can and if this means the best

medical care possible then why not give it so we can function in this world the way we were meant too.

- Get rid of mental health court

- Immediately shut down every fraudulent, negligent, unqualified recovery center by creating strict regulation of the entire industry. Make it a requirement that any center that charges for service use EVIDENCE BASED TREATMENT and follow standard DSM diagnosis guidelines. Make it illegal for unqualified crackheads to run a recovery center.

- Provide treatment facilities for me and others like me who are crying out for help by misbehaving. We don′t need negative attention but rather an intervention that will change our ″stinking thinking″

- Offer more community based services and peer supports, and not just for the person with the disorder, but for parents, siblings and the entire family. When one person is sick, the whole family suffers. Offer respite opportunities so caregivers can have a break and care for their own mental wellbeing, and make recreational activities available that can accommodate the needs of those with mental health disorders. Make these things available in each and every community, town, city and neighborhood, because it shouldn′t be an ordeal to access this type of help.

- Stop putting the mentally ill in jail or prison and start treating the actual problem. Stop ignoring those that suffer from invisible illnesses such as depression or bipolar disorder. Substance abuse needs to be treated not ignored. There need to be more accessible programs for those in need.

- It would have helped most to have had access to effective supports in his childhood. In adulthood, he could use effective peer to peer supports that fill immediate needs. Quality psychosocial rehabilitation that provides real opportunities for prosocial relationships, work opportunities, leisure ...

- I would ask for cameras in the classroom so we could see how our children were being treated. So many times he came home with bruises and no one could explain to us how it happened. I would tell him Head Start is removing children with behavior problems from there programs. If we want parents to work and get off welfare then help support us with day care, medical care and services. Also I would say with the intervention we received and sue for made our [child] become a taxpayer instead of tax burden.

- Make more long-term services available. My son was an 18 yr old heroin addict (with a family history of addiction) and because we could afford private treatment, he was in primary care treatment for 7 months and a sober living environment for another 8 months. He is now in college and doing amazing.

- Better post-adoption services for children with mental health issues.

- More coaching for under 1 year in recovery.

- It's a long process. We need long term programs to be successful in this fight.

- I have worked in Substance abuse field for the past 7 years, the whole field needs to be revamped. Severe MHMR clients need their own substance abuse facility instead of throwing them in with addicts and alcoholics. Neither understand the other and most of the time they are the most disruptive in a substance abuse facility

- Finding a place to live and work once you've recovered with felonies is very, very hard.

- The degree to which my family history of SUD is deep and wide. Every first second and third degree family relation, except my children, are addicts and alcoholics. I am the first to pursue recovery.

- The school has kids for 40-50hrs per week but do not want to be part of the treatment network. We had great support when another child was diagnosed with a heart problem, as well another child with asthma. Mental illness equates to bad behavior but with intellect not challenged, they will make sure they are not off campus during the TAKS or TAAS or whatever standardized tests are being given.

- I would like to say one more thing. I am a mother of 3 girls and knowing that I'm mentally ill people thought I would hurt or kill my children and I was always under a microscope. I didn't think that was fair, but I am very blessed because God has always been beside me. My children were my reason for living even though it was just us with no family support what so ever struggling with my demons. I raised 3 beautiful daughters all by myself. 1 in

college, another graduating next year and my last daughter an A and B honor roll. People like me never get notice for our achievements in life, but my two oldest also have a diagnosis due to me and yet they attend their appointments and I make sure they listen to what I have to say, because my kids are the future.

- AA is not the only way to get sober. Maybe look at some European countries or any alternative methods to consider other options. I have stayed sober for years starting at the age of 17 despite what i went through. I am not writing any of this from a place of anger, rather out of hope that the ACA will revolutionize the way we treat addiction/alcoholism in this country. Now that government money is flowing in, they actually have to produce results...

- Please help our children. Stop making a pipeline to prison for our youth who have not had proper intervention. I am a Master level Social Worker and a Special Education Teacher and I have worked in the 4th largest city juvenile justice system in the United States. I lived in the treatment center with my child to learn everything I could. I have been on both sides of the table and have walk the walk. Texas has not gone forward but backwards in helping our children with special needs. If we as parents are willing to work with you then please walk on day in our shoes and learn to work with us. We are only trying to be the good parent. We would never wish our sorrow on anyone however we get so burned out hearing the same promise year after year. Charging a child as an adult when they do not understand the actions they are taking causes harm is unforgiveable in a civilized country.

Service Funding

- Use my net income, not gross, to determine eligibility.

- Make treatment affordable for those who want and need it. As a mom, I am constantly helping others in need, and most of the problems arise when it comes down to paying for treatment that is unaffordable.

