Promoting Learning and Working During Young Adulthood: Adult System Perspectives

The 27th Annual Children's Mental Health Research & Policy Conference

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Acknowledgements

The Transitions RTC aims to improve the supports for youth and young adults, ages 14-30, with serious mental health conditions who are trying to successfully complete their schooling and training and move into rewarding work lives. We are located at the University of Massachusetts Medical School, Worcester, MA, Department of Psychiatry, Center for Mental Health Services Research.





<u>tm</u>

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State-of-the-Science Conference Goal

- 1. Help adult systems recognize the need
 - Poor career starts
 - Few services & supports with evidence of efficacy
 - Developmentally appropriate and appealing services & supports
- 2. Obtain adult system perspectives on knowledge needed for system change

"Career"

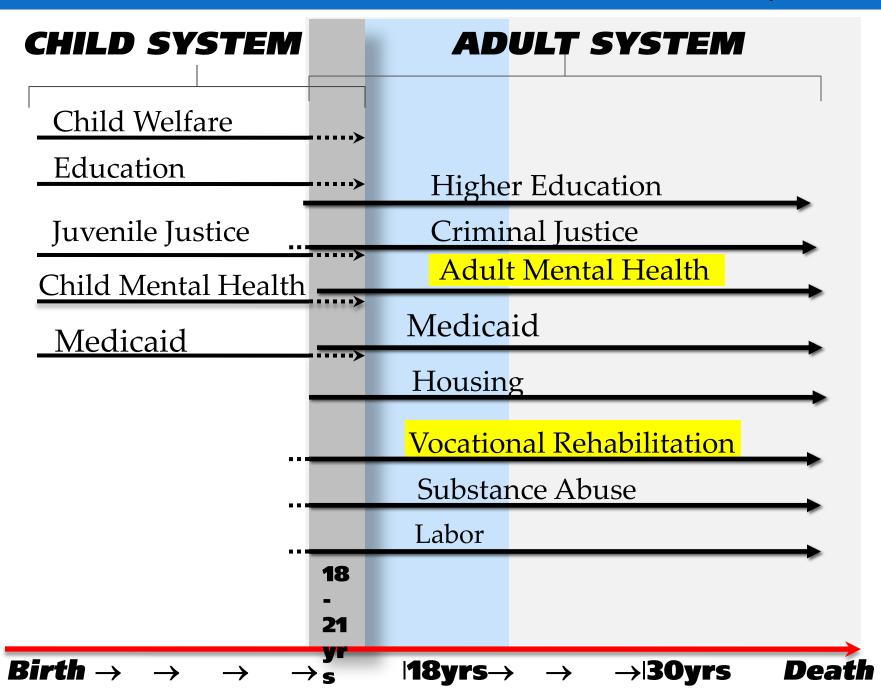
- Careers are occupations with opportunities for growth, that are undertaken for a significant period of a person's life – skilled, unskilled, or professional
- Career <u>development</u> is comprised of the learning and cognitive elements that influence career choices, activities, performance and attainment



"Young Adults"

Chronologically: Ages 18-30 years





Conference Attendees:

Federal programs influencing adult systems including;

- Department of Labor
 - Youth Team Office of Disability Employment Policy
 - Employment & Training Administration, Disabilities Program
- Substance Abuse and Mental Health Services Administration
- Rehabilitation Services Administration
 - Office of Special Education & Rehabilitative Services
- Department of Education;
 - Office of Special Education & Rehabilitative Services
 - Office of Postsecondary Education
- Centers for Medicare & Medicaid Services
- Social Security Administration; Office of Employment Support Programs
- National Institute on Disability and Rehabilitation Services
- Health Resources & Services Administration; Maternal & Child Health Bureau
- Administration for Children & Families
 - Department of Justice, Office of Juvenile Justice & Delinquency Prevention

Conference Attendees:

- Young adults with lived experience
- Family members of young adults with lived experience
- Research programs and researchers focused on education/employment/careers, mental health, disabilities, rehabilitation
- State level administrators



