

CHAPTER VI

YOUTH VOICE

“The universe is made of stories, not of atoms.”

—**MURIEL RUKEYSER**

CHAPTER V

YOUTH VOICE

**Final Draft Report of
The Findings of the Transition Age Youth (TAY) Focus Groups Conducted for the
California Mental Health Directors Association (CMHDA) Transition Age Youth
Subcommittee and the California Institute for Mental Health (CIMH)**

A report on the findings from four focus groups of transition age youth facilitated and recorded by transition age youth in Modesto, Eureka, San Diego and Long Beach, California in July, August and September of 2003

On November 5, 2003, several youth and some family members made a direct report to the Transition Age Youth Subcommittee. They made many compelling statements about the problems with the way services are provided:

“Requiring parental consent for treatment is a barrier to service, because a youth may have run away from home and the parent may be the cause of the person needing services” – Youth

“Should have a family detox even when the kids aren’t using, so kids can see their parents get clean and sober. Separation is devastating” – Youth

“You need to know you aren’t going to lose your kids if you ask for help” – Parent

**April 8, 2004
Sacramento California**

ABSTRACT

All kids want is to be regular kids and not be judged by being in mental health.

Integrating consumer perspectives is a core value of California mental health services. To provide such input to the TAY subcommittee, youth focus groups were conducted in Stanislaus, Humboldt, Los Angeles and San Diego. Youth, from AB 2034 services (integrated services to people with psychiatric disabilities that are homeless) or from transition age youth Supportive Housing Initiative Act (SHIA) projects, facilitated the focus groups. The focus groups addressed what resources and services youth needed and what does and doesn't help them to achieve their goals.

Key services the youth identified as important include:

- Employment and job training
- Education
- Housing subsidies
- Transportation
- Fun outings
- Mental health services

Youth also described helpful providers as being:

- Open-minded
- Able to listen to youth's experiences
- Committed to working with them
- Helpful, friendly and outgoing
- Understanding

A major highlight of the endeavor was the meeting at which youth facilitators from the Humboldt and San Diego sites reported in person to the TAY sub-committee on their focus groups. The sub-committee was very impressed with the seriousness of the issues that youth and their families confront. The discussion with the sub-committee uncovered additional issues that were not highlighted in the focus group reports. The youth's enthusiasm for the process and their willingness to speak with us were memorable.

BACKGROUND

PURPOSE OF THE FOCUS GROUPS

As the subcommittee developed themes for the chapters of this resource manual, members acknowledged the difficulty they were experiencing involving youth in the committee meetings due to scheduling problems. The members of the CMHDA, Adult System of Care (ASOC), & Children's System of Care (CSOC) sub-committees on Transition Age Youth wanted input from youth to inform our work. There was difficulty involving youth on an ongoing basis in the sub-committee. To provide an opportunity for consumer feedback in this volume, we decided to conduct focus groups with transition age youth in established TAY programs (AB 2034 and SHIA).

PROCESS OF CONDUCTING THE FOCUS GROUPS

To encourage youth to speak candidly, we trained TAY to facilitate and take notes. Staff at TAY program sites asked youth in the programs if they were interested in facilitating these groups.

Youth from four sites volunteered to conduct focus groups. Two to three youth and staff from the four programs were trained in conducting and recording focus groups using a web-cast training format. The training was adapted, with permission, from Simon, J.S. (1999), Conducting Successful Focus Groups. The PowerPoint presentation emphasized that focus groups provide an opportunity for people to speak openly in a safe environment. In the training, the youth selected four questions to guide the focus groups:

1. What kind of resources do you need (anything, not just mental health services)?
2. Do you need services? Why?
3. What is helpful?
4. What isn't helpful?

The youth facilitators identified and invited diverse groups of seven to ten youth to participate in the focus groups. The youth conducted the focus groups between July and September 2003. Youth from each site compiled the results of the focus group and submitted them to CIMH. CIMH staff compiled the results that are attached in the appendices.

REPORT TO THE CMHDA TAY SUBCOMMITTEE

After completing the focus groups, youth from one site requested that the youth be able to report the results in person to the TAY Subcommittee. The subcommittee scheduled a meeting with the youth on November 5th. Four youth, two from each of two sites, attended the meeting and elaborated on the information contained in the written summary. An added bonus was the participation of some of their family members. This fostered a lively discussion about the impact of separation on youth and their family members. Additional issues raised in the meeting are identified in the results section below.

