

Supporting Young Adults with Mental Health

Melissa Levin, MSW, LICSW

Ariel Schwartz, PhD, OTR/L

Written with gratitude for the youth, adults and
families

who have opened up their lives to us



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Tomorrow ready.

Presenter Introductions

- Melissa Levin, LICSW, MSW
 - Professional history: group home staff, clinical outpatient therapist, Children's Hospital LEND fellow, a clinical supervisor, intervention researcher, and currently a school social worker supporting families with disabilities and co-occurring mental health diagnoses
- Ariel Schwartz, PhD, OTR/L
 - Professional history: work with young people with IDD since childhood; clinical work: community-based OT and inpatient mental health OT; research focused on intervention for young adults with IDD and co-occurring mental health conditions



Audience Introductions

- By a show of hands:
 - People with disabilities (PWD)
 - Family member to PWD
 - Clinician or educator to PWD
 - Service system manager



- Be aware of how you are feeling
 - It is okay to take a break if you need to!
 - It is okay to stand or stretch if that helps with your learning
 - During a few points, we will briefly talk about hospitalization



Today's Objectives

- Through discussion and break-out activities, we will:
 - Review research on the co-occurrence of mental health and developmental disabilities
 - Develop a shared understanding of mental health, symptoms, coping strategies, triggers, and other key concepts
 - Discuss best practices and tips for people with disabilities, family members, and professionals



Mental health and people with disabilities

- Between 1/3-1/2 of people with disabilities have co-occurring mental health conditions
 - Mood disorders, OCD, etc.
- Children and teens with disabilities 4-5 times more likely to be diagnosed with a mental health condition than children and teens without disabilities
- Suicidality
 - Higher rates of suicidal ideation and attempts in people with disabilities
 - Emerging evidence of even higher risk for people with ASD
- Diagnostic overshadowing



Mental health experiences and needs of people with disabilities

- What did we do?
 - Partnership with the Arc of the United States and an advisory board composed of self-advocates, professional and family members
 - National web-based survey
 - “Story telling” sessions
- Interviews with young adults with IDD and co-occurring mental health conditions about their experiences in the workplace
 - Young adults also completed surveys about challenges and accommodations
- Focus groups with professionals supporting young adults with IDD and co-occurring mental health conditions to attain and maintain employment



Mental health experiences and needs of people with disabilities

What did we find?

- Priority topic areas:
 - Support needed for transition to adulthood
 - Challenges of insurance and financial constraints
 - Lack of professional competence
 - Communication challenges
 - Force hospitalization
 - Medication
 - Alternatives to medication
 - Social supports

