

# LANGUAGE OF MENTAL HEALTH

THE PARENT PERSPECTIVE



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*PREPARED BY, THE VOINOVICH SCHOOL OF LEADERSHIP AND PUBLIC AFFAIRS*

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## EXECUTIVE SUMMARY

Although rates of mental illness do not differ from rural to urban areas, rural mental health utilization rates have been shown to be lower than urban rates, with rural populations being “less likely to access services with frequency and less likely to receive quality services when they did access them” (Heflinger & Christens, 2006, p. 383). Focus groups conducted with parents in the rural Appalachian region of Southeastern Ohio, the majority of whom indicated they or an immediate family member had accessed services for a mental health concern, revealed some themes consistent with what is known about mental health in rural areas, but some differences emerged as well. Our overall aim was to explore how parents in the region talk about mental health in order to improve mental health service utilization. Through the words and phrases used during our focus group discussions, the participants offered a window into how the language surrounding mental health affects attitudes, behaviors and opinions regarding mental health service utilization. During the project we also discovered that much of what was learned relates to broader themes about mental health.

The New Freedom Commission on Mental Health (2004) explains three variables that influence rural persons’ underutilization of mental health services – accessibility, availability, and acceptability. According to their findings, these factors lead individuals to enter care later in the course of the illness, resulting in more serious, persistent, and disabling symptoms that require more expensive and intensive treatment responses. In terms of accessibility to services, the Commission notes three components that disadvantage rural residents in receiving services: knowledge, transportation, and financing. Regarding accessibility issues, focus group participants discussed lack of payment methods such as insurance, and a small number noted transportation barriers. Regarding availability, some participants discussed their perception of services being better elsewhere and the limited number of local providers. However, the greatest barrier identified by parents in this study was acceptability.

In addition to such barriers as lack of transportation, economic constraints and limited knowledge about effective treatments, unique cultural factors are also likely to influence utilization of mental health services. Appalachian families often are notably independent and highly value and rely upon extended family for social, economic, and health support. Due in large part to a history of social and geographic isolation until well into the 20<sup>th</sup> century, as well as chronic economic depression, Appalachian culture is often characterized by a mistrust of

outsiders and an emphasis on self-reliance (Beaver, 1988 & The Rural and Appalachian Youth and Families Consortium, 1996). Although the characteristics of independence and strong extended family support are clearly strengths, they unfortunately often result in Appalachian families accessing health and mental health services “too little, too late”. Research has demonstrated that individuals with high levels of stoicism are less likely to seek help and that cultural values of self-reliance influence psychological help-seeking behaviors (Judd, Jackson, Komiti, Murray & Fraser 2007).

Consistent with the Commission report, the focus groups suggested that stigma surrounding mental health impacts the acceptability of mental health services. However, this study also revealed that concerns regarding service quality as well as a lack of understanding about the provision of care and a general sense of fearfulness contribute to the construct of stigma, such that it involves more than simply carrying a mental health label. The perceived quality of the services provided was more frequently discussed than stigma as contributing to the acceptability of mental health services.” Many participants noted dissatisfaction with service quality. They felt that they, their child, or other family member with a mental health concern was not receiving appropriate treatment, and that the treatment provided was not properly explained. Thus, there was a mismatch between patient (or family) expectations and what mental health services generally entail.

Fear was a significant factor across groups and was expressed in a variety of areas related to mental health. Some participants’ fear appeared to stem from a lack of understanding of mental health care or, in other words, what would happen during treatment. Others expressed a fear of having things done to them or to their children and not having any control in the process as well as a fear of medication and fear of potential consequences of seeking mental health services. These consequences were related to having children removed from their care as well as fear of being looked down upon for seeking care.

Focus group findings are not intended for generalization. Rather, the purpose is to learn in-depth information about a topic or condition. In this study, for example, there may well be others in the community for whom accessibility is a significant barrier. However, with the exception of payment issues, access topics were raised infrequently across the focus groups. Structural barriers of accessibility such as distance and transportation are perhaps perceived as less of an issue than other accessibility issues such as cost and far less of a barrier than

acceptability. It must be noted that although acceptability of care was a reported barrier, the majority of participants did access services for themselves or a family member, even though few reported receiving ongoing care for that individual.