RESULTS

The nature of the relationship that youth have with staff was identified as a major factor in successfully providing services. Youths said that it is important to have staff that is seen as caring, uncritical, and able to listen. The services most frequently identified as important were employment and job training and meeting basic needs. The reporting varied from group to group, making accurate totals regarding the frequency of particular responses difficult. The lists below include the responses that were mentioned at least four times amongst all groups:

- 1. What kind of resources do you need (anything, not just mental health services)?**
 - a. Job training/employment/work
 - b. Education
 - c. Section 8/money for furniture
 - d. Open-minded people
 - e. People who listen more closely and follow-up

2. Do you need services? Why?

- a. Job training
- b. Budgeting/Money Management
- c. Transportation
- d. Psychological Services, including depression/anxiety group
- e. People who are committed, care, listen, are helpful, friendly and outgoing

3. What is helpful?

- a. Staff/doctors/job coaches, personal service coordinators, program directors, nurses
- b. More fun/group outings

4. What isn't helpful?

- a. Lack of sympathy
- b. Lack of services (e.g., counseling)
- c. People who are greedy, selfish, rude and stuck up

ADDITIONAL INFORMATION FROM THE YOUTH DIALOGUE WITH THE TAY SUBCOMMITTEE

Two youths from San Diego County, three youths from Humboldt, and the mother and aunt of one of the youths attended the November sub-committee meeting. This was an especially influential event because the youth's mother and aunt (her sister) had just been reunited the day before, due to the youth's efforts to bring his mother's family together. His mother and her siblings had been separated and sent to different foster homes when they were young. The family told their stories and presented a painful picture of the devastating impact of our systems on the lives of children and, in turn, their children. The discussion highlighted the reasons that people in trouble, especially parents, are very reluctant to seek services for fear of losing their children.

Specific issues raised in the discussion with the youth included:

1. Barriers to serving youth

- a. Lack of confidentiality
- b. Requirement for parental consent for youth's treatment
- c. Placing parents in residential treatment programs that don't serve children, thereby separating the youth and parents
- d. Lack of information

2. Ideas to improve services

- a. Putting informational brochures in doctor's offices
- b. Funds for youth to participate in community recreational activities, (e.g., entrance fee to the skate park). Youth want to do the things that all youth do.

GENERATION OF LOCAL ACTIVITY

Another unanticipated result of the project was that the youth in Humboldt decided that they wanted to do a focus group with law enforcement. It was successful in that the youth and law enforcement were able to listen to and hear their complaints and fears about one another. As a

result of the group, the youth and law enforcement officers were able to identify a joint activity in which they could partner – removing graffiti.

CONCLUSIONS AND RECOMMENDATIONS

Youth in the focus groups identified positive, supportive relationships with service providers and meeting basic needs (including employment) as important components of mental health services. Listening to youth and family stories in face-to-face dialogue highlighted the youth's need for connection with their family, a need to belong. Recommendations include:

- Providers should consider entering into similar dialogues with youth as they may generate innovative ways to improve services.
- Youth need to be involved in various levels of program development, including participating in local advisory boards. Youth need to be compensated in some way for their time. In the SAMHSA Federal System of Care grants, they found that motivators to increase youth participation include stipends, transportation assistance, childcare, and food during the meetings.

APPENDIX #5.1

QUESTIONS AND SCRIPT FOR TAY FOCUS GROUPS

Conducted for the California Mental Health Directors Association Transition Age Youth Subcommittee and the California Institute of Mental Health

July, 2003

Set-up:

- Have people in a circle, preferably with something to write on, like around tables
- Have refreshments and something to drink
- Have paper and pencils/pens for people to write on
- Have the easel, flipchart and pens ready for the recorder
- Tent Cards: If the facilitator and recorder don't know everyone in the group, you might want to have name tags for people or use "tent cards" (a piece of paper folded in half on the table in front of the person, with their name printed on the paper).

As the participants come in, fill out the demographic sheet that is attached to this script. Please note that you don't use people's names on the demographic sheet or the recording sheets.