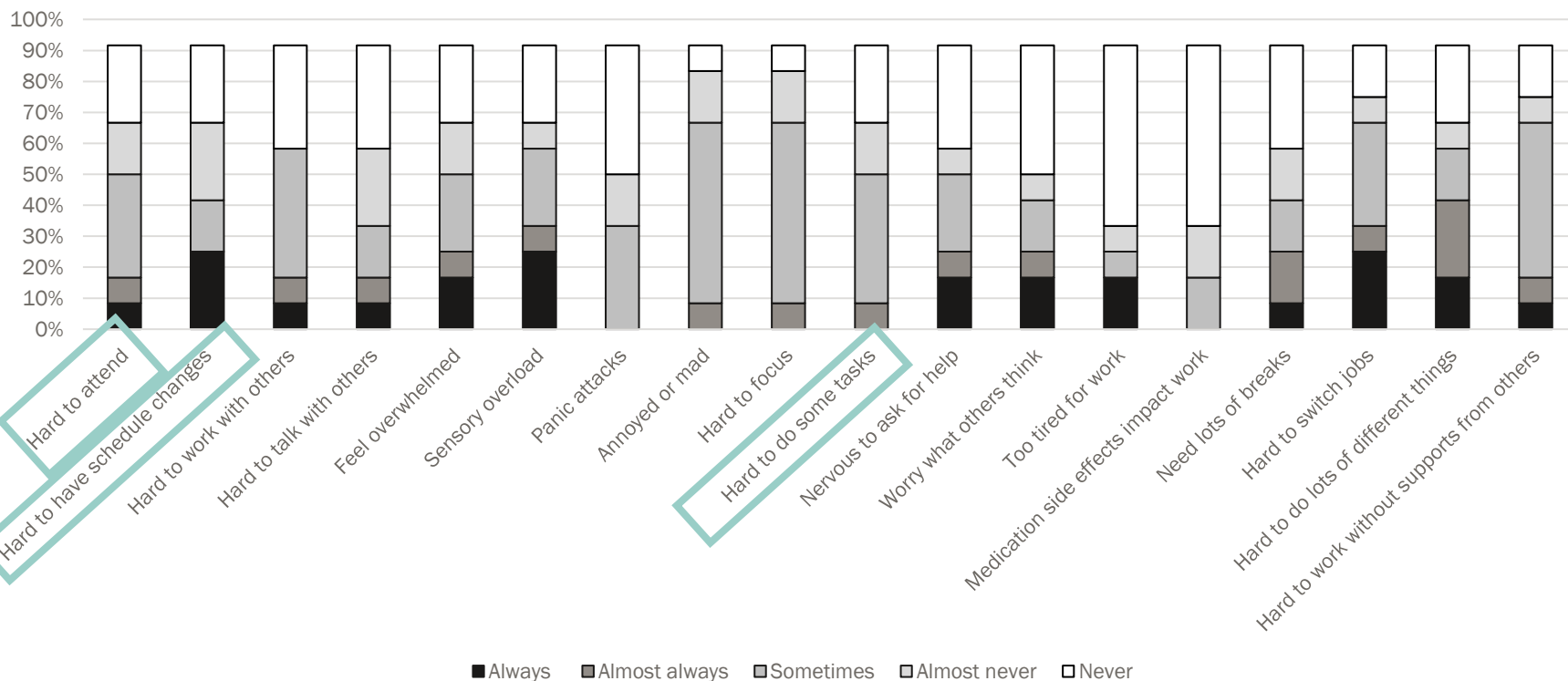
Kramer, J. M., Schwartz, A. E., Watkins, D., Peace, M., Luterman, S., Barnhart, B., ... & Alexander, J. S. (2019). Improving research and practice: Priorities for young adults with intellectual/developmental disabilities and mental health needs. *Journal of Mental Health Research in Intellectual Disabilities*, 12(3-4), 97-125.



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Workplace experiences

Frequency of Mental Health Impacts



What next?

Lack of social support

- We found only 26.5% of young adults have a mental health support group they can belong to
- Stories of being misunderstood

Challenges with doctors

- Misunderstood and disrespected
- Offered medication, but no alternatives, but people really benefited from alternatives to medication

Mental health impacts work performance in an individualized way



What next?

Solution!?

Peer mentoring!?

- Best practice for people with mental health conditions without disabilities
- In the community
- Focused on *doing*
- Social support



Peer mentoring program

- Developed in collaboration with young adults with IDD and co-occurring mental health conditions
- Addressing self-awareness and initiation of coping strategies
- Currently conducting feasibility testing



Key mental health concepts: The language & activities we use



What is mental health?

Mental health is all about how we think, feel, and act. Mental health is about how we handle stress. **A mental health condition** is when a person is having a hard time with how they think, feel, and act.



HAVING A HEALTHY MIND
IS JUST AS IMPORTANT
AS A HEALTHY BODY



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What is mental health?

- Sometimes teens and young adults feel embarrassed to talk about mental health. Sometimes people don't even want to talk about mental health out loud because they are so afraid about being judged and that makes them afraid to ask for help.
- *Reassurance is critical:* a mental health condition is not something you have to be afraid of or embarrassed having. Having a mental health condition does not mean you are bad, did something wrong, or are crazy.