Research Reviews

- Reviews of the Research Literature in
 - Education/Training
 - Working/employment
 - Systems/Policy
- Each paper included young adults with lived experience
- Each review included a research agenda
- "Response" paper
 - Panel of experts with a variety of perspectives



Responders

Young Adults, Family Members, Members of cultural minorities, Senior Researchers

Crystal Blyler

Gary Bond

Shannon CrossBear

Mark Courtney

Marianne Farkas

Melanie Green

Vivian Jackson

Krista Kutash

Eric Lulow

Joseph Marrone

Kim Mueser

Michelle Mullen

Trina Osher

Mark Salzer

Ashli Sheidow

Sandra Spencer



Reviews & Responses Presented to Attendees

- General Discussion
- Break-out group discussion focused on future research needs
- Future research suggestions & new ideas from groups
- Voted on future research priorities



Presenters

- Nancy Koroloff, Ph.D. Systems and Policy Issues
- Marsha Ellison, Ph.D. Education and Training
- Maryann Davis, Ph.D. Employment/Careers
- Amanda Costa, A.A. Young adult perspectives
- Steven Reeder, MEd, CPRP, CRC State perspective



System And Policy Considerations For Strong Career Launches In Young Adults With Psychiatric Disabilities

Nancy Koroloff, Maryann Davis, Jim Wotring, Lacy Kendrick Burk, Lauren Grimes, Theresa King, Steve Reeder.



System And Policy Challenges: Where Do Young People Fit In Adult Mental Health



 1) What are the challenges of moving from child to adult mental health systems?

• 2) Are young people able to get effective, age appropriate services in adult mental health system?



How many young adults need services in adult systems?

- Estimates of 6%-7% of non-institutionalized young adults have a serious mental health challenge (NSDUH 2010-2011, GAO 2008)
- Point in time estimate 13% of young adults have a psychiatric disorder. (Copeland et al. 2011)



Are young adults under-represented in adult services?

- Study in one state
 - 21% of general adult population between 18-25 yrs
 - 6.7% of the mental health service population between 18-25 (Fisher et al. 2011)

Most states have the data sets to compute this kind of benchmark.



Are young people unique?

- First time taking medication and adapting to side effects
- Level of risk taking behavior is higher, may be handled differently than older adults.
- Peers are more important; stigma takes on a different meaning
- Engaging in education and career development, typical activity.
- Still developing skills for living independently as an adult, typical activity
- Different relationship and expectations with families.



What is the availability of age-appropriate services?

Survey of each state's adult mental health system

- 49% of states offered any age-tailored services
- 10% of states offered age-tailored vocational support
- 0 offered age-tailored educational support

(Davis, Geller & Hunt, 2006)



Research regarding the impact of offering age-appropriate services.

- Does offering age-appropriate educational and career development support increase sustained access to services for young adults?
- Does provision of this type of service reduce service needs at later ages?
- What is the impact in terms of system costs overall?



What are the barriers to availability of ageappropriate services?

National study of administrators in the adult mental health system

- Insufficient funding to do anything special for this small group (63%)
- No specific funding available (39%)
- Lack of leadership focused on young adults (56%)
- Issue just not a priority (51%)
- No individual or group clamoring for a change (44%)



(Davis & Hunt, 2005)

Barriers to availability of age-appropriate services-part 2.

- Difficult to fund vocational supports because hard to get Medicaid reimbursement
- Few vocational supports for adults of any age
- Age group isn't a priority, hasn't gotten any traction.
- Adult consumer groups don't advocate for issues important to young adults.
- General mental health services are available to all adults.



Research regarding the implementation of offering these services

- What are the current systemic barriers and facilitators to offering age-appropriate services?
- What will it take to overcome these barriers?
- How do barriers vary by system level, by funding mechanism and other system factors?
- Does increased contact and collaboration between child and adult mental health services result in greater implementation of age-appropriate services?