Facilitator Script:

Welcome everyone and thank you for coming. My name is _____ and I am your facilitator for the day. My colleague, _____, will be the recorder for this focus group.

We are conducting this focus group to provide information on what youth want in their lives and the kind of help they think they need to do what they want. We are here to get information, not to solve specific concerns or problems. We need direct feedback from youth. We need positive and negative information, so please be honest and open in your responses. We are one of three places in the state that are conducting these focus groups: Modesto, Eureka and Los Angeles.

The reason we are doing this is because there is a statewide committee that is putting together a resource manual for mental health providers to use in developing services for youth our age (from 16 – 25). People on that committee want to make sure that they are hearing from youth. What we come up with here today will be included in that information manual, but it is important for you to know that the responses are kept anonymous. Names are not used in recording your answers to the questions.

This will take us about one and a half hours. If you need to go to the bathroom or take a stretch, just excuse yourself. We will take a break half way through if we need to. In a few minutes, I'm going to talk about how we are going to do this focus group, but first, I would like everyone to introduce themselves.

EVERYONE INTRODUCES THEMSELVES

Before we go any farther, we need to set some guidelines for how we will act with one another in this group. We'll call this a Comfort Agreement. The recorder will write down what we want to agree to. Some examples of what we might want to include are:

- There are no wrong answers
- We will listen to each person

FACILITATOR ASKS GROUP TO TELL WHAT IS IMPORTANT TO THEM AND MAKES SURE THE SUGGESTIONS ARE WRITTEN DOWN BY THE RECORDER. WHEN THE GROUP IS DONE, THE FACILITATOR ASKS IF EVERY ONE AGREES TO WHAT HAS BEEN WRITTEN DOWN. MAKE SURE THAT EVERYONE NODS AGREEMENT.

Now, I'm going to describe what we are doing today. We have a series of four questions. When I ask a question, we will each take a couple minutes to jot down two or three answers. Then we will take turns going around in a circle answering the question. We will keep going around the circle until we run out of new answers. The recorder will write down what someone says. We won't have a discussion and we won't debate specific items. We are just trying to get information. Remember, there are no wrong answers.

We will do this with all four questions. When we have finished the questions, all the people in the group (not the facilitator or recorder) will take a pen and for each question put a check mark on what you consider the four most important answers under each question.

Are there any questions?

Questions:

We are trying to find out what you think will be helpful to you as you move forward to your adult life:

1. What kind of resources do you need (anything, not just mental health services)?

Facilitator will indicate one person to start. Keep the group moving along – no more than 15 minutes per question. If someone is taking too long, ask them to make the point in two or three words, or if you think you understand their point, summarize it and ask if that is what they mean. If someone wants to talk about what someone else says, remind them that we are not here to discuss the issues, only to list them. Tell them that people can hang out later to have a discussion about the points people raised. [Remember that people have to feel safe in order to say what they think. If other people are allowed to argue with them, they will not feel safe – you also won't get through your focus group.]

2. Do you need services? Why?

[Facilitator picks a different person to start answering the question.] Cut off at 15 minutes.

3. What is helpful?

[Pick another person to start answering the question] Cut off at 15 minutes.

4. What isn't helpful?

[Pick another person to start answering the question] Cut off at 15 minutes.

These are all important points, but we want to figure out which ones may be more important than others to you.

- Each of you take a pen and under each of the four questions, put a check mark beside the four answers you think are the most important. So make four check marks for question #1 and four for question #2, etc.
- After everyone makes their check marks, facilitator can point out which items have the most check marks for each question.

Closing:

Thank everyone for coming and let them know that they will get a copy of the results for their discussion group.

Reporting:

The recorder then types all the answers to each question and put the number of check marks by each item that has check marks. A sample form is attached. Send the information to Vicki V. Smith at vsmith@cimh.org.

SAMPLE COMFORT AGREEMENT (from training):

- There are no stupid questions
- Be responsible for your own learning – ask questions
- Listen when others speak
- Treat each other with respect
- Maintain confidentiality
- Accept people as they are
- Pay attention to individual differences

People to invite. Invite 7 to 12 people.