## **METHODOLOGY**

This project is based upon a request by Integrating Professionals for Appalachian Children (IPAC) and the Ohio University College of Medicine (OU COM) to The Voinovich School of Leadership and Public Affairs at Ohio University to conduct focus groups informed by Community-Based Participatory Research (CBPR), investigating how parents in this Appalachian region of Ohio talk about mental health. A partnership of 19 university and community health care organizations in Appalachian Ohio, IPAC focuses on improving how our local health, mental health and allied health providers deliver services to families whose children have developmental and behavioral concerns. Anchored in collaboration, the partnership selected CBPR to inform the design of our research. CBPR integrates research and action for the mutual good of all involved, promotes co-learning and capacity-building, emphasizes local relevance, and broad dissemination of results. Toward that end, IPAC and OU COM purposefully identified a variety of stakeholder groups to participate in the research team, including a community health nurse, a clinical counselor, an Ohio University College of Medicine faculty member, a community parent and two Voinovich School researchers.

After identifying the research team, development of a focus group moderator guide began. Adhering to CBPR principles, development of the guide included community input from professionals and laypersons on question phrasing, language and question order. The research team then spent further time revising the focus group moderator guide. The guide was piloted with a group of parents and community members to test the questions and, based on their feedback, additional minor revisions were made. Although Voinovich School researchers facilitated, recorded, and transcribed the focus groups, the entire research team was involved throughout the project.

Voinovich School researchers provided training on focus group analysis methods for the remaining research team members, prior to the analysis sessions. By listening to the focus group audio recordings and reviewing transcripts or notes, the team members were immersed in the discussions prior to analyzing the data. Each team member brought their professional expertise

and experiences to the process of interpreting the data. Three analysis sessions were held during which the team members discussed various themes as well as specific language and phrasing used by the focus group participants. Voinovich School researchers authored this report with input from the other research team members.

Results of this study will be shared broadly with IPAC, local mental health service providers and potential referring providers in an effort to inform referral and service provision practices. The purpose is to understand how language influences mental health service utilization in an effort to improve rates of utilization by altering language used by referring agents, whether they are clinicians, physicians or nurses.

## **FOCUS GROUP PARTICIPANTS**

Thirty-two residents of Southeastern Ohio (31 females and one male) attended the four focus groups for this project. Half indicated they had lived in Southeastern Ohio all their lives while 20 others stated that they had lived in the area for five or more years. The focus groups were held at the McArthur branch of the Vinton County library, the Nelsonville Family Center in Athens County, the New Lexington Head Start in Perry County, and Trimble Elementary School in Northern Athens County, Ohio. In addition to participating in the group discussions, attendees were asked to complete a short demographic survey, results of which are included below.<sup>1</sup>

The majority of participants (72%) indicated they had sought help for an immediate family member for a mental health concern, which may be reflective of the recruitment strategies. A combination of general recruitment (for example, flyer distribution at schools) and targeted recruitment strategies were used. Local social service agency and school staff assisted with recruitment for all of the groups and, based on the topic, recruited participants who they knew had sought such help. Community level agency employees who provided help with recruitment either through direct notification or through broad distribution of surveys included a school social worker, a school nurse, a home-visiting social worker, a Head Start site director and a family center director. As a participation incentive, focus group attendees received a forty dollar store gift card. Four of the participants were between the ages of eighteen and twenty-

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<sup>1</sup> The facilitator completed the survey questions regarding gender, whether the participant was a parent or guardian, the number of children living in the home and whether or not someone in the family had received help for a mental health concern for the two participants who did not complete the survey. The answers were determined based on information provided by the two participants during the discussion.

five, fourteen were between the ages of twenty-six and thirty-five, and ten were between the ages of thirty-six and forty-five. Three provided no answer to this question, and one was between forty-six and fifty-five.

The participants in this study are mostly categorized as low- or very low-income. Twenty-five (78%) reported a household income of less than \$15,000 yearly. Thirteen of the families in this lowest income category reported that four or more people are dependent upon that income. Two reported incomes between \$16,000 and \$25,000, and two between \$26,000 and \$35,000. One participant had an annual household income of between \$46,000 and \$55,000, and two did not reply to the question. On average, four individuals per household were reportedly dependent upon the incomes indicated. The average number of children in participants' households was two, but ranged from one to seven. Eleven participants had just one child. The average age of the participants' youngest child was five at the time of the survey (excluding one outlier whose youngest child was 26).

