

# Subjective Experiences of Having and Managing a Serious Mental Health Condition in Young Adulthood

Kathryn Sabella, Ph.D.

Laura Golden, B.A.

Emma Pici-D'Ottavio, B.A.

Transitions to Adulthood Center for Research

University of Massachusetts Medical School

March 4, 2019



*The Transitions to Adulthood Center for Research*

# 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, Independent Living, 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, and/or SAMHSA you should not assume endorsement by the Federal Government.*



*The Transitions to Adulthood Center for Research*

# Summary of Symposium

1. Introduction, Method, Description of sample
2. Initial mental health experiences
3. Patterns of mental health treatment experiences
4. Hospitalizations
5. Take-home messages



# Background

The Collecting Histories of Education and Employment  
during Recovery (CHEER) Study



*The Transitions to Adulthood Center for Research*

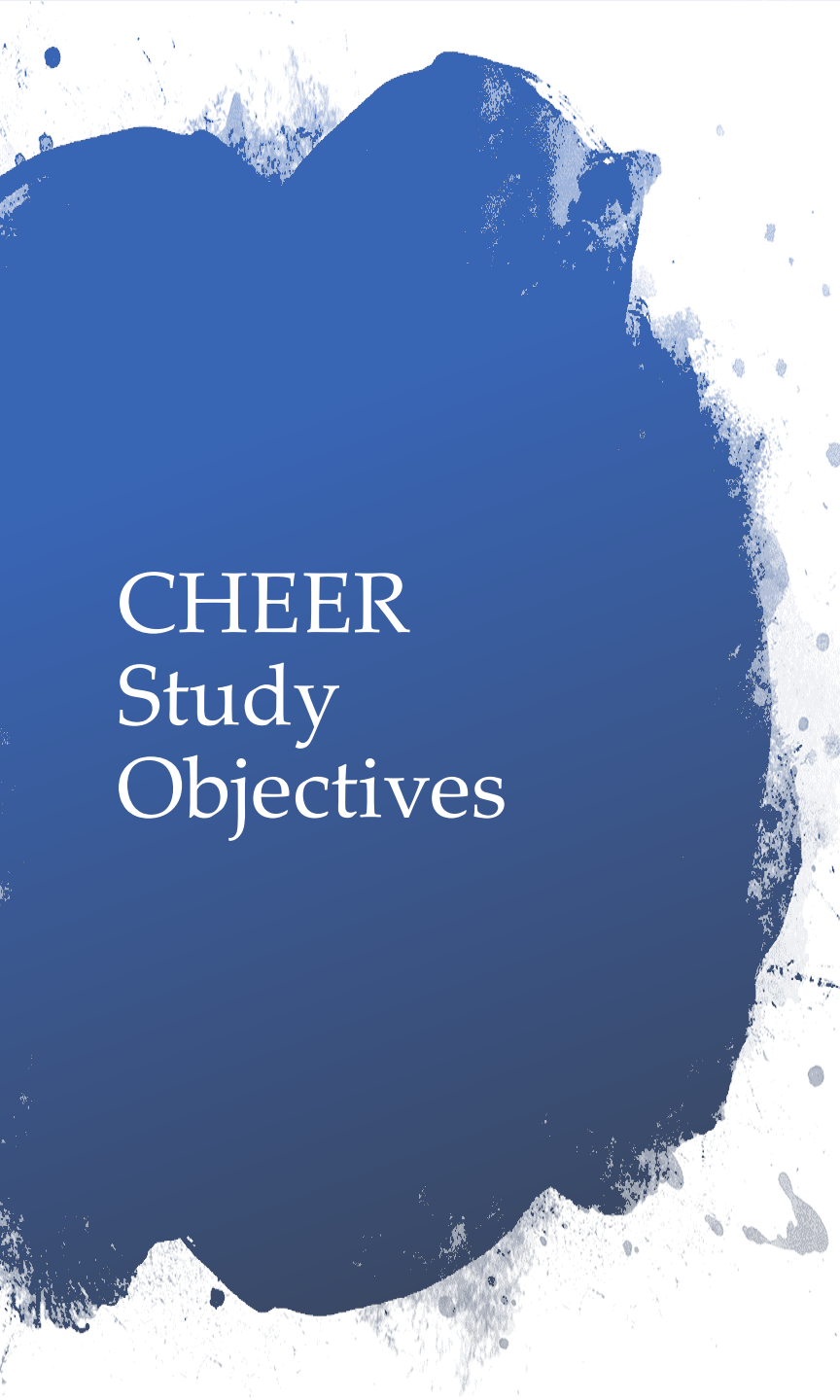
# Young Adulthood: A Critical Time

Young adulthood is a critical time for establishing a foundation for an adult working life.

Young adults with serious mental health conditions (SMHC) often have lower rates of

- High school graduation
- Enrollment in post-secondary education
- Employment

And face additional challenges (e.g., justice system involvement, co-occurring disorders, homelessness)



# CHEER Study Objectives

- Explore *how* young adults with SMHC navigate employment, education, and training activities while managing a serious mental health condition
- Identify potential malleable factors that hinder or facilitate school, work, and training activities

# Mental Illness “Careers”

- Dynamic process of having and managing a mental illness that unfolds over time
- Represented by patterns to and from treatment systems
- Shaped by social contexts, experiences, and life events
- Majority of mental illnesses diagnosed by mid-20s
