

IN THEIR OWN WORDS: YOUNG ADULTS NAVIGATING SCHOOL AND WORK WHILE LIVING WITH A MENTAL HEALTH CONDITION

Transitions to Adulthood Center for Research
Systems and Psychosocial Advances Research Center
Department of Psychiatry
University of Massachusetts Medical School

Kathryn Sabella, M.A., Ph.D. cand.*

Emma Pici-D'Ottavio, B.A.

Laura Golden, B.A.

*Department of Sociology, University of Massachusetts Boston



The Transitions to Adulthood Center for Research

Acknowledgements

The Learning & Working Center at Transitions ACR is a national effort that aims to improve the supports for youth and young adults, ages 14-30, with serious mental health conditions to successfully complete their schooling and training and move into rewarding work lives. We are located at the University of Massachusetts Medical School, Worcester, MA, Department of Psychiatry, Systems & Psychosocial Advances Research Center. Visit us at:

<http://www.umassmed.edu/TransitionsACR>

Transitions ACR incorporates Participatory Action Research with young adults with lived experience in the design, conduct and interpretation of research and knowledge translation activities.

The contents of this presentation were developed under a grant with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research, and from the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services (ACL GRANT # 90RT5031, The Learning and Working Transitions RRTC). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). Additional funding provided by UMass Medical School's Commonwealth Medicine division. The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS, SAMHSA, and you should not assume endorsement by the Federal Government.



The Transitions to Adulthood Center for Research

Summary of Symposium

1. Introduction/Methods
2. Description of Sample
3. School and work activities of young adults with serious mental health conditions
4. Influential factors on school and work during young adulthood
5. The role of disclosure, support, and flexibility on school and work activities



INTRODUCTION

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 time for establishing a foundation for an adult working life.
- Young adults with serious mental health conditions (SMHC) often have poor outcomes with school and work
 - Lower rates of high school graduation and enrollment in post-secondary education
 - Lower rates of employment
 - Additional challenges (e.g., justice system involvement, co-occurring disorders, homelessness)

(e.g., Davis and Vander Stoep, 1997; Newman, et al., 2011; Waghorn, et al., 2009; Vander Stoep, et al., 2000)



Research Objectives

- Research is lacking first-person narratives that could invaluablely inform services and supports
- Explore *how* young adults with SMHC navigate employment, education, and training activities



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



Procedure

- 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
 - The influence of SMHC, other life circumstances and events (e.g., hospitalizations) on these activities