Context: Young Adulthood and Transition

- Life stage: trying out new responsibilities, desire to be as independent as possible
 - Goal: a more flexible mindset about what it truly means to be independent
 - Rigid thinking: being independent means asking for no help
 - Reliance on others // apprehension to be more independent
- Mixed feelings about what comes next
 - Oftentimes excitement and anxiety go hand-in-hand
 - Sadness and happiness about changing relationships
- Lack of appropriate services
 - “I will soon age out of the good care I have been getting and am having trouble finding adult care that understands my disability”



Symptoms



Symptoms can be upsetting thoughts, strong or big emotions, and feeling a need to do certain behaviors. If symptoms are really big/strong or go on for a long time, they can cause problems with people's daily life.

- *Activities to enhance understanding of the term:*
- Card Sort
- Start off by talking about physical symptoms
- Watch NAMI videos



Examples of mental health symptoms

- Feeling really sad for no reason
- Feeling really worried and really scared for no reason
- Feeling super excited and can't calm down
- Big mood changes from feeling really happy and excited to feeling really sad
- Feeling irritated without knowing why
- Confused thinking
- Inability to stop intrusive thoughts
- Hearing voices that other people don't hear
- Seeing things that other people don't see
- Believing that people want to hurt you when they don't
- Believing that you have special powers or that you can do impossible things
- Thinking about hurting yourself or other people
- Major decline from baseline functioning



Symptoms Card Sort

- An activity you can do by yourself, with a loved one, teacher, or therapist

<p>I can't stop having thoughts I don't like.</p> 
<p>I feel really worried or really scared about things I know I shouldn't be scared about.</p> 

<p>I feel sad and I can't figure out why</p> 	<p>I feel too worried to do new things or go to new places</p> 
<p>I feel super-excited and can't calm down</p> 	<p>I feel so sad that I don't enjoy things that I usually like</p> 



Triggers

- Some people have topics or words that make them very upset to talk about. These are topics or words that are “triggers” for them.
- A topic or word that makes me upset is _____. Please don’t talk about this with me.
- If me or my mentor talks about a topic or uses a word that is a trigger, we will remind each other. Some examples might be “ouch,” “that’s a trigger,” or “pass.” What do you think we should say?

- *Activities to enhance understanding of the term:*
- *Purposeful self-disclosure*
- *Self-disclosure and role-modeling*
- *Role-playing how to communicate the ‘reminder word’*



What makes mental health symptoms worse?

When people have a mental health condition, some things and situations can make mental health symptoms worse. ***Increased symptoms are a warning sign saying: please pay attention to your mental health right now!***



Common Stressors causing Increased MH Symptoms

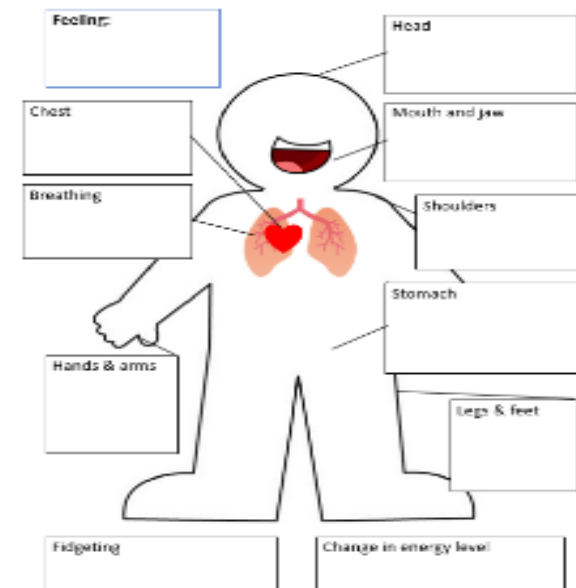
- Meeting new people // being isolated
- Having too much school work
- Changes in my schedule
- Changes in my personal life
- When my plans are changed, but no one tells me
- When I am reminded of a sad or scary experience from my life
- When I don't have enough information to do something I need to do
- Forgetting to take my medication or skipping medication
- Staying up too late and getting little sleep
- Having too much unstructured free time // having too many scheduled activities
- Medical issues