- People from 16 – 25 years of age
- People currently using services, or would use services if they were different
- People who are falling through the cracks

APPENDIX #5.2

Preliminary Draft Report of The Findings of the TAY Focus Groups Conducted for the California Mental Health Directors Association Transition Age Youth Subcommittee and the California Institute of Mental Health

**A report on the findings from four focus groups of transition age youth facilitated
and recorded by transition age youth in Modesto, Eureka, San Diego and Long
Beach, California in July, August and September of 2003.**

**November 4, 2003
Sacramento California**

FINDINGS OF THE FOCUS GROUPS (This section will be summarized in the final report and the grids will be moved to the appendices):

2. What kind of resources do you need (anything, not just mental health services)?

	Stanislaus	Humboldt	LA-Long Beach	San Diego	Total
More \$ for clothes			1		
Job Training/Employment/ Work	6	X	3	1	
\$ For Furniture/Section 8 Housing			3	1	
\$ for food			1	1	
\$ for Transportation (taxi				1	
Food, Housing & Recreation		X			
Access to Medical Care & counseling		X			
Access without parental consent		X			
Confidentiality		x			
Education	7		1		
Open minded People	4				
People who listen more closely & follow-up	4				
Group Activities	2				
Less prying	2				
More Case Managers/PSCs	2		1		
Business Outlets			1		
Direction			1		
Doctors			1		
Merchant			1		
Goals			1		
Money			2		
To take options			1		
True friends			1		

2. Do you need services? Why?

	Stanislaus	Humboldt	LA-Long Beach	San Diego	Total
Job Training	6			1	
Budgeting/Money Management	5			1	
More Transportation Services				5	
Sometimes can't accomplish goals on our own		X			
Don't realize what is going on in situations		X			
Help in coping with dilemmas		X			
Support		x			
Psychological Services	4				
Crime Prevention group	2				
Depression/Anxiety groups	4				

3. What is helpful?

	Stanislaus	Humboldt	LA-Long Beach	San Diego	Total
Section 8 vouchers/Housing			2	2	
Help in getting SSI right away			1	2	
More fun outings/group outings	3			3	
Positive reinforcement		X			
Funding for scholarships		X			
Free services with experienced staff		X			
Friendly nonjudgmental staff		X			
Independent Living Programs	2				
Case Managers	2				
Peer Support	2				
Bus Passes/transportation	3				
Groups/Counseling	1		1		

Help in contacting family	1				
Devereux			1		
Employment			1		
CBCC			1		
Nothing			1		
Talking			1		
The Village			1		
Business Partners					
People who are committed/care/ listen/honest/helpful/ friendly/kind/outgoing			8		
Staff/doctor/job coaches/PSCs/program directors/nurse			6		
Korean/Japanese staff			2		
Specific staff			3		
Other members			1		

4. What isn't helpful?

Outings with older people with disabilities				2	
People who don't smell good				1	
Not returning phone calls right away				3	
Cop harassment		X			
Lack of sympathy & empathy/ People with bad attitudes/angry/ Prejudice against youth/ Blaming youth		X	5		
Criticism of staff	5				
No counseling services	4				
Lack of stability	3				
[Doesn't] give benefit of doubt	2				
A new job			1		
Inexperienced people			1		
Lack of knowledge/ education/unwise			2		
Living in motels/ on the			2		

street					
None			1		
Not going to sober living			1		
People who don't care			2		
The others			1		
Drug Dealers/gang members			3		
People who are greedy/ selfish/rude/ stuck up			4		
People who don't want to work/ don't want to help			2		
Members					
Mom/sometimes family & friends			3		
US			1		
British			1		

Appendix #5.3

Transition Age Youth Focus Group: Demographic Information

County	Modesto	Humboldt	LA-Long Beach	San Diego	Total
Date of Focus Group					
<u># of Participants</u>		13	10	7	
<u>Gender</u>					
Male		8		4	
Female		5		3	
<u>Age</u>					
16					
17					
18					
19				1	
20				3	
21				1	
22				1	
23				1	
24					
25					
<u>Ethnicity (optional)</u>					

County	Modesto	Humboldt	LA-Long Beach	San Diego	Total
Caucasian				5	
African American					
Hispanic				1	
Asian American					
Native American					
Pacific Islander					
Earitrean				1	
Other					
Uses MH Services				7	
Doesn't Use MH Services					