This project entailed gathering personal information about a somewhat sensitive topic. Prior to starting the study, the research team gained approval from Ohio University's Institutional Review Board.



## FOCUS GROUP FINDINGS

The participants in this study were all parents and openly discussed their thoughts of the mental health service system, which revealed that the perception of the mental health system and available services influences whether people seek help or continue to receive services. Their perception of the referral source's willingness to help also has an impact. Regardless of what or how care is actually provided, the client's view of an agency or referral source and the resulting impact on accessing and receiving care for their children emerged as a central theme. The following sections describe the specific language, associated perceptions and actual experiences that participants had related to mental health, mental health services and referrals for mental health services.

The following questions were posed in the group discussions, along with numerous prompts and queries in order to clarify responses, follow conversational themes and gather additional details.

1. What are the places or agencies that you think of when you hear mental health?
2. What do you think of when you hear mental health?
3. What helps people talk about mental health?
  - a. Other people's experiences?
  - b. When you hear about people getting better?
4. What makes it hard to talk about mental health?
5. What are some of the things that stop people from asking for or getting help for mental health?
6. What things make it easier to ask for or get help for mental health?
7. What about when it comes to kids, what happens that gets people to look for information about mental health?
8. What do you know about people's experiences with mental health services for kids around here?
9. If your own child was given a mental health diagnosis, what thoughts would run through your mind?
10. What would you *do* if you were told your child had a mental health problem and needed help?
  - a. Are there certain people you would talk to? Wouldn't talk to?
  - b. Are there certain places you would go for help? Wouldn't go?
  - c. Who else around here helps kids, mental health related or other services? (Are there specific agencies or groups that help kids?)
  - d. What should those places do, or not do, as far as mental health for kids? (Facilitator note: If only school age children are discussed, query re younger children)
11. Where do you think is the best place to offer mental health services for kids? Ideally?
12. What is it about those places, that makes them better locations?

13. Of all the issues around mental health that we talked about today what do you think are the biggest issues?
14. Finally, was there anything related to mental health that we didn't talk about today but should?

### **ACCESSIBILITY/AVAILABILITY/ACCEPTABILITY**

Acceptability issues in terms of stigma and, in particular, perceived quality of care were the biggest barriers identified by focus group participants, dwarfing both accessibility and availability. Though revealed as somewhat less of a barrier, availability of services was also discussed in a variety of forms. According to the U.S. Department of Health and Human Services (USDHHS, 2005), 55 percent of rural counties in the country have no practicing mental health professionals. This is consistent with data from the past 40 years that shows “approximately 60% of rural America has been underserved by mental health professions” (New Freedom Commission on Mental Health [NFCMH], 2004). NFCMH (2004) goes on to say, “Rural areas are experiencing serious shortages of health and behavioral health providers and programs,” and “most specialty mental health (psychiatry and psychology) care is available regionally only in larger trade centers or locally only through periodic visits by itinerant providers.” Moreover, the three counties involved in this investigation have all been designated as Mental Health Professional Shortage Areas (<http://www.hrsa.gov/>).

In all four groups, participants were able to identify the local, multi-county mental health provider or a local satellite provider, and most had received services from this agency at some point for themselves or a family member. A few participants across the groups discussed the limited range of mental health care options available in their rural communities. Comments such as, “*you don't have that many choices*” and “*...there's really not a second choice around here*” reflected participants' concern about choice of providers. One participant discussed being on a waiting list for nearly a year as she switched from one county to another within a single provider. Another directly addressed the shortages described by NFCMH:

*I don't think there's enough help available around here. I think that there's more demand than supply. Do you know what I mean? More people need it and there's [sic] not enough doctors to take care of the people that need it.*

## PERCEPTION OF LOCAL SERVICES

Most participants in all four groups reported dissatisfaction with services provided by the local mental health agency and went on to state a preference for the services of providers in other areas—typically, larger providers in urban areas—even if they had not received services from them. One participant who took her son to see two different providers said, “*I have a lot more faith in [provider in other county] than I do in [local] county.*” Another stated, “*I’m going to have my boy diagnosed at [larger hospital], with a different person and a different mental ward, to see.*” In a couple of cases, participants believed the services at a neighboring county satellite clinic were of better quality than those offered at a clinic operated by the same local provider in their own county. Not all of the participants who commented on this had actually received services in the satellite clinic, but were basing their opinion on comments made by family members and friends.