Self-Monitoring

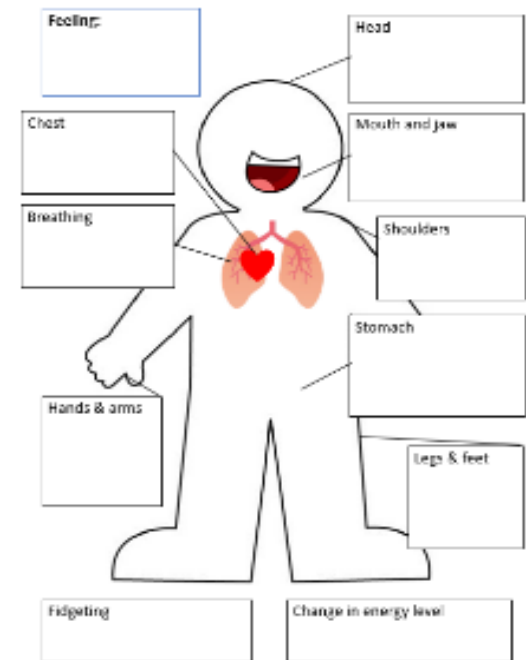
- Sometimes it can be hard to know how you are feeling or to notice your feelings. When you know how you are feeling, you can do something to feel better.
- Figuring out how you are feeling is called “self-monitoring.” Self-monitoring means paying attention to how you are feeling. When you self-monitor, you can learn more about how you are feeling. This can help you change your thoughts and feelings to feel better.

- *Activities to enhance understanding of the term:*
- *Body scan*
- *Mood log*



Self-Monitoring: Body Scan Practice

- All you need is the body scan sheet
- We will start off by brainstorming our vocab
- Listen to the following questions we will read out loud



Self-Monitoring: Mood Log Practice

- All you need is the mood log
- Consider having young adults choose their own emojis

	Happy	<input type="text"/>
		Not A little Very
	Sad	<input type="text"/>
		Not A little Very
	Angry	<input type="text"/>
		Not A little Very
	Ok	<input type="text"/>
		Not A little Very
	Anxious	<input type="text"/>
		Not A little Very
	Calm	<input type="text"/>
		Not A little Very



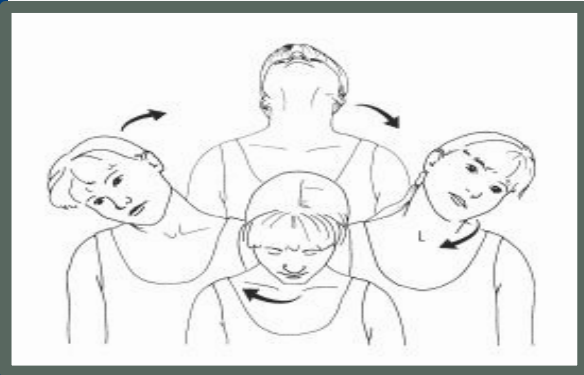
Facilitating development of self-monitoring

- Start general. If/when more prompting is needed, then ask more specific questions
- Point out observed non-verbal indicators and behaviors in a calm, non-confrontational way
- Be respectful as to when and where you have these conversations
- Use the body scan during positive, neutral, and more challenging moments



Preparing to discuss strategies

- Before we move into discussing strategies, this is a time to stretch and take some deep breaths
- Notice how you are feeling



Coping Strategies

Activities to enhance understanding of the term:
Card Sort



- **Coping strategies** are what people do to deal with stress. They are activities and ways of thinking that make us feel good.
- We take care of our mental health by using coping tools that help us notice our emotions, find ways to relax, and ways to make peace with upsetting feelings and thoughts.



