

Youth Focus Group Project

Background and Purpose

In 2008, the Behavioral Health Collaborative's Consumer Satisfaction Project tried to complete a Satisfaction Survey with youth who receive services in the behavioral health system. Approximately 50 youth were surveyed using a version of the Family Survey. From our experience in doing this survey we learned several things:

- 1) Youth do not appreciate being called children.
- 2) The survey was too long, repetitive, and used language that was overly difficult for youth to understand.
- 3) Many youth had significant difficulty reading the survey.
- 4) Youth rated all domains in the survey (Access, Appropriateness, Satisfaction, Empowerment, and Effectiveness) much lower than did families or adults who were surveyed.

It became clear that we needed to dig a little deeper to find out youth's opinions about the services in which they participate. We also were painfully aware that the youth voice was largely missing from policy and planning activities in ways that their adult and family member counterparts were not. We needed to explore in more depth the opinions that youth have about the services they receive and obtain information about their interest in participating in policy and planning activities.

Methodology

Twenty-nine youth were interviewed in group settings. The youth were identified by asking community based service provider agencies to gather youth who were participating in their programs and services. The group interviews were approximately 1 ½ to 2 hours in length and youth were provided with pizza, soft drinks, and community service certificates. Youth were informed that the information they provided was confidential, (i.e., we would not tell their service providers, probation officers, or social workers what they said in the interviews. Staff from the programs were asked to leave the room to allow the youth to speak more freely.

Demographics

Four focus groups were conducted in with youth who have participated in behavioral health services across the state in Santa Fe, Albuquerque, and Las Cruces. Efforts were also made to conduct groups in other more rural communities, but no others were able to be completed. Although the focus groups were held in New Mexico's more urban settings the youth came from all over the state including the communities of Espanola, Ojo Caliente, Alamo, and Cebolla. The youth ranged in age from 13 to 19 years old. Additional demographics are as follows:

Gender:	Female – 66%; Male – 34%
Race/Ethnicity:	Hispanic/Chicano – 42%; Anglo/Caucasian 21%; Mexican – 10%; Bi-Racial – 10%; Native American – 7%; African-American – 3%; Missing – 7%
Juvenile Justice Involvement:	Yes – 45%; No – 48%; Missing – 7%
Foster Care Involvement:	Yes – 17%; No – 69%; Missing – 7%
Out of Home Placement (Ever):	RTC – 24%; Group Home – 48%; TFC – 21%
On Psychotropic Medication:	Yes – 55%

Questions, Answers, and Comments

- 1. Do youth have a say in how behavioral health services are designed and delivered? If not, should they? Why?**

 - Youth do not have input into how services are designed or delivered.
 - Youth do not have choices about behavioral health care in spite of the fact that youth have more experience than adults in regard to receiving services.
 - *Example: A therapist is assigned to you and if you do not get along with that person, or you have a prior relationship with another therapist, it does not matter. Youth reported that they are told that they have to continue seeing that therapist.*
 - Youth are not listened to about program design.
 - *Example: The group gave an example of how they wrote a letter to management expressing concerns about a particular rule. The staff person did not even respond to the letter.*
 - Youth believe program rules are designed for the convenience of the staff or to avoid problems without identifying whether something is actually a problem; not out of necessity.
 - *Example: Boys are not allowed to go into a girl's room (in a transitional living program). But if the youth are friends and one of them really needs someone to talk to there is no place for the two to have privacy and not break the rule.*
 - Rules are implemented inconsistently and there is favoritism by staff towards youth.
 - Youth are not consulted as to whether programs are effective.
 - Youth sometimes feel they have no recourse to challenge authority.
 - *Example: If the youth wants to tell the staff that the rule should be changed they are told that if you don't like the rules then you can leave (the program).*
 - *Example: When a rule is broken, staff reminds the youth of the contract they signed agreeing to the rules; so even if the youth has a legitimate reason it is not taken into account.*
 - *Example: Staff says that you should know what is right and not make mistakes but youth make mistakes and then the staff make you feel guilty.*
 - *Example: If we make too much of a fuss about a problem with services then we could get sent to the doctor and get put on meds.*
- 2. Are you able to access behavioral health services when you want or need them? What are some of the challenges with getting the services you want or need?**

