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Developing an Integrated Model of Career Services for Young Adults with Mental Health Conditions

30th Annual Research & Policy Conference on Child,
Adolescent, & Young Adult Behavioral Health

Kathryn Sabella, Katie Holloway, and Rachel Stone

March 6, 2017

Special Thanks: Marsha Langer Ellison & Michelle Mullen

Acknowledgements

HYPE (Helping Youth on the Path to Employment) is a joint research venture between Rutgers University Department of Psychiatric Rehabilitation and the University of Massachusetts Medical School Transitions Research and Training Center.

www.umassmed.edu/TransitionsRTC

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Overview of the Symposium

- Part 1: The Initial Development and Research Activities for the HYPE Project
- Part 2: The Process of Developing Agreement Between National Experts and Young Adults with Lived Experience
- Part 3: Participatory Action Research in the HYPE Project: The Importance of Youth Voice

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Part 1: The Initial Development and Research Activities for the HYPE Project

What is HYPE?

Helping Youth on the Path to Employment (HYPE) is

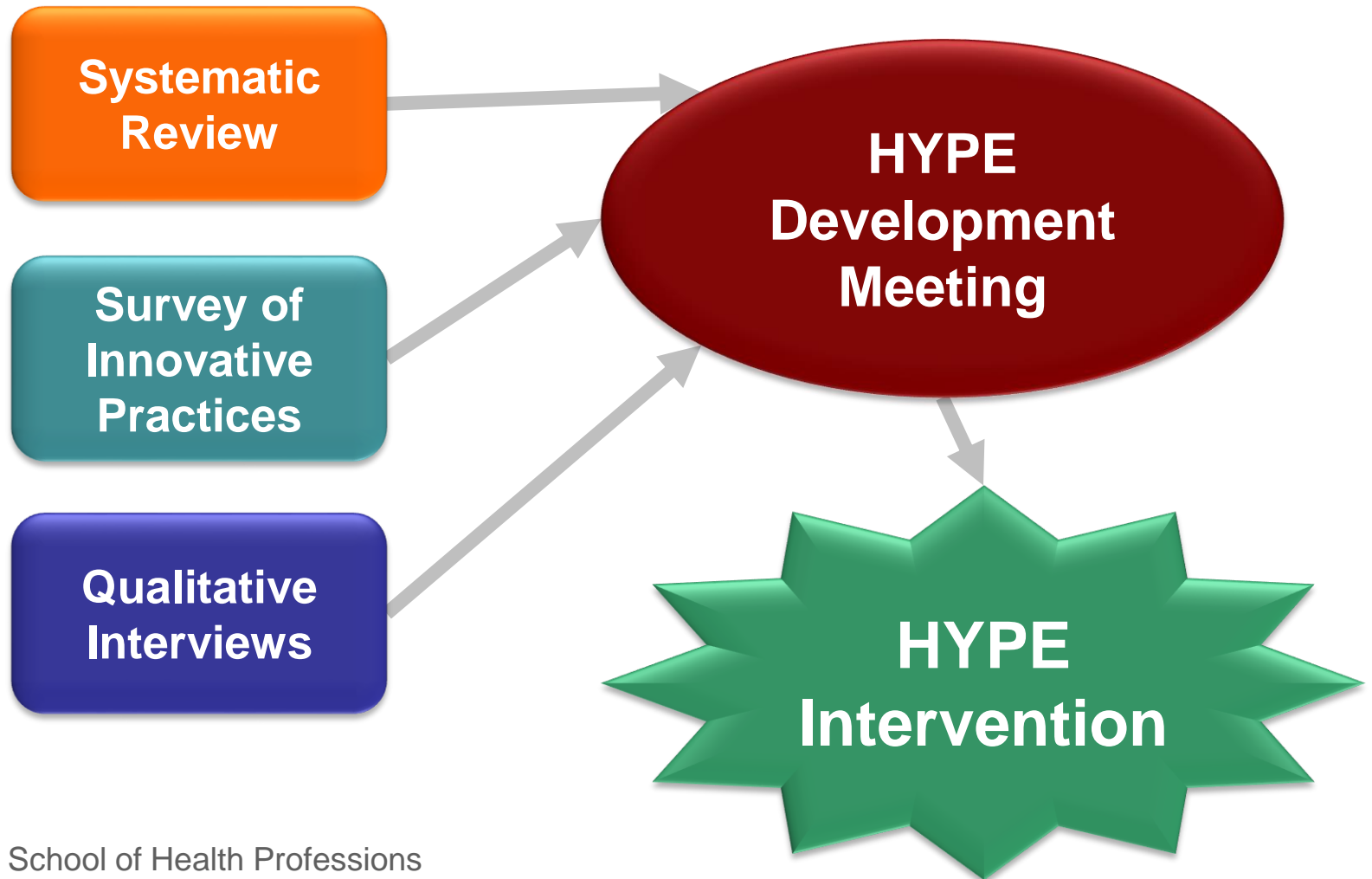
- an innovative set of services that is being developed to better support the career development of young adults with mental health conditions.
- a **manualized intervention** aimed at **assisting supported employment programs in integrating supported education interventions** into services to assist young people in maintaining or returning to the role of student.