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

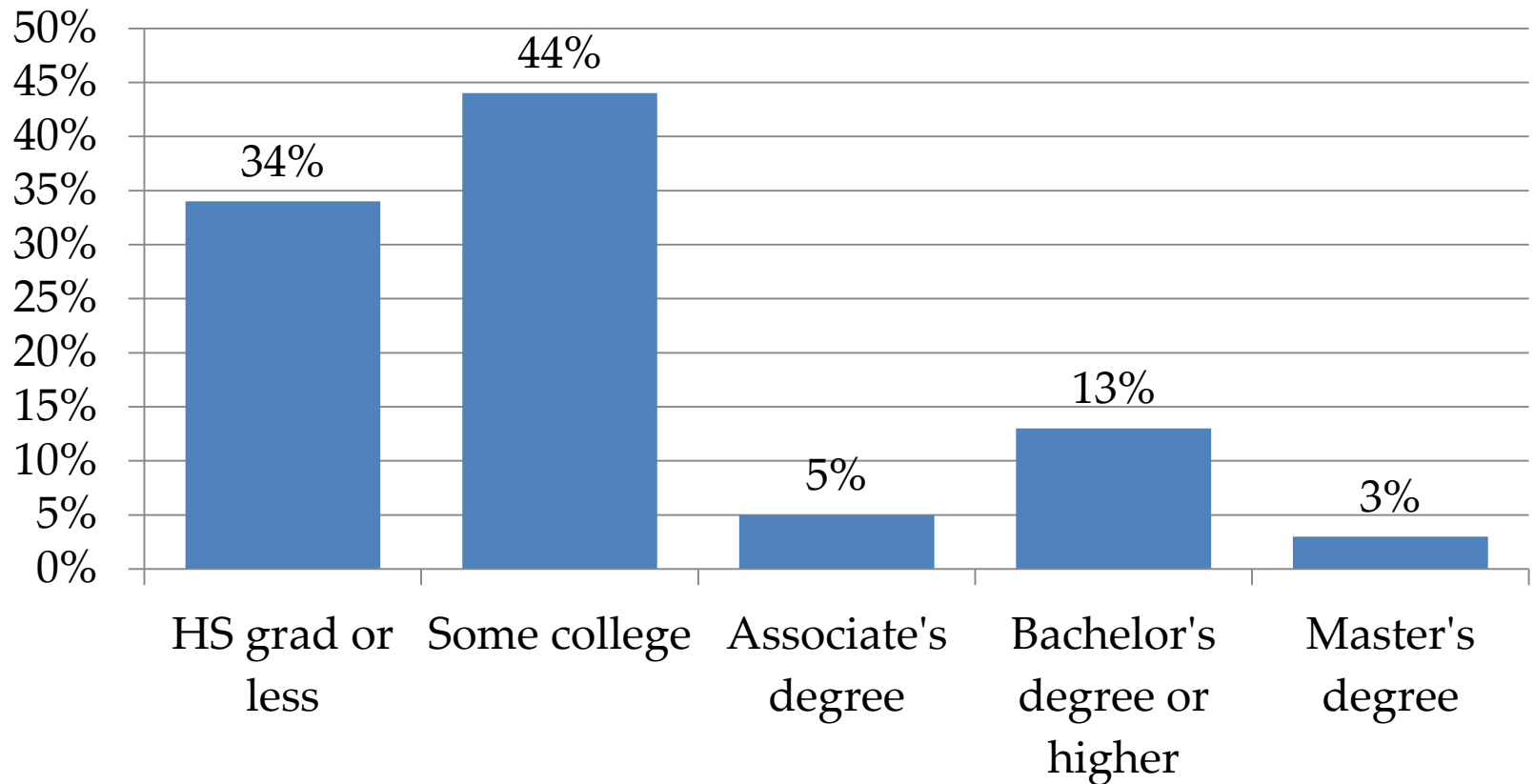
Race	
White	77%
Black/African American	11%
Other	12%
Ethnicity	
Not Hispanic or Latino/a	88%
Hispanic or Latino/a	12%

- 19 (31%) are parents



Demographics (N=61)

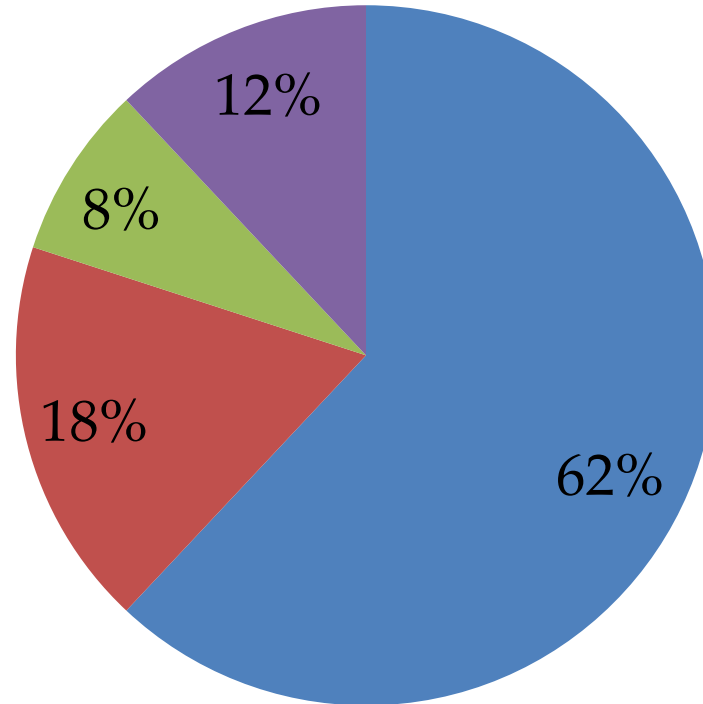
Highest Education Level Completed



Demographics (N=61)

Annual Income

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



Mental Health Diagnoses

of Diagnoses Reported

Range	1-6
Average	3

Age of 1st Diagnosis

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

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

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%



Hospitalizations

- **82%** report at least 1 hospitalization (i.e. overnight hospital stay) due to mental health issues

# of Hospitalizations Reported (n=50)	
1	18%
2	8%
3-4	30%
5-10	24%
10+	20%



School and Work Activities of Young Adults with Serious Mental Health Conditions

Kathryn Sabella, M.A., Ph.D. cand.