Strategies 101

Strategies should...

- Provide an opportunity for emotional processing
- Build self-confidence
- Lead to small successes (*Is it feasible?*)
- Be individualized



Think about:

- Is the strategy cognitively and physically accessible? (e.g., reminders, visuals)
- Preferred mix of communication style, visuals, and technology?
- How does sensory input affect self-regulation?



Activity: Strategies Brainstorm

General categories of strategies:

- Activities I can do alone vs. social activities
- Arts and Crafts
- Electronics
- Music
- Making things
- Outdoor activities
- Physical activity
- Talking with someone
- Spending time with animals
- Using sensory activities
- Other: _____

What are coping strategies used by audience members in the room?



Preferred Strategies of Transition-Age Youth with I/DD & MH

- Activities I can do alone vs. social activities
- Arts and Crafts
- Electronics
- Music
- Making things
- Outdoor activities
- Physical activity
- Talking with someone
- Spending time with animals
- Using sensory activities
- Other: _____



Implementing Strategies

- Knowing when it's a good time to use the strategy:
 - What signs in your body will tell you it is time to use this strategy?
 - What emotions, feelings, or thoughts will tell you it is time to use this strategy?
- Brainstorm when/how a coping strategy can be used during the day:
 - Using a coping strategy before an activity that is typically stressful
 - Take a break during the activity to do the coping strategy then return to activity
- If you feel a need to use a coping strategy while you are at school or work, what you will do? How could you use/access _____?



Example Grounding Exercises

Take a deep belly breath to begin

5 - LOOK: Look around for 5 things that you can see, and say them out loud.






4 - FEEL: Pay attention to your body and think of 4 things that you can feel, and say them out loud.

3 - LISTEN: Listen for 3 sounds. It could be internal or external sounds - the sound of traffic outside, the sound of typing or the sound of your stomach rumbling.

2 - SMELL: Say two things you can smell. If you can't smell anything at the moment or you can't move, then name your 2 favorite smells.

1 - TASTE: Say one thing you can taste. It may be the toothpaste from brushing your teeth this morning, or BBQ sauce from lunch. If you can't taste anything, then say your favorite thing to taste.

5 4 3 2 1 Grounding Exercise

	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
	<input type="text"/>	<input type="text"/>	<input type="text"/>		
	<input type="text"/>	<input type="text"/>			
	<input type="text"/>				



Technology & Coping Strategies

Helpful Websites:

- GoNoodle
- KidsHealth
- Teachers Pay Teachers
- Annaka Harris Meditation



YouTube:

- The Honest Guys
- Preferred relaxation music



TV/Movies

- Born this Way
- Inside Out



Apps















- Relax Melodies
- Pictello (visual story creator)
- Calm
- Headspace
- Andrew Johnson Meditation



Problem solving

Strategies don't always work as expected....

Everyone has different barriers and supports. Something can be both a barrier and a support. Or, some parts of the activity might not be barriers or supports, so you don't have to circle thumbs up or thumbs down. You can circle the thumbs up, thumbs down, both, or none.

Part of the activity	
Do you have the space you need to do it? -Is there enough space? -Do you need a special space?	 
Do you have the materials you need to do it?	 
Can the weather help or make it harder?	 
Do you know how to do it? -Are there any steps you don't know how to do?	 
Do you know where you can do the activity? -Is there a special place you need to go? -Can you do it everywhere?	 
Are there rules about when and where you can do it? -Can you do it at home? -Can you do it at school? -Can you do it at work?	 
How does the activity make you feel? Does it help you feel better? Or does it make you feel worse?	 