How was HYPE developed?

In order to accomplish our goals, we wanted to:

- Understand the unique experiences and needs of transition age youth and young adults
- Seek and utilize feedback and input in all phases of the project from
 - Experts in research and practice (National Advisory Council – NAC)
 - Experts through lived experience (Participatory Action Council – PAC)
- Understand the current innovative practices being delivered and the evidence-base for current interventions that aim to support the education and employment goals of young adults with SMHC

Overview of HYPE: Developing an Intervention





Survey of Innovative Practices: The State of the Art

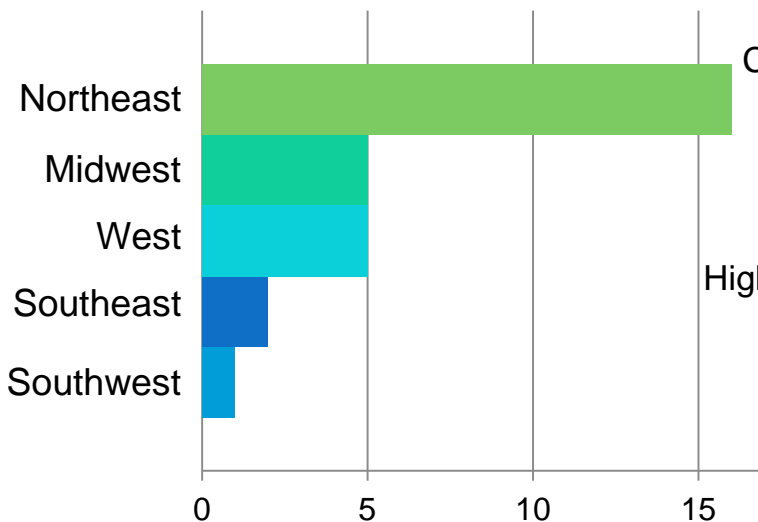
Marsha Langer Ellison, Ph.D., Sloan
Huckabee, Ph.D., & Rachel Stone, B.A.

What is the Survey of Innovative Practices?

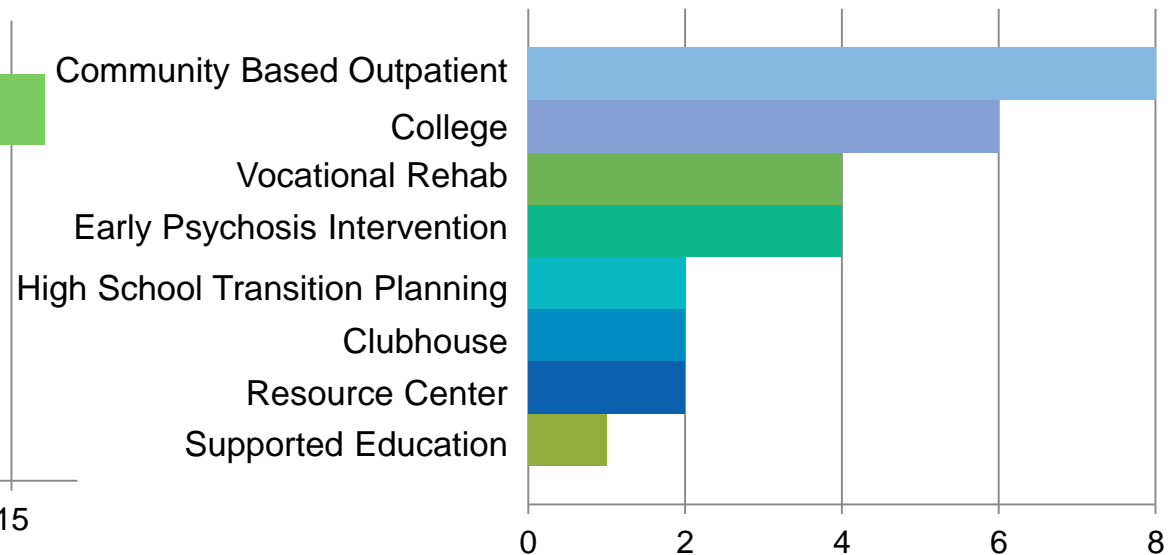
- Interviewed providers and state agencies
- Gathered both current and promising practices being used in the field
- Collected information about well-established approaches and innovations
- Focus on Employment and Education

