



HELPING YOUTH ON THE PATH TO EMPLOYMENT

Engaging Youth in the Development, Creation,
& Refinement of Innovative Services

Presented by:
Rachel Stone and Katie Holloway

Special thanks to: Michelle Mullen, Dr. Marsha Ellison, Dr. Judy Thompson,
Kathryn Sabella, and all the members of our PAC and NAC

Agenda

- Introduction & Overview of HYPE
- Summary of Research Activities
 - Scoping Review
 - Survey of Innovative Practices
 - Qualitative Interviews with Young Adults
- HYPE Development Meeting
- Final thoughts

Our Mission

(Why Did we Develop HYPE?)

- We wanted to:
- Understand the unique experiences and needs of transition-age youth and young adults
- Seek and utilize feedback/input in all phases of the project from:
 - Experts in research and practice (NAC-National Advisory Council)
 - Experts through lived experience (PAC-Participatory Action Council)
- We wanted to use this information to:
- Contribute significantly to the change of Career Services for young people with mental health conditions
 - Focus on Education and Employment

The Importance of HYPE: According to PAC Members

Matt:

- 28 years old
- Started facing mental health challenges during early high school, but didn't seek any formal treatment until he was in college
- Working towards becoming a Certified Peer Specialist (CPS)

*“When I learned what the HYPE project was about, I felt like, “Wow!” **This was exactly what I wish I had** when I went through college and started to look for a job after. This is exactly the sort of support and education that I needed when I was in school. **I could use the experience of what didn’t go so great and use that to inform how other people were helped.**”*

Overview of HYPE: Developing an Intervention



About our PAC Members

Ages	21-32, average 27.3
Gender	9 female 6 male 1 gender fluid
Ethnicity	11 Caucasian 4 African American 2 Hispanic 1 Asian or Pacific Islander 1 Native American
Self-reported mental health condition(s)	7: depressive disorder 6: bipolar disorder 5: anxiety disorder 2: ADHD 2: schizoaffective disorder 1: eating disorder 1: substance-use disorder (comorbid)
Highest education	1: High school diploma 6: some college 7: college degree 2: graduate or professional degree

About our NAC Members

in alphabetical order

Barbara Blacklock, M.A.	University of Minnesota
Crystal Blyler, Ph.D.	Mathematica Policy Research
Hewitt B. “Rusty” Clark, Ph.D.	University of South Florida
Maryann Davis, Ph.D.	University of Massachusetts Medical School
Darrin L. Harris	Ekhaya Youth Project, New Orleans, LA
Kim T. Mueser, Ph.D.	Boston University
Wayne Munchel, LCSW	Transition Age Youth Academy, Long Beach, CA
Pat Nemec, Psy.D.	Boston University; Rutgers University
Lisa Razzano, Ph.D.	University of Illinois, Chicago
Melissa M. Roberts, Ph.D.	Rutgers University
Anne Sullivan-Soydan, Sc.D.	Boston University
Luana Turner, Psy.D.	UCLA Aftercare Research Program
Janet Walker, Ph.D.	Portland State University

How does the PAC contribute to this project?

- PAC members participate in monthly meetings via web conference
- Provides guidance to all parts of the project
- Contributes knowledge of different systems as well as relevant, contemporary experiences
- Guide the research team's focus, questions, and interpretations

Other Youth Involvement:

- The research team includes researchers with their own lived experience, and were involved in every element of the project

How does the PAC contribute to this project?

Ryan:

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

*“When we left the conference I also must have left with probably 20 Rutgers ink pens. So, I use them a lot, and people always see them and ask me questions about Rutgers and then I just share my experience with the PAC and just kind of the project and what I’ve been a part of. So that’s been really cool, and I always love talking about it with people and telling people about it. **Everybody that I’ve told about it always has a very positive outlook and feels that, you know, that type of work is what’s going to impact the future.**”*

How does the PAC contribute to this project?

Alexis:

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

*“I always came from **two different perspectives**. One was always like, **the teacher perspective**, and then the other was **my lived experience** of kind of following the beat of my own drum. So I was able to be very candid, just expressing the way I might respond in situations, knowing that’s different from the way other people might respond. **I would like to think that I helped them kind of think outside the box a little.**”*



QUESTIONS?



Scoping 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 Scoping 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?

