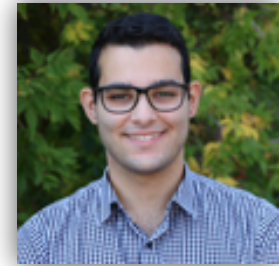


TIPS AND TRICKS TO STARTING A YOUNG ADULT COUNCIL

Raphael Mizrahi, B.S.



Tania Duperoy, B.A.



Objectives for this Workshop

1. Describe how youth councils voice can help:
 - a) Promote a national diverse youth voice
 - b) improve and educate the mental health community and beyond
2. Describe successes and challenges of facilitating a national youth council to infuse meaningful youth input into service delivery and development
3. Identify concrete tools for authentically infusing national youth voice in diverse organizations



Acknowledgements



The mission of the Transitions to Adulthood Center for Research is to promote the full participation in socially valued roles of transition-age youth and young adults (ages 14-30) with serious mental health conditions. We use the tools of research and knowledge translation in partnership with this at risk population to achieve this mission. Visit us at: <http://www.umassmed.edu/TransitionsACR>

The contents of this presentation were developed with funding from the National Institute on Disability and Rehabilitation Research, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, United States' Department of Health and Human Services (NIDILRR grant number 90RT5031). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The content of this presentation does not necessarily represent the policy of NIDILRR, ACL, HHS or of SAMHSA, and you should not assume endorsement by the Federal Government.



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What is the Transitions ACR?

National Center that aims to:

- Improve supports for the successful completion of schooling and movement into rewarding work lives among young people, ages 14-30, with serious mental health conditions (SMHC)

How do we do that?

1. Conduct research that supports the employment and education goals of YA
2. Develop and translate knowledge to the public
3. Infuse Participatory Action Research (PAR) into all activities



WHAT ARE YOUTH COUNCILS?



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Youth Advisory Councils: What are they?

- Developed to provide young adults with a *meaningful* opportunity to have a voice in decisions made about resources, policies and services for this age group.
- Councils run by and for young adults, with “silent” support of facilitators/organizations (Martin et al., 2007)
- Young adults provide feedback and develop recommendations to make youth research/services more young adult-friendly



How Would a Youth Council Benefit Your Organization?

- Generates discussions, action plans and solutions that are most relevant to YA daily lives, needs and preferences as members:
 - Share their opinions about what is relevant for people of their age group and background
 - Ensure treatment and research practices are culturally appropriate.
- Staff education:
 - Staff gain a sensitivity toward life as a young adult with mental health issues
 - Staff are made aware of community resources/supports
 - Staff have an opportunity to engage with young adults respectfully
- Provides opportunity for collaboration across organizations, states, and systems



Member Benefits of Youth Councils: Fostering Youth Voice

- Young adult members:
 - Gain an expertise on themselves as individuals (personal experience);
 - Feel validated by telling their story and seeing that their opinion is valued
- Members gain experience in research/service development
 - Research has shown that young adults are more likely to engage in services/supports they have had an active voice in! (Kirby et al. 2003; Oliver et al. 2006)
- Opportunity to practice professional development
- Members gain an ability to use their lived experience for a constructive purpose and learn to tell their story effectively
 - This helps them gain mental health literacy which is great because research has shown that as young adults gain mental health literacy, they become more likely to seek out services (Rickwood et al. 2005).
- May help reduce stigma surrounding mental health within the council and in the larger community



Examples of Advisory Councils

- Massachusetts' DMH Statewide Youth Advisory Council (SYAC)
- MHE & YOU Advisory Council at SPARC
- Delaware Statewide Youth Advisory Council
- The Youth Advisory Board



Mass. DMH Statewide Youth Advisory Council



WHAT IS THE YOUTH ADVISORY BOARD?



