Spring 2021

Care Conversations:

Designing a Human-Centered System

Idaho's behavioral health system is undergoing substantial change. Planned change efforts often result in structural changes with little net improvement in care outcomes. Customer-led design provides a way to direct change towards meaningful improvements in care experiences and outcomes. Focus groups and interviews conducted with over 50 youth and caregivers provide a set of practices which could increase the helpfulness of care. Desired and disengaging practices at each care process are described.

In the Spring of 2021, the Idaho Federation of Families conducted three focus groups with 16 caregivers of youth currently or recently involved in the public behavioral health system. Idaho Department of Health and Welfare staff conducted 43 interviews with system-involved youth and their caregivers. The focus groups and interviews identified helpful and unhelpful practices across the course of care. These are summarized below, providing a clear set of practices that would signal a shift to human-centered care.

> **"I got a referral, gave them a call and they set us up right away."**

Access. Participants indicated that three characteristics drive satisfaction with access: understandably describing what care is currently available, providing care when first requested, and having access to personalized care. Disengaging practices included: connecting the family to inappropriate care, delaying access due to provider failure to complete paperwork, and failing to address geographic and cost barriers to care.

Assessment. When providers used the assessment to draw out a person's strengths, worked to understand the individual in-depth, and provider persons involved with assurance and control during the assessment, it was experienced as helpful. Assessment was unhelpful when experienced as only about a person's needs or deficits, repetitive, or dismissive of the individual's perspective.

> **"I remember being very impressed with how well they covered everything."**

> **"They asked questions like what do we want.... to get out of the process."**

Matching Care to Goals. A collaborative planning process was recommended in which services are clearly described, families are also linked to supports for getting to appointments, services are individualized. When goals are set by outside parties, services offered are not actually available, and when the treating professional does not have specific expertise or appropriate depth of experience, it is experienced as de-motivating.

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Working together. An engaging style, teaching useful skills, providing whole-family supports (e.g., family psychotherapy, family support partner, team-based care) and frequently checking on and adjusting care all created progress. Experiencing progress is more difficult when one service is used to gatekeep access to other services, services are provided inconsistently, or there is poor communication about progress made.

> **"I feel like I'm talking to someone who really understands."**

> **"…she was self-harming. I let the counselor know. She saw both of us the next day."**

Preventing and Addressing Crises. Key elements of effective crisis care included: fast and easy availability of supports, professionals with clear knowledge of supports available in the community and beyond, and constructive advice. Caregivers also talked about very negative experiences with crisis, including being judged for their parenting and having to educate professionals and take on case management responsibilities.

Transitioning. Parents and youth described three characteristics of a helpful transition. These are: transition being a planful process, transition itself as a choice, and the ability to easily and quickly return to care should the need arise. In contrast, transition is unhelpful when it is abrupt, when it forces a return to a waitlist, or when it is the result of failure to help parents and youth with resources to make their appointments.

> **"We talked about things to continue to try. If things reverted, we should pick it [back] up."**

System Recommendations.

Idaho's youth and caregivers have described a clear set of practices for improving the impact of care. Systematically laying out these practices is only a first step. Systems which make substantive improvements in care quality and outcomes engage in the following additional steps. They:

- formalize the role of youth and families in developing new types of care;
- create a clear, ongoing process for assessing the extent to which routine practices are experienced as collaborative and family- and youth-directed;
- provide infrastructure for training and coaching providers on collaborative, effective practices;
- routinely collect, publicize and act on information linking particular practices to specific care outcomes for children and families.

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