

A Webinar from AUCD's Mental Health Aspects of I/DD Special Interest Group

**Needs & Experiences of Young Adults
with IDD Using Mental Health Services:
Recommendations for practice & research**

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Young Adulthood

- Life course perspective:
 - Transition from adolescence to adulthood can have lasting impacts into adulthood





Young Adulthood

- Employment & Meaningful Work
 - Identity development
 - Poverty
 - Health



- Moving out/ Gaining autonomy from family
- Changing social networks
 - School: consistent structured activities with the same people



Young Adulthood

- Research has not sufficiently explored the experiences and needs of young adults with IDD-MH.

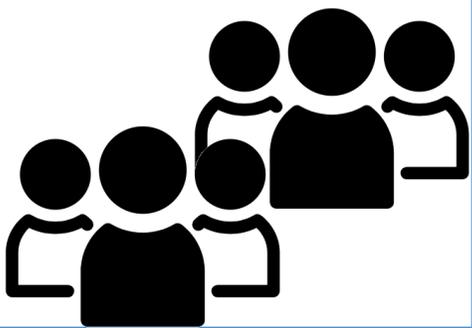




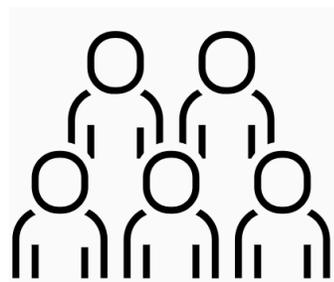
IDD-MH Research Partnership

- Intellectual and Developmental Disability Mental Health (IDD-MH) Research Partnership:

6 young adults



5 professionals/
researchers



Youth and Young
Adults
Empowerment,
Leadership, and
Learning (YELL) Lab



- **Goal:** Learn about the experiences and needs of young adults with IDD-MH while accessing and using mental health services.



What we did

- Easy read web survey
 - 76 young adults with IDD-MH who were:
 - Ages 18-30
 - Living in the United States
- Storytelling Sessions
 - On the phone and at the 2018 SABE Conference
 - 10 young adults with IDD-MH
 - 6 parents of young adults with IDD-MH



8 Priority Areas



Transition to Adulthood

- Transition to adulthood can be hard for everyone.
- Lack of supports and services in areas like employment, independent living, and adult health care can contribute to a decline in mental health for young adults with IDD as they transition out of school and into adulthood.



Transition to Adulthood

- “It's difficult to find independent living that knowledgeably supports me with an IDD and mental illness. I'm living with my parents and would like to move out, but we can't risk a relapse.”
(National Web Survey)