PROCESS:

- Initial searches produced **over 12,800** unique articles
- Currently **less than ½ of 1% included**
- Young adult research assistants:
 - Searched databases for sources
 - Analyzed articles to determine if they should be included

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
- Targeting cognitive and social-cognitive impairments appears to facilitate improvements in employment outcomes for young people with schizophrenia
- Supported-education services can improve educational and employment outcomes



QUESTIONS?



Survey of Innovative Practices: The State of the Art

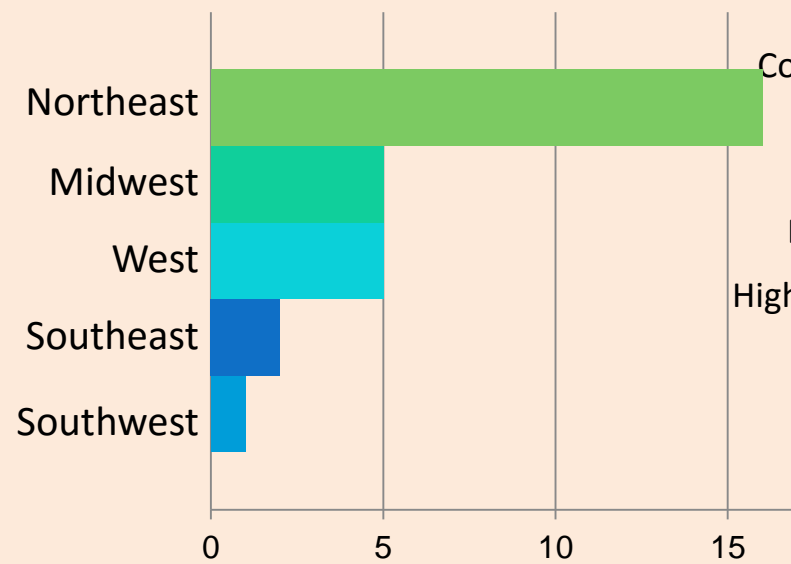
Marsha Langer Ellison, Ph.D., Sloan
Huckabee, Ph.D., & Rachel Stone

What is the Survey of Innovative Practices?

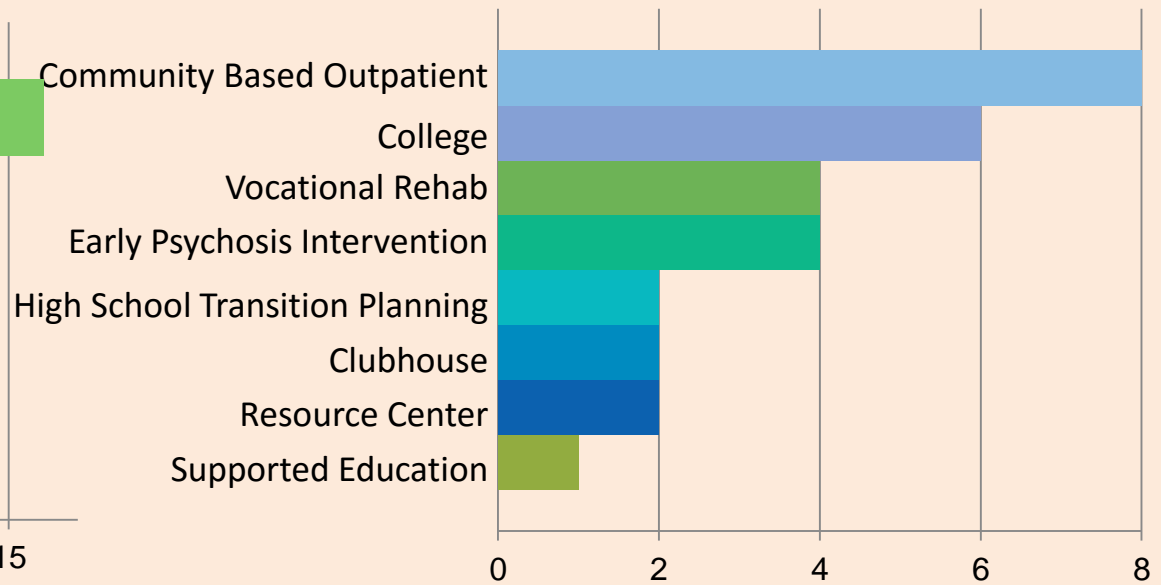
- Interviewed providers and state agencies
- Gathered both current and promising practices being used in the field
- Collected information about well-established approaches and innovations
- Focus on Employment and Education