PROGRAM CHARACTERISTICS

Regional
Distribution
N = 29

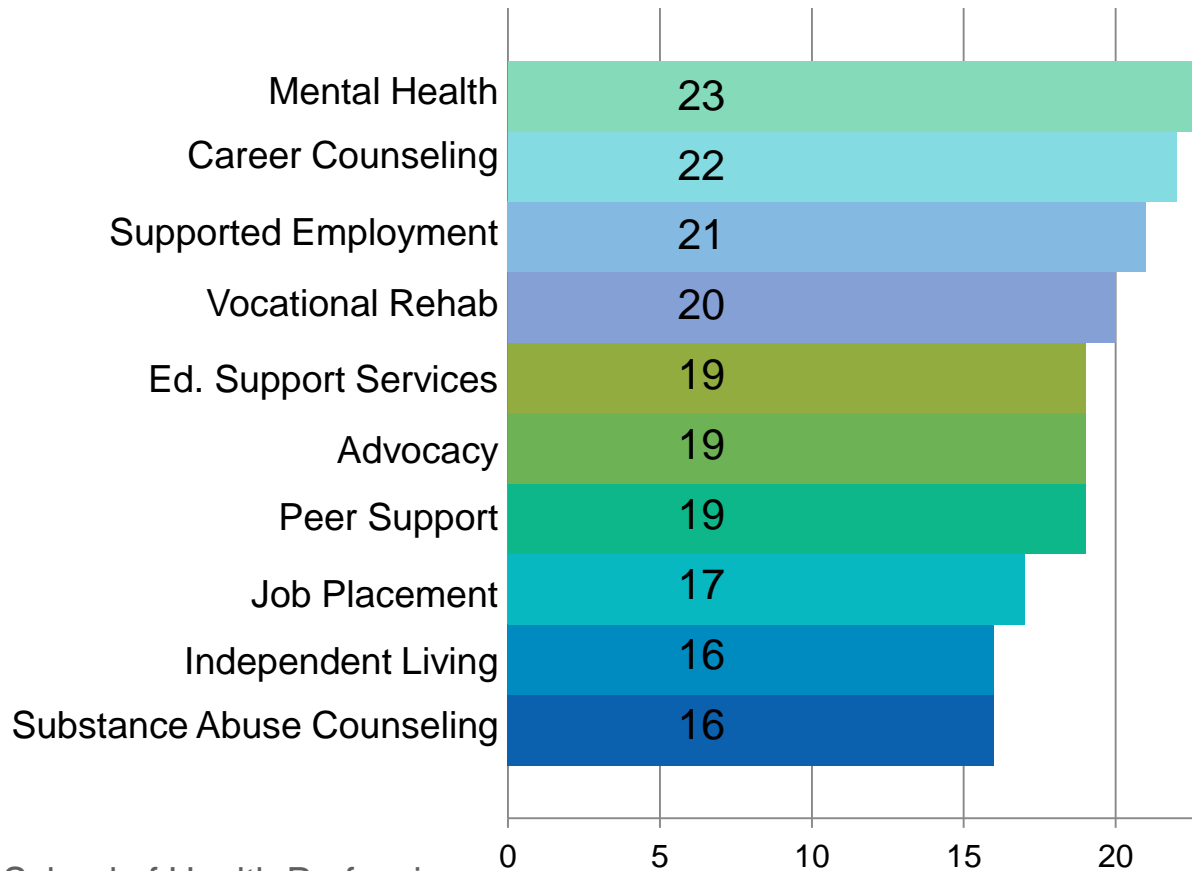


Program
Types
N = 29



PROGRAM CHARACTERISTICS, CONTINUED.