Emma Pici-D'Ottavio, B.A.

Laura Golden, B.A.



The Transitions to Adulthood Center for Research

Overall Patterns of School/Training

- Non-linear
 - Multiple attempts, starts and stops
 - Trying different schools/programs
- Lack of clear goal or motivation for pursuing post-secondary schooling (i.e. “everyone else is doing it”)
- Dropping courses after add/drop period = accrued student debt
- Trainings and Certifications
 - Phlebotomy, hair dressing/cosmetology, Personal Care Asst.



Overall Patterns of Work

- Service or Retail
 - Big box stores (Target, grocery chains)
 - Restaurants (pizza delivery, McDonalds, upscale restaurants)
- Short duration jobs
 - Quitting/no-showing
 - Getting fired
 - Seasonal
- Sizable gaps in working
- Some pursuing work and school at the same time
- Limited growth over time but honing in on likes/dislikes



“Rebecca’s” story (age 28)



Employment or Education Status

	N	%
Not in school or work	25	41.0%
Temporary, per-diem, sheltered employment	6	9.8
School or training, primarily (sometimes with work)	7	11.5
Employed in non-peer jobs	13	21.3
Employed as a peer worker or utilizing lived experience	10	16.4



Not in school or work (n=25, 41%)

- More than half (n=15) also had very minimal work and school backgrounds, even by age 26/27/28
- 10 had “active” histories but mostly sporadic and in service industry
- About a third expressed wanting to work or actively seeking work
- Many involved in clubhouses or other formal services
- 2/3 of those with Schizophrenia or Schizoaffective in this category (10 out of 15)
- High occurrence of co-occurring disorders



Temporary, per-diem, sheltered employment (n=6, 9.8%)

- Sheltered work = low paying, time-limited jobs, usually reserved exclusively for people with disabilities, often require additional supervision by mental health staff (Waghorn and Lloyd 2005).
- Liberty Tax “mascot”, staffing a donation drop-off “pod”
- Contract or per-diem work
- Seasonal
- Very minimal work histories



NPR.org



Primarily enrolled in school/training (n=7, 11.5%)

- 2 pursuing graduate degrees
- 4 pursuing undergraduate degrees
 - Perseverance!
- 1 pursuing Personal Care Assistant (PCA) training

“At the time there were breaks when I was younger. But now I feel like I can’t stop...and I am going to do this right.”



Employed as a Peer Worker/Using Lived Experience (n=10, 16.4%)

- Young adult peer workers more established in MA
- Intrinsic benefits of helping other people and power of utilizing personal lived experience (i.e. silver lining)
- Often provided a path for individuals who were floundering

“My work as a peer mentor has helped me with my—I don’t know if you want to call it my recovery or whatever-- because I can use my negative experiences, and I realize that that can help people.”



Employed in non-peer settings (n=13, 21.3%)

- 5 working part time
 - Includes bagging at a grocery store, working in a school cafeteria
- 8 working full time
 - 4 had bachelor's degree
- More active school and work histories, even if in service industry

“I started in a restaurant, so I mean that was my first job. I was like the prep cook/salad person. Really that’s just all I’ve ever really done....I just started really young and never stopped.”



Benefits of Working & School

- Not just economic
- Many expressions about how work and school contributed to self-perception and emotional well-being
 - Feelings of pride and self-worth
 - Builds confidence
 - Instills hope and more positive future outlook

“It helped me to grow...to see the person I should be and will be later.”

- Social benefits

“It’s also helped me be more friendlier like to people that I don’t know and be more confident and outgoing because I’m around all these people.”



Influential Factors on School and Work during Young Adulthood

Laura Golden, B.A.

Emma Pici-D'Ottavio, B.A.

Kathryn Sabella, M.A., Ph.D. cand.



