Youth Consumer Views of Mental Health Services

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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

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 17th 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

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

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

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<thead>
<tr>
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<tbody>
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<td>Listening/attending</td>
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<td>Engagement</td>
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<td>7</td>
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<td>Consistency/accessibility</td>
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<td>5</td>
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<tr>
<td>Felt supported</td>
<td>5</td>
<td>3</td>
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<td>Empathy/understanding</td>
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<td>2</td>
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<tr>
<td>Authenticity</td>
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<td>1</td>
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<tr>
<td>Other personality</td>
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<td>6</td>
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<tr>
<td>characteristics</td>
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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”

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<tr>
<th>Theme</th>
<th>N</th>
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<tbody>
<tr>
<td>Didn’t listen</td>
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<td>28</td>
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<tr>
<td>Didn’t get along/ didn’t like</td>
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<td>10</td>
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<tr>
<td>Stigma</td>
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<td>5</td>
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<tr>
<td>Doesn’t care about me</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Allied with system/guardian</td>
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<td>4</td>
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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:
Ineffective/ not helpful

- “They talk, but when I leave, everything is the same as before”
- “They don’t seem to do much”

- “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

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<tr>
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<td>Medication issues</td>
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<td>23</td>
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<td>Ineffective/not helpful</td>
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<td>10</td>
</tr>
<tr>
<td>Coerced/mandated treatment</td>
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<td>7</td>
</tr>
<tr>
<td>Physical restraint</td>
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<td>4</td>
</tr>
<tr>
<td>It made me worse</td>
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<td>2</td>
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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