*...it’s hard to get in there because [pause]. My friend, her daughter goes there, and she said to make an appointment is very hard because people from [local county] is [sic] going to [neighboring county] to try to get help.*

The perception of the quality of mental health services appears to be rooted in how well a person understands the available treatment options. The experiences reported by participants in this study indicated they often do not understand actions taken during the therapeutic process, including how providers arrive at diagnoses, or what the therapeutic value is of activities that occur during sessions. Even if the quality of care is high, the perception of it may be diminished due to a person’s lack of understanding of the reasons for the actions taken. As a result, patients believe the service was not useful to themselves or a family member. Examples of this issue are evident in the comments of several different participants:

*There’s no way you can get anything out of playing checkers for three days and come tell me that they’ve got a lot of built-up anger.*

*I just don’t understand how they could call it in five minutes. I mean, he was in there no longer than five minutes, and he said he was ADHD. I don’t see how you can figure that out in a child that’s five years old in five minutes.*

*I think they diagnose way too quick. I don't think they try.*

*Like my son, he didn't even see the psychiatrist. She read over the paper that we checked off, the teacher and myself, and she decided by that.*

*[Referring to adult inpatient] The whole time you're there you're coloring or something like that. I wanted to learn about mental health. They said their job is to have you wait until you are calm and then you leave. I want to learn about how to be mentally healthy.*

Several participants stopped taking a child to their local provider after having what they identified as a “*bad experience*”. One participant stated, “*Honestly, a lot of people are having bad help.*” Another said, “*Every person I ever talked to has taken their kid to different places and never really had, I think, a lot of luck*”.

In one group, the facilitator asked what would make for a positive experience, and participants had a difficult time identifying what that would look like. For some, the possibility of ever accessing care again from the local provider was ruled out. After some discussion, one participant clarified this point, “*I think that probably what she means is once you have one negative experience, it's hard to find the positive in any other experience. Or maybe because if you had a negative experience, you just give up.*” Related to the issue of fear discussed in more detail later in the report, another responded to this statement by saying, “*Yeah, you're afraid to have another bad experience like the one you've already had.*” Although the parents in this group felt they were unable to respond to this direct question, they were able to speak about the factors that would assist them to seek help for themselves or a child, as were participants in the other groups. The factors identified by participants are discussed in more detail in another section of the report.

Although most of the participants in all four groups had reached out for help in the past, many were generally skeptical of diagnoses given to children. This skepticism seems to be associated with the same lack of understanding of the process discussed earlier related to treatment. Because diagnostic procedures are not well explained or understood, parents often mistrust the diagnosis. One participant succinctly stated, “*You've gotta [sic] watch for*

*misdiagnosis at mental health.*” In all groups, several participants expressed the belief that Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) are overly diagnosed. According to one mother, *“There’s [sic] just so many kids now that they say have that whatever it is... ADD. It’s just constant, all the time.”* There were also concerns about whether a diagnosis is given *“for the sake of other people”*, more specifically school personnel. The concern is exemplified by the following statement:

*And I’m not rich. So am I doing this for my child or am I doing this for the teachers to have an easier day? That’s what I want to know: if my kid’s really got something the matter with him. Not, diagnose him because the school says so.*

Only one participant countered this and the perception about schools discussed above, *“...there’s a lot of teachers at school that I don’t think believe in ADHD, and they don’t believe in giving them medication.”*

## **MEDICATION**

Related to the perception surrounding diagnosis and other services, many participants did not fully understand the medications being prescribed to their children. Fear and mistrust of medication and the impact of medication on their children’s growth and development were discussed at length in three of the groups; while in one group medications were discussed but somewhat more positively. In that group, medications were recognized as often having a more positive impact and only one individual spoke negatively of medications. The concerns expressed by participants are evidenced by the following types of statements:

*Because they’re not going to tell you there’s a way to deal with it [ADHD] without drugs ...they would up his dosage, then lower it, and up it, and lower it... Finally I’d just had enough of it and I took him off of it.*