Services Offered
N = 29



What Did We Learn?

- The youth population is unique
 - Avoiding diagnosing/labeling due to stigma
 - Tolerance for missed appointments and gaps in services
 - Protecting non-patient role (non-treatment environment)
 - Continuous support
 - Focus on **both** work and school
 - Youth-oriented engagement practices (social media, texting, etc.)

What We Didn't Find

- Specified or manualized approaches
- Emphasis on skill development
- Systematic approach to career development
- Well articulated or defined practices
- Systematic program evaluation



Systematic Review: The State of the Science

Judy L. Thompson, Michelle G. Mullen,
Sean Karyczak, David Crandall, Rachel
Stone, Emily Simpson, Sandy Ghaly &
Katie Holloway

**With special thanks to John Westbrook*

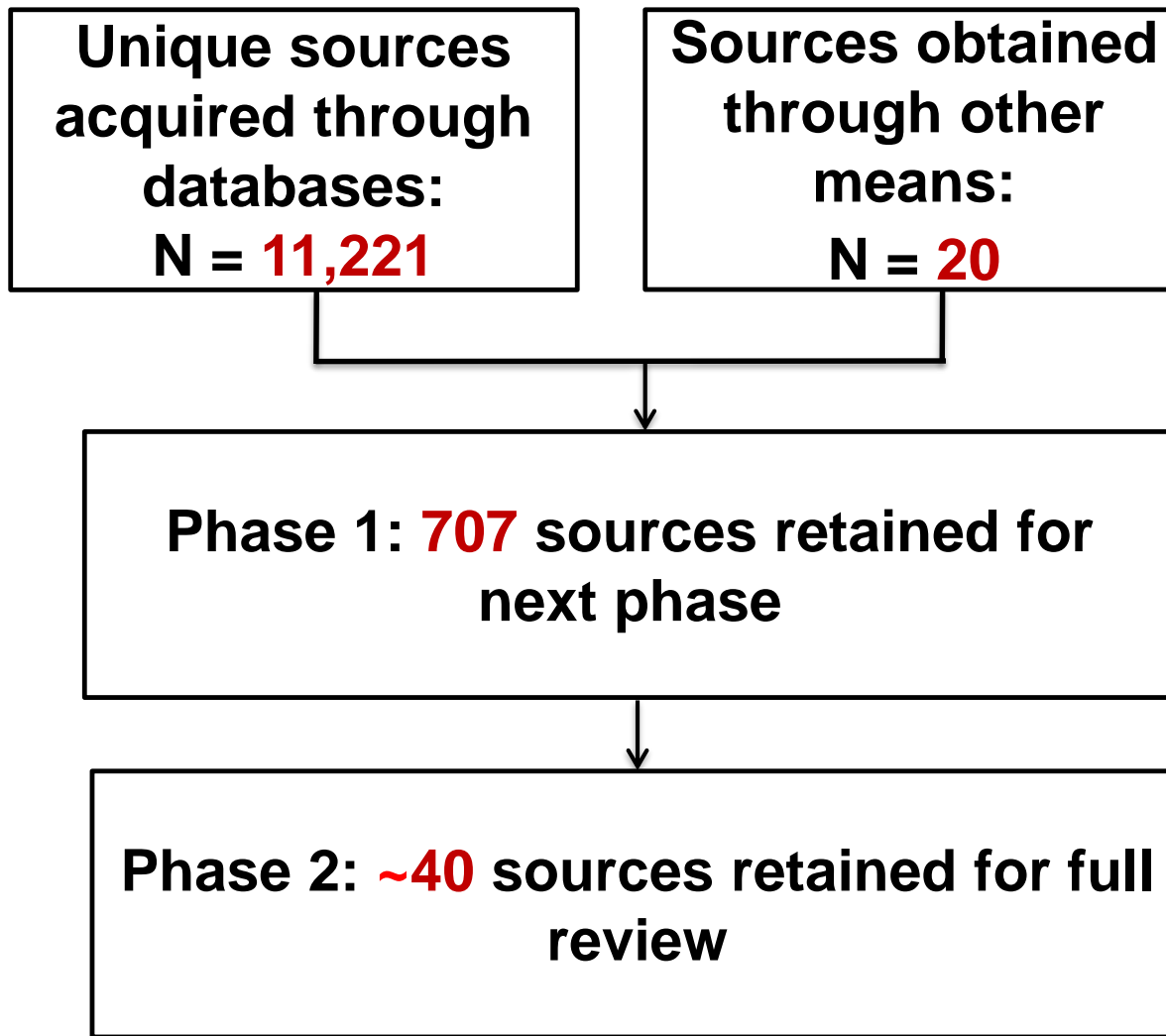
What is the Systematic Review?