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The Youth Advisory Board

	Now (2016-Now)
Who	Young adults with mental health conditions ages 14-30 from diverse backgrounds
	8-10 paid consultants (average age- 23)
What	All research and dissemination activities at the Transitions ACR
When	Monthly for 2 hours
Where	Virtual/Online Meeting Platform (Go to meeting/Zoom)

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Diversity in the YAB

Depression Bipolar-Disorder
African-American
Eating-Disorder Adoption
Arizona Multi-ethnic Residential-Work
Clubhouse Hospitalization
College Christian
YouthMOVE Inner-City Child-Services
Parent New-York Counseling Stigma-Fighting
Trauma Maryland Foster-Care
Korean Rural Latino Kentucky Educating
Anxiety DC Legal-Studies Family
High-School Advocacy Miami Connecticut Social-Work
California Therapy Substance-Use Research-Experience
Psychology Queer-Youth-Work ActiveMinds LGBTQIA
New-Mexico Psychosis Domestic-Abuse
Massachusetts Peer-Mentor
Graduate-Program



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How We've Benefitted from YAB involvement

- More authentic/rich interviews
- Stronger tip sheets and knowledge sharing materials
- Benefits in engaging youth research participants
- Stronger connection to media/technology
- Strengthened relationship with local and national mental health community



Member Experiences

“I can give advice to those who need it, those who have lived experience might need those services and you can find out about resources from other members”

“Being able to learn from other people, you can take that knowledge and grow from that and garner life experience”

“Because we are all from different areas, we can all see the different perspectives of people from around the country”



YAB Member Roles/Expectations

- Provide feedback on research and knowledge translation activities
- **Disclosure Expectations:** members are encouraged to share details about their personal mental health lived experience in presence of a small audience if they feel comfortable but are not required to share
- **Attendance Expectations:** 6 month commitments
- Joining 4/6 calls in any given 6 month period
 - Providing 24-hour notice if not able to join call
- Professional etiquette fitting a paid consultant



Facilitator Roles/Expectations

- Clearly distinguish responsibilities between the facilitators if more than one facilitator
- Provide regular reminders before each meeting (ex: the week of, the day before, the day of)
- Bring refreshments and/or give a break (if possible)
- Be mindful of language so as not to pressure members to sharing if they don't feel comfortable doing so
- Check in with members annually/biannually
- Be a neutral party
- Ensure every voice is heard, moderate/gatekeep so that no one person is dominating the conversation
- Make it fun!



Guest Speaker Roles/Expectations

- Researchers or clinicians who may be interested in obtaining feedback from a young adult advisory board may request or be invited to join a meeting as a guest speaker
- Cardinal rule of guest speaker etiquette: Let the members do more of the talking than the speaker/s
- Welcome and listen to all feedback regardless of whether or not it is able to be implemented
- Don't overwhelm members with information and stop for questions frequently
- Be considerate of the diverse educational and employment experiences of the group, some will be more experienced, others will not



Comfort Clause

- A set of rules that is made by the council for the council to create a safe space for everyone to use



- ✓ Using **person-first language**
- ✓ **Stay engaged!**
- ✓ Vegas Rule! ---Confidentiality
- ✓ **Open honesty!** --- No judgement!
- ✓ The “Oops” Clause
- ✓ Comfort Clause **can be changed!**



HELPFUL TIPS



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Preparing Your Team and Young Adults

For the Team

- Ensure clarity across the organization on roles & responsibilities of the facilitators
- Train facilitators and staff on effectively working with YA members
- Train guest speakers (continuously) about proper etiquette when engaging young adult members

For Young Adults

- Provide thorough and comprehensive training
- Ongoing mentoring
- Support ongoing professional development
- Little things may not seem important to a “seasoned professional,” but can make all the difference to a young adult (bus times, filling out W-9 forms, etc)



Are you a young adult with lived experience of a mental health condition?

Would you like to have **YOUR** voice heard and help shape future research that aims to improve services young adults receive?

Are you passionate about improving the lives of young adults?

We want you to join the Youth Advisory Board!

What is the Youth Advisory Board?

The Transitions Research and Training Center has research and knowledge-sharing projects that aim to support young adults like you in your goals towards education and work.

We are seeking young adults to become members of our **Youth Advisory Board (YAB)** to help shape our activities and make them relevant to you and your experience!

Are you interested?

What does involvement in the Youth Advisory Board look like?

What the Youth Advisory Board (YAB) has to offer:

- Great Resume/Experience Builder
- Influence National Research
- \$30/Hour Compensation

Interested?