*The medication—there’s supposed to be counseling with the medication. And my son took medication for years, and someone said, ‘Well, do you take him for counseling?’ I said, ‘No.’ They said, ‘They’re supposed to be going to counseling with the medication.’ I said, ‘Nobody ever sent me to counseling with him!’*

*They always want to go straight to medication. And, unless you refuse that medication, they don't tell you about the other things that can be done without medication.*

*See, I wouldn't want a pill. I'd want some suggestions on what you could do though.*

Participants of one group that had substantial concerns about their children becoming drug dependent, live in a community with a significant and widely acknowledged drug abuse problem. Parents from that community made such statements as:

Participant A: *I mean, they'll tell their friends, "I take a pill."*

Participant B: *That's like a drug-addicted attitude, and I don't want my kid to have it. I'm afraid it's going to lead to drug problems when he gets to be an older person.*

Among all of the groups, twelve individuals expressed concerns about the use of medications, some with significant intensity. A smaller number reported they saw improvements in behavior because of medications, but far more had concerns about effectiveness, addiction, and the potential for serious physical side effects (for example, liver damage)..

There was also a common perception that children and adults are being overmedicated. Part of the fear of medication seems to relate to a lack of understanding of their child's diagnosis and the perception that their input regarding symptoms and side effects were not valued in the process of adjusting dosages or modifying medication treatment regimens. The use of medications was perceived as something that happens to their children, rather than something that may help their children. For example, *"Did they stick him on another med?"* This type of statement also points to the sense of powerlessness and lack of involvement in the decision-making process expressed by many of the parents. Most of the participants wanted to know more about how the medications would be prescribed and used as part of treatment.

## FEAR AND FRUSTRATION

Fear is often the result of participants' lack of understanding and perceived powerlessness in relation to medication use, mental health services, and other forces of authority in their lives such as schools and social services agencies. A number of parents felt they had little control over what was happening. For example, they noted that school staff may insist on evaluations of children or medication. They also felt as though little explanation was provided about diagnoses. Fear was a natural response to the perception of having no control over what was happening and frustration resulted from feeling as though no one was listening.

*Yeah. And they threaten you. They say, "Your child has ADHD. You need to get them treated or we will expel you, or blah blah blah." Like at our school here, if a child has ADHD they're automatically put in special classes.*

Some participants felt that child protective services workers blame mothers for their children's condition, and eight participants from three of the four groups expressed fear that a consequence of seeking mental health services might be having children removed from their care. Additionally, a parent at one site said "*child services we all fear.*" It was unclear, whether this comment was about fear of having children removed from their care, or simply fear of Children Services. Not wanting to "*lose kids*" was a direct response to the facilitators' questions of, "what makes it difficult to talk about mental health?" and/ or "what are some of the things that stop people from asking for, or getting help for mental health?" This was demonstrated by the following exchanges during two of the groups:

### Group 1-

Participant A: "*Scared. Scared that they're going to turn around and stick it to you. Take your babies from you.*"

Participant B: "*Oh, yeah, that's a big fear.*"

### Group 2-

Participant A: "*I think it's especially hard for people with children if you think you have any kind of a mental [health issue]... Obviously, it's something that could affect your children. And I think they're afraid they're going to get their kids taken away or something like that happening, because of... they're just replications of [the parent]... I think some people wouldn't talk about it at all for fear of something like that you know.*"

Facilitator: *It would be used against them?*

Participants A, D & E: *Yeah.*

Participant F: *I think a lot of people are actually afraid of the word “mental health,” and what it can do to you. I mean, even going: What’s going to happen to me? What’s going to happen to my kids? Are they going to say I’m crazy, or are they really going to understand?”*

The focus of these exchanges was on perceived reprisal for seeking services or having children taken away for revealing that they, the parent, have a mental health concern. With fear of such consequences as “losing kids” as a barrier, the reluctance to seek care is not surprising. This is a significant finding because seeking treatment should be encouraged, not discouraged due to perceived threats.

These responses point to lack of information about mental health care and mental illness. They indicate a belief that seeing a mental health professional will result in a significant diagnosis or that seeking treatment for mental health issues is a sign of weakness and incompetence. These beliefs generate fear of consequences from other community systems. The fears also may stem from the expressed belief that the system somehow knows more about them than they know themselves. The fact that rural areas generally have lower levels of education may contribute to this lack of understanding and exacerbate the fears. Research indicates that the lower educational attainment levels in rural regions (15 percent of persons in rural areas are college-educated versus 28 percent in urban areas) impact utilization of mental health services (NFCMH, 2004).