- Early mental health experiences influence long-term mental health trajectories





# Today's focus

Explore the mental health experiences of young adults with serious mental health conditions



# Methods

The Collecting Histories of Education and Employment  
during Recovery (CHEER) Study



*The Transitions to Adulthood Center for Research*

# Eligibility Criteria

- 25-30 years old (22-30 if a young parent)
- Have been diagnosed with at least one of the following:
  - Major Depression
  - Anxiety Disorder
  - Post-Traumatic Stress Disorder
  - Schizophrenia or Schizoaffective Disorder
  - Bipolar Disorder
  - Eating Disorder
  - Borderline Personality Disorder
- Reported significant treatment or disruption due to SMHC
  - Inpatient hospitalization
  - Partial hospitalization
  - Client of MA DMH
  - Received Special Education Services
  - Formal Leave of Absence
- Some school and work history



# Data Collection

- One-time, 90 minute qualitative interviews
- Instrument was developed through iterative process with input from young adults with SMHC
- Participants were asked to describe:
  - Their education, training, and employment experiences
  - How decisions were made regarding these activities
  - Their mental health experiences and how they influenced education, training, and employment



# Recruitment Methods

- Recruitment Sources from Central MA:
  - Mental health providers, drop-in resource centers, clubhouses, referrals from contacts within MA Department of Mental Health
- Interviews conducted in the community
- Interviews and recruitment conducted by young adult staff members
- \$30 gift card incentive



# Coding and Analysis

- Most interviews recorded
  - All transcribed
- Dedoose coding software
- Inductive, Modified Grounded Theory
- Codebook developed through group process
  - 3 coders, inter-rater reliability of at least 80%



# DESCRIPTION OF SAMPLE

The Collecting Histories of Education and Employment  
during Recovery (CHEER) Study