AIM:

- Summarize results of interventions that target education and/or employment outcomes among young people with mental health conditions.

QUESTION:

- What are the services and supports that show evidence of supporting career development for young people with mental health conditions?



Summary of Results

- Very few studies of services that target employment and/or educational outcomes for young adults
- Interventions based on IPS principles can improve employment outcomes among young adults with mental health conditions
 - Results are promising but less clear regarding educational outcomes
- Targeting cognitive and social-cognitive impairments appears to facilitate improvements in employment outcomes for young people with schizophrenia
- Specialized supported-education services based on psychiatric rehabilitation principles (including programs using the Choose-Get-Keep framework) can improve educational and employment outcomes



Qualitative Interviews: The State of Need

Michelle G. Mullen, Judy L. Thompson, Katie Holloway, Rachel Stone, Amanda Costa, Emily Simpson, Olga Anagnostis, David Crandall, Sean Karyzcak & Sandy Ghaly

***With special thanks to the PAC**

Learning from Young People First Hand...

- Interviewed young adults (18-35) with mental health conditions
- Focus of questions guiding ~90-minute QI “discussion”:
 - Impact of mental health condition, especially regarding school and work;
 - Participant’s school, work, and long-term career goals & aspirations;
 - Barriers and facilitators: what has helped and what has gotten in the way.

Demographic and Clinical Characteristics (N=20)

Mean age (SD)	25.30 (4.61)
Age range	18-33
Gender, n	16 female 4 male
Ethnicity, n	14 Caucasian 3 Asian 4 African American
Self-reported mental health condition(s)	13: depressive disorder 10: anxiety disorder 6: bipolar disorder 3: ADHD (comorbid) 2: eating disorder 2: schizoaffective disorder 2: schizophrenia 1: substance-use disorder (comorbid)

Impressions & Implications

- The need for additional support and information is critical
 - Implications for school loans & financial aid
 - Unaware of existing supports
 - Lack clear vocational direction
- Periods of absence from work and school corresponded with greater mental health issues for some
- Families can be amazing supports or real barriers to resiliency
- College campuses need targeted interventions
- Vocational Rehabilitation needs assistance in better understanding young adults and the need for higher education

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Part 2: The Process of Developing Agreement Between National Experts & Young Adults with Lived Experience

Presented by: Kathryn Sabella

Step 1: Synthesizing the Results of Development Activities

- Identified the important interventions, service elements, and practitioner competencies from the previously mentioned activities
- Organized into three areas:
 - Guiding Principles & Practices
 - Agency & Program
 - Practitioner Knowledge & Competencies
- Items were unique to young adults and career development
 - Retained items that converted employment services to career services (e.g. education related)

Step 2: Career Development Checklist

- Used Delphi method for experts to rate the level of importance to the HYPE intervention
 - Send out the “checklist” to young adults and researchers/practitioners to rate items they thought were critical to a career development service for young people
 - Anonymous participation, although “membership” was identified

Agency and Program

In this section, we have identified agency-level and program-level policies, practices, or procedures that likely influence the operation and delivery of career development intervention for young people. We would like for you to rate how important each item is to implementing a high-quality, career development service for young people.