What are some overarching system and policy issues?

- Income support for young adults with psychiatric disabilities (SSI, SSDI)
- How important is the availability of health care benefits?
 To whom?
- What is the role of eligibility criteria in including or excluding young adults
- What is the role of young adults in planning and evaluating services and policies?



Promoting Learning During Young Adulthood¹

Children's Mental Health Research & Policy Conference Tampa, Fl., March, 2014

Presented by:

Marsha Langer Ellison, Ph.D.

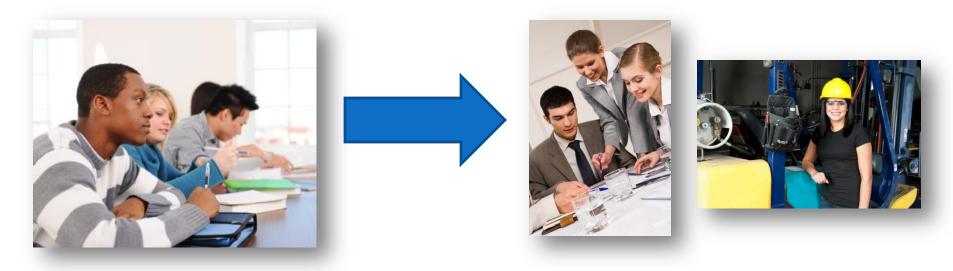


Overview of Presentation

- Scope of the Challenge
- School-based Supports and Interventions
- Supported Education
- Lessons Learned
- Next Steps for Research



Higher education leads to better income and careers¹





Impairments associated with psychiatric disabilities impact educational performance and attainment²

Students with psychiatric disabilities (PD) struggle at every level of education

- Over 50% of students with a mental disorder drop out of high school ³
- Special education serves a smaller proportion of the total number of high school students with mental disorders ⁴



Only 11% of special education students with PD go to a four- year college 5

There are increasing numbers of students with PD at college:

- → 9 18% of all college students have mild to significant mental health issues ⁶
- Increasing numbers of students seek help for mental health issues on campus 7
- Higher rates of suicide ideation, attempts, and completion among college student with PD 8

Those that do go on to college tend to:

- Have delayed enrollment after high school
- ➤ Enroll as part-time students 9
- ➤ Have high drop-out rates 10



Students with PD report difficulties in or unwillingness to seek help at college:

- ≥21% do not report their disability the highest of any disability group¹¹
- Perceptions that student disability offices don't know how to help¹²
- A fear of being stigmatized
- Uncooperative responses to requests for accommodations¹³



School-based Supports And Interventions



School-based Supports and Interventions - Secondary Education

Individuals with Disabilities Education Act (1997) specifies Transition Planning

High school completion among special education students with PD increased from 47.4% (1990) to 78.1% (2005).

This 2005 rate is similar to that of general education peers. 14





School-based Supports and Interventions - Vocational Rehabilitation

State Agencies of Vocational Rehabilitation (VR) are an important resource for improving education outcomes

- > Youth ages 16- 24 account for one third of all VR clients¹⁵
- VR can support education and training in the service of a vocational goal¹⁶
- States are innovating to improve transition of high school students to VR services and employment¹⁷
- Ten percent of young adult VR clients with PD received educational support. Nearly half completed their VR goal. 18

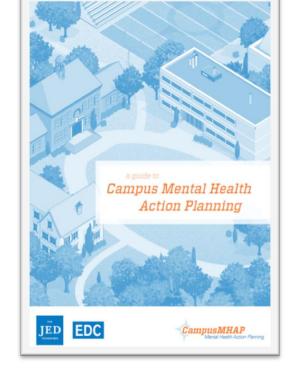


College Based Supports and Interventions

Environmental Supports 19

- Improve communication
- Educate the college community
- De-stigmatize mental illness