The Transitions to Adulthood Center for Research

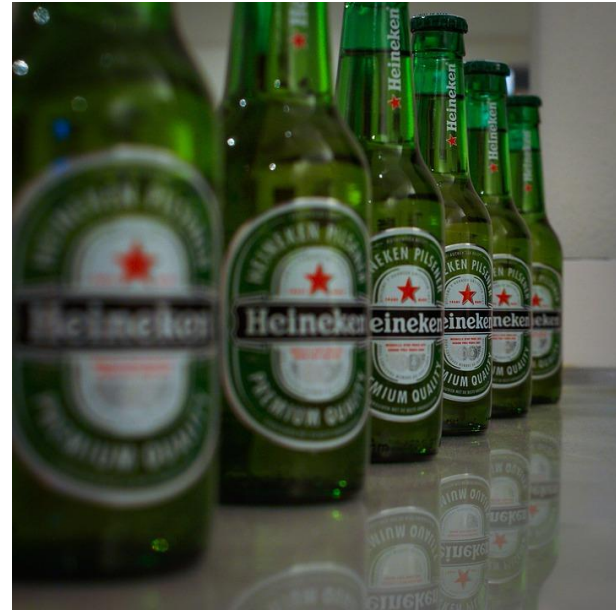
Substance Use

- Self-medicating to “numb” stress and anxiety

“So...that’s how I dealt with it.

After work I would drink.

Or you know use the stupid cough and cold medicine to numb my body out so I wouldn’t feel anything.”



- Impaired performance

“...I’d be kind of hungover going to work... And then once it wore off, then I would have the anxiety and depression kick in. And so it made it a lot harder to...do a full day of work.”



Housing Instability

- 22 participants - homelessness and/or housing instability at some point in their YA lives

“...it’s kind of hard to address things that are extracurricular or even regular in your life when your basic needs aren’t met, you know?”



“...having a job was like the hardest part. Because like I didn’t know where I was going to be the next night...How would I get there or anything like that? ... I was always embarrassed to like have to either leave work or get fired.”



Parenting Young Children

- Most young parents we spoke to were single mothers



“So that’s been a huge barrier, is trying to figure out like how am I going to find a job that will you know work with me being primarily responsible for her?”

- Daycare=expensive (vouchers helpful but hard to get)



Intersectionality of Mental Health & School/Work



The Transitions to Adulthood Center for Research



Social Anxiety

At school

“If the professor calls on you, you had to – I had a huge problem with that, because I didn’t want to get the answer wrong.”

At work

“...because it was a front desk job, I got a lot of anxiety...and I was like in the middle of the whole gym and everybody is coming up to me and signing up. So after a while, I got overwhelmed.”

- Socialization with peers at both school and work



Anxiety/stress/panic attacks in relation to certain jobs or tasks

At school

“And I was doing two classes at once...I just got super, super overwhelmed with the amount—it wasn’t even a lot of work. It’s just the anxiety of like I can’t do this....So as of right now I have not gone back just because I’m terrified of schooling.”



At work

“...I sort of took on too much, and I got promoted before my 90-day trial period was even up. And it was a retail job. I was a front end supervisor. Pretty stressful, and eventually I had a breakdown and had to quit working.”



Attendance

“You know I couldn’t bring myself to class when I really felt like, you know, I wanted to hurt myself or I didn’t care anymore. So any class that was based on attendance, I really struggled in.”



“Well I like – what happened was my mental health was getting bad. And I was like absent all the time. Like I was calling in. And she said like instead of her firing me, I just had to write my two weeks.”



Impact of medication side effects

- Most common side effects:
 - Drowsiness
 - Inability to concentrate



“I was on so many medications. I was reducing the medications so that I could wake up in the morning and be on time. And not be sleepy all day.”

“And you go into class, you’re nauseous. You can’t focus. You’re dizzy. You know you just feel like crap. There’s no way in hell nobody is going to be able to tell what the hell the teacher is saying.”





The Transitions to Adulthood Center for Research

The Role of Disclosure, Support, and Flexibility on School and Work Activities

Emma Pici-D'Ottavio, B.A.

Laura Golden, B.A.

Kathryn Sabella, M.A., Ph.D. cand.