*The Transitions to Adulthood Center for Research*

# Demographics (N=61)

Gender	
Female	62%
Male	36%
Transgender	2%

Age	
Range	22-30
Average	27

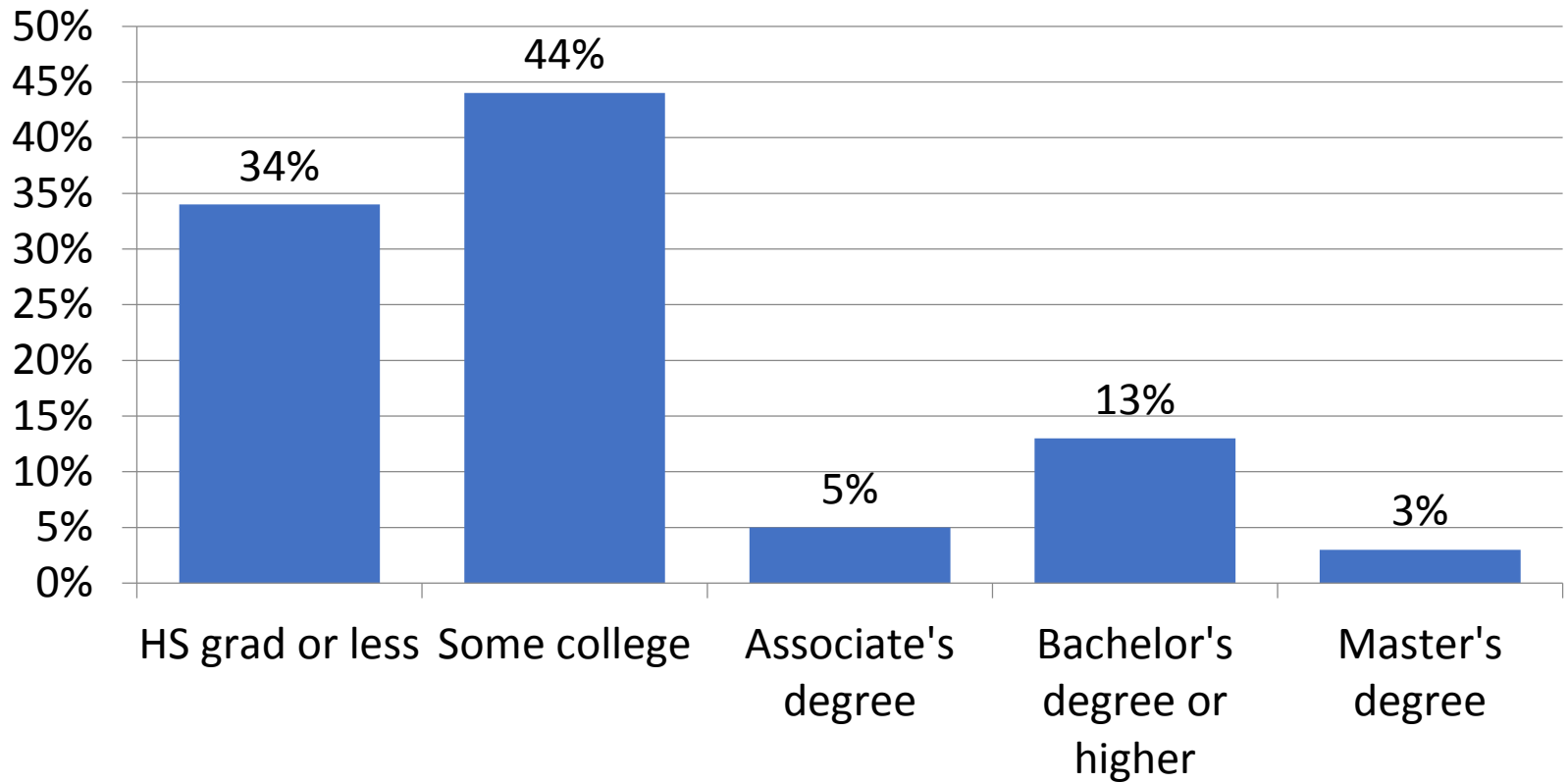
Race	
White	77%
Black/African American	11%
Other	12%
Ethnicity	
Not Hispanic or Latino/a	88%
Hispanic or Latino/a	12%