Remembering Coping Strategies

Technology-based cues:

- Reminders in phone
- Screenshot background listing out strategies
- Put relaxation apps on the front screen for ease of usage

Non-technology based cues:

- Envelope or key ring with options for coping strategies
- Post-it notes in a variety of locations

Asking for help and/or accepting help from others:

- Incorporate reminders at first → fade out reminders over time



Workplace accommodations

- School-based accommodations = starting point
- Scheduling
 - Flexible schedules
 - Consistent schedules
 - Specific shifts
 - Shorter shifts
- Breaks
 - Planned
 - As needed for self-regulation

Breaks were times when young adults could use coping strategies



Workplace accommodations

- Social supports
 - Job coach
 - Co-workers (assigned, or not)
- Accommodations that young adults thought would help:
 - Environmental adaptations to reduce sensory stimuli (e.g., less light or noise)
 - Consistent positive feedback
 - Extra check-ins with supervisor
 - Assignment of less non-stressful tasks



Tips for People with Disabilities

- Advocate for when you need space
- Develop questions ahead of time before appointment
- Bring a support person
- Have a scribe or audio recorder when going to the doctor
- Don't be afraid to share what you know about yourself!
- Advocate for how you want to communicate



Tips for Family Members

- Importance of validation-even if it isn't how you feel
- Prepare young adult to ask questions with providers or repeat information or slow down
- Write out or record important information from appointments that can be reviewed at a later time
- Share personal examples from your own adolescence - What was stressful for you? How did you cope with it?
- Listen first before giving advice
- Talk in private
- Share what is going well, before what is difficulty



Tips for Professionals

- Importance of giving space—not too much talking
- Incorporate preferred language and metaphors that are personally relevant to your client with IDD
- Accessible communication and choice
- Why getting medication-what does it do, etc.
- Allow longer time for appointments when have client with IDD
- Include the client with IDD in the decision-making of what information will be shared out with parents, providers, etc.



Break Out Activity

Think about everything we have just learned and talked about today. Apply what you have learned to think about supporting the mental health of someone who you know (or yourself).

- How would you approach or introduce the topic of mental health with this person? What would you say and do? What words would you use?
- How would you support this person in becoming more self-aware of their mental health?
- What would you do to help them identify a coping strategy?
- What would you do to help them evaluate the effectiveness of strategies?
- Do you have any other thoughts, questions, concerns? What else do you need to know to support them?



Getting professional help



Seeking professional help: Finding the right fit

- Does the provider have experience and/or formalized training working with people with disabilities?
- If the provider doesn't have formal experience working with people with disabilities, does the provider have any personal experience with disabilities?
- Does the provider have experience with Universal Design for Learning / making modifications to therapy based on a person's learning and developmental profile?

Ask for suggestions: ** NADD.org ** Federation for Children with Special Needs ** DDS, DMH, MRC Case Manager ** Disability-specific orgs such as AANE, Lurie Center, MDSC, UCP ** SPED dept. ** NAMI

JF&CS Disability Resource Line 781-693-5640: Free information, referral, and consultation service

Index: <https://disabilityinfo.org/> Up-to-date online index of all kinds of providers and programs.

Seeking professional help: finding the right fit

- **William James Referral Line INTERFACE**
 - 888-244-6843
 - Describe what you are looking for in a therapist, in addition to your insurance, demographic info, etc.
 - They will work with you until you find a therapist that is a good fit
- **National Association of Social Workers Therapy Matcher**
 - <https://therapymatcher.wordpress.com/>
 - 800-242-9794 or email us at info@therapymatcher.org
 - Even if therapist doesn't have specific experience with DS, could ask about their treatment methods, whether they have any family or other professional experience with DS



Future opportunities

- Peer mentoring for young adults with IDD and co-occurring mental health conditions, ages 16-25
 - Contact Ariel: aschwartz1@mghihp.edu



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Contact us:

aschwartz1@mghihp.edu

Melissa_Levin@newton.k12.ma.us



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ADDITIONAL SLIDES...



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What is a mental health condition?