Send us an email at Raphael.mizrahi@umassmed.edu with your

1. Name
2. Age
3. State of Residence
4. A letter (a paragraph or so) about your experience with mental health

We look forward to hearing from you!

For more information about the YAB, please e-mail Raphael Mizrahi at Raphael.mizrahi@umassmed.edu.

Recruitment

We recruit with this flyer via:

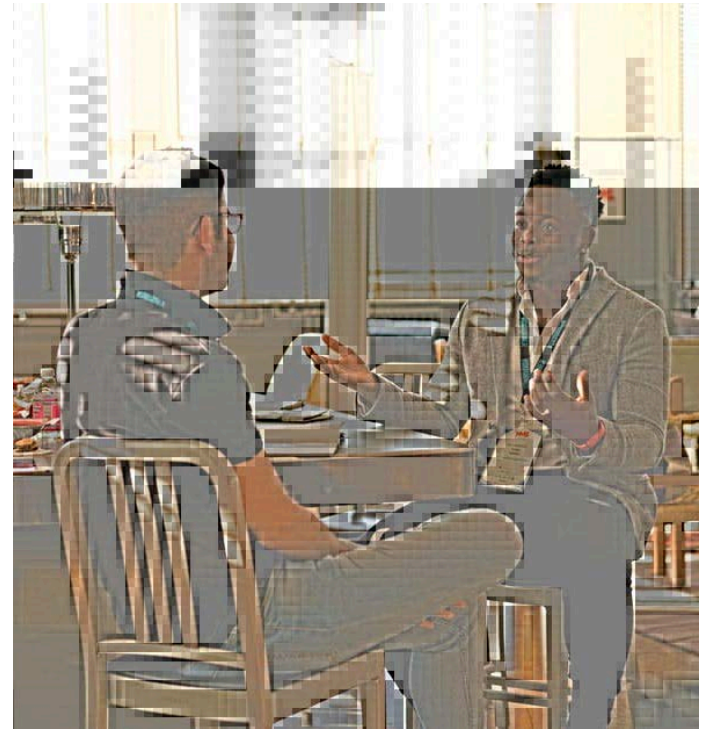
- Online site
- Social media
- Emailing youth mental health champions or other well-connected people in the field
- YAB Members can share



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Interviewing and Training

- Conduct informal interviews with new members to:
 - Get to know them
 - Show new members about the purpose of the council, and
 - Discuss logistical details of the council such as compensation and scheduling



Mission/Vision Development

- Should be created with council members
 - Helps focus the group and orient them toward goals that they would like to accomplish together
- It's okay for facilitators to provide examples of what a mission/vision looks like or to gather ideas and create a rough draft for members to edit



Sample Agenda

Intro- Icebreaker

15 minutes

Part 1 – HYPE 2.0 Project Grant Proposal

40 minutes

Break

10 minutes

Part 2 – NITT-HT Young Adult Survey

40 minutes

Outro- Details about next meeting

15 minutes



Genuine Youth Involvement Versus Tokenism

Organizations that are tokenistic:

- Have youth just to say they have youth
- Are not willing to make changes and not really listening
- Have few youth and a non-diverse group giving feedback on everything youth-related
 - One young person, no matter how smart or experienced, cannot fairly represent the voices of all young people
- Approach young members unequally for opinions and decisions



SUCCESSSES AND CHALLENGES WITH THE YAB



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Scheduling, scheduling, scheduling...

Flexibility is Key!

- Finding a time and location that works for YAs to attend is challenging given their frequent changing schedules due to school and work
- If meeting with young adults monthly, we recommend checking in with members to find times that they are available 3 times during the year to accommodate for the semester and summer schedules:
- Doodle Polls are very helpful!
- Finding locations can be challenging, aim to find a central location on a transportation route where most people can attend
- Check in with members about their attendance regularly, especially if certain members find it challenging to attend



Motivation

- Provide members with examples of how their feedback was used to improve research/services
- Provide comments from speakers post-call:
 - “YAB members reviewed their online survey which led to cutting an entire module, addition of two YA-g geared videos, and shortening of length from 1 hour to 40 minutes”
- The Disclosure in the Workplace Tip Sheet added two additional pages based on YAB feedback on content



Tip Sheet 12

Transitions RTC

August 2017

The “Achieving a Better Life Experience” Act, or ABE Act, is a federal law that was passed in 2014. It gives people who have a disability a way to save money. This landmark legislation offers people living with disabilities, including those with serious mental health conditions, a chance to pursue their hopes and dreams in a realistic way without as many financial obstacles.