- Lower deductibles on health plans and "practical parity" in terms of more providers needed in-network on health plans.

- Better programs, better coverage on insurance.

- Stop focusing on just AOD issues and fund services for the other issues that are out there and just not so openly accepted and talked about. We are ignoring huge and problematic issues.

- The best psychiatrists do not accept Medicaid. We have to pay out of pocket for quality treatment and drive 3 hours for it.

- Quit taking away funding for the services we need and make them more accessible no matter the income

- Please make more money available for all mental health services.

- Make unaffordable and inaccessible resources affordable and more easily accessible.

- Ensure proper funding and reimbursement so agencies and organizations will want to offer these services.

- Not everyone can afford psychiatric doctors with no insurance and the places available are underfunded and over capacity as of now.

- I would tell the governor to open the door to Medicaid waiver programs.

- Help with financial assistance

- By providing long term treatment (especially for young people) the state could save much money. More money up front to help could save much money that is spent later. And save lives. The sad part is that if we didn't have financial resources, I doubt my son would have been successful. Long term treatment.

- Have more assistance in obtaining psychiatric medications. They are outrageously expensive and most people cannot afford them, which leads back to the cycle of mental illness worsening.

- More low cost treatment centers.

- State funded programs, fund groups aimed at supporting the 1-5 year contingent.

- Incredibly frustrated at the lack of sufficient supports for indigent populations.

- Cannot afford food at most times and the food stamps program is not working. There are not enough assistance programs for families like mine. I can't work due to my child's mental health issues and constant Dr.'s appointments.

Centralized Resources and Advocacy

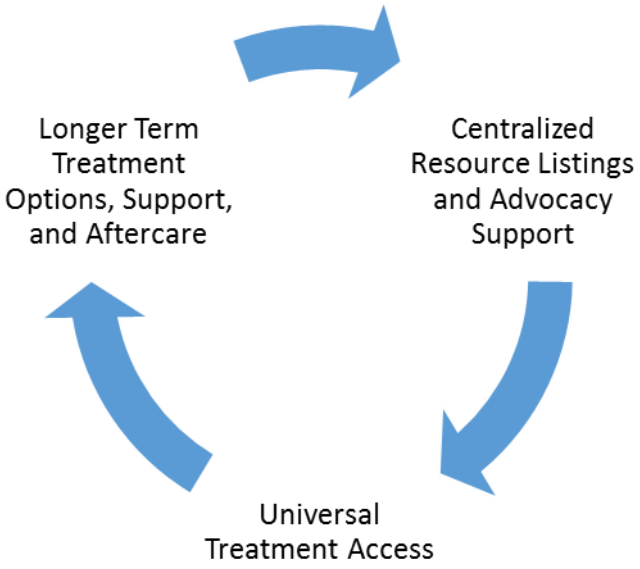
- First, establish regional family organization support and training centers that are coordinated by the Texas Federation of Families. These could be housed in the Regional Education Centers and should be staffed with family trainers with lived experience. They should in turn be charged with providing support and supervision for the LMA family partners, for establishing local family run organizations and supports that provide advocacy, family to family supports to all Texas families with mental health needs. They should also assure that families have a meaningful voice in the development of local services.

- The waiting list in Texas is 10 years long. Parents need to know at an early age about signing them up for services. It should be required when they start receiving services in a school they also be signed up for all services with the state.
- Increased awareness of recovery resources available. Often it's hard to find what's out there.
- A single website that lists supports for indigent populations.

What Does All This Data Mean?

Unlike a traditional grounded theory approach, the constructivist grounded theory recognizes that there is intersectionality in our experiences and our approach to change. The data generated in this project was no different. Two main needs emerged. One focused on the flaws within the system itself, and the other focused on the providers within that system. Both speak to important aspects of systemic change.

Treatment Needs – The Systems Approach



Three main needs emerged within the state of Texas. The first is the need for a complete centralized listing of resource supports throughout the state. As all individuals with lived experience can testify, local resource lists are often incomplete and out of date and individuals spend huge amounts of time trying to navigate through it to get help. Hand in hand with this need is advocacy support in accessing these services. Many individuals do not know how to navigate the system, what their rights are, and how to make sure they access the best treatment available. And quite often, even with the best advocacy skills, we are unable to access the needed treatment.

This leads to the second need: Funding for treatment regardless of income. Most of the individuals surveyed were middle class. In mental health, these are the individuals who slip through the cracks. The wealthy can afford the best treatments out there, and the very poor have federal insurance programs that cover treatments that private insurance providers do not (PHPs, IOPs, RTCs, longer term inpatient services). While the upfront costs will be much higher, the savings to society over the lifespan of the individuals we treat will be enormous. As noted earlier, one respondent commented that the right services for her son allowed him to be a tax payer in adulthood instead of a tax burden.