- Youth report that staff are usually responsive to the needs of youth.
- Youth report that it is difficult to access services once you turn 18.
 - *Example: Young people at age 18 can access adult programs, but the programs are not understanding of the issues facing young adults, but they are not willing to support the young person in navigating the system.*
- Youth report that if their primary staff person leaves their position, there can be gaps in service.
 - *Example: One youth reported that she had found MST services helpful in her abstaining from substance use. Then her therapist left and the youth reported that she started using substances again. There was a lag in her being assigned to another therapist and she reported that her substance use got worse and worse until she got into trouble with the law again.*
- Youth cited transportation as being a barrier in accessing services.
- Program rules can sometimes be a barrier to access. Gaps in services are created because of age, insurance, or emancipation status.
 - *Example: One youth voluntarily left a group home and has been told that since she made the choice to leave, she is not allowed the option to come back and is currently homeless.*
- Youth have difficulty accessing services outside of being enrolled in a program.
 - *Example: One youth reported being on a waiting list for transitional living, but prior to being admitted she cannot access services to alleviate her current problems.*

3. Are the behavioral health services that you receive helpful?

- Youth stated that sometimes services are helpful, but it depends on what you need and how you approach services.
 - *Example: You have to ask for what you need.*
- The most helpful part of services is when staff listen to you and give you advice.
- Often services are not individualized and expectations for youth in programs are sometimes overly high.
 - *Example: Life skills classes are too basic like how to open a savings account when what youth need to know is how to take out a loan.*
 - *Example: Participants in one transitional living program reported that they have to do counseling, have a job, go to school, participate in life skills classes, and do community service work.*
 - *Example: Sometimes staff issue directives on what a youth is supposed to do, but don't explain how to go about doing the directive.*

4. From your perspective, what makes a great service provider?

- The most important quality in staff is that they listen.
- Occasionally, staff say things that are hurtful or yell at youth.
 - *Example: One youth asked for help with reading the rules handbook he was given. He reported that the staff's response was, "What are you stupid or something? Read it yourself."*
- Confidentiality is very important to youth, particularly those youth in residential care.
 - *Example: Youth were on an outing at a store and wanted to buy something. The staff say "No you can't because that's against the rules"; and then everyone knows that the youth are in a program.*
- Lack of privacy is a problem in residential programs.
 - *Example: One youth shared a story of a youth who wanted to change roommates (residential program) and staff did not listen to her request. Finally, the youth told staff that she was suicidal so they would listen to her and she could change rooms.*

- The staff who are closest to working with youth on a daily basis seem to be the ones who understand youths' struggles and challenges the most and are the ones who are the most helpful. Youth stated that it seems like the higher up the staff person is in the administrative structure of an agency, the less responsive he or she is to youth.
- Youth reported that the types of services that are the most needed are housing programs, shelter, child care, and help with education.

5. Do you believe it is important for Youth to have input into policies regarding behavioral health services?

- Youth believe that they have a lot to offer in terms of policies regarding behavioral health services, but they are not asked.
- When youth offer opinions about changes to programs, they feel they are not listened to.
 - *Example: When youth ask about changing the rules, they are told that the staff do not have control over the rules and therefore are not able to change them. Later, staff implement new additional rules for the programs.*
- Often youth do not receive adequate explanations when they ask questions about policies or program rules. Also, it is then not explained to the youth why their input for solving a problem was unacceptable.
 - *Example: In transitional living programs, boys and girls are not allowed to be roommates because of the possibility of sexual activity. However, there are no such rules when one of the youth identifies as gay or lesbian. They still are roommates with people of the same gender.*
- Some youth report that they don't have opportunities to support the development of services. They would if they had an opportunity to do so.
- One youth pointed out that youth need to take some responsibility for not pursuing issues when they feel that your voice is not heard.

6. What kinds of things do you think youth could do to help improve services?

- Youth reported that if adults asked their opinions about improving services they could contribute by giving the youth perspective on policies and service delivery.
- Whatever way that was developed to support youth in improving services would need to be meaningful.

7. To what extent do you have a say in the services you receive?

- The youth surveyed reported that they do not feel they have much choice in the services they receive.
- The youth in one focus group agreed that they should have about a 40% say in decisions that are made and that adults should have a 60% say in how services are delivered.
- Youth report that they often do not have a choice of services or providers, but rather that they are sent to a program.
- One group reported that they had a voice in their service or treatment plans about 70% of the time, when asked specifically about their treatment goals.
- Often programs are a bundle of services, and if you are in the program, you have to participate in all the services within that program.
- Sometimes youth are invited to agency events, but that it seems that it is more "for show" or for political purposes rather than to engage youth in meaningful input.