## **STIGMA**

Participants in all four focus groups reported numerous negative connotations related to seeking mental health services, suggesting that the traditional stigma associated with mental health continues to flourish within these communities. Though the majority had accessed services, concern over how others perceive people who acquire mental health care or have a mental health diagnosis was a common thread. Participants noted their children were “*marked*” as one parent referred to it, and expressed concerns about their children being “*labeled*” with a mental health diagnosis. Specifically, parents fear their children will be treated differently by



schools and by other children, *“I think there’s also a fear that your child will be treated differently, or excluded, or you know. Not given the same chances everyone else is”*. They reported there was *“embarrassment or shame,”* that people are *“looked down upon”* for seeking mental health services and that these perceptions stop people from getting help. The stigma is exemplified by the following comment: *“Like she [another participant] said, if you have any kind of a mental health issue, that’s not something that’s looked upon as a great thing. So people are afraid of negative feelings that might come toward them.”* Being perceived as weak for having a mental health concern was also reported as demonstrated by the following comment: *“I mean, people think that they’re weak if they’re asking for help, or to talk to someone. Or if they see someone at a mental health facility, they think, oh, they must be nuts.”*

Unfortunately, the stigma may be more severe in rural areas. Heflinger and Christens (2006), argued that population size “has been shown to be inversely correlated with the stigma surrounding reception of mental health services – in other words, the more rural and small the place, the higher the level of stigma (p. 386). NFCMH (2004) states that persons in rural areas view receiving mental health services more negatively than urban persons. In addition, social isolation and libertarian values are characteristics of rural culture that may limit acceptance of mental health treatment (Starr, Campbell, & Herrick, 2002). The libertarian stance of independence was apparent and evidenced by the following type of comment: *“I don’t know if you’re from Southeastern Ohio, but most people around here won’t ask for help unless it’s the very last possible option. Everybody thinks they have to be self-sufficient, you know? Nobody wants to ask for help.”* There may also be less anonymity in seeking help for family and interpersonal challenges in rural areas, leading families to avoid mental health services due to stigma (USDHHS, 2005).

## **DESCRIPTORS USED**

Researchers “have noted a tendency among rural clients to frame psychiatric symptoms in terms of physical complaints [for instance, fatigue or ‘nerves’ instead of depression] and a general preference for using primary care settings over psychiatric treatment (Heflinger & Christens, 2006, p. 384). However, for these parents, most of whom had experience with mental health services, this was not the case. When asked what they think of when they hear “mental health,” they replied with such statements as *“major depression,” “a psych ward,” “it just*

*sickens me,” “suicidal,” “I feel that mental health destroys your life if you don’t get the help you need,” “crazy” and “mass confusion for everyone in the family....there is so much focus on that one person [with mental illness], and they don’t look at the rest of the family.”* A smaller number used language like *“your state of mind”*, but in general the statements were negative and more severe.

Interestingly, none of the groups referred to mental health as a spectrum that could range from very healthy to very ill. Few, if any, used the terms “disorder”, or “mild to severe.” There was far more focus on significant diagnoses or institutions. In other parts of the conversation, many parents talked about ADHD, ADD, and Bipolar. Further, the language that was used was negative and stereotypical. In a number of cases, this was attributed to how the media (particularly film) portrays mental health, as demonstrated by the following: *“because, you watch TV and hear these horror stories of people who find out... or I have this hidden thing that I didn’t know was there.”*

## **THE PATIENT-PROVIDER RELATIONSHIP**

Summers and Barber (2003) state, “Although the concept of the alliance has emerged historically in the psychodynamic literature, the strength of the collaborative relationship between patient and therapist has been recognized as crucial by therapists from different theoretical backgrounds”. In their literature on Motivational Interviewing (1999), which focuses on helping a client move through the stages of change—pre-contemplation, contemplation, preparation, action, and maintenance—the Center for Substance Abuse Treatment at the Substance Abuse and Mental Health Services Administration (SAMHSA) discusses the need to establish rapport and build trust, show empathy, present options, set goals, and provide feedback. These characteristics are discussed in different forms throughout the literature on building a therapeutic alliance and were identified by the parents participating in this study. Furthermore, participants indicated these characteristics are determining factors when receiving referrals or assistance from other professionals, such as doctors and school personnel.