	Not at all important	Slightly important	Neutral	Important	Very Important
1 Age-specific programming is provided such that young people are served separately; programs understand that young people may not be best served by encouraging involvement in program-related activities with older adults.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2 The agency and staff have extended evening and weekend work hours to accommodate the scheduling preferences of the young people being served.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3 The agency adequately reimburses practitioners for the costs associated with meeting young people in the community (e.g., for gas, food).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4 The program implements formal and informal assessments of fidelity to the career-services principles on which services are based: the results of these	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Step 2: Career Development Checklist (cont.)

- Results were analyzed to identify where there was disagreement
- Checklist allowed us to identify what topics to bring to our experts (young adults and researchers/practitioners) to better understand why there were differences between or within groups.

Result: 14 topics with <80% agreement:

- 4 topics to be discussed among Young Adults
- 4 topics to be discussed among Researchers/Practitioners
- 6 topics for larger discussion between both groups

Step 3: HYPE Development Meeting

- To ensure services are in-line with young adults and their needs as well as evidence-based and innovative we need to have young adults at the table
- Structure of meeting (September 2015):
 - Completely in-person discussion-based, 2 ½ day meeting
 - Based on disagreement of important items on the checklist within & between advisory councils
- Participants:
 - Young Adult advisory group (n=14)
 - Researcher-Practitioners advisory group (n=12)
 - Rutgers & UMASS research faculty & staff (n=16)

Small Group Discussion Structure

- Each group met separately to discuss why they had differences in opinion
- Each group had three “facilitators”
- Each room had two scribes
- As a group, they created a “summary” before moving onto the next item
- Questions were developed and posed to the other advisory group on the second day

Discussion Topics for Young Adults

- **STRATEGIC SELECTION**

- How should HYPE practitioners best help young people to be strategic in their selection of courses, commitments, and workload?

- **DEVELOPING EXPERIENCES**

- How can HYPE practitioners best help young people to develop experiences that relate to their long-term goals (e.g. summer employment, internships, and volunteering)?

- **ROLE OF BENEFITS**

- How should HYPE practitioners determine with the young person when or whether an SSA application is beneficial?

- **FAMILY INVOLVEMENT**

- How should families be involved in the development, planning, and implementation of employment and education goals for their loved one?

Discussion Topics for Researchers & Practitioners

- **ENHANCING MOTIVATION**

- How should HYPE practitioners support young people who have difficulty maintaining motivation and commitment to successfully engage in education and employment pursuits?

- **GENERALIST VS SPECIALIST**

- How should programs be staffed to best serve the needs of young people who are pursuing long-term goals that may switch between work and school?

- **ENHANCING COGNITION**

- How should practitioners support young people who show signs of difficulty with higher-level cognitive process that may create barrier to successfully engaging in higher levels of education and employment?

- **SKILL DEVELOPMENT**

- How should practitioners identify the areas of critical skill that require development in order to be successful in work and school?

Following Smaller Group Discussions: Large Group Discussion

Large Group Discussion: Two phases

First Phase

- Groups reported back on their topics
- Asked questions of their counterparts to gather additional information

Second Phase

- Discussed topics where groups disagreed
- Topics were structured to better understand what practitioners need to *know* and what they need *to do*.

Large Group Discussion Topics

- **MINIMIZING DISRUPTIONS**

- How can HYPE practitioners best help young people minimize the amount and length of disruptions to continuous participation in human capital development (involvement in work and school)?

- **JOB SUPPORT**

- How can practitioners best support young people who have demanding jobs that require advanced skills, e.g. independent work, planning, managing multiple roles/responsibilities, managing other people, etc.?

- **DETERMINING A CAREER GOAL**

- How can practitioners best help young people to discover, integrate, and use their interests, values, and experiences to inform their education and career goals?

Large Group Discussion Topics (cont.)

- **COORDINATION OF SERVICES**
 - For those young people who are not in the public mental health system, how should HYPE practitioners help coordinate mental health, housing, and career services?
- **AGE-SPECIFIC SERVICES**
 - What are the advantages and disadvantages of age-specific programming where young people are separated out from older adults?
- **PEER SUPPORT GROUPS**
 - What are the advantages and disadvantages of support groups in career development services for young people?