- 19 (31%) are parents



# Demographics (N=61)

## Highest Education Level Completed

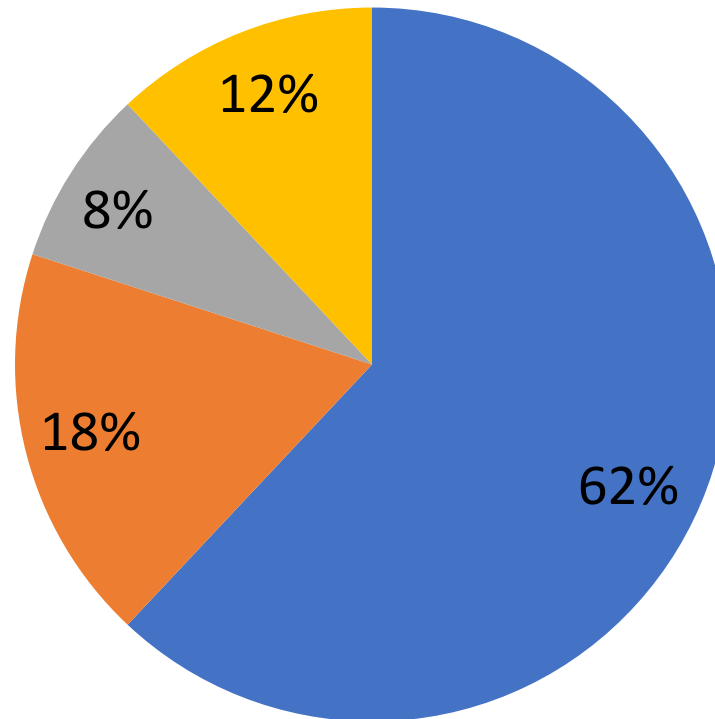




# Demographics (N=61)

## Annual Income

■ <\$10,000   ■ \$10K-\$20K   ■ \$20-\$30K   ■ >\$30K



# Mental Health Diagnoses

Diagnoses Reported	
Major Depression	74%
Anxiety Disorder	62%
PTSD	43%
Bipolar Disorder	41%
Schizophrenia	13%
Schizoaffective Disorder	11%
Eating Disorder	11%
Borderline Personality Disorder	8%
Other	10%

Almost 1/3 had co-occurring learning disability and/or Autism Spectrum Disorder



# The realization that “something is wrong”: initial contact with mental health treatment

Kathryn Sabella, Ph.D.



*The Transitions to Adulthood Center for Research*

# Initial mental health experiences

The first experiences of certain emotions  
(e.g., sadness, anger, hopelessness)

The recognition of those feelings as  
symptoms of a larger problem

How those symptoms were managed  
inwardly and outwardly,

How and when individuals ultimately sought  
help or interacted with mental health  
professionals.

# Mental Health Diagnoses

## Age of 1st Diagnosis

Under age 16	67%
Between 16-21	30%
Between 22-30	3%

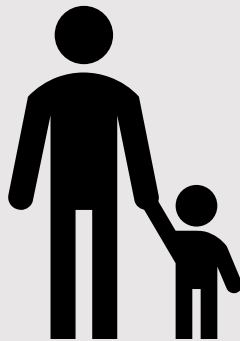
## # of Diagnoses Reported

Range	1-6
Average	3



# #1. Early Identification and Treatment

---



Very little time passed between symptom onset and diagnosis or interactions with the mental health treatment system

- Result of outward behavioral problems, co-occurring ADHD or ASD
- Treatment decisions led by parents or professionals, talked about very passively



## #2. Delayed Identification and Treatment

Feeling symptoms of a mental illness (e.g. sadness, mood swings, anxiety) for several years before recognizing an issue, telling anyone, officially seeking help, and/or getting diagnosed





## Lack of mental health literacy

*I thought it was something normal because I had been experiencing the social anxiety for so long that I didn't know it could be treated*

*When I started like having more anxiety, the only way I could express it was telling people "My head is really hot, there's too much things in my brain, it hurts." And nobody really knew why. They were like "You know, she's a little girl, she's dramatic". So it started when I was nine but I didn't get diagnosed until I was 16.*



# The choice to hide symptoms

*The trauma was from my childhood and I actually did not tell anyone until my teenage years and kept it very much hidden. So it did definitely have an effect on my really just collapsing in my teenage years. I was just unable to go to school and do anything really.*

*My brother was diagnosed with bipolar disorder and so I had seen them (parents) kind of having to deal with that and I just didn't want to add to the problems.*



# Result of delayed identification

*Everything just came on top of me right from there on...I didn't really realize it, it just kind of built up and built up and built up.*



# Sporadic and erratic patterns of mental health treatment

Kathryn Sabella, Ph.D.