By far, participants indicated the biggest factor in talking to someone, either in an interpersonal or therapeutic relationship, was if they felt they could trust them. In addition, trust is an important determinant in accepting a referral and following through to access services. One participant’s statement can be used to sum up what was said across all of the groups: *“Trust. I*

*don't think you can talk about it unless you trust somebody. ... [Mental health] is not the first subject that people are willing to talk about. So, there has to be trust there.”* In referring to the negative connotations that participants believe go along with mental health, she went on to say, *“And break down that stereotype that usually goes with mental health, before people will trust you and talk to you about it.”*

Some of the factors participants identify as contributing to the development of trust include: 1) they know the person has been through the same thing; 2) the person is genuine and sincere; 3) the person actively listens; and 4) the person helps set goals and provides feedback and resources. Examples of how participants discussed these traits include:

*Somebody going through the same thing, or you know they've been through it.*

*To me, the more that somebody knows me, the more that I can get more help.*

*They need to show that they're actually listening to what you have to say, and actually trying to help you through it.*

*You can vibe from them if they're really interested. ...They take their time with you. [They] ask what's going on, the things that you care about, instead of just wanting to talk about the issue that you're there for. Because you're not going to directly open up and talk to somebody about something that you think is an issue.*

*[Participants' counselor] takes it in and gives you feedback.*

Throughout the conversations, these traits were discussed as part of participants' expectations from service providers, but also for referral sources. Family doctors and pediatricians were the most cited professionals from which participants would first seek help; however, not all participants thought they had received adequate assistance when attempting this in the past. A negative experience is represented in the following exchange between participants in one group:

Participant A: *It's about finding the right one, though, who'll actually do something because--*

Participant B: *I understand.*

Participant A: -- *you know, I've been to a lot. And they wouldn't do nothing for me [sic].*

Participant B: *There are really a lot of bad family doctors around here. There's [sic] some good specialists, but bad family doctors. [Laughs]*

[Participant D nods in agreement]

Facilitator: *So that could really stop somebody? If they feel like they weren't being heard by their family doctor?*

Various Participants: *Yeah.*

Participant C: *And if they don't refer you, you just feel helpless...because, what are you supposed to do?*

Many of these parents felt as though professionals do not listen to them and that they have little say in the process of care.

Those who had positive experiences with doctors as referral sources believed they had established a good relationship and the doctor had demonstrated characteristics of a therapeutic relationship. One woman thought her child's pediatrician paid more attention to her because they had a long-standing relationship since her childhood, when he was her pediatrician. Referring to her child's pediatrician, another participant discussed the doctor's willingness to explore all options, "*He does everything before putting them on medicine. He'll send you to a counselor; he'll talk to you, before he puts you on drugs to help.*"

## **AWARENESS**

Research suggests people in rural areas often are unaware of the need for assistance and are not as knowledgeable about the symptoms and treatment options for mental illness (NFCMH, 2004). However, many of the parents in this study were keenly aware of the need for assistance. Several reported intuitively knowing there was "*something wrong*" with their child but that they were not sure exactly what it was. One stated, "*I know. I see him every day; I'm with him every single day. And I know how he acts and stuff. It makes me mad when they say there's nothing wrong with him.*" Although they often were not knowledgeable about the available treatment options, in most cases they had reached out to others to seek help. Two of the participants who reflected on this idea stated:

*I know that he was having problems at home. I know that he was having problems at school. I know that something had to be done.*

*I just know that there's something happening. She's feeling like something's wrong with her.*

Participants in two of the groups discussed how, compared to previous generations, people seem more willing to talk about mental health. This shift in attitude may have influenced these participants' decisions to go from an inner awareness of a problem to reaching out; however, without a control group who has not sought services, it is uncertain if the perceived shift in attitude is widespread. Regardless, the majority of participants in these groups sought assistance for children or other family members in the past.