Important Themes from Group Discussion

- Peer Support
- Role of Mentorship
- Disability Services trained on mental health conditions
 - Accommodations & assistive technology
- Comprehensive mental health services on college campuses
- Communication strategies
 - “Text me, until I tell you not to...”

Important Themes from Group Discussion (cont.)

- Talk/ask about thoughts of suicide
- Professionalism vs self-identity
 - Large discussion about what was/is considered taboo (e.g. tattoos for doctors)
- Services to maintain *wellness*
- Enhance state VR services to better serve those with higher education goals

Outcomes of the HYPE Development Meeting

- **Authentic inclusion of youth and young adult perspectives in the development of an age-tailored intervention**
- Reaffirmed current approach to services
- Clarified important areas for young adults regarding families, disclosure, engagement, peer-support
- Informed the development of practice, values, and principles

Next Steps

- Since the Development Meeting we've been revising and finalizing the HYPE manual
- Feasibility Assessment: testing out the manual with two partner agencies
 - Fall 2017 through Spring 2018

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**Part 3: Participatory Action Research
in the HYPE Project:
The Importance of Youth Voice**

Presented by: Katie Holloway and Rachel Stone

Participatory Action in HYPE

- What is Participatory Action Research?
 - Participatory Action Research (PAR) is a process in which researchers and community members, or members of the population being researched, work collaboratively to combine knowledge and action
- How does HYPE utilize PAR?
 - Young adult research assistants with lived experience participated in every aspect of the project
 - Participatory Action Council (PAC) provided guidance throughout the project

Participatory Action in HYPE

- Participatory Action Council (PAC)
 - Diverse group of about 15 young adults with lived experience
- Members participate in monthly meetings via web conference
- Provide guidance to all parts of the project
- Contribute knowledge of different systems as well as relevant, contemporary experiences
- Guide the research team's focus, questions, and interpretations

How the PAC Contributes to HYPE

- Creating the Qualitative Interview Script
 - Language: "Mental health condition"
 - Addition of specific questions regarding stigma and discrimination, including self-stigma, and a question on "advice to your younger self"
- Product Development
 - Integrating feedback into dissemination of results

What PAC members say about participating in the HYPE project

Jessica:

- Health activist, writer, speaker, and high school debate coach
- Has multiple chronic health conditions, including bipolar disorder, polycystic ovarian syndrome, myasthenia gravis

“Being a part of HYPE has really helped me help other people. The other day a man contacted me, he emailed me after he watched my TEDx talk, and he said, “You mentioned your work with Rutgers. I have a son in college, he has bipolar disorder and he struggles with depression.” And he wanted to be connected to our resources, not just for himself and his family, but then he could help other young adults with mental illness. It’s nice to be able to tell people, “Yeah, I can help you with that.” That means a lot.”

What PAC members say about participating in the HYPE project

Alexis:

- 25 years old
- Special education teacher, works at a school for deaf children
- Recently married

“I never was a part of anything like this before. I never talked about really anything involving mental health, as it pertained to me. I was always just kind of talking about things abstractly. So that was a really good experience, and still is a really good experience for me. But also it was **really cool to meet people**, when we were at the conference, so many people who were older, who were like in established jobs and you know, **doing really cool things, who struggled with some of the same things that we go through every day. It was really kind of inspiring to me.**”

What PAC members say about participating in the HYPE project

Ryan:

- 33 years old
- Husband, father, and homeowner
- Certified Recovery Specialist, Certified Peer Specialist, CPS supervisor

*“Getting connected in that way was really empowering to me, and it felt like **my voice mattered** and what I brought to the table really mattered. You know, looking back on it, it was really a **life changing experience** for my professional and personal life.”*

Final Thoughts

- Innovative process of the development meeting
- Authentic inclusion of young adult voice

*"I feel **a sense of mutuality**... yeah I'm participating in this as a person with lived experience, but I am an equal, just as they are, so we're all in this together. It's not about like, this person is here to just share their lived experience. **We're all just equal, we're colleagues.**"*

*"It was also really cool just being in a room full of PhD's and all these super accomplished people, and just them listening to what we had to say. **That was impacting what they were doing,** it was really cool."*

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Thank You!

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