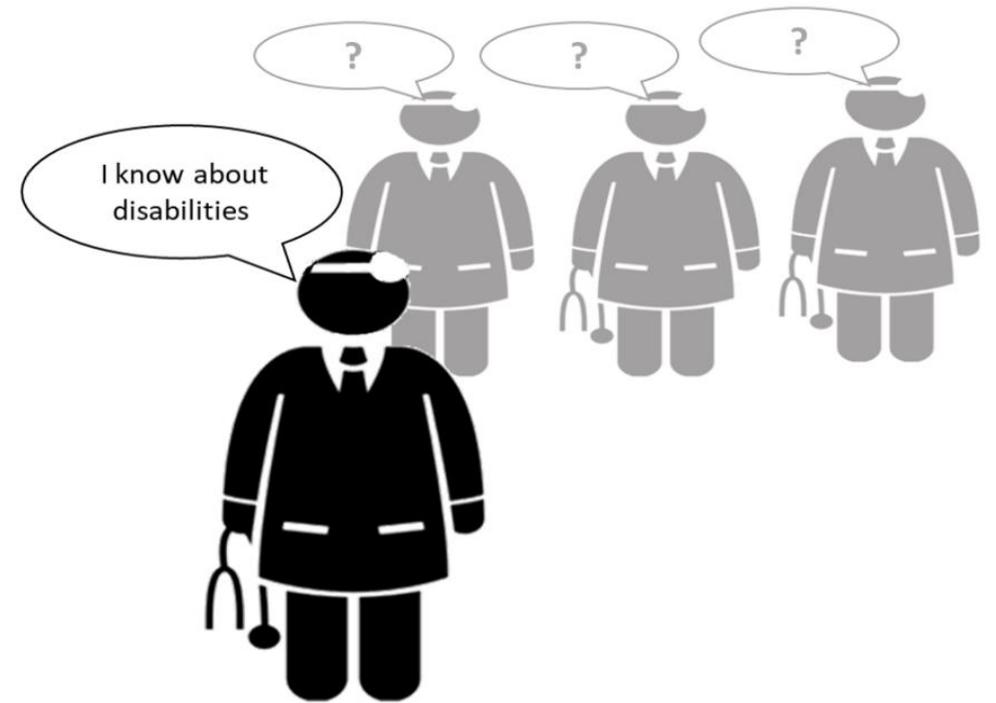


Transition to Adulthood

- “Seeing all of their peers and siblings going off to college and having all of these major life changes and they are not, contributes to a lot of their anxiety and feeling different.”
(Virtual Storytelling Session).

Professionals' Competence

- Not enough professionals have the appropriate skills and knowledge to work with young adults with IDD-MH.
- 65.2% said it was hard to find a doctor who knows about IDD-MH.





Professionals' Competence

- “Doctors don't understand how autism, anxiety and depression can coincide.”
(National Web Survey)



Professionals' Competence

- “I went to one therapist and I talked to them about all of the anger that I had...Instead of supporting me ...he attacked me.”
(Virtual Storytelling Session)



Professionals' Competence

- “It's hard to find doctors because they go too fast (stressful and I don't understand) or speak like I'm a baby because they see I'm cognitively disabled.”
(National Web Survey)



Insurance and Financial Resources

- Insurance can limit young adults' choices for mental health treatment.
- Accessibility to appropriate mental health treatment can be cost prohibitive, even with insurance.





Insurance and Financial Resources

- “I could not afford to get mental health treatment until I moved to a state where I could get Medicaid.”
(National Web Survey)



Insurance and Financial Resources

- “I would have loved to have my son at home but there was no way to have him cared for at home. So, my only choice was for him to live in residential care. No family could pay over six figures a year for care...It takes money to take care of people with mental health and special needs, but their life matters, too.”
(Virtual Storytelling Session)

Understanding the experiences of people who communicate differently

- It can be hard to figure out if mental health treatment is effective when people with IDD have communication differences.



Understanding the experiences of people who communicate differently

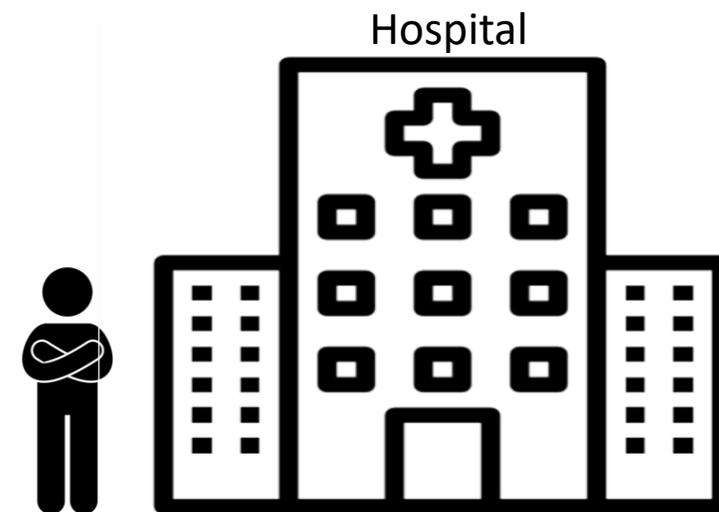


- “Having a hard time explaining symptoms.”
(National Web Survey)
- “We have to judge how medication is affecting our son based on his behavior, his facial expression, his body language. It's been a long and hard process.”
(Virtual Storytelling Session)



Hospitalization

- Lack of appropriately trained staff can make inpatient hospitalizations a traumatic experience for young adults with IDD.
- 26.1% were forced to go to the hospital for their mental health when they did not want to.





Hospitalization

- “[I] was in the hospital for over one month, because doctors did not know what medicine would work best.”
(SABE Storytelling Session)



Hospitalization

- “I would constantly discuss how I wanted to die without being direct about it, out of a fear I would be hospitalized.”
(Virtual Storytelling Session)



Hospitalization

- “I lived in an institutional orphanage for the first few years of my life, and so there's trauma around that. So, I do not like any type of institutional setting.”
(Virtual Storytelling Session)



Medication

- Young adults want choice and control over the use of medication.
 - Almost 30% didn't get to choose their medication
 - Almost 30% were given a medication they did not want to take

- They want their choice to be respected and supported.





