Youth and Family Behavioral Health Service Priorities:
Identifying Outcomes that 'Matter'

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Motivation and goals of the project

Family goals for bringing a child to mental health services should drive behavioral health research, policy, and practice for children and youth. However, funding for behavioral research and services is often tied to narrowly defined service outcomes that are easy to measure and well-validated. Families and researchers know there is a disconnect between outcomes that matter to families and outcomes acceptable for research and practice. While the outcomes used widely in research and policymaking are well-known and widely disseminated in peer-reviewed publications and policy documents, the behavioral health service outcomes that matter most to youth and families have not been formally collected and reported. This project aims to document outcomes that are most important to families and youth who use behavioral health services.

Findings

Through a series of focus groups conducted with youth and young adults using behavioral health services and caregivers and parents of children and youth using behavioral health services, the behavioral health service outcomes most important to participants were collected and are summarized in the graphic below. More detailed information about these outcomes can be found at https://www.fredla.org/wp-content/uploads/2023/08/Expanded-Outcomes.V4.pdf.
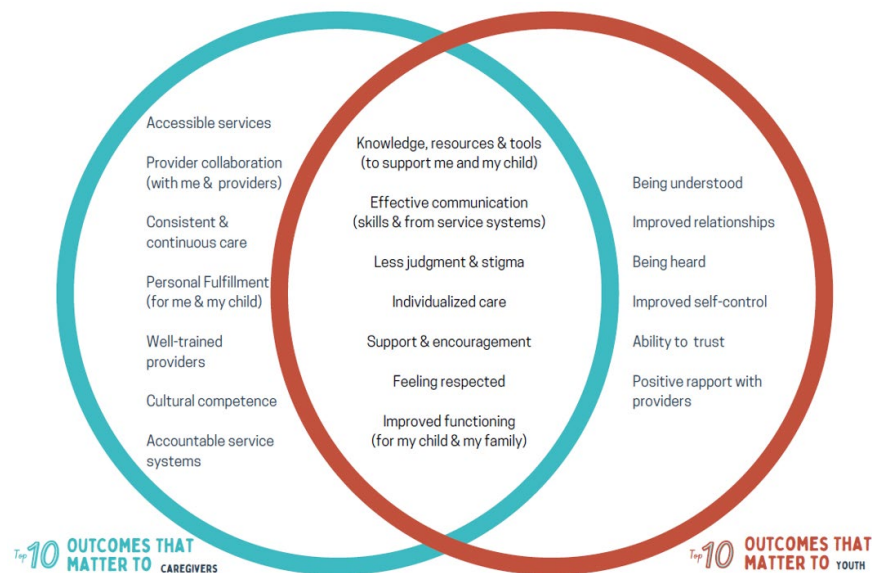
Implications

While much of child and youth behavioral health services research focuses heavily on clinical and functional improvements, families care most about the quality of their service experience. Discussions with families revealed that the service experience feels essential to achieving service goals related to improving well-being and functioning of youth and their families. These results provide a foundation to build new evidence on measuring and validating outcomes that matter to families and support partnerships in services to incorporate in future research.

Methods

FREDLA partnered with six Family-Run Organizations (FRO) to each convene two rounds of both parent/caregiver and Youth and young adult (YYA) virtual focus groups in six communities across the U.S. (Nevada, Mississippi, Pennsylvania, Washington, North Carolina, and Arizona). Each FRO recruited approximately six YYA participants and six parents/caregivers to participate in two rounds of focus groups. The six YYA focus groups were conducted separately from the parent focus groups. Partner organizations received compensation for their project involvement, and participants were incentivized to participate. Groups included youth and young adults with behavioral health needs ages 14-21 years (N=36) and parents of children or youth with behavioral health needs (N=36).

The focus groups were scheduled for 1-hour each and were held in virtual formats. The first round of focus groups took place in February 2023, followed by the second round in April 2023. Focus groups were recorded and transcribed. Each convening was collaboratively facilitated by a researcher (Dr. Thomas or Dr. Graaf) and a local YYA-led or FRO staff member or volunteer (who is a peer).

In addition to meeting with FROs to recruit their participation, plan participant recruitment, and schedule the focus groups, additional meetings were held with partner FROS to design the structure and processes for the focus groups. Detailed focus group guides were developed entirely in collaboration with FROs to identify language and norms to maximize participant participation and discussion. In Round 1, using the following questions, the facilitation team led a semi-structured discussion with participants to identify what positive or successful experiences of behavioral health system interactions look like to them:

1. What results do you hope for when you/your child uses or receives services?
2. What results do you hope to see for yourself/your caregiver when you/your child uses services?
3. What results do you hope to see for your family when you/your child uses services?
4. What makes a good experience in using services?
5. From our conversation today, what are the top three most important outcomes to you?

Information collected in Round 1 Focus groups was consolidated and summarized for review in the Round 2 focus groups. Two passes of inductive qualitative coding using MAXQDA software were applied to the transcripts for all Round 1 focus to capture the service outcomes YYA and parents/caregivers report caring about the most. Inductive coding allowed youth or family perspectives not previously considered and accounted for in existing frameworks to be captured. The first pass of coding used in vivo to apply initial codes, which were refined, combined, and reorganized for a second pass of coding. Code clouds were used to visualize the most recurrent themes in which the size of a word or phrase (code) represented how often that code was used.

Code clouds were generated for responses to the final round 1 question ("From our conversation today, what are the top 3 outcomes that are most important to you?") to guide Round 2 focus groups. Code clouds for YYA were generated separately from code clouds for parents/caregivers, as the content for each group was unique. The second round of focus groups focused on

presenting the code clouds, explaining the clouds' premise to their respective groups, and clarifying content, phrasing, and the meaning of outcomes reported by participants. To structure the discussion, the facilitation team asked the following questions:

1. Is there something here you don't agree with?
2. Is there anything missing that we talked about that isn't reported here?
3. Pick your top 3 most important outcomes from this code cloud.

If time permitted, clarification of phrases, word choice, and differentiating meaning of terms and phrases was discussed with participants to guide the final coding scheme structure and code application.

Round 2 focus groups were recorded and transcribed. Using the coding scheme from Round 1 transcripts, Round 2 was coded inductively, adding codes as needed. A second pass of coding for Round 2 transcripts was conducted to refine and collapse codes. Round 1 and Round 2 transcripts were combined, and themes from both rounds' responses to the final Top Three question were used to generate a draft list of service outcomes. This draft guided two discussions with partner FROs aimed at refining terminology and gathering feedback about the format and content of final dissemination products.

Following both dissemination discussions with partner FROs, a final complex coding scheme was developed from the coding schemes in the first two passes of coding Round 1 and Round 2 transcripts. The final coding scheme was applied to Round 1 and 2 transcripts, followed by additional auto-coding and code merging. Two independent coders completed all coding with an intercoder reliability (*kappa*) of 0.82. Code relationship matrixes were generated by each coder for the Top Three responses to determine the top ten most frequently reported outcomes for YYA and parents/caregivers.