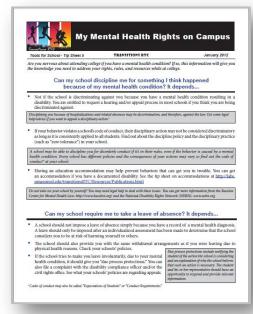


College Based Supports and Interventions

Changes in Policies 20

- Leave of absence protocols
- Individualized re-entry requirements
- Policies for self-harm other than zero tolerance
- MOUs with local hospitals



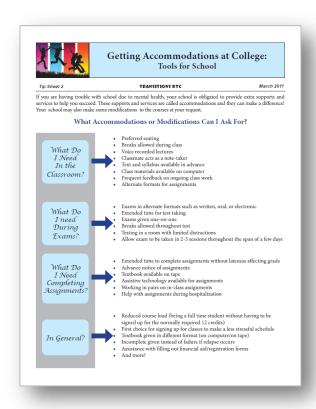


Campus Based Supports and Interventions

Educational Accommodations 21

- Students are unaware of rights or fear disclosure
- Disability staff don't know how to accommodate PD

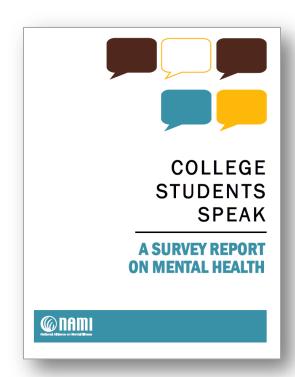




College Based Supports and Interventions

- Campus Mental Health Counseling
- Peer Support
- Suicide Prevention





Supported Education

Adult System Perspective



Supported Education - Definitions

- Services that enable a person to choose an educational goal, pursue activities needed to achieve that goal, then maintain those activities until goal achievement (Choose, Get, Keep)
- Interventions designed to assist individuals in making choices about education and training and to assist them in maintaining their "student status" until their educational goal is achieved ^{22,23}



Key Components²⁴

- Coordination with mental health services
- Use of specialized SEd staff
- Career/vocational counseling
- Help with financial aid
- Help to develop skills to cope in academic settings

- On campus information about rights/resources
- Off campus mentorship and support
- Access to academic supports
- Access to general supports



Values of Supported Education

Similar to the values of supported employment and rehabilitation in general

- Integrated educational settings
- Choice and self-determination
- Provision of supports as needed and wanted
- Focus on skill development rather than on symptoms/diagnosis/pathology alone

Supported Education - State of the Field

- SEd developed/tested mostly with adults who have serious mental illness
- SEd has typically been offered through adult MH agencies
- SEd meant for young adults may need to be adapted, e,g.:

means of communicating information and providing support may need to change



Effectiveness of Supported Education-Systematic review–1990-2010; updated in 2013²⁵

- Writings on the principles and processes of providing supported education
- Found 41 articles; 21 reviewed for research quality
- Very limited number of rigorous studies
- >Simple pre post studies; descriptions of models
- ➤ One large RCT in the literature
- Two new fidelity measures are available 26,27, but could not locate research studies utilizing fidelity assessments

Outcomes Generally Examined in SEd

- >Educational engagement
- >Enrollment in educational setting
- Educational attainment (components completed, acquisition of degree)
- >Employment outcomes
- Subjective measures such as self esteem/mastery
- ➤ Quality of life



Effectiveness of SEd

➤ No evidence from a randomized trial or well controlled quasi experimental trial that participation in a supported education intervention results in significantly greater educational engagement or enrollment

No significant difference in the employment rates at follow-up of individuals participating in a supported education intervention versus those not participating



Effectiveness of SEd

- Suggestive evidence of improvements in employment and educational status as a result of participation in a supported education intervention
- Self esteem/quality of life may improve
- Individuals who remain engaged in SEd may complete courses and achieve satisfactory GPA



Conclusions

- Several studies suggest that SEd is a viable model
- Improvements in educational status and attainment suggestive, but studies weak and older
- Therefore: not enough evidence to say that there is robust effectiveness data for SEd models