PROGRAM CHARACTERISTICS

Regional Distribution N = 29



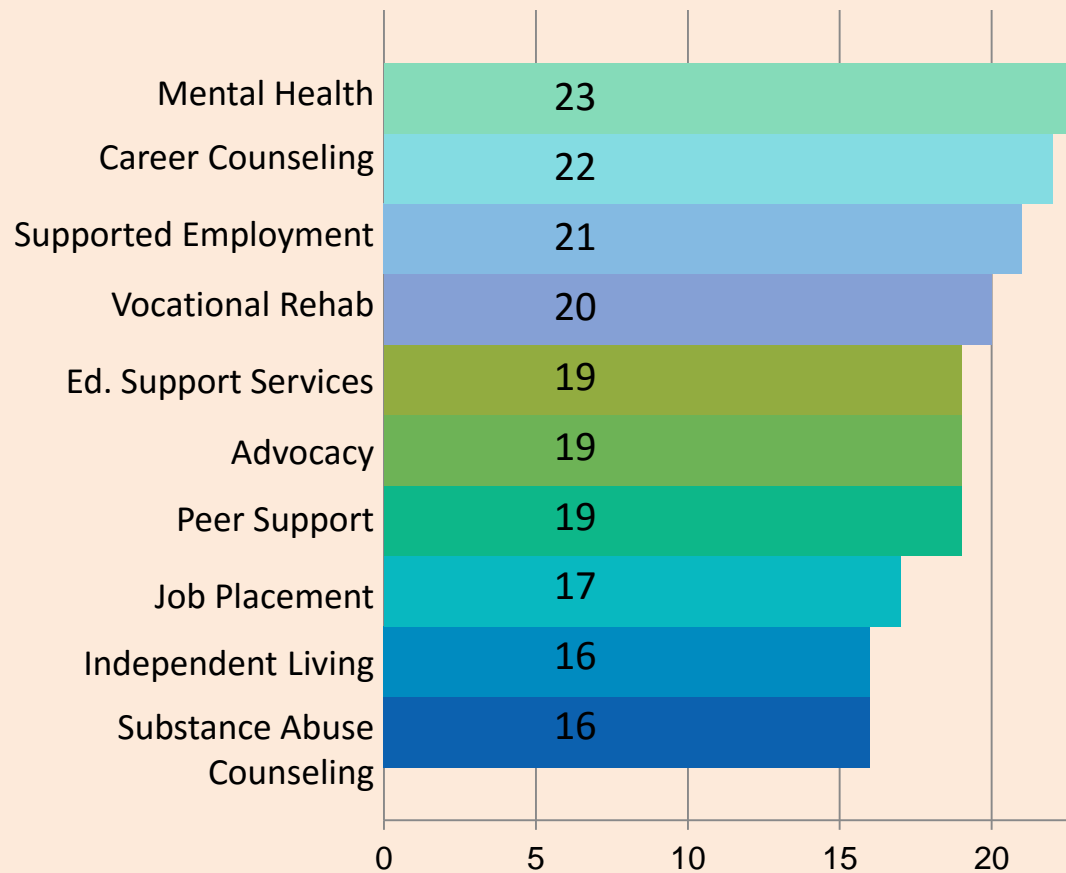
Program Types N = 29



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

Youth Involvement in the SIP

- Interviewing, recruitment, data analysis
- Throughout the process, the PAC was involved as well
 - Provided feedback on the practices and innovative supports we saw emerging



QUESTIONS?



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...

- 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.

Super-helpful Input From our PAC

- Recruitment materials – creating more youth-friendly flyers.
- Language – “mental health condition.”
- Adding specific questions to the QI interview:
 - Regarding their experience of stigma or discrimination, including self-stigma.
 - What advice would you give a younger version of yourself?

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)

When asking about goals...

“To be self-supporting. To just live either by myself for 100% or with roommates so I’m not under my parent’s [roof]. You know be financially self-sufficient and just have a house, routine, and a schedule, like I get up and go to work. This is my Monday through Friday, and you know this is what I do...So that’s kind of my goal and have a dog.”