*The Transitions to Adulthood Center for Research*

# Diagnosis “trial and error”

Being given alternate or corrected diagnoses to replace original diagnoses, usually in conjunction with changing providers or in response to medications not improving symptoms

*I've had different diagnoses from different doctors.*

*The whole diagnosis is kind of a blur because they're never quite sure what exactly I have.*



## Repercussions of diagnosis trial and error

*Honestly, sometimes I get diagnosed and don't feel that I'm that category...I thought they were just labeling me, like whatever*

- Confusion and ambivalence about diagnosis
- Lack of confidence in their diagnosis and field of psychiatry

# Medication “trial and error”

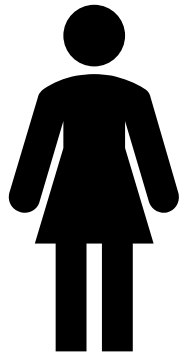


Periods of experimentation with different medications under the supervision of a psychiatrist to find the right ones or the right dosage

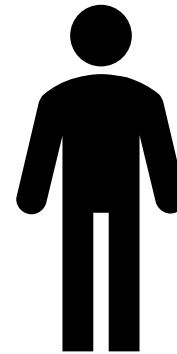
*So some doctors, they me on things just to put me on them, pretty much like a guinea pig to see (what happens).*

# Associated Challenges

*So that was a whole other drama in and of itself. It's like taking the prescriptions, some of them would work and some of them would have a lot of side effects...strong side effects.*



*So they (hospital) put me on Lithium. And when I got out of the hospital, I was just like a vegetable. I went to live at my sister's. She's like, "what's wrong with you? You're not even talking, like you couldn't even walk right, you know." It was just like, it made me get off the medication.*





## Medications as helpful

*They put me on Clozaril and that's worked wonders. That's like the miracle pill they had put me on. And I feel great, like I don't even feel like I have a mental illness*





# Quitting “cold turkey”

not always a choice.....



*What happens is sometimes you're on a regular medicine regimen, and you're like, oh, for the past four months I've been fine. So I'm just going to stop my meds now because I don't think I need them anymore. Because you think you're all right. It's like the little head game the disease plays with you. And you think you're okay. And then what happens is when you stop taking the medicine, you end up falling into a downward cycle very fast.*

# The Role of Hospitalizations

Laura Golden

Emma Pici-D'Ottavio



*The Transitions to Adulthood Center for Research*

# Causes of Hospitalization

Suicide attempts or  
suicidal ideation

Anxiety/panic  
attacks

Psychotic  
episodes/paranoia

Going off  
medications

Life circumstances  
(finances, school  
pressures,  
relationships)

# Admission to hospital or partial hospitalization

- **Self-initiation**


- Participants brought themselves to PCP or ER when concerned, leading to admission



- **Parent involvement**

- frequently called 911 or drove young adult to hospital





Admission to  
hospital or  
partial  
hospitalization

Deferring to authorities (DCF, justice system)

*“I actually punched somebody in the face because they made me mad, a staff member ... so they decided to put me in front of the judge. And the judge said, “Well there’s no criminal charge for being punched in the face. But we’ll put her in the hospital for 6 months.”*

# Age of First Hospitalizations

15 participants	<15 years old
9 participants	15 - <18 years old
20 participants	18 - 25 years old
0 participants	Age 26+

\*17 participants – age of first hospitalization unknown

- 17 spent time in residential facilities, several in adolescence



# of  
Hospitalizations  
Reported

# of hospitalizations	# of participants	% of participants
0	11	18%
1	10	16%
2	4	7%
3-4	14	23%
5-10	12	20%
10+	10	16%





# Frequency

---

- *“I was there you know for 30 days. Came out probably six months down the line. Went back in somewhere. Came out six months down the line, went back in somewhere. And that probably happened for a good you know four years.”*







# Differences between child, adolescent, and adult units

---

*“They expect you to like take care of yourself...It’s different in the younger units. You get away with a lot more too in the younger units.”*

*“And so that was my first and only time on an adult unit. Absolutely terrifying. It was very terrifying. They had put me on an acute unit with adults who had severe, severe mental health needs.”*



# Hitting Pause



- *“I liked the hospital...It was just a break. I’ve done a lot of work my whole life...And when I went to the hospital it was just like, eat what you want. You know like you just hang out.”*
- *“That stay was low stress...I was able to interact with the people who worked there...I just kind of wanted to decompress.”*

# Physical Confinement

- Restlessness
- Boredom
- Lack of exercise



*“...they stick you in a locked dorm and give you nothing to do...just like the boredom of it was kind of hard.”*



# Perceptions of Staff

Although some reported positive relationships, many negative accounts were shared...