Promise on the Horizon

- Nuechterlein-recent onset schizophrenia-career development intervention based on SEd-IPS model²⁸
- RAISE study—multisite NIMH study focusing on young adults
- Salzer/Gill/Mullen -2013 RCT underway but effectiveness data not yet available



Lessons Learned-Landscape of Supports

- Young adults with SMHC lag behind general population in educational attainment
- ➤ Policy innovation in special education has been beneficial—but we don't know why it is effective
- College campuses seem unprepared to assist with challenges of SMHC population
- Literature includes support strategiesbut few are tested

Lessons Learned

- Adaptations of existing models for young adults are needed
- Further adaptation and innovation is needed for special populations such as those involved in foster care or the criminal justice system
- No data currently exist that speak to long term outcomes of Supported Education, such as employment

Next steps for research—we need:

- Additional data about barriers and facilitators to educational attainment— especially from a cultural perspective
- Specification and rigorous testing of SEd models
- Innovations and evaluation of environmental approaches to supporting young adults with SMHC on campus



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Employment And Careers In Young Adults With Psychiatric Disabilities

Maryann Davis
Jonathan Delman
Tania Duperoy



Career Development



Unique Aspects of Career Development in Young Adulthood

- By the mid-20's, there are significant career differences between those who pursue college degrees, and those who don't, and those who start families, and those who don't (Osgood et al., 2005; Sandefur, Eggerling-Boeck, & Park, 2005)
- By their mid-20's, most young adults are in long term or career-consistent jobs (Osgood et al., 2005)
- Important cognitive aspects of career development crystallize during young adulthood (Swanson, 1999)
- Insufficient career activities (e.g. career exploration) can interfere with adult career roles (Herr, 1993; Super, 1988)
- Career efforts during young adulthood predict later career success (De Vos, De Clippeleer, & Dewilde, 2009)

Employment Appears Low

- Young adults with anxiety or depression less employed than mature adults (Waghorn, Chant, & Harris, 2009)
- Young adults that have psychiatric disabilities in adolescence have lower employment rates compared to same age peers in other disability groups or in the general population (Frank, 1991; Neel, 1988; Newman et al., 2011; Vander Stoep et al., 2000)
- No studies of age differences in employment in young adults in adult systems



Summary of the State of the Science

No research has examined the career development process in young adults with psychiatric disabilities

No research identifies the malleable factors that are unique to these young adults' development of strong careers – relative to other young adults or mature adults with PD



Research on interventions to support career development in this population in its infancy



Employment Interventions

- Vocational rehabilitation (VR) services
- Guideposts for Success
- Clubhouses
- Supported employment focused on the Individualized Placement and Support (IPS) model
- Career development interventions



Effect of Interventions on careers

- The impact of these interventions on "Careers" has not been examined
- IPS model has the strongest research findings; consistently better employment outcomes for adults compared to several other interventions
- Analyses of young adults from clinical trials of IPS suggest it produces better outcomes than usual services (small sample)
- None have achieved more than low-wage mostly part time work



Individualized Placement and Support – Young Adults

- Two versions for young adults with early stages of psychosis have growing supportive research findings
 - Combine supported employment with supported education (Killackey, Jackson, & McGorry, 2008)
 - Curriculum on working, substance abuse information, family education (Nuechterlein et al., 2008)
- Transitions RTC young adults with psychiatric disabilities (PI-Ellison)
 - Supported employment/supported education
 - Peer mentors



Less research specifically in young adults

- Guideposts random assignment, no fidelity measure, better outcomes than usual services for youth with disabilities
- No "clinical trials" research focused on young adults in VR services or Clubhouses
- Some evidence that outcomes in young adults better than mature adults, but broad age groups, no detailed understanding of why