Why is ABE a big deal for me?

The ABE Act is important for young adults living with mental health conditions because it allows them to save money for “qualifying expenses” such as a car, college, training, healthcare, prevention and wellness, and other eligible expenses without being taxed by the government. Such opportunities can allow you to have more independence and a better quality of life. An ABE account is an easier way to access your savings compared to other types of savings accounts.

- You can put up to \$14,000 a year into your ABE account.
- If you are a Supplemental Security Income (SSI) recipient, you can save up to \$100,000 in an ABE account without losing your SSI benefits!
- Your Medicaid eligibility and other public benefits (e.g., foodstamps, housing assistance) are not affected by having an ABE account.
- The total maximum amount that can be put into an ABE account varies by state, but they are generous, ranging from \$200,000 to \$400,000!
- Save money without getting taxed on any interest that’s accrued.
- The money in an ABE account earns interest, so it can grow!



President George Bush signing into law the Americans with Disabilities Act. L to R, sitting: Evan Kemp, Chairman, Equal Employment Opportunity Commission, Justin Darr, Chairman, President’s Committee on Employment of People with Disabilities. L to R, standing: Rev. Harold Wilke and Swift Parrino, Chairperson, National Council on Disability.

- b. Complete a disability certification form from the IRS that documents your disability (for example, a primary mental health condition that meets the definition of SSI). OR
- c. Be a recipient of childhood disability benefits, disability insurance benefits or disabled widow’s or widower’s benefits based on disability or blindness.

Who is eligible for an ABE account?

In order to be eligible to open an ABE, you must:

1. Have a physical or psychiatric disability
2. Have become disabled before the age of 26 years old, and
3. Either:
 - a. Collect Supplemental Security Income (SSI)OR

Note: Not all states have an active ABE program yet. States may have different rules about how to get a disability certification; some states just need some kind of doctor’s note that talks about your disability while others need a form completed by you and your doctor.



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TAKE-HOME MESSAGES



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Take-Home Messages

- Advisory councils are an excellent way of making research/services more accessible and relevant to the target population
- Councils can be hosted in a variety of settings
- Special considerations for the young adult age group can be made to make youth councils successful
- Young adult councils are becoming more widely used to infuse youth voice into research and services and can be implemented in your organization as well!



More Resources

Stay tuned for a “**Tips and Tricks to Starting a Young Adult Council**” tip sheet later this year!

See our “**Nothing About Us Without Us: Growing Meaningful Young Adult Involvement in Your Organization**” webinar on our website at <https://www.umassmed.edu/TransitionsACR/publication/webinars/>



Special thanks to our
**Youth Advisory
Board**
for giving feedback
on this presentation!

And Thank You!

Contact us at:

Raphael.Mizrahi@umassmed.edu

and/or Tania.Duperoy@umassmed.edu

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References

Kirby P, Lanyon C, Cronin K, Sinclair R. *Handbook - Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation*. Nottingham: Department for Education and Skills;2003.

Martin, S., Pittman, K., Ferber, T., & McMahon, A. (2007, July). Building Effective Youth Councils: A Practical Guide To Engaging Youth In Policy Making. In *Forum for Youth Investment*. Forum for Youth Investment. The Cady-Lee House, 7064 Eastern Avenue NW, Washington, DC 20012-2031.

Oliver K, Collin P, Burns J, Nicholas J. Building resilience in young people through meaningful participation. *Adv Mental Health*. 2006;5(1):34-40

Rickwood, D., Deane, F. P., Wilson, C. J., & Ciarrochi, J. (2005). Young people's help-seeking for mental health problems. *Australian e-journal for the Advancement of Mental health*, 4(3), 218-251.