In several cases, participants who sought mental health care believed no one was fully listening to their concerns and observations. Some even indicated that specific requests for referral did not receive adequate response or attention. Thus, there was awareness of the need for services, but a perceived lack of responsiveness from the medical provider. A larger number of participants suggested more could be done to involve parents and family members in the care given to children, at both the referral and service level. This speaks not only to the patient-provider relationship but also to awareness of the need for care and the need for family involvement in care provided to children. Descriptions of previous experiences indicated this perceived lack of inclusion contributes to not fully understanding the diagnosis or treatment process previously discussed. Some of the comments made by different participants are highlighted below:

*Here I'm sitting with a little girl, and I don't even know how to explain to her the diagnosis that she has.*

*My son was in counseling and they pretty much just gave him a piece of paper and said, 'Here, color us a picture.' And like, you look at them and tell them what you thought was going on, because you're around your kid all day. They just kind of look at you like you're dumb.*

*Because really, when you go there, they don't really interact with you. They interact with the kid. I mean, you can ask questions, but you've got, what, an hour at the most? And by the time you really get to start asking the questions, and they get to explaining it, you don't have the time to finish explaining it. So you go home not knowing more than you knew when you got there, not unless you look into it on your own.*

*I think there's something wrong with my son, and everyone says there's not. But he just... I don't know... he's different from any kid I've seen. [Same participant later in the conversation] I know. I see him every day; I'm with him every single day. And I know how he acts and stuff. It makes me mad when they say there's nothing wrong with him.*

## **CONCLUSION AND CONSIDERATIONS**

Many needs were revealed by these group discussions with parents accessing care for family members dealing with mental health issues. Some of the findings warrant further study in order to fully understand the extent of the problems. However, at the local level, this report indicates improving communication during referral, diagnostic, and therapeutic processes is a priority. Although specific considerations are put forth for potential referral sources and service providers, the most important recommendation is that the two groups collaborate on the referral process and mental health service provision in order to move families in need of assistance from referral to access and acceptance. It is also recommended that the mental health service provision system work to educate referring professionals such as teachers, physicians and school counselors about the service provision process to demystify mental health.

### **REFERRAL CONSIDERATIONS**

These parents are clearly fearful about mental health issues and skeptical regarding mental health services. In this study, the fear is pervasive. Referring providers, including physicians, mental health service providers and school staff may be unaware of the fear level in presenting patients, but it is very real and addressing it may help patients follow through with care recommendations. Two particular items could improve follow-through by patients/parents: a trusting relationship between patient/parent and provider and a clear explanation of mental health service provision processes. Those in a position to refer people could explain the general process of accessing mental health services, from forms to assessment, possible diagnosis, and treatment options.

Further, patients may need reassurance from referring providers such as pediatricians or family physicians regarding the quality of care available at the local level. To improve action on referrals, the referral source may need to begin to break down the stereotypes associated with mental health and begin to normalize the person's feelings, explaining many people have similar experiences. Referring sources may also want to discuss realistic consequences associated with choosing to seek or not seek mental health services. Specifically, it may be useful to highlight that help-seeking behaviors are often viewed as positive steps.

## **SERVICE PROVISION CONSIDERATIONS**

This study reveals a need for better communication from counselors/providers with parents and patients about the service being provided and the therapeutic value of activities being conducted with children. Parents who are more informed about what typically takes place at an appointment or during the diagnosis process may feel more committed to, and less fearful of, continued engagement. Specifically, it may help if parents are given an explanation of what behaviors or other indicators, such as affect, providers look for when determining a diagnosis. For example, explaining what transpired while “playing checkers” that led to a particular diagnosis. In addition, providers could discuss what parents may be able to do at home to help their child as well as talk to their child about his or her condition. In fact, some parents specifically articulated the need for more education about how to help their children while others clearly revealed that need through their statements even if they did not explicitly request it. Further, parents must be brought into the decision-making process about their children’s care; if not, the risks of parental noncompliance and/or discontinuation of treatment are substantial.

To address the fear and negative connotations associated with mental health, it is recommended that providers discuss positive aspects of mental health, not just the presenting problem. During assessment, it would be helpful to ask about the quality of any previous experiences with mental health services and to actively work to improve negative perceptions. It is recommended that providers explain general diagnostic and therapeutic processes to referral sources so they can prepare people for services ahead of time. Finally, patients/parents would benefit from assurances that local services are qualified and equipped to meet their mental health needs.



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