Models under development

- RENEW -Rehabilitation, Empowerment, Natural Supports, Education, and Work-(Hagner, Cheney, & Malloy, 1999) – positive change from baseline
- Career Visions positive results
 (Sowers, 2013) – small clinical trial with
- Social Enterprise Intervention for Homeless Young Adults (Ferguson, 2012) –encouraging preliminary qualitative findings
- IPS-Peer Mentors (PI Ellison)
- Multisystemic Therapy-Emerging Adults; Coaches (PI Davis) "coaches" that deliver career development and employment curriculum to VR services and standard coaches encouraging preliminary findings

Models under development – shared features

- Emphasis on career exploration, assessment and planning
- Support of concurrent employment and education or training
- Support of young adults leading and improving their capacities for career planning and implementation
- Include family members as potential supports



Research Agenda- Most Endorsed

Continue research with developing models to test their career development efficacy

 Establish efficacy for improving current employment and developing careers



Research Agenda Endorsement

- 2) IPS-focused research to identify subgroups that experience better or worse outcomes (which could inform IPS modifications, or the development of alternative or complimentary approaches)
- 3) Longitudinal research about young adult careers (eg., quality of employment and capacity over time)
- 4) Identify similarities and differences between young adults with psychiatric disabilities and young adults with other disabilities
- 5) Research to illuminate the specific mechanisms of IPS that produce better employment outcomes in young adults



The Emerging Adult Perspective





Emerging Adult Involvement

- 1. Assessing the State of the Science:
 - Emerging Adult co-authors on all 3 topic papers (employment, education and policy)
- 2. Emerging Adult Panel
 - Young Adults from Washington DC Metro Area
 - Shared personal experiences on
 - Child and Adult MH systems
 - Struggles with education and employment





Systems/Policy

- Unique population with unique system needs
- Need support staff who are knowledgeable about both Child & Adult systems
- Services and policies need to address all areas of YA life, not just MH management (employment/relationships/housing/transportation/etc)



Education

- Difficulties balancing work and school life
- Transition Planning for IEPs- not "up to par"





Education cont...

- Stigma prevents help-seeking on campus
- Need more self-advocacy or peer support opportunities
- No continuity of supports/services across universities

"My senior year of college was tough. I had a full-time course load and worked as much as I could. Also, having recently acquired knowledge of having a mental health condition and learning how to cope with it consumed much of my time and energy"



Employment

- Important factor of recovery
- Diversity in definition of "career path"
 - Sustaining employment vs. "moving up"
- Providing age-tailored employment services
- Allowing for career exploration and "job hopping"



Employment cont...

Finding employment with a criminal record

Fear of disclosure/repercussions

"I was once let go simply because I disclosed and not because I was symptomatic...My experience may make me afraid to disclose, but I always feel that honesty is the best policy. Finding the right fit with a job is thus very important"



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Mental Hygiene Administration









The 27th Annual Children's Mental Health Research & Policy Conference Hilton Tampa Downtown, Florida March 4, 2014



Steve Reeder, Director, Office of Adult Services, Mental Hygiene Administration

Why Focus on this Age Group?

- 1995 State legislation established a Statewide Interagency Transition Plan & comprehensive statewide strategy (Governor's Office for Individuals with Disabilities)
 - Initially focused on developmental disabilities.
 - Identified youth with mental health needs as underserved population most in need of services.



Why Focus on this Age Group?

- Grassroots family advocacy led to:
 - Establishment of Governor's Interagency Transition Council (Executive Order)
 - Mental Hygiene Administration and mental health advocates as mandatory partners
 - Elevated profile of needs of youth with mental health needs and served as catalyst for incremental change:
 - Cross-training for stakeholders
 - Resource mapping
 - Interagency website
 - Interagency Strategic and Annual Operational Plans- single point of accountability (leveraged funding and pooled resources).



Why Adult System should focus on this age group?

- Longitudinal evidence suggests that a disproportionate percentage of children and adolescents do reach adulthood.
- Single largest growing age segment of the population served by the Public Mental Health System (21% adults served between 18 and 25).
- Adult Systems has priority focus on outcomes most desired by youth and young adults: employment, post-secondary education, and housing.
- Emergent data shows the potential cost savings of providing developmentally appropriate services.



