

## Youth Consumer Views of Mental Health Services

---

Bethany Lee, LCSW  
Curtis McMillen, Ph.D.  
George Warren Brown School of Social Work  
Washington University in Saint Louis

Funding provided by the National  
Institute of Health, R01-MH-61404

## Consumer Input on Quality Care

---

- Consumer=Parent
  - Martin, Petr, & Kapp, 2003; Brannan, Sonnichsen, & Heflinger, 1996
- Consumer=Youth
  - Shapiro, Welker, & Jacobsen, 1997; Garland & Besinger, 1996
- Parent≠Youth
  - Godley, Fiedler & Funk, 1998; Lambert, Salzer & Bickman, 1998; Garland, Lewczyk-Boxmeyer, Gabayan et al, 2004

## Why Youth Perspectives Matter

---

- Empower youth to have a “say”
- Inform underutilization of mental health services
- Guide quality improvement efforts

## Purpose

---

- To identify what youth like and don't like in their experiences with mental health providers

## Methodology

---

- Larger study of older youth transitioning from foster care in MO
- 406 youth followed longitudinally
- In-person interview at 17<sup>th</sup> birthday
- Phone interview six months later

## Interview questions

---

- “Particularly positive” experiences
- “Particularly negative” experiences
- What do you like about:
  - Primary outpatient therapist?
  - Residential therapist/case manager?
  - Residential direct care worker?

## Qualitative Analysis

---

- Independent reviewers identified emerging patterns
- Themes named, codebook developed
- 30% of data coded to establish inter-rater reliability
- Overall agreement = .75

## Sample Characteristics (N=389)

---

- 56% Female, 56% Youth of color
- Lifetime mental health service use
  - 76% outpatient therapy
  - 80% residential treatment
  - 43% inpatient psychiatric hospitalization
  - 38% currently prescribed psychotropic medication

## Results

---

- 144 youths (37%) shared positive experience
- 101 youths (26%) shared negative experience
- Specific provider feedback:
  - Primary Therapist (N=89)
  - Residential Case Manager (N=110)
  - Residential Direct Care Worker (N=113)

## Benefits of mental health services: Helped with personal issues

---

- *"Helps me with my problems"*
- *"Mr. \_\_\_ helped me cope with my father and brother's deaths. Pushed me to cope even though I got mad"*
- *"Helped me get my life on track – kept me in school, stopped me from some bad stuff"*

## Benefits of mental health services: Helped me feel better

---

- *"Everything changed from dark to good"*
- *"They made me feel better about myself and things that were going on in my life"*
- *"She eased my pain with my problems away"*

## Benefits of mental health services: Promoted behavior change

---

- *"I've changed my ways"*
- *"Taught me how to control my behavior"*
- *"One kept me from harming myself"*

## Benefits of Mental Health Services

Theme	N	%
Help with personal issues, coping skills	29	20
Helped me feel better	22	15
General helpfulness	18	13
Promoted behavior change	14	10
Help develop insight/self-awareness	13	9
Catharsis/emotional release	10	7
Advocated to help me get what I needed/wanted	10	7
Help with practical and concrete matters	9	6
Medication management	6	4

## Relationship with provider: Listening and attending

- *"They are good listeners, good to talk to"*
- *"Every experience with my therapist is positive. She listens and doesn't see [me] as something to diagnose"*

## Relationship with provider: Engagement

- *"We would take walks and talk about problems"*
- *"My therapist took me to a conference to try to help me figure out what I want to do with my life"*
- *"Our staff takes us places"*

## Relationship with provider: Consistency

- *"I could see him anytime I wanted"*
- *"She would always come talk to me, even if she didn't really have time"*
- *"I can count on him"*

## Relationship with a Provider

Theme	N	%
Listening/attending	29	20
Engagement	10	7
Consistency/accessibility	7	5
Felt supported	5	3
Empathy/understanding	3	2
Authenticity	2	1
Other personality characteristics	9	6

## Negative Experiences

- Relationship with Mental Health Provider
- Treatment Concerns
- Unprofessional/Questionable Behavior

**Relationship with Provider:**  
Didn't listen

---

- *"They put words in your mouth"*
- *"[He] didn't hear what I said and told me that I would never change"*

**Relationship with Provider:**  
Didn't get along/ didn't like

---

- *"We clashed, so therapy wasn't good"*
- *"I got into an argument with my counselor and was put back into foster care"*

**Relationship with Provider**

Theme	N	%
Didn't listen	28	28
Didn't get along/ didn't like	10	10
Stigma	5	5
Doesn't care about me	4	4
Allied with system/guardian	4	4

**Treatment Concerns:**  
Medication management

---

- *"They tell me I'm crazy and put me on meds and I don't like being on them"*
- *"They try to drug you up; you can't function"*

**Treatment Concerns:**  
Medication management

---

- *"They try to drill it in my head that I need medicine"*
- *"Dr. \_\_\_\_\_ slapped meds on me the first day she met me. She didn't even take the chance to listen"*

**Treatment Concerns:**  
Ineffective/ not helpful

---

- *"They talk, but when I leave, everything is the same as before"*
- *"They don't seem to do much"*

## Treatment Concerns

Theme	N	%
Medication issues	23	23
Ineffective/not helpful	10	10
Coerced/mandated treatment	7	7
Physical restraint	4	4
It made me worse	2	2

## Unprofessional/Questionable Behavior

- *"One therapist told me I was a black male and that I needed to be more masculine and not gay"*
- *"I didn't like one counselor. She told the staff at the center something that was confidential and I got teased by other patients"*

## Unprofessional Behavior (continued)

- *"She fell asleep one time and I told her pink monkeys flew out of my butt and she said, 'That's nice' and went back to sleep."*

## Unprofessional Behavior (continued)

- *"In order to get me to talk, my therapist would wrap me up in a blanket and my foster mom would sit on me.... My therapist would make me sit on her lap like I was a little kid and I was 13"*
- *"They yell"*

## Feedback for Specific Professionals

- Primary outpatient therapist
- Residential case manager or therapist
- Residential direct care worker

## Communication Skills

- *"She's cool and funny. She talks like a normal person"* (Outpatient therapist)
- *"She talks to me like I'm normal"* (Residential direct care worker)
- *"Easy to talk to and not judgmental"* (Residential therapist)

## Helpfulness

---

- *"She's really good at getting a hold of our caseworkers and getting information for us" (Residential Therapist)*
- *"She comes up with good solutions for my problems" (Outpatient therapist)*
- *"She helps me out a lot. If I have a problem or something, she's there for me." (Residential direct care worker)*

## Relationship skills

---

- *"He looked at me as a kid, not for what I had done" (Direct care worker)*
- *"He treats me like a person, not a foster kid" (Residential therapist)*
- *"He's a great guy; basically a father to me" (Outpatient therapist)*

## Limitations

---

- Sampling frame
- Methodology

## Implications

---

- Youth are able to evaluate care
- Medication management is a key concern
- Youth value relationships with providers