8. Do you feel that you have enough information about behavioral health services to make informed decisions about your care?

- Youth agreed that they get lots of information about the services they receive, but often that information is not useful.
 - *Example: Youth reported that they get a handbook on services and are told to read the handbook. However, the information is often written in a way that they do not understand. When they ask for clarification, they are often directed to read the handbook again.*
- Youth report that they are often placed on medication or medication is changed and they are not informed about possible side effects, why they are on the medication, or why their medication has changed.
- One group reported that for the most part they understand the documents that they are required to sign, but often they don't have a choice in signing the documents.
 - *Example: Youth do not agree with some of the statements made on documents, but in order to participate in the program and receive the other resources, they have to sign the documents.*

9. If you feel you need more information, what types of information would be useful to you?

- Youth reported that it would be helpful if the information they have would be written in a way that they could understand and respond to.

10. Would you be interested in decision making around how the state manages behavioral health services?

- Yes.

11. What would you need in order to participate?

- Youth stated that they would need information before, during, and after participating in meetings so that they felt prepared to participate in a meaningful way.
- Youth also stated that it would be helpful to have two or three youth participate in any one meeting at a time. This was for support purposes, but also, and more importantly to them, because “not all youth have the same life experience, opinions, or ideas”.
 - *Example: Youth participating should come from different backgrounds. One from foster care and one from probation and so on.*
- Youth stated that they would need a lot of education and background information in order to understand what was happening at meetings with a lot of adults.
- Youth reported that it would be important to have a safe comfortable environment. Adults should be approachable, nice, and not look mad or angry.
- Having food is nice.
- Youth should be able to say what they want to without getting in trouble. The youth said that it would be better for youth to come together in smaller groups at first and then get those smaller groups together every once and a while.
- Some youth said that when there is a meeting it should consist of more youth than adults. This way there is more one on one attention for the youth.
- Youth said that having paper and pen to write questions would also help.
- Youth reported that it would be helpful to have an adult partner but not a staff person from a program that they are participating in. There was distrust that staff won't tell the whole story of what is going on.
- The youth reported that they need some leadership and support in order to participate in meetings. They would need one or more “translators”, people who would brief them ahead of time about the purpose of the meeting, the participants, etc as well as to sit by them during meetings and help explain what was going on.

- *Analogy: Going to meetings without support or translators would be like being told to find a path through thorn bushes without getting hurt or scratched. It would be really hard to accomplish, and you wouldn't feel good after it was over.*

12. What incentives would encourage you to attend meetings in which you would participate by providing input about BH services?

- One group reported that the only incentive that they needed to participate was the knowledge that they would be listened to and taken seriously. They reported that they did not feel that they needed to be compensated through community service hours, school credit, or financially.
- One group stated that having a stipends or money would be good because they need to have money. Community service hours would also be helpful for some youth. Youth said that seeing actual changes in the services is an incentive in itself.
- School credit, community service hours and work hours.
- Youth reported that they thought that it was somewhat insulting to offer them incentives to participate in policy meetings—that the opportunity to participate was enough as long as their participation was meaningful and they were really listened to.
- Youth were concerned that transportation and the timing of meetings could be a big barrier for them.

13. How do you think youth representatives should be chosen?

- The youth reported that they thought it was important for youth representatives to be smart, willing to talk in meetings, and that they have some experience receiving services.
- Youth reported that representatives should volunteer and that they should be able to be available consistently as well as be able to get to the point quickly. Youth stated that representatives should be responsible, respectful, and be able to listen.
- One group suggested getting a larger group of youth together and selecting representatives from that group, so that youth are choosing their own representatives.
- One group had differing ideas about how youth should be chosen: youth that have good ideas; youth that have stayed in services the longest; youth who are quiet because they aren't usually picked; and/or youth who can speak up.
- The youth reported that they felt their representation at meetings should be proportional to the adult representation. It is helpful for there to be multiple youth at each meeting as youth have differing opinions about things, just as adults at meetings would have differing opinions about things.