Maryland Transition Age Youth (TAY) Initiatives (2000 to present)

- FY2000 Governor provided time limited appropriation
- Conceptualized as Adult Services initiative
 - provide TAY with sufficient skills/supports during transition to minimize/prevent further involvement in the Adult Service system
 - Diversion: a bridge to adulthood not to long-term adult services
- 12 TAY-specific programs in local mental health authority or Core Service Agency (CSA) jurisdictions (20 CSAs), based on competitive selection of CSA proposals
- Annualized each year since
- Currently 24 programs statewide

Maryland Transition Age Youth (TAY) Initiatives (2000 to present)

- 12 TAY-specific programs in local mental health authority or Core Service Agency (CSA) jurisdictions (20 CSAs), based on competitive selection of CSA proposals
- Annualized each year since
- Currently 24 programs statewide (Joint Chairman's Report)



The Maryland Center of Excellence: Early Intervention Program (EIP) FY2014

Purpose: alter the course of illness, reduce disability, and maximize the likelihood a person with early signs of psychosis will be able to manage their illness, move successfully through the appropriate developmental stages of growth, and establish a life of their choosing.

EIP is composed of three components:

- Outreach and Education Services will provide general background on clinical high risk and early psychosis to behavioral health providers, schools and primary care settings
- Clinical Services for 12-30 year olds who present with clinical high risk symptoms,
 early signs of psychosis or those in initial stages of psychoses. Services will include:
 - The Clinical High Risk Clinic
 - Two first episode clinics: Maryland Psychiatric Research Center First Episode Clinic and University of Maryland Division of Community Psychiatry First Episode Program
 - Consultation service
- Regional Early Intervention Learning Collaborative Teams (EIT's)
 - Create a statewide learning collaborative so that EITs and others providing services to those with early psychosis can collaborate, share resources, and provide support and coordination of service delivery

Maryland Transition Age Youth (TAY) Initiatives (2000 to present)

- Initiatives varied in scope, focus, age range (14-25), and type of intervention/service modality
- The set of services promoted innovation & allowed for model testing
- Services now consistent with and informed by the Transition to Independence Process (TIP)(Clark & Unruh, 2009)
- Goal: develop expertise in empirically-supported approaches that can be brought to scale and replicated statewide



Strategies

- Leveraged existing services and resources in the Public Mental Health System (PMHS), while funding those discrete services and supports not otherwise covered in the PMHS benefits package
- Key policy change: Expanded diagnostic eligibility
- Granted access to EBP supported employment at age 16 prior graduation from high school



Evidence-Based Supported Employment System Transformation

- Single point of entry to supported employment across both Mental Health (MH) and Vocational Rehabilitation (VR) systems
- Deemed status approval for MH SE providers
- Presumed eligibility of consumers for VR
- Guest access to MH system data for VR counselors
- Braided funding streams
- Incentives for fidelity, outcomes, and performance
- Shared definitions, data, and outcomes
- Policy aligned with EBP across both agencies



TAY Outcomes, Considerations, and Lessoned Learned from TAY Initiatives

- Average length of TAY-specific service is approximately two years in duration
- 70% of 16-25 yr. olds enrolled in TAY-specific programs are engaged in competitive employment vs. 46% of 16-25 yr. olds enrolled in any service within the Public Mental Health System (PMHS)



Conclusions from MD Experiences

- Develop services and supports which are designed specifically for TAY and which transcend the age transition cliff (ages 16-25), rather than retro-fit child and adolescent or adult services to met the unique needs of TAY
- Leverage funding and pool resources across multiple systems
- Workforce Development: Enhance core competencies in developmentally appropriate and empirically supported practices for TAY through
 - Systematic and targeted training, technical assistance, and consultation strategies
 - Which emphasize both practice improvement and organizational change



Discussion

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