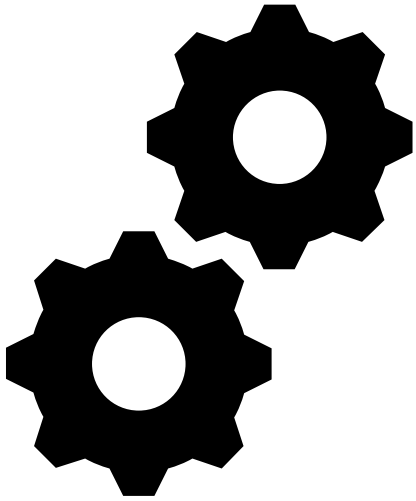
*“The staff. I didn’t care for. They had a lot of anger issues, like they weren’t nice people.”*

*“...I went to go tell them I didn’t feel well. And I passed out. And they started yelling at me. I woke up to them yelling at me.”*

*“...I was in a residential program when I got restrained every other day for like – for no reason.”*



# Working the System



- Learn what to say to be discharged
- Learning what to say to avoid hospitalizations
- Going through partial hospitalization as part of the process

“...you’re a teenager and you don’t want to be hospitalized. So at that point I started telling doctors what they wanted to hear so that I could be discharged.”



# Partial Hospitalizations

33 participants  
attended partial  
hospitalizations

Mixed Feelings

- *“It was something to keep me occupied and busy, and something to provide structure to the day.”*
- *“Looking back it was really chaotic and crowded, and you just kind of drew smiley faces all day.”*
- *“It was kind of like a day care for adults.”*





## Hospitalization Benefits

Several reported benefits of hospital stays coming after release:

- Referrals to outpatient therapists
- Psychiatry/medication management

*“Actually I think the one thing that was helpful was that they prescribed me a different medication...And that’s what I’ve been on since...It’s working.”*

# Effects on Outside Life

*I regretted going in every time...it interrupted my work and my school. And back then, I didn't have the benefits I have now. So, it was like if I didn't go to work, I didn't get paid.*



*...it's hard not just with work, but with – it's life in general, especially being a parent. And having kids and having to take care of them. And then having to stop everything because I needed to be hospitalized.*





# Conclusions



*The Transitions to Adulthood Center for Research*



# Initial mental health experiences

- There are diverse pathways to mental health treatment
- Lack of mental health literacy and trauma contribute to delayed treatment
  - First mental health treatment experiences are while in crisis
- Initial experiences can have implications for long-term mental health treatment decisions

# Treatment experiences

01

Discontinuity in care and providers = multiple diagnoses and medication

02

Changing diagnoses/labels can influence self-perceptions and identity

03

Medication changes are difficult to navigate & detrimental to school, work, and independent living

# Takeaways about Hospitalizations



- Tended to start at a young age and occur frequently
- Life gets put on hold
- Open to hospitalization as needed
- Mixed experiences while in treatment
- Linkages to helpful outpatient providers/programs/medication routines

# Thank You!

Contact us:

Kathryn Sabella: [Kathryn.Sabella@umassmed.edu](mailto:Kathryn.Sabella@umassmed.edu)

Laura Golden: [Laura.Golden@umassmed.edu](mailto:Laura.Golden@umassmed.edu)

STAY INFORMED!

Sign up for our e-mail newsletter for our products and announcements!

Text [TRANSITIONSACR](https://www.umassmed.edu/TransitionsACR) to 22828

Visit us at [umassmed.edu/TransitionsACR](https://www.umassmed.edu/TransitionsACR)



*The Transitions to Adulthood Center for Research*