- Everyone has a hard time with their mental health sometimes. A mental health condition isn't the same as having a little or medium feeling of stress, sadness, or anger that comes and goes. Everyone has these feelings sometimes.
- A mental health condition is when you've been having a hard time with your thinking, feeling, or acting for at least 2 weeks and it gets in the way of doing the things you want and need to do.



Contributing Factors

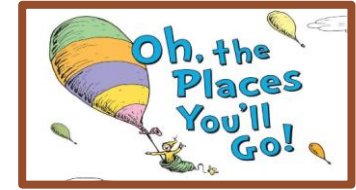
- Genetics— biological cause. Genetics is the information passed onto you from your family. Many times, people who have mental health conditions have many family members who also have mental health conditions.
- Brain chemistry –biological cause. It's the type, amount, and movement of chemicals working in your brain. Some people have a lot of “feel good chemicals” in their brains, but some people don't have as many “feel good chemicals” in their brains.
- Life events – situations you deal with in your life such as family changes including the birth of siblings, divorce, and death; starting at a new school, moving, having major medical issues
- Traumatic events - something that is really terrible and hurts you physical or emotionally. It might be something that makes you really sad, scared, or mad when you remember it.



- What do you do when people need significant care
- No appropriate inpatient care
- Prevent hospitalization (sprinkle in PCORI stuff)
 - Identifying outpatient provider
 - Before a patient turns 22, exit with counselor in place
 - Crisis planning
 - Being connected in the community
 - Mobile crisis –can come anywhere (put link in there)
 - If happens, have to advocate a ton so the treatment is appropriate and accessible



Turning 22



Plan ahead & provide as much as exposure as possible!

- Visit program on a frequent basis - ↑frequency of visits as transition date approaches
- Create something tangible that recaps what to expect (e.g., social stories, checklists, photos/slideshow, videos) to be reviewed on a consistent basis or as questions arise.

Transitional Object

- Favorite book, photograph, board game, information-sharing item (binder, journal)

Create positive associations

- Pair a non-preferred experience with an enjoyable experience

Take on a new role/responsibility

- Preferred interest/knowledge that can be transmitted into a role?
- Build on strengths! Little successes = confidence boosters
- Educating others (e.g., alumni speaker, tour leader)



When is it time to meet with a therapist?



- There are times when young adults should see a therapist or psychiatrist right away. These right away times to meet with a therapist or psychiatrist include:
- Mental health symptoms are worsening, and tools tips and techniques that used to work are no longer working
- Feeling so anxious or depressed that you can't get out of bed, out of your home, and/or do things that you used to do
- Having thoughts that are scary, intrusive and/or hard to control
- Using drugs and alcohol to make yourself feel better
- When you want to hurt or kill yourself, or hurt or kill other people



Mental Health Emergencies

A mental health emergency is when a person has thoughts about hurting or killing themselves or thoughts about hurting or killing someone else. Some of the signs include:

- Isolating, which is when you want to be by yourself and stay away from family, friends, or other people who are an important part of your life
 - Having really unsafe behavior like doing things that you know are dangerous and risky
 - Having big changes with your mood like feeling really happy, then feeling really sad
 - Having big changes with your sleep, like barely sleeping for several days or weeks at a time
- If you or someone who you know has a plan to hurt themselves or others, get help ***right away by calling 911.***
 - When a person has a mental health emergency, they need to get help right away. ***If you ever have a mental health emergency, it is very important that you talk to a parent or trusted adult right away.***



Seeking Professional Help

What to expect in outpatient therapy...

- The first session
 - Will involve paperwork, such as signing consent forms
 - You will be asked to share background information about yourself (your son/daughter) and what brought you to therapy
 - You will be asked to share behavioral indicators, such as how things looked before the transition, the emergence of symptoms, and your current level of functioning

It's important to share how you learn and process information best

- Share how you best learn and process information
- Talking? Visuals? Art? Role-Play? Using technology?
- Length of session (also including other key supports?)

