Serving transition-aged youth with dual diagnoses

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Project Purpose
To identify best practices for transition to adulthood services for young people aged 16-24 with both developmental and mental health disabilities and challenges facing service providers working with this population.

Study Process
• Iterative qualitative study with emergent design in 2 phases:
  • Phase 1 interviews with 12 people: policy-level researchers, program directors
  • Phase 2 interviews with 14 program directors, service providers, and experts identified as providing best practices

Phase I: Findings
• Few professionals have knowledge and skills to serve people with both DD and MH
• Need for best practices for this population
• Collaboration between the mental health and developmental disability systems is challenging
• Findings were used to guide development of Phase 2 interviews

Ideal Program Characteristics (NASMHPD, 2004)
• Assessment by trained staff
• “No reject” stance
• Individualized/person-centered services
• Flexible funding
• Staff trained in both MH and DD
• Evidence-supported interventions
• Attention to trauma
• Caregiver support
• Least restrictive environments
• Cross-system collaboration
Phase 2 Interviews

Semi-structured interviews:
- Accessibility and eligibility
- Screening and assessment
- Availability of caregiver support and services
- Individualized/person-centered practice
- Best practices
- Least restrictive environment
- Program funding
- Staff preparation and training
- Cross-system collaboration

Data Collection & Analysis

- 14 telephone interviews with program directors, providers, and experts who specifically serve this population
- Interviews were taped and transcribed
- Content analysis used to develop case studies of 8 programs
- Transcripts were coded independently by team members
- Draft case studies reviewed by interview participants
- Participant feedback incorporated in final case studies
- Three programs are highlighted today:

The Intercept Center

- Services for children and youth ages 5 to 21 with a developmental disability and a mental illness.
- Services include individual, group, and family therapy and medication evaluations. Youth may be served in the day treatment program or intensive outpatient services. Youth often receive services until they transition to adult services.
- Referrals come from Children's Hospital, DHS, the ARC and schools in Colorado.

Project Search

- The High School Transition Program is a one-year educational program for students with disabilities in their last year of high school.
- It is targeted for students whose main goal is competitive employment.
- The program takes place in a healthcare or business setting where total immersion in the workplace facilitates the teaching and learning process through continuous feedback and application of new skills.
- 3-10 week work rotations for 5 hrs/day with hour of curriculum per day.
- Replicated in 125 programs in the U.S. Programs in Australia, Canada and England.

The Center for START Services

- Cross-systems linkage model to address barriers to collaboration.
- Provides technical assistance, support, training, and consultation to mental health and developmental disabilities services.
- Includes funders, decision makers, team members, families.
- Focus is on addressing the failures of systems to accommodate the needs of people with complex needs – to prevent crises and assist individuals to stay in community environments.
- Promotes use of multi-modal comprehensive assessment and evaluation of outcomes.

Finding #1: Youth who are dually eligible benefit from mental health interventions modified to fit their needs

- Intercept Center
  - Modifying DBT and TF-CBT
  - Use appropriate assessment instruments
- Francis Foundation
  - Use of video, drawing, collages.
  - Need to understand how the person thinks and remembers.
- Serendipity
  - Onsite access to mental health services for students and teachers
Finding #2: Training and supervision is a critical ingredient to improve services

- The Francis Foundation provides training on:
  - Attachment as the primary motivation to behavior
  - Learned helplessness
  - Cognitive development
  - Emotional development
- Christie School invites youth from OFSN to talk to staff; provides information about behavior that is new to staff.
- Vermont Intervention Network's level I service is to provide training as requested and level II is to provide training on site.

Finding #3: It is important to consider what may be influencing behaviors

- Behaviors are often related to trauma.
- Behaviors are learned in institutional settings.
- Behaviors are age appropriate.

"People aren't losing their jobs because of skills but because of behaviors which may not have been identified or properly dealt with."

Finding #4: Interventions are needed to address trauma

- Christie School
  - Using a trauma consultant.
  - Training and consultation about institutionalization.
- Trillium
  - ABC and Collaborative Problem solving (CPS) method to connect current behavior to past experiences.
- Intercept Center
  - Trauma assessment instrument.

Finding #5: Program components are specific to the needs of youth

- Policies support self advocacy and self determination.
- Trillium youth are expected to know details about medications.
- Project Search focuses on jobs in health care and banking. Youth interest are analyzed for essential skills. These skills are focus of the internship.

Continued: Program components are specific to the needs of youth

- Setting needs to be appropriate for success
  - Project Search looks for work setting that offer accessible healthy food options and exercise facilities.
- Including caregivers
  - Francis Foundation provides caregivers with information about emotional and cognitive functioning and attachment.
  - ChristieCare makes a point, with permission of the youth, to call caregivers when there are celebrations and accomplishments. Residents also host pot lucks and invite family.

Continued: Program components are specific to the needs of youth

- Continuity of care
  - All programs are available to youth as they transition into adult services
- Flexibility
  - Considering the age 16-24 services need to be flexible as the person is figuring out what they want and who they are
Finding #6: Collaboration is important

- Cross system collaboration which includes youth and families is needed
  - Youth Collaboration
    - PACER
    - Westchester County System of Care
  - Organizational Collaboration
    - Project Search
  - System Collaboration
    - Project Start

Ideal Characteristics Revisited

- Assessment varied, some refer out
- Few are able to embrace "no reject"
- All provided individualized, person-centered services
- Most providers trained in either DD or MH
- Funding through Medicaid or Medicaid waiver

Ideal Characteristics Revisited

- Some services evidence-based
- Most recognized need for trauma informed services
- All incorporated caregivers
- All provided services in less restrictive settings, some group homes
- Collaboration between DD and MH varied

Conclusions

1) Literature describes characteristics of population, challenges and needs.
   - Limited focus on effective intervention
   - Little focused on issues of transition to adulthood

2) Two organizational structures identified.
   - Program organized specifically for individuals with dual diagnosis
   - Program organized for individuals with mental health challenges that provides special programming for those who are dually eligible

Conclusions

3) Emerging understanding that young adults with DD can benefit from mental health intervention.
   - Better understood by DD professionals
   - Influenced by lack of research evidence
   - Cross training between MH and DD would support
Conclusions

4) Major differences between the philosophy and approaches of mental health and developmental disabilities
   - Beliefs about potential for independent adulthood
   - Life long support vs recovery
   - Funding streams in silos
   - Differences in eligibility criteria

Other observations

- Dependence on congregate living
- More likely to use crisis services
- Etiology of mental health challenges
  - Rooted in developmental disability
  - Difficulties communicating
  - Trauma from institutions

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