Medication

- “Medication, at first, was a disaster, but once my dosage was adjusted and I grew to tolerate it, it worked *wonders* for me.”
(Virtual Storytelling Session)



Medication

- “I need better medicine with fewer side effects.”
(National Web Survey)



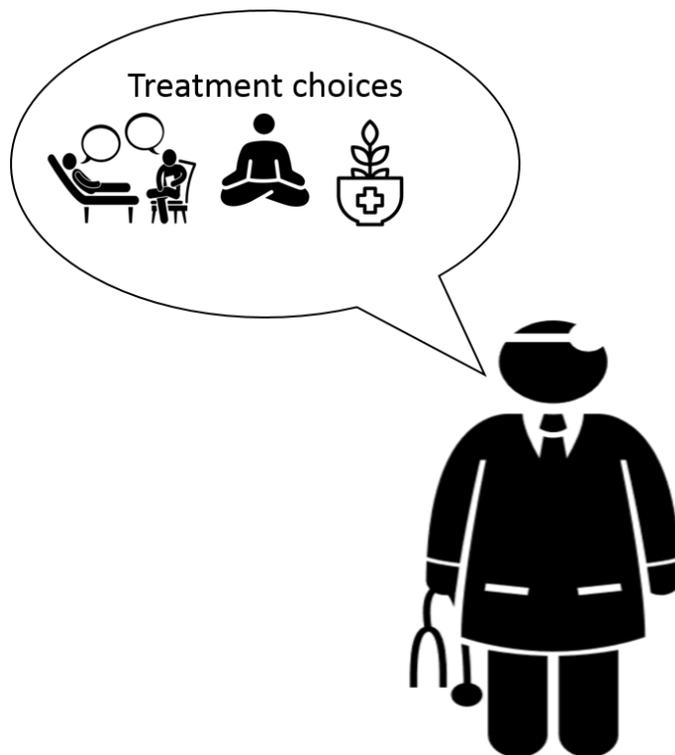
Medication

- “We did try medication ... It actually had an adverse effect because of how he was not able to metabolize the medication.”
(Virtual Storytelling Session)



Alternatives to Medication

- Young adults with IDD-MH use strategies, supports, and options other than medicine to help their mental health.





Alternatives to Medication

- Many young adults reported that therapy and involvement in community activities helped their mental health.
 - 40% said that they are not able to do activities they enjoy in the community as much as they want.





Alternatives to Medication

Reported Non-Pharmacological Strategies

- Relaxation strategies, such as deep breathing and meditation
- Therapy (therapists or counselors)
- Doing activities they enjoy and make them feel good
- Exercise
- Doing art and other creative activities



Alternatives to Medication

Reported Non-Pharmacological Strategies

- Spending time with pets
- Spending time alone
- Cognitive behavioral therapy
- Listening to music or watching TV/movies
- Medical marijuana
- Involvement in self-advocacy to learn to stand up for themselves



Alternatives to Medication

- “I try to do something creative like writing or doodling to get my mind off things.”
(National Web Survey)
- I got started in the self-advocacy movement, and I stand up for myself and what I want for my treatment.
(SABE Storytelling Session)



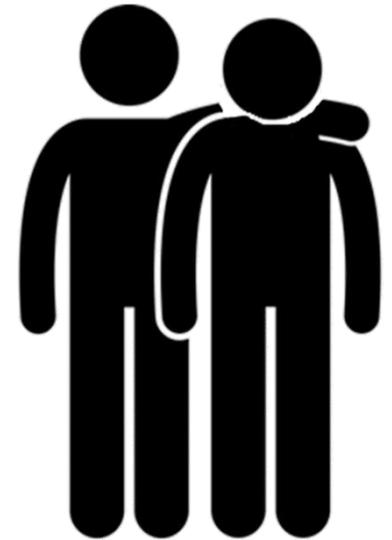
Alternatives to Medication

- “She needs less medication and more hands-on kind of therapy other than taking more pills.”
(Virtual Storytelling Session)
- “My son... has the right to go to church but couldn’t go. Pretty sure no one’s mental health is better when you lock them up, take away everything that gives them life.”
(Virtual Storytelling Session)