The Transitions to Adulthood Center for Research

Disclosure at School and Work

- Disclosure is typically required to access formal services or flexibility at school and work.
- Many participants chose not to formally disclose at their job or post-secondary education.
- Those who did disclose at school or work tended to...
 - Disclose only if something happened (e.g., hospital stay)
 - Disclose informally (e.g., confiding in supervisor or instructor privately when struggling)



Reasons to Not Disclose

- Fear of discrimination

“I feel like that would’ve disqualified me for a job, or they wouldn’t want to hire someone with a mental health condition.”

- Experienced judgment

- Feeling of being “viewed differently”

“And unfortunately people do view you differently if you have a mental health diagnosis. That’s the reality of the world we live in.”

- Perceived discrimination

- Some felt they had experienced outright discrimination in the past



Reasons to Disclose

- Disclosure can lead to increased understanding and support, willingness to accommodate
- Obtaining a leave of absence
- Getting formal accommodations
- Advocating for flexibility
- Using one's lived experience to help others (e.g., peer mentor)

“I like to open up to try and help other people with similar experiences so they can know that even though you've been through this, there is something more afterwards.”



Use of Accommodations

- Difficulties navigating process
 - Unsure how to get accommodations
 - Some expressed they couldn't get the right support
- Few utilized formal accommodations at college
 - Some “non-traditional” accommodations
 - Choice who to disclose to and what to disclose
- Formal accommodations at work were uncommon
 - Job requirements perceived as less flexible



Formal Leave of Absence

- Leaves of absences were utilized fairly often during both school and work
 - Sometimes participant initiated, sometimes encouraged by officials
 - Some leaves were formal, some informal
- Challenges of taking a leave
 - Instances of insensitivity or lack of understanding
 - Difficult process to navigate while struggling
 - Isolating (e.g., away from social interaction)
 - Challenges returning from leave
- Strong familial supports were helpful for this process



Flexibility

- Relaxed or “easy-going” environment
- Flexible schedule or hours
- Able to take breaks
- A level of independence

“Having a relaxed atmosphere for a job really helped. So that I knew if I needed a break, I could go take it. If I needed just a moment to calm down, you know I had that. Or if I needed to adjust my hours, you know there were things in place for me to be able to do things like that. And that was helpful.”



Supportive Supervisors and Instructors

- Decision to disclose often based on supervisor/instructor
“I disclosed to professors who I was comfortable with. It was a lot of trial by error. One person I disclosed to, it didn’t work. So I just learned how to feel it out.”
- Supportive supervisors are very influential
“Having an employer like that is so helpful when you have a mental illness. You don’t have to feel like you’re being judged. You’re just being helped so that you can do your job.”



CONCLUSIONS AND IMPLICATIONS

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



The Transitions to Adulthood Center for Research

Conclusions

- 1/2 participants unengaged or had minimal work history
- Many attempted college but did not complete
- Influential factors include:
 - Housing instability
 - Co-occurring disorders (e.g., substance use, learning disabilities)
 - Parenting at early age
- Mental health symptoms often impact school and work
- Potential facilitators to success include:
 - Supportive supervisors or instructors
 - Flexibility
 - Disclosure/Accommodations



Practice Implications

- Individualized holistic approaches
 - Explore and recognize individual strengths and challenges
 - Services and supports to develop career interests and goals
- More thoughtful approaches to college
 - Identify goals and motivation early
 - Plan for financial impact
- Positive benefits of working – encouraging young adults to not work or go to school may exacerbate feelings of depression and low self-worth
- Thinking ahead regarding disclosure, flexibility, accommodations and expectations of the job/school



Research Implications

- Future research utilizing first-person narratives is needed to understand the unique experiences of vulnerable subgroups and young adults from different racial/ethnic backgrounds
- These findings should inform future research that tests and explores mechanisms for better supporting the needs of youth and young adults with SMHC



Thank You!

Contact us at... Kathryn.Sabella@umassmed.edu,
Emma.PiciDOttavio@umassmed.edu, Laura.Golden@umassmed.edu

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

Text **TRANSITIONSACR** to **22828**

Visit us at
umassmed.edu/TransitionsACR



The Transitions to Adulthood Center for Research