The last articulated need is that of longer term treatment options, with consistent follow through. Treatments tend to be reactive instead of proactive and based on mitigating a crisis. When individuals are stabilized and released, they often return to the same patterns of behaviors and relationships that caused the crisis to begin with. Most people who were offered continuity of care utilized those supports. There is an enormous need to help individuals build a supportive, sober network after they regain equilibrium. Finding a safe place to live, a job, supports in staying sober, appropriate follow up counseling and medication management were all cited as services that were needed in their communities.

Relational Needs – The People Approach

Four main relational needs rose from the data. These needs were termed relational, as they are less about the actual treatment system and more about the individuals who work within it. Essentially, while we need more capacity to treat individuals, the services also need to be of a quality and nature that promotes long term recovery.

The need for trained peer providers was either spoken to deliberately, or implied throughout the survey. Individuals with lived experience expressed deep appreciation for working with others who understood their situation, and operated from a "been there and I can help" approach to treatment. Peer providers are also exceptional at teaching individuals the skills they need to advocate for themselves and their families, rather than perpetuating more reliance on the treatment system. A systematic approach to building more peer supports into communities with the training they need to be effective is a cost effective strategy to helping Texas families.

Of course, this suggestion begs the question. Do all licensed treatment providers need to also be peers? Of course not, though it is a great help when a licensed (or otherwise professional) individual with lived experience works with families. Even if we have some lived experience, no individual experiences are exactly the same. But we can tap into our empathy as licensed treatment providers to break down the walls of stigma and shame. Licensed treatment providers with advanced degrees have the benefit of training and perspective, but are not experts regarding the personal experiences as others. Changing how we train our professional providers can make a huge difference in outcomes. Communities who train their police and school officials in crisis intervention have found an enormous reduction in the use of restraint and other forms of force (Johnson, 2010; NAMI, 2015).

Providing ongoing training to treatment professionals about an empathic deshaming treatment approach is equally valuable. Metaanalytic research of evidence based practices have found that that the core of all therapeutic relationships is the relationship itself. If individuals feel heard and valued by their treatment provider, they trust them that they will get better. And then they do (Wampold, 2011).

Another interesting emerging trend, was the amount of engendered violence that was attached to the experience of both active use and the treatment experience. While all the individuals who discussed this story did say they received appropriate counseling for the abuse, their stories do lend support to another training and public education need. Violence has no ethic group, socioeconomic status, religion, or country of origin. Violence does have a gender, however. Murder is a crime that is committed by men 90% of the time, 6.2 rapes are reported every minute in the United States, while the estimates are three to four times that high (Solnit, 2014). These numbers were substantiated in this survey, as all the domestic violence victims were women. When the treatment programs themselves felt unsafe, again the victims were women. Violence, mental illness, and substance use have become a recursive cycle which is continuously triggered. And while data within our survey matches national statistics, it is also known that men tend to under report sexual violence (Bullock & Beckson, 2011). Therefore we need to be aware that while violence is more likely perpetuated on women, many men have had a similar experience. Trauma informed care communities (not just sequential trauma informed therapy) is an essential part of the long term recovery experience.

Ensuring that all care take heed of the violence and trauma history likely among those seeking services (especially women) is invaluable. Creating mechanisms to keep individuals safe during the treatment process will go far into keeping them engaged in treatment. Teaching individuals about the cycle of violence and the notion of consent as both a prevention measure and an intervention measure may prove to be invaluable.

Finally, many people noted the stigma associated with their experience. Advocate and parent Liza Long (among others) have done amazing work in recent years destigmatizing the need for mental health and substance use treatment. There is a significant amount of misinformation about what treatment and recovery are, and what quality care entails. Infusing accurate knowledge within public health curriculum in the school systems as well as continued campaigns to educate the general public has the potential to change how we view individuals and families who are living with mental illness and substance use issues.

Conclusions

An exploratory survey of this nature is not without its faults. While we had many people speak openly and honestly about their experiences, we did not have as many participants who were still youth receiving services in the system. Including their voice in future research will be vital. However, despite the flaws inherent in a social science research paradigm, we believe that the data collected forms an excellent grounding in seeking systemic change in the treatment system.

In short, the willingness of individuals to share their stories with such depth and reflexivity was a humbling experience for us. Survey participants were articulate, thoughtful, and took a great deal of time to go through each question and answer with depth and care. We are grateful for their stories and hope that their willingness to share is the first step in systemic change.