Social Supports

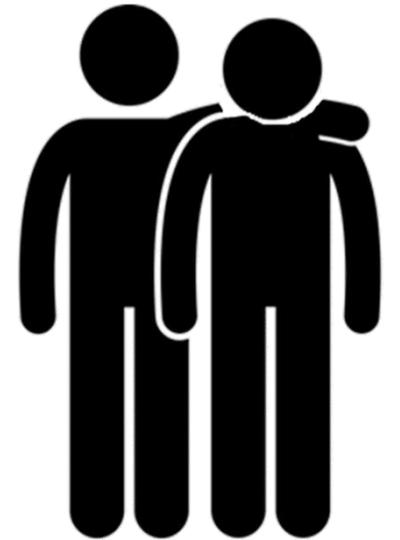
- Young adults with IDD-MH need support from people they can trust and who understand their experiences.
- Family and friends can provide strong supports for young adults' mental health.





Social Supports

- But young adults often don't get the social support they want and need for their mental health.
- Only 26% belong to a mental health support group.





Social Supports

- “I like talking with and spending time with my family and my friends, a lot. ‘Cause it helps me a lot...friends are always the best medicine.”
(SABE Storytelling Session)



Social Supports

- “[I am] always depressed and people are tired of hearing about it.”
(National Web Survey)



Social Supports

- “It's been so helpful for us to have these other families that understand our daily frustration and can share information and also be part of our mental health team.”
(Virtual Storytelling Session)



Recommendations



Steps and Actions Mental Health Professionals Can Take



Improve medication management by....

- Not assuming medication is the first or best option for treatment.
- Respecting young adults who choose to not take medication or use natural/homeopathic remedies.



Improve medication management by....

- Collaborating with young adults and families to identify the medication(s) that produce the greatest benefit and have the fewest side effects.
- Explaining the risks and benefits of medications, including side effects, in a way young adults can understand.



Improve communication by....

- Asking young adults with IDD-MH how they best understand information (for example, written, oral, pictures) and follow their request during appointments.
- Checking for understanding and consent.
- Communicating directly with young adults with IDD-MH, rather than their parents/staff.



Improve communication by....

- Allowing more time for appointments when working with young adults with IDD.
- Learning how behavior is a form of communication.
- Listening carefully to family members and support personnel who know young adults best.



Steps and Actions Health Systems Can Take



Improve reimbursement by....

- Identify innovative ways to deliver mental health counseling and supports at lower costs, such as mHealth or tele-health, to young adults with IDD-MH.
- Insurance companies should provide reimbursement for non-pharmaceutical services/supports at a rate equal to reimbursement for pharmaceutical and inpatient services.
 - For example: counseling, health and wellness services, community-based treatment, and transportation



Improve delivery of care by....

- Hospitals should adopt a trauma-informed approach to care for all individuals, including young adults with IDD-MH.
- Service systems, hospitals, and independent providers should have high and low tech communication devices available for use by young adults with IDD-MH.
- All materials about mental health conditions and treatments should be published in plain language/easy read so young adults with IDD-MH can understand.



Steps and Actions States and Policymakers Can Take

Provide community-based treatment options



Some examples are:

- Crisis prevention and planning for young adults with IDD-MH, their families, and direct care providers.
- Adaptation of day treatment or partial hospitalization programs currently available to people with mental health conditions, so they are appropriate for young adults with IDD-MH.



Provide comprehensive, wrap-around supports for young adults with IDD transitioning to adulthood

This includes:

- Medicaid waiver programs that include MH services & supports.
- Improving access to and programming for post-secondary education.
- Improving access to affordable housing in the community.
- Include planning for MH needs in IDEA transition plans.

Include young adults with IDD in peer-mediated recovery services



This includes:

- Develop “peer-to-peer” networks for young adults with IDD-MH.
- Harness knowledge and experience of IDD-MH advocates and advocacy organizations.
- Best practices in family support “Parent-To-Parent” should address mental health and provide mental health resources.

Conclusion

- Choices that respect the autonomy and values of YA IDD-MH.
- Need more community based supports:
 - Accessible day treatment
 - Support groups
 - Participation in leisure, independent living, and work
- Need for health care providers that understand their mental health needs.

Thank you!

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