Transitions

*“You know it was a huge transition. You know moving to a new city and not knowing anybody, and starting a new job, and my first job, and that kind of stuff. **And there were times when it was really hard, and there were times where everything was okay.**”*



Supports Needed: Work

*[talking about DVR] “Like they’re just like “Get a job.” “Oh, congratulations, you’re working at Shoprite.” That’s not a job. I mean it is, but not really. **It’s not a self-sustaining job.** You can’t live off that. And I don’t think they know how to help because **they don’t have a lot of clients that are high functioning, but still struggling, they’re big time struggling.”***



Supports Needed: School

*“I go to class, but then I don’t pay attention. So it’s not even that I don’t go. It’s like I’m there, I’m sitting and then the teacher’s talking, but then **none of it gets internalized**. Like I try to read the words on the board...but then it’s not like I actually learn it. Then I go back and then I look at the notes, but then **every time I look at it, it feels like I’m looking at it for the first time, and that’s frustrating.**”*



Barriers: Social Stigma

*“My brother treats me so differently. He’s like ‘Oh, like she can’t manage her life any more...I’m not sure we can trust her around the kids.’ It’s really disgusting...And I hate it. It makes me—I can’t even like go over there anymore because it makes me so upset. **It hurts me bad.**”*



Barriers: Financial

*“I think the main problem that I’m running into... **counseling is extremely expensive**, and it doesn’t matter what your insurance is...very rarely is it completely covered. You mostly get you know four visits a year. And that’s it. And the co-pays are extremely high. And even if you’re going off of your own income on a sliding scale, **you’re still paying \$75/\$80 [per visit]. For a college student, that’s—it’s not do-able.**”*



Words of Encouragement

*“I mean I was told that...as many horrible things that I’ve been through, you know all I can do is really change the future. **I can’t change the past.** And I can use my past to help other people. I can still be upset about it, but **I can show others through my example that it’s possible.** So it kind of turned me around and made me not quite as bad about everything that I went through because **I can use that to you know, inspire.**”*



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

Youth Involvement in the QI

- Youth with lived experience were part of the research team and helped in every step
 - Developing the interview questions
 - Recruiting and screening participants for eligibility
 - Conducting interviews
 - Reviewing and coding the interview transcripts
 - Interpreting the results



QUESTIONS?



The HYPE Development Meeting

September 30 - October 2, 2015

What was the Development Meeting?

- The PAC & NAC came together to discuss the critical components to be included in the HYPE intervention
 - If the item met 1 of the following criteria:
 - 1) It is unique to young people, meaning that it is not broadly relevant to all age groups
 - 2) It is unique to career development
 - 3) It is critical to either young people or career development
- At the meeting we discussed (in large and small groups) items that people did not agree on

Results of the Development Meeting

- Gained valuable feedback from youth
 - The role of peer support in assisting young people
 - Continuously reaching out to those who are unengaged
 - Don't be a “dream killer”
- Detailed notes were taken during the entire conference to help inform the development and refinement of the HYPE intervention
- Provided framework for creating the principles of HYPE

How Did We Engage Youth?

- Full group discussions with both the PAC and NAC
- Breakout groups of just PAC members, facilitated by the young adult researchers
- Continuous participation for youth
- Ability to meet and share in-person was powerful and allowed for greater/deeper discussion than is feasible when doing online conferencing
 - *“By getting to know the others, and **more than just my own story**, I was able to **focus my contributions towards major issues**”*
 - *“Having a room of supportive adults and young adults made it **easier to speak up**. Even in tense moments where people disagreed, **it felt like a safe space** to bring these thoughts to the table”*

How Was Youth Voice Heard?

Matt:

*“It was also really cool just being in a room full of, you know, 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.”*

Ryan:

*“You know, one of the things that I feel a sense of is mutuality, you know, like yeah **I’m participating in this as a person with lived experience, but like, I am an equal**, you know, 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.**”*



Final Thoughts

How have PAC members been influenced by their participation in HYPE?

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.”

How have PAC members been influenced by their participation in HYPE?

Alexis:

“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.”

How have PAC members been influenced by their participation in HYPE?

Alexis:

*“I was able to articulate myself, I wasn’t embarrassed to approach other people, because I had spent so much time talking professionally about myself and various mental health conditions. **The biggest thing I think was that it allowed me to be more candid at work, which allowed me to develop a better support system at work.** Everybody needs a support system, especially me, it was really important for me.”*

How have PAC members been influenced by their participation in HYPE?

Ryan:

*“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.”*

How have PAC members been influenced by their participation in HYPE?

Matt:

*“I’ve really enjoyed doing it, I like that you know I’ve been able to use some of the negative experiences I’ve had in my life to help other people have a more positive experience as they go through college and start employment. It’s been like, **really meaningful**, and it’s exactly, like, what I want to do in the future is work with this age range.”*



QUESTIONS?

Thank You!

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